Development, evaluation and the effects of the VIPS practice model for the person-centred care of patients with dementia

An intervention study in Norwegian nursing homes

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Hold sinnet ditt várt og villig
som greina i brisen;
en hvileplass for fugler
med vingen blå av himmelduft

– Hans Børli –

Keep your mind gentle and willing
like the branch in the breeze
a resting place for birds
with their wing blue from celestial scent

(Translated by J.R)

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Attachment

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Abstract

As the threshold for the use of psychotropic drugs in persons with dementia is getting higher because of modest effect and potential serious adverse effects, the need for research of the effectiveness of psychosocial interventions is urgently needed. Person-centred care (PCC) is a social-psychological care philosophy based on Professor Tom Kitwood's work that is regarded as one of the most promising psychosocial approaches in care for persons with dementia. The cornerstone of person-centred care is that of personhood, defined 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.*" Persons with dementia are dependent on others and less able to take the initiatives that would lead to their needs being met. Therefore, their basic psychological needs for comfort, attachment, inclusion, occupation and identity are emphasized in PCC in addition to physical needs. Clinical manifestations of dementia are understood as arising from a complex interaction between the patient's personality, biography, physical health, neurological impairment, and the social psychology that permeates the environment.

The 'VIPS' framework developed by Dawn Brooker sums up the elements in person-centred care for persons with dementia as Values, Individualised approach, the Perspective of the person living with dementia and Social environment. There are six indicators for each element providing concrete requirements for what constitute PCC.

Few models of implementation of PCC exist and few randomized controlled studies have been conducted, rendering the evidence of effect limited. The overarching aim of this thesis was to translate the values of PCC into practical daily care by use of the VIPS framework, and to evaluate the effect on neuropsychiatric symptoms in persons with dementia in nursing homes. In particular, this study aimed to determine the following

a. To examine whether a model developed for practical use in the VIPS framework could be implemented in a Norwegian nursing home setting
b. To investigate the effects of this model on neuropsychiatric symptoms
c. To identify any organizational factors associated with the effects of the model

The VIPS framework has been operationalized into the VIPS practice model (VPM). The VPM incorporates an education and coaching approach, clearly defined staff roles, and patient-focused outcomes in a cycle to support improvements in quality of care. It is based on regular structured team work, supervision and supportive management, elements highlighted by Kitwood. The model focuses on the process between the staff in the ward, and the building of a shared base of values and knowledge in the staff. The hub of the VPM is the weekly consensus meeting in the units using the VIPS framework to analyse a challenging interaction between a patient and a nurse. The analysis emphasizes how the patient might experience the situation and how his/her neurological impairment, physical health, personality, life history and psychosocial needs might impact on his or her reactions. Each consensus meeting follows a set procedure where the staff exerts their defined functions and takes part in the decision on how to proceed to prevent agitation or other neuropsychiatric symptoms in the patient. The purpose is to make the staff aligned in a person-centred view of the situation (Paper 1).

An initial evaluation of the VPM was conducted with a qualitative evaluative study design. The VPM was trialled in a 9-week pilot study in two nursing homes and evaluated in four focus groups using Qualitative Content Analysis (Paper 2). Seven registered nurses (RNs) and five auxiliary nurses (ANs) participated from nursing home A, four RNs and seven ANs participated from nursing home B. Five themes emerged: (1) Legitimacy of the model was secured when central roles were held by nurses representing the majority of the staff; (2) The model facilitated the staff's use of their knowledge of PCC; (3) Support to the persons holding the internal facilitating roles in the model was needed; (4) The authority of the leading registered nurse in the ward was crucial to support the legitimacy of the model; (5) Form of organisation seemed to be of importance in how the model was experienced. The VPM was found to be feasible in the nursing home setting with some revision.

We hypothesized that the VPM was more effective than educating the nursing home staff about dementia (control group) in reducing agitation and other neuropsychiatric symptoms among nursing home patients. A 10 month cluster randomized controlled trial (RCT) was conducted to examine the effect of the VPM together with Dementia Care Mapping (DCM), another model based on PCC (Paper 3). The RCT was conducted in the period from January to December 2011. All 51 nursing homes located in the city of Oslo were invited to participate in the study. The 15 nursing homes that accepted the invitation were randomized into three groups according to their size defined as small (30–49 patients; six nursing homes), medium (50–69 patients; six nursing homes) or large (70–95 patients; three nursing homes). One group received intervention with DCM, one group received intervention with the VPM and the last group constituted a common control group for both intervention groups. DCM consists of in-depth four to six hours observations (mappings) of persons with dementia consisting of the standardized coding of the patients' well-being and behaviour in the dining area or the living room. Descriptions of interaction between staff and patients were also recorded. The observations were followed by a feedback session within one week in which the care staff was invited to reflect upon the findings and to plan future actions to improve care. The care staff and their leaders then implemented the action plans in the nursing home units without any further involvement of the researchers. After 6 months, the DCM observations and feedback were repeated. Two care staff members from each ward attended a basic DCM course certifying them to use DCM in their own nursing homes. The rest of the care staff received a three-hour introduction to PCC and DCM in the form of lectures from the researchers. The DCM observations were carried out by the researchers in collaboration with the internal DCM-certified staff.

In the VPM intervention the leading registered ward nurse, an auxiliary nurse from each ward and a registered nurse appointed as the internal VPM coach in each nursing home attended a three-day basic course before implementing the VPM in each unit. The directors of the nursing homes were also invited. The course, conducted by the researchers, focused on the main elements in PCC and the structure of the VPM. A DVD illustrating the perspective of the person with dementia was used as a basis and starting point for discussions of PCC. Another DVD showing the structure of the consensus meeting in practise was shown before all the participants got to try out their roles and functions in role plays. Time was set aside for the participants from each nursing home to plan the introduction to the rest of the staff and make a schedule for the consensus meetings in the units and the supervision sessions. The VPM coach then conducted a three-hour introduction to

PCC and the VPM for the rest of the staff in their nursing home. All staff also received the VPM manual. The VPM was implemented in the units as described above.

All three groups received five DVDs with lectures (30 min each) about dementia. Thus, the staff of the control group received only this intervention.

Fourteen nursing homes with a total of 40 wards and 624 patients with dementia were included in the study (one nursing home withdrew from participation after randomization). As 178 (29%) were lost to follow-up assessments, most of them because of death, a total of 446 patients were included in the efficacy analysis. In the VPM intervention group 4 nursing homes with 13 wards (range 12 – 29 patients) and 138 patients were analysed. In the DCM intervention group 5 nursing homes with 13 wards (range 24-32 patients) and 158 patients were analysed. In the control group five nursing homes with 14 wards (range 9-34 patients) and 150 patients were analysed (Paper 3).
The primary outcome was change on the Brief Agitation Rating Scale (BARS). Secondary outcomes were changes on the 10-item version of the Neuropsychiatric Inventory Questionnaire (NPI-Q), the Cornell Scale for Depression in Dementia (CSDD) and the Quality of Life in Late-Stage Dementia (QUALID) scale.
Change in the primary and secondary end points was defined as the difference between the follow-up and baseline scores. The intra-class correlation coefficient (ICC), which is the average correlation between patients from the same unit compared to the average correlation between patients from different units, was calculated. As there was a cluster effect in the data, the association between the change in the end points and the type of intervention as main predictor was assessed by regression models for hierarchical data. Such models take possible correlations between members of the same cluster (nursing home ward) into account and might prevent false significant findings. The associations were further controlled for age, gender, the CDR sum of boxes, general physical health, numbers of patients in a ward, type of ward and staff-patient ratio at baseline.

The results of the RCT showed that changes in the BARS score did not differ significantly between the VPM and the control group after 10 months, nor between DCM and the control group. However, we did find significantly less agitation as measured by the NPI-Q agitation subscale in patients of both intervention groups, as compared to the control group. Both the VPM and DCM had significant effect (less symptoms) on the total amount of neuropsychiatric symptoms and on psychotic symptoms compared to the control group as measured by the NPI-Q. The RCT showed a significant reduction in depression for the VPM intervention group compared to the control group measured by the CSDD which was not found for the DCM intervention group. Likewise, there was significantly less deterioration in quality of life in the DCM group measured by the QUALID scale compared to the control group, whereas the less deterioration in quality of life found in the VPM group was not significantly different compared to the control group.

The results of the RCT indicated that a substantial proportion of the total variance of the effects of the VPM (as well as for the DCM) was related to conditions in the particular unit (ward). Therefore, it was of interest to know which factors explained this variance. The VPM sub-set of data from the RCT was explored using multilevel linear regression (Paper 4). The dependent variables were the change in scores on the NPI-Q and the CSDD. The results showed that the unit in which the patient was living explained 22% of the VPM's total variance in effect on the NPI-Q and 13% for the CSDD. Organizational factors related to the unit were found to be more influential than factors at the institutional level when implementing PCC by use of the VPM. Of the variables in the multilevel model, unit size was the variable that explained the most of the variance in effect of the VPM. A unit was defined as an administrative unit of the nursing home with their own leader. The effect of the VPM was best in the small units.

In conclusion, the present thesis shows that the VIPS Practice Model developed for practical use of the VIPS-framework for person-centred care for persons with dementia is feasible in a Norwegian nursing home setting. The project also demonstrates that implementing PCC by the use for the VPM might reduce the total amount of neuropsychiatric symptoms, psychotic symptoms and depression in patients with dementia. The effects seem to be best in small size units.
Further research should continue to focus on how staff can gain more knowledge of neuropsychiatric symptoms, more insight into how the world might look from the

perspective of the persons with dementia, and how person-centred care best can be implemented in different types of dementia care settings.

Sammendrag

Ettersom terskelen for å gi psykofarmaka til personer med demens er høy på grunn av at denne typen legemidler har moderat effekt og kan ha alvorlige bivirkninger, er det et stort behov for forskning på effekt av psykososiale tiltak for personer med demens. Professor Tom Kitwood utviklet en sosialpsykologisk omsorgsfilosofi som han kalte personsentrert omsorg. Denne ses på som en av de mest lovende psykososiale tilnærmingene som kan anvendes i omsorgen for personer med demens. Kitwood tok utgangspunkt i Carl Rogers psykoterapeutiske tilnærming som la vekt på autentisk kontakt og kommunikasjon. Hjørnesteinen i personsentrert omsorg er «personhood», på norsk gjerne oversatt til «personverd». Personhood defineres som "..*en status som gis til et menneske av andre i sosiale relasjoner. Det innebærer anerkjennelse, respekt og tillit".* Å kunne tilfredsstille grunnleggende behov for trøst, tilknytning, inklusjon, beskjeftigelse og identitet er framhevet i personsentrert omsorg, siden en person med demens er avhengig av andre og i mindre grad i stand til å ta initiativ til å få dekket behovene selv. Hvordan demens framstår klinisk blir i denne omsorgsfilosofien forstått som et resultat av et kompleks samspill mellom pasientens personlighet, livshistorie, fysisk helse, nevrologiske (og nevropsykiatriske) symptomer og sosiale og psykologiske forhold som preger miljøet. VIPS rammeverket, som ble utviklet av Dawn Brooker, summerer opp elementene i personsentrert omsorg for personer med demens som: Verdier, Individuell tilpasset tilnærming, Perspektivet til personen med demens og det Sosiale miljøet. Hvert element inneholder seks indikatorer som beskriver hva som kreves for at omsorgen skal være personsentrert.

Det finnes få modeller for å innføre personsentrert omsorg, og fordi det er utført få randomiserte kontrollerte studier finnes det lite bevis for effekt. Det overordnede målet for denne avhandlingen var derfor å implementere verdiene i personsentrert omsorg i daglig, praktisk omsorg ved å bruke VIPS rammeverket, og å evaluere

effekten av dette på nevropsykiatriske symptomer hos personer med demens i sykehjem. Spesielt var vi interessert i

1. Å undersøke om en modell utviklet for praktisk bruk av VIPS rammeverket kunne implementeres i norske sykehjem
2. Å undersøke effektene av en slik modell på nevropsykiatriske symptomer
3. Å undersøke, om modellen har effekt, hvilke organisatoriske faktorer som har sammenheng med effektene til denne modellen

VIPS rammeverket er blitt operasjonalisert i det som har fått navnet VIPS praksismodell (VPM). VPM anvender undervisning og veiledning, definerte roller for personalet og fokus på hvordan omsorgen påvirker pasienten i en prosess for å utvikle kvaliteten i omsorgen. Den er basert på et strukturert samarbeid, veiledning og aktiv støtte fra ledelsen, elementer som Kitwood framhevet. Modellen fokuserer på prosessen i personalgruppen på avdelingen, og på å bygge felles verdigrunnlag og kunnskapsbase i personalet. Navet i VPM er et ukentlig fagmøte på avdelingen der VIPS rammeverket brukes til å analysere en utfordrende samhandlingssituasjon mellom pasient og pleier. Analysen legger vekt på hvordan situasjonen oppleves for pasienten og hvordan hans/hennes nevrologiske symptomer, fysiske helse, personlighet, livshistorie og psykososiale behov kan virke inn på hans/hennes reaksjoner. Hvert fagmøte følger et fast program der personalet har definerte roller og er med på å fatte beslutningene om hvordan omsorgen best kan tilrettelegges for å forebygge agitasjon eller andre nevopsykiatriske symptomer hos pasienten. Hensikten er at personalet skal bli samkjørte i et personsentrert syn på situasjonen (Artikkel 1).

VPM ble først evaluert i en 9 uker lang pilot studie i to sykehjem. Studien hadde et kvalitativt design og evalueringen ble gjort i fire fokusgruppeintervju der sju sykepleiere og fem hjelpepleiere deltok fra sykehjem A, og fire sykepleiere og sju hjelpepleiere deltok fra sykehjem B. Qualitative Content Analysis ble brukt til å analysere fokusgruppeintervjuene (Artikkel 2). Fem hovedtema ble identifisert: (1) Modellen fikk legitimitet når pleiere som representerte flertallet i personalgruppen hadde sentrale roller; (2) Modellen la til rette for at personalet fikk bruke kunnskapene sine om personsentrert omsorg; (3) Det var nødvendig med støtte til personene som var tildelt framtredende roller; (4) Avdelingslederens autoritet var avgjørende for å opprettholde modellens legitimitet i personalet; (5) Organisasjonsform hadde betydning for personalets opplevelse av modellen. VPM ble vurdert som velegnet i norske sykehjem etter litt justering.

Vi framsatte en hypotese om at VPM kunne være mer effektiv enn å gi undervisning til personalet om demens for å minske agitasjon og andre nevropsykiatriske symptomer hos sykehjemspasienter. En 10 måneders randomisert kontrollert studie (RCT) ble gjennomført for å måle effekten av VPM og Dementia Care Mapping (DCM), en annen modell basert på personsentrert omsorg, sammenlignet med å gi undervisning om demens til personalet (Artikkel 3).

RCT-studien ble gjennomført fra januar til desember 2011. Alle de 51 sykehjemmene i Oslo fikk tilbud om å delta i studien. Ved hjelp av loddtrekning ble de 15 sykehjemmene som takket ja fordelt i tre grupper etter størrelse; lite sykehjem (30-49 pasienter; seks sykehjem), middels stort sykehjem (50-69 pasienter; seks sykehjem) eller stort sykehjem (70-95 pasienter; tre sykehjem). En gruppe fikk DCM som intervensjon, en gruppe fikk VPM som intervensjon og en siste gruppe utgjorde en felles kontrollgruppe for de to intervensjonsgruppene.

DCM består av å utføre nøyaktige observasjoner av atferd (mappings) av personer med demens og bruker standardisert koding av pasientenes uttrykk for velvære og atferd. Mapping gjennomføres i fire til seks timer i spisesal eller stue. Det blir laget beskrivelser av samhandling mellom pleiere og pasienter. Innen en uke etter observasjonene blir det gitt tilbakemelding der personalet blir oppmuntret til å reflektere rundt funnene og planlegge tiltak for å forbedre omsorgen. Deretter blir personalet og deres ledere oppfordret til å utarbeide tiltaksplaner i sykehjemsavdelingene uten videre medvirkning fra forskerne. Etter seks måneder ble DCM observasjon og tilbakemelding gjentatt i studien. Ved studiestart deltok to pleiere fra hver avdeling på et innføringskurs i DCM der de ble sertifisert til å bruke DCM på sykehjemmene de arbeidet ved. Resten av personalet fikk et tre timers introduksjonskurs om personsentrert omsorg og bruk av DCM i form av forelesninger fra forskerne. DCM-observasjonene ble utført av forskerne i samarbeid med de interne pleierne som hadde fått DCM sertifisering.

I VPM intervensjonen deltok avdelingslederen, en hjelpepleier/helsefagarbeider fra hver avdeling og en fagutviklingssykepleier fra hvert sykehjem som fikk rollen som intern VPM veileder, på et tredagers introduksjonskurs før VPM ble innført på

avdelingene. Institusjonslederne ble også invitert. Kurset ble holdt av forskerne og fokuserte på elementene i personsentrert omsorg og strukturen i VPM. En DVD som illustrerte perspektivet til en person med demens ble brukt som utgangspunkt for å diskutere personsentrert omsorg. En annen DVD som viste hvordan fagmøtet i VPM fungerer i praksis ble vist før alle deltakerne fikk prøve ut sine roller og funksjoner i rollespill. Det var satt av tid slik at deltakerne fra hvert sykehjem fikk planlegge introduksjonen til resten av personalet og lage en plan for fagmøtene på avdelingene samt veiledning. Hver interne VPM veileder ga så en tre timers introduksjon om personsentrert omsorg og VPM til resten av personalet i sitt sykehjem. Personalet fikk også en VPM-manual. VPM ble innført på avdelingene som beskrevet.
Alle tre grupper fikk fem DVDer som inneholdt foredrag (à 30 min) om demens, for kontrollgruppen ble dette deres intervensjon.

Fjorten sykehjem med totalt 40 avdelinger og 624 pasienter med demens ble inkludert i studien (et sykehjem falt fra etter randomiseringen). Ettersom 178 (29%) falt ut før andre måling (10 måneder), hovedsakelig på grunn av dødsfall, ble tilslutt 446 pasienter inkludert i effektanalysene. I VPM-gruppen ble fire sykehjem med 13 avdelinger (pasientantall fra 12 til 19) og 138 pasienter analysert. I DCM-gruppen ble fem sykehjem med 14 avdelinger (pasientantall fra 24 til 32) og 158 pasienter analysert. I kontrollgruppen ble fem sykehjem med 14 avdelinger (pasientantall fra 9 til 34) og 150 pasienter analysert (Artikkel 3).
Primært effektmål var endring i skåren på Brief Agitation Rating Scale (BARS). Sekundære effektmål var endring i skårene på Neuropsychiatric Inventory Questionnaire (NPI-Q), Cornell Scale for Depression in Dementia (CSDD) og skala for Quality of Life in Late-Stage Dementia (QUALID). Endring i primært og sekundære effektmål var definert som differansen mellom skårene på måling etter 10 måneder og skårene ved oppstart av RCT-en (baseline). Intra klasse koeffisienten (Intra-class (cluster/klynge) coefficient, ICC) ble beregnet. ICC er den gjennomsnittlige korrelasjonen mellom pasientene fra samme avdeling sammenlignet med den gjennomsnittlige korrelasjonen mellom pasientene fra ulike avdelinger. Ettersom det ble funnet en gruppeeffekt (klyngeeffekt) i dataene, ble sammenhengen mellom endring i effektmål og type intervensjon beregnet ved hjelp av regresjonsmodeller for hierarkiske data. Slike modeller tar hensyn til mulig korrelasjon mellom medlemmer av en gruppe (sykehjemsavdeling) og kan slik

forhindre falske signifikante funn. Forskjellen mellom første måling og andre måling innen hver gruppe ble beregnet ved bruk av t test for parvise utvalg. Kontinuerlige effektmål i intervensjonsgruppen og kontrollgruppen ble sammenlignet ved bruk av t test for uavhengige utvalg. Sammenhengene ble kontrollert for alder, kjønn, grad av demens, generell somatisk helsetilstand, antall pasienter i avdelingen, type avdeling og pleier-pasient ratio ved første måling.

Resultatene viste at endringene i BARS-skåre ikke var signifikant forskjellige mellom VPM gruppen og kontrollgruppen etter 10 måneder, heller ikke mellom DCM og kontrollgruppen. Derimot fant vi en signifikant forskjell i agitasjon målt ved subskalaen for agitasjons på NPI-Q i favør av begge intervensjonsgruppene sammenlignet med kontrollgruppen. Både VPM og DCM hadde signifikant og positiv effekt på totalt antall nevropsykiatriske symptomer og på psykotiske symptomer sammenlignet med kontrollgruppen målt med NPI-Q. RCT-en viste en signifikant reduksjon i depresjonssymptomer for VPM intervensjonen sammenlignet med kontrollgruppen målt ved CSDD, en effekt som ikke ble funnet for DCM intervensjonsgruppen. Likeså var det en signifikant mindre forverring i livskvalitet i DCM-gruppen målt ved QUALID-skalaen sammenlignet med kontrollgruppen, mens den reduserte forverringen av livskvalitet som ble funnet i VPM-gruppen ikke var signifikant sammenlignet med kontrollgruppen.

Resultatene fra RCT-studien indikerte at en substansiell del av den totale variasjonen i effektene av VPM (og av DCM) hadde sammenheng med forhold på hver avdeling. Derfor var det interessant å få innsikt i hvilke faktorer som forklarte variasjonen i effekt. Datagrunnlaget for VPM-gruppen ble derfor analysert ved bruk av multilevel lineær regresjon (analyseteknikk for data ordnet hierarkisk) (Artikkel 4). Endring i skåre på NPI-Q og CSDD ble brukt som avhengige variabler. Resultatene viste at avdelingen som pasienten bodde på forklarte 22 % av den totale variasjonen i effekt for VPM for NPI-Q og 13 % for CSDD. Organisatoriske faktorer relatert til avdelingen viste seg å ha større innvirkning på effekten av VPM enn faktorer på institusjonsnivå. I analysen var avdelingsstørrelse den variabelen som forklarte mest av variasjonen i effekt av VPM. En avdeling var definert som en administrativ enhet i sykehjemmet med egen leder. Effekten av VPM var best i små avdelinger.

Konklusjonen i denne avhandlingen er at VIPS praksismodell (VPM), som ble utviklet for å bruke VIPS rammeverket til å innføre personsentrert omsorg for personer med demens, passer til bruk i norske sykehjem. Prosjektet viser også at å innføre personsentrert omsorg ved hjelp av VPM kan redusere nevropsykiatriske symptomer totalt, psykotiske symptomer og depresjon hos pasienter med demens. Effekten synes å være best i små avdelinger med egen leder. Videre forskning bør fokusere på hvordan personalet kan få økt kunnskap om nevropsykiatriske symptomer, mer innsikt i hvordan verden kan oppleves fra perspektivet til en person med demens, og hvordan personsentrert omsorg best kan innføres på ulike arenaer for demensomsorg, for eksempel i dagsenter og hjemmesykepleie.

List of papers

1. Røsvik J., Brooker D., Mjørud M. & Kirkevold Ø. (2013) What is person-centred care in dementia? Clinical reviews into practice: The development of the VIPS Practice Model. Reviews in Clinical Gerontology 2013;23:155–163

2. Røsvik J., Kirkevold M., Engedal K., Brooker D. & Kirkevold Ø. (2011) A model for using The VIPS framework for person-centred care for persons with dementia in nursing homes: a qualitative evaluative study. International Journal of Older People Nursing 2011;6:227–236

3. Rokstad A.M.M[1]., Røsvik J[1]., Kirkevold Ø., Selbæk G., Saltyte Benth J. & Engedal K. (2013) The Effect of Person-Centred Dementia Care to Prevent Agitation and Other Neuropsychiatric Symptoms and Enhance Quality of Life in Nursing Home Patients: A 10-Month Randomized Controlled Trial. Dementia and Geriatric Cognitive Disorders 2013;36:340–353

   [1] shared first authorship

4. Røsvik J., Engedal, K. & Kirkevold Ø. (2013) Factors associated with effect of the VIPS practice model on neuropsychiatric symptoms in persons with dementia in nursing homes. Dementia and Geriatric Cognitive Disorders
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Abbreviations

AN	Auxiliary nurse
BARS	Brief Agitation Rating Scale
CDR	Clinical Dementia Rating Scale
CMAI	Cohen-Mansfield Agitation Inventory
CSDD	Cornell Scale for Depression in Dementia
DCM	Dementia Care Mapping
DSM-5	Diagnostic and Statistical Manual of Mental Disorders 5
ICD-10	International Classification of Disease and Related Health Problems
NPI	Neuropsychiatric Inventory
NPI-NH	Neuropsychiatric Inventory nursing home
NPI-Q	Neuropsychiatric Inventory Questionnaire
QUALID	Quality of Life in late-stage Dementia scale
PCC	Person-centred care
RCT	Randomized controlled trial
RN	Registered nurse
SCU	Special Care Units
VIPS	Values, Individualized care, Perspective of the person, Social inclusion
VPM	VIPS Practice Model

1 Introduction

Like in most countries throughout the world, the population is ageing in Norway, which has led to a significant rise in the number of people with dementia. It is estimated that 35.6 million people throughout the world had dementia in 2010, and this number is predicted almost to double every 20 years, to 65.7 million in 2030 (Prince et al., 2013). Presently, it is estimated that about 70,000 persons have got dementia in Norway (Norwegian Ministry of Health and Care services, 2008). This means that dementia and dementia care have become priority research areas in order to meet the population's future health-care needs.

Dementia is a chronic progressive brain condition, which is caused by various brain disorders. Dementia leads to a decline in multiple areas of cognition and an increase in neuropsychological symptoms, such as agitation and depression, as well as dependency because of the inability to perform daily living activities (Engedal & Haugen, 2004). The threshold for the use of psychotropic drugs in patients with dementia is increasing, so there is an urgent need to study the effectiveness of psychosocial interventions (Lyketsos, 2010). Kitwood's care philosophy; i.e., person-centred care (PCC) (Kitwood, 1997a), is regarded as one of the most promising psychosocial approaches. However, it has been difficult to translate the PCC philosophy into practical daily care (McCormack, 2004). At present, the evidence base for the effectiveness of PCC is limited, which is partly because few models for implementation of PCC were available.

This thesis describes the development of a model for implementing Kitwood's PCC philosophy, the VIPS Practice Mode (VPM), it attempts to provide evidence for the positive effect of PCC by use of the two PCC models VPM and DCM, as well as identifying factors that may influence the implementation and the effects of using the VPM.
My college Anne Marie Mork Rokstad was responsible for the DCM intervention and has described this in her thesis.

2 Background

2.1 Dementia

2.1.1 Prevalence and incidence

Engedal & Haugen (1993) examined the prevalence of dementia in elderly Norwegians aged 75 years and above using a representative sample from a population surveyed in Oslo. The estimated total prevalence in that study was 16.3%, and the incidence of dementia was estimated to be 10,000 people per year. The number of people aged over 75 years is rising, so the number of people with dementia will double, and it is estimated to reach about 130,000 in 30–40 years (Engedal & Haugen, 1993). These figures fit well with figures from international prevalence studies from other European countries.

2.1.2 The diagnosis of dementia

Dementia is a chronic irreversible brain syndrome. There are various underlying causes, but all lead to cognitive impairment, a reduced ability to function in daily life compared with that previously possible, and changes in social functioning. The first cognitive symptom in most cases is reduced memory, except in fronto-temporal dementia, where changes of behaviour are the hallmarks. Other cognitive symptoms include impaired orientation, impaired reasoning, impaired spatial orientation and speech problems. A person with dementia will also develop symptoms behavioural and neuropsychiatric symptoms such as irritability, depression or changes in personality, and motor symptoms such as a loss of balance and incontinence (Engedal & Haugen, 2004).

Two sets of criteria which do not differ much in their content are used for the diagnosis of dementia, as follows.

- International Statistical Classification of Diseases and Related Health Problems, 10th revision (ICD-10) Version 1993 (WHO, 1993)
- Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) (American Psychiatric Association, 2013) (APA).

In ICD-10, the term dementia is defined as a “*mental and behavioural disorder*”. It is a syndrome characterized by dysfunction in at least two cognitive areas, which usually begins with memory deficits or impaired executive functions. Other areas such as orientation, language and general intellectual function become affected gradually. Cognitive impairment affects a person’s capacity to deal with everyday activities. This is the definition of dementia in ICD-10:

> *“Dementia is a syndrome due to diseases of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain”*.
> (International Statistical Classification of Diseases and Related Health Problems,10th revision (ICD-10) Dementia (F00-F03)

Textbox 1 Research criteria for dementia according to ICD-10

I

1. Memory impairment, especially for new information
2. Impairment of other cognitive functions (judgment, planning, thinking, abstraction)

Mild: Affects the persons capacity to cope with everyday activities
Moderate: The person cannot live independently.
Severe: Continuously care is required.

II. Clear consciousness

III. Impairment in emotional control, motivation or social behaviour in at least one of the following:

1. Emotional instability
2. Irritability
3. Apathy
4. Coarsening of social behaviour

IV. The condition must have a duration of at least 6 months

From World Health Organization, 1993

DSM-5 (APA 2013) uses the term "*neurocognitive disorder*", although "*dementia"* can still be used. DSM-5 defines the core feature of neurocognitive disorder as acquired cognitive decline in one or more cognitive domains based on a concern about cognition and performance in an objective assessment that falls below the expected level (see textbox 2).

Textbox 2 Diagnostic criteria for Major Neurocognitive Disorder according to DSM- 5

A. Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains (Complex attention, Executive function, Learning and memory, Language, Perceptual-motor, Social cognition) based on:
    a. Concern of the individual, a knowledgeable informant, or the clinician that there has been a significant decline in cognitive function; and
    b. A substantial impairment in cognitive performance, preferably documented by standardized neuropsychological testing or, in its absence, another quantified clinical assessment.

The cognitive deficits interfere with independence in everyday activities (i.e., at a minimum, requiring assistance with complex instrumental activities of daily living such as paying bills or managing medications).

B. The cognitive deficits do not occur exclusively in the context of a delirium.

C. The cognitive deficits are not better explained by another mental disorder (e.g., major depressive disorder, schizophrenia).

