

**Annika Tetrault**

## **If not now, when?**

Advance Care Planning in early-stage dementia care  
– a relationship-centered process





# Annika Tetrault

Born 1967

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Master's degree in Health Sciences, Åbo Akademi University, 2017

Registered Nurse, Bachelor of Healthcare in Nursing, Novia University of Applied Sciences, 2012

Associate's degree, Accounting, Ivy Tech, Indiana, USA, 1996

If not now, when? The quote is by Hillel the Elder c.110 BCE, died 10 CE, a Jewish religious leader and scholar. Full saying: "If I am not for myself, who will be for me? And being only for myself, what am I? And if not now, when?"



## If not now, when?

Advance Care Planning in early-stage dementia care  
– a relationship-centered process

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Vaasa, Finland, 2024

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## ***The Journey by Mary Oliver***

*One day you finally knew  
what you had to do, and began,  
though the voices around you  
kept shouting  
their bad advice—  
though the whole house  
began to tremble  
and you felt the old tug  
at your ankles.  
"Mend my life!"  
each voice cried.  
But you didn't stop.  
You knew what you had to do,  
though the wind pried  
with its stiff fingers  
at the very foundations,  
though their melancholy  
was terrible.  
It was already late enough,  
and a wild night,  
and the road full of fallen  
branches and stones.  
But little by little,  
as you left their voices behind,  
the stars began to burn  
through the sheets of clouds,  
and there was a new voice  
which you slowly  
recognized as your own,  
that kept you company  
as you strode deeper and deeper  
into the world,  
determined to do  
the only thing you could do—  
determined to save  
the only life you could save.*



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Doktorsavhandlingen skulle inte ha varit möjlig utan olika former av stöd, bidrag och uppmuntran. Jag har erhållit värdefullt ekonomiskt stöd från nämnden för forskning och forskarutbildning vid Åbo Akademi i form av en tillfällig doktorandanställning samt forskarstipendier från Högskolestiftelsen i Österbotten, från Sjuksköterskeföreningen i Finland, r.f., från Suomen Sairaanhoitajat, från Österbottens välfärdsområde (Statens forskningspengar) och från Tehy. Min tidigare arbetsgivare Korsholms kommun och min nuvarande arbetsgivare Österbottens välfärdsområde har beviljat tjänstledigheter som frigjort tid för studierna.

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och nu till doktorsexamen, utan dig skulle resan inte ha varit möjlig. Du har sett till att hjärtat finns med i min tidvis något kliniska text. Tack för ditt stöd och din vänskap.

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Brändö, Vasa, den 20 januari 2024



# Abstract

Tetrault Annika, 2024: If not now, when? Advance Care Planning in early-stage dementia care – a relationship-centered process

Supervisors: Professor Lisbeth Fagerström, Åbo Akademi University; Senior Lecturer Heli Vaartio-Rajalin, Turku University of Applied Sciences, Master School & Docent Åbo Akademi University; Senior Lecturer Maj-Helen Nyback, Novia University of Applied Sciences

**Background:** Dementia is a global issue of concern with the number of people living with dementia expected to double every two decades. The financial cost of caring for people with dementia aside, the human suffering of people with dementia and their family caregivers needs to be noted and alleviated. People with dementia are at times denied care in accordance with human rights and are not enabled to participate in care decision-making processes. The ethical complexities reach a higher level when the person has a dementia diagnosis and current laws and directives are not enough to guide healthcare professionals in providing care. Dementia affects decision-making capacity and the ability to foresee and plan for future events. A person in the end-stage of dementia is no longer able to make decisions for himself/herself and the family is often tasked with decision-making about end-of-life care. Advance Care Planning (ACP) can be a valuable way to alleviate suffering and improve quality of life for both people with dementia and family caregivers. ACP needs to be introduced while the person with dementia retains the capacity to participate.

**Aim:** This doctoral thesis aims to explore ACP in early-stage dementia and to present a model for the ACP process in early-stage dementia care.

**Methods:** This thesis is anchored in the pragmatism research paradigm as the overall aim of the study is to produce knowledge useful to all stakeholders and with the input of all stakeholders. For the first study, the scoping review method was used. The search identified six studies describing interventions aimed at people with dementia in the early phase of dementia. The second study was a qualitative interview study with an inductive approach and a semi-structured interview guide. Interviews with people with dementia (n=10) were conducted. During eight of the interviews, the person with dementia was accompanied by his/her spouse (n=8). The third study was a qualitative study with semi-structured focus group interviews conducted with dementia care professionals. Three focus group interviews with dementia nurses and geriatricians were conducted. The majority of professionals participating were registered nurses (n=13), geriatricians (n=2), one social worker, and one professional of applied gerontology. For both the second and the third study, field notes, observations, and reflections on the interviews were included as part of the material. In the second and the third study, the data material was analyzed using a modified version of the Qualitative Analysis Guide of Leuven.

**Results:** In study I, the scoping review identified six studies describing ACP interventions for early-stage dementia patients. A relatively wide range of intervention types are described in the studies. Most of the study participants (people with dementia and family caregivers) were affected in mostly positive ways and indicated satisfaction with the interventions used despite the significant differences between the interventions. The feeling of being listened to and engaged in the care planning seems to be of most importance, not the intervention design itself. The results from study II show that the views of people with dementia are characterized by a complex storyline involving tensions and movement within the themes of wants, beliefs, and levels of insight. Participants wanted to think about the future but also wanted to live in the here and now. The findings from study III describe the views of dementia nurses and geriatricians on ACP in dementia care. The participants expressed a generally positive view of ACP in dementia care, but at the same time held a number of views about favorable and unfavorable factors, which affect the conditions for conducting ACP.

**Conclusions:** In an abductive reasoning process, the results of the three studies were combined with the findings from previous studies and reflections on theoretical perspectives to present an ACP model for the Finnish early-stage dementia care context. A supportive structure allows for focusing on ACP in early-stage dementia through early detection and early ACP initiation while the person with dementia retains self-determination and decision-making capacity. The result of the supportive structure is relationship-centered care where relational autonomy supports self-determination and enhances dignity for all members of the triad. An undeveloped structure and inadequate resources contributes to factors that may lead to suffering related to care, missed care, and a loss of dignity. The suggested ACP model in early-stage dementia care demonstrates the practical need for resources, tools, and training. Further studies that include people with dementia in the early phase of the illness trajectory are important for the continued development and improvement of ACP in dementia care. Acknowledging the suffering of both the person being diagnosed with dementia and their family caregiver and balancing that recognition with a focus on positivity and the maintenance of quality of life, is a valuable skill of a dementia nurse. The development of that skill needs to be supported and further studied.

**Keywords:** early-stage dementia, advance care planning, model, intervention, pragmatism, scoping review, qualitative study, Qualitative Analysis Guide of Leuven, self-determination, dignity, relational autonomy, relationship-centered care, missed care, dementia nurse

# Abstrakt

Tetrault Annika, 2024: Om inte nu, när? Föregripande vårdplanering i tidig fas av minnessjukdom – en relations-centrerad process

Handledare: Professor Lisbeth Fagerström, Åbo Akademi; Överlärare Heli Vaartio-Rajalin, Turun Ammattikorkeakoulu, Master School & Docent, Åbo Akademi, Överlärare Maj-Helen Nyback, Yrkeshögskolan Novia

**Bakgrund:** Minnessjukdomar är en global utmaning. Antalet personer som lever med minnessjukdom förväntas fördubblas vartannat årtionde. Bortsett från de ekonomiska kostnaderna för att vårda personer med minnessjukdom behöver det mänskliga lidandet för personer med minnessjukdom och deras närstående uppmärksammas och lindringen av detta lidande betonas. Personer med minnessjukdom erhåller ibland inte vård enligt sina mänskliga rättigheter och ges inte möjlighet att delta i beslut angående sin vård. Den etiska komplexiteten når en högre nivå när personen har en minnessjukdomsdiagnos och där nuvarande lagar och direktiv inte är tillräckliga för att vägleda vårdpersonalen. Minnessjukdom påverkar beslutsförmågan och förmågan att förutse och planera för framtida händelser. En person i slutstadiet av minnessjukdom (demens) kan inte längre fatta beslut för egen del och familjen får då ofta i uppgift att fatta beslut om vården i livets slutskede. Föregripande vårdplanering / Advance Care Planning (ACP) kan vara ett värdefullt sätt att lindra lidande och förbättra livskvaliteten för både personer med minnessjukdom och närstående och borde introduceras medan personen med minnessjukdom fortfarande har förmåga att delta.

**Syfte:** Avhandlingens syfte är att utforska ACP vid minnessjukdom i ett tidigt skede av sjukdomen och att presentera en modell för ACP-processen vid vården i det tidiga skedet av sjukdomen.

**Metod:** Denna avhandling är förankrad i det pragmatiska forskningsparadigmet emedan det övergripande syftet med studien är att producera kunskap som är användbar för alla intressenter och med bidrag från alla intressenter. I den första studien användes metoden scoping review. Sökningen identifierade sex studier som beskrev interventioner riktade till personer med minnessjukdom i tidig fas av sjukdomen. Den andra studien var en kvalitativ intervjustudie med en induktiv ansats och en semistrukturerad intervjuguide. Intervjuer med personer med minnessjukdom (n=10) genomfördes. Under åtta av intervjuerna hade personen med minnessjukdom sällskap av sin make/maka (n=8). Den tredje studien var en kvalitativ studie med tre semistrukturerade fokusgruppsintervjuer som genomfördes med minnesskötare, minnessrådgivare, minneskoordinatorer och geriatriker. Majoriteten av deltagarna var legitimerade sjukskötare (n=13), geriatriker (n=2), en socialarbetare och en geronom. I både den andra och den tredje studien ingick fältanteckningar, observationer och reflektioner över intervjuerna i materialet. I den andra och den tredje studien analyserades

datamaterialet med hjälp av en modifierad version av analysmetoden Qualitative Analysis Guide of Leuven.

**Resultat:** I studie I identifierade scoping review-översikten sex studier som beskriver ACP-interventioner för minnesklienter i tidigt skede av sjukdomen. Ett relativt brett spektrum av interventionstyper beskrivs i studierna. De flesta av studiedeltagarna (personer med minnessjukdom och närstående) påverkades på mestadels positiva sätt och uppgav att de var nöjda med de interventioner som användes trots de betydande skillnaderna mellan interventionerna. Känslan av att bli lyssnad på och engagerad i vårdplaneringen verkar vara av störst betydelse, inte själva interventionsdesignen. Resultaten från studie II visar att åsikterna hos personer med minnessjukdom kännetecknas av en komplex berättelse med spänningar och rörelser inom teman som önsknningar, övertygelser och nivåer av insikt. Deltagarna ville tänka på framtiden men ville också leva här och nu. Resultaten från studie III beskriver vårdares och geriatrikers syn på ACP inom minnesvården. Deltagarna uttryckte en generellt positiv syn på ACP i minnesvården, men hade samtidigt ett antal åsikter om gynnsamma och ogynnsamma faktorer som påverkar förutsättningarna för att genomföra ACP.

**Slutsatser:** I en abduktiv resonemangsprocess kombinerades resultaten från de tre studierna med resultaten från tidigare studier och reflektioner över teoretiska perspektiv med syfte att presentera en ACP-modell för den finländska minnesvården i tidigt skede av sjukdom. En stödjande struktur gör det möjligt att fokusera på ACP vid minnessjukdom i tidig fas genom tidig upptäckt och tidig initiering av ACP medan personen med minnessjukdom behåller självbestämmandeförmåga och förmåga att fatta beslut. Resultatet av den stödjande strukturen är relations-centrerad vård där relationell autonomi stödjer självbestämmande och ökar värdigheten för alla medlemmar i vårdtrian bestående av personen med minnessjukdom, närstående och minnesskötare/koordinator. En utvecklad struktur och otillräckliga resurser bidrar till faktorer som kan leda till lidande i samband med vård, utebliven vård och förlust av värdighet. Den föreslagna ACP-modellen för minnesvård i tidigt skede visar på det praktiska behovet av resurser, verktyg och utbildning. Fortsatta studier som inkluderar personer med minnessjukdom i den tidiga fasen av sjukdomsförloppet är viktiga för den fortsatta utvecklingen och förbättringen av ACP inom minnesvården. Att bekräfta lidandet hos både personen med minnessjukdomsdiagnos och dennes närstående och balansera denna bekräftelse med ett fokus på positivitet och upprätthållande av livskvalitet är en värdefull färdighet för en minnesskötare, -rådgivare, -koordinator. Utvecklingen av denna kompetens behöver stödjas och studeras ytterligare.

**Nyckelord:** minnessjukdom i tidigt skede, föregripande vårdplanering, modell, intervention, pragmatism, scoping review, kvalitativ studie, Qualitative Analysis Guide of Leuven, självbestämmande, värdighet, relationell autonomi, relations-centrerad vård, utebliven vård, minnesskötare

# Tiivistelmä

Tetrault Annika, 2024: Jos ei nyt, milloin? Ennakoiva hoitosuunnittelu muistisairauden alkuvaiheessa – ihmissuhdekeskeinen prosessi

Ohjaajat: Professori Lisbeth Fagerström, Åbo Akademi; Lehtori Heli Vaartio-Rajalin, Turun Ammattikorkeakoulu Master School & Dosentti, Åbo Akademi; Lehtori Maj-Helen Nyback, Novia Ammattikorkeakoulu

**Taustaa:** Muistisairaus on maailmanlaajuinen huolenaihe, sillä muistisairautta sairastavien ihmisten määrän odotetaan kaksinkertaistuvan joka toinen vuosikymmen. Väestön ikääntyminen aiheuttaa yhä suurempia taloudellisia ja sosiaalisia vaikutuksia. Muistisairautta sairastavien ihmisten hoidon taloudellisten kustannusten lisäksi on otettava huomioon muistisairautta sairastavien ihmisten ja heidän omaishoitajiensa inhimillinen kärsimys ja painotettava tämän kärsimyksen lievittämistä. Muistisairautta sairastavilta ihmisiltä evätään toisinaan ihmisoikeuksien mukainen hoito, eikä heille anneta mahdollisuutta osallistua hoitoa koskevaan päätöksentekoprosessiin. Eettiset ongelmat nousevat entistä korkeammalle tasolle, kun henkilöllä on muistisairausdiagnoosi, eivätkä nykyiset lait ja ohjeet riitä ohjaamaan terveydenhuollon ammattilaisia hoidon tarjoamisessa. Muistisairaus vaikuttaa päätöksentekokykyyn ja kykyyn ennakoida ja suunnitella tulevia tapahtumia. Muistisairauden loppuvaiheessa oleva henkilö ei enää kykene tekemään päätöksiä omasta puolestaan, ja perheelle annetaan usein tehtäväksi päättää elämän loppuvaiheen hoidosta. Ennakoiva hoitosuunnittelu (Advance Care Planning, ACP) voi olla arvokas keino lievittää kärsimystä ja parantaa elämänlaatua sekä muistisairaille ihmisille että omaishoitajille, ja se on otettava käyttöön niin kauan kuin muistisairastunut henkilö on vielä kykenevä osallistumaan siihen.

**Tavoitteet:** Tämän väitöskirjan tavoitteena on tutkia ACP:tä varhaisvaiheen muistisairauden hoidossa ja esittää malli ACP-prosessista varhaisvaiheen muistisairauden hoidossa.

**Menetelmät:** Tutkimuksen yleisenä tavoitteena on kaikkien sidosryhmien panoksella tuottaa kaikille sidosryhmille hyödyllistä tietoa. Ensimmäisessä tutkimuksessa käytettiin kartoittavaa katsausmenetelmää (scoping review). Haun avulla löydettiin kuusi tutkimusta, joissa kuvattiin muistisairaille henkilöille suunnattuja interventioita muistisairauden varhaisvaiheessa. Toinen tutkimus oli kvalitatiivinen haastattelututkimus, jossa käytettiin induktiivista lähestymistapaa ja puolistrukturoitua haastatteluohjetta. Tutkimuksessa tehtiin kymmenen haastattelua muistisairautta sairastavien henkilöiden kanssa. Kahdeksassa haastattelussa muistisairaahan henkilön mukana oli hänen puolisonsa. Kolmas tutkimus oli kvalitatiivinen tutkimus, jossa tehtiin puolistrukturoituja fokusryhmähaastatteluja muistisairauden hoitoalan ammattilaisille. Kolme fokusryhmähaastattelua tehtiin muistihoitajien, muistikoordinaattorien ja geriatrien kanssa. Suurin osa osallistuneista ammattilaisista oli sairaanhoitajia

(n=13), geriatreja (n=2), yksi sosiaalityöntekijä ja yksi geronomi. Sekä toisen että kolmannen tutkimuksen aineistoon sisällytettiin kenttämuistiinpanot, havainnot ja reflektointi. Toisessa ja kolmannessa tutkimuksessa aineisto analysoitiin käyttäen muunnettua versiota Qualitative Analysis Guide of Leuven-menetelmästä.

**Tulokset:** Tutkimuksessa I löydettiin kuusi tutkimusta, joissa kuvattiin varhaisvaiheen muistipotilaille suunnattuja ACP-interventioita. Tutkimuksissa kuvailtiin suhteellisen monenlaisia interventiotyyppejä. Useimmat tutkimukseen osallistuneet (muistisairautta sairastavat ja omaishoitajat) olivat kokeneet intervention enimmäkseen myönteisesti, vaikka interventioiden välillä oli merkittäviä eroja. Tunne kuulluksi tulemisesta ja osallistumisesta hoidon suunnitteluun näyttää olevan tärkeintä, ei niinkään itse interventiosuunnitelma. Tutkimuksen II tulokset osoittavat, että muistisairautta sairastavien ihmisten näkemyksille on ominaista monimutkainen tarinankerronta, johon liittyy jännitteitä ja liikettä toiveiden, uskomusten ja ymmärryksen teemojen sisällä. Osallistujat halusivat ajatella tulevaisuutta, mutta halusivat myös elää tässä ja nyt. Tutkimuksen III tuloksissa kuvataan muistihoidajien ja geriatrien näkemyksiä ACP:stä muistihoidossa. Osallistujat ilmaisivat yleisesti ottaen myönteisen näkemyksen ACP:stä muistihoidossa, mutta samalla heillä oli useita näkemyksiä tekijöistä, jotka vaikuttavat ACP:n toteuttamiseen edellytyksiin.

**Johtopäätökset:** Tutkimusten tulokset yhdistettiin abduktiivisessa päättelyprosessissa aiempien tutkimusten tuloksiin ja teoreettisten näkökulmien pohdintaan, jotta voitiin esittää ACP-malli suomalaisen varhaisvaiheen muistihoidokontekstiin. Mallin tarjoama rakenne mahdollistaa keskittymisen ACP:hen varhaisvaiheen muistisairauden hoidossa varhaisen havaitsemisen ja varhaisen ACP:n aloittamisen kautta, kun muistisairaalla henkilöllä vielä on itsemääräämisoikeutensa ja päätöksentekokykynsä. Mallin tuloksena on ihmissuhdekeskeinen hoito, jossa suhteellinen autonomia tukee itsemääräämisoikeutta ja lisää muistisairaahan henkilön, hänen omaishoitajansa ja muistihoidajan/muistikoordinaattorin ihmisarvoa. Puutteellinen ACP-prosessi ja riittämättömät resurssit edistävät tekijöitä, jotka voivat johtaa hoitoon liittyvään kärsimykseen, hoidon laiminlyöntiin ja ihmisarvon menettämiseen. Ehdotettu ACP-malli muistisairauden varhaisvaiheen hoidossa osoittaa, että resursseja, välineitä ja koulutusta tarvitaan käytännössä. Lisätutkimukset, joissa muistisairautta sairastavat henkilöt ovat mukana sairauden varhaisessa vaiheessa, ovat tärkeitä, jotta ACP:n kehittämistä muistihoidossa voidaan jatkaa. Sekä muistisairautta sairastavan henkilön, että hänen omaishoitajansa kärsimyksen tunnistaminen ja elämänlaadun ylläpitämiseen keskittymisellä on tärkeä kompetenssi muistihoidajille ja koordinaattoreille. Tämän kompetenssin kehittämistä on tuettava ja tutkittava edelleen.

**Avainsanat:** varhaisvaiheen muistisairaus, ennakoiva hoitosuunnittelu, malli, interventio, pragmatismi, kartoittava, kvalitatiivinen tutkimus, Qualitative Analysis Guide of Leuven, itsemääräämisoikeus, ihmisarvo, ihmissuhdekeskeinen hoito, hoidon laiminlyönti, muistihoidaja, muistikoordinaattori.

# List of original articles I-III

## ARTICLE I

Tetrault, A., Nyback, M-H., Vaartio-Rajalin, H., & Fagerström, L. (2021). Advance Care Planning interventions for older people with early-stage dementia: A scoping review. *Nordic Journal of Nursing Research*, 42(2). First published online 20 May 2021. <https://doi.org/10.1177/20571585211014005>

## ARTICLE II

Tetrault, A., Nyback, M-H., Vaartio-Rajalin, H., & Fagerström, L. (2021). Advance Care Planning in dementia care: Wants, beliefs, and insight. *Nursing Ethics*, 29(3), 696–708. <https://doi.org/10.1177/09697330211035498>

## ARTICLE III

Tetrault, A., Nyback, M-H., Vaartio-Rajalin, H., & Fagerström, L. (2023). 'A perfect storm' or missed care? Focus group interviews with dementia care professionals on Advance Care Planning. *BMC Geriatrics*. Published May 21, 2023. <https://doi.org/10.1186/s12877-023-04033-7>

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# 1. Introduction

Different types of dementia belong to the most challenging issues in current healthcare. Dementia is a global issue of concern with the number of people living with dementia expected to double every two decades. As people age, the prevalence of disorders leading to the syndrome of dementia increase (Nair et al., 2016; Livingston et al., 2020). The number of people with an Alzheimer's disease diagnosis is estimated to reach 152 million in the year 2050 (Patterson, 2018). In Finland, every year about 14,500 persons are diagnosed with Alzheimer's disease or other types of dementia (Muistisairaudet, 2018). The worldwide annual cost of caring for people with dementia is predicted to reach 2 trillion USD by 2030. Global social and economic development could be undermined by the total cost of dementia care and health and social services could be overwhelmed (Prince et al., 2015). Aging populations bring on an increasing economic and social impact in general and there is an increasing pressure to shift dementia care away from specialist care to primary care (Prince et al., 2016; Terveyskylä, 2023). The financial cost of caring for people with dementia aside, the human suffering of people with dementia and their family caregivers needs to be noted and the alleviation of that suffering emphasized. Behind the statistics and the alarming financial impact on healthcare and social services systems, there are human beings at their most vulnerable in need of attention, support, and care.

Worldwide, dementia is underdiagnosed and typically diagnosed relatively late in the disease process. For people with dementia, pathways for long-term care from diagnosis until the end of life are often fragmented or lacking all together. Stigmatization and barriers to diagnosis and care are the results of lack of awareness and understanding of dementia. In both the community and in care homes people with dementia are at times denied care in accordance with human rights and are not enabled to participate in care decision-making processes. Their preferences and wishes for care are frequently not respected (WHO, 2017). The care of people with dementia raises many ethical issues as the ability to communicate one's wishes is diminished in severe dementia (Banovic et al., 2018). Nurses specialized and trained in caring for people with different types of dementia, play an important role supporting people with dementia and their families in maintaining quality of life and independent living (Deshaies, 2023).

In Western societies, laws and directives guide the care of older people. The rights of older people are established in laws pertaining to autonomy and the right to care (Act on the Status and Rights of Patients, 1992; Act on the Status and Rights of Social Welfare Clients, 2000). When it comes to end-of-life issues, there are ethical guidelines as well. The older person has the right to knowledge about their illness, treatment alternatives, and consequences of different choices. The person also has the right to refuse treatment (ETENE, 2008). The ethical complexities reach a higher level when the person has dementia diagnosis and laws and directives are

not enough to guide healthcare professionals in providing care. Dementia affects decision-making capacity and the ability to foresee and plan for future events (Banovic et al., 2018; Livingston et al., 2020). The right to autonomy and self-determination turns from a straightforward thought into a thought full of complexities. Questions arise regarding autonomy, capacity, decision-making, and what these concepts mean to a person with dementia and their family caregivers. In early-stage dementia, a person can experience cognitive decline and the need to adapt to diminishing functional abilities, but still be capable of active participation in discussions that concern his/her values and wishes for future care (Sampson et al., 2011; van den Steen, Radbruch et al., 2014). A vulnerability that is extraordinary is one of the characteristics of people with dementia. The dialogue is the base for providing the most appropriate and dignity-enhancing care for the person with dementia, the on-going discussion, and trying to understand the other person (Gastmans, 2018).

When it comes to Advance Care Planning (ACP) and end-of-life care, cancer patients have historically received more attention from healthcare professionals than other patient groups with life-limiting illnesses (Harrison Denning, 2017). More than double the number of patients die from cardiovascular diseases than from malignancies and almost as many die from dementia (WHO, 2018). One of the reasons that older people with multi-morbidities do not receive the care needed at the end of life, is the unpredictability of such diseases as chronic heart failure, chronic kidney disease, chronic obstructive pulmonary disease, and dementia (Detering et al., 2017). While the development of medical science has resulted in the possibility to treat serious illness, consequently, the final stage of an incurable disease can be prolonged (Cohen-Mansfield et al., 2018).

A person in the end-stage of dementia is no longer able to make decisions for himself/herself and the family is often tasked with decision-making about end-of-life care. In these circumstances, families need to deal with complex questions regarding aspects of illness, technological interventions, limited quality-of-life, the value of life, and the desire not to cause added suffering (Harrison Denning, et al., 2016). ACP can be a valuable way to alleviate suffering and improve quality of life for both people with dementia and family caregivers (Harrison Denning, 2017) and needs to be introduced while the person with dementia retains the capacity to participate. The majority of ACP research has focused on advanced-stage dementia (Arcand et al., 2013, Dixon et al., 2018, Brazil et al., 2018, Vandervoort et al., 2014), which will be described further in Chapter 5 Previous research and knowledge gap. This doctoral thesis aims to explore ACP in early-stage dementia and to present a model for the ACP process in early-stage dementia care.

## 2 Dementia

The focus of this chapter will be on the terminology used, different stages of dementia, symptoms, treatment, and care.

### 2.1 Dementia terminology

As the world in general and healthcare in particular moves forward, the words and the terminology we are using change. In the Swedish-speaking part of Finland, the term *minnessjukdom* has replaced the word *demens* (dementia) in health care contexts. The term *minnessjukdom* can be translated to *memory illness*. The term comes from the Finnish word *muistisairaus* (*memory illness*). The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) was released in 2013 by the American Psychiatric Association (APA). In this manual, the term “dementia” is replaced with the terms “mild neurocognitive disorder” and “major neurocognitive disorder” (Diagnostic and Statistical Manual of Mental Disorders, 2013). The introduction of the new terms aims to reduce the stigma associated with dementia illness and the relation of the word “dementia” to a Latin word for “mad” or “insane” (Crisis Prevention Institute, 2015).

However, the terminology changes faster in some areas than in others. The word “dementia” is still in common use and easily understood by the public, thus the “dementia” term is likely to remain in use. (Crisis Prevention Institute, 2015). The terms cognitive impairment, cognitive decline, and mild neurocognitive disorder are used to describe the early stages of illness. Many diseases and conditions, such as Alzheimer’s disease, can eventually in the late stages of illness, cause the symptoms referred to as dementia (Dementia terminology, 2020). Dementia entails more than memory lapses. The end-stage consequences of dementia include multiple symptoms such as incontinence, dysphagia, and frequent infections as well as increased risk of falling and fractures (Kumar & Kuriakose, 2013; Livingston et al., 2020). Dementia means the eventual complete loss of the self, mind and body and not just the loss of memories and memory capability.

As the dementia term is in common use internationally in general, as well as in the research context, I have chosen to use the term *dementia* throughout the thesis and to clarify the context by using the terms early-stage, mid-stage and end-stage when appropriate.

## 2.2 Dementia stages and treatment options

Mild cognitive impairment (MCI) has been defined as an intermediate state between physiological aging and dementia. Petersen et al., (1997) defined MCI as “a clinical and neuropsychological syndrome which is characterized by emerging cognitive impairment”. MCI has been recognized as a pathological condition due to its potentially progressive character. MCI is closely related to mild neurocognitive disorder as a less severe state of cognitive decline than dementia (American Psychiatric Association, 2013). Since 1997, the recognition of MCI has evolved as an early state in the Alzheimer’s disease spectrum (Jack et al., 2018) as well as in the vascular cognitive impairment spectrum (Skrobot et al., 2018). Symptoms of MCI include decline in cognitive functioning, increased difficulty in the performance of activities of daily living, and absence of dementia (Jack et al., 2018). As MCI progresses to clinically diagnosable dementia at a higher rate than normal cognition (Roberts & Knopman, 2013; Langa & Levine, 2014), a better understanding of MCI, its causes, underlying processes, and early identification have become an important public health priority (Winblad et al., 2016). The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) has demonstrated that multi-domain lifestyle changes can have a preservative effect on cognitive functioning and reduce the risk of cognitive decline among people with MCI. Lifestyle changes include regular physical activity, engagement in mentally stimulating leisure activities, social engagement, and reducing vascular and metabolic factors that cause high blood pressure, high cholesterol, obesity, and diabetes. Other FINGER lifestyle changes include stress reduction, giving up smoking and reducing alcohol use (Rosenberg et al., 2020).

Neurocognitive disorders are classified in different ways depending on the context. Dementia can be genetic, primary or secondary, late or early onset. Dementia can also be differentiated by brain area and by pathology. Different clusters of symptoms may suggest distinct types of dementia; Alzheimer’s disease, vascular dementia, mixed dementias, dementia with Lewy bodies, Pick’s disease, HIV-associated, Parkinson’s disease-associated, prion diseases, progressive supranuclear palsy, corticobasal degeneration, and Huntington’s disease (Gale et al., 2018; Current care guidelines, 2021). Alzheimer’s disease is the most common form of dementia, contributing to about 60-70% of cases (WHO, 2017). The main symptoms of AD and many other types of dementia are cognitive symptoms, behavioral and psychiatric symptoms, functional impairment, and personality change (Bature et al., 2017; Livingston et al., 2020). The APA Dictionary of Psychology (2023a) defines cognition as “all forms of knowing and awareness, such as perceiving, conceiving, remembering, reasoning, judging, imagining, and problem solving”.

There is an absence of curative treatment options for dementia (Perneczky, 2019). Pharmacological approaches may improve function (Laver et al., 2016) and have an effect on behavioral and psychological symptoms (BPSD) (Dyer et al., 2018).

Among non-pharmacological approaches, exercise has been shown to have an effect in reducing functional decline in people with dementia. Interventions that focus on person with dementia – family caregiver dyad with the aim to maximize quality of life, are also associated with a positive effect on activities of daily living (Laver et al., 2016). Non-pharmacological options for BPSD include functional analysis-based interventions aimed at identifying unmet needs and music therapy (Dyer et al., 2018). When it comes to pharmacological treatment, caution is recommended. It is important to take potential harm, costs, and benefits into consideration. Exercise and dyadic interventions are noted as more effective and not associated with side effects (Laver et al., 2016).

Common symptoms in early-stage dementia can appear some time before a diagnosis is made. These symptoms include difficulty concentrating, memory loss, difficulties carrying out familiar daily tasks, finding the right word or struggling to follow a conversation, confusion about time and place, and mood changes. Symptoms may start mildly and get worse very gradually. The person affected may not notice these symptoms. Memory problems are more specific to Alzheimer's disease and may be less obvious in the early stages of vascular dementia. Symptoms specific to dementia with Lewy bodies include visual hallucinations, physical slowness, and sleep disturbances. Personality changes, lack of social awareness, and language problems may be early symptoms of frontotemporal dementia (Symptoms of dementia, 2020). In the early stage, people with dementia face cognitive loss, adjustment to cognitive decline, and are capable of taking an active role in contemplating and discussing values and future care preferences (Harrison Denning et al., 2016; Orsulic-Jeras et al., 2016).

The Global Deterioration Scale (GDS) (Reisberg et al., 1982) and the Functional Assessment Scale (FAST) (Sclan & Reisberg, 1992) are widely used to measure the severity of cognitive decline. The GDS scale rates severity of illness from level 1 to level 7. Level 1 means no dementia and independent function. Levels 2 and 3 describe mild dementia. In the moderate to moderately severe dementia in levels 4 and 5, the person with dementia may have difficulty recognizing family members, have impaired judgement, require constant supervision, and need assistance with all activities of daily living. Level 6 and 7 entail severe or very severe dementia. The person may be unable to communicate and at level 7 be in a vegetative state. Full-time care is needed in the latter stages (Reisberg et al., 1982). The disease can progress for many years with the average survival ranging from 7 to 10 years (Todd et al., 2013; Kua et al., 2014).

The end-stage of dementia is characterized by psycho-behavioral symptoms such as depression, agitation, wandering, and delusional behavior. In the late severe stages, the illness progresses to aphasia, inability to walk, to sit up unaided, and to hold the head up. The ability to communicate needs and wishes is lost (Eisenmann et al., 2020; Livingston et al., 2020). The progress of the disease is further complicated by episodes of better condition followed by episodes of worsening condition largely due to the patient's somatic condition (Wang et al., 2018). It is

generally recognized that patients dying from dementia have similar needs as patients dying from cancer (Godwin & Waters, 2009, Mitchell et al., 2009, Moens et al., 2014). Most of the symptoms experienced by dying people are similar, i.e., pain, anxiety, nausea, and dyspnea despite different diagnoses. Common features of end-stage dementia are refusal to swallow and/or open the mouth leading to inadequate calorie intake and mouth hygiene problems leading to fungal infections. Difficulties swallowing or swallowing wrong may lead to aspiration risks and pneumonia. Difficulties moving may lead to immobility, pressure wounds and infection. The tendency to frequent falls may lead to fractures. Other complications are constipation, incontinence followed by urinary tract infections and pyelonephritis, and lastly, medication difficulties followed by a risk for unwanted consequences both physically and psychologically. A downward spiral gets started easily with one complication leading to another (Sampson et al., 2018, Eisenmann et al., 2020).

People are dying with dementia in increasing numbers but the evidence for best end-of-life care is sparse. (WHO, 2017). Dementia is a disease that fulfills the criteria for palliative disease. The criteria include disease progression and shortening of life span without curative treatment (WHO, 2002; 2023). It can be difficult to determine when the late phase of dementia begins. Disability is severe in the last year of life for people reaching the advanced stage (Gill et al., 2010, Sampson et al., 2018). Multi-morbidity is very common in the older patient and an enormous challenge in dementia especially due to the difficulty in organizing care (Livingston et al., 2020). In addition to the dementia diagnosis, the patient often suffers from frailty, general pain, constipation, and depression. Diabetes, COPD, and cardiovascular diseases are also common. These co-morbidities have to be taken into consideration when care is planned for and given (Harrison-Dening, 2017). Only about 25% of people dying with dementia reach the severe stage of dementia while most people with dementia might die from other causes while still in the mild to moderate stage (Aworinde et al., 2018).

## **2.3 Good care in dementia care**

A core challenge for people with dementia is the loss of autonomy associated with having dementia (De Waal, 2014). An individual's capacity for self-determination is referred to as autonomy. Self-determination refers particularly to behaviors that improve one's circumstances, including decision making, problem solving, self-management, self-instruction, and self-advocacy. (Dementia and self-determination, 2013). As part of cognitive decline in early-stage dementia, the capacity to make abstract decisions about future care might be lost early in the disease process (Dening et al., 2017; Cotter, 2017). However, it should not be assumed that people with dementia are incapable of making decisions. In the early to moderate stage of illness, many retain capacity, are still able to express appreciation, reasoning, and choice and have the right to participate fully in their



care planning (Okonkwo et al., 2008; Burlá et al., 2014).

A dementia diagnosis in the early stage of illness, the diagnosis disclosure, and the discussion of management and prognosis are important and may have a substantial long-term impact on the person with dementia and their families (Werezak, & Stewart, 2009; van den Dungen et al., 2014; Riva et al., 2014). People living and dying with dementia belong to a complex patient group. The complex patient has been described with such terms as comorbidity, multi-morbidity, poly-pathology, or multiple chronic conditions in combination with social determinants of the health framework (Manning & Gagnon, 2017). People with dementia have various health conditions and are situated in multiple social relations. Their care needs to be informed by the complexity of their situation and health professionals need to be supported, equipped, and prepared to handle this in practice (Manning & Gagnon, 2017).

In the primary care setting, nurses make up the largest workforce (Freund et al., 2015). Before, during, and after the patient meets with the physician, nurses have a vital role in coordinating the care and taking responsibility for chronic disease management, patient education, clinical care, and risk assessment (Norful, et al., 2017; Swanson et al., 2020). In the promotion of care quality and meeting healthcare needs of people with dementia, nurses have been identified as critical (Bail & Grealish, 2016; Evripidou et al., 2019). People with dementia and their families rely on the care management that nurses provide in both home-based and clinical settings. Communication and education about symptoms, progression of illness, treatments, interventions, and the coordination of services are an important part of dementia nursing care (Deshaies, 2023). The benefits of shifting dementia care from specialist care to a primary care led approach includes the potential for a more holistic care and more cost-effectiveness in the use of healthcare resources (Frost et al., 2020).

The recommendations of Duodecim, the Finnish Medical Society, for good care in dementia care emphasize a holistic approach with tailor-made health and social services for people with dementia. The dementia nurses work together with the physician. After the diagnosis, the follow-up care is concentrated to the dementia nurses to ensure continuous and flexible care. Different types of services needed to support independence need to be available at the right time and place as the illness progresses. The care is to be planned with the needs of the person with dementia as the basis and in collaboration with other healthcare professionals. Comorbidities should be treated in a holistic manner. The care goal is to ensure quality of life in all stages of illness by taking into account the lifestyle and background of the person with dementia, preserve dignity and social networks, and ensuring autonomy. Measures that support independence and autonomy include guidance and advice, physical rehabilitation, assistive devices and technology, support groups and activities, home health care, meal services, transportation services, short-term care as needed, and financial subsidies (Current care guidelines, 2021).

In early and mid-stage dementia, care continues as the illness trajectory nears its end. In a Delphi study from 2013 optimal palliative care for older people with dementia was defined. Communication and decision-making about care is the most important area influencing all other areas when it comes to quality end-of-life care. The importance of prognostication and the avoidance of aggressive treatments as well as the applicability of palliative care are emphasized to define optimal palliative care for people with dementia (van der Steen, Radbruch, Hertogh et al., 2014). A 2022 study calls for a paradigm shift in the approach to palliative care for older people with dementia. Symptoms need to be looked at according to the four pillars of palliative care, physical, psychological, spiritual, and emotional; however, the focus is usually on physical and psychological symptoms. A palliative care approach is appropriate from the time of diagnosis and ACP should be seen as a continuous process begun early in the course of dementia, involving the person with dementia (Timmons et al., 2022).

Good care in dementia care has become synonymous with the concept of person-centered care (Manthorp & Samsi, 2016), an approach that is increasingly included in the national guidelines and dementia strategies of many countries (National Institute for Health and Care Excellence, 2018; The National Board of Health and Welfare, 2017; Danish Health Authority, 2019; Norwegian Ministry of Health and Care Services, 2015). Personalized care is also mentioned in the Finnish national memory program. The title of the program is ‘Creating a “memory-friendly” Finland’. The program suggests a case management approach to dementia care where each patient’s personal situation and need for care are assessed and a personalized care plan is created (National Memory Programme 2012-2020, 2013). The concept of person-centered care will be described further in Chapter 7 Theoretical Perspectives.

## 3 Advance Care Planning

In this chapter, the focus will be on the concept of advance care planning, its background, the definition of ACP, the role of the nurse in ACP, and its role in dementia care. ACP is a process used to extend the autonomy of patients beyond the loss of competency (Thomas, 2017; Russel, & Detering, 2017; Rietjens et al., 2017; Brinkmann-Stoppelenburg, Rietjens, van der Heide, 2014). ACP is based on the principles of autonomous decision-making, respect for health care choices and legal consent (Yeun-Sim Jeong, Higgins & McMillan, 2007).

### 3.1 Advance Care Planning and related concepts

As ACP models evolved, Rietjens et al. (2017) convened a large, multidisciplinary Delphi panel of ACP experts in 2017 in order to reach a consensus on an extended definition and a brief definition of ACP. The extended definition:

*Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions. Rietjens et al., 2017)*

The brief definition is as follows:

*“Advance care planning enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate.” (Rietjens et al., 2017)*

The 2017 definition acknowledges the movement towards a person – family caregiver conversation with the objective to reflect on goals, wishes, and values and to prepare and plan for future care (Thomas, 2017). Research shows that ACP for older people, including those with dementia, can increase palliative treatment decisions and reduce inappropriate hospitalization (Robinson et al., 2012).

The United States is seen as the birthplace of ACP with the term ‘living will’ being used as early as 1967 (Russel, & Detering, 2017). A living will is a legal document that communicates the instructions of the individual in the event the person suffers

from irreversible illness or terminal illness. The instructions concern healthcare interventions desired or not desired. The document is written and signed by the individual in the presence of witnesses. Interventions addressed in living wills have traditionally been cardio-pulmonary resuscitation, nutrition, and hydration. Other interventions addressed may be the use of antibiotics, blood product transfusions, invasive procedures such as blood tests, spinal taps, and X-rays as well as the desire to stay at home or to be hospitalized. A living will form is a type of advance directives. Other types of advance directives are durable healthcare power of attorney and combined living will/healthcare power of attorney document. The durable healthcare power of attorney is a legal document that a person can use to appoint a healthcare surrogate or proxy who is given the power to make healthcare decisions for the person in question, should the person become unable to communicate decisions personally (Kinzbrunner & Gomez, 2011).

Due to the limitations of advance directives, in 1997, the Institute of Medicine coined the term 'advance care planning' as something more meaningful and expansive than advance directives (Silveira & Rodgers, 2017). In 1995, Gillick described the key goals of ACP; patients learn about their medical condition, prognosis, and treatment options, as well as associated complications. Patients then, together with their physician, evaluate this information and decide on broad goals of care (Gillick, 1995). Do Not Resuscitate-decisions and/or advance directives may be part of the ACP process. However, there is support for the view that ACP should be more than just the completion of documents (Thomas, 2017; Russel, & Detering, 2017; Kolarik et al., 2002).

### **3.2 Advance Care Planning in dementia care**

ACP was originally developed in cancer care (Harrison Denning, 2017) and is now seen as improving the quality of end-of-life care for other conditions as well, including dementia (Harrison Denning, 2017; Dixon et al., 2018). End-of-life care received by patients suffering from dementia is often poor (Martinsson et al., 2018). The reason for this may be due partly to few people with dementia having an advance care plan. There is a consensus that ACP in dementia care can be a valuable way to alleviate suffering for both people with dementia and family caregivers. ACP for dementia patients provides an opportunity for relationship-centered triad care that includes people with dementia, family caregivers, and professional care staff (Harrison Denning, 2017). As ACP is based on the principles of respect for health care choices, legal consent, and autonomous decision-making, (Yeun-Sim Jeong et al., 2007), concepts that are affected by dementia progression, the ACP process needs to be adapted to dementia care circumstances (Butler, et al., 2014; Jones et al., 2016; Harrison Denning et al., 2019; Visser et al., 2022)

People with dementia and their families need support with future care decision-making through ACP (Harrison Denning, 2017). Guidance pertaining to the timing of

ACP as well as to the approach chosen when introducing the ACP concept to patients and their family members are key challenges (Harrison Denning, 2017; Jones et al., 2016; Cotter et al., 2017; Dickinson et al., 2013). The choice of the correct moment in the disease progression as well as the correct choice of words may have a significant effect on the outcome of an ACP conversation (Thomas, 2017). When it comes to ACP in dementia care, the timing is of even more importance as the person with dementia will progressively lose cognitive and functional abilities (Cotter et al., 2017; Harrison Denning et al., 2011; van der Steen et al., 2014).

The Mini Mental State Examination (MMSE) (Folstein et al., 1975) is frequently used to assess ACP decision capacity but it should not be used as a substitute for asking direct questions or assessing the patient's understanding of making ACP decisions. It also seems like family members are unprepared for decision-making even though they are often called upon to do so when the dementia patient can no longer make decisions about their care. Concern for family members could be used as an incentive for older people to create an ACP. Family members' decision-making might be facilitated by clear prognostic information, knowledge about previous views held by the patient, and by family support. The heavy effects of the illness, feelings of guilt and failure, and lack of information on the trajectory of the disease, leaves the family unprepared for decision-making regarding end-of-life care for the patient (Harrison Denning et al., 2011; Gabbard et al., 2020).

Family members are more likely to opt for treatments rather than waive them. Some family members are motivated by what they believe the person suffering from dementia would have wanted as compared to what would be in the best interests during current circumstances. Family members might also be influenced by their own priorities and wishes for future care. Family members may also have a negative belief about the poor quality of life of a patient with dementia. The family members' ability to make an objective decision on behalf of their relative is impacted by all of the above factors. In addition, decisions about life-sustaining treatment are often presented at a time of a crisis whether medical or social, a time of great stress for family members. It may be difficult to discern whether the decisions made are truly made in the patient's best interests and will genuinely reflect his preferences (Harrison Denning et al., 2011). The family members of people with dementia are affected psychologically, socially and practically. At the same time, the family is the most important resource concerning quality-of-life for the person with dementia (Moon et al., 2022). Findings from international studies indicate that nurse practitioners and nurses are well suited to initiate and lead ACP conversations and well positioned to participate in ACP process development (Dickinson et al., 2013; Cotter et al., 2017; Lewis et al., 2015; Poppe et al., 2013; Yeun-Sim Jeong et al., 2007; Splendore & Grant, 2017).

### **3.3 Palliative care and Advance Care Planning in Finland**

In the Finnish national dementia program of 2013 (National Memory Programme 2012-2020) the financial burden of dementia care is mentioned. The program focuses on rehabilitation and care given in the homes of people with dementia in order to delay transfer to long-term nursing home care. Palliative care is mentioned in one paragraph towards the end of the program description. The objective is to make people with dementia close to the end of life as comfortable as possible. Personalized palliative care plans and documentation are needed to coordinate the work of healthcare professionals, alleviate suffering and maintain quality of life. The concept of ACP is not mentioned as a way to alleviate suffering and clarify care goals (National Memory Programme 2012-2020).

The Ministry of Social Affairs and Health in Finland published national guidelines and recommendations for palliative care in 2010. The guidelines state that palliative care is a human right. The foundation for care is respect for the autonomy of the patient. The patient's decisions regarding the care should be accepted and respected (Ministry of Social Affairs and Health, 2010). In the updated recommendations from 2017 and 2019, care planning and care goals are mentioned. Care planning and advance directives are to be discussed early enough in the disease process. The treating doctor and the care team are to reach an understanding with the patient, his family members or legal representative about the care plan, advance directives, and limits of treatment. The doctor is responsible for carrying out and updating the care plan. The patient is to be supported in making end-of-life care advance directives (Ministry of Social Affairs and Health, 2017; 2019). In the section for developmental needs of the 2017 guidelines, there is no mention of Advance Care Planning. In the 2019 guidelines, a personal ACP is mentioned as an aid in emergencies. The ACP is to contain a living will, the doctor's orders on treatment limitations as well as clear directives on end-of-life care including medications (Ministry of Social Affairs and Health, 2019).

ACP as a systematic process has not received attention in Finland until fairly recently (Lehto et al., 2019; Saarto et al., 2017) and there are few relevant studies in the literature (Lehto et al., 2019). Finland was one of six countries participating in the Palliative Care for Older people (PACE), a European funded project (FP7, 2014-19) where the effectiveness of palliative care for older people in nursing homes was compared. Three studies were performed between 2014 and 2019, including a mapping of palliative care systems, a cross-sectional study of the quality of dying and palliative care, and controlled cluster trial to study the impact of the PACE Steps to Success Intervention program. In the post-final phase of the project, a Massive Open Online Course was launched with the aim to raise awareness and impact of the PACE Steps to Success Programme (Cordis, Europa, 2019). In the PACE program, which has also been translated to Finnish, the first step in implementing the program is to conduct discussions about current and future care with the clients and their family members, i.e., an ACP process (Payne et al., 2018,

Finnish translation 2019). The country specific results showed that in Finland, the PACE Programme was perceived as not fitting the needs and the knowledge level of the nurses and the facility. Staff indicated not learning much from the PACE Programme. The hopes of the Finnish staff had been for training to be more technical (Oosterveld-Vlug, et al., 2019).

Recently an ACP model was developed in the city of Kuopio aiming to support the care of acutely ill older patients. The goal was to ensure that older people with multi-morbidities over the age of 75 have an individual plan for the worsening of their health problems, a plan created by a multi-professional team based on the older person's own values and wishes. The model was implemented during 2021 and 2022 (Juutinen, 2022a). A multi-professional group created a care path for acutely ill older people, a care path based on national recommendations. ACP is part of the care path design. The model used for ACP was modified from the model suggested by Lehto and colleagues (2019) which contains six steps, basic information about the client, the wishes and fears of the client, the goals of care, symptom control and follow-up, treatment restrictions, and guidelines for acute care. The patient him/herself is involved in the care discussion as well as family members with the permission of the patient. As part of implementation, geriatricians and registered nurses were trained in ACP. After a few months, the implementation of the ACP model was evaluated through a survey of the training participants. The results showed that participants saw ACP as useful from the professional aspect as well as from the client perspective. It was also found that ACP implementation requires time, training and follow-up. Its implementation needs to be supported in every way possible and its results followed to be able to show its effectiveness (Juutinen, 2022b). However, this model is a local one and not specifically aimed at people with dementia.

In 2022, the Finnish Institute for Health and Welfare (THL) published national quality recommendations for palliative care and end-of-life care. The recommendations focus on ten quality areas with a total of 50 quality criteria that function as the basis for organizing and providing high-quality palliative and end-of-life care. In these recently published recommendations, ACP is listed as one of ten quality areas with four quality criteria and described as a prerequisite for palliative care of high quality. High quality palliative care is realized through ACP, which THL describes as discussions about the wishes, fears, and needs of the patient as well as care restrictions, implementation, and the responsibilities of stakeholders. The care plan is to be made together with healthcare professionals, the patient, and with family members with the consent of the patient. THL suggests that the occurrence of ACP is documented with certain codes, making follow-up easier on regional and national levels (Saarto et al., 2022).

## 4 Previous studies and knowledge gap

The chapter on previous studies and knowledge gap will start from a wide perspective and be narrowed down to topics of the current study. Table 1 illustrates the growing field of research in ACP in dementia care. Table 1 shows the results from a search with the words ‘advance care planning’ AND ‘dementia’. The PubMed search was conducted on February 19, 2023.

**Table 1.** PubMed search results ‘advance care planning’ AND ‘dementia’

Years	Search results
1985-1994	79
1995-2004	194
2005-2014	289
2015-2/2023	634

To identify gaps in existing evidence, map previous studies, and to draw conclusions about the general research within the area of ACP in dementia care, an initial assessment of the research field was made. In order to identify ACP programs, interventions, and their dementia specific components, a search was conducted during the summer of 2019. The search was updated in February of 2023. The appendix provides a description of the search and an overview of ACP programs and interventions (n=56) identified in the 2 searches. The comprehensive programs identified are characterized by a systematic, multi-faceted approach providing general ACP information through extensive websites, brochures, and awareness-raising campaigns aimed at the public as well as courses for healthcare professionals. The regional and local interventions identified offer a wide variety of approaches and tools, if described. It was noted that many of the comprehensive programs had not developed dementia specific guidelines nor guidelines for ACP in early-stage dementia. The majority of the regional and local interventions focused on conditions other than dementia. There is a lack of systematic evaluation of the feasibility and the effects of the programs concerning people with dementia. A low number of published ACP intervention studies include feedback on the interventions from the people with dementia themselves. Important gaps in both the external and internal evaluations of the comprehensive ACP programs were identified.

In a 2021 scoping review, McMahan et al. sought to deconstruct the complexities of ACP outcomes. The answer to the question ‘where do we go from here?’ lies in making sense of ACP’s complexity and to consider the interplay between ACP stakeholders and intervention targets. The stakeholders are the patients, the surrogate decision-makers, communities, clinicians, health systems, and ACP policy. All stakeholders affect ACP intervention outcomes. If social norms do not



support ACP, or health care professionals are not trained, documentation is not optimized, or legislation not supportive, the wishes of the patient may be moot (McMahan et al., 2021). McMahan et al. (2021) calls for testing of combined interventions and implementation strategies as necessary for improving care in real-life situations. The need for coordinated efforts and initiatives to develop a standardized, semi-structured, and simple tool for ACP discussions with this patient group and their family carers have been noted in other studies as well (Butler, et al., 2014; Jones et al., 2016).

## **4.1 Advance Care Planning in early-stage dementia**

The field of research in ACP in early-stage dementia is less developed compared to ACP research in advanced dementia care (see Appendix) but in recent years, several studies have been published (Bolt et al., 2022; Daddato et al., 2022; Bosisio, et al., 2021; Vellani, et al., 2022; Sussman, Lawrence & Pimienta, 2022). Bolt et al. (2022) explored the perspectives of people in early-stage dementia on the future, being cared for by others, and on the end of life. It was found that thoughts about the future and the end of life led to feelings of anxiety and ambiguity but to resignation and contentment as well. The study participants expressed wishes to be recognized as worthy and unique human beings until the end of life (Bolt, et al., 2022). The viewpoints of the other members of the dementia care triad were not included in the study. In the adaptation of a group visit intervention, Engaging in Advance Care Planning Talks (ENACT), Daddato, et al. (2022) recruited person with MCI and family care partner dyads for participation in an advisory panel. In a human-centered design approach, the advisory panel confirmed the importance of prioritizing ACP for people with MCI and suggested improvements for the ENACT intervention. The dyads rated the acceptability positively (Daddato et al., 2022). Healthcare professionals were not included in the study.

In their study, Bosisio, et al. (2021) presented a dementia-specific tool and discussed a pilot trial of ACP promotion among people in early-stage dementia. The feedback from people with dementia was positive and relatives expressed satisfaction with the support of a facilitator when discussing sensitive topics. However, structural and institutional challenges combined with misconceptions about ACP and dementia were found to possibly impede ACP implementation and research (Bosisio, et al., 2021). Healthcare professionals' views were not part of the study. Vellani et al., (2022) tested the feasibility, acceptability, and preliminary efficacy of tailored ACP intervention for people living with mild dementia. The results of the intervention were improvement in decision-making confidence and psychological distress. Their dementia knowledge showed minimal change. However, the authors of the study concluded that people living with mild dementia are able to participate effectively in the identification and expression of their wishes and values for future care (Vellani, et al., 2022). The perspectives of healthcare professionals were not part of the intervention study. In an ACP

intervention using a self-directed ACP engagement workbook, people with dementia assessed by healthcare staff to be in the early stage of illness, were recruited for participation along with family caregivers. The pilot intervention was conducted in two steps. The combined findings were promising as the workbook supported ACP engagement for early-stage people with dementia (Sussman, Lawrence & Pimienta, 2022). Healthcare professionals were not part of the intervention study.

The healthcare preferences of people with dementia are not always known despite the poor prognosis of people in the advanced stage of dementia (Harrison Denning et al., 2016; Hill et al., 2017). The lack of knowledge about healthcare preferences can lead to difficult decision-making for family members and to inappropriate palliative care (Wickson-Griffiths et al., 2014; Crowther et al., 2022). When preferences are not known, the consequences of defaulting to full treatment may be burdensome interventions such as hospitalizations, intravenous therapy, the use of restraints, tube feeding, antibiotics, and life-sustaining (Mitchell, Kiely & Hame, 2004; di Giulio et al., 2008; Mitchell et al., 2009, Harrison, Hunt, Ritchie, et al., 2019). Despite ACP being seen as especially important for people living with dementia as self-determination capacity and abstract thinking ability diminish with illness progression (Brinkmann-Stoppelenburg et al., 2014; van der Steen, van Soest-Poortvliet et al., 2014; Booij et al., 2013), ACP is rarely conducted with dementia patients (Sellars et al., 2019).