From American Psychiatric Association, 2013

Late onset dementia

Late onset dementia is the term applied to all types of dementia with debut after the age of 65. The most common types of late onset dementia are Alzheimer's disease, Lewy body dementia and vascular dementia (Engedal & Haugen, 2004).

Types of dementia

Dementia disorders can be divided into three groups according to the aetiologies: degenerative brain diseases, vascular diseases and secondary dementias.

The differences in the symptoms and signs among the different types of dementia are greatest during the early phase of various dementia disorders.

Degenerative brain diseases

Alzheimer’s disease is a degenerative disease with specific neuropathological changes, which usually include intra-neuronal (neurofibrillary tangles) and extracellular parenchymal lesions (senile plaques) that are accompanied by synaptic losses and vascular amyloid deposits in the brain. Approximately 60% of all people with dementia have this type of dementia. The first cognitive symptom is often reduced memory. In the next phases, motor symptoms often develop, such as loss of balance, as well as behavioural and psychological symptoms, such as apathy, depression and anxiety. In general, Alzheimer’s disease has a gradual progression (Engedal & Haugen, 2004; Gauthier et al., 2010).

According to ICD-10, mixed Alzheimer’s disease is ascribed to people who fulfil the diagnostic criteria for Alzheimer’s disease and cerebrovascular disease (Engedal & Haugen, 2004).

Lewy body dementia is a type of dementia that involves a gradual impairment of cognitive function with fluctuations. Wakefulness varies from day to day, while alertness and short-term memory ebb and flow. Lewy bodies are structures found in degenerating brain cells. A critical feature of this type of dementia is hypersensitivity to neuroleptic medications. Early during progression of the disease, the patient exhibits parkinsonism; i.e., shuffling gait, reduced arm swing during walking, reduced range of facial expressions and stiffness of movements. The patients will often experience visual hallucinations. Disinhibition, sleep disturbances and depression are frequent, and there is an increased risk of falls. About 10–15% of dementia patients have this type of dementia (Engedal & Haugen, 2004)

Fronto-temporal dementia is characterized by atrophy in the frontal and temporal lobes of the brain. In contrast to Alzheimer’s disease, the early cognitive symptoms are reduced executive functions, such as a lack of initiative, impaired problem-solving ability and speech problems, rather than reduced memory. Neuropsychiatric symptoms such as changes in personality with self-neglect and loss of inhibitions, causing inappropriate behaviour, occur early in the disease progression (Engedal & Haugen, 2004)

Vascular dementia

Vascular dementia is often attributable to stroke, small vessel disease or ischemia in the brain. It has a more sudden onset and a more stepwise decline in function than Alzheimer's disease, and it varies with respect to the cognitive symptoms. Neuropsychiatric symptoms such as depression, emotional lability and apathy are common in vascular dementia, especially depression (Engedal & Haugen, 2004).

Secondary dementias

There are numerous other causes of dementia, all of which are relatively rare, including alcohol related brain damages, Huntington's disease, Creutzfeld-Jacobs disease, normal pressure hydrocephalus, HIV infection, syphilis, subdural haematoma, cerebral tumours and many rare neurological disorders (Engedal & Haugen, 2004).

Many specialists maintain that dementia remains a clinical diagnosis, where laboratory or imaging tests still only provide supportive diagnostic evidence (Chertkow, Feldman, Jacova, & Massoud, 2013; Engedal & Haugen, 2004). Others, especially neurologists, would prefer to use biomarkers (surrogate markers of the underlying pathological changes) for the diagnosis of various types of dementia, such as findings based on spinal fluid analyses and brain imaging techniques (Dubois et al., 2010; Dubois et al., 2007).

The majority of older people with dementia have some evidence of vascular and neurodegenerative pathology (Engedal & Haugen, 2004). This thesis considers the common symptoms in people with different types of dementia.

2.1.3 Dementia care in Norwegian nursing homes

Before the Second World War, there were few institutions for the elderly in Norway. However, demographic changes after the war and the expectations of greater welfare resulted in an increase. Based on collaboration between the authorities and non-profit organizations, 476 institutions for the elderly with about 13,400 beds were established by 1940. The term "nursing home" emerged around 1955. The government took legal responsibility for the care of the sick and disabled elderly in 1964. Norwegian nursing homes are publicly funded and were transferred to the jurisdiction of the 435 local authorities in 1984.

In 2013, the population of Norway was just above five million. The number of people aged 80 years and above was 221,585, and about 18% (40,000) of them lived in nursing homes (Statistics Norway, 2013).

The main types of units in the nursing homes are regular (ordinary) units and special care units (SCUs) for persons with dementia, where some have separate strengthened subunits for patients with severe behavioural and neuropsychiatric symptoms. Some nursing homes also have units for rehabilitation and respite care. Sheltered housing units are provided to people in an early stage of dementia who are in physical good health. These units are not defined as institutions, and their legal and funding status differ from the SCUs in nursing homes. Sheltered housing will not be mentioned further in this thesis.

The first SCUs were established in the mid 1980s. The criteria for these units were vaguely defined—i.e., only the size of the units (4–12 patients) was specified—but a thorough examination of patients and a diagnosis of dementia were mentioned in a Regulation of 1988 by the Norwegian Ministry of Health (Norwegian Ministry of Health, 2006) According to the review by Lai et al. (2009), there is no standard definition of a SCU internationally either (Lai, Yeung, Mok, & Chi, 2009), but the following components were described consistently as the defining characteristics of SCUs in a study by Leon (Leon & Siegenthaler, 1994):

1. Admission of patients with dementia
2. Special selection, training and supervision of staff members
3. Specially designed activity programming
4. Family involvement
5. A specially designed physical environment, which is segregated from other areas

The mean number of beds in Norwegian SCUs was 7.9 in 2011, although some had up to 20 beds, mainly because the units were divided into subunits (Kirkevold, Eek, & Engedal, 2012). Many of the units had direct access to safe outdoor areas, such as a garden.

SCUs have an average ratio of three patients per nurse during the day shifts on weekdays and four patients per nurse at the weekends and evenings. About one-third of the front-line staff in nursing homes lacks formal qualifications, and one-quarter of the staff have a college education (Norwegian Directorate of Health, Annual Report, 2010). In 2010, the proportion of registered nurses in SCUs was 28% (Kirkevold, Eek, & Engedal, 2012). In 2004, the proportion of unskilled carers was 11.9% in regular units and 12.6% in SCUs (Kirkevold, Sandvik, & Engedal, 2004). Kirkevold et al. (2008) examined a representative Norwegian sample of 160 regular nursing home units and 91 SCUs, and found that SCUs had significantly fewer quality deficiencies with respect to care for basic needs compared with regular units (Kirkevold & Engedal, 2008). Between 1997 and 2009, the SCU capacity doubled, and the coverage rate for people with dementia increased from 18% to 33%. In 2010, 87% of the municipalities had established SCUs. In 2011, 24% of the nursing home beds were in SCUs for people with dementia 2011 (Kirkevold et al., 2012).

In a study published in 2006, Kirkevold & Engedal found that most patients received good basic care in Norwegian nursing homes. However, the possibility of participating in leisure activities and outdoor pursuits was not prioritized. Low function in terms of mental capacity, activities of daily living and neuropsychiatric symptoms such as aggressive behaviour were factors associated with reduced quality of care (Kirkevold & Engedal, 2006). The same factors, as well as severe dementia, were found to be associated with the use of restraints in a study reported in 2004 (Kirkevold et al., 2004). Almost 37% of the patients in the ordinary (somatic) units and 45% of the patients of SCUs were subjected to the use of restraints.
In ordinary units, 23.3% of the patients were subjected to the use of mechanical restraints, such as fixing to a chair, which also applied to 12.8% of the patients in SCUs. The use of force or pressure during activities of daily living, such as holding the hands while washing when the patient resisted physically, was used towards 0.9% of the patients of SCUs and towards 16.6% of the patients of ordinary units (Kirkevold & Engedal, 2004a). Typically, the staff made the decision to use restraints, the physician in charge made the decision in only 23% of cases. The most common reason given for the use of restraints was to protect the patient or others, or to carry out medical treatment. Routine documentation of the use of restraints was reported to be lacking (Kirkevold & Engedal, 2004b).

2.1.4 Dementia in nursing homes in Norway

A study of a sample of 1,163 nursing home patients from 26 nursing homes in 18 municipalities in four Norwegian counties showed that 80.5% of the patients had dementia (Selbaek, Kirkevold, & Engedal, 2007), with a score of ≥ 1 at the Clinical Dementia Rating Scale (CDR) (Hughes, Berg, Danziger, Coben, & Martin, 1982). In line with the cross-sectional data of this sample, a 53-month longitudinal follow-up study was conducted (Selbaek, Engedal, Benth, & Bergh, 2013). At baseline, the mean age of the patients was 84.5 years, most of the patients were women (74%), 52% had poor or very poor physical health and 75% of the patients used psychotropic drugs on a daily basis. Twenty-five 25% of the patients had mild dementia, 33% had moderate dementia and 42% had severe dementia, according to the CDR scale. Nearly all of the patients exhibited clinically significant neuropsychiatric symptoms (Selbaek, Engedal, Benth, et al., 2013).

2.2 Neuropsychiatric symptoms

Symptoms such as apathy, agitation, depression and disinhibition are part of dementia. Approximately 70–95% of people with dementia develop at least one of these symptoms during the course of their dementia disorder (Selbaek, Engedal, & Bergh, 2013). These symptoms cause discomfort for a person with dementia, and they are predictors of falls for patients in nursing homes, causing considerable morbidity and mortality (Sylliaas, Selbaek, & Bergland, 2012). Furthermore, they are associated with the use of psychotropic medications (Ruths et al., 2013), which may have negative side effects. The symptoms represent a strain on the family (Bergvall et al., 2011) and they may be stressful for the staff in institutions (Zwijsen et al., 2013).

Different terms have been used for the symptoms. These symptoms differ from cognitive dysfunction, so the term “non-cognitive symptoms of dementia” has been used. The terms “behavioural disturbances” and “challenging behaviour” refer to altered behaviour. The term “behavioural and psychological symptoms of dementia” (BPSD) was proposed at the International Psychogeriatric Association’s (IPA) Initial Consensus Conference in 1996. At present, the term “neuropsychiatric symptoms of dementia” is used frequently in the literature and is therefore used in this thesis.

2.2.1 Prevalence of neuropsychiatric symptoms among nursing home patients

In previous international studies, agitation and apathy were reported to be the most prevalent symptoms in patients with dementia in nursing homes (Aalten, de Vugt, Jaspers, Jolles, & Verhey, 2005; Ballard et al., 2001). Wetzels et al. (2010) found that agitation, irritability and aberrant motor behaviour were the most prevalent symptoms (Wetzels, Zuidema, de Jonghe, Verhey, & Koopmans, 2010a).

Bergh et al. (2011) assessed 169 patients from seven Norwegian nursing homes at five time points over a period of 16 months (Bergh, Engedal, Roen, & Selbaek, 2011) using the Neuropsychiatric Inventory (NPI) (Cummings et al., 1994).This study showed that irritability was the most common neuropsychiatric symptom (35%), while aggression / agitation was the second most prevalent symptom (32%). Almost every patient (91.7%) had at least one clinically significant neuropsychiatric symptom during the 16-month period, but individual neuropsychiatric symptoms exhibited a fluctuating course (Bergh et al., 2011).

The findings reported by Bergh and colleges (2011) largely agree with the results of the Norwegian nursing home study of Selbaek and colleges from 2013, except that Bergh et al. found no change in the severity of individual symptoms. Selbaek et al. (2013) found that irritability (29%), apathy (29%) and agitation (27%) were the most prevalent and persistent symptoms during the study period and that these symptoms increased in severity during the follow-up period. Depression and anxiety became less severe. Furthermore, Selbaek et al. (2013) found that more severe dementia was associated with more severe agitation, psychosis and apathy but not with more severe depression and anxiety. Increased severity of psychosis was associated with mild dementia, while moderate or severe dementia was associated with a decrease in the severity of psychosis during the follow-up period (Selbaek, Engedal, Benth, et al., 2013). These inconsistent findings with respect to changes in the severity of individual symptoms may be attributable to the use of different statistical methods (e.g., information about all the patients available during each assessment versus information including only completers in the analysis). In addition, Selbaek et al. (2013) had a longer follow-up period (53 months) and a larger sample size (931 patients with dementia), although both studies used the same scale (NPI).

In summary, nearly all of the nursing home patients with dementia included in these Norwegian studies experienced clinically significant neuropsychiatric symptoms. Irritability, agitation/aggression and apathy were most prevalent, whereas hallucinations and euphoria had the lowest prevalence. This agrees with research from other European countries (Margallo-Lana et al., 2001; Selbaek, Engedal, Benth, et al., 2013; Wetzels, Zuidema, de Jonghe, Verhey, & Koopmans, 2010b; Zuidema, Koopmans, & Verhey, 2007).

Table 1 Weighted means and range of prevalence, persistence, incidence and cumulative prevalence of studies on neuropsychiatric symptoms in persons with dementia in nursing homes as measured by the Neuropsychiatric Inventory

	*WMeans of the prevalence rates (range)	[a]Persistence rates (range)	[b]Incidence rates (range)	[c]Cumulative prevalence rates (range)
Any one neuro-psychiatric symptom	82% (38-95)	51%-89%	20%-56%	48%-97%
Aggression/ Agitation	30% (24-48)	53%-75%	10%-19%	27%-54%
Disinhibition	18% (9-21)	10%-79%	5%-19%	27%-50%
Irritability	31% (20-35)			
Abberant motor behaviour	25% (15-39)	42%-68%	3%-16%	46%-50%
Delusions	19% (11-26)	13%-66%	3%-17%	21%-45%
Hallucinations	9% (5-14)	25%- 100%	0%-8%	10%-18%
Depression	20% (10-26)	0%-85%	3%-14%	27%-46%
Anxiety	21% (12-26)			
Apathy	32% (23-48)	36%-70%	9%-27%	45%-53%

Based on 28 studies, median number of participants:117 (range 86-633). Prevalence studies: a total of 8468 patients, longitudinal studies: a total of 1458 patients. Completed follow-up: a total of 1458 patients, Follow-up: 4 months- 2 years, 2- 5 assessments. *Wmean: weighted mean; weighting the mean by the number of residents in each study. The wmean age: 82.9 years (range 80-84), mean proportion of women: 73.7% range 64-76).

[a] Persistence (N with symptom divided by N with symptom on the previous assessment)

[b] Incidence (N with symptom divided by N without symptom on the previous assessment)

*[c] cumulative prevalence (%): the proportion of patients with a neuropsychiatric symptom at least at one of the assessments.

From Selbaek, Engedal, & Bergh, 2013

2.2.2 Types of neuropsychiatric symptoms

The neuropsychiatric symptoms are not provided with definitions and diagnostic criteria in the ICD-10 or the DSM-5; thus, definitions based on assessment scales such as the NPI are used in the present study. The symptoms included in the NPI are described below.

Delusions

A delusion is a false belief, based on incorrect inference about an external reality, that is firmly sustained despite what almost everyone believes, and despite evidence constituting incontrovertible and obvious proof to the contrary (DSM-5). A typical delusion for a person with dementia is that someone has stolen their purse or that their spouse is being unfaithful.

Hallucinations

A hallucination is a perception without apparent stimulus, which appears real to the person experiencing it. Hallucinations can affect all five senses, but visual hallucinations are the most common type in patients with dementia. To experience hallucinations is one of the criteria for Lewy body dementia, and it affect as many as 50–80% of patients with this type of dementia (Engedal & Haugen, 2004). Misidentification is common in patients with dementia because of confusion or the misinterpretation of stimuli, which should not be mistaken for a delusion or a hallucination. A person with dementia may think that people on television are real, or they may be frightened of reflections in large windows.

A person with dementia may also recall associations from their past and talk about persons that are long dead, which are not signs of delusions or hallucinations (Engedal & Haugen, 2004).

Anxiety

People with dementia may experience anxiety as a reaction to their reduced abilities to comprehend the world around them. Anxiety may be related to or overlapping with agitation, irritability and aggression (Clive-Reed & Gellis, 2011).

Apathy

Apathy—passivity and lack of initiative—is one of the most prevalent neuropsychiatric symptoms in dementia (Selbaek, Engedal, & Bergh, 2013). Apathy is associated with more rapid cognitive and functional decline, depression and increased mortality (Starkstein, Jorge, Mizrahi, & Robinson, 2006; Tagariello, Girardi, & Amore, 2009). Apathy is one of the core symptoms of fronto-temporal dementia.

Disinhibition

Together with apathy, disinhibition is part of the fronto-temporal syndrome, where people exhibit inappropriate behaviour, such as rudeness or aberrant sexual behaviour (Engedal & Haugen, 2004).

Aberrant motor behaviour

Aberrant motor behaviour is frequent in dementia. The review reported by Selbaek and colleges found that 25% of the people with dementia in nursing homes exhibit this symptom (Selbaek, Engedal, & Bergh, 2013). This symptom can take many forms, including wandering or incessant drumming with the fingers on a table.

Sleep disturbances

Sleep disturbances are more prevalent in people with dementia than in those without dementia. Patients may sleep more than others or develop a disturbed sleep pattern because a lack of activity disrupts their diurnal rhythm (Engedal & Haugen, 2004).

Changes in eating

This may be changes like developing a constant request food or seemingly lack of hunger.

Repetitive calling, screaming and hoarding are also common symptoms of dementia (Engedal & Haugen, 2004).

Agitation

Together with apathy, agitation, aggression or irritation are the most common neuropsychiatric symptoms in people with dementia in nursing homes. In the review reported by Selbaek colleges, the mean prevalence of any one agitation symptom measured by the NPI was 82% (range, 38–95%) (Selbaek, Engedal, & Bergh, 2013).

The aetiology of agitation is poorly understood (Ballard et al.,2009), but it is generally considered to be multifactorial, and possible causes include brain changes, genetics, physical diseases (delirium), unmet needs and pain (Cohen-Mansfield, Billig, Lipson, Rosenthal, & Pawlson, 1990; Kovach, Noonan, Schlidt, & Wells, 2005, Gauthier et al., 2010).

Cohen-Mansfield et al. (1989) classified agitation into aggressive behaviours, physical non-aggressive behaviours and verbal agitated behaviour (Cohen-Mansfield et al., 1989). Aggressive manifestations include cursing or hitting, examples of non-aggressive manifestations are constant requests for attention and pacing (Cohen-Mansfield, Juravel-Jaffe, Cohen, Rasooly, & Golander, 2013). Kong (2005) argues that restlessness should be differentiated from agitation because it is described as more continuous and less severe than agitation (Kong, 2005). It has been debated whether aggressiveness should be a subcategory of agitation or regarded as a separate behaviour (Cohen-Mansfield & Billing, 1986). Only a proportion of agitated patients become aggressive (Kindermann, Dolder, Bailey, Katz, & Jeste, 2002). There is no consensus on the concept of agitation, including how it is caused and how it should be measured (Gauthier et al., 2010, Bidewell & Chang, 2011).

Cohen-Mansfield and Billing (1986) defined agitation as: "*Inappropriate verbal, vocal, or motor activity that is not explained by needs or confusion per se*" (Cohen-Mansfield & Billig, 1986). This definition has been used widely in research into agitation in dementia, but it has been criticized for its broadness, the observer's judgement about the appropriateness of behaviour and ambiguity when distinguishing agitated behaviour from need-driven behaviour (Kong, 2005). According to Kong (2005), descriptions of agitation depend on whether the underlying perspective is that of the observer (e.g., "inappropriate" or "disruptive"), the patient ("expression of need") or a neutral perspective (human response) (Kong, 2005). Bidewell and Chang (2011) hold that agitation should be considered to be the sum of the person with dementia's function and the context in which they live, which can be interpreted as unmet needs. In their view, agitation is a form of maladaptive communication, a clinical sign rather than a disorder in itself and a constellation of behaviours rather than a specific behavioural problem. Attributing agitation solely to the dementia itself should be the inference of last resort (Bidewell & Chang, 2011).

According to Cohen-Mansfield, (Cohen-Mansfield, 2001), three theoretical models have generally been applied to understand what was termed "inappropriate behaviours in dementia":

- Unmet needs model
- Learning and behavioural model
- Environmental vulnerability and reduced stress-threshold model

Unmet needs model

The term "need-driven dementia-compromised behaviour" was proposed by Algase and colleges in 1996. They viewed behaviours referred to as "disruptive behaviour" at the time, such as wandering or repetitive questioning, as expressions or embodiments of the goals or needs of the person with dementia. According to the unmet needs model, agitation is the response to a somatic, social or environmental (externally physical) problem (Algase et al., 1996). The unmet needs model contradicts theories that describe agitation as inappropriate verbal or motor activity, which are not attributable to unmet needs (Cohen-Mansfield & Billig, 1986; Cohen-Mansfield, Culpepper, & Werner, 1995). However, Cohen-Mansfield & Billig (1986) noted that needs could simply be unapparent because of communication or interpretation difficulties (Bidewell & Chang, 2011; Cohen-Mansfield & Billig, 1986). According to Algase and colleges (1996), need-driven dementia-compromised behaviour reflects the interaction among the cognitively impaired person's background factors, including neurological cognitive health status and psychological factors. These factors interact with the physical and social environment, as well as the needs and states within the person. Need-driven dementia-compromised behaviour is considered to constitute:

> *“..the most integrated and meaningful response possible, given the limitations imposed by a dementing condition, strengths preserved from the person’s basic abilities and personality, and constraints, challenges, or supports offered by the immediate environment”* (Algase et al., 1996).

Behavioural / learning model

In a behavioural or learning model, agitated behaviours is assumed to be behaviours that have been reinforced in the environment, for instance a person with dementia has learned that she or he can get attention by screaming (Miesen & Jones, 1997). It has been debated whether this is in line with the quality of care principles because it implies ignoring a person with dementia who seeks attention. This could be considered neglectful, especially if the behaviour reflects deficiencies in care (Bidewell & Chang, 2011). Also, a person with dementia will have diminished capacity to acquire new behaviours from recent experience (Cohen-Mansfield, 2000).

Environmental vulnerability and reduced stress-threshold model

This model is based on a theory of progressively lowered threshold because of neuron loss in the brain resulting in reduced tolerance for stress in the person with dementia. Neuropsychiatric symptoms are assumed to be a result of a mismatch between the person’s environment and his or her abilities to cope with the situation (Hall & Buckwalter, 1987).

Depression

Depression is more prevalent in people with dementia than people without dementia (Forsell & Winblad, 1998; Rosenvinge & Rosenvinge, 2003). The prevalence of depression among people with dementia is high, irrespective of the degree and type of dementia (Barca, Engedal, Laks, & Selbaek, 2012). The prevalence rate reported in studies and review papers is 20–25% for major depression and 20–30% for minor depression or depressive symptoms (Barca, Engedal, Laks, & Selbaek, 2010; Selbaek, Engedal, & Bergh, 2013). The incidence rate in nursing home patients in Norway has been found to be 14% in one year (Barca et al., 2010). Studies in nursing homes have reported rates of depression between 12.4% and 41% (Barca et al., 2010; Selbaek et al., 2007). In a recent Norwegian study of 88 nursing home patients, depression was found in 25% of the recently admitted patients (within three months) according to the ICD-10 criteria and in 31% according to the Cornell Scale for Depression in Dementia (CSDD) (a summed score of ≥8) (Iden, Engedal, Hjorleifsson, & Ruths, 2013). In a 53-month prospective cohort study based on four measurements in Norwegian nursing homes, Selbaek and colleges found a persistence rate of depression of ≥50% in the two last intervals (Selbaek, Engedal, Benth, et al., 2013).

Diagnosis of depression in dementia

Depression can be diagnosed based on the clinical criteria in the ICD-10 (WHO, 1993) or the DSM-5 (American Psychiatric Association, 2013). ICD-10 classifies dementia as mild, moderate or severe, whereas DSM-5 uses the classifications of minor and major depression.

According to the ICD-10 criteria, the core symptoms of depression are sadness, loss of interest and lack of energy. Additional symptoms include low self-esteem, feelings of guilt, suicidal thoughts, diminished ability to think or concentrate, agitation or retardation, sleeping symptoms and appetite symptoms. The diagnosis of depression requires two or more core symptoms, as well as two or more additional symptoms, for at least two weeks (see textbox 3).

Textbox 3 Diagnostic criteria for depressive disorder according to ICD-10

A: General criteria must be met:
G1: The depressive episode should have lasted for at least 2 weeks
G2: There have been no previous manic or hypomanic episodes at any time in the individual’s life
G3: The episode is not attributable to psychoactive substance use or to any organic mental disorder

B: At least two of the following three symptoms must be present:

1) Depressed mood to a degree that is definitely abnormal for the individual, present for most of the day and almost everyday, largely influenced by circumstances and sustained for at least 2 weeks
2) Loss of interest or pleasure in activities that are normally pleasurable
3) Decreased energy or increased tiredness

C: An additional symptom or symptoms from the following list should be present, to give a total of at least four

1) Loss of confidence or self-esteem
2) Unreasonable feelings of self-reproach or excessive and inappropriate guilt
3) Recurrent thoughts of death or suicide, or any suicidal behaviour
4) Complaints or evidence of diminished ability to think or concentrate, such as indecisiveness or vacillation
5) Change in psychomotor activity, with agitation or retardation (either subjective or objective)
6) Sleep disturbance of any type
7) Change in appetite (decrease or increase) with corresponding weight change

The depressive episode can be classified by degree:
Mild: A total of at least four symptoms
Moderate: A total of at least six symptoms
Severe: All symptoms in B must be present and at least five symptoms from C must be present, to give a total of at least eight

1) *Severe depressive episode without psychotic symptoms:* no delusions, hallucinations or depressive stupor
2) *Severe depressive episode with psychotic symptoms:* presence of delusions or hallucinations (not those listed as typically schizophrenic in criterion) or depressive stupor.

The ICD-10 and DSM 5 criteria were developed for people without dementia. It has been debated whether depression in dementia is different from depression without dementia. Some studies find that mood symptoms like depressed mood, guilt, hopelessness and suicidal thoughts are less common in depression in dementia than in depression without dementia (Janzing, Hooijer, van't Hof, & Zitman, 2002; Olin, Katz, Meyers, Schneider, & Lebowitz, 2002). However, there is some evidence that people with Alzheimer’s disease with depression do not differ from depressed persons without dementia (Engedal, Barca, Laks, & Selbaek, 2011).

Some studies have reported a relationship between awareness of dementia and depressed mood and diminished quality of life (Harwood, Sultzer, & Wheatley, 2000;

Hurt et al., 2010), but most studies have shown that there is no relationship between the awareness of reduced capacity in dementia and depression (Arkin & Mahendra, 2001). However, the evidence is limited and inconsistent.
The symptoms of depression, such as lack of motivation, anhedonia (the inability to experience pleasure from activities usually found enjoyable), anxiety, irritability, agitation, delusions and hallucinations, are more prevalent in people with dementia than in those without dementia, but the overlap of these symptoms with the symptoms of Alzheimer's disease makes it difficult to discriminate the two. In addition, it is unclear whether the similarities between depression and dementia are a result of common underlying processes or of an interaction between the two conditions (Barca, Selbaek, Laks, & Engedal, 2008). Depression in dementia is associated with impaired quality of life (Gonzalez-Salvador et al., 2000), increased disability (Forsell & Winblad, 1998) and higher morbidity and mortality (Barca et al., 2010).

Because depression and dementia have overlapping symptoms, which can make the diagnosis difficult in people with dementia, an American expert group have developed new clinical criteria for the diagnosis of depression in dementia, which is called "Provisional Diagnostic Criteria for depression in Alzheimer's Disease" (PCD-dAD) (Olin, Schneider, et al., 2002). These criteria require the following.

- Three or more symptoms of depression must be present for at least two weeks.
- Two additional symptoms are included: irritability and social withdrawal.
- The symptoms must not be present every day, or most of the day.
- Alzheimer's disease must be present.

These criteria have not yet been validated and cannot be used in clinical practice. However, the few studies conducted using these new clinical criteria (PCD-dAD) (Barca et al., 2010; Vilalta-Franch et al., 2006) found a much higher prevalence of depression compared with studies using the DSM-IV criteria (which were the valid criteria at that time) in the same patient sample (Vilalta-Franch et al., 2006).

2.2.3 Assessment scales for neuropsychiatric symptoms

Assessment scales have been developed that can be used to assess neuropsychiatric symptoms. Some of these scales measure many symptoms, whereas others assess one specific symptom. A person with dementia of moderate or severe degree is often no longer able to complete questionnaires or to answer standardized questions, so several assessment scales are based on information and observations obtained from staff or relatives (proxy-based information). Several instruments exist, some of which are presented below.

Scales for assessing different neuropsychiatric symptoms (global scales)

The Neuropsychiatric Inventory (NPI) (Cummings et al., 1994) is one of the most widely used scales in dementia research. The original NPI (Cummings et al., 1994), contained 10 items: delusions, hallucinations, agitation, depression, anxiety, apathy, irritability, euphoria, disinhibition and aberrant motor behaviour. Later, two neurovegetative items were added; i.e., sleep and night-time behaviour disorders, and appetite and eating disorders (NPI-12 version) (Cummings et al., 1994; Cummings, 1997). NPI is a proxy-based measure. A version of this scale was used in the present study and is described in detail in paragraph 3.3.4.

The “Behavioural Pathology in Alzheimer’s Disease” scale (BEHAVE-AD) (Reisberg, Auer, & Monteiro, 1996; Reisberg et al., 1987) is another widely used scale, which assesses 25 items that are grouped into seven major categories. It was developed specifically to assess people with Alzheimer’s disease, and it considers delusions, hallucinations, activity disturbances, aggressiveness, diurnal rhythm disturbances, affective disturbances, anxieties and phobias. It does not include apathy and irritability, or disinhibition, which is a core symptom in fronto-temporal dementia. Each symptom is scored on a four-point scale. The scale comprises a four-point global assessment of the symptoms’ severity and degree of disturbance to the carer and/or danger to the person with dementia. It is a proxy-based scale.

Scales for measuring agitation in dementia

All of the following scales for measuring agitation in dementia are proxy based.
The Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield, 1996) was designed to assess the frequency of 29 agitated or aggressive behaviours, which are discrete and readily observable. This scale measures the frequency of agitation; i.e., from never (= 1) to several times an hour (= 7), during the previous two weeks (range 29–203).