The efficacy of ACP in dementia care and subsequent effects on end-of-life care have been evaluated in studies that explore issues pertaining to the advanced stage of dementia in a long-term care setting involving staff and/or family members. (Brazil et al., 2018; Sampson et al., 2010; Aasmul, Husebo & Flo, 2018; Sussman et al., 2017). Brazil et al., (2018) conducted a paired cluster randomized controlled trial (RCT) to evaluate the effectiveness of ACP with family carers in dementia care homes. It was concluded that ACP was effective in reducing decision-making uncertainty among family carers and in improving perceptions of nursing home quality of care. The implications of the study results include recognition of the importance of educating family carers and improving communication between care staff and families. A 2010 RCT explored a complex ACP intervention in severe dementia. The intervention consisted of a palliative care patient assessment, an ACP discussion with the family caregiver who was given an opportunity to create an advance care plan. It was found that even though the family caregivers appreciated the ACP discussion and received specialist support, few of the caregivers wrote an advance care plan (Sampson et al., 2010). In another RCT, an ACP intervention was conducted in 37 Norwegian nursing homes. The focus of the intervention was to educate nursing home staff to implement ACP in their units. Implementing ACP according to predefined criteria was largely achieved. The engagement of staff and leaders were important facilitators while lack of time and competence were seen as barriers (Aasmul, Husebo & Flo, 2018). Illness trajectory specific pamphlets for five conditions were tested in long-term care settings and found to be helpful in initiating reflections and discussions between residents and

their families. Increased staff support was suggested as a way to turn reflection into discussion (Sussman et al., 2017).

## **4.2 Barriers and facilitators in dementia care Advance Care Planning**

The challenges to optimal dementia care include knowledge gaps, uncertainty about the roles of different healthcare professionals, lack of time, and difficulties identifying community resources (Harrison-Dening, Sampson, et al., 2019). As the number of affected people rise, it is important to gain an understanding of the healthcare experience of people with dementia and their family caregivers and to ensure that person-centered care is provided (Prorok, 2013). A 2013 meta-ethnographic study found that the healthcare experience of people with dementia and family caregivers could be improved in several areas such as improving communication and attitudes around dementia and increased awareness of person-centered care among healthcare providers (Prorok et al., 2013). The results of a 2021 systematic review showed that people with dementia preferred to be informed about the diagnosis as early as possible and were eager to participate in medical decisions. People with dementia cared for in institutions preferred individualized and person-centered care (Wehrmann et al., 2021).

Barriers and facilitators for ACP in dementia care have been identified in several studies. Barriers include both family and professional caregiver reluctance to engage in ACP and not taking initiative, passive avoidance, and unclarity about roles for professionals and families, as well as being uncertain about the process of decision-making and possible disease trajectory. Healthcare system and continuity of care factors affected ACP process initiation as well (van der Steen et al., 2014). Other challenges include professional caregivers' lack of knowledge, the assumption that dementia is not a terminal disease, and communication difficulties (Dempsey, 2013; Bosisio et al., 2018), systemic and contextual factors, and time factors (Phenwan et al., 2020). Vandervoort et al. (2014) identified passive and active barriers to ACP, such as people with dementia and their families avoiding of the topic and not realizing the importance of planning until it was too late. It was found that early communication about these issues is of outmost importance (Vandervoort et al., 2014). In 2018, Tilburgs, et al. sought to explore barriers and facilitators for ACP with community-dwelling people with dementia. Semi-structured interviews were conducted with people with dementia, their family caregivers, and with GPs. The viewpoints of case managers and practice nurses were obtained in a focus group meeting. The findings showed that ACP is facilitated by a therapeutic relationship between the dementia care triad. Barriers included the wish of some participants for postponement of ACP until problems arise, time restraints of the GP, and concerns regarding documentation of the outcomes of ACP (Tilburgs, et al., 2018).

Lack of knowledge of the ACP process seems to be a key professional barrier to advanced care planning. The failure to discuss prognostic issues of dementia with the patient and his family and the avoidance of discussions while the dementia patient still has the capacity and cognition to do so, were also important barriers to ACP (Harrison Dening et al., 2011). Complicating the issue further is a delay in diagnosis that has been noted in Europeans survey of family carers' experiences in five countries, including Finland. The mean length of time from symptoms being noticed to diagnosis, was in Finland found to be 2,24 years (Woods et al., 2018). A survey of general practitioners' perceptions on ACP for dementia patients indicated that most respondents agreed that discussions in the early stages would make decision-making easier during the advanced stage of the disease. Many were reluctant to hold these discussions at the time of diagnosis. The optimal timing was viewed as being determined by the readiness of the patient and family to acknowledge the end-of-life considerations (Brazil et al., 2015). Key facilitators include dedicated professionals available to educate families and healthcare professionals about ACP and the timing of ACP early in the disease trajectory (Harrison Dening et al., 2011). End-of-life care education and supportive ACP programs for both professionals and relatives reduce unnecessary hospital admissions. Barriers may be overcome by active, early intervention by professionals involved in the early care of the patient diagnosed with dementia (Harrison Dening, et al., 2011).

### **4.3 Roles and responsibilities of healthcare professionals in Advance Care Planning**

In a survey of general practitioners, most respondents held the view that the general practitioner (GP) should initiate these discussions (Brazil et al., 2015). The role of GPs has been explored in several studies (Bally, Kronen & Jox, 2019; van der Steen et al., 2021; de Vlemnick et al., 2016; Tilburgs et al., 2020). The role of the nurse seems less explored. In their recommendations for healthcare professionals concerning ACP in dementia, Piers et al. (2018) state that all healthcare professionals can be involved in discussing ACP. Having some knowledge of the disease trajectory, a trusting relationship with the person with dementia and their family, and communication with the GP are important (Piers et al., 2018). Dening, Sampson, and De Vries (2019) emphasize the case management approach in dementia as beneficial in supporting decision making and introducing ACP. Harrison Dening, et al. (2017) see the best approach for dementia care as a case manager with specialist dementia knowledge coordinating the input from other disciplines as needed. A 2007 case study in the residential aged care facility context, introduced the Nursing Brokerage Model where ACP is implemented by an advanced practice nurse who acts as a broker negotiating, advising, and acting as an advocate for the resident. The role of the advanced practice nurse was that of an ACP process facilitator and mediator between people involved (Yeun-Sim Jeong et al., 2007).

Improving or sustaining quality of life is the aim in the care of people with dementia (Zabalegui et al., 2014). Dementia care guidelines recommend tailoring care to the wishes and needs of individuals (Fazio et al., 2018). The support of a family member or someone close to the person with dementia facilitates living as well as possible with dementia (Tuijt et al., 2021). The health care professional forms the third part of the dementia care triad and contributes to establishing support for the person with dementia (Fortinsky, 2001). Some studies focus on the physician as the healthcare professional of the triad (Stubbe, 2017; Fortinsky, 2001; Jensen & Inker, 2015) while other studies acknowledge that the healthcare professional in dementia care triad can differ greatly and include nurses, medical specialists and other professions as well as physicians (Tuijt et al., 2021). A 2021 systematic qualitative review and thematic synthesis sought to bring together the experiences and perspectives of the members of the dementia care triad in order to reach “greater understanding of the dynamic nature of their relationships and how these may facilitate or hinder optimal dementia care”. For the functioning of a dementia care triad, the following themes emerged: active participation and autonomy, care expectations and triad role, relationship building and trust, communication, care continuity, and relationship dynamics. Healthcare professionals need to involve the person with dementia, clarify expectations of every triad member, establish trust, and enable communication within the triad as well as beyond (Tuijt et al., 2021).

The role of the nurse has been explored in studies that indicate that nurse practitioners and nurses are well suited to initiate and lead ACP conversations and well positioned to participate in ACP process development (Dickinson et al., 2013; Cotter et al., 2017; Lewis et al., 2015; Poppe et al., 2013; Yeun-Sim Jeong et al., 2007; Splendore & Grant, 2017). Nurses’ understanding of ACP has been examined in a 2010 study. Community nurses involved in cancer care saw ACP as an important part of good nursing care and their role in ACP as facilitating family communication and engaging with patients to explore care preferences (Seymour et al., 2010). Nurses’ experiences of ACP have been explored in a study where they reported lacking skills in to implement ACP. Community nurses were most likely to consider ACP part of their responsibility while others felt they lacked the time, training, and resources for ACP (Robinson, et al., 2012). Fan and Rhee (2017) described nurses’ confidence levels and motivation for ACP. The attitude towards ACP was in general positive and there was a belief that ACP would be beneficial for the community. The interest in ACP training and education was high, however, nurses also expressed concern over legalities of ACP, their understanding of end-of-life care options, and ethical considerations (Fan & Rhee, 2017). In a study specifically exploring ACP in dementia care, the results of a training needs analysis of Admiral Nurses in the United Kingdom showed that the skills and confidence of nurses would benefit from combining communication training with supervised practice, shadowing, and access to materials that facilitate discussion (Harrison Denning, Scates, McGill & DeVrie, 2019).

## **4.4 Conclusion on previous research and knowledge gap**

The number of interventions and studies that have included feedback from people with dementia themselves is relatively low (see Appendix). While there is an increase in ACP studies that involve people with dementia, there is still a need for further studies in the field of ACP for people with dementia in the early stage of the illness trajectory with a focus on the feedback and opinions of the people with dementia themselves. To the author's knowledge, people in early-stage dementia in the Finnish dementia care context have not been included in research focusing on planning for future care. Chapter 2.3 in this thesis describes good dementia care, as it ought to be based on research and recommendations. However, it has been found that dementia diagnosis is often delayed and that ACP is rarely conducted in dementia care. There is a need for studies that focus on how to incorporate ACP in everyday dementia care practice and how to make ACP a part of dementia care in all stages of illness. The roles and responsibilities of different healthcare professionals need to be explored with a specific focus on the role of the dementia nurse and the interactions of the dementia care triad. The role of the GP has been extensively explored but the role of the nurse less so. As ACP in general is not a well-known concept in Finland, studies focusing on people with early-stage dementia and on dementia care professionals in Finnish dementia care is relevant for the development of ACP in this context.

## **5 Theoretical perspectives**

The vulnerability, dignity, suffering, and care concepts have been studied and defined by many caring and nursing theorists. For this thesis, the ethics of the caritative caring philosophy as developed by Eriksson (1994a) guide the overall aim of the study as well as the research questions.

Gastmans's (2013a) dignity-enhancing ethical framework and the concept of person-centered care were chosen to provide the theoretical perspectives as they both emphasize holistic care, vulnerability, dignity, and respect. These concepts are integral to the ACP process as ACP seeks to respect the wishes of the patient, provide support in planning and decision-making, and in extension enhance the dignity of people in a vulnerable state.

### **5.1 The caritative caring philosophy**

The ethics behind the philosophy of caring science guide the search for knowledge and the research questions stated. The purpose of asking the questions must be to achieve knowledge that benefits the patient (Arman & Rehnsfeldt, 2006). From the caring science perspective, an ethical approach is significant for all aspects of nursing. An ethical approach can be seen as the foundational approach of the nurse in a caring relationship with a fellow human being, in other words, ethos. The three key dimensions of the ethical approach are caritas as compassionate love, the dignity of the human being, and virtue as a strength (Fagerström, 2021).

Suffering is a phenomenon closely related to all forms of caring and nursing. Human suffering as well as the desire to alleviate or eliminate suffering is the motivation behind all caring acts (Arman & Rehnsfeldt, 2006). To suffer is part of human life and existence; however, suffering can also be seen as an attack on the dignity of a human. Having to ask for help and the experience of not being seen and not being understood means a loss of dignity, a suffering (Eriksson, 1994b). The patient, the suffering person, is in need of care that makes the suffering endurable. "The alleviation of suffering presupposes a recognition and confirmation of suffering in its different shapes and expressions, and an understanding in its deepest sense" (Eriksson, 1994a).

Eriksson describes three types of suffering related to care: suffering due to illness, suffering due to care and/or treatment, and suffering related to living. Suffering related to living is caused by the threat to the very life of a person and the connected emotions, the loss of oneself as a whole person (Eriksson, 1994b). When a person suffers, her family and friends suffer as well as an expression of mutual dependence. The family's importance for the health and the suffering of a person is significant. When the care is planned and given from a family perspective, there are at least three different angles to be attentive to: the support (or lack thereof) for

the person from the family, the family's suffering and need of support, and the family as a unit with its own needs and interaction. The family can experience almost unbearable suffering when witnessing the suffering of a family member. There is a conflict between one's own suffering and the suffering of the ill family member, a conflict that creates role insecurity and doubts in one's abilities to support and help (Arman & Rehnsfeldt, 2006). Suffering caused by care stems from the violation of the person's dignity, exercise of power, and the lack of care (Eriksson, 1994b) Power and responsibility are deeply connected. The attitude of the nurse has the power to create an experience of insecurity, unsafety, and alienation, as well as the power to create the opposite experience (Lassenius, 2012). The suffering of a person with illness is doubled when the person suffers but is prevented from showing the suffering. Suffering caused by care can be seen as a gap between the needs and expectations of the ill person and the attitude with which care is offered (Arman, 2012).

## 5.2 Care ethics according to Gastmans

The concept of absolute dignity of a human is the deepest motive of care ethics according to Eriksson (2010) while Gastmans (2018) talks about vulnerability as the motivation for care. The vulnerable position of the patient motivates care, the more vulnerable the person, the stronger the appeal to care for that person becomes (Gastmans, 2018). Gastmans's dignity-enhancing ethical framework and Eriksson's caritative theory support each other in their emphasis on holistic care, vulnerability, dignity, and respect. Eriksson provides abstract reflections on the what-question of ethics, Gastmans provides answers to the how-question, how to act in real-life situations.

According to Gastmans (2018), the increasing number of older people with dementia calls for new responsibilities to prepare for the future on both the individual and the societal level. Clinical developments regarding dementia prevalence, diagnosis, and treatment have resulted in significant new responsibilities for people with dementia to consider effects of the disease, quality of life, future care, and end-of-life care. What do they consider to be good care and what is their own responsibility in preparing for the future (Gastmans, 2013b)? In *Theories of Caring as Health* from 1994, Eriksson writes that the nurse should respect the human being as the unique individual she is and respect the right of the individual to shape her own life. To take responsibility for the life of another human being requires the capacity to enable the patient to take responsibility for her own life (Eriksson, 1994a).

The principles of biomedical ethics (Beauchamp & Childress, 2009), respect for autonomy, beneficence, non-maleficence, and justice have been the dominant guidelines for nursing ethics for decades (Gastmans, 2013a, 2013b). Respect for autonomy is at the forefront and cognitive capacity is important (Gastmans, 2018).



However, this approach does not fit dementia care practices. Instead, the focus needs to move from individual autonomy and self-determination to relational autonomy that takes the relationship between care-receivers, care-providers, and family members into account. The bond between these stakeholders is a prerequisite for the person's autonomy. This personalist approach sees the human person as a whole in himself with many dimensions as well as a part of and relating to the whole reality. (Gastmans & Lepeleire, 2008). Gastmans (2013a) calls for a further development of care ethics with the foundational ethical framework: dignity-enhancing nursing care. The three pillars of the framework are 1) the lived experience aspect, what IS, 2) the process-oriented dialogical-interpretative aspect, and 3) the normative aspect, what OUGHT to be (Gastmans, 2018). It is the lived experience of the patients, the whole care process, and the relationships between everyone involved in the care process that are important (Gastmans, 2013a, 2013b).

While principlism starts from autonomy, Gastmans's ethical framework starts from vulnerability. Vulnerability is the key-concept of the first pillar and the motivation for care (Gastmans, 2018). Due to the ambiguity and irrationality of people when it comes to decisions about end-of-life care, people are not always clear in their communication. People do not always understand each other, which makes interpretation necessary. In ethically sensitive dementia care practices ethical decision-making takes place in a dialogue with all stakeholders involved. The nurse enters into a relationship with the vulnerable person. With competency, responsibility, and attentiveness the nurse searches for the most appropriate and adequate care. Attentiveness means trying to understand what is happening with the other person. Care is seen as the key-concept (Gastmans, 2018). Communication and interpretation connect Gastmans and Eriksson as the ethical approach, the ethos of the nurse affects and determines how the nurse understands and interprets the needs of the patient, how she/he responds to and cares for the patient, how suffering is alleviated, and whether the patient receives a dignified death (Fagerström, 2019).

The normative fundamental ethical question is: why should we care for people with dementia? The following is the applied ethical question: what is good dementia care? There is a gap between what we say and what we do when it comes to dementia care. The care goal should be the promotion of the dignity of the person by providing good care in all dimensions. The key-concept of the third pillar is dignity (Gastmans, 2018). The dignity pillar also connects Gastmans to Eriksson. To violate the dignity of a human being is to remove vitality and hope as well as to cause suffering. A basic thought in all caring is to safeguard the dignity of the patient (Eriksson, 2010). Vulnerability can affect a person in all dimensions and results in dignity itself being threatened (Gastmans, 2018).

## 5.3 Person- and relationship-centered dementia care

Carl Rogers used the term ‘person-centeredness’ in his work on client-centered psychotherapy in the 1940s (Rogers, 1961) and since then providing person-centered care has become an important imperative in healthcare (Britten et al., 2020). The co-creation of care through the partnership between patients, families, and health professionals is the core-component of person-centered care (Ekman et al., 2015). Tom Kitwood (1993, 1997) was the first to emphasize personhood in dementia care and the first to use the term in the dementia care field, developing the concept of person-centered dementia care in response to the biomedical view of dementia (Edwardsson et al., 2008; Ballenger, 2006). The three core elements of personhood are relationship, uniqueness, and embodiment. The ethos of person-centered care contains specific elements, treating people as individuals, valuing people with dementia and their caregivers, encouraging a positive social environment, and looking at the perspective of the person with dementia (Brooker, 2003). The conceptual approach to care developed by Kitwood (1997) provides care staff with a way of thinking, acting, and caring according to principles that support personhood and well-being throughout the illness trajectory. The focus is more on how things are done, not on what is done (Kitwood, 1997) a focus that connects Kitwood to Gastmans.

Building on the work of Kitwood and Bredin (1992), Brooker (2003, 2006), Fazio et al. (2018) supports the following practice recommendations for person-centered care in dementia care:

- 1) Know the person living with dementia, her past and present values, beliefs, interests, likes, dislikes, and abilities. Use the knowledge to inform every experience and interaction.
- 2) Recognize and accept the person’s reality, see the world from the perspective of the person with dementia. Recognize behavior as communication and connect with the person in an empathetic and effective way.
- 3) Identify and support ongoing opportunities for meaningful engagement with the person with dementia, be present in the interaction.
- 4) Build and nurture caring and authentic relationships. The individuality of the person with dementia should be supported and the person treated with respect and dignity.
- 5) Create and maintain a supportive community for individuals, families, and staff, a supportive community provides opportunities for shared experiences, engagement, and autonomy.
- 6) Evaluate care practices on a regular basis and make changes when appropriate (Fazio et al. (2018)).

The dementia care practice recommendations of the Alzheimer’s Association build on the work of Fazio, Pace & Maslow (2018) and emphasize assessment as an ongoing care approach (Molony et al, 2018). Nolan et al. (2004) noted person-centered care indirectly focuses on independence and autonomy rather than

relationships. Nolan et al. (2004) take the relationship between the caregiver and the care recipient a step further by suggesting a triad with the nurse in a relationship with the person with dementia and their family. Each member of a dementia care triad needs to feel the senses of belonging, security, continuity, purpose, achievement, and significance (Nolan et al., 2004). The next development of person-centered care may be seen as relationship-centered care with more emphasis on the relationship between the care recipient and the caregiver (de Witt & Fortune, 2017).

## 6 Aim, research questions and design

The aim of the thesis is to describe a model for the ACP process in early-stage dementia care. The research questions are:

1. What type of ACP interventions for people with dementia are in use internationally and what is the feedback from people with dementia and their family caregivers? (Study I)
2. What are the views of people with dementia and their family caregivers on ACP and planning for future care? (Study II)
3. How do healthcare professionals in dementia care view ACP in dementia care? (Study III)

The thesis consists of three studies. The first study is a scoping review (N=6) with the aim to advance the state of knowledge about ACP interventions aimed at older people with early-stage dementia and to describe the effects of various interventions as well as the feedback on the interventions from this patient group and their family caregivers. The second study is a qualitative study where people in the early stage of dementia (N=10) were interviewed together with their caregiver spouses (N=8). The aim was to explore the view of people with dementia and their family caregivers on planning for future care. The third study is a qualitative focus group study with the purpose to investigate the views of dementia care professionals (N=17) regarding ACP for people living with dementia and their family members.

## **7 Methodology and methods**

A research paradigm refers to the basic sets of beliefs or philosophical assumptions that determine the perspective and the actions of the researcher (Lincoln et al., 2011). This thesis is anchored in the pragmatism research paradigm, as the overall aim of the study is to produce knowledge useful to all stakeholders and with the input of all stakeholders. Pragmatism is a fitting paradigm for patient-oriented research as the scientific method of inquiry is combined with values of social justice and democracy. Pragmatism is to be understood not only as a philosophical position but also as a set of philosophical tools valuable for addressing and solving practical problems in the real world (Creswell & Clark, 2011; Maxcy, 2003; Rorty, 2000). To address issues where complex social problems need multipronged approaches, pragmatists use the most appropriate research methods (Allemang et al., 2022).

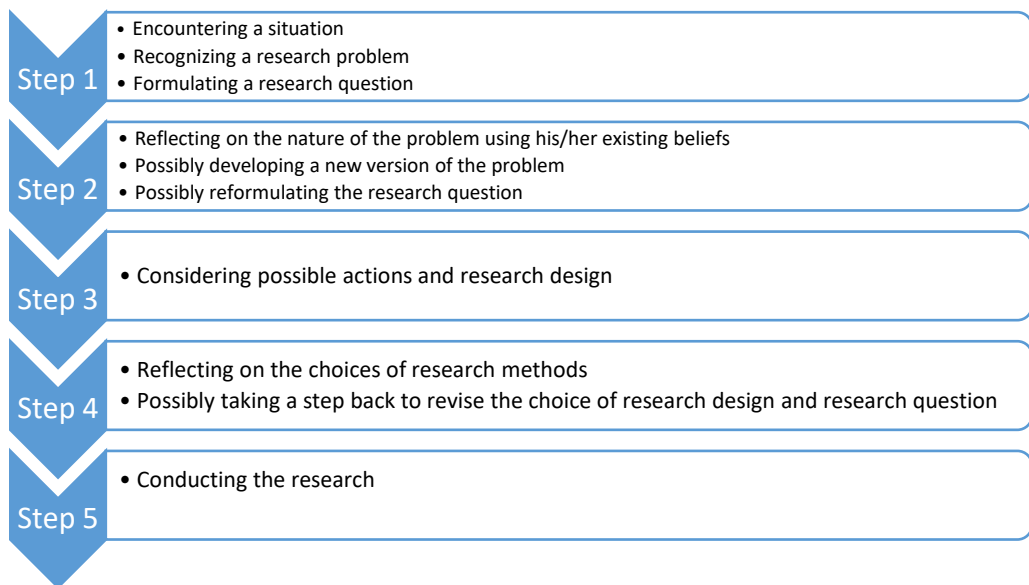
### **7.1 Pragmatism as overall study design**

From a pragmatic research standpoint, researchers ought to use the methodological and philosophical approach that is best suited for the specific research problem of interest (Tashakkori & Teddlie, 1998). The focus is not on the methods but rather on the research questions and effect of the research (Creswell & Clark, 2011). According to pragmatist epistemology, knowledge is always based on experience. The unique experiences of each person creates the unique knowledge of that person. However, much knowledge is created from socially shared experiences making much of knowledge socially shared as well (Morgan, 2014). Dewey (1931, 1938) saw inquiry as an investigation to understand part of reality, to change that part of reality, knowledge is needed. The primary objective of inquiry is the creation of knowledge for the sake of change and improvement (Goldkuhl, 2012).

Actions are central in pragmatism. According to pragmatists, knowledge is only meaningful when combined with action (Grayling et al., 2005). Action is a way to change existence, to change the world (Goldkuhl, 2012; Maxcy, 2003; Morgan, 2014). Central in the pragmatic approach to health research is the focus on issues and data important for decision-making and acting in a strong alignment with patient-centered outcomes research (Selby et al., 2012). Pragmatism aims to 1) create useful knowledge, 2) study whole systems in context, 3) understand research as continuous learning process, 4) focus on the social effects of research and interventions, 5) value the input of all stakeholders, 6) value the democratization of research and knowledge, 7) encourage the use of multiple methods, and 8) prioritize understanding over methodological or theoretical purity (Long et al., 2018). The importance of pragmatism for the development of nursing knowledge is emphasized by the goal- and problem-solving orientation in specific clinical situations in the practice discipline of nursing (Kim & Sjöström, 2006).

Pragmatism allows for mixed methods approach where both quantitative and qualitative methods contribute to addressing the research question. A pluralism of methods provides multiple perspectives to be structured and explored in various ways to in the end gain understanding (Long et al., 2018).

Dewey (1933) introduced a five-step model for understanding problem solving. Morgan (2014) later revised the model, illustrating a dynamic system of pragmatist research methodology. The five-step model is shown in Figure 1. Before proceeding to the final step of conducting the research, the researcher may move in several rounds from step to step, reformulating the research problem, the research questions, the research design, methods selections, and reflecting on choices made in a process called “abduction”. The abduction process is based on an if-when relationship. The researcher reaches a conclusion, “if you act in a particular way, then you are likely to produce a specific set of outcomes” (Morgan, 2014, emphasis in original). The pragmatist methodology means reflecting on the nature of a problem, on its possible solutions, on the nature of the possible solutions, and the likely action. The process of designing the research is connected to the core research question and the design concerns are connected to the method choices. The researcher’s beliefs, the shared beliefs of the research community, personal experiences, and experiences of others guide the researcher throughout the process (Morgan, 2014). When designing the current study, the researcher moved through the five-step model in the abduction process as described in the following chapter.



**Figure 1.** The five-step model for understanding problem solving (Dewey, 1933; Morgan, 2014)

The notion of pre-understanding developed originally within hermeneutics and states that knowledge is not developed from zero but relies on some form of prior understanding of the phenomena to be investigated (Gadamer, 1960/1994; Feher, 2016). Pre-understanding is unavoidable and guides our commonsense understanding. Pre-understanding affects knowledge development and can be used more deliberately and actively in research. When a researcher is very emotional about a theme, it may be difficult to gain enough critical distance for productive use of pre-understanding. (Alvesson & Sandberg, 2022). Alvesson and Sandberg (2022) propose a framework that “enables researchers more actively, systematically and explicitly to bring forward their pre-understanding as a positive research input alongside formal data and theory”. The framework suggests that the pre-understanding of the researcher can be brought forward as source of inspiration to think differently in relation to theory and data, to broaden the empirical base as an addition to formal data, and to evaluate the novelty and relevance of the knowledge being developed (Alvesson & Sandberg, 2022).

The author of this thesis started nursing studies in mid-life and came into the healthcare field with a certain degree of life experience. As a layperson, she had experienced the deterioration of close relatives suffering from dementia and relatives being cared for in nursing homes. The first workplace practices of the nursing studies took place in a long-term care ward with older people in the advanced stage of dementia. Patients often lacked individual care plans for end-of-life care, resulting in frequent intravenous treatment with antibiotics and/or fluids and at times referrals and transfers to acute care in the last weeks or days of life. The author decided to pursue continued training in palliative care with a focus on older people with multi-morbidities. In her master thesis focusing on communication in palliative care, the conclusion pointed to the concept of advance care planning in older people care as something important in palliative care in general and especially so in the care of older people with dementia. The research for this doctoral thesis can be described as pre-understanding driven research as pre-understanding has been used as the main input in generating research ideas and in making empirical claims. However, existing theory and empirical work have been used and consulted, and critical distance maintained.

The author’s identification of advance care planning in her master thesis can be seen as the first step in the Dewey-Morgan (1933; 2014) five-step model for problem solving; encountering and recognizing a situation as a research problem, a research problem beyond the current expertise of the researcher. In the second step, the author reflected on the nature of the problem using her existing beliefs and experiences. The author saw the nature of the problem as older people with advanced dementia not receiving comfort care and a ‘good death’ due to the lack of planning and communication about illness and care at the end of life. She also realized that the advanced stage of dementia was too late for involving the person with dementia in the care plan. In the third step, possible actions were considered and the potential research design. The author needed to educate herself about ACP in general and specifically ACP in dementia care. She also wanted to explore the

views of people in the early stage of dementia and the view of their family caregivers. Lastly, she needed the views of dementia care professionals in order to get opinions of as many stakeholders as possible. The viewpoint of the organization in the form of opinions from the management level and politically appointed decision-makers is missing, but it will be addressed in post-doctoral studies. In the fourth step, the best choice of methods was considered. The last and final step was the conducting of the research.

## 7.2 Description of the studies

The studies of the thesis are presented in Table 2 with aim, material, setting, and methods included.

**Table 2.** Studies of the thesis

<b>Study</b>	<b>Aim</b>	<b>Material</b>	<b>Setting</b>	<b>Methods</b>
I	This study aims to advance the state of knowledge about ACP interventions aimed at older people with early-stage dementia, and to describe the effects of various interventions as well as the feedback on the interventions from this patient group and their family caregivers.	The search identified six studies describing interventions aimed at people with dementia in the early phase of dementia. The studies included feedback from the people with dementia themselves.	Three studies took place in a home setting. Three took place in a clinical setting.	Scoping review as described by Arksey and O'Malley (2005) and further advanced by Levac, Colquhoun and O'Brien (2010) as well as by Peters et al. (2015)
II	This study aims to explore the view of people in the early stage of dementia on planning for future care. How do they describe and understand their current circumstances and	10 interviews with people with dementia. During eight of the interviews, the person with dementia was accompanied by his/her spouse who also participated in	The own homes of the participants	The study is a qualitative interview study with an inductive approach and a semi-structured interview guide. The material was analyzed



	their ability to affect their future situation?	the interview and gave his/her own views. Two people with dementia were interviewed without a caregiver spouse. Field notes, observations, and reflections on the interview.		using a modified version of the Qualitative Analysis Guide of Leuven (Dierckx de Casterlé et al., 2012; Dierckx de Casterlé et al., 2020).
III	This study aims to explore the views of dementia care professionals on advance care planning for people with dementia.	Three focus group interviews with dementia nurses and geriatricians. The majority of professionals participating were registered nurses (n = 13), geriatricians (n=2), one social worker, and one professional of applied gerontology. Field notes, observations, and reflections on the interview.	The own venues of the participants	The study is a qualitative study with semi-structured focus group interviews conducted with dementia care professionals. The material was analyzed using a modified version of the Qualitative Analysis Guide of Leuven (Dierckx de Casterlé et al., 2012; Dierckx de Casterlé et al., 2020).

## **7.3 Study participants**

Different strategies were used to recruit study participants. Study I is a review study and thus had no participants. In Study II, older people with dementia and their family caregivers participated. Dementia care professionals participated in Study III.

### **7.3.1 Study II: Interview study**

The dementia nurses from memory clinics in four municipalities were asked to assist in the recruiting of people with dementia, as they know their clients well. Study information and recruitment forms were mailed to 95 people in four municipalities. The recipients were all living in their own homes as opposed to assisted living facilities or nursing homes. None of the participants had any regular home care services at the time of the study. Due to confidentiality reasons, the research team did not have access to the client registers. The dementia nurse determined which of her clients would receive the study information and recruitment form. The decision was based on the nurses' own assessment of the cognitive abilities and illness insight of the person with dementia, as understanding of the purpose of the interview and ability to give informed consent were necessary. The dementia nurses were asked to keep careful records of the number of recruitment forms mailed out as well as the age span of the recipients. A certain minimum number of points achieved in MMSE or CERAD testing was not set as a criterion as there is disagreement about whether these fully indicate and assess the capabilities of the person with dementia to understand and participate in an interview situation (Bassett, 1999; Kim & Caine, 2002; Gregory et al., 2007). A limit was not set on time since diagnosis as the progress of dementia is highly individual and time since diagnosis is not an indicator of ability to participate in a study (Stages of Alzheimer's, 2021). Study participant characteristics are illustrated in Table 3. The published article contains more details.

**Table 3.** Participant information

Participant	Gender	Age	Time since Diagnosis	Diagnosis	CG present	CG gender	Age
1	Female	85	1 year	Alzheimer's	X	Male	89
2	Male	79	6 months	Unknown	X	Female	71
3	Male	82	3.5 years	Alzheimer's	X	Female	79
4	Male	71	3 years	Alzheimer's	X	Female	67
5	Female	76	1 month	Unknown		-	-
6	Male	82	2 years	Alzheimer's	X	Female	80
7	Female	83	5 months	Alzheimer's		-	-
8	Female	75	1 year	Alzheimer's	X	Male	81
9	Female	65	3 months	Alzheimer's	X	Male	69
10	Male	68	4 years	Benson's syndrome	X	Female	65

### 7.3.2 Study III: Focus group interviews

An invitation to participate in the study was sent by e-mail to 29 dementia care professionals within a Finnish welfare district in Western Finland. Researcher networking was utilized to identify interviewees and recruitment was purposeful. The participants work within a primary care area with a wide geographical spread. The interviews were arranged in the own venues of the participants. In two of the focus groups, the participants were co-workers. In the third group, most of the participants were co-workers and other participants in the group were acquainted with each other from before. The inclusion criteria for participants were experience in outpatient dementia care and willingness to participate in the interview. Seventeen of the invitees participated in the study. The majority of professionals participating were registered nurses (n = 13), geriatricians (n=2), one social worker, and one professional of applied gerontology. All participants were female. All participants had worked with dementia clients in memory clinics and/or in a home care setting. Work experience in dementia care ranged from 20+ years to 1,5 years. Nine of the nurses had continued education in dementia care.

## **7.4 Data collection**

### **7.4.1 Scoping review**

The purpose of the first study was to advance the state of knowledge about ACP interventions aimed at older people with early-stage dementia, and to describe the effects of various interventions as well as the feedback on the interventions from this patient group and their family caregivers. The number of recently published scientific articles on ACP, in combination with the development of many national and regional ACP-programs, supported the rationale for conducting a scoping review. The method used for the study is scoping review as described by Arksey and O'Malley (2005) and further advanced by Levac, Colquhoun and O'Brien (2010) as well as by Peters et al. (2015). As ACP program evaluation reports were expected to provide part of the data material for the current study, a scoping review was determined to be the most relevant study method. Electronic databases, reference lists of scientific articles and book chapters, Google and Google Scholar were searched to generate data for the scoping review. The search started with a wide perspective to gain a broad picture of the field of ACP studies related to dementia care. The aim of the search was to identify ACP programs and interventions. Literature searches were conducted according to Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines (Tricco et al., 2018). The search terms used were 'advance care planning dementia', 'complex advance care planning', 'advance care planning AND early dementia', 'advance care planning AND community setting', and 'advance care planning intervention AND dementia'.

### **7.4.2 Interview Study**

To explore the views of people with dementia and their family caregivers on planning for future care, a semi-structured interview was seen as the most appropriate form of data collection for the second study. Interviews are especially appropriate when dealing with sensitive issues where participants may not want to discuss the topic in a group environment (Gill et al., 2008). Methods of data collection in qualitative research include observations, visual or textual analysis, and interviews. The most common methods in healthcare research are interviews and focus groups (Britten, 1999; Legard et al., 2003). The purpose of the research interview is to provide a deeper understanding of phenomena by exploring the experiences, views, motivations, and beliefs of people on specific matters (Silverman, 2000). Research interviews can be unstructured, semi-structured, or structured (Gill et al., 2008). Semi-structured interviews are most commonly used in healthcare research and include several key questions that define the areas to be investigated. The format also allows for flexibility and for diverging to pursue responses in more detail (Britten, 1999).

Data was collected from July 2018 to April 2019. The interviews lasted between 28 minutes and 85 minutes with the average interview lasting about 60 minutes. The interviews were recorded with the permission of the person with dementia and the caregiver spouse (when present), and transcribed verbatim. Immediately after each interview, the interviewer recorded field notes, observations, and reflections on the interview. Field notes were also transcribed verbatim. Box 1 provides the semi-structured interview guide. The questions were informed by the results of study I, results from previous research, and a person-centered approach.

**Box 1.** Semi-structured interview guide.

Can you tell me about the information you have received about your illness?

- Did you understand the information? Is there something you would like to know more about?
- What was your experience of the care received in connection with the investigation and when you received your diagnosis?

What is your opinion on planning for future care already in this early stage of illness?

Have you thought about how you would want to be cared for at the end stage of the illness?

- Have you talked to anyone about it?
- Do you want to talk to care staff or your doctor in advance?
- Do you have experience of dementia in close relatives or friends?
- How have you been affected by that experience?

Who do you want to make decisions for you when you are no longer able to make your own decisions?

- Does that person know your wishes?
- Which role do you want your family to have in decision making?

What is your view on living wills?

- Would you want your wishes to be documented in a living will? Why? Why not?

Would you like to add something?

How did it feel to talk about this?

### 7.4.3 Focus group interviews

For the third and final study, the focus group interview method was chosen. Focus groups have a lot in common with less structured interviews. A focus group is organized for research purposes and the discussion is guided and monitored by the researcher (Kitzinger, 1994; Morgan, 1998). In the last decades, the use of focus

group interviews in qualitative health research has been increasing. Focus groups have the potential to provide in-depth information in a relatively short period of time (Krueger, 2002; Gundumogula, 2020). The participants are selected based on their experience and/or knowledge about the specific matter at hand (Anderson, 1990). As focus groups are useful for gathering information on collective views and on what lies behind those views, it was deemed an appropriate method for the third study where the views of dementia care professionals were investigated.

In the invitation to participate in the study, introductory questions and themes were listed. Box 2 provides the introductory questions and themes. The questions were based on the results of sub-studies I and II and the results from previous research.

**Box 2.** Focus group interview introductory questions.

In what phase of dementia illness should ACP be initiated?

Whose responsibility is it to initiate ACP in dementia care?

What are the ethical aspects in conducting ACP as well as in refraining from ACP?

How could ACP be organized to be beneficial for the person living with dementia and his/her family caregiver?

Data were collected by two researchers (the first and the second author) in August 2022 with three semi-structured focus group interviews. The focus groups included four, five, and eight participants respectively. The two geriatricians who participated were included in the group with eight participants. All interviews proceeded according to a similar structure starting with a description of the PhD project and proceeding to open-ended questions. The first author, who possesses extensive ACP knowledge, functioned as moderator posing questions and moving the discussion forward while the second author observed, took notes, at times asked follow-up questions, and in conclusion presented a summary of the interview. After each session, the second author debriefed with the moderator and gave feedback on the session. Each focus group interview was digitally recorded and lasted an average of 1 hour 5 minutes. A research assistant performed verbatim transcription of the interview recordings.

## **7.5 Data analysis**

The choice of methods for data analysis will be presented in the following chapters. The strengths and limitations of each method will be further explored in the chapter 11 Methodological considerations.

### **7.5.1 Study I**

The methodological framework for conducting a scoping review consists of six stages. In stage one, a broad research question with a clearly articulated scope of inquiry is recommended (Levac et al., 2010; Peters et al., 2015; Peters et al., 2020). The following steps are to identify relevant studies, select studies, chart, collate, summarize, report the result and, finally, optional consultation (Arksey & O'Malley, 2005; Levac et al., 2010). When using the scoping review method, the extracted data is charted and presented in a descriptive and logical summary of the results (Peters, et al., 2015, Peters et al., 2020). The data is not analyzed in, for example a thematic analysis as qualitative content analysis is not considered necessary in a scoping review.

### **7.5.2 Study II**

A modified version of the Qualitative Analysis Guide of Leuven (QUAGOL) was used for the data analysis (Dierckx de Casterlé et al., 2012; Dierckx de Casterlé et al., 2020). The interview transcripts were thoroughly read and commented on using the Word comment function. Field notes taken immediately after each interview were used as a base for the narrative reports. The narrative reports were used to create conceptual interview schemes, which produced a master list of concepts. In the second part of the process, each interview was read again. The researcher proceeded to an across-case analysis of the concepts where isolated concepts were integrated into a meaningful conceptual framework in response to the research questions. The research team discussed and evaluated the list of concepts. In the final step, essential and common concept and themes were described and integrated into a meaningful conceptual framework or story line forming a complex story in response to the research questions. The framework was verified against all interviews and interview schemes.

### **7.5.3 Study III**

A modified version of the Qualitative Analysis Guide of Leuven (QUAGOL) (Dierckx de Casterlé et al., 2012; Dierckx de Casterlé et al., 2020) was used for the two-step analysis. In this modified version, a software program for analysis was not used. As

the interviews were conducted in both Finnish and Swedish, the use of a software program for coding was deemed inappropriate. In the first part of the process, the interviews were thoroughly read and re-read. The researcher extracted significant statements in the interviews. The interviews and the field notes served as a basis for the narrative reports. The narrative reports and significant interview statements were used to create conceptual interview schemes where the preliminary analysis results were discussed within the research team. The interviews were reread with the conceptual interview scheme in mind to verify that the contents of the scheme reflected the most important concepts and provided an answer to the research questions. The schemes were adapted and refined as needed in an iterative dialogue with data. In the second part of the process, common themes were identified in within-case and cross-case analyses. The conceptual interview schemes produced a master list of nonhierarchical concepts conveying the essential meaning of the dementia care professionals' viewpoints.



## 8 Ethical considerations

Involving people with dementia in research gives rise to various ethical issues and concerns (Götzelmann et al., 2021). People with diminishing cognition have rarely been heard from in research despite being a group that is growing. People with dementia have been left out of research or their participation minimal (Skovdahl & Dewing 2017, Dewing 2002). People with dementia account for a large minority group within all populations worldwide and need to be treated as citizens with personhood (Bartlett & O'Connor, 2010). In the late 1990s and early 2000s, with the increased interest in person-centered care, there was a growing recognition in the research community that people with dementia should be included in research as participants and not merely as subjects or objects. It is possible to include people with dementia in research and it is important to do so (Hellström et al., 2007). During the First WHO Ministerial Conference on Global Action Against Dementia 2015, participants stressed the importance of giving people living with dementia and their family caregivers a voice in the creation of policies, plans, interventions, and actions (WHO, 2015).

In 2014, the Scottish Dementia Working Group (SDWG) published an article on the core principles for involving people with dementia in research. SDWG is an international campaigning group of people with dementia. The core principles address the value and involvement of people with dementia in research, lived experience as valid knowledge, the safety of the person with dementia both physically and emotionally, the accessibility of the research, researcher training, and sensitivity about the experience of time and time management of the person with dementia (Skovdahl & Dewing 2017, Scottish Dementia Working Group Research Sub-Group UK 2014). Murphy et al. (2015) identified key strategies for the meaningful inclusion of people with dementia in qualitative research. The strategies focus on gaining consent, maximizing responses, telling the story, and ending on a high note.

The thesis is comprised of three studies, each with its own ethical challenges and approaches. All researchers operating in Finland must take into consideration the ethical principles of research with human participants and within the human sciences. The ethical principles of The Finnish Advisory Board on Research Integrity (2019) have guided the current thesis. An approved application for permission to conduct the PhD project with its three sub-studies was obtained from the Board for Research Ethics (FEN) at Åbo Akademi University. The application included an approved plan for data protection and storage as well. Ethical approval was not required for study I, a scoping review. The included studies had been conducted with their own ethical approval and were considered secondary data.

People with dementia were asked to participate in study II, making the study ethically challenging. For study II, permission was granted by the healthcare committee of each municipality participating in the study. Participants were

recruited specifically among people in the early stage of dementia that the dementia nurse deemed capable of understanding the purpose of the study and participating. Details about the recruitment process can be found in the published article. Hellström et al., (2007) discuss the issue of informed consent in dementia research. Obtaining informed consent is of considerable concern when involving people with dementia in the research process. Dewing (2002) argues that there can be no one method for inclusionary consent as the remaining cognition and non-cognitive ways of knowing must guide and inform the research. Using a simplified consent form with plain language can improve understanding (Dunn & Jeste, 2001, Kim & Kim 2015). In study II, the researchers consciously used plain language in the consent form and the interviewer reviewed the consent form with each participant and their caregiver spouse before the interview. Participants were informed of their right to withdraw at any time, interview confidentiality, how their identity would be protected, and about the recording of the interview. They were told about the potential discomfort experienced when discussing illness progression and end-of-life care. At the conclusion of the interview, the participants were told they could contact the researcher with further questions or concerns. They were also reminded of the local memory clinic and dementia nurse as support systems.

For study III, permission to conduct the study was granted by the Research, development and innovation department of the Wellbeing services county in which the study took place. All participants received both written and oral information about the aim of the study. They were informed of the voluntary nature of participation, that the interviews would be recorded, and that results would be presented on a group level so that individual participants could not be identified. Participants gave their written informed consent before the interviews. Detailed background data was not collected due to the small sample size. Data storage is an important aspect of ethical research. During all stages of the study, the privacy of the participants should be protected. In the handling of the data from sub-studies II and III, personal information such as names and contact information were kept separate from transcripts. Voice recordings and transcripts were stored in password protected computer files. In the transcripts, any personally identifiable information was removed. Only the PhD candidate and her supervisors had access to the files. The participants in the studies cannot be identified through reading of the published articles.

In study II, the participants were interviewed individually or together with a caretaker spouse. Participants were not informed about the other people participating in the study. In study III, the focus group interview setting made keeping anonymity among participants difficult. However, the risks of participating in can be considered low as the themes and topics related to the focus group interview are everyday work experiences in dementia care. In a focus group interview situation, it is also possible for participants to choose to refrain from talking about sensitive and/or personal information. The overall aim of the author of the current thesis and accompanying articles has been to ensure that the

research has been conducted responsibly and transparently. Throughout the research project, attention has been paid to confidentiality and participant autonomy as dementia and advance care planning for end-of-life care could be considered sensitive topics. All participants were informed of the right to withdraw from the studies at any time for any reason.

Fabrication, falsification, and plagiarism are different types of possible misconduct in research and in reporting research results. A thorough and careful description of the steps of the analysis process creates transparency. The work of other researchers and scholars has been respected by citing their publications in an appropriate manner. Principles regarding authorship have been followed with all authors having contributed significantly to the design of the studies, analysis of data, and drafting of articles. The thesis and the resulting articles from the sub-studies have been peer reviewed before publication. Financial support received for the thesis and no conflicts of interest have been declared and provided separately within the published articles. For study I, the scoping review, the study was reported according to PRISMA-ScR guidelines (Tricco et al., 2018). Sub-studies II and III were reported with conscious respect for the lived experience of the participants.

## **9 Findings of the studies**

The findings of the sub-studies are presented in the following chapters and lastly in the form of a results matrix.

### **9.1 Findings of study I**

In study I, a scoping review identified six studies describing ACP interventions for early-stage dementia patients. The six studies were charted and summarized. A relatively wide range of intervention types such as counselor sessions (Orsulic-Jeras et al., 2016; Whitlatch, 2006), seminars (Lewis et al., 2015), and video images (Volandes et al., 2009), among others are described in the studies. Most of the study participants (people with dementia and family caregivers) were affected in mostly positive ways and indicated satisfaction with the interventions used despite the significant differences between the interventions tested in the included studies. Effects connected to the interventions include relief from having discussed the future, an improved person with dementia-family caregiver relationship (Lewis et al., 2015; Orsulic-Jeras et al., 2016; Poppe et al., 2013) increased confidence about decision-making and feeling better prepared for the future Orsulic-Jeras et al., 2016; Poppe et al., 2013). Negative effects were reported from one study where some of the people with dementia found it difficult to discuss the future without knowing what the future will bring and the ACP discussion disheartening (Poppe et al., 2013). A supportive structure was helpful for both people with dementia and family caregivers. When describing lessons learned from a pilot study of the patient-centered ACP interview, Briggs (2004) states that “listening is the intervention”. The feeling of being listened to and engaged in the care planning seems to be of most importance, not the intervention design itself.

### **9.2 Findings of study II**

The results from study II show that the views of people with dementia are characterized by a complex storyline involving tensions and movement within the themes of wants, beliefs, and levels of insight. Participants wanted to think about the future but also wanted to live in the here and now. The people with dementia and their spouse caregivers who participated in study II, acknowledged a need to plan but also expressed a wish to live in the present and not bother themselves too much with dreary thoughts. Thinking about the future elicited worries and fears but at the same time, there was hope that the illness would somehow not get worse. Some of the participants had thoughts about other illnesses leading to death before the dementia worsened, something that would eliminate the need to plan for future care. Participants with dementia wanted and trusted their spouse to care for them, but they did not want to be or become a burden. There was a belief and trust that

society would care for them if needed but simultaneous doubt about future access to a place in a nursing home and the quality of older people care in general. Most of the people with dementia were aware of lost functions, but they were at times not aware of how the illness affected them and their caregiver spouse. At the end of the interviews, some of the caregiver spouses expressed gratitude for the opportunity to talk about their situation and for the attention, they felt people with dementia were given throughout this study. The study participants did not feel that it was a negative or burdening experience to talk about end-of-life care and ACP.

### **9.3 Findings of study III**

The findings from study III are one main theme and three sub-themes describing the views of dementia nurses and geriatricians on ACP in dementia care. The main theme is the 'perfect storm' with sub-themes connected to the person with dementia, the care process, and to the care professional. The participating dementia nurses and geriatricians expressed a generally positive view of ACP in dementia care, but at the same time held a number of views about favorable and unfavorable factors, which affect the conditions for conducting ACP. The favorable factors concern creating a trusting and caring relationship, getting to know the person with dementia and their family, using intuition and sensitivity in the timing of the ACP conversation, as well as receiving support in the form of coaching and time to reflect with co-workers. The unfavorable factors are the nature of the illness and the associated stigma, unclarity in the suggested care path with inadequate guidelines for ACP, the demands placed on dementia nurses and geriatricians, as well as insufficient resources.

### **9.4 The results matrix**

The results matrix presents the findings in condensed detail, as significant statements related to the person with dementia, the dementia care process, and to the dementia care professional, have been collected in the matrix.

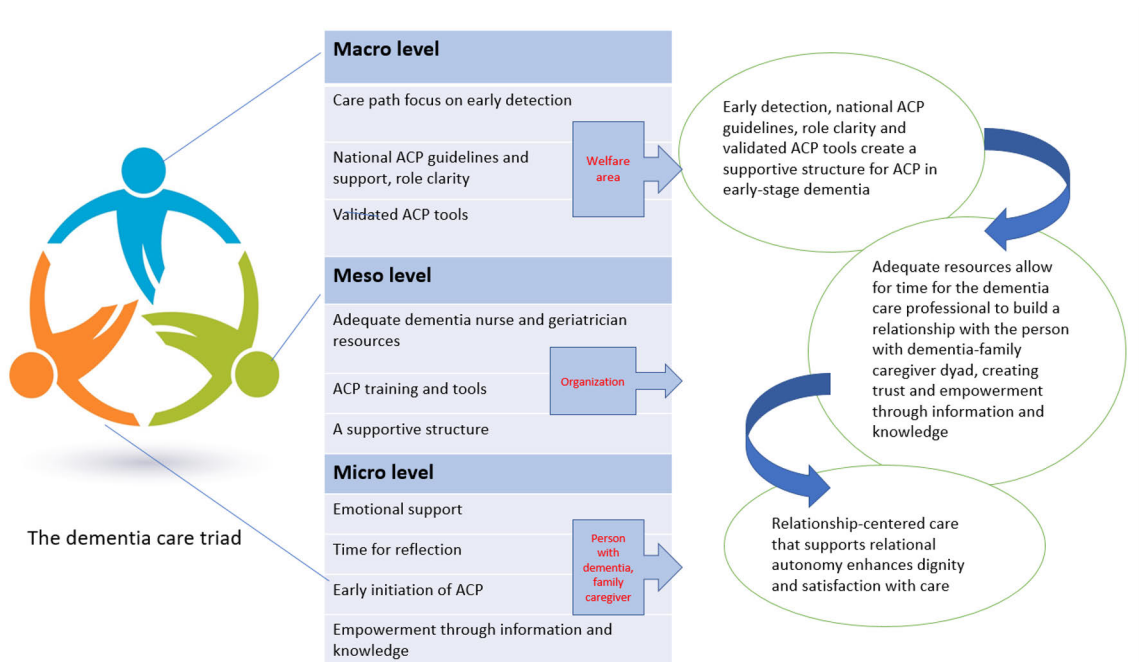
**Table 4:** Results matrix.

Source	Findings connected to the person with dementia	Condensation
Study I	Effects of ACP interventions: More in control of the situation Improved family relationships Overall relief from having discussed the future Increased quality of life More coping strategies Feeling dispirited and finding the topic difficult to discuss.	General feedback on ACP interventions is <b>positive</b> , several positive effects including <b>relief</b> associated with having taken part
Study II	To not want to think about or be reminded of what the future might hold A need to plan for the future A wish to live in the present Take spousal help for granted To not want to be a burden Personal experiences of the dementia illness and death of relatives or friends Lacking knowledge about dementia	People with dementia and their family caregivers have <b>mixed emotions</b> about planning for the future, <b>rely on their families</b> for support and at times <b>lack knowledge</b> about their illness and its progression
Study II	None of the participants felt that it was a negative or burdening experience to talk about end-of-life care. Some of the spouse caregivers expressed gratitude for the opportunity to talk about their situation and for the attention.	Planning for future care was not felt to be a burden, family caregivers appreciate the <b>opportunity to talk</b>
Study III	Assessment and diagnosis late in the disease trajectory Patients lacking knowledge about dementia Patients denying illness	The nature of the illness creating <b>barriers</b> to ACP
Findings connected to dementia care process factors		
Study I	A supportive structure is helpful in difficult discussions. The feeling of being listened to and engaged in the care planning is the most important, not the intervention design itself.	<b>Listening</b> is the intervention. A <b>structure</b> is helpful in the discussion
Study III	Dementia care professionals agree that ACP should be introduced early. The first time one meets the person with dementia is not the right time. The first follow-up visit after 4-6 months is a better time.	<b>Timing</b> is a challenge, what is too soon, what is too late
Study III	The living will form is not always completed together with the person with dementia unless he/she requests it. There is no easy way to document the wishes of a person with dementia in a quickly visible manner.	Patients are at times left <b>alone</b> with the forms. Documentation challenging.
Study III	Study participants stated that a checklist would not work as each person with dementia is an individual.	A checklist would not work in this care context

Study III	The visits with a physician are limited to one or two visits; the responsibility for ACP falls to the dementia nurse.	<b>Clarity</b> about roles and <b>responsibility</b> is lacking
Study III	Too many clients reduce time for deeper conversations. Time for reflection and the support of co-workers was seen as important in facilitating ACP. The time to build a trusting relationship was seen as a prerequisite for introducing conversations about sensitive issues.	<b>Time for building a relationship</b> with clients, <b>time for reflection, support</b> from co-workers are necessities for ACP
<b>Findings related to dementia care professionals</b>		
Study 1	Family caregivers noted the importance of staff style and skill.	People with dementia and their family caregivers noted the importance of <b>staff skill and training</b>
Study III	Intuition and sensitivity to the emotions of the person with dementia and their family caregivers when approaching sensitive issues. Conscious or unconscious avoidance of difficult conversation topics with people with dementia. The need to be grounded in oneself to find the courage to initiate such conversations.	Using <b>oneself as a tool</b> in a care context requires <b>self-knowledge</b> and awareness of potential avoidance
Study III	Insecurity related to role confusion Lack of knowledge about ACP, lack of support and the lack of a strong base to stand on for ACP. More support and training in how to approach ACP and when to do so. Not enough training to handle dementia patients in acute psychological crisis caused by a dementia diagnosis.	There is a lack of clarity about roles, <b>lack of ACP knowledge, lack of support</b> and a base for ACP.
Study III	A fear of saddening their patients with ACP conversations. Speaking about the end of life and living wills too soon ACP conversations would lower the quality of life for their patients.	Speaking about plans for end-of-life care would be <b>saddening</b> for people with dementia
Study III	Study participants: a living will form, and lasting power of attorney should be a natural part of every person's life and something that everyone, whether ill or not, should complete and document, preferably before reaching old age.	Advance directives are something everyone should have

## 9.5 The Advance Care Planning model for the Finnish early-stage dementia care

When describing the role of abductive reasoning for modeling competence, Upmeier zu Belzen and colleagues (2021) state “abductive reasoning begins with the perception of a phenomenon, for which the step of data collection takes place in an exploratory or theory-based manner” (Upmeier zu Belzen, et al., 2021). With the support of a knowledge base and observations, abductive reasoning can be used to generalize a conclusion (Baral, 2000). In an abductive reasoning process, the results of the three studies have been combined with the findings from previous studies and reflections on theoretical perspectives to present an ACP model for the Finnish early-stage dementia care context. The model is presented in Figure 2.



**Figure 2.** An ACP model in early-stage dementia care

The person with dementia, the family caregiver and the dementia nurse as separate, yet connected. The family caregiver and the person with dementia share a vulnerability that calls for and motivates the dementia nurse to care. The dementia nurse is tasked with three relationships, the one with the person with dementia, the one with the family caregiver separately, and the one with the dyad.