The Brief Agitation Rating Scale (BARS) (Finkel, Lyons, & Anderson, 1993*)* is a short form of the CMAI, which measures the frequency of 10 items: hitting, pushing, grabbing, wandering, restlessness, repetitive sentences, repetitive mannerisms, complaining, screaming and making strange noises. The Norwegian version consists of nine items, the item screaming was left out. This scale was used in our study and is described in detail in paragraph 3.3.4.

Scales for measuring depression in dementia

The Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos, Abrams, Young, & Shamoian, 1988) is a proxy-based scale for assessing depression in patients with dementia. It is a 19-item scale, which includes mood symptoms, physical signs, behavioural disturbances and vegetative symptoms. This scale was used in our study and is described in detail in paragraph 3.3.4.

The Dementia Mood Assessment Scale (Sunderland & Minichiello, 1996) is a scale that was developed specifically to measure depression in people with mild to moderate dementia, and it is not intended for people with severe dementia. The original version contained 24 items, where items 1–17 rated the severity of depression and items 18–24 rated the overall severity of dementia. The factor structure includes depressive affect, environmental interaction, diurnal patterns, agitation/suspicion and somatic indicators (Onega & Abraham, 1997). The ratings are determined by trained interviewers based on information obtained from nursing staff in institutions or from family caregivers if the patient with dementia is living at home.

2.2.4 Psychosocial interventions for neuropsychiatric symptoms

The terms “psychosocial treatment” or “psychosocial intervention” are often used interchangeably with “non pharmacological treatment”. In this thesis psychosocial intervention will be used unless another term is used in the text that is being referred to.

Types of psychosocial interventions

There are many types of psychosocial interventions that has been classified in many ways, sometimes similar terms have different contents (see table 2). Psychosocial interventions may be used at individual or group level.

Table 2 Examples of classification of psychosocial interventions

Vernooij-Dassen et al 2010)	O’Neil et al (2011)
Behaviour oriented	*Behaviour Management Techniques*
Simplifying instructions, redirecting patients, increased monitoring, establishing regular routines and modifying environment with visual prompts	Functional analysis of specific behaviours Rewards for good behaviour Habit training Progressive muscle relaxation, Communication training Behavioural or cognitive-behavioural therapy Various types of individualized behavioural reinforcement strategies
Emotion oriented	*Cognitive/Emotion-oriented Interventions*
Talking about old times, discussing personal photographs, or undertaking familiar activities with people they recognise	Reminiscence Therapy Simulated Presence Therapy (use of audiotapes made by family members) Validation Therapy
Stimulation orientated	*Sensory Stimulation Interventions*
Physical exercise or recreational activities such as music, pets, cooking and hobbies	Acupuncture Aromatherapy Use of fragrant oils from plants Light Therapy Massage and Touch Music Therapy Snoezelen Multisensory Stimulation Therapy
Cognitive oriented	*Other Psychosocial Interventions*
Group activities, games and puzzles, calendars and clocks	Animal-assisted Therapy Physical exercise

Staff training interventions

This term refers to approaches where training courses are provided for internal front-line care staff to help them understand and manage neuropsychiatric symptoms (Spector, Orrell, & Goyder, 2013). Examples include nursing assistant communication skills programmes (McCallion et al., 1999), staff training in assisted living residences (Teri, Huda, Gibbons, Young, & van Leynseele, 2005), training programmes to reduce agitation and the use of restraints on nursing home patients (Testad, Ballard, Bronnick, & Aarsland, 2010).

Structural approaches

Structural approaches represent a more comprehensive type of psychosocial treatment, which involves programmes for patient assessment, choice of interventions and evaluation of effect. An example of this is the multidisciplinary care programme Treatment Routes for Exploring Agitation (Cohen-Mansfield, Libin, & Marx, 2007).

Culture change models

Culture change models are another form of psychosocial treatment. Hill et al. (2011) divided culture change models into two categories, as follows.

1. Interventions that target specific effects at the patient level
2. Comprehensive culture change models

Person-centred care (PCC) is placed in the first category described by Hill (2011). However, in the literature PCC is placed in a category of its own (Ballard & Corbett, 2010) because it reflects a care philosophy that encompasses every aspect of care for the patient, which affects all levels of the care institution, including the front-line staff and the management (Brooker, 2007). According to Stein-Parbury et al. (2012), PCC requires a whole-system approach because it involves more than care for individual people (Stein-Parbury, Chenoweth, Jeon, Brodaty, & Haas, 2012).

The second category, comprehensive culture change models, represents the broadest application of culture change, which occurs through comprehensive plans that transform the facility's decision-making, physical environment, organizational design and leadership practices (Hill, Kolanowski, Milone-Nuzzo, & Yevchak, 2011).

Examples of models in this category are the Eden Alternative (Coleman et al., 2002), the Wellspring Innovative Solutions for Integrated Health Care (Kehoe & Van Heesch, 2003) and the Pioneer Network (Kantor, 2008). These models were developed in the early 1990s, and they have been adopted by nursing homes in the USA, Canada, Europe and Australia. They share a common emphasis on small living communities, staff empowerment and environments modified to include animals, plants and children. According to Hill et al. (2011), PCC is at the core of the culture change movement (Hill et al., 2011).

The definition of psychosocial intervention may not be as straight forward as it seems. If it is defined as "*any intervention that emphasizes psychological or social factors rather than biological factors*" (Richter, Meyer, Mohler, & Kopke, 2012), the focus is on an interpersonal dialogue and communication (i.e., "talking"). According to such a definition, interventions without psychosocial components but solely based on physical or sensory factors are not considered psychosocial interventions (Richter et al., 2012). This excludes interventions like light therapy, which may be labelled "non-pharmacological treatment" rather than "psychosocial interventions". Such a definition differs from others commonly referred to, but allows for reflection on the search for one specific type of psychosocial intervention for one specific neuropsychiatric symptom for persons with dementia in general. Emerging evidence shows that psychosocial interventions are most effective when they are individualised and tailored to the specific needs of the patient (Cohen-Mansfield, 2001; Cohen-Mansfield et al., 2007).

Evidence for the effect of psychosocial interventions

A large body of research describes the efficacy of different types of psychosocial interventions for neuropsychiatric symptoms in dementia. The following is a summary of reviews on the effects of psychosocial interventions that have been published since 2005. Reviews that focus on single symptoms, such as apathy or wandering, are not included in this summary.

In a comprehensive review, Livingstone et al. (2005) included 162 studies with quantitative outcome measures, which were either direct or proxy measures for neuropsychiatric symptoms. The majority of studies were small, and few of the psychosocial intervention approaches led to significant reductions in behavioural issues, while the quality of studies was also limited (Livingston et al., 2005).

In a systematic review of non-pharmacological interventions for the management of neuropsychiatric symptoms by Ayalon et al. (2006), three RCTs and six single-case designs met the inclusion criteria (the American Psychological Association guidelines). This review concluded that recent cumulative research supported the effectiveness of individually tailored behavioural interventions, interventions that addressed unmet needs, interventions that included caregivers, and bright light therapy. More high-quality research is required to confirm these findings (Ayalon, Gum, Feliciano, & Arean, 2006).

A meta review by Vernooij-Dassen (2010) provided an appraisal of research reviews, which included 28 reviews related to long-term care psychosocial interventions. There were positive effects on behaviour or physical condition, or reduced depression, with behavioural management techniques and behavioural therapy that emphasized pleasant events, cognitive stimulation using information processing rather than factual knowledge to address problems in functioning, and physical activities (such as walking) (Vernooij-Dassen, Vasse, Zuidema, Cohen-Mansfield, & Moyle, 2010). However, methodological weaknesses precluded definitive conclusions.

O’Neil et al. (2011) analysed systematic reviews of non-pharmacological interventions for dementia. They identified 21 good-quality systematic reviews that each examined a single non-pharmacological intervention and seven good-quality systematic reviews of a variety of interventions used for the treatment of behavioural symptoms. Their summary provides a comprehensive review which is summarized below (O'Neil et al., 2011):

Reminiscence therapy: The seven small RCTs of reminiscence therapy identified were insufficient to support the use of this therapy for the treatment of behavioural symptoms of dementia.

Simulated presence therapy (SPT): Well-conducted studies were lacking. The evidence that SPT reduces behavioural symptoms was inconsistent, and SPT may have adverse effects in some patients.

Validation therapy: The effects of validation therapy in three RCTs and other study designs were examined in four systematic reviews. Mixed effects were found, and insufficient evidence was found to draw conclusions about the efficacy of validation therapy for behavioural symptoms, depression and the emotional states associated with dementia.

Acupuncture: No rigorously conducted RCTs were found, so no good-quality evidence indicates the benefit or harm of acupuncture for the treatment of behavioural symptoms in dementia.

Aromatherapy: There is insufficient evidence that aromatherapy may be an effective treatment for agitation and other behavioural symptoms.

Bright light therapy: Six studies, including two RCTs, were identified in two systematic reviews. The studies had small sample sizes and were of poor quality, and they did not provide sufficient evidence to draw definitive conclusions about the effects of bright light therapy in managing sleep, behaviour or mood disturbances.

Massage and touch: Two small RCTs suggest that hand massage and touch therapy may have beneficial effects compared with no treatment.

Music therapy: Four systematic reviews were found that examined a variety of study designs. Three RCTs reported reduced aggression, agitation, and wandering while listening to music. Other studies found similar reductions in behavioural symptoms, although there was no evidence of long-term effects. All of the studies were limited by methodological issues. Overall, well-conducted studies are lacking, but music interventions have the potential to reduce agitation in patients with dementia in the short term.

Snoezelen multisensory stimulation therapy: Six RCTs were identified in four systematic reviews. The evidence did not demonstrate a consistent or sustained effect on behavioural symptoms, but the findings were encouraging and warrant more research.

Behavioural management techniques: Seven RCTs and two more recent trials identified in three systematic reviews provide some evidence of effect. However, the inconsistent findings, the variety of intervention types, and methodological concerns suggest that more research is needed to confirm these results.

Animal-assisted therapy: No RCTs have evaluated the effectiveness of this therapy, but nine non-randomized studies of pet therapy were found. The findings suggest that pet therapy has positive potential effects, but more rigorous studies are needed.

Exercise: Three systematic reviews identified 59 studies with inconsistent effects. The studies varied in the intensity of the exercise intervention, the severity of dementia and the outcome measures evaluated, as well as methodological limitations, which made it difficult to reach firm conclusions.

In summary, mainly because of methodological limitations, it is difficult to draw firm conclusions about the effects of different types of psychosocial interventions on neuropsychiatric symptoms. Many of these approaches are potentially beneficial, but their sustainability or feasibility appears to be limited.

Staff training interventions

Staff training is an approach that aims to reduce neuropsychiatric symptoms in patients by improving the knowledge, attitudes or skills base of the care staff. Evaluations and comparisons of these interventions are difficult for two main reasons. First, there is no consistent measure of success. Second, some studies evaluated the effects on the neuropsychiatric symptoms of patients, whereas others focused on the effect of training on changes in the knowledge or attitudes of different staff groups staff (McCabe, Davison, & George, 2007). The following is a summary of reviews published since 2003.

Aylward et al. (2003) reviewed previous general studies of the effectiveness of continuing education programmes in long-term care. Of the 48 studies reviewed, 19 focused on mental health and behaviour. The results showed that educational initiatives were somewhat effective in the short term. However, there was minimal evidence that the knowledge was sustained in the long term because of a lack of follow-ups (Aylward, Stolee, Keat, & Johncox, 2003).

Kuske et al. (2007) reviewed 21 studies of the effectiveness of in-service training in dementia care. Only two studies used patient outcomes, whereas the remainder (19 studies) examined staff-level outcomes. Eight of these studies measured the effectiveness at the staff and patient levels. Most reported positive effects, but the methodological quality was low, and the results must be interpreted with caution. The main outcome measure at the patient level was change in the rate of inappropriate behaviour (48% of studies). Three randomized studies had relatively good methodological quality, with one reporting significantly reduced agitation and another detecting significantly reduced depression in patients. Extensive interventions with ongoing support demonstrated the sustained implementation of new knowledge among staff. In simpler interventions, there was little or no evidence for the transfer of knowledge when no reinforcing factors were provided (Kuske et al., 2007).

A review by McCabe et al. (2007) examined 19 intervention studies that aimed to increase the knowledge or skills of staff. However, the outcome measures used in most of these studies also focused on the impacts on the behavioural problems of patients. Many of these studies had limitations in terms of the research design, which made it difficult to evaluate them and to reach any conclusions about their effectiveness. The studies were classified according to whether the research design did or did not include a control group. The results of interventions with control groups seemed to indicate that the training programmes had a positive impact on patient functioning, including a reduction in the severity of behavioural symptoms. Continuing refresher courses may be required for these changes to be sustained (McCabe et al., 2007).

Levy-Storms (2008) reviewed research on the effectiveness of staff training on nursing aides' therapeutic communication in institutional long-term care settings. The literature review covered 13 papers from 1999 to 2006, 10 of which were RCTs and three of which included pre–post tests. The number of staff participants ranged from 32 to 655, and the number of patients ranged from 30 to 146. They concluded that some evidence existed to support the hypotheses that therapeutic communication techniques can be taught and that verbal and non-verbal communication behaviours, such as open-ended questions, positive statements, eye contact, affective touch and smiling, can benefit the quality of life of patients. Ongoing dedicated supervision of the psychosocial aspects of care was needed (Levy-Storms, 2008).

Vasse et al. (2010) reviewed research on staff communication techniques used in daily routines, which comprised two RCTs and three non-RCTs. The number of staff participants ranged from 31 to 124, and the number of patients ranged from 22 to 194. The findings indicated that care staff can improve their communication with patients with dementia if strategies are embedded in their daily care activities or if the interventions are single-task sessions at set times. Improvements might be obtained in the quality of care, but not direct reductions in neuropsychiatric symptoms. They concluded that more research is needed to study the effects of communication interventions on neuropsychiatric symptoms (Vasse, Vernooij-Dassen, Spijker, Rikkert, & Koopmans, 2010).

Spector et al. (2013) considered 20 studies in their review of staff training interventions, which comprised 13 RCTs and seven non-randomized studies. The quality of the available evidence was regarded as poor, which led to inconsistencies in the findings, and this made it difficult to reach firm conclusions that might agree with earlier reviews. Seven RCTs found that the training interventions were effective in reducing neuropsychiatric symptoms, and three reported positive trends but no significant results. This review concluded that there is evidence that staff training programmes can reduce neuropsychiatric symptoms in people with dementia who live in nursing homes (Spector et al., 2013).

In summary, some evidence exists to support the hypothesis that staff training has an effect on patient outcomes. Many reviews recommend the provision of ongoing support to staff so that the effects can be sustained.

Culture change models

There is little published evidence of the effects of culture change models. An evaluation of the Wellspring model reported a better quality of life for patients, although the evaluation suffered from limited data quality and confounding organizational factors (Stone et al., 2002). A review of the literature related to the Eden Alternative found that previous research was very limited in terms of size and academic rigour, which prevented it from providing adequate empirical evidence. These studies were descriptive, quasi-experimental or case studies (Petersen & Warbuton, 2010). Munroe (2011) stated that the early phases of a culture change process last for approximately three years, which may be a barrier to evaluation. Identifying the outcomes of these evaluations was also challenging (Munroe, Kaza, & Howard, 2011).

2.2.5 Pharmacological treatment of neuropsychiatric symptoms

Pharmacological treatments and their evidence base for the treatment of neuropsychiatric symptoms are described briefly because they are not the focus of the present thesis.

Classes of psychotropic drugs

Different classes of psychotropic drugs are available for the pharmacological treatment of neuropsychiatric symptoms, such as anti-psychotics or anti-depressants. The use of newer psychotropic drugs, including atypical anti-psychotics, selective serotonin reuptake inhibitors (SSRIs) and hypnotics (z-hypnotics), has increased in nursing homes because of their apparently more favourable safety profiles (Lovheim, Sandman, Karlsson, & Gustafson, 2009, Ruths et al., 2013). Atypical anti-psychotics, such as risperidone and apriprazole, are also known as second-generation anti-psychotics. This group of anti-psychotic tranquilizing drugs is used to treat psychiatric conditions such as depression and psychotic agitation in persons with dementia. Atypical anti-psychotics are claimed to differ from typical anti-psychotics because they are less likely to cause extrapyramidal motor control disabilities in patients, such as Parkinson’s-disease-type symptoms (body rigidity and involuntary tremors) (Culpepper, 2007).

Prescription of psychotropic drugs in nursing homes

Ruths and colleges (2012) analysed six cross-sectional studies conducted in Norwegian nursing homes between 1997 and 2009, which included 7,661 patients (mean age, 85.2 years; 72.6% women). This study showed that the prevalence of prescribing psychotropic drugs had increased considerably in nursing homes, especially regarding anti-depressants, which had a prevalence of 50.9%. For the treatment of neuropsychiatric symptoms, the overall prevalence of all psychotropic drugs was 70.5%, anxiolytics accounted for 21.9% and hypnotics comprised 22.9%. The prevalence of anti-psychotics varied between 21.1% and 25.6%. The predictors of use of psychotropic drugs were female gender (except anti-psychotics), age > 80 years and residency in SCUs (except hypnotics) (Ruths et al., 2013).

Evidence for the effects of pharmacological treatments

A brief description of the evidence for the effects of pharmacological treatments on neuropsychiatric symptoms is presented below.

Agitation and aggression

The meta-analysis by Ballard & Waite indicated that atypical anti-psychotic drugs were the only effective psychotropic drugs for the treatment of aggression in people with Alzheimer’s disease (Ballard & Waite, 2006). However, this review also reported that the effect was moderate and that these treatments had severe adverse effects, such as sedation, falls, extrapyramidal symptoms, cardiovascular and anti-cholinergic symptoms and increased mortality. In their review of the evidence in 2009, Ballard et al. found that further clinical trials of pharmacotherapy for agitation and aggression in

Alzheimer’s disease were needed, although preliminary data indicated that memantine, citalopram and carbamazepine might be promising alternatives to atypical anti-psychotics. The review concluded that the use of anti-psychotic medications should be limited to short-term treatment (up to 12 weeks) in most situations (Ballard & Corbett, 2010).

Depression

Little evidence supports the efficacy of anti-depressants for mild or moderate depression and for depression with coexisting dementia (Banerjee et al., 2011; Nelson & Devanand, 2011). A prospective study indicated the high persistence of depression in nursing home patients, regardless of whether they were treated with anti-depressants (Barca et al., 2010). Lindstrøm demonstrated that anti-depressants could be successfully withdrawn from half the patients on long-term treatment (Lindstrom, Ekedahl, Carlsten, Martensson, & Molstad, 2007), whereas Bergh et al. detected an increase in depressive symptoms when anti-depressants prescribed for neuropsychiatric symptoms without depression were withdrawn (Bergh, Selbaek, & Engedal, 2012).

Neuropsychiatric symptoms in general

Seitz et al. (2013) conducted systematic review of pharmacological treatments for the neuropsychiatric symptoms of dementia in long-term care based on parallel-group randomized controlled trials (RCTs). Most participants had moderate to severe dementia. Twenty-nine RCTs were included in the review (4,954 participants in total; range, 14–625). Compared with the placebo, statistically significant improvements in neuropsychiatric symptoms were reported by some trials that assessed the efficacy of the atypical anti-psychotics risperidone (two of six trials) and olanzapine (two of four trials). Twenty-one studies assessed withdrawals due to adverse events. Significantly higher rates of withdrawals due to adverse events were detected by single trials for risperidone and olanzapine compared with the placebo. Twenty-three trials assessed mortality, and one study reported that the mortality was significantly higher with risperidone than the placebo (Seitz et al., 2013).

Table 3-I Effect and side effects of psychotropic drugs in the treatment of behavioural symptoms in dementia

	Type of medication Evidence of effect Evidence of effect of removal	**Authors**
The affective sub syndrome: depression and anxiety	**Selective serotonin re-uptake inhibitors or serotonin-specific reuptake inhibitor (SSRIs) antidepressants**	
	Low grade evidence for effect on depression in persons with mild/moderate dementia	Bains, Birks, & Dening, 2000, Edhag & Norlund, 2006
	Severe depression in Alzheimer's disease: Some effect Mild depression in Alzheimer's disease: no effect Depression in other dementias lack of studies	Lyketsos & Olin, 2002
The agitation sub syndrome: agitation/ aggression disinhibition irritability	**SSRIs** Some singular trials have shown that SSRIs have effect on symptoms like agitation and psychosis, but no reviews show this	
	Studies on withdrawals: 30% got more agitated after withdrawal of SSRI compared to those who continued	Bergh et al., 2012
	Conventional antipsychotics	
	Limited effect on psychotic symptoms	Schneider, Pollock, & Lyness, 1990
	Haloperidol reduces aggression but not agitation	Lanctot et al., 1998
	Caution must be taken because of side effects	Lonergan, Cameron, & Luxenberg, 2004
	Cholinesterase inhibitors	
	Very limited effect	Trinh et al., 2003
	Reduces neuropsychiatric symptoms in Alzheimer's disease	

Table 3-II Effect and side effects of psychotropic drugs in the treatment of general neuropsychiatric symptoms in dementia

	Type of medication Evidence of effect Evidence of adverse effect Evidence of effect of removal	**Authors**
Neuropsychiatric symptoms	**Cholinesterase inhibitors** Reduces neuropsychiatric symptoms in Alzheimer's disease. Limited effect	Tariot et al., 2000,Trinh, Hoblyn, Mohanty, & Yaffe, 2003
	Antiepileptic Limited effect	Lonergan & Luxenberg, 2009 Amann et al., 2009
Psychotic symptoms in dementia	**Conventional antipsychotics** Limited effect	Schneider et al., 1990
	Side effects: Stroke, death, Parkinsonism Akatisi, Tardive dyskinesia, Acute dystonia central anticholinerg effect, Ortostatisme, Malign nevroleptic syndrome (MNS)	Rochon et al., 2008
	Atypical antipsychotics	
	Olanzapine better effect than placebo	Seitz et al., 2013 Street et al., 2000,
	Risperidone better effect than placebo	Brodaty et al., 2003
	Aripiprazol better effect than placebo	Mintzer et al., 2007
	Olanzapin, risperidon, quetiapin no difference compared to placebo	Lee et al., 2004
	Side effects Higher risk of stroke and mortality compared to placebo.	Schneider, Dagerman, & Insel, 2006, Rochon et al., 2008
	Cholinesterase inhibitors Reduce psychotic symptoms in Lewy body dementia	McKeith et al., 2000

2.3 Quality of life in people with dementia

In recent years, greater efforts have been made to consider and explore the subjective experiences of people with dementia (McCabe & 2008; Sloane et al., 2005). Describing how care affects the quality of life has become an important outcome measure in research (Banerjee et al., 2009; Kane et al., 2005; Thorgrimsen et al., 2003).

Definitions of quality of life

Quality of life is a concept that has been much debated. It is difficult to define, and possibly more so with regard to persons with dementia. The WHO has defined quality of life as an *“individual’s perceptions of their position in life in the context of the culture and value system in which they live, and in relationship to their goals, expectations and standard*” (WHO, 1995). This definition implies communication of one’s perceptions, which is problematic for people with cognitive impairment. Deficits in memory, attention and language may affect the individual’s ability to communicate their subjective state coherently. However, it has been shown that people with mild to moderate dementia can report their quality of life (Arlt et al., 2008; Brod, Trigg, Jones, & Skevington, 2007), as well as those with severe dementia, to some extent (Thorgrimsen et al., 2003).

In the field of dementia research, quality of life has been defined as the integration of cognitive functioning, activities of daily living, social interactions and psychological well-being (Whitehouse et al., 1997). Lawton’s model (Lawton, 1994) has been the pervasive conceptualization of quality of life in dementia (Moyle, Gracia, Murfield, Griffiths, & Venturato, 2012). Lawton described quality of life in people with dementia as a combination of two external dimensions and two internal dimensions. The two external dimensions are as follows.

1. Behavioural competence, defined as a person’s ability to evaluate and participate in social gatherings
2. External environmental factors that can be evaluated physically and socially

The two internal factors are as follows.

1. The person’s subjective self-image
2. The environment evaluated using subjective criteria

Most researchers describe the quality of life of people with dementia as a multidimensional concept with subjective and objective values (Lawton, 1994; Moyle & Murfield, 2013).

Quality of life, neuropsychiatric symptoms and degree of dementia

Studies based on proxy information have shown that the quality of life of a person with dementia living in a nursing home decreases as their neuropsychiatric symptoms increase, especially depression and anxiety (Banerjee et al., 2009; Barca, Engedal, Laks, & Selbaek, 2011; Beerens, Zwakhalen, Verbeek, Ruwaard, & Hamers, 2013; Shin, Carter, Masterman, Fairbanks, & Cummings, 2005).

The literature provides no clear understanding of the relationship between the degree of dementia and the quality of life (Banerjee et al., 2009; Beerens et al., 2013). Some studies have reported an association between the severity of cognitive impairment and reduced quality of life (Barca et al., 2011; Lyketsos & Olin, 2002), whereas others have found no such association (Hoe, Hancock, Livingston, & Orrell, 2006; Hoe, Katona, Roch, & Livingston, 2005). There are vast individual differences in the quality of life of people with dementia and wide variations in their quality of life over time (Vogel, Bhattacharya, Waldorff, & Waldemar, 2012).

2.3.1 Assessment scales for the quality of life of people with dementia

Some of the scales developed for assessing the quality of life of people with dementia are presented below.

The Quality of Life in Late-Stage Dementia (QUALID) scale (Weiner et al., 2000) is an instrument used to rate the quality of life in persons with late stage Alzheimer’s disease and other dementing illnesses. QUALID is a proxy-based scale, which records the frequency of 11 observable behaviours in a person with dementia during the previous week. This scale was used in our study and is described in detail in paragraph 3.3.4.

The Quality of Life – Alzheimer’s disease (QOL-AD) scale (Logsdon et al., 2002), is a scale that was designed specifically to assess the quality of life of people with Alzheimer’s disease. It is completed by the person with dementia and the caregiver. Internationally, the QOL-AD scale is one of the most widely used self-reported measures (Whitehouse, Patterson, & Sami, 2003). Caregivers complete a questionnaire about the patient's quality of life and the person with dementia is interviewed about their own quality of life. People with mild to moderate Alzheimer's disease (Mini Mental State Examination scores of 10 or higher) can usually complete it without any problems. A four-point Likert scale, which ranges from 1 = "poor" to 4 = "excellent", is used to rate each item. The measure yields a single mean score, which ranges from 15–60, where higher scores indicate a better quality of life.

The Dementia Quality of Life questionnaire (DQOL) (Brod et al., 1999) is an interviewer-administered self-reporting instrument, which measures the quality of life from the perspective of the person with dementia. This instrument has 29 items, which address five domains of the quality of life: self-esteem, positive affect, absence of negative affect, feelings of belonging and sense of aesthetics. It also includes a final item, which captures an optional global measure of quality of life. The 29 items are rated on one of two five-point Likert scales, which measure either frequency (from 1 = "never" to 5 = "very often") or enjoyment (from 1 = "not at all" to 5 = "a lot"). The scores for each subscale are calculated by computing the mean score of the component items. The optional single item for assessing the overall quality of life is also rated on a five-point scale, which ranges from 1 = "bad" to 5 = "excellent". Higher scores indicate a better quality of life.

2.4 Person-centred care (PCC)

Tom Kitwood introduced the concept of PCC (Kitwood, 1997a) around 1990, and this social–psychological care philosophy, which focuses on personhood in dementia, has since been endorsed and advocated by politicians and health administrations as a central component of quality care (Abdelhadi & Drach-Zahavy, 2012). From the perspective of Kitwood, the question is: "*whether some of the neuropsychiatric symptoms of dementia might be due more to a failure of understanding and care than to a structural failure of the brain of the person with dementia*" (Kitwood, 1997a)(p 3). One of Kitwood's first studies explored the subjectivity and interpersonal processes of dementia. He wanted to make a transition from an *"organic mental disorder* to *"the social psychology of dementia"* (Kitwood, 1997a)(p 4). Kitwood suggested that the clinical manifestations of dementia may be understood as arising from a complex interaction between personality, biography, physical health, neurological impairment and, not least, the social psychology that permeates the environment (Kitwood, 1993).

Attempts to provide positive interventions had already emerged before Kitwood presented the PCC, such as reality orientation (Taulbee & Folsom, 1966), validation therapy (Feil, 1982, 1993), reminiscence (Butler, 1963; Coleman, 1986), and sensory stimulation (Threadgold, 1995). Kitwood found these approaches encouraging but considered that they lacked a coherent theoretical basis. He stated: *“Progress will occur much faster if there is a clear theoretical frame; a good care needs to find a voice”* (Kitwood, 1997a)(p 55). Kitwood drew on the ideas and practices of psychotherapy, with an emphasis on Rogerian psychotherapy in authentic contact and communication (Rogers, 1951, 1961). The term *“person-centred care”* was selected to reflect these principles (Brooker, 2004).

The cornerstone of PCC is the concept of personhood, other elements include basic psychological needs, malignant social psychology and positive person work, which are described below.

Personhood

To identify an appropriate basis for developing a theory of dementia care, Kitwood posed the old philosophical question: *“What is the state which we might properly call being a person?”* (Kitwood & Bredin, 1992b). Personhood should be viewed essentially as social , and that it is provided or guaranteed by the presence of others (Kitwood & Bredin, 1992b). According to Kitwood, the concept of personhood is linked to transcendence, ethics and social psychology; a being is sacred in itself (transcendence), each person has absolute value (ethics), the place of an individual in a social group is linked to given roles and self-esteem (social psychology) (Kitwood, 1997a)(p 8).

Kitwood relied heavily on the arguments of Stephen Post (1995) that the emphasis on autonomy and rational capacity in Western society is gravely misplaced (Post, 1995). Kitwood made a clear separation between personhood and cognitive ability, and he contended that personhood should instead be linked more strongly to emotion and relationships, which is a view that renders patients with dementia as competent persons (Kitwood & Bredin, 1992b).

Martin Buber is another philosopher with a great influence on Kitwood’s concept of personhood. Buber contrasted an I–it relationship, which implied coolness, detachment and instrumentality, with an I–Thou relationship, which implied going out towards the other, self-disclosure and spontaneity (Buber, 1937)(p 2).

Based on these pillars, Kitwood 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.”* (Kitwood, 1997a)(p 8). He stated that not being recognized as a person could cause severe ill-being, or even a state of vegetation. He predicted that not being recognized as a person would erode the global psychological states that are fundamental for all human beings; i.e., self-esteem, sense of agency, social confidence and hope (Kitwood, 1997a).

Malignant social psychology

The I–it relationship of Buber brings us to Kitwood’s concept of malignant social psychology. This term refers to the effects of a social psychology with exclusion and the devaluation of persons with dementia. Although unintended, this is a consequence of the (unconscious?) view that those affected with dementia are not real people anymore. Kitwood made observations of nursing home care to describe the type of interaction that constituted this depersonalization, which undermined the personhood of patients with dementia. This resulted in a list with 17 elements (op.cit pp 46-47), some of these are cited in textbox 4.

Textbox 4 Indicators of malignant social psychology

- Treachery: using deception to distract, manipulate or force into compliance
- Disempowerment: not allowing a person to use their remaining abilities
- Infantilization: patronizing a person in that same manner that an insensitive parent might treat a very young child
- Intimidation: inducing fear
- Labelling: using the category of dementia as the main basis for the interaction with a person and for explaining their behaviour
- Stigmatization: treating a person like a diseased object or an outcast
- Outpacing: providing information at a rate too fast for the patient to understand, or putting them under pressure to perform tasks more rapidly than they can bear
- Objectification: treating a person like a lump of dead matter that needs to be pushed, lifted or fed
- Ignoring: continuing a conversation or action in the presence of a person as if they were not present

Adapted from Kitwood 1997

Basic psychological needs

After describing practical examples in care where personhood was undermined, the next step was to improve the quality of interaction so that personhood could be enhanced. According to Kitwood, the main task for dementia care is to maintain personhood in the face of declining cognitive abilities and mental powers. He described the life and emotions of people with dementia as intense and lacking in the normal forms of inhibition; i.e*., "in tune with the body and closer to the life of instinct"* (Kitwood, 1997a)(p 5-6). He considered a cluster of five very closely connected needs as expressions of the one and all-encompassing need, our need for love. These five needs are: comfort, attachment, inclusion, occupation and identity (op.cit p 81). Although common to all human beings, these needs were seen as more obvious in people with dementia, who are clearly dependent on others and less able to take an initiative that would lead to their needs being met. These needs were described as follows.

Comfort

Comfort is defined as tenderness, closeness, the soothing of pain and sorrow, the calming of anxiety and the feeling of security that comes from being close to another. A person with dementia must deal with all the losses that come with diminishing cognitive abilities, so their need for comfort is often especially great.

Attachment

This is an instinct-like need, which is particularly associated with early childhood (Bowlby, 1979). Attachment creates a type of safety net when the world is experienced as full of uncertainties and anxieties, and it provides the sense of security and reassurance needed for a person to function well. Miesen (1992) suggested that people with dementia continuously find themselves in situations that they experience as "strange", which activates the attachment need very strongly (Miesen, 1992).

Inclusion

As human beings, we are social in nature, so being part of a group is essential. The need for inclusion is strong for all human beings, and being excluded and ignored may take away a person's confidence and result in depression. A person with dementia often loses the abilities needed to take social initiative, which makes them more vulnerable.

Occupation

Kitwood described occupation as being "involved in the process of life in a way that is personally significant and which draws on a person's abilities and powers" (Kitwood, 1997a)(p 83).

Identity

Identity is defined as knowing who you are in terms of both cognition and feeling. This implies a sense of continuity with your past, but it is also influenced by the subtle messages about yourself conveyed by others.

Positive person work

Kitwood's term "positive person work" refers to types of positive interactions that enhance personhood. In line with the list describing malignant social psychology, he made another list with 12 types of positive interactions that constitute positive person work; some of these are cited in textbox 5.

Textbox 5 Indicators of positive person work

- Recognition: to be acknowledged as a unique person. This may be achieved by greeting a person by name, listening to a person over a long period or by making eye contact.
- Negotiation: consultation with a person with dementia about their preferences, thereby giving highly dependent people some degree of control over everyday issues and the care they receive
- Collaboration: working together by involving the initiative and abilities of a person with dementia in their daily activities and personal care
- Validation: validating the experience of a person with dementia by acknowledging that their emotions and feelings are real to them and providing responses to them, irrespective of the lack of correspondence with the current reality
- Facilitation: helping a person to perform tasks that they cannot achieve without assistance; to provide support with the components of an activity that are lacking, but only those components

Adapted from Kitwood 1997

Dementia Care Mapping (DCM)

Kitwood worked closely with Kathleen Bredin, and they published the main body of their work on PCC between 1987 and 1995. They started the development of DCM, which is a method for evaluating the quality of care in formal settings with a focus on the perspective of the person with dementia. DCM incorporates the observations of malignant social psychology, the five basic psychological needs and positive person work (Kitwood & Bredin, 1992a). DCM is most likely the most well known model for implementation of PCC. It is an observational tool that consists of standardized coding of the patients' well-being and behaviour and descriptions of interaction between staff and patients. DCM is delivered as a cyclic intervention with systematic observation, feedback to staff resulting in action plans to make changes in the care based on the observed needs of the patient. Staff must attend the basic and advance training courses and pass exams to be certified dementia care mappers. The training enables the mappers to observe, report and provide feedback to staff and to assist the staff in making action plans (Brooker & Surr, 2005).

The perspective of the persons with dementia

Kitwood posed the hypothesis that contact with persons with dementia takes people out of their customary pattern of hypercognitivism and draws them into a way of being where emotion and feeling have larger roles. In his view, good dementia care requires an exploration of what the experience of dementia might be like and using this perspective to develop forms of interaction that enhance personhood (Kitwood & Bredin, 1992b). The uniqueness of each individual's experience of dementia is related to personality and defence processes. Kitwood outlined routes for obtaining insights into the subjective world of dementia, including listening carefully to what people with dementia say and attending carefully and imaginatively to their utterances and attempts at action (Kitwood, 1997b). Although it is impossible to enter fully into another person's frame of reference, empathy represents an attempt to understand what a person is conveying by drawing on our own experience: "Not feeling their emotions, but feeling the resonances of those emotions within ourselves" (Kitwood, 1997b)(p. 17).

2.4.1 The VIPS framework for PCC for people with dementia

The publication of Kitwood's book "Dementia reconsidered: the person comes first" in 1997 marked a watershed in dementia care. PCC became synonymous with quality care. However, the term PCC has often been used synonymously with "individualized care" since it was first proposed by Kitwood, and the emphasis on relationships has been lost (Brooker, 2004, 2007). Dawn Brooker, who worked closely with Kitwood at Bradford University in England, published the paper "What is person-centred care in dementia?" in 2004, which proposed the much-welcomed VIPS framework to clarify what constituted PCC (Brooker, 2004). The acronym VIPS (commonly understood as "very important persons") synthesizes the different threads that emerged in the literature and the rhetoric of PCC, while still maintaining the sophistication of Kitwood's original ideas. It describes PCC as having four major elements:

- **V**aluing persons with dementia
- **I**ndividualized care
- the **P**erspective of the person with dementia
- **S**ocial inclusion

Given the complexity of defining PCC, it was considered helpful to delineate a set of practical indicators against which care providers could benchmark their services. Pilot indicators were reviewed by around 50 care providers and service user organizations worldwide to arrive at a detailed description of what a PCC provider should have in place. This list of 24 indicators is grouped around the four elements of the definition set outlined above (textbox 6).

Textbox 6 The VIPS framework with six indicators for each element of person-centred care

V Does where we work show value and respect for the experiences of people with dementia and their families?

1. Does where I work feel welcoming to people with dementia and their families?
2. Does where I work value good quality direct care for people with dementia and their families?
3. Does where I work empower staff to act in the best interests of people with dementia and their families?
4. Is our work-force skilled in person-centred dementia care?
5. Generally are our physical and social service environments easy for people with dementia and their families to use?
6. Does where I work, know about and act upon the needs and concerns of people with dementia and their families?

I Are systems in place to enable staff to get to know the person and to ensure the person feels like a unique individual?

1. Do I know this person’s strengths and needs?
2. Am I alert to changes in this person?
3. Do I know what personal possessions are important to this person?
4. Do I know this person’s likes and dislikes and preferred everyday routines?
5. Do I know this person’s history and key stories?
6. Do I know how to engage this person in an enjoyable activity for them?

P Have we taken time to understand the Perspective of the person with dementia and their family.

1. Do I check out preferences, consent and opinions?
2. Do I try to imagine how this person is feeling?
3. Do I make the physical environment as comfortable as possible for them?
4. Am I vigilant about physical health needs that the person may not be able to tell me about?
5. If the person is showing “challenging behaviour” do I try to understand why and what the person may be trying to communicate?
6. Am I treating the rights of the individual with dementia as important as the rights of other people in the same situation?

S Are we providing a Supportive Social Psychology to enable the person to feel socially confident and that they are not alone?

1. Do I help the person feel included and not “talked across”?
2. Am I treating this person respectfully and not using a “telling-off” tone or using labels to describe people?
3. Do I come across as warm and caring and not cold and indifferent?
4. Do people know that I take their fears seriously and not leaving people alone for long periods in emotional distress?
5. Do I help people to be active in their own care and activity as far as possible and not just do things to people without communicating with them?
6. Do I try to help the person use local community facilities and make sure that they can stay in touch with people and activities they value?

Brooker 2007

2.4.2 Criticism of PCC and related theories

PCC has been very influential in the field of dementia care, but it has also received some criticism. According to Dewing (2008), who wrote her doctoral thesis on Kitwood's work, Kitwood's writings failed to address fully the person as an embodied being, despite clearly rejecting Cartesian dualism. However, Kitwood's work on malignant social psychology and positive person work had a focus on the lived experience that partly encompassed this aspect (Dewing, 2008).

There are objections to Kitwood's emphasis on the concept of personhood. In the philosophical literature, the term "personhood" includes attributes that are required to be considered as a person (Dresser, 1994; Singer, 1993). Thus, it follows that it is possible to be judged as a lesser person or not having personhood (not being a person). As a consequence, it might be argued that Kitwood's philosophy of care for people with dementia is built on a concept where it is implied that a human being may be disqualified from being a person. Referring to Post, (Post, 1995) Dewing (2008) suggested that it would have been better if Kitwood had rejected the concept of personhood altogether and rather focused on radical human equality (Dewing, 2008).

Kitwood's own concern that PCC may remain more word than deed (Kitwood, 1997a; Nolan, 2001) was echoed by Nolan who posed the question: "How do we know PCC when we see it, and what must we do to achieve it?" (Nolan, 2001). This concern was also acknowledged by Kitwood's successor, Dawn Brooker, who developed the VIPS framework (Brooker, 2004). Kitwood's PCC has also been criticized by Nolan and colleges for not capturing the interdependencies and reciprocities that underpin caring relationships for older persons (Nolan, Enderby, & Reid, 2002). Nolan argued that Kitwood's vision had been lost and that the focus of PCC on individuality and autonomy would further marginalize those living and working in care homes (Nolan, Davies, & Brown, 2006). Nolan and colleagues proposed relation-centred care as an alternative that could be applied using the Senses framework (Nolan, Davies, Brown, Nolan, & Keady, 2006) which summarizes its key principles. This framework comprises six senses, which capture subjective and perceptual aspects of care that should be experienced by both patients and staff: a sense of security, continuity, belonging, purpose, achievement and significance. The aim of relation-centred care is to meet the needs of patients, their families and staff. Dewing (2008) did not agree with this criticism and suggested that, although it could have been stated more clearly, Kitwood’s ultimate purpose of moral concern for others includes family, carers and staff (Dewing, 2008).

The recovery-based approach to dementia care nursing (Gavan, 2011) is derived from the recovery model of mental health nursing (Caldwell, Sclafani, Swarbrick, & Piren, 2010). This approach proposes the expansion of PCC by the addition of “taking a more optimistic outlook by framing and informing nursing practice with notions of hope” (Gavan, 2011). This is achieved by assessing a person’s strengths, which enhances the positive aspects of dementia care nursing (Adams, 2008). Recovery is described as managing wellness, recovering identity, managing lives, and finding a sense of belonging and a meaningful life in the community (Davidson & Roe, 2007; Martin, 2009).

Gavan (2011) criticizes PCC for not having an explicit emphasis on the need for a therapeutic relationship between the nurse and the person with dementia. A therapeutic relationship promotes understanding by “*listening to the person’s own story and using it to work with the person in finding ways to address their needs”* (Gavan, 2011). PCC does not fully capture the importance of reciprocity, which may lead to an unbalanced relationship, with patronizing and inappropriate care (Adams, 2008; Wilson & Neville, 2008). This loss of mutuality leads to the “voice” of the person with dementia being unheard. This, in turn, leads to disempowerment of the person with dementia (Gavan, 2011) and the potential for negative attitudes that reinforce stigma and marginalization within our society (Wilson & Neville, 2008).

In a review of person-centred gerontological nursing, McCormack (2004) concluded that there has been little research into the meaning of PCC and the impact that it has on users (McCormack, 2004). According to McCormack (2004), person-centred gerontological nursing (or care) has the following four aspects.

- Being in relationship (social relationships)
- Being in a social world (biography and relationships)
- Being in a place (environmental conditions)
- Being with self (individual values)

McCormack (2004) considered personhood, authentic humanistic caring practices that embrace all forms of knowing and acting, and choice and partnership in care decision-making as central components of person-centred gerontological nursing (McCormack, 2004)(p. 36).
McCormack and McCance (2006) developed a person-centred nursing framework that comprised four constructs.

- Prerequisites, which focus on the attributes of the nurse
- The care environment, which focuses on the context where care is delivered
- Person-centred processes, which focus on delivering care through a range of activities
- Expected outcomes, which are the results of effective person-centred nursing

The relationship between the constructs suggests that the delivery of person-centred outcomes demands a consideration of the prerequisites and the care environment that are required to provide effective care throughout the care process (McCormack & McCance, 2006).

2.4.3 Evidence for the effects of Person-centred care

The following describes previous research into the implementation of PCC using RCTs. When our study was conducted (spring 2010), the largest and most recent studies in this field were those of Fossey and colleges (Fossey et al., 2006) and Chenoweth and colleges (Chenoweth et al., 2009). These studies are of central importance because of their rigorous designs and positive findings (Ballard & Aarsland, 2009).

Fossey and colleges (Fossey et al., 2006) conducted a cluster RCT that included 346 patients in 12 specialist nursing homes for people with dementia in England. The main outcome measures were the proportion of patients in each home who were prescribed neuroleptics and the mean levels of agitated and disruptive behaviour measured by the CMAI. The intervention comprised weekly training and ongoing support in the application of PCC, care planning and behavioural management techniques for groups and individual staff. The control group received usual care. A medication review was performed by a consultant old-age psychiatrist and a senior member of the nursing home every three months.

The study failed to affect the levels of agitation measured by the CMAI, but after 10 months of intervention, the percentage of patients who were prescribed neuroleptics in the intervention homes was significantly lower in the intervention group.

No manual was provided for the PCC intervention, which means that the educational programme of Fossey and colleges (2006) would be difficult to replicate. Like many staff training interventions, the training programme was performed by specially trained professionals, so it may be difficult to implement in routine practice where there is limited access to resources (Ballard et al., 2009).

The study conducted by Chenoweth and colleges (Chenoweth et al., 2009) was a cluster-randomized clinical trial, which included 298 people with dementia in 15 residential care facilities in Australia. The patients were assigned randomly to PCC, DCM or usual care. The nursing homes were selected because of their task-focused approach to care, as well as their similar management structures, staffing levels, standards and size. The selection criterion for the patients was persistent need-driven behaviour, which made it difficult for staff to provide them with quality care.

The PCC intervention comprised a two-day training session for two staff from each of the five sites. The staff received two visits and regular telephone calls from the researchers to assist the development and implementation of PCC practices.

In the DCM intervention, external mappers were used (two of the researchers) in addition to two trained internal care staff. The main outcome was agitation, which was measured using the CMAI, while neuropsychiatric symptoms were measured by the NPI-NH, and quality of life was measured with QUALID. The PCC and the DCM interventions reduced agitation compared with usual care at the end of the four-month treatment phase. There were no effects on the other outcome measures.

The study of Chenoweth and colleges (2009) has been described as explanatory in character because the interventions were conducted by the researchers, and the settings were well resourced and tightly controlled. Van de Ven et al. (2013) suggest that this form of implementation does not address the demand for evidence about real-world risks (van de Ven et al., 2013).

To employ usual care as the control condition has been criticized because there will probably be non-specific benefits from being part of a study. An education-alone comparator might be better because it will probably have a minimal effect, but it can control for the non-specific benefits (Ballard & Aarsland, 2009).

The cluster RCT conducted by van de Ven and colleges (van de Ven et al., 2013) tested the effectiveness of DCM in 34 SCUs for people with dementia in 11 nursing homes including 434 patients. Two nurses from each intervention nursing home were trained and certified as dementia care mappers. Similar to the study by Chenoweth and colleges (2009), the control group received usual care during the four-month trial. The main outcome measure was agitation, which was measured by the CMAI, while neuropsychiatric symptoms were measured using the NPI-NH. The quality of life was measured using QUALIDEM, which is a dementia-specific quality of life instrument from The Netherlands (Ettema et al., 2007). This pragmatic trial did not confirm the effect of DCM on agitation reported by Chenoweth et al. (2009). The results showed that there were more neuropsychiatric symptoms in the intervention group compared with the usual care group, but there were no significant effects on the quality of life of patients.

Dawn Brooker applied the VIPS framework in the Enriched Opportunities Programme for people with dementia (EOP), which is a multilevel intervention that focuses on improving the quality of life for people with dementia. The programme includes: a specialist staff role (“the EOP Locksmith”), staff training, individualized case work, liaison with health and social care teams, activity and occupation, and leadership (Brooker, Woolley, & Lee, 2007). A repeated measures within-patients design was employed, where data were collected at three points over a 12-month period at each facility with a follow-up 7–14 months later. Participants were 127 patients with a diagnosis of dementia or enduring mental health problems in three specialist nursing homes in the UK. DCM was used to observe well-being, the quality of life was measured using the DQOL instrument (Brod et al., 1999) and depression was measured using the CSDD.
A statistically significant increase in the levels of observed well-being and in the diversity of activity following the intervention was found. Overall, there was a statistically significant increase in the number of positive staff interventions but no

change in the number of negative staff interventions. There was a significant reduction in levels of depression (Brooker et al., 2007).

In summary, there is a limited evidence base for the effectiveness of PCC. The number of studies is small, but the findings are encouraging, provided that the feasibility and resource requirements of the treatment approaches agree with the reality in clinical practice.

Table 4 Effect of studies based on Kitwood's care philosophy on neuropsychiatric symptoms in dementia

Study	*Design*	*Sample*	*Intervention*	*Outcome*	*Result*
Fossey et al., 2006	10 months Cluster RCT (2 arms)	6+6 specialist nursing-homes 346 patients analysed	-PCC staff training Control: Usual care	-Use of neuroleptics -Agitation (CMAI) -Quality of life (DCM)	-Significantly lower use of neuroleptics in the intervention groups compared to the control group
Brooker et al., 2007	18 months Repeated measures within-patients design	3 specialist nursing homes 127 patients with a diagnosis of dementia or enduring mental health problems	Staff training in PCC activity program and cooperation with specialist expertise	-Quality of life (DCM, D-QOL) -Depression and anxiety (CSDD)	-Statistically significant increase in the number of positive staff interventions -no change in the number of negative staff interventions overall. -Significant reduction in depression
Chenoweth et al., 2009	4 months Cluster RCT (3 arms)	5+5+5 task-focused care facilities 236 patients with persistent need-driven behaviour completed the study	-PCC staff training -DCM Control: Usual care	-Agitation (CMAI) -Neuro-psychiatric symptoms (NPI) -Quality of life (QUALID) -Use of restraints -Use of psychotropic drugs	-Reduced agitation compared to usual care -No other significant results
van de Ven et al., 2013	4 months Cluster RCT (2 arms)	7+7 care homes 180 persons with dementia were analysed	-DCM Control: Usual care	-Agitation (CMAI) - Neuro-psychiatric symptoms (NPI-NHI) -quality of life (QUALIDEM)	-No effect on agitation or compared to usual care, -more neuropsychiatric symptoms in the intervention group than in the usual care group -No significant effect on patients' quality of life

RCT: randomized controlled trial, D-QOL: Dementia Quality of Life Instrument, NPI-NHI: Neuropsychiatric Inventory–nursing-home version, CMAI: Cohen-Mansfield Agitation Inventory, QUALID: Quality of life in Late-stage Dementia, DCM: Dementia Care mapping, CSDD: Cornell Scale for Depression in Dementia, Qualidem: Quality of life in Dementia instrument

2.5 Implementation in health-care settings

Implementing PCC by use of a structured method implies implementing changes to the way that care staff work, which has proved to be a great challenge. The effectiveness of an innovation depends on the effectiveness of its implementation, and a multitude of factors influence the degree of success of an implementation. Innovation in service delivery and organizations has been defined as: "*a novel set of behaviours, routines, administrative efficiency, cost effectiveness, or users' experiences that are implemented by planned and coordinated actions*" (Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004).The next chapter describes the different aspects of implementation and their many interactions.

Implementation has been defined as the process of putting to use or integrating an evidence based intervention within a setting (Rabin, Brownson, Haire-Joshu, Kreuter, & Weaver, 2008). Implementation is considered to be complex in health-care settings because it is delivered through the actions of individuals as well as organizations. Implementation is a social process, which means that the context will impact on the process, and there may be barriers at the patient level, the provider team or group level, the organizational level or the market/policy level (Fixsen & Blase, 2009; Ferlie & Shortell; 2001, Grol, Bosch, Hulscher, Eccles, & Wensing, 2007,).
A multitude of implementation models exist, which have relatively comprehensive lists of factors that may affect implementation (Damschroder et al., 2009; Feldstein & Glasgow, 2008; Greenhalgh et al., 2004). Some implementation models describe how organizational factors can promote a positive context for implementation, but there is limited evidence regarding which variables are key factors. The conceptual model of Greenhalgh et al. (2004) is described by the authors as: "*a memory aide for considering the different aspects of a complex situation and their many interactions*" (Greenhalgh et al., 2004). The model of does not specify the interactions between the constructs that are believed to influence implementation. Thus, the specific mechanisms of change and interaction remain to be developed and tested empirically (Greenhalgh et al., 2004).

The Consolidated Framework for Implementation Research (CFIR) proposed by Damschroder and colleges (Damschroder et al., 2009) built on the extensive literature review conducted by Greenhalgh and colleges (2004), which considered how innovations in health service delivery can be spread and sustained. Damschroder and colleges (2009) included 18 more recent published models, theories and frameworks that facilitate the translation of research findings into practice. The CFIR comprises five major domains (Damschroder et al., 2009):

I. The intervention
II. Inner setting
III. Outer setting
IV. The individuals involved
V. The process followed to accomplish the implementation

These domains overlap partially with the basic structure of other implementation models in health care, particularly the Promoting Action on Research Implementation in Health Services (PARiHS) framework, which is based on evidence, context and facilitation (Kitson, Harvey, & McCormack, 1998; Rycroft-Malone et al., 2002). The CFIR domains I-V with constructs and short definitions of the topics (Damschroder et al., 2009) (Additional file 3) are presented in the Attachment.

2.6 Complex interventions

In research, the implementations of innovations in the health-care sector are considered to be complex interventions. According to the revised Medical Research Council guidelines (Craig et al., 2008) a complex intervention has the following characteristics.

- Numerous interacting components within the experimental and control interventions
- The number and the difficulty of the behaviours required by those delivering or receiving the intervention
- Numerous groups or organizational levels are targeted by the intervention.
- The number and variability of the outcomes
- The degree of flexibility or tailoring permitted by the intervention

The Medical Research Council guidance for the evaluation of complex interventions (Campbell et al., 2000; Craig et al., 2008) describes the sequential phases of developing RCTs for complex interventions, although the phases required to develop and evaluate a complex intervention do not always follow a linear sequence. The phases are as follows.

Reviewing the theoretical base

Explore relevant theory to ensure the selection of the best choice of intervention and to develop a hypothesis that predicts the major confounders and strategic design issues. The components of the intervention must be defined after exploring relevant theory.

Modelling the intervention

Identify the components of the intervention and the underlying mechanisms that influence the outcomes. This enables the identification of evidence to predict how the components are related and how they interact. Preliminary work is often essential to establish the likely active components of the intervention so that they can be delivered effectively during the trial.

Piloting and feasibility

A pilot provides information on the feasibility of the intervention, as well as showing whether it can be implemented in a research setting and whether it is likely to be widely implementable should the results be favourable. However, a lack of effect may reflect implementation failure rather than genuine ineffectiveness, and a process evaluation is required to identify implementation problems. Qualitative methods are recommended for assessing acceptability and feasibility.

Exploratory trial

Describe the constant and variable components of a reproducible intervention and prepare a feasible protocol for comparing the intervention with an appropriate alternative.

Definitive RCT

Compare a fully defined intervention with an appropriate alternative using a protocol, which must be theoretically defensible, reproducible and adequately controlled in a study with appropriate statistical power. A detailed description is necessary so that the intervention can be implemented correctly and replicated by others.

Long-term implementation

Determine whether others can replicate your intervention reliably and in uncontrolled settings over the long term.

Qualitative methods are recommended for assessing the acceptability and feasibility of complex interventions (Campbell et al., 2000; Craig et al., 2008). The validity standards used in qualitative research incorporate rigor and subjectivity, as well as creativity, in the scientific process (Whittemore, Chase, & Mandle, 2001). Lincoln and Guba translated the scientific criteria for quantitative research into the following criteria, which can be applied specifically to qualitative research (Rolfe, 2004; Lincoln & Guba, 1985):

a. Credibility (in preference to internal validity)
b. Transferability (in preference to external validity/generalizability)
c. Dependability (in preference to reliability)
d. Confirmability (in preference to objectivity)

3 The present study

PCC is acknowledged to be one of the most promising approaches to the care of people with dementia, but few models of PCC implementation were available in Norway when the present study started in 2010. The studies of Fossey and colleges (Fossey et al., 2006) in the UK and Chenoweth and colleges in Australia (Chenoweth et al., 2009) documented effectiveness of DCM and PCC, but the programmes used in these two PCC interventions were not published as models with manuals and training materials that allowed the interventions to be implemented elsewhere.
The VIPS framework was used as described by Brooker (Brooker, 2007) in two Norwegian nursing homes in 2009 to evaluate the care and detect what needed to be improved for the care to be person-centred. The feedback from the staffs of the nursing homes was that this procedure did not give incentives to changes at the unit level because the evaluation was too general. To implement PCC in a manner that affected care directly, there seemed to be a need to develop a model for the use of the VIPS framework by the front-line staff in their daily work at the unit level. The experiences of this preliminary pilot study were of importance for the present thesis.

3.1 Aim of the thesis

The overarching aim of this thesis was to translate the values of PCC into practical daily care using the VIPS framework and to evaluate its effect on the neuropsychiatric symptoms of people with dementia in nursing homes.
In particular, we aimed:

- To examine whether a model developed for practical use of the VIPS framework could be implemented in a Norwegian nursing home setting
- To investigate the effects of this model on neuropsychiatric symptoms
- To identify any organizational factors associated with the effects of the model

3.2 Design

To achieve these aims, we conducted four sub studies, which were published in four papers.

Sub study 1 was a non-systematic review of the theoretical foundation of the VPM.

Sub study 2 was a nine-week pilot study with subsequent focus groups, which were analysed by use of qualitative content analysis to evaluate the feasibility of the VPM.

Sub study 3 was a 10-month RCT with baseline assessments in January 2011 and follow-up assessments in November 2011, which evaluated the effect of the VPM (and DCM) on neuropsychiatric symptoms.

Sub study 4 was based on a multilevel regression analysis, which explored the variance in effect of the VPM based on the RCT.

Table 5 Content, methods and participants in the four sub studies

Content	Paper 1 Theoretical foundation of the VPM	Paper 2 Development of the VPM	Paper 3 Effectiveness of the VPM	Paper 4 Factors that influenced the effect of the VPM
Methods	Review of the literature to assess the main elements of the VPM	Pilot study for the VPM Focus groups Qualitative content analysis	RCT with three arms	Sub study of the RCT Multilevel analysis of the VPM intervention group
Participants		Two nursing homes 11 RNs, 12 ANs	14 nursing homes 624 patients	Four nursing homes 138 patients
Duration		Nine-week pilot study	10 months	

3.3 Methods

Like most intervention studies in the health-care sector, the present study was a complex intervention. The development phases of a complex intervention do not always follow a linear sequence (Craig et al., 2008).

3.3.1 What is person-centred care in dementia? Clinical reviews into practice: The development of the VIPS Practice Model. Review of the theoretical base

To ensure the selection of the best choice of intervention components in a model for the use of the VIPS framework by front-line staff, relevant theory was explored during the preparation of the study protocol. The challenge of building a shared base of person-centred values in the staff was addressed in the development of the VPM because this is central in PCC, as expressed in the V-indicators in the VIPS-framework. As previous research has shown that organizational and cultural factors may prevent staff from applying knowledge from training consistently in practice (Lintern, 2001; Burgio et al., 2002), literature on organization theory and social learning theory was used to guide the choice of intervention components for the VPM that could fit with existing resources and routines in the nursing home setting. To model the intervention, preliminary discussions were held with registered nurses (RNs), auxiliary nurses (ANs) and nursing management representatives to obtain their views on a draft of the VPM components to establish the likely active components of the intervention (Campbell et al., 2000). These discussions were not analysed but were used as an aid to develop the VPM to the point where it could reasonably be expected to have a worthwhile feasibility, acceptability and effect.

Paper 1 is a non-systematic review of the theoretical foundation for the components in the VPM which was conducted after the VPM had been tried out in a pilot study (Paper 2) to test its feasibility, adjust and finally define its components. Paper 1 may be seen as a supplement to Paper 2, with a more in-depth description of the components of the VPM.