There are prerequisites needed to achieve good dementia care, a relationship-centered care. The dementia nurse needs different types of resources to be able to



provide good care. Supporting ACP on all levels of healthcare by providing adequate dementia nurse resources to reduce the number of clients per nurse, increasing geriatrician resources, supporting the dementia care professionals emotionally, and developing and providing ACP training and tools for ACP are also prerequisites. Relationship-centeredness means listening to the person with dementia and their family caregiver, respecting the ambiguity and anxiety connected to thoughts on end-of-life care, engaging the person with dementia and family caregiver dyad in planning and decision-making, empowering the person with dementia and family caregiver dyad through information and knowledge, and advocating for the person with dementia. A supportive structure allows for focusing on ACP in early-stage dementia through early detection and early ACP initiation while the person with dementia retains self-determination and decision-making capacity. The result of the supportive structure is relationship-centered care where relational autonomy supports self-determination and enhances dignity for all members of the triad. Satisfaction with care, contentment, relief, a sense of security, and improved end-of-life care are part of enhanced dignity. On the other hand, an undeveloped structure and inadequate resources contributes to factors that may lead to suffering related to care, missed care, and a loss of dignity. These factors will be further discussed in Chapter 10.6.

## 10 Discussion

The aim of the study is to present a model for the ACP process in early-stage dementia care. The initiative to the study came from the question: what can be done to improve end-of-life care for people with dementia? The research questions are: what type of ACP interventions for people with dementia are in use internationally and what is the feedback from people with dementia and their family caregivers? What are the views of people with dementia and their caregivers on ACP and planning for future care? Lastly, how do dementia care professionals view ACP in early-stage dementia care?

To the author's knowledge, this is the first PhD thesis on ACP in dementia care in the Finnish healthcare context. The perspectives of three different dementia care stakeholders have been analyzed and combined. The consensus is that ACP is important and that clients need to be diagnosed in an earlier stage of the illness trajectory. Trust is created by the prerequisites for relationship-centered care. Self-determination and decision-making capacity diminish as the illness progresses but relationship-centered care remains. The thesis provides an in-depth discussion of ACP in early-stage dementia care and its relation to supported self-determination, relationship-centered care, relational autonomy, and enhanced dignity. The thesis also shines a light on the resources needed and necessary steps for enabling adherence to the Finnish Medical Society guidelines for good dementia care.

The guidelines of the Finnish Medical Society (Duodecim) list best care practice steps as follows: 1) the dementia diagnosis should be explained to both the person with dementia and the family caregiver, 2) a care plan should be made after diagnosis, 3) symptom-based medication for progressive dementia needs follow-up, 4) expertise is needed for anticipation and treatment of behavioral symptoms, 5) there needs to be a holistic approach to the general health of the person with dementia, including an assessment of nutritional status, 6) the following documents should be part of the care; guardianship and lasting power of attorney as well as a living will (Current care guidelines, 2021). The guidelines mention advance directives, lasting power of attorney, and wills. The guidelines recommend that a living will should be made while the dementia is in the early stage to guarantee that the wishes and values of the person with dementia are respected. However, the guidelines do not offer detailed guidelines and tools for ACP.

The study consists of three sub-studies. The first study created knowledge about ACP interventions aimed at older people with early-stage dementia and knowledge about the effects of various interventions. In the second study, a qualitative study, the views of people with early-stage dementia and their caregiver spouses on planning for future care, were explored. The third study investigated the views of dementia care professionals (mostly dementia nurses) regarding ACP for people living with dementia and their family members. The combined findings of the sub-

studies demonstrate the aspects of ACP in dementia nursing care and the multiple forces and unfavorable circumstances coming together simultaneously, making ACP in early-stage dementia a challenging process. The scope and findings of this thesis will be discussed in relation to the results of the sub-studies, to the theoretical perspectives, and to international and national guidelines. The combined results of the three sub-studies describes the prerequisites for an ACP model in the Finnish early-stage dementia care context: a supportive structure, relational autonomy, and relationship-centeredness. These prerequisites have different meanings for the stakeholders in dementia care.

## **10.1 The importance of equality and human rights of people with dementia**

The United Nations (UN) defines human rights as “rights we have simply because we exist as human beings” and they are inherent to us all regardless of any status such as nationality, sex, ethnic origin, color, religion, or language (Universal Declaration of Human Rights, 1948). During the First WHO Ministerial Conference on Global Action Against Dementia in 2015, Kornfeld-Matte, the independent expert on the enjoyment of all human rights by older person noted the importance of adopting a human rights-based approach to people with dementia. The dignity, needs, and wishes of people with dementia are to be protected and respected in all phases of the illness (Kornfeld-Matte, 2015). In 2016, Kornfeld-Matte spoke again of the “critical need to promote a human rights-based approach to the care of older persons in general, and those with dementia and in need of palliative care, in particular” (Kornfeld-Matte, 2016).

Related to the equal treatment of people with dementia, is the enjoyment of legal capacity on an equal basis with others. Legislation is needed that ensures informed consent to treatment, supported decision-making, and procedures for implementing advance directives (WHO, 2015). In 2021, the UN Independent Expert on the enjoyment of all human rights by older persons visited Finland to identify good practices and gaps in the implementation of existing policies and laws relating to the human rights of older people. The UN independent expert found that legislation on promoting the right the self-determination in health and social services is limited with very few provisions on restrictions of the right to self-determination or fundamental rights in general. It was also found that dementia is viewed as an age-related issue and not as a disability. The UN independent expert concluded that the goals for the future should be a person-centered approach and the inclusion of all older people in specific measures. Finland is encouraged to advocate and apply a human rights-based approach in relation to older people (United Nations Human Rights, 2022). Viewing dementia as an age-related issue and not as a disability has also been noted in an article by Hoppania et al., (2017) discussing the Act on Supporting the Functional Capacity of the Older population and on Social and Health Services for Older Persons (2012). The Act (2012), while

ambitious and significant, has left people with dementia at a disadvantage. The disadvantaged state of people with dementia is not unique for Finland. Dementia Alliance International (DAI) has on a global scale called for the recognition of dementia as an invisible disability (Dementia Alliance International, 2016).

In 2017, Alzheimer Europe published a position paper on the legal rights and protection of people with dementia. The position paper recommendations are based on respect for human rights. The importance of an early diagnosis is a key element in respecting the human rights of people incapacitated by dementia. Knowledge of the diagnosis is essential for decision-making. Among the guiding principles of the position paper are the maintenance and enhancement of autonomy, that the range of capacities and incapacities should be assessed, capacity seen as relating to specific decisions, and that decisions about proxy decision making should be made by the person whilst still mentally capable (Alzheimer Europe, 2017).

According to the European Dementia Monitor 2020, in Finland there is a legal framework for advance directives, legal mechanisms for people to appoint healthcare proxies and financial proxies (European Dementia Monitor, 2020). The national quality recommendations for palliative care and end-of-life care published in 2022 by the Finnish Institute for Health and Welfare (THL) state “all people have the right to high-quality palliative care regardless of their age, diagnosis, cultural background or place of residence”. The recommendations provide an important step forward in the development and improvement of palliative care in Finland. However, THL has found that there are great regional variation and considerable deficiencies in the quality and availability of palliative care, end-of-life care, and staff competence (Saarto et al., 2022). In the recommendations, people with dementia are not mentioned as requiring special attention when it comes to ACP and the quality recommendations do not give advice or guidelines about ACP at the grassroots level.

## **10.2 The ethical complexities of Advance Care Planning**

The underlying goals of ACP have been under development and diversification since the 1990s when the first accounts of ACP were published. More patient groups and even healthy individuals are included. In a 2020 literature analysis, the range of underlying goals that comprise the legitimacy of ACP were identified as respect for individual patient autonomy, improvement of care quality, strengthened relationships, preparation for end-of-life, and reduction of overtreatment. Each underlying goal has corresponding objections to consider. Accomplishing all underlying goals might not be possible and there may be conflicts between the interests of different stakeholders. An open discussion and a balancing and prioritizing of goals may be necessary (Fleuren et al., 2020). The ethical complexities of ACP are heightened in dementia care with the issue of timing and

cognitive decline (Cotter et al., 2017; Harrison Denning, et al., 2011; van der Steen, van Soest-Poortvliet et al., 2014). While establishing preferences and wishes in advance may provide a sense of control, it can also paradoxically feel like relinquishing control and preventing deviations from made plans. ACP is further complicated as preferences may change as the condition progresses and family members may find it difficult to adhere to what was previously decided in light of present circumstances (Lemos Dekker & Bolt, 2022).

As has been noted, ACP interventions, ACP programs and related studies have increased during the last decade. With intensified research and findings, ACP in general and especially in dementia care, is under increasing scrutiny. Robinson-Browne, Palmer and Komesaroff (2014) argue that the argument that “ACP is desirable because it enhances autonomy by improving knowledge about what the patient would have wanted” is seriously flawed. It is not self-evident that good decision-making is rational and detached nor that a person can hold interests that are independent of relationships with others. The emphasis on autonomy at the expense of all other moral concerns is seen as problematic. The risks of routinization are also described with ACP becoming another item on a checklist to be ticked off. ACP must be tailored to meet the needs of the patients and their families (Robinson-Browne et al., 2014).

In a 2017 article, Johnson and colleagues questioned the routine implementation of ACP and argued that ACP has limited capacity to solve ethical problems with patient autonomy and to improve the quality of end-of-life care. The importance of autonomy is not self-evident when it comes to achieving a ‘good death’ (Johnson et al., 2017). Not all patients are able and willing to engage in ACP and medical decision-making (Rietjens et al., 2016). Some patients prefer not to discuss what is going to happen in the future and strongly reject ACP (Johnson et al., 2016). Good quality end-of-life care seems to be more connected to ‘being treated as a whole person’, effective communication, shared-decision making, respect, expert care, compassion, trust, and support for families than to preference expression and control over decision-making (Virdun et al., 2015). According to Johnson and colleagues (2017), the focus needs to be redirected to the quality of end-of-life care and the limitations of ACP acknowledged. While ACP seems to have some beneficial effects on care such as increased out-of-hospital care and increased compliance with patients’ end-of-life wishes, it was not found that ACP had a significant effect on caregiver strain, symptom management, patient anxiety and patient depression in the last weeks of life (Brinkmann-Stoppelenburg, Rietjens & van der Heide, 2016; Houben et al., 2014; Baidoobonso, 2014).

In study II, the participants with dementia did not want to be or become a burden to their families but simultaneously wanted and trusted their spouse to care for them. They harbored doubts about the quality of elderly care in general but still believed and trusted that society would take care of them if needed. Such ambiguity and vacillation in trust need to be respected and addressed by dementia care professionals. The people in early-stage dementia and their family caregivers who

participated study II acknowledged worries and fears for the future and a need to plan. They also expressed a wish to live in the present and had hopes that the illness would somehow not progress. They had notions about other illnesses leading to death before the dementia worsened, thereby eliminating the need to plan for future care. Some of the study participants with dementia showed signs of anosognosia, lacking insight into their illness. All participants seemed to have difficulties imagining a future where the illness had progressed and what it would mean for themselves and their spouse caregiver. Similar results have been found in other studies as well (Bolt, van der Steen, et al., 2021; Dickinson et al., 2013; de Boer et al., 2012; Clare, 2003). Denning, Jones, and Sampson (2013) and Jones and colleagues (2016) found that successful participation in an ACP intervention is affected by the ability of the person with dementia to consider their future and how life may change as the illness progresses. People with dementia may experience trouble when considering their future selves and make assumptions about retained independence. People are also reluctant to think about their own death or the death of loved ones (Lund et al., 2015). Hirschman et al., (2008) identified remediable barriers to ACP discussions, including not knowing what to talk about, when to talk, and waiting until it was too late.

Other barriers to ACP that were identified in study II include people with dementia and their family caregivers not recognizing dementia as a life-limiting illness. Some seemed to view dementia as a normal part of aging, especially when reflecting over the illness trajectories of their own parents or older relatives with dementia. These findings were corroborated by findings from study III where dementia nurses and geriatricians reported a lack of knowledge among people with dementia and their family caregivers about illness trajectory, prognosis, and dementia in general. These views are supported by a survey in which family carers from five European countries (including Finland) participated (Woods et al., 2019) and other studies as well (Andrews et al., 2017; van der Steen, Onwuteaka-Philipsen, et al., 2013).

The participants in study III highlight wanting to do good and to act in the best interests of the patient. They state that they know what ought to be done, but planning for future care with their patients and family caregivers does not at times take place. It was seen as potentially anxiety inducing to talk about death and end-of-life care. Diverting from the sorrow, grief, and anxiety of the person with dementia by focusing on a positive attitude and lacking the time and the support to dive into challenging conversations, contribute to “skimming the surface” of the ACP process. It was felt by study participants that discussing the progressive and terminal nature of dementia is contradictory to focusing on living well with dementia. Similar results have been found in other studies as well (Moore et al., 2019; Dooley et al., 2018).

Moral barriers and facilitators encountered by physicians in ACP discussions with people with dementia were identified in a recent meta-review. The findings described moral dilemmas that can lead to avoidant behavior concerning ACP (Keijzer-van Laarhoven et al., 2020). The weariness of a heavy workload and the

burden of a high patient to nurse ratio reduces time available with each patient and contributes to an avoidance of emotional and challenging subjects. The dementia nurses in study III felt a need to protect their patients from feelings of hopelessness and anxiety and function as advocates, similar to findings in an oncological context (Vaartio-Rajalin et al., 2014). Moore, Goodison, and Sampson (2018) noted that dementia clinics have mixed views about the appropriateness of disclosing the terminal nature of dementia to people with dementia. The mixed emotions about informing people with dementia and their family caregivers about potential illness progression has been well documented (Robinson, Dickinson, et al., 2012; Perin, Ghirrotto & De Panfilis, 2020) and was noted in study III as well.

### **10.3 A supportive structure for the Advance Care Planning process**

The results of study I indicate that the type and style of ACP intervention is not of the most significance. A supportive structure was helpful for both people with dementia and family caregivers. The feeling of being listened to and engaged in the care planning, i.e., participation in decision-making, seems to be of most importance, not the intervention design itself. The results of study III indicated that dementia nurses and geriatricians express a generally positive view of ACP in dementia care, but at the same time hold a number of views about factors, which affect the conditions for conducting ACP. The ACP conversation is impeded by people and family caregivers contacting the memory clinic late in the illness trajectory. Dementia being diagnosed later in the illness trajectory may give the dementia nurse and the geriatrician the perception that it is already too late to introduce ACP. Causes for the delay were investigated in a 2018 survey of family carers' experiences in five European countries (Woods et al., 2019) in which Finland was included. A high prevalence of the person with dementia refusing to seek help was reported by 46,3% of Finnish carer respondents. Another cause for the delay was the first professional seen not considering anything to be wrong, as reported by 26,3% of respondents. Referrals to diagnostic services taking a long time were reported by 15,4% (Woods et al., 2019). The view that it is already too late to introduce ACP is deepened by the long intervals between follow-up visits. An undisturbed environment and time are factors that facilitate ACP discussions were seen as important by study participants. Building relationships with clients in dementia care was seen as key in enabling ACP discussions, as has been noted in other studies as well (van der Steen, van Soest-Poortvliet et al., 2014).

A supportive structure entails a focus on ACP in early-stage dementia through early detection and early ACP initiation while the person with dementia retains self-determination and decision-making capacity. A supportive structure allows for time for dementia care professionals to build relationships with clients and their family caregivers and with each other. Different types of dementia differ from other illnesses in that abstract thinking and decision-making are affected (Cotter 2017; Livingston, 2020). Timing is of importance in ACP discussions and even more so in

dementia care as the person with dementia will progressively lose cognitive and functional abilities (Cotter, 2017; Denning, Jones & Sampson, 2011; van der Steen, van Soest-Poortvliet et al., 2014). For the person with dementia and the family caregiver time is required to come to terms with the diagnosis and is also important when discussing future care decisions in the early stages of the disease (Orsulic-Jeras et al., 2016; Poppe et al., 2013). The expected deterioration in health as dementia progresses means that priorities, wishes, and plans of the person with dementia for end-of-life care need to be addressed before obvious cognitive and functional decline takes place (Dixon et al., 2018). Time is also an aspect of organizational support in allowing time for de-briefing with co-workers and regular coaching. Time is connected to resources as well as adequate geriatrician resources have the potential to reduce time to establish a diagnosis. Time for and with each client would increase if the client to nurse ratio was increased so that each nurse would have fewer clients to follow-up and attend to. For ACP to become an integrated component in established dementia care processes, it needs to be supported on all levels of healthcare from the micro level of the individual dementia nurse to the macro level of national regulations and guidelines.

Tools are also part of the ACP process. A semi-structured ACP tool can serve as a starting point for the conversation, be helpful for new dementia nurses, and be adapted to the individual situation as needed. Numerous studies have investigated various tools used in ACP in order to assist facilitators in achieving the optimal ACP structure. ACP decision aids have been described as supportive of certain key components of the process, such as learning about care options, reflecting on care options, what to expect, and communicating preferences for future care (Butler et al., 2014). There is a call for easily accessible, understandable, readable tools appropriate for patients working across various settings and with various facilitators (Butler et al. 2014). Volandes et al. (2009) conducted ACP research with the help of video images, a tool often conveying more understanding than a text describing the same phenomena. Patients who viewed the video were more likely to choose a comfort-oriented approach compared to patients in the control group who received a verbal description instead. The participants also indicated that video support tool was highly acceptable (Volandes et al., 2009). The question remains whether it may be too distressing for people with dementia and their family caregivers to watch images of what their own future condition and relationship could potentially be. The lack of guidelines and tools for ACP in dementia care adapted to the Finnish care context further challenges the initiation of ACP conversations. As ACP has not received much attention in everyday healthcare work in Finland (Lehto et al., 2019; Saarto et al., 2017), there is not only a lack of guidelines but also a general lack of knowledge of the ACP process.



## 10.4 Resources in the Advance Care Planning process

Nurses and nurse practitioners are well positioned to initiate and lead ACP discussions as well as suited to participate in the development of ACP processes and models as indicated by studies (Dickinson et al., 2013; Cotter et al., 2018; Lewis et al., 2015) and supported by the results of Study III as well. It has been suggested that outpatient memory clinics with properly trained and resourced staff are suitable for the initiation of ACP discussions (Lewis et al., 2015; Poppe et al., 2013). In a scoping review of experiences of ACP for people with dementia conducted by Jones et al., (2016) it was found that community nurses and palliative care specialists had the most experience of discussing and developing ACP and were therefore the most confident in initiating ACP. When describing the clinical nurse consultant role as a broker, Yeun-Sim Jeong et al., (2007) highlight the role of the nurse in ACP. The nurse acts as an intermediary in decision-making (between family and doctors), collects information, initiates interventions, educates clients and peers, and acts as client advocate. Cotter et al., (2017) in turn, state that nurse practitioners have a responsibility to facilitate the ACP discussion with people in the early phase of dementia. However, a systematic review by Blackwood et al., (2019) found that there is a need for increased focus on the training and education required for both nurses and other healthcare staff for ACP to become a routine part of clinical practice.

Roles and the responsibilities of the nurse and of the physician need clarification. In countries with a general practitioner (GP) system where a GP has often known their patients and their families for a long time, it has been noted that the framework does not allow for time for GPs to conduct ACP discussions on their own (Bally et al., 2020). In a country like Finland where patients do not have a personal physician, the healthcare system does not support relationship-building with a physician, a prerequisite for a supportive ACP discussion. The Finnish system does allow for a long-term care relationship with a dementia nurse once the assessment has taken place and has led to a dementia diagnosis. In this context, the dementia nurse can be seen as the natural facilitator of the ACP process with physician support as needed. However, the question about the necessity of a long-term relationship needs to be noted. Can a skilled ACP-facilitator build the rapport and trust with a new client? In their 2015 explanatory systematic review of implementation studies, Lund and colleagues (2015) reached the conclusion that the creation of a specialist cadre of ACP facilitators is unlikely to be sustainable solution for removing barriers to ACP. Lund and colleagues (2015) focused on implementation problems. It was found that the interventions most likely to facilitate the ACP process are simple tools that do not require high levels of specialist preparation, providing front line staff with a structured framework for action without being too time-consuming (Lund et al., 2015).

The dementia nurses in study III felt knowledgeable about forms relating to Advance Directives, illness trajectory, and the care path recommended by national

dementia care guidelines. However, it was noted that clearer role distribution between nurses and physicians as well as more distinct ACP guidelines, would facilitate ACP in dementia care. Support from the physician is often necessary and indeed mandatory when it comes to decisions such as medication or palliative care decisions. The detailed checklist approach is not seen as helpful, which is a notion supported by a 2017 editorial discussing ACP and Advance Care Directives. In the editorial, Komesaroff (2017) states that what is needed is not complicated and refined protocols and checklists, but a “continuing awareness of the key role of open ethical dialogue in the practice of all aspects of clinical care”. In addition to ACP facilitator skills and the ability to reflect on the patient’s values, the dementia nurse needs to be knowledgeable about the course of the disease, the common and anticipated complications, and decisions that can be expected (Bally et al., 2020). Support on the organizational level also includes assessment of training needs and organizing the appropriate training with skilled ACP facilitators. Training includes advice on how to approach sensitive topics, timing, trying to normalize ACP conversations and making them part of routine care as well as using critical moments or key triggers to initiate the ACP process. Critical moments such as the termination of mitigating medication, the need for home care services, or contemplating moving to a nursing home, can be seen as moments to introduce planning for future care.

## **10.5 Relational autonomy and relationship-centeredness in the Advance Care Planning process**

Relational autonomy is a concept that has emerged as a challenge to the individualistic interpretation of autonomy in medical ethics (Gómez-Virseda et al., 2019). Oshana (2020) describes relational autonomy as “the term used to designate a variety of conceptions of personal autonomy, all of which are united in the belief that autonomous beings are, of necessity, socially situated and interdependent”. Oshana offers that social relations constitute an essential part of what is involved in self-determination and suggests that autonomy be treated as a multidimensional phenomenon (Oshana, 2020). Denier and Gastmans (2022) bring forward that autonomy is shaped within the caring relationship between the cared for and the caregiver. Dignified dementia care is realized in a process of shared decision-making involving all the stakeholders (Denier & Gastmans, 2022). A 2021 study highlights the need for a person-centered approach in the support of people with dementia to claim their rights. People with dementia and family caregiver views regarding the meaning of autonomy were explored. The study concluded that autonomy from the perspective of people living with dementia means more than the two concepts of independent and relational autonomy. When supporting people with dementia to live autonomously, personal preferences of person with dementia and the role of relationships in their lives should be seen as paramount (Wolfe et al., 2021).

In the context of dementia care, the term ‘person-centered’ care was first used by Kitwood (Brooker, 2006; Fazio, Douglas, Flinner et al., 2018) emphasizing the lived experience of people with dementia along with the importance of communication and relationships (Brooker, 2006; Kitwood, 1997). The uptake of the specific elements of the person-centered care ethos has been widespread; however, the implementation of these elements varies in practice (Olsson et al., 2013). Harrison Dening (2017) suggests that in dementia care, a person-centered approach is not enough as it may cause conflict with the perspectives and preferences of a family caregiver and vice versa. Harrison Dening (2017) goes on to suggest that a relationship-centered approach may be more appropriate. In a relationship-centered approach, the whole family may be included. Nolan et al. (2004) suggests a relationship centered dementia care model where the nurse works together with the person with dementia and the family caregiver in a triad, to promote senses of belonging, security, continuity, purpose, achievement, and significance. When striving to maintain dignity and protect this vulnerable patient group, ‘knowing the patient’ (Vaartio et al., 2006; Vaartio, 2008; Fagerström, 2019) is of outmost importance in the dementia care ACP process. ‘Knowing the patient’ is at the core of person-centered care and positively influences the provision of compassionate care and the evolution of a caring relationship (Dewar, 2011; Zolnierik, 2014; Fagerström, 2019). In the current thesis, relationship-centeredness means listening to the person with dementia and their family caregiver, respecting the ambiguity and anxiety connected to thoughts on end-of-life care, engaging the person with dementia and family caregiver dyad in planning and decision-making, and empowering the person with dementia and family caregiver dyad through information, knowledge, and patient advocacy.

The notions of person- and relationship-centered care carries over to Gastmans’s (2013a; 2013b) foundational ethical framework for dignity-enhancing nursing care where lived experience and the dialogical-interpretative process are two of the framework’s pillars. In contemporary bioethics respect for autonomy is a key concept together with principles of beneficence, nonmaleficence, and justice (Beauchamp & Childress, 2013). Dignity-enhancing nursing care offers an approach that goes beyond contemporary bioethics and the dominant model in medical ethics. There are arguments for the understanding of autonomy from a relational perspective (MacDonald, 2007; Nolan et al., 2005). The practices of ACP and shared decision-making in end-of-life decisions are more satisfying in a relational autonomy context (Goméz-Virseda et al., 2019). Denier and Gastmans (2022) note the anthropological approach of dignity of the human person where the person is worthy of dignity also without the ability to communicate clearly or rational capacity. Dignified dementia care is realized in a shared decision-making process between all the relevant stakeholders. In this relational process, the focus is on the needs, preferences, and wants of the person with dementia. The needs, preferences, and wants are clarified through an ongoing relational process of interpretation, dialogue, and assessment regarding the right thing to do in actual care situations. (Denier & Gastmans, 2022). Gastmans and Denier (2022) introduce the relational autonomy approach as a dynamic and relational phenomenon that

“essentially takes shape within and throughout the caring relationship between the caregivers and the cared-for.”

In the dignity-enhancing ethical framework, the vulnerability of people with dementia is seen as an extraordinary vulnerability, requiring carers to have the ethical attitudes of responsibility and competency (Gastmans (2013a). According to Gastmans (2013b), care practices must be situated in a relational and dialogical context. When this frame of mind is brought to the ACP process in dementia care, it opens for a dialogical-interpretative process based on lived experience with the aim of protecting and maintaining the dignity of the person with dementia. ACP in dementia care can be seen as an interpretative dialogue, a care process where the nurse/ACP facilitator in a time of uncertainty supports and guides the person with dementia and the family caregivers in the decision-making process regarding future care. A successful ACP process enables the individual to shape her own life as it is in the present as well as beyond the loss of cognition and decision-making capacity. When it comes to illness trajectory, the ethical challenges in dementia care move to the forefront. For people with dementia to be able to make informed decisions about care, information is needed about the possible illness trajectory, different care alternatives, and the consequences of these alternatives. Do people with dementia want information about illness progression and about what can be expected in the late stages? Such information can enhance self-determination and aid in decision-making about future care but may also promote a sense of hopelessness and despair (Perin et al., 2020). Healthcare professionals are faced with an ethical conflict as to how and how much they should inform the person with dementia and their family caregivers about the clinical situation and expected illness trajectory (Perin et al., 2020).

## **10.6 Suffering related to care and missed care in early-stage dementia care**

The experience of not being seen and not being understood means a loss of dignity, a suffering. The suffering related care stems from the violation of the person’s dignity and the lack of care (Eriksson, 1994b). The lack of care connects the suffering related to care concept to the concept of missed care. Missed nursing care is a relatively recently defined concept referring to an act of omission. Missed care or care left undone is any aspect of nursing care that is delayed or altogether omitted in whole or in part (Kalisch et al. 2009). According to Suhonen and Scott (2018), missed care can be seen as “an outcome of activities and processes performed (or not performed), consciously or unconsciously, by professional nurses”. Nurses in a variety of settings have been found to be completely aware of missed care but it is not openly acknowledged or discussed. Reasons for not talking about it can be guilt, powerlessness, or fear of repercussions, retributions, or blame. When the concept of missed care started to receive attention in the early 2000s,

one of the focus questions was how nurses make decisions as to what care to give, delay or omit (Kalisch et al., 2009). Inadequate time, skill mix, and staffing level contribute to the failure to carry out or to withholding of necessary nursing tasks (Schubert et al., 2008).

A 2014 study of NSH hospitals in England reported that most of the missed care related to aspects of relational care such as health education and talking with patients. It was also noted that the incidence of missed care was significantly associated to the nurse-to-patient ratio where low nurse staffing levels negatively affect safety and quality (Ball et al., 2014). The topic of missed care has mostly been studied in acute care hospitals but has been found to be a common issue in nursing contexts (Suhonen & Scott, 2018). The emerging body of research on missed care in the community and primary care setting has been conducted mostly in Ireland, the United Kingdom, Australia and the USA (Senek et al., 2020). A recent study focusing on missed care in community and primary care settings found that there is a high prevalence of understaffing in community nursing, making missed care more likely to occur (Senek et al., 2022). Suhonen and Scott (2018) suggest considering the ethical basis for resource allocation and highlight resource constraints on available nursing time as a necessary and urgent public, national and international discussion.