3.3.2 A model for using The VIPS framework for person-centred care for persons with dementia in nursing homes: a qualitative evaluative study

To examine the feasibility, acceptability and implementation fidelity of the VPM, a nine-week pilot study was conducted in two nursing homes from April to June 2010. Focus groups were used to evaluate the VPM pilot study.

Participants

Nursing home A had 122 staff and 67 patients, nursing home B had 110 staff and 55 patients. All of the patients had dementia. Nursing home A had wards split into two smaller units with a nursing pool that comprised three RNs who served the whole institution. ANs were administrative managers in five of these units, and RNs were managers in two of the units. Nursing home B had a traditional form of organization with RNs as managers in all six wards.

Data collection

We conducted separate focus groups for RNs and AN in each nursing home. All of the RNs and ANs holding roles in the VPM during the pilot study were asked to take part in the focus group interviews, which also included the leading RN from each unit. Seven RNs and five ANs took part from nursing home A, and four RNs and seven ANs from nursing home B. The RNs and ANs were aged between 27 and 63 years in both institutions. All except one of the ANs were women.
An interview guide was used in the focus groups, where the themes included the following.

- Their general opinion of the VPM
- How the VPM fitted with their form of organization
- Experience of the roles and functions of the VPM
- What kind of support they needed

- Their suggestions about changes

They were also asked about their opinion of the components of the VPM in practice, the allocation of roles and their general feedback about the acceptability and feasibility of the VPM. The focus groups lasted 60–70 minutes.

3.3.3 The VIPS practice model (VPM)

The final VPM is based on Kitwood's person-centred care, Brooker's VIPS-framework and the results of sub studies 1 and 2.

The foundation of the VPM

The VPM was based on regular structured team-work, supervision and supportive management, which are elements highlighted by Kitwood and the VIPS framework (Brooker, 2007; Kitwood, 1997a). PCC is characterized by the relationship between each nurse and each patient with dementia, as well as the psychosocial environment in the ward, so the VPM focused on the process between the staff in the ward and the building of a shared base of values and knowledge in the staff (McCormack, 2004). The aim of this process was to create a shared person-centred view of the situation in the staff by allowing them to take part in decisions on how to proceed to provide person-centred care.

The consensus meeting

The hub of the VPM was a consensus meeting, which was held each week in the units. The consensus meeting used the VIPS framework to analyse challenging interactions between patients and nurses. The analysis focused on how the patient might experience the situation and how their neurological impairment, physical health, personality, life history and psychosocial needs might affect their reactions. Each consensus meeting adhered to the following procedure (see textbox 7).

Textbox 7 The Consensus meeting in the VPM

1. Presentation of a situation from the perspective of the person with dementia by the primary nurse.
2. The VIPS framework was used to analyse an actual situation during the daily care for one person with dementia by assessing it in the context of all four VIPS elements. One or two indicators were selected and used as the focus of the subsequent discussion.
3. A discussion was held to share relevant knowledge about the person with dementia, including their current care and relevant experience and knowledge about psychosocial interventions.
4. Decisions were made about any new interventions that might improve the quality of care for the patient.
5. The interventions selected were scrutinized from the perspective of the person with dementia by the primary nurse.
6. A date was set for an evaluation of the intervention.
7. Documentation was undertaken by the primary nurse.

Roles and functions

The front-line staff had roles and functions in the VPM, as well as leadership.

- The resource person was the leader of the consensus meetings. This role was held by an AN, who is a representative of the most numerous group of nurses in Norwegian nursing homes.

- The function of the leading RN in the unit was to schedule, attend and support the consensus meetings. Their job description states that they must ensure the quality of care and give professional support during decisions and the evaluation of interventions.

- The primary nurse had a role as the spokesperson for the person with dementia. The primary nurse knows the patient best and is the staff contact person for the patient's family. Most patients have ANs as their primary nurse because ANs form the majority.

- The function of the PCC expertise group in the overall institution was, on request, to support the staff by that held VPM roles in the units. This group comprised four experienced senior staff.

- To show active support, the senior-level management of the institution (the director) attended the introduction to the staff, ensured that the necessary resources were in place and that time was set aside for consensus meetings and supervision.

Training

All of the staff in the participating units was given a brief introduction (3 hours) to the principles of PCC and the VPM. Those appointed by the director to hold roles in the VPM attended another three-hour session where role-play was used to learn their functions in the weekly consensus meeting in the VPM. The three RNs in each nursing home who were selected to constitute a PCC expertise group received four one-hour supervision sessions from the research team during the pilot study. The purpose of these sessions was to discuss how to support the staff holding roles in the different units, as well as situations that appeared on the agenda in the consensus meetings in the units. The other staff holding roles attended the first session, which focused on their functions in the consensus meeting.

The VPM manual

Each member of staff received a VPM manual with an introduction to the main principles of PCC, including practical knowledge and examples of psychosocial interventions related to the indicators in the VIPS framework. Each indicator was accompanied by stories from everyday care situations with an emphasis on the perspective of the person with dementia. Each story included suggested interventions with explanations of why they were appropriate in the actual situation. The manual included a description of the structure of the VPM consensus meeting. Assessment tools for well-being, challenging behaviour, pain, etc. were explained and attached.

3.3.4 The Effect of Person-Centred Dementia Care to Prevent Agitation and Other Neuropsychiatric Symptoms and Enhance Quality of Life in Nursing Home Patients: A 10-Month Randomized Controlled Trial

The cluster randomized controlled trial (RCT) was conducted in nursing homes in Oslo, Norway between January and December 2011. All 51 of the nursing homes located in the city of Oslo were invited to participate in the study. The 15 nursing homes that accepted the invitation were randomized into three groups. One group of nursing homes received an intervention with DCM, one group received an intervention with the VPM and the final group was a common control group for both intervention groups.

Before randomization, the 15 nursing homes were divided into three blocks according to their size, which was defined as small (30–49 patients, six nursing homes), medium (50–69 patients, six nursing homes) or large (70–95 patients, three nursing homes).

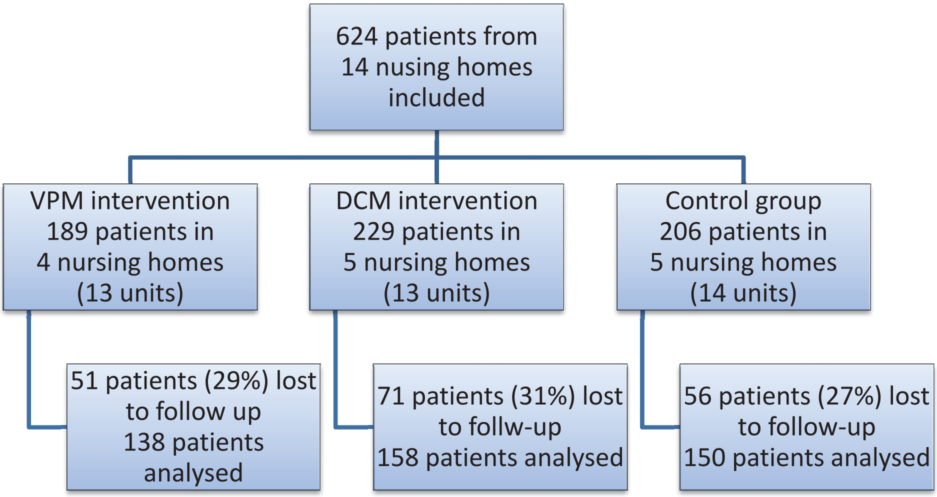
Randomization

The randomization was conducted by drawing lots, and each of the three intervention groups comprised patients from two small, two medium and one large nursing home. One nursing home that belonged to the VPM group withdrew after randomization.

Participants

Fourteen nursing homes with a total of 40 wards and 624 patients with dementia were included in the study. Subsequently, 178 (29%) were lost in the follow-up assessments, mainly because of mortality, so a total of 446 patients were included in the efficacy analysis (figure 1). The details are described in paper 3.

Figure 1 Flow of participants



Interventions

Dementia Care Mapping (DCM)

The DCM intervention involved four to six hours of in-depth observations (mappings) of people with dementia, which comprised the standardized coding of the well-being and behaviour of patients in the dining area or the living room room (Brooker & Surr, 2005; Brooker & Surr, 2006) (see section 2.4). Descriptions of interactions between staff and patients were also recorded. The observations were followed by a feedback session within one week, where the care staff was invited to reflect upon the findings and to plan future actions to improve care. The care staff and their leaders then implemented the action plans in the nursing home units without any further involvement by the researchers. After six months, the DCM observations and feedback were repeated. Two care staff members from each ward attended a basic DCM course, which certified them to use DCM in their own nursing homes. The rest of the care staff received a three-hour introduction to PCC and DCM in the form of lectures from the researchers. The DCM observations were made by the researchers in collaboration with the internal DCM-certified staff.

The VIPS Practice Model (VPM)

The leading registered ward nurse, an AN from each ward and a RN appointed as the VPM coach in each nursing home attended a three-day introduction course before implementing the VPM in each unit. The VPM coach replaced the VPM expertise group that was removed from the model as a result of the evaluation of the pilot study (see Paper 2). The directors of the nursing homes were also invited. The course, which was conducted by the researchers, focused on the main elements of the PCC and the structure of the VPM. A DVD illustrating the perspective of the person with dementia was used as a basis and starting point for discussions of PCC. A DVD showing the structure of the consensus meeting was shown before all of the participants tested their roles and functions during role-play. Time was set aside for the participants from each nursing home to plan the introduction to the rest of the staff and to prepare a schedule for the consensus meetings in the units and the supervision sessions. After the introduction course the VPM coach conducted a three-hour introduction to PCC and the VPM for the rest of the staff in their nursing

home. All staff also received the VPM manual (described in paragraph 3.3.1). The VPM coaches were invited to meet each other at the office of the researchers to share their experiences. Four such meetings were conducted with a mean attendance of two internal coaches.
The VPM was implemented in the units as described in paragraph 3.3.1

Distinguishing features of the interventions
The main difference between the two PCC methods was the use of external involvement to implement PCC. DCM employed observation of care and feedback to staff by external experts. In the VPM, the staff was given central roles and functions in a decision-making process, which facilitated the sharing of knowledge among peers, but no external experts were involved.

Control group
All three groups received five DVDs containing lectures about dementia (30 minutes each). For the nursing homes in the control group these DVDs constituted their intervention.

Data collection
Assessments were made at baseline before randomization and after 10 months. The data were collected by 13 (baseline) and 10 (follow-up) research assistants. These assistants received a one-day training course in the use of the questionnaires in groups of five to 0 persons, which were conducted by the researchers. Most of those who collected the data had participated in similar studies previously and knew the instruments well. They collected data from the patient records and interviewed the patients' primary nurse, who was either an RN or an AN. The project leaders were available during the data collection period and could be consulted at any time. Those who collected the data were not part of the research group and were not given information on the groups to which an individual patient belonged.

Assessment scales

In the RCT, the assessment scales were administered by research assistants who interviewed the nurse in the nursing home who knew the patient best.

The Brief Agitation Rating Scale (BARS)

The primary end point was the change in the summed BARS score. BARS (Finkel et al., 1993) is a short version of the CMAI, which was developed to enable nurses in nursing homes to make a rapid assessment of the level of agitation. The original BARS version comprised 10 items: hitting, pacing or aimless wandering, screaming, making strange noises, grabbing, repetitive mannerisms, repetitive sentences or questions, complaining, pushing and restlessness. One item (screaming) differed from the original in the Norwegian version (Sommer & Engedal, 2011; Sommer, Kirkevold, Cvancarova, & Engedal, 2010). Therefore, BARS used in this RCT did not include this item. The frequencies of these symptoms were rated from 1 (never) to 7 (several times per hour) based on the reported frequency of agitated behaviour during the preceding two weeks. The summed score ranged from nine to 63, where a higher score indicated more agitation.

Secondary end points were changes in scores on scales measuring neuropsychiatric symptoms, depression and quality of life.

The NPI Questionnaire (NPI-Q)

The 10-item NPI-Q (Kaufer et al., 2000) was used to assess neuropsychiatric symptoms. The NPI-Q is a proxy-based questionnaire and one of the most widely used scales. The original, the NPI (Cummings et al., 1994), contained 10 items: delusions, hallucinations, agitation, depression, anxiety, apathy, irritability, euphoria, disinhibition and aberrant motor behaviour. Later, two neurovegetative items were added; i.e., sleep and night-time behaviour disorders, and appetite and eating disorders (NPI-12 version) (Cummings et al., 1994; Cummings, 1997). The 12-item version assesses the frequency (0–4) and severity (0–3) of the symptoms, and an item score is generated by multiplying the frequency and severity (0–12), and the summed score of the scale ranges from zero to 120.

The NPI-Q is a version of the 10-item NPI which does not include the frequency scale (Kaufer et al., 2000). The symptoms were registered as present or not during the preceding week, and if present, the severity of the symptom ranged from 1 to 3, thereby yielding an item score ranging from zero to 3 and a summed score on a scale ranging from zero to 30.

The NPI contains symptoms as diverse as apathy and aggression, so adding them and using the total score of the NPI as a measure of the burden of the symptoms for the patient is problematic. Studies have divided the NPI scale into sub syndromes based on factor analysis. We analysed the change in the summed NPI-Q score and the change in the subscales for agitation (agitation + irritability + disinhibition) and psychosis (delusions + hallucinations) based on a factor analysis of a large sample of Norwegian nursing home patients (Selbaek & Engedal, 2012).

The Cornell Scale for Depression in Dementia (CSDD)

CSDD was used to assess depression (Alexopoulos et al., 1998). The CSDD comprises 19 items with categories that include mood-related signs, behavioural disturbance, physical signs, cyclic functions and ideational disturbance (e.g., delusions). The CSDD records the symptoms that have been present during the preceding two weeks. Each item is rated on a three-point scale: 0 (absent), 1 (mild or intermittent) and 2 (severe). The option “not applicable” can be used when scoring an item is inappropriate. The score range is zero to 38, where a higher score indicates more depressive symptoms.

The QUALID scale

The QUALID scale (Weiner, 2000) was used to assess quality of life. QUALID records the frequency of 11 observable behaviours in the patients during the previous week (range 11 to 55): smiles, appears sad, cries, has a facial expression of discomfort, appears physically uncomfortable, makes statements or sounds that suggest discontent, is irritable, enjoys eating, enjoys touching, enjoys interacting, and appears emotionally calm and comfortable. A higher score indicates a poorer quality of life.

Clinical Dementia Rating (CDR)

The CDR scale (Hughes, 1982) was used to measure the degree of dementia. The CDR rates six domains of functioning: memory, orientation, judgement and problem solving, community affairs, home and hobbies, and personal care. Each domain is rated on a five-point functioning scale, as follows: 0, no impairment; 0.5, questionable impairment; 1, mild impairment; 2, moderate impairment; and 3, severe impairment (personal care is scored on a 4-point scale where a 0.5 rating is not available). Using an algorithm, the severity of dementia is staged as none, possible, mild, moderate or severe dementia. Adding the scores for each item generates the “sum of boxes”(0–18), which is highly correlated to the CDR score (O’Bryant, 2008).

The Physical Self-Maintenance Scale (PSMS)

PSMS (Lawton & Brody, 1969) was used to assess performance of the activities of daily living. This scale has six domains: toilet, feeding, dressing, grooming, physical ambulation and bathing. Each domain has five levels, ranging from total independence (1) to total dependence (5). A higher score indicates greater impairment (6–30).

A modified version of the General Medical Health Rating scale (Lyketsos et al., 1999) was used to assess general physical health. This scale was used to categorize the patient’s physical health as good, fairly good, poor or very poor.

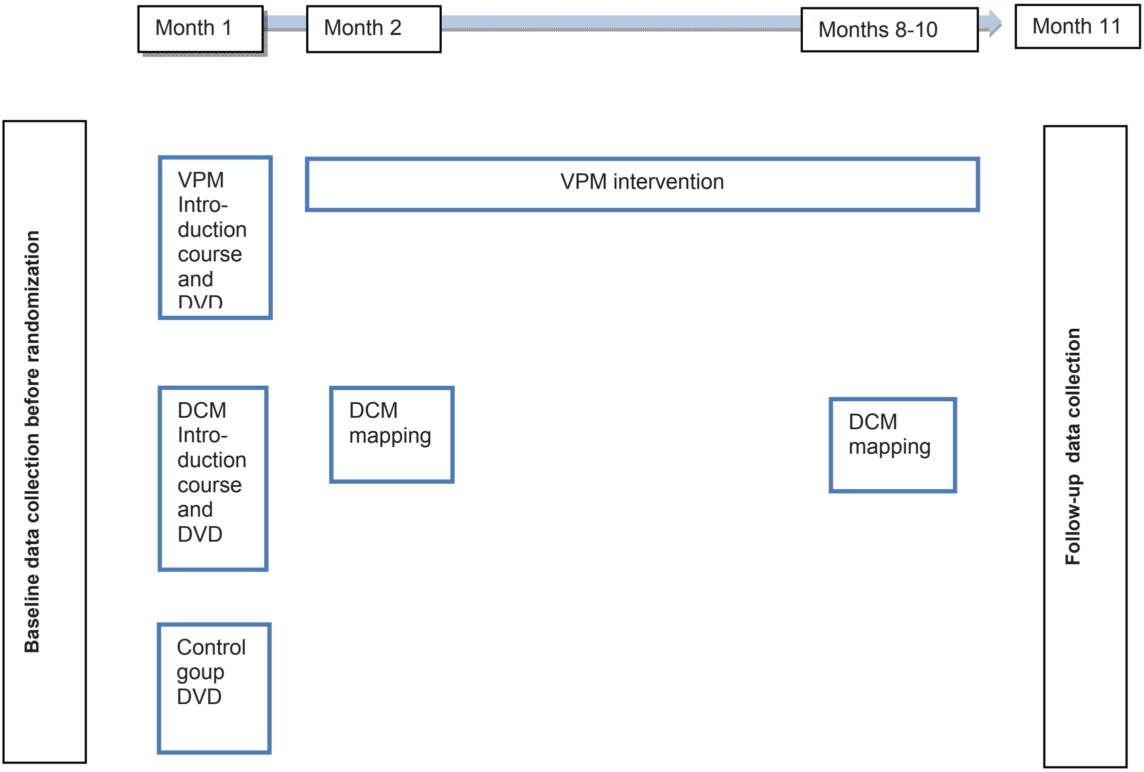
Patient characteristics

Patient characteristics such as age and gender were obtained from the patient records.

Ward characteristics

Information on ward characteristics was obtained by interviewing the registered nurse in charge using a questionnaire, which determined the type of ward unit, the number of patients per ward and the patient–staff ratio on day shifts.

Figure 2 Study design



3.3.5 Factors associated with effect of the VIPS practice model on neuropsychiatric symptoms in persons with dementia in nursing homes

Sub study 4 used the VPM intervention group sub set of the data from the RCT.

Participants

Five nursing homes (two small sized, two medium sized and onelarge sized) were allocated to the VPM intervention. One nursing home consisting of threewards and 36 patients withdrew and did not receive the intervention. Four nursing homes with 13 wards (range 12 – 29 patients) and 189 patients received the intervention. Fifty-one (27%) of the patients were lost to follow-up, 138 (73%) patients with dementia were analysed (see figure 1).

Outcomes and explanatory variables

The outcome variables were the change in scores on the NPI-Q and the CSDD. Explanatory variables were the Clinical Dementia Rating scale (CDR), the physical self-maintenance scale (PSMS), the General Medical Health Rating scale, patients' characteristics and ward characteristics.

3.4 Analyses

3.4.1 A model for using The VIPS framework for person-centred care for persons with dementia in nursing homes: a qualitative evaluative study

Information from the the focus groups were analysed using qualitative content analysis (Graneheim & Lundman, 2004) which has predominantly a naturalistic paradigm in interpretation, focuses on subject and context and deals with manifest as well as latent content in a text. The goal of this approach is ‘to validate or extend conceptually a theoretical framework or theory’ (Hsieh & Shannon, 2005). As the

VIPS practice model is constructed on the care philosophy of Kitwood (Kitwood, 1997a) and prior research, the directed content analysis approach was chosen. This approach starts with a theory or relevant research findings as guidance for initial codes.

The tapes with the recorded focus group interviews were listened to and the transcriptions read several times to get an overall impression. The interaction and progression of the debate in the groups were noted, as it reflects the development of a group perspective or position among a particular set of people (Reed & Roskell Payton). The analysis began by coding statements on how the nurses experienced the VIPS practice model into the pre-set categories which were the elements highlighted by Kitwood (1997a) and the VIPS framework: structured team work, supervision and supportive management (Kitwood, 1997a; Brooker, 2007). Next, thematic units relating to the same central meaning were identified, condensed and classified into themes and subthemes. Finally, the themes and sub-themes were validated by assuring that the descriptions were faithful to the original content of the focus-group texts.

3.4.2 The Effect of Person-Centred Dementia Care to Prevent Agitation and Other Neuropsychiatric Symptoms and Enhance Quality of Life in Nursing Home Patients: A 10-Month Randomized Controlled Trial

For the RCT, the analyses were performed by an external statistician who had no knowledge of the interventions according to an analysis plan, before the randomization code was known.

The patient and ward characteristics were subjected to descriptive analyses.

The differences between the intervention and control groups were assessed using ANOVA for continuous variables and a $\chi 2$ test for categorical variables.

The differences between baseline and follow-up within each group were assessed using a one-sample t-test for continuous outcomes and McNemar’s test for dichotomous outcomes.

The change in the primary and secondary endpoints was defined as the difference between the follow-up and baseline scores. Most of the scores were skewed at follow-up. However, all of the differences were close to being symmetrically distributed, which is a desirable property when using parametric methods.
For the dichotomous outcome, use of psychotropic drugs, the changes for those using and not using psychotropic drugs at baseline was examined separately.

The continuous endpoints in the intervention and control groups were compared using an independent-samples t-test, Z-test for proportions was used for dichotomous outcomes.

The intra-class correlation coefficient (ICC) was calculated to assess the degree of clustering within a nursing home ward; i.e., the average correlation between patients from the same unit was compared with the average correlation between patients from different units (Hox, 2002). There was a clustering effect in the data, so the association between the change in the endpoints and the type of intervention was assessed using regression models for hierarchical data. These models consider the possible correlations between members of the same cluster (nursing home ward), and they may avoid false significant findings. For each continuous outcome, a linear mixed model (SAS MIXED procedure) with random effects for the intercepts was estimated. A logistic regression model for hierarchical data (the SAS GLIMMIX procedure) with random effects for intercepts was fitted to detect change in the dichotomous secondary outcome. This was done separately for those not using psychotropic drugs at baseline and for those using it.
The associations were also controlled for age, gender, the CDR sum of boxes, general physical health, numbers of patients in a ward, type of ward and staff–patient ratio at baseline. The statistical analyses were conducted using SAS version 9.2 and SPSS version 18.0. Differences were considered significant when $p < 0.05$.

3.4.3 Factors associated with effect of the VIPS practice model on neuropsychiatric symptoms in persons with dementia in nursing homes

In sub study 4, we analysed the subset of the data from the RCT that focused on the patients, units and nursing homes allocated to the VPM intervention group using multilevel analysis. Multilevel analysis is used because contextual variables in a hierarchy, such as a unit in a nursing home, introduce dependency into the data, which violates the basic assumption of independence of observations in standard statistical tests (Field, 2005).

A multilevel linear regression model was used where the change in score on the NPI-Q and the CSDD from baseline to 10-month follow-up were the dependent variables. The data were treated in a hierarchical manner, with the patients' data on level 1 and the unit data on level 2, because the patients constituted the first level in a hierarchy of data where the units could be viewed as the second-level variable and the nursing home as the third-level contextual variable.

The analysis had three stages. First, the ICC was calculated without any predictor variable in the model (the "null" model). In the second stage, each of the possible variables was tested. Finally, to test for the effect of the institution level, we repeated the null-model test with the institution as level 2 (cluster) and the patient as level 1. To analyse the effects explained by the unit as a contextual variable, a hierarchical multilevel linear regression model was built using the software package MLWIN 2.25 (Bristol, UK).

First, the ICC was calculated as described above. To find the model that best explained the variance at the unit level and the patient level, a univariate linear regression was performed for each of the explanatory variables with NPI-Q and CSDD as dependent variables. The results were used to construct a multivariate linear regression model with the patient level and the unit level, as described by Hox (Hox, 2002). The model was built in a stepwise manner by adding the variables that explained most of the variance in the univariate analysis first. Variables that did not explain any of the variance were not included in the model.

Table 6 Outcomes and explanatory variables in sub studies 3 and 4

	Sub study 3 RCT	Sub study 4 VPM multilevel analysis
Primary outcome(s)	The Brief Agitation Rating Scale (BARS)	The Neuropsychiatric Inventory Questionnaire (NPI-Q) The Cornell Scale for Depression in Dementia (CSDD)
Secondary outcome(s)	The Neuropsychiatric Inventory Questionnaire (NPI-Q) The Cornell Scale for Depression in Dementia, (CSDD) The Quality of Life in Late Stage Dementia scale (QUALID)	
Explanatory variables	The Clinical Dementia Rating scale (CDR) The Physical Self-maintenance Scale (PSMS) The General Medical Health Rating scale Patient characteristics Diagnoses of dementia Ward characteristics	The Clinical Dementia Rating scale (CDR) The Physical Self-maintenance Scale (PSMS) The General Medical Health Rating scale Patient characteristics Ward characteristics

3.5 Ethical considerations

The World Medical Association (1964) developed the Declaration of Helsinki as a statement of ethical principles to provide guidance in medical research involving human subjects. The participants must be volunteers and informed participants in the research project. For participants who are not competent to give informed consent, consent must obtain from the authorized representative. Researchers have a responsibility to ensure that the physical, social and psychological well-being of research the participant is not adversely affected by the research. Researchers should seek to minimise disturbance to those participating in the research, anticipate and guard against consequences for research which can be predicted to be harmful and try to anticipate the long-term effects on individuals or groups as a result of the research. Researchers should take special care where research participants are particularly vulnerable by virtue of age, social status and powerlessness.

No patients were directly involved in the pilot study (sub study 2). We could not see that any of the patients would be affected in any negative way by the VIPS practice model, rather the opposite. The nurses were given written information about the pilot

study and asked for their consent to participate and for the use of the tape recorder in the focus groups. A clear statement of the purpose of the focus group was provided, to allow them to make an informed decision about participation. The topics discussed were of a practical nature and not particularly sensitive as they concerned their opinion of the VPM and how it fitted with the form of organization of their work-place. Even so, confidentiality was observed, minimal information was revealed that could be used to identify the participants.
The study was approved by the Regional Ethical Committee of South-East Norway.

All patients at all stages of dementia in the participating wards were invited to take part in the RCT (sub study 3). People with dementia in Norwegian nursing homes often lack the capacity to give informed consent, so thorough ethical deliberations are required before conducting research involving these patients. The possibility of using a person with dementia as an informant must be considered before making the decision to use proxy informants. Of the patients who participated in this study, those who were competent gave informed written consent. The relatives of patients who lacked the capacity to give informed consent were given the opportunity to decline participation on behalf of the patients based on written information.
Persons with dementia are dependent and thus constitute a vulnerable group, great care must be taken not to violate their integrity. The data collected in this study were aggregated and analysed at the unit level, and they cannot be traced back to the individual patients. As proxy informants were used, the patients were not directly involved in the data collection. If any patients were affected by the implementation of the PCC intervention, it is considered to be to their benefit. The information gathered plays an important role in the development of good quality care for persons with dementia.

The trial was registered at ClinicalTrial.gov in January 2011 (study ID number: NCT 01280890) and approved by the Regional Ethics Committee for Medical Research in Eastern Norway.

4 Results - Abstracts of the four papers

4.1 Paper 1 What is person-centred care in dementia? Clinical reviews into practice: The development of the VIPS Practice Model.

The VIPS framework is a four-part definition of person centred care for people with dementia (PCC), which arose out of an earlier review article for this journal. The definition has assisted in the practical application of person-centred care. It has been operationalized into the VIPS practice model (VPM), which has been patient to a recent randomized controlled trial within Norwegian nursing homes. The VPM provided a vehicle for the VIPS framework to be utilized during reflective practice meetings focusing on understanding care situations from the perspective of patients with moderate to severe dementia. VPM incorporated an education and coaching approach, clearly defined staff roles, and patient-focused outcomes in a cycle to support improvements in quality of care. The use of VPM in practice is discussed. VPM was built utilizing the literature from organizational change. The role of literature reviews in bringing about change in practice is highlighted.

4.2 Paper 2 A model for using The VIPS framework for person-centred care for persons with dementia in nursing homes: a qualitative evaluative study.

Background: The 'VIPS' framework sums up the elements in Kitwood's philosophy of person-centred care (PCC) for persons with dementia as values, individualised approach, the perspective of the person living with dementia and social environment. There are six indicators for each element.

Aim: To conduct an initial evaluation of a model aimed at facilitating the application of the VIPS framework.

Design: Qualitative evaluative study.

Methods: A model was trialled in a 9-week pilot study in two nursing homes and evaluated in four focus groups using qualitative content analysis.

Results: Five themes emerged: (1) Legitimacy of the model was secured when central roles were held by nurses representing the majority of the staff; (2) The model facilitated the staff's use of their knowledge of PCC; (3) Support to the persons holding the internal facilitating roles in the model was needed; (4) The authority of the leading registered nurse in the ward was crucial to support the legitimacy of the model and (5) Form of organisation seemed to be of importance in how the model was experienced.

Conclusion: The model worked best in wards organised with a leading registered nurse who could support an auxiliary nurse holding the facilitating function.

4.3 Paper 3 The Effect of Person-Centred Dementia Care to Prevent Agitation and Other Neuropsychiatric Symptoms and Enhance Quality of Life in Nursing Home Patients: A 10-Month Randomized Controlled Trial

Aims: We examined whether Dementia Care Mapping (DCM) or the VIPS practice model (VPM) is more effective than education of the nursing home staff about dementia (control group) in reducing agitation and other neuropsychiatric symptoms as well as in enhancing the quality of life among nursing home patients.