Study III participants reported having a higher patient load than national recommendations. Not having enough time with each person with dementia causes a conscious or unconscious prioritizing of care tasks where the focus often lands on daily activities and concerns. Dementia nurses and physicians reported a shortage of staff, which increases the number of clients to dementia nurse as well as the amount of time between follow-up visits. As allotted time per person with dementia becomes increasingly pressured, ACP conversations tend to be left undone or to take a back seat to matters that are considered more urgent, such as medication reviews and the challenges of living at home with a caregiver spouse. Study III participants saw a trusting relationship as a prerequisite for ACP but the current resources and dementia care structure with infrequent follow-up visits with their client do not always provide the basis for such a relationship. It can be argued that omitting the ACP and advance directives part of the dementia care path is a form of missed care caused by multiple factors. While the missed care concept has been connected to nursing care, the omission of physicians in diagnosis disclosure and the failure to provide illness trajectory information can be seen as a form of missed care as well. It is the ethical right of the patient to be informed of the diagnosis (The Act on the Status and Rights of Patients, 1992). Avoidant behavior on the behalf of healthcare professionals in dementia care may be increasing the suffering of the person with dementia and their family caregiver. According to Arman (2012), the suffering of a person with illness is doubled when the person suffers but is prevented from showing the suffering (Arman, 2012). The attitude of the nurse has the power to create an experience of insecurity, unsafety, and alienation, as well as the power to create security, safety, and connection (Lassenius, 2012).

# 11 Methodological considerations

In this chapter, methodological considerations will be reviewed. The first five steps of the mixed research process involve identifying the goal, objective, rationale, purpose, and questions (Leech & Onwuegbuzie, 2010). The aim of the study is to present an ACP model in early-stage dementia care. The purpose of the study is also to gain a multi-professional consensus about how ACP should be introduced in this group of patients. The strengths and limitations of individual studies are discussed in detail within each article associated with this thesis. The goal of the study, the research objective of each study, the rationale for a mixed research study, and the research questions have been made explicit according to quality criteria for mixed methods studies.

## 11.1 Pragmatism – challenges and pitfalls

For the current study, pragmatism was the natural choice of research paradigm as it aims to create useful knowledge, study whole systems in context, focus on the social effects of research and interventions, and value the input of all stakeholders (Long et al., 2018). According to Morgan (2014), pragmatism means reflecting on the nature of a problem, on its possible solutions, on the nature of the possible solutions, and the likely action. For pragmatists the overall issue is whether the methodology is useful and instrumental in producing anticipated or desired results and to prioritize the research question (Goles & Hirschheim, 2000; Tashakkori & Teddlie, 2008). The problem-centered nature of pragmatism can be seen as limiting its ability to identify structural social problems (Thompson, 1997) and to observe potential different layers of a research problem (Feilzer, 2010). A pragmatist researcher always considers the consequences that the choice of a particular design and the conduct of a research project will have. After considering various choices, the researcher proceeds with her own warranted beliefs, beliefs that are shaped by previous experiences of the researcher (Morgan, 2014). The choices of research question and methodology are influenced by the personal history of the researcher, her belief system, and her sociopolitical location (Morgan, 2007). The personal history, experiences and beliefs of the researcher have been described in Chapter 8.2. For the pragmatist researcher the primary objective of inquiry is the creation of knowledge for the sake of change and improvement (Goldkuhl, 2012). The pragmatic approach focuses on how useful an intervention model is in guiding action in real-world settings (Glasgow, 2013).

The strengths of the current thesis lie in the attempt to fulfil the aim of pragmatic research. In order to create knowledge about previous ACP interventions in dementia care, general ACP programs and interventions were mapped. A scoping review identified ACP interventions aimed at older people with dementia. Knowledge was also created from two different types of interview studies. A qualitative interview study was conducted with people with early-stage dementia

and their family caretakers to explore their views on ACP. Focus group interviews provided the viewpoints on ACP from healthcare professionals working in dementia care. The input of all stakeholders was sought and valued, and multiple methods used. For the third study, a quantitative method can be seen as more appropriate for eliciting the views of as many dementia care professionals as possible. Indeed, a pre-existing questionnaire was translated from English to Swedish and Finnish and sent by e-mail to approximately 1,100 dementia care professionals in Finland. However, with a response rate of only 2%, the result was not adequate for statistical analysis. As the questionnaire approach failed, the author needed to take a step back to reconsider the method. At that point, focus group interviews were seen as a pragmatic alternative. As the results were described and analyzed, certain preconceived notions diminished while others were strengthened. The research problems, research questions, and methods were reflected on and revisited. The third study went through several revisions.

## **11.2 Reflections on scoping review studies**

In the last two decades, scoping review has emerged as one of the most prevalent types of knowledge synthesis within health professions education journals (Maggio, et al., 2020). The scoping review method allows for the inclusion of different forms of literature, as the researcher is not limited to peer-reviewed literature (Peters, et al., 2020; Arksey & O'Malley, 2005). It should be noted that the scoping review method requires that literature on the research topic is sufficient (Mak & Thomas, 2022). The method is seen as useful for mapping what has been studied about a certain topic. The results of mapping aid the reader in the comprehension of the scope of existing studies and the identification of gaps in the literature (Young et al., 2020).

Scoping reviews being viewed as quicker and easier than other forms of reviews, or less rigorous is a common misconception (Mak & Thomas, 2022). A research team that works in a rigorous manner will ensure a robust contribution to the field of study (Thomas et al, 2017). As scoping reviews can be seen as a starting point for empirical research (Mak & Thomas, 2022), the method was deemed well suited for the first study of the current thesis. As the field of ACP research and the amount of literature have grown rapidly (see Table 1, chapter 4), the possibility of including different types of (grey) literature allowed for casting a wide net to capture the available literature. The challenges associated with the scoping review method include the selection of search terms (Mak & Thomas, 2022) and the resource intensity (Maggio et al, 2018). These challenges were experienced in study I as well. The selection of the search terms required a careful thought process. The high yield of scientific articles possibly suitable for inclusion required a lot of time to review and discuss. In fact, the execution of study I required more time than studies II and III. The differing perspectives and experiences of the PhD student and her

supervisors allowed for the reflection required for the production of meaningful results.

### **11.3 Reflections on interview studies**

The interaction between participants in the interview situation can be both beneficial and challenging. In study II the caregiver spouse participated in the interview in eight out of ten interviews. The two participants in a dyadic interview commonly share a pre-existing relationship, such as caregiver-patient or a married couple (Kvalsvik & Øgaard, 2021). The presence and participation of the caregiver spouse might have affected the responses (Bell & Campbell, 2014). The interviews conducted jointly resulted in a shared narrative where there is the risk that the voice of the people with dementia is overpowered (Arksey, 1996; Caldwell, 2014). Other disadvantages may include the interviewer only getting the 'public' story (Bell & Campbell, 2014.) However, dyadic interviewing is also considered a method of triangulation and as an accommodation for people with dementia (Bell & Campbell, 2014). Other potential advantages of dyadic interviews are ideas and thoughts rising from participant interaction (Morgan et al., 2013; Eisikovits & Koren, 2010). Dyadic interviews can also promote a sense of safety and allow participants more time to formulate their response (Morgan et al., 2013). However, the research into dyadic interviews is still incomplete and fragmented (Kvalsvik & Øgaard, 2021). The interview situations in study I were characterized by warmth and a mutual interest in the topic. The dynamics between the dyads differed from interview situation to interview situation where in some the person with dementia was the dominating person and in others the caregiver spouse, possibly a pattern established earlier in the marriage. However, in none of the interviews it was felt that one voice overpowered the other. At times, the participants lost track of the purpose of the interview and the semi-structured format deviated from in friendly conversations. Duncombe and Jessop (2012) note interviews turning into therapeutic conversations. The parts of the interviews containing personal information not related to the research questions were not transcribed and left out of the data set.

In study III, focus group interviews were conducted as the method for data collection. The strengths of focus group interviews include access to a larger number of participants, the synthesis and validations of concepts and ideas as well as discovery of the collective perspective. Drawbacks of the focus group interview situation may be problems with confidentiality, conflicts in the group interaction, and poor results caused by weak moderator skills. Participants' complex verbal and non-verbal responses may make interpretation and analysis challenging (Halcomb, et al., 2007). Gibbs (2012) notes that the benefits to the participants in focus groups should not be underestimated. Debating a topic that participants feel strongly about and the group dynamic may make participants feel empowered and energized. The advantage for researchers may be a better understanding of the gap



between what people say and what they do (Gibbs, 2012). In the focus groups in study III, the pre-defined structure of the focus group interviews ensured that different topics pertaining to the research questions were covered. The semi-structure of the interviews made the narratives similar to each other and comparable, which made the analysis easier. However, the semi-structured nature of the interviews may have influenced the participants (Wilson, 2014). The focus group participants were not strangers to each other. Some of them were co-workers, which was both beneficial and a drawback at times. The familiarity opened up for honest discussions about shared challenges and feelings while the group dynamic from every-day work may have carried over to the focus group interview situation with certain personalities at times dominating the discussion and interrupting others. The moderator and the observer took care in ensuring that all voices were heard.

## **11.4 QUAGOL strengths and pitfalls**

In sub-studies II and III, the QUAGOL (Dierckx de Casterlé et al., 2012; Dierckx de Casterlé et al., 2020) was used as the guiding tool it is intended for. The strengths of the method are among others a case-oriented approach where within-case and cross-case analysis are balanced, use of the constant comparative method, and the combination of analytical approaches. The potential stumbling blocks of the method include information overload, losing track of the research question, and the focus on intuition and creativity (Dierckx de Casterlé, et al., 2012; Dierckx de Casterlé et al., 2020). The method development team emphasizes developing a good understanding of the data material as a whole before starting the breakdown of the data and entering codes into a qualitative software program. Engaging with the data and slowing down the analysis process means that the most important analytical work is done before the use of software. The QUAGOL guide is intended to facilitate and support the analysis process. According to the method development team, it is indeed a guiding tool and not a strict procedure that needs to be implemented step by step (Dierckx de Casterlé et al., 2012; Dierckx de Casterlé et al., 2020). In the two sub-studies of this thesis, a modified version of QUAGOL was used in that a software program for analysis of qualitative data was not used. The coding was done manually in a slow and painstaking process. The risk of information overload and not being able to distinguish relevant information from less relevant information was reduced by a strong focus on the essence of the material and on the research question. The trustworthiness of the analysis process was enhanced by the documentation of reflections and field notes, which were used in the narrative reports and conceptual interview schemes. Continuous research team discussions were held about data analysis and emergent results, which affirm credibility.

## **11.5 Reflections on the challenge of time**

In a field where research has steadily grown and especially so during the last 10 years, time is a challenge when writing a thesis. The growing field of research in ACP in general and in dementia care was noted in chapter 5. The work on the thesis started in 2017 when ACP studies involving people with dementia and healthcare professionals in a community setting were still rare. As the years have gone by, the included studies are now studies among others with a similar approach. Completing a PhD thesis is training in how to conduct research and thus the publication pace is possibly slower than that of more experienced research teams. The PhD student, who once considered herself to be at the forefront of a “hot” research topic, might find that the research has taken major steps forward while she finalized her thesis. However, the steps taken and new interventions studied contribute to ideas and innovative paths possible for post-doctoral research and projects.

## 12 Conclusion and implications

Challenges for ACP in dementia care are connected to the delay in diagnosis, the decline in cognition associated with progressing dementia illness, the reluctance to plan for future care, and the misconceptions and lack of knowledge about dementia and ACP. Other challenges concern the dementia care professional resources, such as a lack of competence, lack of guidelines and tools, lack of institutional support and adequate resources in the form of employee numbers reducing the amount of time spent with each person with dementia. These challenges have the potential to lead to impaired self-determination, diminished dignity, misconceptions about dementia and ACP, anxiety, avoidant behavior, and missed care. In a viewpoint text in *Gerontology*, Bally and colleagues (2020) calls for regulations on the meso- and macrolevel of organizations, regions and national institutions as a necessary precondition for ACP programs and interventions of high quality. There is a need for guidelines and regulations on who should be responsible for conducting ACP discussions, how, when, and in what kind of context. The national quality recommendations for palliative care and end-of-life care published by the Finnish Institute for Health and Welfare (THL) in 2022 have listed ACP as one of ten quality areas with four quality criteria. The four quality criteria are: 1) every person with advanced illness has an advance care plan for end-of-life care, 2) the advance care plan is part of palliative care and end-of-life care, the advance care plan is made in discussions in which the wishes of the patient are included and limits to the care stated, 3) every patient gets the ICD-10 diagnosis code Z51.5 at the appropriate time in conjunction with discussions with the patient and his/her family, and 4) a palliative care plan with defined palliative care pathway based on the needs and wishes of the patient is made for every patient with a palliative goal of care (Saarto et al., 2022). For these quality criteria to be fulfilled there is a need for healthcare organizations to invest in adequate time, support, and resources for ACP. This thesis provides a structure and an argument for the development of ACP in early-stage dementia care.

A summary of the discussion offers that a focus on early-stage dementia care that ensures a supportive structure, a relationship-centered approach, and resources is essential. Trust between the members of the dementia care triad is a product of relationship-centered care and a requirement for the ACP process. The here and now is the starting point for ACP, with the questions about how the person with dementia wants to live and how that wish can be fulfilled. The pragmatic approach of the thesis focuses on how useful the described model is in guiding action in real-world settings. The suggested ACP model in early-stage dementia care demonstrates the practical need for resources, tools, and training. There is a need for adequate dementia nurse resources to reduce the number of clients per nurse thus enabling more frequent and longer visits as needed. Increased geriatrician resources are needed to reduce time to diagnosis. ACP training, semi-structured, and simple ACP tools need to be developed and/or provided for dementia care professionals together with coaching and emotional support as needed.

The model is a relationship-centered dementia care model where the nurse works together with the person with dementia and the family caregiver in a triad. This type of dementia care model is seen as ideal and promotes senses of continuity, security, purpose, achievement, and significance (Keady & Nolan, 2003; Nolan et al., 2004). Sensing continuity, security, purpose, achievement, and significance contributes to the experience of dignity for all members of the dementia care triad. It should, however, be noted that not all people with dementia live with a family caregiver which requires special attention to the relationship with professional caregivers. The person with dementia – family caregiver dyad may also be part of multiple triads with different healthcare providers (Tuijt et al., 2021). A relationship-centered ACP process enables informative discussions to take place in early-stage dementia while the person with dementia has the necessary capacity to partake in decision-making about future care. The professional group responsible for these discussions should be explicated and the necessary training and support provided. In the Finnish dementia care context, the dementia nurse is the key healthcare professional best situated to manage the ACP process.

Suffering and dignity belong to the core concepts of caritative caring philosophy. This thesis connects suffering and dignity to dementia care in profound way. The three forms of suffering related to care described by Eriksson (1994b) all exist in the care of people with dementia and their family caregivers. The existential suffering connected to being diagnosed with dementia, an incurable illness leading to death (suffering related to living) and the suffering related to losing functional ability (suffering due to illness) need to be acknowledged and seen so as to avoid causing suffering related to the lack of care and the violation of dignity. Another brick has been laid in the caring science foundation, connecting the core concept of suffering to the missed care concept and the caring science ethos to Gastmans's dignity-enhancing ethical framework (Gastmans, 2013a).

The suggestions for further research can be divided into two interconnected areas, one having to do with the practicalities of ACP and the other with emotions and lived experiences of all stakeholders of the dementia care triad. The practicalities include a lack of validated tools to evaluate ACP intervention feasibility and acceptability from the perspective of the people with dementia themselves. Person-centered planning refers to different approaches to help people in need of health and/or care services to express choices and plan for the present and the future (Mansell & Beadle-Brown, 2004). Initially used in learning disability services, it is emerging as a new alternative in advance care planning in services for people with dementia and in end-of-life care (Sinclair et al., 2016). An approach that incorporates human-centered design (Searl et al., 2010) with an understanding of the challenges faced by people with dementia and care staff is important to improve quality of care and vital to the development of ACP interventions for people with dementia and their family caregivers. These approaches may help society take care of the needs of an aging population in a cost-effective way, which is one reason for the rapid acceptance of the concept of person-centered care by government policy makers (Manthorpe & Samsi, 2016) and need to be further explored.

The argument that everyone should have a living will no matter what health issues and diagnoses has been suggested. As Gaster, Larson and Curtis (2017) noted, there has been progress in the development of conversation kits and tools in ACP in dementia care, but many patients do not have access to simple written documents that could assist in decision-making and provide clarity in personal values and goals. Gaster, Larson and Curtis (2017) call for such advance directives to be completed by patients before the development of dementia as an opportunity to provide guidance about desired care should dementia occur (Gaster et al., 2017). Educating the general public about dementia, lasting power of attorney, and living wills, in short Advance Care Planning, remains a complex subject to be further studied.

With the approach of planning for the eventuality of dementia, some of the aforementioned barriers connected to the illness, such as difficulties in imagining the future (Denning et al., 2013) and the lack of awareness (de Boer et al., 2012), may be overcome. Dickinson et al. (2013) noted the reluctance by people with dementia and family caregivers to 'think too far in advance', something also noted by de Boer et al. (2012) and in Study II as well. However, this may be a human trait, common for humans in general and thus a difficult barrier to overcome in the ACP process in general. The number of studies identified that have included feedback from people with dementia was low. As interest in ACP research in dementia care has steadily increased, this type of studies will likely increase as well. Further studies that include people with dementia in the early phase of the illness trajectory are important for the continued development and improvement of ACP in dementia care. Acknowledging the suffering of both the person being diagnosed with dementia and their family caregiver and balancing that recognition with a focus on positivity and the maintenance of quality of life, is a valuable skill of a dementia nurse. The development of that skill needs to be supported and further studied.

# 13 Svensk sammanfattning

## 1 Introduktion och bakgrund

Olika typer av minnessjukdom och demens hör till de största utmaningarna inom dagens hälso- och sjukvård. Minnessjukdomar är en global utmaning där antalet personer som lever med minnessjukdom förväntas fördubblas vartannat årtionde (Nair et al., 2016; Livingston et al., 2020). En åldrande befolkning medför ökade ekonomiska och sociala konsekvenser i allmänhet. Det finns ett ökande tryck att flytta minnessjukdomsvård från specialsjukvården till primärvården (Prince et al., 2016; Terveyskylä, 2023). Bortsett från de ekonomiska kostnaderna för att vårda personer med minnessjukdom behöver det mänskliga lidandet för personer med minnessjukdom och deras närstående uppmärksammas och lindringen av detta lidande betonas.

Personer med minnessjukdom nekas ofta sina mänskliga rättigheter och inkluderas inte i beslutsprocesser (WHO, 2017). Den etiska komplexiteten når en högre nivå när personen har en minnessjukdomsdiagnos och där lagar och direktiv inte är tillräckliga för att vägleda vårdpersonal i vården. Minnessjukdom påverkar beslutsförmågan och förmågan att förutse och planera för framtida händelser (Banovic et al., 2018; Livingston et al., 2020). En person i slutstadiet av minnessjukdom kan inte längre fatta beslut för egen del och familjen får då ofta i uppgift att fatta beslut om vård i livets slutskede (Harrison Dening, et al., 2016). Föregripande vårdplanering (Advance Care Planning, ACP) kan vara ett värdefullt sätt att lindra lidande och förbättra livskvaliteten för både personer med minnessjukdom och närstående (Harrison Dening, 2017) och borde introduceras medan personen med minnessjukdom fortfarande har förmåga att delta. Majoriteten av ACP forskning har fokuserat på minnessjukdom i sen fas (Arcand et al., 2013, Dixon et al., 2018, Brazil et al., 2018, Vandervoort et al., 2014). Denna doktorsavhandling avser att utforska ACP i minnessjukdom i en tidig fas av sjukdomen och att presentera en modell för ACP processen i vården av personer med minnessjukdom i tidig fas.

## 2 Syfte

Avhandlingens syfte är att utforska ACP vid minnessjukdom i ett tidigt skede av sjukdomen och att presentera en modell för ACP-processen vid vård i tidigt skede av sjukdom. Forskningsfrågorna är:

1. Vilka typer av ACP interventioner används internationellt för personer med minnessjukdom och vad är återkopplingen från personer med minnessjukdom och från deras närstående? (Studie I)

2. Vilka åsikter har personer med minnessjukdom och deras närstående om ACP och att om att planera för framtida vård? (Studie II)
3. Hur ser vårdpersonal inom minnesvården på ACP? (Studie III)

Avhandlingen består av tre studier. Den första studien är en scoping review, en översikt med syftet att stärka kunskapen om ACP interventioner för personer i en tidig fas av minnessjukdom samt att beskriva effekterna av olika interventioner och denna patientgrupps och deras närståendes återkoppling angående interventionerna. Den andra studien är en kvalitativ studie där personer i en tidig fas av minnessjukdom (N=10) intervjuades tillsammans med sina närstående (N=8). Syftet var att utforska minnessjuka personers och deras närståendes åsikter om att planera för framtida vård. Den tredje studien är en kvalitativ fokusgruppstudie med syfte att utforska hälsovårdspersonals (N=17) åsikter om ACP för personer med minnessjukdom och deras närstående.

### **3 Metodologi och metoder**

Denna avhandling är förankrad i det pragmatiska forskningsparadigmet med anledning av att det övergripande syftet med studien är att producera kunskap som är användbar för alla intressenter och med bidrag från alla intressenter (Long et al., 2018).

Målsättningen med den första studien var att stärka kunskapen om ACP interventioner skapade för äldre personer i den tidiga fasen av minnessjukdom, att beskriva effekterna av de olika interventionerna samt notera återkopplingen på interventionerna från denna patientgrupp och deras närstående. För studien användes metoden scoping review (Arksey & O'Malley, 2005; Levac et al., 2010). Valet av scoping review-metoden motiverades med antalet nyligen publicerade vetenskapliga ACP-studier kombinerat med utvecklingen av många nationella och regionala ACP-program. Valet av kartläggningsslag metod motiverades också av utvärderingsrapporter förväntades ingå i data materialet. Elektroniska databaser, vetenskapliga artiklars referenslistor, bokkapitel, Google och Google Scholar genomfördes. Sökningen utgick från ett brett perspektiv för att nå en bred bild av ACP-studier relaterad till vård av minnessjuka personer. Sökningen identifierade sex studier som beskrev interventioner riktade till personer med minnessjukdom i tidig fas av sjukdomen.

Den andra studien var en kvalitativ intervjustudie med en induktiv ansats och en semistrukturerad intervjuguide. Intervjuer anses vara lämpliga när potentiellt känsliga ämnen hanteras och deltagare kan vara motvilliga till att diskutera ämnet i en grupsituation (Gill et al., 2008). Syftet med en forskningsintervju är att nå en djupare förståelse för fenomen genom att undersöka människors erfarenheter, åsikter, motivering och antaganden om specifika ämnen (Silverman, 2000). Semistrukturerade intervjuer används ofta inom hälsovårdsforskning och

inkluderar nyckelfrågor för att definiera forskningsområdet. Formatet tillåter också flexibilitet och avvikelser från ämnet för att undersöka svar mer detaljerat (Britten, 1999). Tio intervjuer med personer med minnessjukdom genomfördes. Under åtta av intervjuerna hade personen med minnessjukdom sällskap av sin make/maka.

Den tredje studien var en kvalitativ studie med tre semistrukturerade fokusgruppsintervjuer som genomfördes med personal inom minnesvården. Tre fokusgruppsintervjuer med minnesskötare, minnesrådgivare, minneskoordinatorer och geriatriker genomfördes. Under de senaste årtiondena har användningen av fokusgruppintervjuer ökat inom kvalitativ hälsovårdsforskning. Fokusgrupper har potential att ge djupgående information på en relativt kort tid (Krueger, 2002; Gundumogula, 2020). Deltagarna väljs baserat på erfarenheter och/eller kunskap om ett visst ämne (Anderson, 1990). Eftersom fokusgrupper är lämpliga för att samla information om gemensamma åsikter och vad som ligger bakom dessa åsikter, ansågs metoden vara användbar för den tredje delstudien där åsikter hos yrkesmänniskor inom vården av personer med minnessjukdom utforskades. Majoriteten av de yrkesverksamma som deltog var legitimerade sjukskötare (n=13), geriatriker (n=2), en socialarbetare och en yrkesverksam inom tillämpad gerontologi. I både den andra och den tredje studien ingick fältanteckningar, observationer och reflektioner över intervjuerna som en del av materialet. I den andra och den tredje studien analyserades datamaterialet med hjälp av en modifierad version av analysmetoden Qualitative Analysis Guide från Leuven (Dierckx de Casterlé et al., 2012; Dierckx de Casterlé et al., 2020).

Avhandlingens studier presenteras i tabell 1 med syfte, material, kontext och metoder inkluderade.

**Tabell 1.** Avhandlingens delstudier

Studie	Syfte	Material	Kontext	Metoder
I	Syftet med studien är att öka kunskapen om Advance Care Planning interventioner ämnade för äldre personer med minnessjukdom i tidig fas samt att beskriva de olika interventionernas effekt och återkoppling från denna patientgrupp och deras närstående.	I sökningen identifierades sex studier som beskriver interventioner ämnade för äldre personer med minnessjukdom i tidig fas. Studierna inkluderade återkoppling från personerna själva.	Tre av studierna ägde rum i en hem-kontext. Tre ägde rum i en klinisk kontext.	Scoping review enligt Arksey och O'Malley (2005), Levac, Colquhoun och O'Brien (2010) samt Peters et al. (2015)



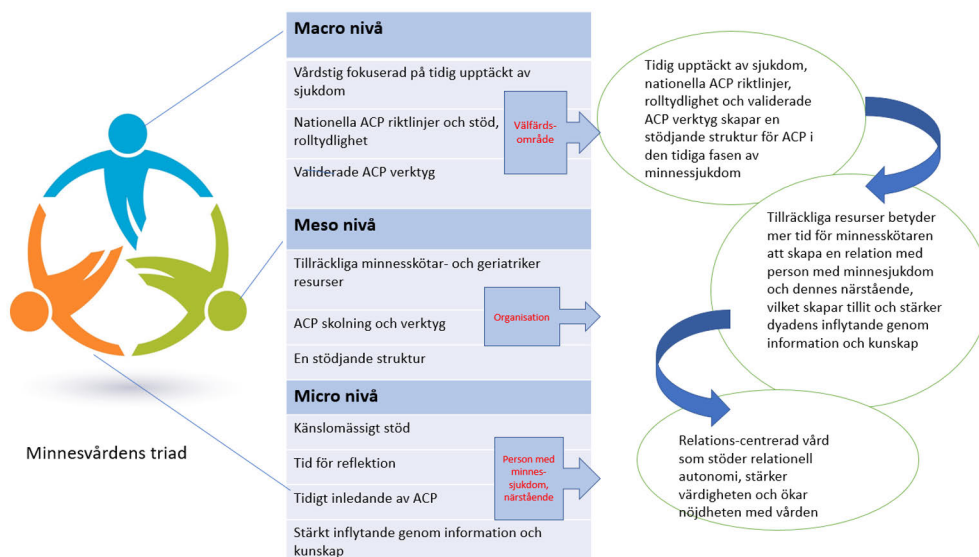
II	<p>Syftet med denna studie var att utforska åsikter hos personer i en tidig fas av minnessjukdom angående att planera för framtiden.</p>	<p>Tio intervjuer med personer med minnessjukdom. Under åtta av intervjuerna var en make eller maka närvarande och deltog i intervjun samt uttryckte sina egna åsikter. Två av personerna med minnessjukdom intervjuades utan en närstående närvarande. Fältanteckningar, observationer och intervjureflektioner</p>	<p>Hemma hos deltagarna</p>	<p>Studien är en kvalitativ intervjustudie med ett induktivt närmelsesätt och en semi-strukturerad intervju guide. Materialet analyserades enligt en modifierad version av Qualitative Analysis Guide of Leuven (Dierckx de Casterlé et al., 2012; Dierckx de Casterlé et al., 2020).</p>
III	<p>Studien syftade till att utforska åsikterna hos yrkesmänniskor inom minnesvården angående Advance Care Planning för personer med minnessjukdom.</p>	<p>Tre fokusgrupp-intervjuer med minnesskötare, -koordinatorer, -rådgivare och geriatriker. Majoriteten av deltagarna var sjukskötare (n = 13), geriatriker (n=2), en socialarbetare och en geronom. Fältanteckningar, observationer och intervjureflektioner.</p>	<p>Deltagarnas egna arbetsplatser</p>	<p>Studien är en kvalitativ studie med semi-strukturerade fokusgruppintervjuer med yrkesmänniskor inom minnesvården. Materialet analyserades enligt en modifierad version av Qualitative Analysis Guide of Leuven (Dierckx de Casterlé et al., 2012; Dierckx de Casterlé et al., 2020).</p>

## 4 Resultat

I studie I identifierade scoping review-översikten sex studier som beskriver ACP-interventioner för minnesklienter i tidigt skede av sjukdomen. Ett relativt brett spektrum av interventionstyper beskrivs i studierna. De flesta av studiedeltagarna (personer med minnessjukdom och närstående) påverkades på mestadels positiva sätt och uppgav att de var nöjda med de interventioner som användes trots de betydande skillnaderna mellan interventionerna. Känslan av att bli lyssnad på och engagerad i vårdplaneringen verkar vara av störst betydelse, inte själva interventionsdesignen. Resultaten från studie II visar att åsikterna hos personer med minnessjukdom kännetecknas av en komplex berättelse med spänningar och rörelser inom teman som önskningar, övertygelser och nivåer av insikt. Deltagarna ville tänka på framtiden men ville också leva här och nu. Resultaten från studie III beskriver minnesskötares, -koordinatorers och -rådgivares samt geriatrikers syn på ACP inom minnesvården. Deltagarna uttryckte en generellt positiv syn på ACP i minnesvården, men hade samtidigt ett antal åsikter om gynnsamma och ogynnsamma faktorer som påverkar förutsättningarna för att genomföra ACP.

## 5 Slutsatser

I en abduktiv resonemangsprocess (Upmeier zu Belzen, et al., 2021; Baral, 2000) kombinerades resultaten från de tre studierna med resultaten från tidigare studier och reflektioner över teoretiska perspektiv med syfte att presentera en ACP-modell för den finländska minnesvården i tidigt skede av sjukdom.



**Figur 1.** ACP-modellen i minnessjukdomens tidiga fas

En stödjande struktur gör det möjligt att fokusera på ACP vid minnessjukdom i tidig fas genom tidig upptäckt och tidig initiering av ACP medan personen med minnessjukdom fortfarande har självbestämmandeförmåga och förmåga att fatta beslut. Resultatet av den stödjande strukturen är relationscentrerad vård där relationell autonomi stödjer självbestämmande och ökar värdigheten för alla medlemmar i vårdtriaden bestående av person med minnessjukdom, närstående och minnesskötare. En utvecklad struktur och otillräckliga resurser bidrar till faktorer som kan leda till lidande i samband med vård, utebliven vård och förlust av värdighet. Den föreslagna ACP-modellen för minnesvård i tidigt skede visar på det praktiska behovet av resurser, verktyg och utbildning. Fortsatta studier som inkluderar personer med minnessjukdom i den tidiga fasen av sjukdomsförloppet är viktiga för den fortsatta utvecklingen och förbättringen av ACP inom minnesvården. Att bekräfta lidandet hos både personen med minnessjukdomsdiagnos och dennes närstående och balansera denna bekräftelse med ett fokus på positivitet och upprätthållande av livskvalitet är en värdefull färdighet för en minnesskötare, -rådgivare, -koordinator. Utvecklingen av denna kompetens behöver stödjas och studeras ytterligare.

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# Appendix

## An assessment of the research field

The search in 2019 started with a wide perspective in order to gain a broad picture of the field of ACP studies. The following electronic databases were searched: Academic Search Premier, CINAHL, and PubMed. In the initial search for studies was limited to the period of January 2006 to June 2019. The program websites, material, reports, and studies had to be in English. Studies focusing on specific ethnic groups were excluded. Studies focusing on Advance Directives only were also excluded. Full-text articles were not available for all programs or interventions identified. If the abstract provided the information necessary for the charting of the data, the abstract was included. The search terms used were ‘advance care planning dementia’, ‘advance care planning AND early dementia’, ‘advance care planning AND community setting’, and ‘advance care planning intervention AND dementia’. The ACP program names were also used as search words in combination with ‘dementia’ and ‘intervention’. The reference lists of full-text articles on ACP, ACP program reports, and book chapters were searched manually. A general internet search (Google and Google Scholar) for ACP programs was conducted as well. ACP programs were also identified through lectures during the *European Association for Palliative Care World Research Congress* in Dublin 2016 as well as through brochures obtained during the congress. A total of 56 national and regional ACP programs and interventions were identified and assessed for their dementia approach. Data consisting of program or intervention description, target group, and dementia specific components were extracted. The search was updated in February of 2023 with the time frame July 2019 – January 2023. An additional 11 interventions were identified. The comprehensive programs (n=15) are listed first, followed by regional programs and interventions (n=41).

### Mapping and description of Advance Care Planning programs.

Target group key: Person with dementia (PWD), Other patient group (OPG), Family carer (FC), Staff (S), Organization (O)

Note: if the program or intervention does not mention PWDs specifically in its description and material, PWD has been omitted in the target group column even though PWDs can be seen as belonging to the general patient group.

	ADVANCE CARE PLANNING PROGRAMS COMPREHENSIVE	
PROGRAM	PROGRAM DESCRIPTION	TARGET GROUP
*database search **grey literature search ***identified 2023		
ACP Decisions[1] <a href="http://www.acpdecisions.org">www.acpdecisions.org</a>	A non-profit foundation consisting of a group of clinicians who want to empower patients and families with video support tools. Video support tools are crafted after undergoing rigorous review by leading experts in medicine, geriatrics, oncology, cardiology, ethics, and decision-making[1].	PWD, OPG, FC, S, O

	<p>Several studies have been conducted, among them a randomized controlled trial was conducted for ACP in dementia. The results showed that participants who received both a verbal narrative describing advanced dementia and watched a video depicting a patient with advanced dementia (intervention group) were more likely to choose comfort care over life prolonging care[2].</p>	
<p>Advance Care Planning Australia /Respecting Patient Choices[3]** (2001)  <a href="https://www.advancecareplanning.org.au">https://www.advancecareplanning.org.au</a></p>	<p>Based on US program Respecting Choices[3].</p> <p>Implementation has occurred in a range of settings, the government recognizes the importance of ACP, strategy, legislation, resources and programs have been developed and promoted, access and uptake facilitated[3].</p> <p>'Start talking' is an education program developed by ACPA in partnership with Dementia Australia. The program includes ACP and dementia resources: eLearning modules, facilitator education program and manual, participant education program and manual, mentoring support and evaluation. A national collaborative study of patient and caregiver perspectives on ACP and end-of-life care in dementia is under way and will help to inform resources required for these groups[3].</p> <p>Studies that have been conducted within the Advance Care Planning Australia organization include an examination of whether plans for loss of capacity had been made by dementia care clinic clients with mild cognitive impairment or dementia[4] and a prospective comparative effectiveness cohort study comparing two models of ACP provision for community aged clients[5]</p>	<p>PWD, OPG, FC, S, O</p>
<p>Advance Care Planning / Our voice-tō tātou reo[6]** (2011)  <a href="http://www.advancecareplanning.org.nz/">http://www.advancecareplanning.org.nz/</a></p>	<p>Based on the Canadian ACP model[7].</p> <p>Systems approach to increasing consumer health literacy and engagement. ACP as the foundation of people powered health. Facilitates collaboration of interest groups with consumers, provides an environment for innovation. Educates clinicians, carers and the public, keeps the patient and their family/whanau values at the center of the process. Five-step process: thinking about, talking about, planning for, sharing, and reviewing[8].</p> <p>A co-design methodology is used to create tools and campaigns. Tools include 5 page-planning template and online guide as well as training manuals for healthcare professionals[8].</p> <p>The web site includes a link to the SuperSeniors web site[9], which contains general information for the elderly. The web site is run by the Office for Seniors through the Ministry of Social Development. The SuperSeniors web site contains a link to Dementia – Plan for the future[10].</p> <p>In December 2021, a link to ACP and dementia videos was added.</p>	<p>OPG, FC, S, O</p>

<p>The Coda Alliance[11]**  <a href="https://codaalliance.org">https://codaalliance.org</a>  The Go Wish Game[12]*  <a href="http://gowish.org/index.php">http://gowish.org/index.php</a></p>	<p>The Go Wish Game is a set of game cards created by Coda Alliance[11], a non-profit organization aiming to help individuals and their families plan and prepare for the concluding passages of life. The Coda Alliance works collaboratively to partner with the various care giving segments of the community including healthcare practitioners and institutions, hospices, and faith-based organizations[11].</p> <p>The Go Wish cards have been translated to Spanish, Portuguese, French, Japanese, Chinese, Vietnamese, Swedish, and Hebrew.</p> <p>Not specifically aimed at dementia patients.</p>	<p>OPG, FC, S, O</p>
<p>The Conversation Project[13]**  <a href="https://www.theconversationproject.org">https://www.theconversationproject.org</a></p>	<p>The Conversation Project is an Institute for Healthcare Improvement initiative to engage the public in having every person's wishes for end of life care expressed and respected. The Institute for Healthcare Improvement is a not-for-profit organization[13].</p> <p>The web-site offers conversations starter kits including an Alzheimer's/Dementia Starter Kit[13].</p>	<p>PWD, OPG, FC, S, O</p>
<p>Five Wishes[14]*  <a href="https://www.fivewishes.org/">https://www.fivewishes.org/</a></p>	<p>A program created by Aging with Dignity, a national non-profit organization and a leading advocate for the needs of elders and their caregivers. Five wishes is an Advance directive-document legally valid in most US states. Resources are offered to individuals and families as well as customized programs for healthcare providers, faith communities, attorneys, financial advisors, and any business or employer[14].</p> <p>A general program, not specifically for dementia patients. Studies not aimed at dementia patients.</p>	<p>OPG, FC, S, O</p>
<p>Gold Standards Framework[15]** (2000)  <a href="http://www.goldstandardsframework.org.uk">www.goldstandardsframework.org.uk</a></p>	<p><b>The National Gold Standards Framework</b> is a systematic, evidence-based approach to optimizing care for all patients approaching the end of life, delivered by generalist frontline care providers[7].</p> <p>GSF encourages increased advance care planning discussions. Offering all people identified to be in or approaching the last year or so of life the chance to have an open, person-centered advance care planning discussion is intrinsic within GSF programs, evaluations and accreditation. Advance Care Planning in 5 Simple Steps: Think, Talk, Record, Discuss, Share[15].</p> <p>GSF Dementia Distance Learning Program to enable staff to provide bespoke care for people with dementia nearing the end of their lives. The 4 modular online courses with 2 interactive workshops are offered to frontline staff working with people with dementia. It includes: awareness of the impact on the person and their families and person-centered care, communication and Advance Care Planning with people with dementia,</p>	<p>PWD, OPG, FC, S, O</p>

	assessment and management of pain and distress in people with dementia, and means to reduce inappropriate hospitalization with more living and dying in their usual place of residence[15].	
Let Me Decide[16]* <a href="http://www.letmedecide.org/">http://www.letmedecide.org/</a>	The Let Me Decide Advance Care Directive program aims to allow persons to plan their own future healthcare in advance. Individuals are given the opportunity to choose different levels of treatment according to his or her own wishes with the aim to help relieve family and friends of responsibility for decisions in times of crisis. The program also provides guidance for health care practitioners in making vital decisions when family members are unavailable[16]. The program offers online education about Advance Directives and EOL-discussions.  Studies aimed at nursing home implementation. Primary care setting studies not dementia specific.	OPG, FC, S, O
Living and Dying Well (Scotland)[17]** <a href="https://www.palliativecarescotland.org.uk/content/living_dying_well/">https://www.palliativecarescotland.org.uk/content/living_dying_well/</a>	Living and Dying Well, a national action plan for palliative and end of life care in Scotland. The objective is to improve people's experiences of living with declining health, death, dying and bereavement. Promotes open discussion about death, dying and bereavement. Strives to improve palliative care in different settings including nursing homes [17]. Includes links to different organizations for long-term conditions such as dementia on its web-site.	PWD, OPG, FC, S, O
National Framework for Advance Care Planning in Canada[18]** (2008)  <a href="http://www.advancecareplanning.ca">www.advancecareplanning.ca</a> <a href="http://www.planificationprealable.ca">www.planificationprealable.ca</a>	Multifaceted approach with significant national leadership, key stakeholder participation and consumer engagement strategies. Goals: raise awareness, normalize ACP conversations, provide the tools needed, and assist professionals in facilitating ACP. Online Workbook and printable Workbook (PDF) as well, toolkits specific for cancer, primary care and CPR decision making as well as illness trajectory brochures. Tools, manuals and other resources for healthcare professionals[18].  No toolkits specific for dementia patients found on the web site but when using the search word 'dementia' on the web-site, the result is a number of short texts focusing on ACP in geriatric care.	OPG, FC, S, O
Physicians' Orders for Life Sustaining Treatment (POLST) (1990s)[19]**  <a href="http://www.polst.org">www.polst.org</a>	The National POLST Paradigm is an approach to end-of-life planning that helps elicit, document and honor patient treatment wishes. The POLST Paradigm emphasizes: advance care planning conversations between patients, healthcare professionals and loved ones; shared decision-making between a patient and his/her healthcare professional and ensuring patient wishes are honored[19].  The POLST web site offers general information about ACP as well as links to additional resources and toolkits for ACP but none of them dementia specific.	OPG, FC, S, O

<p>Planning Ahead Tools[20]**  <a href="https://planningaheadtools.com.au">https://planningaheadtools.com.au</a></p>	<p>A web-site that provides information and advice for future legal, health and financial decisions[20]. The web-site provides dementia specific information.</p> <p>The campaign came to an end in 2020 and the web-site is no longer active.</p>	<p>PWD, FC</p>
<p>PREPARE[21]*  <a href="https://prepareforyourcare.org/welcome">https://prepareforyourcare.org/welcome</a>  (2008)</p>	<p>A step-by-step, web-based guide to provide skills needed to identify life goals and preferences for medical care and to communicate preferences to surrogate decision makers and physicians[21].</p> <p>A general program, not specifically for dementia patients. Studies include Sudore et al. (2014)[22] and Lum et al.[23] Lum et al.[23] conducted a study where the objective was to compare the effects of an easy-to-read advance directive (AD) versus the PREPARE web site plus the AD. Results: the PREPARE plus AD resulted in greater increases in all Behavior Change Processes subscales and Actions related to decision makers, quality of life, and flexibility[23].</p>	<p>OPG, FC</p>
<p>Respecting Choices (1990)[24]**  <a href="http://www.respectingchoices.org/">www.respectingchoices.org/</a></p>	<p>Coordinated approach to ACP where trained facilitators in collaboration with physicians assist patients and their families to reflect on goals and values, discuss and document future care choices[25].</p> <p>The mission of Respecting Choices (RC) is to guide organizations and communities worldwide to effectively implement and sustain evidence-based systems that provide person-centered care. RC has educational programs to support an organization or community transformation to a person-centered healthcare culture. RC aims to provide health systems and healthcare personnel with education and guidance with implementation of the program[25].</p> <p>RC does not have dementia specific information on its web site.  The RC evaluation studies are not dementia specific.</p>	<p>S, O</p>
<p>Think Ahead[26]**(2009)  <a href="http://www.hospicefoundation.ie/programmes/public-awareness/think-ahead/">www.hospicefoundation.ie/programmes/public-awareness/think-ahead/</a></p>	<p>Developed by the Irish Hospice Foundation (IHF) as a project of the Forum on End of Life in Ireland. Goals: to develop initiatives to help the public engage with end-of-life issues and plan their own responses. The IHF offers education for professionals as well as ACP tools in the form of brochures and publications[26].</p> <p>Offers workshops to help staff providing care to PWD to be able to communicate more effectively. The Changing Minds Programme is a suite of guidance documents to support healthcare staff working with PWD in palliative care in all care settings[26].</p> <p>Guidance documents published 2015 and 2016 offer support for ACP discussions with a person with dementia and ethical decision-making in end-of-life care of a PWD[26].  Studies not aimed specifically at dementia patients in the early stage of the disease.</p>	<p>PWD,  OPG, FC,  S, O</p>

<b>INTERVENTION</b> *database search **grey literature search ***identified 2023	<b>REGIONAL AND LOCAL ADVANCE CARE PLANNING INTERVENTIONS</b>	<b>TARGET GROUP</b>
The ACP framework tool[27]***	<p>An ACP framework tool for use with PWDs in primary care based memory clinics. Both user (health professionals) and recipient (PWD) experiences were described[27].</p> <p>Full text not available.</p>	PWD, S
The ACP+intervention[28]**	<p>The ACP+Intervention was developed to meet the need for context-specific ACP tools to aid nursing home care staff in ACP conversations. The intervention consists of three tools; an ACP conversation guide, a conversation tool, and an ACP document for recording the outcome of the conversation. Nursing home residents, including PWDs, families, and healthcare professionals are to be involved[28].</p>	PWD, FC, S, OPG
The ADIA intervention[29]**	<p>An ACP tool developed at the Zurich University hospital was used in the intervention aimed at PWDs in the early phase of dementia. The tool focuses on shared decision-making about goals of care. The decision aids were simplified to make them easier for PWDs to read and understand. The discussion was structured to include dementia specific scenarios. The aim was also to empower the surrogate decision-maker. Specially trained ACP facilitators conducted the pilot intervention.</p> <p>Results: the tool was well received by the PWD and FC. However, practical issues and structural challenges impede research in the field[29].</p>	PWD, FC
The Advance Care Planning Family Carer intervention[30]*	<p>The intervention consisted of trained facilitator, family education, family meetings, documentation of ACP decisions, and intervention orientation for general practitioners and nursing home staff. The aim of the study was to evaluate the effectiveness of the intervention in a paired cluster randomized controlled trial. Participants were the family carers of nursing home residents with dementia judged as lacking decisional capacity to participate in APC in 24 nursing homes. Results: family carer uncertainty in decision-making about the care of the resident was reduced[30].</p> <p>Intervention and study aimed at family carers and care staff of nursing home residents with advanced dementia.</p>	FC, S
The Advance Care Planning Interview intervention[31]*	<p>An interview schedule intervention with the purpose to encourage discussions about future care. The aim of the study were to explore the acceptability of the interview schedule and to explore the suitability of such discussions, the timing, their nature and their impact. Twenty-two patients, relatives and user group members participated in the focus group study. Results: not all patients may feel ready to discuss end-of-life care. The timing of the discussion likely influences the effect and acceptability. The person taking the</p>	OPG, FC



	<p>discussion initiative should be skilled and the discussions should take place over a number of meetings[31].</p> <p>Study focused on palliative and oncology patients.</p>	
APPROACHES – Aligning Patient Preferences – a Role Offering Alzheimer’s patients, Cargivers, and Healthcare providers Education and Support[32]***	<p>APPROACHES was a project developed to test and evaluate a staff-led program in nursing homes. Nursing home staff receive standardized training and implement the ACP Specialist program. The program targets nursing home residents with dementia[32].</p>	S
Brief Negotiated Interview (BNI) Interventions[33]*	<p>The BNI intervention was developed in order to empower older adults with life-limiting illness to communicate medical care goals to their primary outpatient clinicians. Adult patients with serious illnesses were enrolled and received the brief negotiated interview intervention. The encounters were video-recorded and later assessed for intervention fidelity based on adherence to the BNI steps and communication skills[33].</p> <p>Intervention not specifically aimed at dementia patients. Full text not accessible.</p>	OPG, S
The Collaborative educational intervention[34]*	<p>An educational intervention aimed at improving the ACP confidence of pre-clinical medical students. The intervention consisted of a case-based workshop facilitated by an ACP experienced physician. The workshop was added to an existing ACP curriculum. One group received both the workshop and the existing curriculum while the other group received the curriculum only. Results: no statistically significant differences in ACP knowledge or confidence were seen post-intervention. Overall confidence with ACP tasks remained relatively low[34].</p>	S
The Compassion Intervention[35]*	<p>The intervention consisted of an interdisciplinary care leader led two core intervention: integrated, interdisciplinary assessment and care as well as education and support for paid and family carers. A naturalistic feasibility study of intervention implementation was conducted. Thirty nursing home residents with advanced dementia were assessed of whom nine were participated in the study. Four of these residents’ family members were interviewed. Twenty-eight nursing home and external healthcare professionals participated in the interviews. Results: the intervention led to improvements in ACP, pain management and person-centered care[35].</p> <p>Intervention aimed at persons with advanced dementia and studies performed in nursing homes.</p>	FC, S

The Conversation Group Medical Visit[36]*	<p>The aim of the intervention was to engage patients in ACP discussion and support ACP actions. A pilot demonstration of an ACP planning group visit in a geriatrics clinic was conducted. Patient groups met in 2 sessions of 2 hours each facilitated by a geriatrician and a social worker. Results: most participants evaluated the group visit as better than usual clinic visits for discussing ACP[36].</p> <p>Intervention not specifically aimed at dementia patients.</p>	OPG
The Cosmos Intervention[37]*	<p>The Cosmos acronym stands for Communication (in the form of Advance Care Planning), Systematic assessment and treatment of pain, Medication review, Organization of activities, and Safety. The aim of this study was to investigate the effect of an ACP intervention on nursing home staff, patient and family communication. The COSMOS trial was a 4-month cluster randomized controlled trial with a 9-month follow-up. The ACP intervention consisted of an education program aimed at nursing home staff and managers[37].</p>	S, O
The Early Diagnosis Dyadic Intervention (EDDI)[38]*	<p>The EDDI intervention program provided a structured, time-limited protocol of dyadic and one-on-one dyadic counseling for family caregivers and PWDs in the early stages of dementia. A feasibility trial was conducted where 31 dyads participated in the EDDI program. Results: participant and counselor evaluations of the EDDI program indicated that the intervention was satisfactory and acceptable to all participants, and that the objectives were achievable[38].</p> <p>Note: EDDI was later developed into SHARE[39]</p>	PWD, FC, S
ENACT – Engaging in Advance Care planning Talks Group Visits intervention[40]***	<p>Human-centered design, rapid-cycle prototyping, and multiple methods were used to adapt the ENACT intervention for people with mild cognitive impairment (MCI). An advisory panel of people with (MCI) and their care partners was engaged to refine the intervention. Results: intervention participants strongly agreed that group discussions provided useful information and recommended the intervention[40].</p>	PwMCI, FC
The Family Carer Decision Support intervention[41]***	<p>The Family Carer Decision Support Intervention was developed to inform family carers about end-of-life care options for PWDs in the advanced stage of dementia. The implementation process will be studied and factors that determine the effectiveness of the intervention will be studied[41].</p>	FC, S
The Goals of Care Intervention[42]*	<p>An intervention consisting of a video decision aid and a structured care plan meeting for family decision makers for persons with advanced dementia. The objective of the study was to test a goals of care (GOC) decision aid intervention to improve quality of communication and palliative care for nursing home residents with advanced dementia. A single-blind cluster randomized clinical trial, including 302 residents with advanced</p>	FC

	<p>dementia and their family decision makers in 22 nursing homes. Results: with the GOC intervention, family decision makers reported better end-of-life communication and better quality of communication[42].</p> <p>Intervention focused on family carers of persons with advanced dementia living in nursing homes.</p>	
The Information pamphlets intervention[43,44]*	<p>A project funded by the Canadian Frailty Network. The project team developed five condition specific pamphlets[44] based on current evidence, patient education literature, and the team's collective expertise in ACP, palliative care, and EOL care. The pamphlets include the relevance of ACP, a description of the specific condition, signs and symptoms of advanced stages of the illness, advice for caregivers, and links to online resources. A study was conducted to explore whether using the pamphlets in long-term care settings can encourage residents and families to engage in ACP discussion with each other and with staff. Results: access to the pamphlets encouraged residents to reflect on future care and increased comfort in talking about end-of-life care. Questions to ask were also clarified[43].</p> <p>Intervention aimed at long-term care patients, one of five pamphlets dementia specific.</p>	PWD, OPG, FC
Interactive decision-aid for patients with amyotrophic lateral sclerosis (ALS)[45]*	<p>The study participants (forty-four patients with ALS) tested an interactive computer-based decision-aid. Results: the mean concordance between patient wishes and the clinical team decisions was significantly higher post-intervention and clinical team members reported greater confidence that their decisions accurately represented each patient's wishes post-intervention. Patients reported low decisional conflict and high satisfaction with the decision-aid[45].</p> <p>The intervention focused on patients with ALS.</p>	OPG, S
The LEAD Guide – Life-planning in Early Alzheimer's and Dementia[46]***	<p>The LEAD Guide is a dementia-focused EOL planning instrument for use by healthy adults, people in early-stage dementia, FCs, and clinicians to document EOL care preferences and values. The instrument was developed with the help of healthy older adults, PWDs in the early stage of illness, and family caregivers.</p> <p>Results: the LEAD Guide has the potential to facilitate discussion and documentation of EOL care preferences and values and has utility for healthy adults, patients, families, healthcare providers, and researchers[46].</p>	OPG, PWD, FC, S
Let Me Talk[47]*	<p>The purpose of the Let Me Talk-intervention was to clarify the end-of-life care preferences of frail elderly in nursing homes and to facilitate communication regarding care preferences among them, their family and health professionals. The study aimed to test the plausibility of engaging</p>	OPG, FC, S

	<p>nursing home residents in ACP. The study was quasi-experimental where three assessments were conducted at six-month intervals to monitor the program effects. A storytelling approach was used. Results: the treatment preference stability was significantly higher in the intervention group and significantly more participants in the group also communicated their treatment preferences to caregivers or to their family[47].</p> <p>Not specifically aimed at persons with dementia.</p>	
The Magiq Questions communication tool[48]*	<p>A communication tool that provides a simple framework for exploring the sense of meaning and purpose in life of seriously ill persons and promotes the development of a person-centered treatment plan. The aim of the study was to describe the Magiq Questions script approach and to identify key elements of person-centered ACP documentation that lead to successful care outcomes. Fifty medical trainees were surveyed about their satisfaction with the Magiq Questions tool to promote communication. Results: the experience of the medical trainees was uniformly positive and self-reported satisfaction was high[48].</p> <p>Not specifically aimed at dementia patients.</p>	OPG, FC, S
Making Advance Care Planning a Priority Program (MAPP)[49]*	<p>The MAPP program was designed to identify nursing home residents at high risk of death. The program aims to establish a relationship with the nursing home, to assist in identification of hospice eligible residents, to provide consultation to residents, and to provide support for the staff[49].</p> <p>Studies aimed at nursing home residents. Levy et al. (2008) evaluated end-of-life care outcomes for nursing home residents at high risk of death through a retrospective chart review before and after implementation of the MAPP program. Results: following implementation of the intervention, nursing home residents were less likely to die in the hospital. They were also more likely to get palliative care referrals[50].</p>	OPG, S, O
The Mindfully Optimizing Delivery of End-of-Life (MODEL) Care intervention[51,52]*	<p>The MODEL intervention was developed for adults with cancer and their family caregivers. The intervention provides 12 hours of experiential training. The training included mindfulness practices, mindful communication skills development, and information about ACP[51,52].</p> <p>Studies are aimed at oncology patients and their caregivers.</p>	OPG, FC
The Modernisation Initiative End of Life Care Programme[53]* <a href="https://www.ambercarebundle.org/Resources/Resources.aspx">https://www.ambercarebundle.org/Resources/Resources.aspx</a>	<p>The Advanced Care Planning in Early Dementia tool (APC-ED) is a document to be used in ACP discussions. The acceptability of the ACP intervention was explored in a study: Qualitative evaluation of advanced care planning in early dementia (ACP-ED). In-depth interviews were conducted with 12 patients, 8 carers, and 6 staff</p>	PWD, FC, S

	members from a memory clinic and a community mental health team. Results: PWDs and family carers found ACP a positive intervention that enabled PWDs to make their preferences known and lessened their worries about the future[54].	
The Multimedia Educational Program[55]*	<p>The multimedia educational intervention regarding end-of-life care and ACP was aimed at community-dwelling older persons. One hundred twenty-three cognitively intact older adults participated in a community-based cluster randomized trial. The efficacy of a 4-week multimedia educational intervention followed by telephone consultations was evaluated. Results: 100% of participants in the intervention group signed Advance Directives and selected hospice program care for end-of-life care. Those in the control group were less likely to do both[55].</p> <p>Aimed at cognitively intact persons. Full text not accessible.</p>	OPG
Patient Participation ACP intervention[56]*	<p>The intervention was developed to improve patient participation in nursing homes. The study was a pair-matched cluster randomized clinical trial with eight wards in eight nursing homes. All patients above age 70 were included. The intervention used a whole-ward approach. Regular staff perform ACP and invite all patients and family members to participate. Results: the patients in the intervention group wards participated more often in end-of-life treatment conversations. In addition, patients' preferences, hopes and worries were more often documented. The concordance between provided treatment and patient preferences increased. Family participation in ACP increased[56].</p> <p>Cognitively impaired persons were also included in the intervention. Full text not accessible. A detailed description of the intervention was not available.</p>	PWD, OPG, FC, S, O
Person-Centered Oncologic Care and Choices (P-COCC)[57]*	<p>A whole-patient centered ACP initiative. In a randomized trial, study participants were asked ten questions and then asked to assess the P-COCC questions for content, tone, clarity and comfort. In the second part of the study a goals-of-care video was viewed by the study participants[57].</p> <p>Aimed at patients with advanced gastrointestinal cancer.</p>	OPG
The Planning for the Future Project[58]**	<p>End-of-life care project at dementia specific unit at a hospital in Ireland. The aim of the project was to develop a framework to support staff with initiating discussions around end-of-life care with residents and families, adapting aspects from the Gold Standard Framework[58].</p> <p>The project was conducted through an action research process which started with a literature overview, staff questionnaires, resident care plan audit, and group discussions. Challenges were</p>	PWD, FC, S