Methods: A 10-month three-armed cluster-randomized controlled trial compared DCM and VPM with control. Of 624 nursing home patients with dementia, 446 completed follow-up assessments. The primary outcome was the change on the Brief Agitation Rating Scale (BARS). Secondary outcomes were changes on the 10-item version of the Neuropsychiatric Inventory Questionnaire (NPI-Q), the Cornell Scale for Depression in Dementia (CSDD) and the Quality of Life in Late-Stage Dementia (QUALID) scale.

Results: Changes in the BARS score did not differ significantly between the DCM and the control group or between the VPM and the control group after 10 months. Positive differences were found for changes in the secondary outcomes: the NPI-Q sum score as well as the subscales NPI-Q agitation and NPI-Q psychosis were in favour of both interventions versus control, the QUALID score was in favour of DCM versus control and the CSDD score was in favour of VPM versus control.
Conclusions: This study failed to find a significant effect of both interventions on the primary outcome. Positive effects on the secondary outcomes indicate that the methods merit further investigation

4.4 Paper 4 Factors associated with effect of the VIPS practice model on neuropsychiatric symptoms in persons with dementia in nursing homes.

Background / Aims: A recent cluster-randomised controlled study showed that the VIPS practice model (VPM) for person-centred care had a significant effect on neuropsychiatric symptoms in nursing-home patients with dementia. The RCT indicated that a substantial proportion of the total variance of the effects was related to conditions in the particular unit (ward). We have explored which factors explain the variance in the effect of the VPM.

Methods: The VPM sub-set of data from the RCT was explored using multilevel linear regression. The dependent variables were the change in scores on the Neuropsychiatric Inventory Questionnaire (NPI-Q) and the Cornell Scale for Depression in Dementia (CSDD).

Results: The unit in which the patient was living explained twenty-two per cent of the VPM's total variance in effect on the NPI-Q and thirteen per cent for the CSDD. The intra class coefficient (ICC) for the unit level was explained mainly by unit size on both scales and was considerably higher than for the institutional level.

Conclusion: The unit is the most influential level when implementing PCC by use of the VPM. The unit size explains most of the variance of effect of the VPM, and the effects were best in the small units.

5. Discussion

Papers 1 and 2 will be discussed in the first part of the discussion, and Papers 3 and 4 in the last part.

5.4 The VIPS Practice Model (VPM)

The VPM will be discussed in light of the constructs in The Consolidated Framework for Implementation Research (CFIR I-V) (Damschroder et al., 2009) (Additional file 3) which is presented in the Attachment.

5.4.1 Evaluation

The findings of the focus group interviews after the pilot study indicated that the VPM was feasible in a nursing home setting, after some revision. The revision comprised to replace the VPM expertise group with an internal VPM coach, and to expand the training for those holding VPM roles (Paper 2).

The PCC concept is often perceived as synonymous with good-quality care (Brooker, 2004), and person-centeredness has an emotional appeal to many nurses, because it “has the right feel’ for them and nurses believe it ‘feels right’” (Dewing, 2004). PCC accords with the humanistic nursing theory used in Norwegian education for RNs and ANs. Thus, because the VPM was based on PCC, it may have been perceived by staff as an intervention with a reliable evidence base (see CFIR construct I: “Evidence Strength and Quality”, Damschroder et al., 2009; Grol et al., 2007). Clinical experience may also be perceived as evidence by staff (Dopson, FitzGerald, Ferlie, Gabbay, & Locock, 2002; Rycroft-Malone et al., 2002), and Kitwood’s descriptions of care that undermines personhood (malignant social psychology, see section 2.4) are examples from a reality that unfortunately is often recognizable to staff.

Another finding from the focus group interviews was that the VPM facilitated the staff’s use of their knowledge of PCC. Janzen et al. (2013) conducted a qualitative study of 44 staff from five care facilities in Canada and found that agitation was interpreted differently depending on the educational background of the staff members, as well as how they were trained to evaluate the situation and to recognize the needs (Janzen et al., 2013). The CFIR IV construct “Knowledge and beliefs” includes skills, (Damschroder et al., 2009, Additional file 4) which are described as a cognitive function that relies on knowledge of the underlying principles of the intervention (Rogers, 2003). Even if PCC is intuitively appealing to most nurses, PCC may still be difficult to accomplish in practical care. Kitwood perceived dementia as a complex interaction between the person’s personality, biography, physical health, neurological impairments due to the brain disorder, and the social psychology that permeates the environment the person lives in (Kitwood 1993). This implies that nurses in dementia care need to have knowledge of types of dementia and neuropsychiatric symptoms, and the ability to recognize unmet needs. Ervin et al. (2012) concluded that there are significant knowledge gaps in dementia care with respect to neuropsychiatric symptoms that are not recognized by staff. Their study demonstrated that the perceived level of knowledge was higher than the actual level of knowledge and competence when measured (Ervin, Finlayson, & Cross, 2012). Beer et al (2009) found that nursing home staff perceived their current knowledge about dementia as “good”, but a need for education regarding assessment and care planning, challenging behaviour, inter-professional communication, communication with persons with dementia as well as communication with family carers was identified (Beer et al., 2009).

5.4.2 Implementation components

External expertise was not involved in implementation of the VPM in the units. After receiving training, the internal staff exerted their VPM roles and functions in the weekly VPM consensus meeting. In this respect, the number of steps required to implement the VPM can be regarded as low, although PCC itself might be regarded as complex because it involves behavioural change (CFIR I construct “Complexity”). Simple and clear implementation schedules and task assignments have been shown to contribute to successful implementation (Gustafson et al., 2003). A general finding in reviews of psychosocial interventions is that the feasibility of several interventions appeared to be limited because specialized staff was required to implement the intervention (Ballard et al., 2009).

One of the core elements of the VPM was regular structured team-work. Groups are important arenas for sharing experiences and facilitating learning (Dopson et al., 2002), and effective teamwork has also been highlighted as a core property for successful implementation (Ferlie & Shortell; 2001). An overview of Dopson et al., (2002) of qualitative studies suggested that knowledge must be made social and assimilated into the shared knowledge of other individuals in order to contribute to organizational change (Dopson et al., 2002). If the skills are not sufficient, the risk for rejection and discontinuance of the intervention is high (Greenhalgh et al., 2004), which renders the implementation vulnerable to rejection and failure. In the case of the VPM, this highlights the importance of the leader's presence in the consensus meetings, because middle managers, like leading ward RNs, are the repositories of a significant body of knowledge and experience (Carlstrom & Ekman, 2012). The leader's role as a supervisor in the VPM is important because their skills can be applied and shared during actual discussions. If the consensus meeting identifies gaps in knowledge and skills, the leader can take measures to remedy these deficits. As described in Paper 1, the leader also represents the cultural norms that affect the staff and is in a position to influence organizational changes strongly (Adorian, Silverberg, Tomer, & Wamosher, 1990).

For an intervention to be adopted and adhered to, the users must perceive an effectiveness advantage from implementing the intervention (CFIR construct I "Relative advantage") (Feldstein & Glasgow, 2008; Greenhalgh et al., 2004; Gustafson et al., 2003). A subtheme of the focus group analysis described the conflicting opinions of the RNs in the nursing pool in nursing home A. Apparently, the VPM was not advantageous for these RNs compared with their present way of working, whereas it was for the rest of the staff. This finding might be viewed in relation to the impact of the type of organization on the feasibility of the VPM (see CFIR I, construct "Adaptability"). In the type of organization with a leading RN (formal leader or middle manager) in each unit, the authority of the leader was found to be crucial in upholding the legitimacy of the VPM. The leader provided support to the ANs who held facilitating roles in the VPM. In the CFIR V, those in these roles are referred to as "champions". The literature is mixed on the influence of the role of champions on implementation. There is some evidence that front-line champions may move other members of staff to fully embrace the intervention because effective champions can build a broad base of support, while supervisors or manager champions can empower the front-line champions (Dopson et al., 2002; Grol et al., 2007; Rogers, 2003). However, it was clear from the pilot study that a form of organization with leaders based in the units fitted best with the model.

The pilot study showed that setting aside time for consensus meetings appeared to be a problem. None of the units conducted consensus meetings every week, and the median number of meetings was 1.4 per month. If the leading RN did not attend, the consensus meetings were often cancelled (Paper 1). This agrees with the CFIR III's emphasis on "Leadership Engagement", which highlights the commitment and involvement of leaders. Repenning (2002) stated that an implementation is doomed to fail without full support from the leaders (Repenning, 2002). If the employees perceive that implementation of the intervention is a key organizational priority that is promoted and supported, the implementation climate will be strong, and the staff will not regard the intervention as something that disturbs them in their daily work (Klein, Conn, & Sorra, 2001). The importance of the role of the middle manager to overcome barriers of implementation was also emphasised in the literature reviewed in Paper 1.

5.4.3 Methodological considerations

The findings of a pilot study of such short duration (nine weeks) might not capture the aspects of an implementation that take longer to emerge, which are the results of building the experience and knowledge of a team over time. Given that this is in the nature of a pilot study, it is not a methodological problem, but it should be considered when making inferences from the findings.

As recommended for complex interventions, qualitative research was used to assess the acceptability and feasibility (Campbell et al., 2000; Craig et al., 2008). Qualitative research is contextual and subjective, rather than generalizable and objective (Whittemore, Chase, & Mandle, 2001), because all such interpretations are influenced by the interpreter's history and tradition (Gadamer, 1998)(p 307). To ensure credibility, a conscious effort must be made to establish confidence in the interpretation of the data. This can be achieved by asking the participants to confirm the findings. However, to reconvene the members of a focus group might be difficult, and even if possible, the group dynamics will not be the same (Kidd & Parshall, 2000). In our study, therefore, member checking was performed in real time when the focus group interview was conducted. The essence of the discussion was summed up and recounted to the participants to obtain their confirmation of the interpretation, before leaving one topic and starting on another (Kidd & Parshall, 2000).

Authenticity refers to reflection on (all) the meanings and experiences that are lived and perceived by participants, so conflicting perceptions and opinions must be reflected to secure authenticity (Whittemore, Chase, & Mandle, 2001). In our study, authenticity could have been reinforced further by using individual interviews, in addition to the focus group interviews, because there is always a risk that some of the participants have views and opinions that they do not divulge. However, the focus groups displayed apparent polarization, so this was not a pressing concern. In addition, the topics discussed were of a practical nature and not particularly sensitive. However, exploring the causes of the observed interplay and the conflicts of opinion by using individual interviews might have provided useful information, so this approach is recommended for future research projects in this field.

A key criterion for confirmability (see section 2.6) is the extent to which the researcher admits their own predispositions and is conscious that they are not an objective observer (Abulad, 2007). The interpreter must be aware that all interpretations are influenced by their history and tradition. Therefore, they must keep an open mind to allow the unexpected and unfamiliar, and seek to understand a phenomenon rather than to provide an explanation. It is also of great importance to acknowledge the context and situated location of interpretation. Beyond this, there are no fixed or rigid guidelines for interpretation and analysis (Gadamer, 1998)(p 307). The main supervisor of Paper 2 and a college took part in the preparation of the interview guide, the focus group interviews and the debriefing after the focus group interviews, and they were consulted about the analysis. This was important for challenging the preconceptions and unconscious assumptions made by the main investigator. Confirmability may also be supported by consistency with the findings from other studies. The findings from our pilot study agree with the findings of implementation research in other health-care settings, as discussed above. However, inconsistency is not proof of a lack of confirmability.

5.5 The effect of the VIPS practice model on neuropsychiatric symptoms in persons with dementia in nursing homes

5.5.1 Effect on agitation

We did not find a significant difference in the agitation measured using BARS between the VPM group and the control group, which was our main outcome variable. However, we did find a significant difference in agitation measured using the NPI-Q agitation subscale. This was surprising because BARS has a broader range of items (nine items) and a wider frequency scale (1–7) compared with the NPI-Q agitation subscale, which comprises three items; agitation, irritability and disinhibition (Selbaek & Engedal, 2012), and a frequency scale that ranges from 0 to 4.

One explanation might be that BARS does not assess irritation and disinhibition, which are symptoms that might have been prevented or positively affected by the VPM intervention if the staff had discussed how to avoid situations that provoked the patient or created frustration.

Another explanation might be related to differences in the information captured by the two scales. Sommer et al. (2009) found an almost significant outcome of treating patients with dementia with oxcarbazepine to prevent agitation and aggression when measured using BARS, but no significant effect when the effect was measured with the NPI agitation subscale (Sommer et al., 2009).

The finding might also be related to the different scopes of the two scales. The broader scale of BARS may give an unintended modified rating compared with the narrower scale of the NPI-Q. If the proxy informant wants to signify a change in the patient by rating the behaviour one grade up or down compared with the baseline measurement, one step up on the BARS frequency scale has a lesser effect on the BARS scale than one step up on the NPI-Q agitation subscale.

The two previous RCTs of PCC used the CMAI to measure agitation. Fossey and colleges (Fossey et al., 2006) failed to detect an effect on the levels of agitation measured using the CMAI between the PCC intervention group and the control group. Chenoweth and colleges (Chenoweth et al., 2009) detected a significantly lower agitation with CMAI in their study for patients in the PCC intervention group compared with the patients in the control group. Although the results of these two studies using CMAI were different, it might have been more appropriate to use the CMAI in the present study to measure agitation as the primary outcome. The CMAI assesses 29 agitated or aggressive behaviours, so it might have been more sensitive to changes and could have resulted in higher total summed changes in the scores compared with BARS. We selected BARS because this instrument has been used widely in clinical trials, and it measures the clinically relevant dimensions of dementia (Sommer et al., 2010).

However, the significant effect on agitation (less symptoms in the VPM group versus the control group, adjusted regression coefficient; –0.9) when measured using the NPI-Q agitation subscale indicates that this PCC approach can affect (reduce) agitation in the patients in nursing homes. This is encouraging because symptoms such as agitation and aggression, disinhibition, and irritability are known to be some of the most persistent symptoms in people with dementia (Selbaek, Engedal, Benth, et al., 2013). Furthermore, it is important that efforts should also be made to prevent these symptoms from occurring because they seem to be particularly persistent after they have become established (Selbaek, Engedal, Benth, et al., 2013).

5.5.2 Effects on the total amount of neuropsychiatric symptoms

The VPM and DCM had significant effects on the total amount of neuropsychiatric symptoms (reduction in symptoms) compared with the control group, according to the NPI-Q (adjusted regression coefficient for DCM: –2.7, for the VPM: –2.4). The NPI-Q total score provides a measure of the average change in all neuropsychiatric symptoms measured in the patients of the unit. The fact that the VPM and DCM both affected this variable, despite their different approaches, might be because the focus of PCC is not the treatment of a specific neuropsychiatric symptom. Instead, the aim of PCC is to support the personhood of a person with dementia by facilitating and nurturing positive and enriching relationships (Brooker, 2004; Kitwood, 1997a), which may have prevented neuropsychiatric symptoms in general over time.

5.5.3 Effect on psychosis

The VPM had significant beneficial effect on psychotic symptoms compared with the control group (adjusted regression coefficient: –0.6). This NPI-Q subscale comprises the items “delusions” and “hallucinations” (Selbaek & Engedal, 2012), which are the most commonly encountered psychotic symptoms in patients with dementia; i.e., delusions are the more common of the two according to studies using the NPI (Cipriani, Danti, Vedovello, Nuti, & Lucetti, 2013; Selbaek, Engedal, & Bergh, 2013; Zuidema et al., 2007; Zuidema, van der Meer, Pennings, & Koopmans, 2006).

This finding is difficult to explain. It might be attributable to changes in the staff’s perception of the behaviour of patients; i.e., the focus on psychological needs in PCC may have made staff interpret the delusions or misidentifications of their patients as expressions of, for instance, a need for attachment or identity rather than psychotic symptoms.

This result might be viewed in relation to the finding of reduced agitation according to the NPI-Q. Hallucinations and delusions have been found to be related to what has been termed “abusive behaviours” (Leonard, Tinetti, Allore, & Drickamer, 2006; Volicer, Frijters, & Van der Steen, 2012; Volicer, Van der Steen, & Frijters, 2009), which might suggest a relationship between psychotic symptoms and agitation. Volicer et al. (2012) found that hallucinations increased significantly in a group of patients where agitation increased during the study period. The psychosis score was lower in patients who did not experience agitation compared with the patients who were agitated during the study (Volicer et al., 2012). This positive correlation between psychotic symptoms and agitation might be due to a mismatch between a patient’s environment and their abilities to cope with the situation. If the staff became more aware of overstimulation during the intervention and took care to shield a patient when they observed the patient’s level of agitation was escalating, this might have prevented the development and occurrence of psychotic symptoms in patients. Thus, the effects of PCC might be primarily on psychosis and secondarily on agitation, or the reverse. The present study did not answer this question, but it would be valuable to know the answer.

Given that the VPM intervention led to a change in the efforts of staff to engage the patients in activities that they found enjoyable (see the VIPS framework, paragraph 2.4.1), the reduction in psychotic symptoms might have been related to a more stimulating environment, because hallucinations may be related to a lack of stimulation (Engedal & Haugen, 2004)(p 84). A previous study showed that organized activity significantly reduced the occurrence of delusions and hallucinations (Chen et al., 2013).

People with dementia might experience frightening delusions by misinterpreting their own reflection in a large window as an intruder or by believing that persons on television are present in the room (Engedal & Haugen, 2004)(p 302). If staff had made changes to the physical environment that prevented such misinterpretations during the intervention, this might have affected the prevalence of psychotic symptoms.

There also seems to be a relationship between psychotic symptoms and anxiety (Engedal & Haugen, 2004)(p 279). By taking the fears of patients seriously and providing comfort, by nurturing relationships that provide attachment, security and reassurance, anxiety might be reduced which in turn may lead to reduction in psychotic symptoms.

Our possible explanations of these relationships are still open for discussion, and they should be tested in future research. At present, we lack evidence based on research to support the relationships between these elements of PCC and psychotic symptoms.

5.5.4 Effect on depression

The RCT detected a significant reduction in depression in the VPM intervention group compared with the control group measured using the CSDD, which was not the case in the DCM intervention group (adjusted regression coefficient for the VPM group versus the control group: –2.6). Similarly, there was a significantly lower deterioration in the quality of life in the DCM group measured using the QUALID scale compared with the control group (adjusted regression coefficient for the DCM group versus the control group: –3.0), whereas the lower deterioration in the quality of life in the VPM group compared with the control group was not significant. This was surprising because previous research shows fairly consistently that these two variables are strongly correlated, thereby indicating that quality of life and depression are related phenomena. A Norwegian study found that a diagnosis of major depression was the strongest factor related to poor quality of life for elderly institutionalized patients with dementia (Barca et al., 2011). The association between depression and poor quality of life is as also reported in international studies (Gonzalez-Salvador et al., 2000; Wetzels et al., 2010b).

This lack of parallel changes in quality of life measured by QUALID and depression measured by CSDD for the two methods might be attributable to the qualities and catchment areas of DCM and the VPM. In DCM, the mapping is conducted in common living areas such as the dining room. The feedback given to the staff in the DCM intervention focused on, for example, making meals more enjoyable for the patients, which might have made the staff more observant of items in QUALID such as “enjoys eating”, “enjoys touching/being touched” and “enjoys interacting or being with others” because they are relevant to mealtime situations. Scott et al. (2003a, 2003b) suggested that the quality of various aspects of long-term care may be affected by the extent to which nursing staff consider these aspects to be priority tasks (Scott, Mannion, Marshall, & Davies, 2003). The focus in the feedback from the external DCM experts may have made the staff consider making mealtimes an enjoyable social occasion as a priority task.

In the VPM intervention, the primary nurses presented challenging situations from the patient’s perspective in the consensus meetings. This may have made the nurses more observant of mood symptoms such as anxiety, sadness or irritability in the patients, which are items on the CSDD scale. This focus may have made the nursing staff consider care interventions related to mood symptoms and depression as priority tasks. Challenging situations often arise in the contexts of morning care and toileting (Sloane et al., 2004; Volicer et al., 2009). Depression is considered to be one of the most common factors associated with agitation in nursing home patients with dementia (Volicer et al., 2012), and resistance to care is reported to be related to depression (Volicer et al., 2009). According to Volicer and colleges (2009), interventions that prevent the escalation of resistance to care may decrease depression and prevent agitation in nursing home patients with dementia (Volicer et al., 2009).

The effect of the VPM on depression was encouraging because depression is more prevalent in persons with dementia than persons without dementia, and the use of anti-depressants may have limited benefits (Banerjee et al., 2011; Barca et al., 2010; Lindstrom et al., 2007; Nelson & Devanand, 2011)(see paragraph 2.2.2). Studies have found that depressive symptoms are related to aggression (Leonard et al., 2006; Volicer et al., 2012; Volicer et al., 2009). Of three modifiable factors investigated by Volicer et al. (2012) (depression, psychosis and pain), the presence of depression symptoms was the most important factor related to agitation in nursing home patients with dementia (Volicer et al., 2012). The aetiology of agitation is unclear, but it is believed to include physical diseases (delirium), unmet needs and pain (Cohen-Mansfield et al., 1990; Kovach et al., 2005). Increased awareness of these factors—e.g., by the patient's primary nurse during morning care—might partly explain the reduced depression in the VPM intervention group. Observation of these factors was part of the primary nurse's preparation for the presentation of the patient's perspective and experience of the situation in the VPM consensus meeting (see paragraph 3.3.1). According to Volicer et al. (2012), depression is probably a factor involved in the initiation or maintenance of agitation (Volicer et al., 2012). As with the effect on psychosis, the effect of PCC and the VPM on depression could have been mediated via an effect on agitation or vice versa, but the present study did not address this question.

5.5.5 Variation between the units

The RCT detected significant effects of the intervention in the VPM group as a whole compared to the control group. However, the sub study of the RCT (paper 4) showed that the effects differed substantially between the units in the same nursing home in the VPM intervention group. What may have contributed to this difference in effect between units?

It might have been expected that the type of unit would have had an impact on the effect of the VPM. However, the only strengthened SCU that took part in this study was associated with a lesser effect of the VPM compared with SCUs and ordinary units. If the strengthened SCU were excluded, the type of unit would not have affected the result.

The establishment of SCUs was recommended by the Norwegian Ministry of Social Affairs in a Regulation issued in 1988. The aim was to create a better environment for people with and without dementia, and to help people with dementia to function better. A Norwegian study showed that the patients of SCUs were younger, were less functionally impaired, had better physical health, and exhibited clinically significant psychiatric and behavioural symptoms more often compared with the patients of ordinary units (Selbaek, Kirkevold, & Engedal, 2008). According to another Norwegian study, the average staffing ratio during a day shift was slightly higher in SCUs (2.9 patients per staff) than ordinary units (3.4 patients per staff), whereas the proportion of unskilled staff was higher in SCUs (12.6%) than ordinary units (11.9%) (Kirkevold & Engedal, 2006).

Given that the staff of the SCUs in the RCT were specially selected, trained and supervised, the unit type is a variable that could be hypothesized to tip the scales in both ways. The rationale for a hypothesis of a greater reduction in neuropsychiatric symptoms in the SCUs than the ordinary units may be related to the VPM favouring good processes, thereby exploiting the potential of the special features of a SCU. The rationale for a hypothesis with the opposite result may be related to an initially higher quality of care in SCUs than ordinary units, thereby indicating a ceiling effect of what could be achieved.

We found only a minor difference in effect between the SCUs and the ordinary units, which agrees with the Cochrane review by Lai and colleges (2009). This review concluded that there is little evidence to support the assumption that the care of people with dementia in SCUs is superior to care in traditional nursing units based on the limited evidence base available. Lai and colleges (2009) found that no RCTs had compared the effect of SCUs with traditional nursing units with respect to the management of agitated behaviours in people with dementia. Thus, the conclusion of the review was based on the results of non-RCTs (Lai et al., 2009). In another evidence-based review related to organizational characteristics, Zimmermann and colleges (2013) found that the behaviour and engagement of patients did not differ based on residence in a SCU (Zimmerman et al., 2013). Thus, the Cochrane review of Lai and colleges (2009) and the review of Zimmermann and colleges (2013) both concluded that “implementing best practices may be more important than providing a specialized care environment”. In addition, it is questionable whether the intended features of SCUs represent the reality for most SCUs (Gerdner & Beck, 2001).

5.5.6 Effect of unit size

Our exploration of the variance in the effect of the VPM (paper 4) showed that the unit level was considerably more influential than the institutional level when implementing the VPM. Being aware of which organizational level (team, unit, service line, organization, system level, etc.) is the most influential for the implementation of a particular intervention is acknowledged as important in organization research. Which level is the most influential depends on the scope and nature of the intervention. The implementation climate (CFIR III) at the influential level is held to be decisive for implementation. Another term for this is “receptiveness for change”, which may vary among units (Damschroder et al., 2009, Additional file 4). The two concepts of culture and climate are often used without any clear distinction, but culture is often used as a concept for addressing deeper values and assumptions than climate (Gershon, Stone, Bakken, & Larson, 2004). Despite its variation in use and definition, culture has been shown to have a significant influence on the effectiveness of implementations (Helfrich et al., 2007). We lack data on the culture in the units investigated in the present study, but the number of staff and their proximity to the leader might have bearings on their culture. In the RCT, a unit was defined as an administrative unit of the nursing home with its own leader. We found that small units with their own leaders were favourable for the effectiveness of the VPM. In a systematic review by Wong and colleges (2007) of the relationships between nursing leadership and patient outcomes, there was a statistically significant association between patient satisfaction and a transactional leadership style, which decreased as the number of staff reporting to the manager increased (Wong & Cummings, 2007).The empirical knowledge about the association between nursing leadership and patient outcomes is limited (Wong, Cummings, & Ducharme, 2013). A qualitative study by Rokstad and colleges (2013) which investigated the role of leadership in the implementation of PCC in nursing homes using DCM, found that a leader who was an active role model and who expounded a clear vision was favourable for the implementation of PCC (Rokstad, Vatne, Engedal, & Selbaek, 2013). This may indicate that smaller units with its own dedicated leader benefit the implementation of the PCC.

5.5.7 Methodological considerations

Although there are potential gains in connection with participation in research projects such as the present RCT, nursing homes might have declined to take part because of a strained resource situation. This represents a risk of selection bias. However, the nursing homes were randomized into three groups. The results show that the PCC interventions had significant favourable effects on nursing homes from this population, whereas the control condition did not. However, if we assume that a volunteer effect existed in the present project, this effect is not necessarily a problem. It is not recommended to implement a psychosocial intervention in an organization that is unreceptive or that may have difficulties in adhering to a research protocol without also implementing measures to support the necessary change.

The data were collected by 13 (baseline) and 10 (follow-up) research assistants. Most of these assistants had participated in similar studies previously and were familiar with the questionnaires, whereas others had not. However, all of the assistants participated in a one-day training course prior to the first data collection to ensure that they had a similar understanding of the questionnaires. Still, there is always a risk of individual differences in how the assessors conducted the interviews, although the researchers were available and could be contacted by telephone if the research assistants had questions about the assessment.

The nurses who served as proxy informants for each patient were not always the same at the baseline and at the follow-up assessment. Thus, it is possible that different nurses might have had different standards when assessing the patients. This might have impaired the quality of the data. However, we used validated

Norwegian versions of the instruments with high inter-rater reliability. Any potential differences or errors in the data collection would not have been systematic errors, so they have been distributed randomly among all nursing homes and all three groups. In addition, inconsistencies in the assessment would have prevented us from detecting significant differences in the results among the units, rather than producing unjustified significant findings.

The use of staff as proxy informants is debated because proxy-based information relies upon another person's knowledge of the person with dementia, their ability to understand the person and their knowledge of dementia symptoms. The obvious reason for not interviewing the patients themselves is the impaired memory and reasoning abilities of people with moderate and severe dementia (most of the participants were in one of these two groups), which makes it hard for them to respond appropriately to the rating options in questionnaires. Proxy informants are used often in quantitative research, especially for people with moderate and severe dementia in nursing homes because interviewing the patients would lead to an even greater bias, as well as causing problematic ethical issues.

The VPM intervention in our RCT was conducted in clinical practice by internal staff, so the fidelity to the research protocol was exposed to challenges that could have affected the results. However, van de Ven and colleges (2013) criticized the PCC study by Chenoweth and colleges (2009) because it was a form of implementation that did not address the demand for evidence about real-world risks. The study by Chenoweth and colleges (2009) was explanatory in character because the interventions were performed by the researchers, the settings were well-resourced and tightly controlled, which are rare conditions in clinical reality (van de Ven et al., 2013). Our study may be considered a pragmatic cluster RCT where the staff of the nursing homes performed the intervention in a manner that may inform daily clinical practice.

Participation in a research project entails a Hawthorne effect; i.e., an observer-expectancy effect, where the participants change the behaviour that is being assessed because they know that they are being studied, rather than because of the intervention (French, 1953). The data collection process might have made the staff more attentive to the issues raised in the assessment questionnaires. Thus, controlling for this effect is necessary. In our study, the interventions were compared with a control group, which also received an intervention in the form of participation in the data collection and receiving a DVD containing lectures about dementia by renowned scientists in the field and. The Hawthorne effect would have been present in all three groups, which was considered in the statistical analysis.

Conducting a randomized, controlled psychosocial intervention trial is a complex undertaking, and there will be a large number of confounding factors and practical challenges. However, the fact that psychosocial interventions are complex should not prevent research from being conducted because the result would be a lack of knowledge about psychosocial phenomena. However, other research designs might provide knowledge about various aspects of organizations and social systems, such as nursing homes, which are difficult to obtain using RCTs, but the fact remains that an RCT is considered the gold standard for providing “hard evidence”.

5.6 Clinical implications and proposals for future research

PCC has become an influential psychosocial approach since the publication of Kitwood's work in the 1990s. Evidence for its effect is emerging, and we believe that the present study contributes to the knowledge of the effectiveness of PCC. This development is encouraging because pharmacological treatments of neuropsychiatric symptoms in people with dementia have only modest effects and potential serious adverse effects, while there presently is little evidence for the effectiveness of psychosocial interventions in general because of methodological limitations.
The present project demonstrates that the VPM developed for the practical use of the VIPS framework, which is a summary of the main elements of PCC, is feasible in a Norwegian nursing home setting and that it might reduce neuropsychiatric symptoms in people with dementia. It is encouraging that the use of the VPM may reduce depression, which is highly prevalent and often both undetected and undertreated in this group of patients. Small units with their own professional leaders appeared to be beneficial for the implementation of the VPM.

Further research should continue to focus on how staff can gain sufficient knowledge of neuropsychiatric symptoms and learn to be sensitive towards the perspective of the person with dementia, and incorporate these insights into communication and practical care. This is an essential precondition for PCC, and it may be one of the greatest challenges for the care staff. It is equally important to study the factors that contribute to the maintenance of PCC in the culture of a care unit. The inherent difficulties of this type of research should not dissuade researchers from addressing these issues, and qualitative study designs might be appropriate for this purpose. Research is also needed to obtain knowledge about how PCC might best be implemented in various dementia care settings, such as day care programmes and home care nursing, as well as in nursing homes.

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Attachment

The Consolidated Framework for Implementation Research (CFIR)

I. INTERVENTION CHARACTERISTICS

A Intervention Source
Perception of key stakeholders about whether the intervention is externally or internally developed.

B Evidence Strength & Quality
Stakeholders' perceptions of the quality and validity of evidence supporting the belief that the intervention will have desired outcomes.

C Relative advantage
Stakeholders' perception of the advantage of implementing the intervention versus an alternative solution.

D Adaptability
The degree to which an intervention can be adapted, tailored, refined, or reinvented to meet local needs.

E Trialability
The ability to test the intervention on a small scale in the organization, and to be able to reverse course (undo implementation) if warranted.

F Complexity
Perceived difficulty of implementation, reflected by duration, scope, radicalness, disruptiveness, centrality, and intricacy and number of steps required to implement

G Design Quality and Packaging
Perceived excellence in how the intervention is bundled, presented, and assembled

H Cost
Costs of the intervention and costs associated with implementing that intervention including investment, supply, and opportunity costs.

(Damschroder et al., 2009)(Additional file 3)

The Consolidated Framework for Implementation Research (CFIR)

II. OUTER SETTING

A Patient Needs & Resources
The extent to which patient needs, as well as barriers and facilitators to meet those needs are accurately known and prioritized by the organization.

B Cosmopolitanism
The degree to which an organization is networked with other external organizations.

C Peer Pressure
Mimetic or competitive pressure to implement an intervention; typically because most or other key peer or competing organizations have already implemented or in a bid for a competitive edge.

D External Policy & Incentives
A broad construct that includes external strategies to spread interventions including policy and regulations (governmental or other central entity), external mandates, recommendations and guidelines, pay-for-performance, collaboratives, and public or benchmark reporting.

(Damschroder et al., 2009)(Additional file 3)

The Consolidated Framework for Implementation Research (CFIR)

III. INNER SETTING

A Structural Characteristics
The social architecture, age, maturity, and size of an organization.

B Networks & Communications
The nature and quality of webs of social networks and the nature and quality of formal and informal communications within an organization.

C Culture
Norms, values and basic assumptions of a given organization.

D Implementation Climate
The absorptive capacity for change, shared receptivity of involved individuals to an intervention and the extent to which use of that intervention will be rewarded, supported, and expected within their organization.

1. Tension for Change
   The degree to which stakeholders perceive the current situation as intolerable or needing change.

2. Compatibility
   The degree of tangible fit between meaning and values attached to the intervention by involved individuals, how those align with individuals' own norms, values, and perceived risks and needs, and how the intervention fits with existing workflows and systems.

3. Relative Priority
   Individuals' shared perception of the importance of the implementation within the organization.

4. Organizational Incentives & Rewards
   Extrinsic incentives such as goal-sharing awards, performance reviews, promotions, and raises in salary and less tangible incentives such as increased stature or respect.

5. Goals and Feedback
   The degree to which goals are clearly communicated, acted upon, and fed back to staff and alignment of that feedback with goals.

6. Learning Climate
   A climate in which:
   a. Leaders express their own fallibility and need for team members' assistance and input;
   b. Team members feel that they are essential, valued, and knowledgeable partners in the change process;
   c. Individuals feel psychologically safe to try new methods; and d) there is sufficient time and space for reflective thinking and evaluation.

7. Readiness for Implementation
   Tangible and immediate indicators of organizational commitment to its decision to implement an intervention.
   1. Leadership Engagement; Commitment, involvement, and accountability of leaders and managers with the implementation.
   2. Available Resources; The level of resources dedicated for implementation and on-going operations including money, training, education, physical space, and time.
   3. Access to knowledge and information; ease of access to digestible information and knowledge about the intervention and how to incorporate it into work tasks.

(Damschroder et al., 2009)(Additional file 3)

The Consolidated Framework for Implementation Research (CFIR)

IV. CHARACTERISTICS OF INDIVIDUALS

A Knowledge & Beliefs about the Intervention
Individuals’ attitudes toward and value placed on the intervention as well as familiarity with facts, truths, and principles related to the intervention.

B Self-efficacy
Individual belief in their own capabilities to execute courses of action to achieve implementation goals.

C Individual Stage of Change
Characterization of the phase an individual is in, as he or she progresses toward skilled, enthusiastic, and sustained use of the intervention.

D Individual Identification with Organization
A broad construct related to how individuals perceive the organization and their relationship and degree of commitment with that organization.

E Other Personal Attributes
A broad construct to include other personal traits such as tolerance of ambiguity, intellectual ability, motivation, values, competence, capacity, and learning style.

(Damschroder et al., 2009)(Additional file 3)

The Consolidated Framework for Implementation Research (CFIR)

V. PROCESS

A Planning
The degree to which a scheme or method of behavior and tasks for implementing an intervention are developed in advance and the quality of those schemes or methods.

B Engaging
Attracting and involving appropriate individuals in the implementation and use of the intervention through a combined strategy of social marketing, education, role modeling, training, and other similar activities.

1. Opinion Leaders
   Individuals in an organization who have formal or informal influence on the attitudes and beliefs of their colleagues with respect to implementing the intervention

2. Formally appointed internal implementation leaders
   Individuals from within the organization who have been formally appointed with responsibility for implementing an intervention as coordinator, project manager, team leader, or other similar role.

3. Champions
   Individuals who dedicate themselves to supporting, marketing, and ‘driving through’ an implementation overcoming indifference or resistance that the intervention may provoke in an organization.

4. External Change Agents
   Individuals who are affiliated with an outside entity who formally influence or facilitate intervention decisions in a desirable direction.

C Executing
Carrying out or accomplishing the implementation according to plan.

D Reflecting & Evaluating
Quantitative and qualitative feedback about the progress and quality of implementation accompanied with regular personal and team debriefing about progress and experience.

(Damschroder et al., 2009)(Additional file 3)

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What is person-centred care in dementia? Clinical reviews into practice: the development of the VIPS practice model

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Summary

The VIPS framework is a four-part definition of person-centred care for people with dementia (PCC), which arose out of an earlier review article for this journal. The definition has assisted in the practical application of person-centred care. It has been operationalized into the VIPS practice model (VPM), which has been subject to a recent randomized controlled trial within Norwegian nursing homes. The VPM provided a vehicle for the VIPS framework to be utilized during reflective practice meetings focusing on understanding care situations from the perspective of residents with moderate to severe dementia. VPM incorporated an education and coaching approach, clearly defined staff roles, and resident-focused outcomes in a cycle to support improvements in quality of care. The use of VPM in practice is discussed. VPM was built utilizing the literature from organizational change. The role of literature reviews in bringing about change in practice is highlighted.

Key words: person-centred care, dementia, VIPS framework, model, implementation.

Introduction

Historically, dementia has been portrayed as a slow living death, destroying a human being as a person and moral agent. Although this perspective is no longer prevalent in modern clinical practice, it still influences the way in which people with dementia are related to, considered and conceptualized. Tom Kitwood was the first scholar to use the term 'person-centred' in relation to people living with dementia[1,2] with the aim of bringing together ideas and ways of working that emphasized communication and relationships, rather than medical and behavioural management. Kitwood built on the work of Carl Rogers, one of the founders of the humanistic approach to psychology. Rogers emphasized an empathic understanding of a person's internal frame of reference and the endeavour to communicate this experience to the person.[3,4]

The concept of personhood is at the core of person-centred care (PCC). Personhood emerges in a social context: '*personhood is not, at first, a property of the individual; rather, it is provided or guaranteed by the presence of others*' (Kitwood and Bredin, 1992; [5] p. 275). Kitwood's theoretical perspective stated that being cognitively impaired does not necessarily reduce personhood but rather it was not being recognized as a person that could cause severe ill-being, or even the state of vegetation. He predicted that this would erode the global psychological states that are fundamental for all human beings: self esteem, sense of agency, social confidence and hope.[6]

However, PCC is often used synonymously with individualized care, and the emphasis on relationships that Kitwood promoted gets lost. Indeed, the concept of relationship-centred care was developed as a counter to this emphasis on the individual.[2,5,7] In an earlier review in this journal,[1] a four-part composite definition of person-centred care in relationship to people with dementia was developed. This definition synthesized different threads emerging at that time in the literature and rhetoric of person-centred care whilst maintaining the sophistication of Kitwood's original ideas. Using the acronym VIPS (commonly understood as Very Important Persons)

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person-centred care was defined as having four major elements:

- V a **V**alue base that asserts the absolute value of all human lives regardless of age or cognitive ability;
- I an **I**ndividualized approach, recognizing uniqueness of the person living with dementia;
- P understanding the world from the **P**erspective of the of the person living with dementia;
- S positive **S**ocial psychology in which the person living with dementia can experience relative well-being.

Following the publication of the review, the VIPS definition was incorporated in the NICE/SCIE Guideline on Dementia.[8] Professional dementia care is dependent on attributes of organizations as well as individual practitioners. The VIPS definition was subsequently utilized to provide an evidence-based structure for good practice in person-centred care in the dementia care field – particularly in relation to care home practice.[9] Given the complexity of defining person-centred care it was deemed helpful to delineate a set of concrete indicators that care providers could benchmark their services against. Pilot indicators were reviewed by around 50 care providers and service user organizations worldwide to arrive at a detailed description of what a person-centred care provider should have in place. This list of 24 indicators grouped around the four elements of the definition set out above has become known as the VIPS framework.[9–12] It has been taken up by many English-speaking care providers and the concepts have been translated into German,[13] Japanese and Norwegian, and with translation planned in Portuguese and Spanish.

Recently, the VIPS framework has been utilized as a structure for guiding interactions and communication with health care professionals and people living with dementia[14] from early diagnosis to palliative care. The VIPS elements are used as the general guiding principles for health care practitioners to reflect on their interactions with people with dementia and their families. These reflective questions include:

- Does my behaviour and the manner in which I am communicating with this person show that I respect, **value** and honour them?
- Am I treating this person as a unique **individual**?
- Am I making a serious attempt to see my actions from the **perspective** of the person I am trying to help? How might my actions be interpreted by this person?
- Does my behaviour and interactions help this person to feel **socially** confident and that they are not alone?

These guiding principles can be applied in all professional interactions with people with dementia. They can be applied when professionals or care workers are involved in delivering a clinical procedure such as giving an injection or changing a dressing; they can be applied in situations where the person with dementia is being helped to complete a self-care task such as using the bathroom; equally they can be applied in discussions about care management or in running psychosocial interventions such as a reminiscence group. It is not the task that is person-centred but the way in which that task is done that can make it person-centred or not.

The 24 VIPS indicators provide a checklist that care providers can use as a benchmark to assess the person-centredness of their service for people with dementia.[14] There is still a gap in provision, however, for how to provide a way forwards for using the VIPS framework to implement changes in practice and to provide ideas and practical resources that can be used to meet different challenges. The Care Fit for VIPS website (www.carefitforvips.co.uk) provides an online free tool kit for both undertaking a benchmark, creating an action plan and in locating online resources that can assist with quality improvement plans. This is subject to an on-going evaluation in practice.

The VIPS framework was operationalized into the VIPS practice model (VPM)[15] for achieving person-centred care in Norwegian nursing homes and home care. A recent randomized controlled trial (RCT) showed positive results. The development of the VPM was built on evidence-based practice. It is presented below and its application in practice is reviewed.

The VIPS practice model (VPM)

It is contended that PCC is far more talked about than it is implemented. Kitwood also pointed out that '*The challenge is to get organizations to do it, rather than simply maintain a facade*'

Table 1. *The VIPS practice model (VPM): the vehicle for change*

Education and supporting materials

A programme of education for those with specific roles within VPM and senior staff is the starting point for change. All staff receive a manual (50 pages) with examples of PCC related to each indicator in the VIPS framework and assessment tools. The leaders and the internal coach also receive a manual explaining VPM

Staff roles and functions

- An auxiliary nurse (AN) leads the consensus meetings – a role known as the resource person (RP)
- The leading ward registered nurse (RN) ensures quality by giving professional support
- The primary nurse (PN) has the role as spokesperson for the person with dementia
- An internal coach provides an introduction to VIPS to the rest of the staff and provides ongoing support to the AN, RN and PN staff

The VIPS consensus meeting

The aim is to hold a weekly meeting of the ward/unit team lasting 45–60 min structured as follows:

1. Presentation of the situation from the perspective of the person with dementia. A PN who is concerned about a situation asks the RP to put it on the agenda. If there are several cases put forward, the RP and the leading ward RN agrees when each situation will be put on the agenda
2. The VIPS framework is used to analyse one concrete situation in the daily care for one person with dementia. One to two indicators are chosen and focused on in the following discussion
3. Discussion with sharing of relevant knowledge between the team members
4. Decision on interventions: who will do what, with whom and by when
5. Outcomes relating to the perspective of the person with dementia are agreed
6. Date for review is set
7. Record observations and interventions in the resident's care plan

Minimum of four staff must be present including RP, leading ward RN and PN

(Kitwood 1997;[16,17] p. 115). Kitwood did not offer a comprehensive practice-friendly framework for translating his ideas into action.[17,18] For many professionals and staff, PCC continues to remain an elusive ideal. Nursing staff have been shown to have a limited conception of PCC.[19] Despite the development of the VIPS framework in written and online forms, having a vehicle for how to put these into everyday institutional practice may still be required. Also, in order to evaluate the utility of the framework through an RCT it was necessary to develop a replicable protocol. This led to the development of the VIPS practice model in Oslo, Norway, in 2010. It was trialled in a 9-week pilot study in two nursing homes and evaluated in four focus groups.[15] Adjustments were made following the pilot study and focus groups before it was tested within the RCT mentioned above.

Basing care on PCC values is not simply about adopting a new terminology, it means to develop a culture of care that includes people with dementia in social relations and meaningful activity.[16] Culture has been defined as a link or transition between individual and collective behaviour. Organizational culture can be perceived as something embodied in individuals but shared by the collective.[20,21] The development of the VPM (Table 1) addressed the problems of how to build a shared base of person-centred values in the staff, followed by and intertwined with the challenge of seeing a situation from the perspective of the person with dementia, and the further problem of applying knowledge of PCC acquired at training courses in concrete situations; in other words, how to facilitate the transition of PCC values and knowledge embodied in the individual nurse to collective behaviour of the staff.

The VPM was designed to address these problems within existing resources and routines in the nursing home setting. In Norway the traditional form of organization in nursing homes is wards of 20–25 residents with a registered nurse providing the administrative and professional lead for each ward. Special care units (SCU) for people with dementia have fewer residents (11–15). The staff–resident ratio on a day shift on a week day is normally around 3:10 for regular wards and 3.5:10 for SCUs.[22] In many nursing homes, some of the wards are divided into smaller units, for instance SCUs. The staff in the wards consists of approximately 50–60% auxiliary nurses (AN), 20–30% registered nurses (RN) and 10–15% unskilled workers in addition to other types of health care professionals, with more RNs in the SCUs than in ordinary wards.[23] In the VPM the ANs in the ward have central roles and functions.

The VPM education programme

Practice can be defined as '*a coherent set of human actions characterised by a commonly understood object, or good – i.e. telos; and by a socially structured and commonly accepted repertoire of means, whether instruments or skills (...) as well as commonly understood norms*' (Wartofsky, 1987; p. 364).[24] Previous research has shown that training courses alone are seldom enough to achieve and maintain changes in practice. Repeated feedback and ongoing supervision are necessary to prevent staff from reverting back to previous styles of working.[25–27] It is often difficult for an entire care team to attend the same training course. Those who attend the course face the challenge of conveying new ideas to the rest of the team as well as convincing them of the benefits of change. Studies report concerns that organizational factors may limit the impact of educational programmes or prevent staff from applying ideas from training consistently in practice.[28,29] Implementing ideas acquired at PCC training courses, such as individualized care planning or group activities, often impacts on the routines in the care facility. A routine is a stabilized, rule-governed pattern of acting, the skills of an organization.[21] Reflective thought is needed when institutionalized ingrained behaviours are at odds with changing circumstances;[21] in other words, when the ways of working do not support the new desired values. To be able to see whether routines can be flexible in accommodating change, the routines themselves must be discussed. This can be done by making reflection on practice a part of an activity. The team can formulate hypotheses about important problems and their causes in a selected area which are tested, adjusted and then changes are embedded into the routines.[21]

To facilitate the continuous collective reflection that leads to learning and changes in practice, the VPM makes staff active participants in the decision-making process in the consensus meeting (see Table 1). This is in line with Vygotsky's sociocultural approach to learning,[30] in which the students play an active role in learning, and collaboration is essential in order to facilitate meaning construction.[31] The staff selected to hold key roles within VPM are selected by the management team and attend a two-day course. The director of the institution is also invited and recommended to participate. The course provides an introduction to the main concepts of PCC and the VPM and is regarded as the starting point of the process of implementing PCC.

The perspective of the person with dementia is central throughout the training course. Films and stories are used to illustrate how people with dementia may experience the world around them. Role-plays based on situations from their own practice are utilized to train the participants in understanding the perspective of the resident. All participants try out the different roles in the VPM to be prepared to give support and feedback in the implementation in their work place. After the basic course the education and coaching is continued within the staff group undertaking change. In Norway this would be the staff group in a ward. The staff group receives a three-hour introduction to PCC and the VPM. This is a ready made programme with lectures on DVD covering the main topics in the basic course, and films illustrating the perspective of the person with dementia and the consensus meeting. The films and DVDs can also be used if a ward is having difficulties with the implementation of the VPM or as a part of the introduction to new staff.

A VIPS manual with practical knowledge and examples of PCC and non-pharmacological treatment related to each indicator in the VIPS framework is available at the nurse's station. It also contains assessment tools for wellbeing, behavioural and psychological symptoms of dementia (BPSD), pain, etc., with descriptions of when and how to use them. The staff can take the VIPS manual or the films and DVDs home to look at them on their own. The senior staff also receive a Consensus Meeting Manual, which elaborates on the different roles and how to supervise the staff.

The VPM staff roles and functions

The V-indicators in the VIPS framework describe that if the staff who deliver direct care feel valued for the work they undertake, they will in turn value those they care for on a day-to day basis.[1,9] An AN undertakes the leadership of the consensus meeting, a role known as the Resource Person (RP). As ANs constitute the majority in Norwegian nursing homes, an AN holding this function contributes to the legitimacy of the VPM in staff.[15] The threshold to approach the RP is low for the front-line staff and, being an AN, the RP knows what care situations currently concern them the most. Based on input from the staff, the RP prepares the agenda together with the leading RN in the ward.

The P-element in the VIPS framework is about treating the rights of the person with dementia as important as the rights of other people in the same situation.[1,9] In the consensus meeting the staff reflect on and discuss resident–staff interaction. The VPM has given each resident a spokesperson, the primary nurse (PN), to present their perspective and safeguard their rights when a situation concerning the resident is on the agenda. In a phenomenological-hermeneutic study nurses described difficulty in understanding and interpreting the world of the residents.[32] To help the primary nurse prepare, the VIPS manual contains an example of how a situation can be presented from the resident's point of view by the use of three questions:

(1) How do you think the person with dementia perceives what is happening to her/him?
(2) On what observations or knowledge of the resident do you base your assumption?
(3) What may cause the resident to react the way s/he does? Describe her/his emotional state.

The primary nurse must spend time with the resident and collect information from the family about the resident's life history, important persons and key stories to answer these questions. The resident's symptoms of and reactions to the neurological impairment and her/his general health must also be observed.[16] The function of the leading ward RN is to undertake the responsibility for supporting, encouraging and thereby valuing the staff's commitment to care and their engagement with the residents. The leading ward RN is the repository for a significant body of knowledge.[20] Middle managers, like a leading ward RN, represent attitudes, behaviour and expectations derived from personal factors such as experience, cultural norms and socialization. Middle managers in health care are in a position to strongly influence organizational change.[35] An RN with responsibility for the professional development in the wider institution has the role of an internal VIPS coach in the nursing home. The coach's function is to give the three-hour introduction of the VPM to the whole staff group and to new staff. The coach also provides supervision and support to the RPs and the leading ward RNs in groups or individually when needed.

The VPM consensus meeting

According to organization theory, the organization is conceptualized as a dynamic balance between individual competence, the control that exists in formal structures, and teamwork.[34] Studies from other health care settings have shown the effectiveness of teamwork. Regular team discussions and feedback have significantly improved detection, treatment and follow-up of patients with high blood pressure.[35] Furthermore, teams focusing on listening to all members, carers relatives and residents have been shown to improve risk assessment in mental health care.[36] A supportive culture in teams is a powerful source that benefits change processes;[37] the feeling of belonging to a community can have a favourable effect on readiness for change.[38] Studies have found that organizations that succeed in implementing and sustaining change possess cultures with two seemingly opposite characteristics: openness for change and structure.[39] A regular forum for professional development, the consensus meeting, is the strategy to obtain these qualities in the VPM.

It was recommended that the consensus meeting should be held weekly. It was seen as a continuation of the process of culture change that was initiated by the basic course. The structure ensures that all staff understand their roles; the agenda gives them opportunity to prepare. The main issue on the agenda, chosen from proposals from the staff, is an actual situation that is causing distress for the resident. A common example would be where a resident was agitated whilst being given help with personal hygiene during morning care. At the start of the consensus meeting the PN presents the situation from the resident's point of view. The other staff supply their observations of the resident's needs, habits or reactions. The situation is then assessed in relation to all four elements in the VIPS framework. A few minutes are spent to choose which of the 24 indicators are the most relevant to the situation or the best place to start in order to meet the needs of the resident.

Staff discuss their knowledge and arrive at a workable decision or changes to improve the quality of care. Interventions might also be to use assessment tools to elucidate the underlying causes of behaviour. The interventions are assessed on behalf of the resident by the PN. The date for review of the interventions is set and the PN records the decisions in the resident's record or care plan. Resident-focused evaluation is seen as essential to decide if the interventions benefit the resident and for the staff to stay focused on the resident's well-being.

Barriers in implementation of the VPM

The VPM was designed to fit within existing resources and routines in the care unit and to be easy to implement. Even so, barriers were encountered, particularly the frequency of the consensus meeting.[15] None of the units that took part in the RCT conducted weekly consensus meetings; the median number of meetings was 1.4 per month. The main reason conveyed was that the leading ward RN did not attend the consensus meetings but left it to the RP to handle it. It has been contended that the middle manager is the only one in the organization with the real potential to calm troubled employees, for instance when a process of change occurs.[40] Interventions decided upon in the consensus meeting often did not have legitimacy in the staff if the leading ward RN was not present to sanction and authorize them.[15] Neglect is a concept in organizational research signifying non-management. It may be a deliberate strategy to let competent staff solve problems by themselves, but it could also be a solution to an intolerable situation for a leadership who has too many and conflicting responsibilities and expectations.[20] A study of the implementation of a new IT documentation system in a health care setting found that a co-operative culture combined with a consensus-building leadership led to effective adoption of decisions.[41] In Norway, the absence of the leading ward RN in the consensus meetings may be explained by competing priorities from administrative tasks such as budget management. It may be necessary to discuss how the leading ward RN's time is to be spent, and whether the main task is to be administrative assignments or professional engagement in the ward.

Another barrier in implementation of the VPM was high staff turnover, both among the leading ward RNs and ANs holding roles as RPs. Sometimes this meant that no staff in the ward had attended the basic VIPS course. The internal VIPS coach trained new staff using the films, DVDs and the VIPS manual; still, it meant that the process in the ward was delayed.

Improving and sustaining change using VPM

The future plan of development for the VPM is to make it a part of a system of methods working together as cogwheels running into each other (Figure 1). Supervision from external experts can help staff through difficult periods; for instance, when facing the resident's symptoms of and reactions to the dementing illness is perceived as demanding that it reduces the nurse's confidence in her/his ability as a caregiver.[6,16] Dementia care mapping (DCM)[6,42] or other on-going audits could be utilized as the component providing quality audit and feedback on effects of care routines. To strengthen the structural component, weekly programmes and daily schedules saying who will do what and when may be added to ensure that changes are implemented in daily practice.[43] Together these components are suggested as a means of providing more power to sustain change.

Conclusion

The VIPS framework is a four-part definition of PCC used as the general guiding principles for health and social care practitioners to reflect on their interactions with people with dementia and their families. It was introduced to provide the evidence base for good practice in person-centred care in the dementia care field – particularly in relation to care home practice. To provide a way forwards for using it to implement changes in practice, the VIPS framework has recently been operationalized into the VPM for achieving person-centred care in Norwegian nursing homes. The VPM addresses the problems of how to build a shared base of person-centred values in the staff followed by and intertwined with the challenge of seeing a situation from the perspective of the person with dementia, and further the problem of applying knowledge of PCC acquired at training

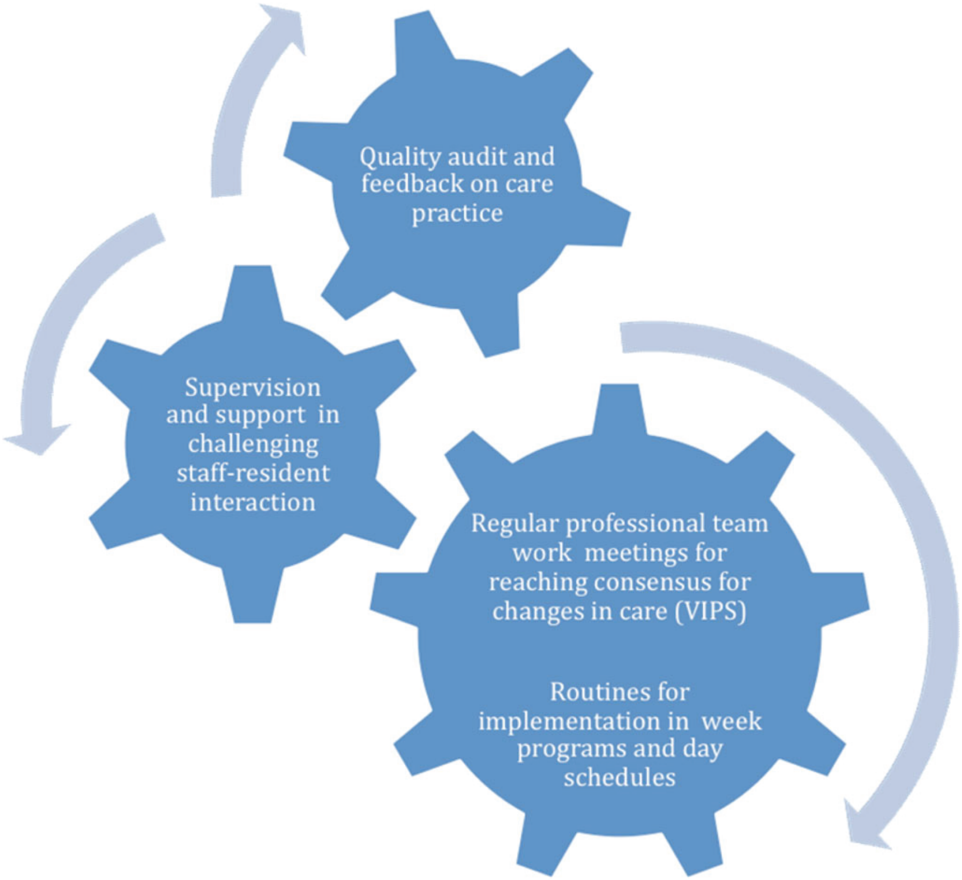

Figure 1. Model with components for implementation and sustainability of person-centred care

courses in concrete situations. It is regarded as feasible in care homes, but is dependent on the engagement of leadership to overcome the barriers of implementation. The next step suggested in order to sustain changes and maintain a PCC culture of care is for the VPM be a part of a system of methods that can work together to provide structure as well as openness for change.

The original VIPS definition of person-centred dementia care grew out of a review of the literature on person-centred dementia care. This has led to a number of practical applications in the dementia care field, VPM being the most recent. VPM as a vehicle for change in Norwegian care homes utilized the literature on organizational change to build a sustainable practical model. Although there were issues with the frequency of the consensus meetings, they still provided a productive reflective space, utilizing principles of clarifying staff roles, education, taking the perspective of the person with dementia, valuing front-line staff, providing coaching and supervision, and having measurable outcomes. Reviewing literature to build models and interventions that have practical applications is central to this work.

Conflict of interest

None of the authors has any conflict of interest to declare.

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Factors to make the VIPS practice model more effective in the treatment of neuropsychiatric symptoms in nursing-home residents with dementia

Running head: Factors influencing the implementation of person-centred care

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Abstract

Background / Aims: A recent cluster-randomised controlled study showed that the VIPS practice model (VPM) for person-centred care had a significant effect on neuropsychiatric symptoms in nursing-home residents with dementia. The RCT indicated that a substantial proportion of the total variance of the effects was related to conditions in the particular unit (ward). We have explored which factors explain the variance in the effect of the VPM.

Methods: The VPM sub-set of data from the RCT was explored using multilevel linear regression. The dependent variables were the change in scores on the Neuropsychiatric Inventory Questionnaire (NPI-Q) and the Cornell Scale for Depression in Dementia (CSDD).

Results: The unit in which the resident was living explained twenty-two per cent of the VPM's total variance in effect on the NPI-Q and thirteen per cent for the CSDD. The intra class coefficient (ICC) for the unit level was explained mainly by unit size on both scales and was considerably higher than for the institutional level.

Conclusion

The unit is the most influential level when implementing PCC by use of the VPM. The unit size explains most of the variance of effect of the VPM, and the effects were best in the small units.

Introduction

The treatment of neuropsychiatric symptoms (NPSs) in persons with dementia living in nursing-homes is important mainly because these symptoms are distressing for the residents [1], but also because they are stressful for those who care for them [2-5]. Depression is one of the most frequent NPSs in dementia and the highest rates are found in nursing-home studies [3, 6-9]. As psychotropic drugs have only a modest effect on NPSs and may cause severe side effects [10], non-pharmacological treatment is recommended as the initial treatment approach [11, 12] for NPSs, including depression. Person-centred dementia care (PCC), introduced by Kitwood [13], has been widely accepted and recommended as good quality care that has the potential to prevent and reduce NPSs [14, 15]. The elements in PCC have been summed up and described by Brooker [16] in the ‘VIPS framework' as valuing people with dementia (V), individualised care (I), understanding the world from the resident's perspective (P) and providing a social environment that supports the needs of the resident (S). The VIPS practice model (VPM) has recently been developed to implement person-centred care in nursing-home units by systematic use of the VIPS framework [17, 18].

A multilevel randomized controlled trial (RCT) conducted in 2011 in Oslo, Norway [19], tested the effect of two interventions based on PCC, the VPM and Dementia Care Mapping (DCM), on NPSs among residents in nursing-homes compared to lectures about dementia on DVD delivered to the staff for free use as the control condition. It was hypothesized that DCM and VPM would be more effective than giving the staff lectures about dementia on DVD in reducing agitation and other NPSs in nursing-home residents. Furthermore, it was hypothesized that the interventions would improve the residents' quality of life (QoL). The RCT showed that the implementation of both PCC methods had a significant effect on NPSs, as measured by the 10-item version of the Neuropsychiatric Inventory Questionnaire (NPI-Q) [20], compared to the control group. In addition, DCM had a significant effect on QoL measured by the Quality of Life In Late-stage Dementia scale (QUALID) [21], compared to the control group, whereas the VPM had a significant effect on depression, as measured by the Cornell Scale for Depression in Dementia (CSDD) [22], compared to the control group. The effects of the two methods implied not only a reduction in NPSs, but also the prevention of exacerbation of these symptoms. Two other studies on the effect of PCC in nursing-home populations have found reduction in use of antipsychotic drugs [23] and decreased agitation in residents [24], respectively.

However, the RCT carried out in Oslo, Norway , indicated a great variation in the effect between the units (wards) taking part in the study. The intra class correlation coefficient (ICC) on unit level was relatively high, 16% for both NPI-Q and for CSDD, indicating that a substantial proportion of the total variance of the effects was related to conditions in the particular unit. In other words, the unit constituted a contextual variable that influenced the effects of the VPM. The ICC represents a measure of dependency in the data. It is defined as the proportion of the total variance of the outcome that is attributable to a contextual variable [25, 26], e.g. that the conditions in a unit have influence on the behaviour of the residents.

To optimize the effect of the VPM we need to know more about which variables contribute to successful implementation of the VPM. Thus, we designed a study aiming to explore the variance of the effects of the VPM intervention separately.

Methods

Study design

The present study is a sub-study of the RCT carried out in Oslo in 2011, which was an intervention used with the staff (group level), with outcomes measured on the residents (individual level) at baseline and 10 months later .

The nursing-homes in the RCT were randomized into three groups. To avoid contamination between units the staff of all the units in each nursing home received the same intervention. One group of nursing-homes was given an intervention with DCM, the next group had an intervention with the VPM and the last group constituted a common control group for both intervention groups. All three groups received five DVDs with lectures (30 minutes each) about dementia. Thus, the staff of the control group received only this intervention.

Randomization was done by drawing lots (2 small, 2 medium and 1 large nursing home in each group). The assessors were independent as they were not part of the research group.

The trial was registered in Clinical Trial (http://clinicaltrials.gov/) in January 2011(study ID number: NCT 01280890) and approved by the Regional Ethics Committee for medical research in eastern Norway (REK-east).

The VIPS practice model (VPM)

The main element of the VPM is a weekly structured meeting in a nursing-home unit lasting for 45 to 60 minutes with set roles using the VIPS framework to analyse an interaction between a resident and a nurse in a situation where the resident has been exhibiting NPSs. The leading registered unit nurse (RN), and an auxiliary nurse from each unit and a RN appointed as the VIPS coach in each nursing home that took part in the study attended a three-day basic course, conducted by the researchers, focusing on PCC and functions in the VIPS practice model. The directors of the nursing-homes were also invited. The VIPS coach then conducted a 3-hour introduction to PCC and the VPM for the rest of the staff in their nursing-home. External VIPS experts did not visit the nursing homes during the implementation process, so the VPM relied entirely on internal facilitators (the staff who had attended the three-day basic course).

Participants

In Norway domiciliary nursing and nursing-home care are within the jurisdiction of the local authorities. The public health care system is the main provider of nursing-home services, although private care providers are playing a growing but still modest role. The nursing-home population mainly comprises people of Nordic ethnic origin. The traditional way of organizing nursing-homes in Norway is to run units of 20-25 residents with a registered nurse (RN) as the administrative leader. The main types of units are regular units (RU) and Special Care Units for persons with dementia (SCUs). RUs are sometimes divided into smaller sub-units with fewer residents, the SCUs may have separate strengthened sub-units (StSCUs) for residents with severe NPSs. A nurse may have a limited leading function in these smaller sub-units, but is not perceived as the authoritative leader by the staff group. How the work and cooperation between the smaller sub-units inside a unit is organized differ considerably. In some units the smaller sub-units are distinctively separated while in others they cooperate closely. The mean number of beds in a SCU is 7.9 [27]. The mean staffing ratio is 0.30 for RUs and 0.35 for SCUs. The proportion of unskilled staff is 11.9% in RUs and 12.6% in SCUs [28].

All 51 nursing-homes with more than 30 beds located in the city of Oslo, Norway, were invited to participate in the RCT. After receiving information about the study, 15 nursing homes accepted the invitation, but one of them withdrew after randomization. Criteria excluding residents from taking part in the study were a severe physical disease or a short life expectancy. If competent, the residents gave informed written consent. The next of kin of residents lacking the capacity to give informed consent were given the opportunity to decline participation on behalf of the resident, basing their decision on written information. For more details of the RCT, see Rokstad, Rosvik et al. 2013 [19]. Eventually, 14 nursing homes with a total of 40 units housing 624 residents with a diagnosis of dementia were included in the RCT.

Of the 624 residents, 189 residents in 13 units in four nursing-homes were allocated to the VPM intervention group at baseline. The mean size of the units was 21 residents (min. 12, max. 29), but the effects of the intervention were not evaluated in all the residents in all the units. Of the 189 included residents 49 died and 2 moved out of the nursing-home (51 (27%) before the 10-month follow-up measurement. Thus, a total of 138 residents with dementia in 13 units were analysed 10 months later in the VPM intervention group with a mean number of 10.7 residents (min. 3, max. 21) in each unit.

Dementia diagnosis

The dementia diagnoses were made by two experienced geriatric psychiatrists in our research group using all the available information from the residents' nursing-home records and the information obtained in the RCT.

Outcome variables

The dependent variables in the present study were change in score on the NPI-Q and the CSDD from baseline to 10-month follow-up. These changes were statistically significant after implementation of the VPM in the RCT.

The NPI-Q contains the items delusions, hallucinations, agitation, depression, anxiety, apathy, irritability, euphoria, disinhibition and aberrant motor behaviour. The symptoms were recorded as present or not and, if present, the severity of the symptom was scored from 1 to 3 giving an item score ranging from 0 to 3 and a sum score ranging from 0 to 30. A higher score indicates more severe NPSs [20].

CSDD is a commonly used scale for measuring depression in dementia. The scale has 19 items evaluating various symptoms of depression. Each symptom is rated on how often it occurs, 0 = never, 1 = periodically and 2 = often. The scale also provides the option for scoring “not possible to evaluate”. Minimum score is 0, maximum score is 38. A higher score indicates more severe depression [22].

Explanatory variables

The degree of dementia was assessed by the Clinical Dementia Rating scale (CDR) [29], a six-item questionnaire that records information about the resident’s cognitive and functional capacity. Using an algorithm, the severity of the dementia is staged as none, possible, mild, moderate, or severe. Adding the scores of each item generates the 'sum-of-boxes' (0–18), which is highly correlated with the CDR score [30].

General physical health was assessed using a modified version of the General Medical Health Rating scale categorizing the residents’ physical health as very good, fairly good, bad or very bad [31].

Residents' characteristics such as age and gender were obtained from the residents’ nursing-home records.

Information on characteristics of the units was obtained by interviewing the RN in charge, using a questionnaire asking for type of unit, number of residents per unit and resident–staff ratio on day shifts .

Statistical analysis

The subset of the data from the RCT with the focus on the residents, units and nursing homes allocated to the VPM intervention group was analysed.

We used a multilevel linear regression model with change in score on the NPI-Q and the CSDD from baseline to 10-month follow-up as the dependent variables. Multilevel analysis is an extended logistic regression analysis which can be used when data are structured in levels (e.g. resident level and unit level). It provides an estimation of the variance at for instance the unit level (difference between units) that corrects for dependency in the data (e.g.conditions in a unit influencing the residents) [25, 26].

The data were treated in a hierarchical manner with the residents' data on level 1 and the unit data on level 2, because the residents constitute the first level in a hierarchy of data in which the units could be seen as the second-level variable and the nursing-home as the third-level contextual variable.
The analysis has three stages. First, we calculated the ICC without any predictor variable in the model (the 'null' model, see figure 1). In the second stage, we tested each of the possible variables. Lastly, as a result of the findings, the institution was treated as a level 2 (cluster) and the residents as level 1.

Figure 1 here.

The construction of the multilevel model

To analyse the effect explained by the unit as a contextual variable we built a hierarchical multilevel linear regression model. As such models take possible correlations between members of the same cluster into account it helps prevent false significant findings. The software package MLWIN 2.25 (Bristol, UK) was used.

We first calculated the ICC as described above. To find the model that best explained the variance of the ICC we then performed a univariate linear regression for each of the explanatory variables with NPI-Q and CSDD as dependent variables. We used the results to construct the multivariate linear regression model with a resident level and a unit level as described by Hox (2002) [26]. The model was built stepwise adding the variables that explained most of the variance in the univariate analysis first (table 3). The variables that did not explain any of the variance were not included in the model.

Results

Table 1 shows the characteristics of the residents by the type of units. We found significant differences between the units with respect to the residents' age, the severity of dementia and the resident–staff ratio on a day shift.

There were no significant differences between the residents that dropped out of the study and those who completed the follow-up period regarding the scores on the CSDD and the NPI-Q or any of the resident and unit characteristics, except for the general physical health status. Those who dropped out before the 10-month follow-up measurement had poorer general physical health (p = 0.02).

On the NPI-Q and the CSDD we found mean changes in scores between baseline and the follow-up at 10 months of -0.70 (SD 6.1) and -0.86 (SD 6.0), respectively. The changes were fairly normally distributed (see figures 2 and 3). Thus, these mean values of change could be used as outcome variables in the linear regression models. A negative change should be interpreted as a reduction in symptoms; a positive change represents an increase in symptoms.

Figure 2 here

Figure 3 here

Table 2 shows the unadjusted mean changes on CSDD and NPI-Q after 10 months as a measure of the effect of the VPM on depression and NPSs at unit and nursing-home level. ANOVA showed a significant difference on the NPI-Q (p = 0.002) but not on the CSDD (p = 0.065) at the nursing-home level. A post hoc analysis showed that the mean change of the CSDD was significant (p = 0.047) between institutions 1 and 2.

The ICC was higher for the unit level (13.3% for CSDD and 21.5% for NPI-Q) than for the institutional level (2.9% for CSDD and 7.8% for NPI-Q).

The residents in institution number 2 exhibited an increase in symptoms as measured on both scales for both units.

Table 2 here

Table 3 below shows the extent to which the variance of a change in NPI-Q score and CSDD score was explained at the resident level (R_1^2) and the unit level (R_2^2) by the multivariate regression model.
Regarding ICC for the CSDD explained by the unit, which was 13.3%, the model explained 51.3%, which is 6.6% (0.13*0.51) of the total variance of the CSDD.
Of the remaining 86.7% variance of the CSDD (among the residents) 15.8% can be explained by the model, which is 13.9% (0.16*0.87) of the total variance of the CSDD.
Regarding ICC for the NPI-Q explained by the unit, which was 21.5%, the model explained 45%, which is 9.9 % (0.22*0.45) of the total variance of the NPI-Q.
Regarding the remaining 78.5% variance of the NPI-Q (among the residents), 11.9% can be explained by the model, which is 9.5% (0.12*0.79) of the total variance of the NPI-Q.
In total the model explained 6.6+13.9=20.5% of the variance for CSDD and 9.9+9.5=19.4% of the variance for NPI-Q.

Table 3 here

On the unit level, smaller units were associated with a better effect than the larger units. The only StSCU was associated with less effect of the VPM compared with the SCUs and ordinary units. Other organizational characteristics like resident-staff ratio, use of temporary workers and characteristics of SCUs and RUs were included as factors in the analyses but did not impact on the effect.

On the resident level, being a woman and being older were both associated with a better effect of the VPM.

Discussion

Difference between units

The already published RCT showed that the VPM had a positive effect on residents' NPS and depression compared with a control group. The present study, which explores the ICC, shows that there is a substantial difference in the effect between the nursing home units. The difference between the units explained considerably more of the effects (22% for the NPI-Q and 13% for the CSDD) than the nursing-home (NH) of the residents did (3% and 8%, respectively).

As shown in table 2, two regular units (RUs) in the same NH could differ substantially. For instance, in unit number 1 in NH number 1, the Cornell scale score increased by 3.76 (SD 2.26) after 10 months, whereas it decreased in unit number 5 by -8.00 (SD 5.55). As a rule, the units had either an increase or a decrease in both CSDD depression and NPI scores after 10 months. Only one of the 13 units had an increase in score on one of the scales and a decrease in the other, two units had no change in scores on one of the scales. This indicates that when the VPM had effect in a unit, the effect was ubiquitous.

The importance of the environment in the unit on the residents' behaviour and mood was also evident in the study of Zuidema et al (2010), which revealed differences in the prevalence of neuropsychiatric symptoms between SCUs that could not be explained by resident-related factors like cognition and psychoactive medication [32].

Impact of conditions in the unit

Few studies have examined whether nursing-home characteristics or unit characteristics influence most on the effects of educational programmes for staff. The results of such studies are in line with our finding that the unit is of most importance, not the nursing-home. The study that evaluated the Wellspring model, which has PCC at the core of its philosophy [33], observed stronger variation in implementation at unit level than at institutional level [34]. It should be noted that the Wellspring evaluation had a limited quasi-experimental design [33, 34]. A study implementing resident-oriented care, which has much in common with PCC, found that the success factors appeared to be related to the ward (unit) level and not to the organizational or project level. Especially the supervisors' role was crucial for a successful implementation. The study had a one group pre-test versus post-test design [35]. A study into residents' sedative drug utilization showed that the use of pro re nata medicines was strongly determined by the characteristics of the ward (unit) the patients lived in, not so much to institutional characteristics [36].

What organizational characteristics at unit level influence the implementation of PCC?

In our study the unit characteristic that explained most of the variance of the effect was the number of beds in the unit. We have not found any other studies focusing on the impact of unit size or other unit characteristic on variation in the effect of the implementation of PCC. We did find studies focusing on the association between unit size and residents' NPSs which may have an impact on the implementation of PCC. The findings of these studies diverge. Zuidema et al. (2010) found no association between unit size for SCUs and the prevalence of residents' NPSs [32]. The study by Sloan et al. (1998) found an association between small unit size of SCUs and a low level of resident agitation [37].

The type of unit was the second strongest explanatory variable of the ICC. This finding needs to be interpreted cautiously as our model has limited statistical power and external validity. The only StSCU taking part in this study was associated with a lesser effect of the VPM compared with SCUs and ordinary units. However, if the StSCU had been excluded, the type of unit would have had no impact on the result. Just 13% (18) of the residents lived in this StSCU. The unit consisted of two sub-units and belonged to nursing-home number 2, which was the only institution with an increase in symptoms on both scales on both participating units indicating that some institutional factors may have affected the results.

Other organizational characteristics like staffing levels and use of temporary workers did not impact on the effect. It has generally been concluded that higher staffing levels are associated with improved care outcomes [38].The staff–residents ratio explained very little of the total variance of our model. The reason for this was that the ratio was almost the same in all the units due to the equal staffing strategy of the local authorities in Oslo where the intervention took place. As we do not know of any studies on the impact of the unit staffing ratio on the implementation of PCC, we have looked at studies with outcome measures that might have a bearing on the variance in effect of the VPM. In a study on quality of care using data from nursing-homes in the whole of Norway, the staffing ratio differed and the units (wards) were divided into high and low ratio groups. In that study the staffing ratio had a clear effect [39]. However, in a review of the literature on the effect of staffing characteristics on quality of care in nursing-homes, Collier et al. (2008) concluded that the limitations of the methodology used had hindered the ability to draw definitive conclusions concerning the staffing ratio [38]. Still, several studies published since 2001 indicate that staffing levels and quality are not linearly related. Improvement did not continue to increase nor did it increase at a constant rate after the staffing had reached a certain threshold [38]. This supports our interpretation that unit size explains most of the variance in effect of the VPM, provided the staff–residents ratio is the same and above a minimum level.

It is maintained that the culture or climate in the team influence implementation of innovations and changes [40, 41]. Data on culture of care of the 13 units in our study might have provided more knowledge about the reason for the differences in effect between the units. However, both culture of care and performance of care are concepts that are extremely difficult to define and operationalize, making the basis for the assessment complicated [42]. The study of [43]from residential homes in Israel found that the service climate in the unit was a link to PCC behaviour. This study had a cross-sectional design which precludes inferences to be drawn. The results of a study including 17 nurses and 222 patients in 5 hospital wards in Sweden indicated that care climates valuing stability and control are beneficial for PCC, but that in the implementation phase a temporary transformation into a climate of flexibility was favourable [44].

Leadership is also held to be of great importance in implementation of innovations [40, 41[45]. The impact of unit size on variation in the effect of the VPM may be related to the implied distance between the staff and the leader. Anderson et al. (2003) found that relation-oriented leadership was related to a lower prevalence of resident behaviour problems [46]. The VPM requires the presence of a leader with authority in a regular forum where decisions about provision of care are made to provide professional supervision and support. This secures proximity between the leader with authority and the staff. Scott-Cawiezell et al. (2005) found that staff from nursing-homes with low scores on quality of care complained of a lack of cohesion or team spirit. They also felt underappreciated and unheard by the leadership, in contrast to staff in high-scoring nursing homes. The study recommends that smaller neighbourhoods with an intimate environment for both staff and residents should be organized, and that the ability of nursing-home leaders to empathise with the staff and facilitate communications and teamwork should be improved [47]. A Norwegian study concluded that leaders have a central role in being continuously supportive to the care staff and taking an active part in the care practice as role models [19]. The VPM may have harnessed the potential of smaller units as it empowers the staff by giving them central roles in the decision-making process regarding daily care. The presence of the leader in this regular forum provides a natural opportunity for the leader to give feedback and recognition on the staff's work.

Impact of resident characteristics

Older residents were associated with a positive effect of the VPM on CSDD on both resident and unit level. The fact that age explains so much of the cluster effect on CSDD indicates an uneven distribution of residents' age between the units. The same was the case for gender. As being female was an advantage for effect of the VPM on both resident and unit level, the gender cluster effect might be the result of an accumulation of women in some units.

Limitations

Most of the variance in the effect of the VPM, 78.5% of the NPI-Q and 86.7% of the CSDD, remains unexplained. Several probable explanatory variables have not been investigated in this study, for instance, the type of leadership, job satisfaction and the physical environment. The culture of care, which is not a variable in this study, is a factor that is considered influential when it comes to implementation [41].

The findings in this study are not necessarily generalizable to other settings even though the units were randomly included. On the one hand, nursing-homes in Oslo may differ significantly from nursing-homes in Norwegian rural areas, as well as from those in other countries. On the other hand, the distribution of gender and age is quite similar to the mean regarding persons with dementia in nursing-homes in Norway [39, 48].

A further limitation is that the results do not assess the quality of care as such, just changes in score after the implementation of the VPM which might disguise a ceiling effect in some units. Neither were differences in form of organisation, special circumstances like change of leadership nor long-term sick leave among key personnel taken into account.

Conclusion

This study explored the variance of the effect of the implementation of the VPM in nursing-homes. The previously published RCT showed that the VPM had effect on NPSs and depression. The exploration of these effects showed that the ICC for the unit level was considerably higher than for the institutional level, and that size of the unit implying proximity to the unit leader was the variable with strongest impact. Thus, we pose a hypothesis that organizational factors inside of the unit to a stronger degree impact on the implementation of the VPM than institution wide factors do. As valuing staff and their needs as well as those of the residents' is one of the main elements of PCC, this hypothesis may apply to PCC interventions in general. We recommend that this hypothesis is researched further.

Clinical implications

The following structural and psychosocial conditions are recommended for institutions implementing PCC by use of the VPM:

- ✓ Units small enough for the leader to fulfil the leadership function described in the VPM
- ✓ Proximity between staff and the leader with administrative, professional and perceived authority
- ✓ Staffing above the minimum level

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Table 1 Resident and unit characteristics of the VPM[a] intervention group

	Ordinary unit	SCU	StSCU	
Gender				
Women	56 (76%)	32 (70%)	10 (56%)	p 0.23**
Men	18 (24%)	14 (30%)	8 (44%)	
Age				
Mean (SD)	86 (8.8)	83 (8.1)	81 (9.1)	p 0.03*
CDR sum of boxes				
Mean (CD)	12.8 (4.3)	15.6 (2.2)	15.5 (1.8)	p<0.01*
Gen. phys. health				
Good	23 (31.1%)	8 (17.4%)	6 (33.3%)	
Fairly good	38 (51.4%)	25 (54.3%)	7 (38.9%)	p 0.53**
Bad	12 (16.2%)	12 (26.1%)	5 (27.8%)	
Very bad	1 (1.4%)	1 (2.2%)	0	
Resident/ staff on day shift				
Mean (SD)	3.7 (0.4)	3.8 (0.4)	2	p < 0.01*

*One way ANOVA ** Pearson Chi-square test (2-sided) [a] The VIPS practise model

Table 2 **Unadjusted mean change (s.d) in CSDD and NPI-Q from baseline to 10- month follow-up measurements on unit level and nursing-home level**

Changes at unit level				**Changes at institutional level (nursing home)**				
Unit	n/N**	CSDD Mean change (s.d.)	NPI-Q Mean change (s.d)	NH	N	CSDD Mean change (s.d.)	NPI Mean change (s.d.)	P value ANOVA
1[1]	9/17	3.76 (2.26)	1.00 (3.28)	1	43	-2.51 (7.38)	-1.67 (5.67)	CSDD 0.065a NPI-Q 0.002b
2[1]	6/17	-1.00 (4.00)	-3.33 (5.24)					
3[1]	8/17	-1.86 (9,34)	0.38 (3.50)					
4[2]	7/12	-4.43 (5.71)	-2.00 (3.70)					
5[1]	10/14	-8.00 (5.55)	-7.00 (4.69)					
6[1]	3/14	0.00 (1.44)	7.67 (5.86)					
7[2]	21/29	0.43 (3.74)	1.29 (5.77)	2	39	1.30 (3.82)	2.08 (6.30)	
8[3]	18/27	2.06 (3.84)	3.00 (6.91)					
9[1]	12/23	-1.42 (5.48)	-2.67 (4.66)	3	28	-1.48 (5.82)	-0.42 (5.97)	
10[1]	8/24	1.00 (5.97)	3.50 (4.44)					
11[1]	8/25	-3.75 (5.99)	-1.00 (7.56)					
12[2]	18/18	0.00 (6.54)	-3.11 (5.72)	4	28	-0.30 (5.55)	-3.32 (5.28)	
13[1]	10/12	-0.78 (3.83)	-3.70 (4.64)					
	138				138			
		ICC 13.3%	ICC 21.5%			ICC 2.9%*	ICC 7.8%*	

CSDD Cornell Scale for Depression in Dementia, NPI-Q Neuropsychiatric Inventory Questionnaire

[1]Ordinary unit, [2]Special Care Unit, [3] Strengthened Special Care Unit.

a Post hoc analysis showed that mean change of CSDD was significant at $p = 0.047$ between institution 1 and 2.

b Post hoc analysis showed that mean change of NPI-Q was significant at $p = 0.022$ between institution 1 and 2, and at $p = 0.002$ between institution 2 and 4.

*Here the institution is treated as level 2 (cluster) and residents as level 1.

** Number of residents with data on effect / number of beds in the unit.

Table 3 The extent to which the variance of change in NPI-Q score and CSDD-score is explained by the multivariate regression model

R_1^2: the proportion of variance at the resident level that was explained by the model.
R_2^2: the proportion of ICC (unit level) explained by the model

The extent to which the variance of change in NPI-Q score is explained

Variable	R_1^2	R_2^2
By adding Number of beds in unit to the model	6.8 %	28.2 %
By adding Unit type to the model	9.3 %	38.9 %
By adding Gender to the model	11.7%	45.0 %
By adding Age to the model	11.9%	45.0 %

The extent to which the variance of change in CSDD-score is explained

Variable	R_1^2	R_2^2
By adding Number of beds in unit to the model	6.0 %	32.9 %
By adding Age to the model	14.7 %	44.0 %
By adding Unit type to the model	15.6 %	49.5 %
By adding Gender to the model	15.8 %	51.3 %

CSDD Cornell Scale for Depression in Dementia
NPI-Q Neuropsychiatric Inventory Questionnaire

Figure 1 Details of the statistical procedures

σ_e^2 = individual level variance (level 1) without any exploratory variables in the model
σ_u^2 = group level variance (level 2) without any exploratory variables in the model
σ_{en}^2 = individual level variance (level 1) with exploratory variables in the model
σ_{un}^2 = group level variance (level 2) with exploratory variables in the model

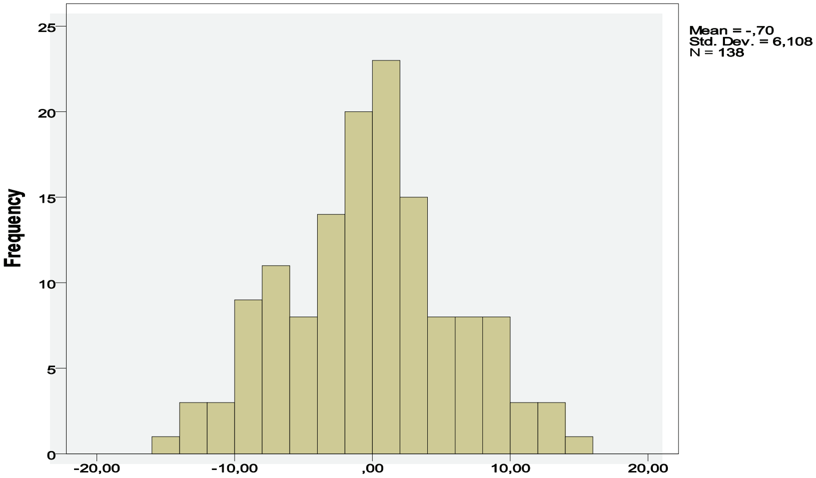
ICC = $\sigma_u^2 / (\sigma_u^2 + \sigma_e^2)$ Meaning that ICC is the proportion of group level variance compared to the total variance when there are no exploratory variables in the model (null model) [23]

The proportion of the variance that is explained is expressed with R^2. In a multilevel model this is expressed by the total error variance. Here, this is done separately for the two levels.
On the first level: $R_1^2 = (\sigma_e^2 - \sigma_{en}^2) / \sigma_e^2$
On the second level: $R_2^2 = (\sigma_u^2 - \sigma_{un}^2) / \sigma_u^2$

Since these formulas are for unbiased estimators and may not combine the information from the two levels correctly, we compensate for this by replacing σ_e^2 with $\sigma_e^2 + \sigma_u^2$ (and σ_e^2 with $\sigma_{en}^2 + \sigma_{un}^2$) at level 1 and at level 2 σ_u^2 is replaced with $\sigma_u^2 + \sigma_e^2/n$ (and σ_{en}^2 with $\sigma_{un}^2 + \sigma_{en}^2/n$) where n is the average size of the clusters.

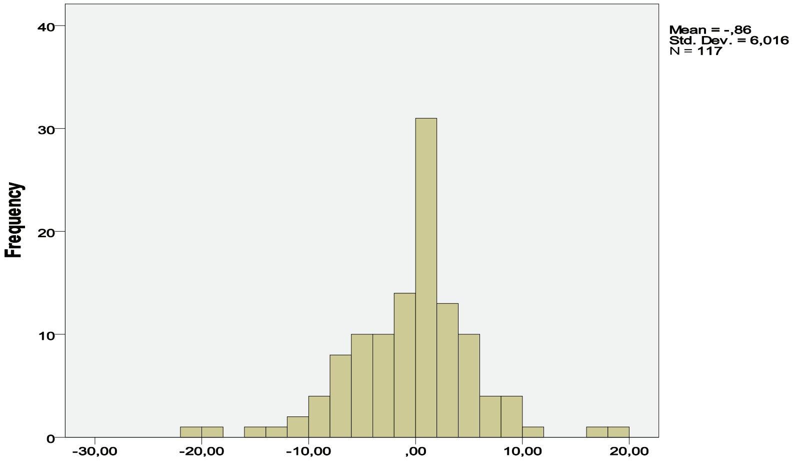
R_1^2 is the amount of variance among the residents that was explained by the model. R_2^2 is the amount of ICC explained by the model.

Figure 2 Mean change in score for NPI-Q* between baseline and follow up



* Neuropsychiatric Inventory Questionnaire

Figure 3 Mean change in score for CSDD* between baseline and follow up



*Cornell Scale for Depression in Dementia

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Using Dementia Care Mapping (DCM) and the VIPS practice model to develop person-centred care in nursing homes: a cluster-randomized controlled trial

- *replaced by*

The Effect of Person-Centred Dementia Care to Prevent Agitation and Other Neuropsychiatric Symptoms and Enhance Quality of Life in Nursing Home Patients: A 10-Month Randomized Controlled Trial