	<p>identified and changes were made. Care plans were developed or adapted, staff educated and empowered, visual prompt cards developed, symptom management guidelines developed, and hospice friendly hospital resources introduced[58].</p> <p>The project focused on persons with dementia residing in a dementia specific unit.</p>	
Practice Improvement ACP intervention[59]*	<p>The ACP dementia educational program was aimed at increasing physician knowledge, attitudes and skills in order to enhance the rate of ACP conversations and documentation in a dementia specialty practice. A pre- and postintervention paired design for physicians and two independent groups for patients was used. A 10-item survey was used pre- and post-educational intervention in order to assess knowledge, attitude and skills[59].</p> <p>Full text not accessible.</p>	PWD, FC, S
Preferred Priorities of Care (PPC)[60]** Preferred Priorities for Care[61]**	<p>Two sets of similar documents used as end-of-life care planning tools[60, 61].</p> <p>No dementia care evaluation identified. Identified study aimed to explore district nurses' experiences of using PPCs in practice. Qualitative, unstructured interviews with 11 nurses and a literature review were carried out. Results: the PPC document was seen as a valuable end-of-life tool by district nurses[62].</p>	OPG
Preserving Identity and Planning for Advance Care (PIPAC)[63]*	<p>An intervention that combines identity-maintaining activities with an advance care planning discussion. A two-group comparison design was used to conduct limited-efficacy testing of the PIPAC intervention on self-reported and proxy-reported health-related and emotional outcomes of persons in the early stages of dementia. Randomization to a four-session, multi-component intervention groups or to a minimal support phone contact comparison group. The multi-component intervention focused on reminiscence and future planning. Results: Clinically meaningful differences at post-treatment for depressive symptoms, quality of life, health-related quality of life indicators, and decisional conflict were found[63].</p> <p>The target group for the intervention was persons in the early stages of dementia.</p>	PWD, FC
Nurse-supported Advance Care Planning (NSACP)[64]*	<p>The NSACP intervention focused on the risks, benefits, or alternatives of the life-sustaining medical procedures addressed in standardized Advance Directive forms. Fifty participants at a Veterans Affairs medical center were randomized to the intervention or a comparison condition[64].</p> <p>Intervention not specifically aimed at persons with dementia.</p> <p>Full text not accessible.</p>	OPG

<p>REACH (Recognise End of life and Care Holistically)[65]*</p>	<p>A toolkit developed as an aid for staff to improve recognition of the clinical features associated with the end phase of dementia. Through a systematic literature review eight signs and symptoms associated with end stage dementia were identified. The signs and symptoms were incorporated in the toolkit which was then reviewed by experienced clinicians. The toolkit was then trialed in six aged care facilities. Result: 182 residents with dementia were identified as being at the end and the toolkit provided a process for communication about the direction of care[65].</p> <p>Intervention and studies focus on advance dementia patients in long-term care setting.</p>	<p>PWD, S</p>
<p>SHARING Choices[66]***</p>	<p>SHARING Choices is multicomponent intervention for older adults with or without dementia with the aim to improve communication by engaging the patient and family in ACP. The effects of SHARING Choices were tested in 3 patient groups, all older adults, PWDs, and those who die. Lay facilitators, nurses, medical assistants, and social workers were used as facilitators. The core of the ACP training was Respecting Choices [66].</p>	<p>OPG, PWD</p>
<p>SPIRIT (Sharing the patient's illness representations to increase trust)[67]*</p>	<p>A theory based, patient- and family-centered advance care planning intervention. The SPIRIT intervention was theory-guided, based on the Intervention Taxonomy from Schulz et al.(2010). The intervention was pilot tested with target patient populations[67].</p> <p>The SPIRIT intervention is being adapted to target people with mild dementia. The SPIRIT intervention will be adapted through a process of modification, pretesting and refinement using persons with mild dementia, family caregivers, and clinicians[68].</p> <p>Full text not accessible.</p>	<p>PWD, FC, S</p>
<p>The Structured conversations intervention[69]*</p>	<p>The 6-month prospective, randomized trial tested the effect of an intervention which consisted of structured face-to-face conversations about end-of-life care options with family members of persons with advanced dementia residing in nursing homes. The comparison group received only social contact via telephone. The structured conversations included goals of care and how to best achieve those goals as well as psychosocial support. Results: the intervention families had higher satisfaction with care than comparison families and were more likely to have decided on medical options listed in residents' advance directives[69].</p> <p>The study focused on nursing home residents with advanced dementia and their family members.</p>	<p>PWD, FC</p>

<p>The Support, Health, Activities, Resources, Education (SHARE) program for dementia[70]*  <a href="http://www.benrose.org/share/">http://www.benrose.org/share/</a></p> <p>Note: SHARE was earlier referred to as EDDI (The Early Diagnosis Dyadic Intervention)[38]</p>	<p>SHARE is an evidence-based care-planning program that provides professionals with the tools they need to help families facing an early-stage dementia diagnosis. Each SHARE session is designed to engage both the person with early-stage dementia and their care partner in discussions about symptoms, communication, care values and preferences, healthy activities and planning for the future[70].</p> <p>The implementation of SHARE was described in a study. The SHARE program for dementia: Implementation of an early-stage dyadic care-planning intervention. Data was collected from 40 early-stage dementia care dyads to determine the acceptability of having structured discussions about future care in the early phase of dementia. The results showed the importance of planning in the early stages while the person with dementia can express their values and preferences for future care[70].</p> <p>The study focused on early stage dementia patients and their family carers.</p>	<p>PWD, FC, S</p>
<p>The Transtheoretical Model (TTM) of behavior change[71]*</p>	<p>Personalized intervention materials in order to promote ACP based on the TTM in which readiness to change is a critical organizing construct. A development study was conducted in order to create an expert system delivering TTM-personalized feedback reports and brochures with general information on ACP and modifications based on the reviews of the participants. The participants were community-living persons aged 65 and older. Results: initial review indicated unacceptable length which led to a revision. After the revision, the majority of the participants rated the materials as easy to read, informative, trustworthy, and increasing interest in ACP participation[71].</p> <p>Intervention and studies not specifically aimed at dementia patients.</p>	<p>OPG</p>
<p>Voice Your Values[72]***</p>	<p>Voice Your Values is an intervention developed for healthcare professionals to help identify and document the values of people living with mild dementia and their family or friends. The intervention was assessed in a pilot study for feasibility, acceptability, and preliminary efficacy in community-dwelling older people. The study resulted in promising evidence that people living with mild dementia can effectively participated in ACP[72]. (Vellani)</p>	<p>PWD, FC, S</p>
<p>weDECide intervention[73]*</p>	<p>The weDECide intervention is educational and aimed at nursing home staff. The intervention educates staff on shared decision-making in the context of ACP for residents with dementia. The study design was quasi-experimental pre-test-post-test and conducted in 18 nursing homes. Results: after weDECide, ACP policy was significantly more compliant with best practice while policy in the</p>	<p>S, O</p>



	<p>control group was not. However, residents and families were not involved in conversations to a higher degree after weDECide, nor was ACP discussed more frequently.[73].</p> <p>The intervention focused on nursing home staff. Full text not accessible.</p>	
<p>Your Conversation Starter Kit-workbook[74]***</p>	<p>A pilot intervention exploring the views of people with dementia and their caregivers on using a self-directed ACP engagement workbook called Your Conversation Starter Kit. The findings of two phases of the study show that the workbook is promising in supporting ACP engagement for people in the early stage of their condition [74].</p>	<p>PWD, FC</p>

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## **Original publications**





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# Advance Care Planning interventions for older people with early-stage dementia: A scoping review

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## Abstract

Advance Care Planning can be used to engage people with dementia in decision-making about future care. The current study aims to advance the state of knowledge about Advance Care Planning interventions aimed at older people with early-stage dementia and to describe the effects of various interventions as well as the feedback on the interventions from this patient group and their family caregivers. The study is reported in accordance with PRISMA for scoping reviews. The search for studies and reports included electronic databases, websites, books, and reference lists. Data from the selected studies, including publication year, title, purpose, study population, intervention, methods, and results, were extracted. Six full-text articles were identified as suitable for inclusion. The six interventions had differing approaches. A supportive structure was helpful for both people with dementia and family caregivers. The feeling of being listened to and engaged in the care planning seems to be of most importance, not the intervention design itself.

## Keywords

Advance Care Planning, aged, dementia, nursing services, scoping review

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## Introduction

Different types of dementia belong to the most challenging issues in current healthcare. A dementia diagnosis is associated with impaired functional abilities, reduced quality of life, psychosocial distress, and social isolation. The number of people with an Alzheimer's disease diagnosis is estimated to reach close to 110 million in the year 2050. In the absence of prevention strategies and therapeutic interventions, an estimated one in 85 people will be living with Alzheimer's.<sup>1–4</sup> Advance Care Planning (ACP) can be used to engage people with dementia and their family members in decision-making about future care.<sup>5,6</sup> In 2017, a large, multidisciplinary Delphi panel of ACP experts reached a consensus on an extended definition and a brief definition of ACP.<sup>6</sup> The brief definition is as follows:

Advance care planning enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate.<sup>6</sup>

Through ACP, the autonomy of patients can be extended beyond the loss of competency.<sup>5–8</sup> Planning for future care is seen as a way to improve the quality of end-of-life care

for dementia patients in some studies,<sup>6,9</sup> while other studies report a lack of evidence.<sup>10,11</sup> The care of people with dementia raises many ethical issues as the ability to communicate one's wishes is diminished as the dementia progresses<sup>4,6,9,12–15</sup> and decision-making abilities are affected.<sup>16–18</sup> In the early stage of dementia, a person might already struggle to imagine what the future might hold and to plan for coming care needs.<sup>19–22</sup> The progressive loss of abilities leads to a vulnerability that becomes total and extraordinary as it is situated in all dimensions of the being.<sup>23,24</sup>

ACP for people with dementia has received attention in recent years. There are a number of recent studies highlighting barriers and facilitators as well as evaluating efficacy of ACP in dementia care and subsequent effects

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on end-of-life care. Most of these studies explore issues pertaining to the advanced stage of dementia and/or long-term care settings.<sup>6,22,25–30</sup> The field of research in ACP in early-stage dementia is less developed. According to van der Steen et al.,<sup>31</sup> the community setting as well as patients' and nurses' perspectives are understudied. The need to determine the most relevant outcome measures for evaluating ACP is urgent<sup>6,32</sup> and even more so when it comes to ACP for people with dementia.

This study is the first in a PhD project with the aim to develop an ACP model for older people in the early phase of dementia and their family caregivers. The purpose of this study is to advance the state of knowledge about ACP interventions aimed at older people with early-stage dementia, and to describe the effects of various interventions as well as the feedback on the interventions from this patient group and their family caregivers. The research questions are: what type of ACP interventions have been developed for people with early-stage dementia? How have people in the early stage of dementia and their family caregivers perceived and been affected by the interventions?

## Design

The method used for the study is scoping review as first described by Arksey and O'Malley<sup>33</sup> and further advanced by Levac, Colquhoun and O'Brien<sup>34</sup> as well as by Peters et al.<sup>35</sup> As ACP program evaluation reports were expected to provide part of the data material for the current study, a scoping review was determined to be the most relevant study method.

### Identifying relevant studies

In order to identify relevant studies and reports describing ACP interventions for people with dementia, a literature search was conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines<sup>36</sup> (supplementary file 1, available online). The following electronic databases were searched: EBSCO (Academic Search Premier), CINAHL, PubMed, SAGE Journals, and FINNA. FINNA is a search service entity providing access to material from Finnish libraries, archives and museums.<sup>37</sup> The search words used were 'advance care planning dementia', 'complex advance care planning', 'advance care planning AND early dementia', 'advance care planning AND community setting', 'advance care planning intervention AND early dementia'. The search words 'complex advance care planning' refer to the difference between Advance Directives which can be seen as more straightforward and 'simple', while ACP is seen as a more complex and meaningful process.<sup>8,38</sup> National ACP program names were also used as search words in combination with 'dementia' and 'intervention'. The search started with a wide perspective in order to gain a broad picture of the field of ACP studies related to dementia care. The search was narrowed with the search words 'early dementia' AND 'intervention'. The

reference lists of full-text articles on ACP, ACP program reports, and book chapters were searched manually.

### Study selection

In order to be included, papers and reports had to be in English and had to describe ACP interventions aimed at older people with dementia in a community setting. The study focused on older people with dementia as prevalence increases with age<sup>39</sup> and young-onset dementia presents different challenges.<sup>40</sup> The studies had to include feedback on the intervention from the people with dementia themselves. The papers had to have been published between January 2006 and June 2019. Studies in a non-Western context and studies focusing on specific ethnic groups were excluded. Studies focusing on Advance Directives only were also excluded. The wide perspective search of the electronic databases retrieved 4799 records after duplicates were removed. The titles of the records identified were screened by the first author for perceived relevance to the focus of the study. Three hundred and five abstracts were reviewed and evaluated independently by two of the authors. Seventy full-text articles and abstracts were assessed for inclusion in the review. In cases of ambiguity, all authors assessed the articles for inclusion to ensure ethical credibility. In the end, six eligible studies were identified as describing ACP interventions for early-stage dementia patients from the person with dementia's point of view and thus were included. A flow chart describing the process is included in Figure 1.

### Charting the data and extracting the results

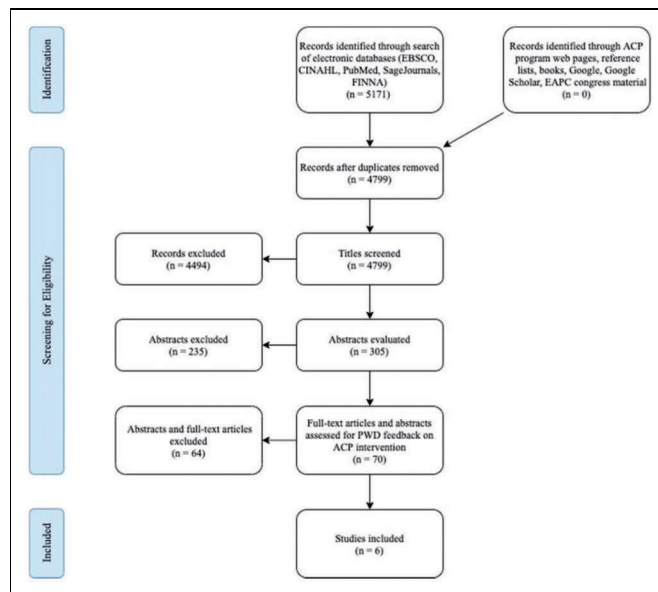
The full-text articles identified as suitable for inclusion in the scoping review ( $n=6$ ) were reviewed by all authors to ensure ethical credibility. Data including publication year, title, purpose, study population, intervention, methods, and results were charted and extracted (supplementary file 2, available online). After data charting and extraction, the data were summarized to provide answers to the research questions.<sup>33,35</sup> In this review, external stakeholders were not involved in the data search, data extraction, nor in the publication process.

### Ethical considerations

This scoping review is the first sub-study in a PhD research project with the aim to develop an ACP model for older people in the early phase of dementia and their family caregivers. The PhD research project has been approved by the ethical committee of Åbo Akademi University. Ethical approval was not required for the scoping review.

## Results

In the search for studies and reports describing ACP interventions for people with early-stage dementia, six scientific studies<sup>41–46</sup> were found (supplementary file 2). The six studies focused on the ACP intervention, the results of



**Figure 1.** Flow chart of the study selection.  
 Note. ACP: Advance Care Planning; PWD: People with dementia.

the intervention, and included feedback from the people with dementia on the ACP process. Despite the low number of studies identified, the studies describe a relatively wide range of intervention types.

### *In-home sessions with trained facilitators*

Three of the ACP interventions for people with early-stage dementia included in-home sessions with facilitators, such as experienced research assistants trained to complete the assessments<sup>41</sup> and trained counselors with dementia expertise.<sup>43,46</sup>

The Preserving Identity and Planning for Advance Care (PIPAC) intervention<sup>41</sup> implemented a two-group comparison design using blocked randomization stratified by gender and race to assign 19 dyads to either a multicomponent intervention group using trained interventionists or a minimal support phone contact comparison group. The dyads consisted of a person with mild dementia and a family contact. The PIPAC intervention focused on the identity of the person with dementia by combining identity-maintaining activities with an ACP discussion. The intervention consisted of four in-home sessions over 4–6 weeks. Trained interventionists combined one future planning component, one reminiscence-based component, and the Cohen-Mansfield Identity Interview. The aim was to enhance well-being and quality of life and to maximize coping in the early phase of dementia.<sup>41</sup> Acceptability and feasibility data were collected through a variety of methods, including a treatment implementation documentation and

a program satisfaction measure. Hilgeman et al.<sup>41</sup> used validated instruments to assess quality of life, meaning in life, emotional support and connectedness, health-related quality of life, perceptions of uncertainty in choosing future medical care, and symptoms such as depression and anxiety.

In the Early Diagnosis Dyadic Intervention (EDDI), Whitlatch et al.<sup>46</sup> used trained counselors with dementia expertise to lead sessions in a feasibility trial. Thirty-one dyads participated in the study. The EDDI focused on viewing both members of the dyad as partners. The intervention consisted of nine sessions performed both jointly and one-on-one with care receivers and family caregivers. The aim of the sessions was to help participants express preferences and concerns and to strengthen the relationship bond. Intervention tools and materials such as notebooks, worksheets, diagrams, and magnetic manipulations boards were designed and used during the sessions. Data were collected through the completion of evaluation forms after each session.

For the Support, Health, Activities, Resources, and Education (SHARE) intervention,<sup>43</sup> extensively trained counselors were used to implement and evaluate a counseling-based care planning intervention for 40 early-stage dementia care dyads. The intervention focused on empowerment and self-efficacy. The intervention consisted of seven structured sessions where care values and preferences were assessed, specific material covered, and a care plan developed. The SHARE approach focused on self-efficacy and empowerment for both the person with

dementia and the family caregiver. Person with dementia and family caregiver comments were analyzed and themes coded. Baseline data from the Care Preference Scale were compared to the post-intervention data.<sup>43</sup> It should be noted that the SHARE intervention<sup>43</sup> is a more recent and re-named version of the EDDI,<sup>46</sup> both of which have been included in this study. During the EDDI study, it was noted that some of the original domain names and tools were too challenging and required simplification. An overlap of material led to a reduction in the number of sessions from nine to seven. Since few dyads completed the homework between sessions, the homework was eliminated. In addition, a pre-session was added in order to gather information and assess appropriateness.<sup>46</sup>

### *Patient choices in a clinical setting*

The remaining three interventions all had differing approaches conducted in clinical settings. Lewis et al.<sup>42</sup> introduced ACP to people with recently diagnosed dementia or mild cognitive impairment in a three-stage project over a period of eight months through a specialist memory clinic. The intervention was based on the Respecting Patient Choices program, which incorporates appointment of enduring powers of attorney, refusal of treatment certificates, and statement of choices used to guide future treatment.<sup>47</sup> Specialist memory clinic clients received a survey in the mail. The survey assessed completed documentation for future care, the understanding of ACP, and interest in further information about ACP. Those participants who were interested in further information were invited to a seminar and provided feedback afterwards. Seminar participants were then invited to complete ACP documentation together with an ACP clinician. Participants in this third stage provided an evaluation of the stage. The initial survey was mailed to 97 clients and 92 carers. In the third and final stage, three clients and two carers remained to complete ACP documentation.<sup>42</sup>

Poppe et al.<sup>44</sup> in turn created a structured ACP tool in order to structure and facilitate the discussion at two memory services. A theoretical model or framework underpinning the ACP tool was not mentioned. The tool included questions such as 'What would you like to know about your care and treatment, how much information do you normally like to have? Are you the sort of person that likes to have all of the information, or would you prefer not to know too much?' People with dementia were identified through two memory services, either from the case load of cases or during the diagnostic assessment. Post-intervention data were collected through in-depth interviews with 12 people with dementia, eight family caregivers, and six care staff members. The interviews were qualitatively analyzed through the constant comparison method.<sup>44</sup>

Lastly, Volandes et al.<sup>45</sup> used a video decision support tool in four primary care clinics (two adult medicine and two geriatric). The effects of the tool were evaluated on preferences for future medical care if advanced dementia were to develop. In the study, a theoretical model or

framework underpinning the ACP tool was not mentioned. Participants were recruited during clinic visits that were part of their usual care. In the randomized controlled trial, a group of 94 people received a verbal description of advanced dementia while the other group of 106 people viewed a two-minute long video depicting a patient with advanced dementia in a nursing home setting. In the group receiving a verbal description, 12 people (11%) had a dementia diagnosis. The video description group had six people (6%) with a dementia diagnosis. The study was included despite not all participants being people with dementia as the number of people with dementia participating was relatively large as compared to the number of participants in the other included studies. The study did not mention a difference in response between people with dementia and people with no dementia diagnosis. Before and after the intervention, data were collected through structured questionnaires where participants chose between options for preferences for goals of care.<sup>45</sup>

### *Post-intervention effects: Participant perspective*

Almost all family caregivers and people with dementia felt comfortable discussing with their dyad partner, which indicates that a supportive structure is helpful when having difficult discussions with each other.<sup>43,44</sup> Overall, there were no significant differences between post-intervention effects reported by people with dementia and family caregivers. However, the importance of staff style and skill was especially noted by family caregivers.<sup>43,46</sup> Both people with dementia and family caregivers suggested that properly trained staff could advise on the right time in the dementia progression to begin the ACP intervention and to initiate the ACP discussions as well.<sup>44</sup>

The post-intervention effects reported by people with dementia included fewer depressive symptoms, increased quality of life (on the Bath Assessment of Subjective Quality of Life in Dementia measure), less overall conflict or discomfort with ACP, as well as feeling more supported in decision-making and having more coping strategies. Family caregivers also experienced fewer symptoms of depression.<sup>41</sup> Other effects included opportunity to express thoughts and feelings and overall satisfaction with having completed the full intervention.<sup>42-44,46</sup> The ACP intervention affected family dynamics in that some person with dementia-caregiver dyads experienced an improved relationship and overall relief from having discussed the future.<sup>42-44</sup> Post-intervention family caregivers felt more confident that the necessary future decisions made would reflect the patient's wishes.<sup>44</sup> The majority of person with dementia-family caregiver dyads felt better prepared for the future, more confident about decision-making, and felt more in control of the situation.<sup>43</sup> In the study evaluating the video support tool, patients who viewed the video were more likely to choose a comfort-oriented approach compared to patients in the control group who received a verbal description instead. The choices of the group

using the video decision support tool were also found to be more stable over time.<sup>45</sup>

Only one of the studies<sup>41</sup> reported a number of neutral effects post intervention; the intervention did not appear to affect self-reported anxiety, social engagement, meaning, anticipated and emotional support, and quality of life as measured by the Quality of Life in Alzheimer's Disease scale. Negative effects on well-being post intervention were reported in one study<sup>44</sup> and included feeling dispirited and finding the topic difficult to discuss. In the six studies included in this review, most respondents (people with dementia and family caregivers) indicated satisfaction with the interventions used. The feeling of being listened to and engaged in the care planning seems to be of most importance, not the intervention design itself. The effects of the ACP intervention as well as the factors associated with a positive or negative intervention impact provide a structure for the optimal ACP discussion.

### *Evaluation of interventions*

In the intervention structure, attention has been given to the number of sessions, session length, session structure, as well as to the material provided and topics discussed. Several different types of interventions were tested in the included studies: seminars, in-depth interviews, counselor sessions, and a video decision support tool.<sup>41–46</sup> A structured design was found to help ground the care dyad to the present, thus enabling a future case discussion in a supportive and safe way.<sup>33</sup>

In five of the six studies, a family caregiver had been included, and the intervention was performed in a person with dementia–family caregiver dyad.<sup>41–44,46</sup> Two of the studies included feedback from care staff in the form of nurses<sup>30</sup> and session counselors<sup>46</sup> in addition to the feedback from the person with dementia–family caregiver dyad. One of the studies was qualitative, using in-depth interviews to evaluate the intervention<sup>44</sup> while the other studies used both quantitative and qualitative methods to evaluate the interventions. Only one of the studies used a randomized controlled trial (RCT) design.<sup>45</sup> The sample sizes were also relatively small, from 18 people with dementia in the RCT study<sup>45</sup> to 80 people with dementia and family caregivers (40 dyads) in the Orsulic-Jeras et al.<sup>43</sup> study.

### **Discussion**

People with diminishing cognition is a group seldom heard and engaged in the research process.<sup>48</sup> In dementia care, an approach that incorporates a human-centered design<sup>49</sup> with an understanding of the challenges faced by patients and care staff is important to improve quality of care and vital to the development of ACP interventions for people with dementia and their family caregivers. In this scoping review, six studies describing ACP interventions for early-stage dementia patients have been charted and summarized. The studies describe a relatively wide range of intervention types such as counselor sessions,<sup>43,46</sup>

seminars,<sup>42</sup> and video images,<sup>45</sup> among others. The majority of the respondents (people with dementia and family caregivers) indicated satisfaction with the interventions used. This satisfaction can be seen in how the ACP interventions affected participants in mostly positive ways. People with dementia and family caregivers indicated satisfaction with the type of intervention used despite the significant differences between the interventions tested in the included studies.

When describing lessons learned from a pilot study of the patient-centered ACP interview, Briggs<sup>50</sup> states that 'listening is the intervention'. The person with dementia–family caregiver dyads experienced relief from having discussed the future as well as an improved relationship.<sup>42–44</sup> One of the ACP interventions explored the concept of family caregiver burden and ways of reducing that burden in a meaningful way.<sup>43</sup> Family caregivers felt increased confidence about decision-making and felt better prepared for the future.<sup>43,44</sup> On the other hand, some of the people with dementia found the ACP discussion disheartening and some felt that it was difficult to discuss the future without knowing what the future will bring.<sup>44</sup>

Several studies have highlighted barriers to end-of-life care planning. Dening, Jones and Sampson<sup>19</sup> and Jones et al.<sup>18</sup> found that successful participation in an ACP intervention is affected by the ability of the person with dementia to consider their future and how life may change as the illness progresses. People with dementia may experience trouble when considering their future selves and make assumptions about retained independence. People are also reluctant to think about their own death or the death of loved ones.<sup>51</sup> Hirschman, Kapo and Karlawish<sup>26</sup> identified remediable barriers to ACP discussions, including not knowing what to talk about, when to talk, and waiting until it was too late.

These factors of the care dyad and future care discussion begin to paint a picture of the optimal ACP structure. Findings show that dyads that are able to work together are able to create a preliminary care plan that is based on the care values of the person with dementia, and is balanced and realistic.<sup>43</sup> The person with dementia may be able and willing to talk about future care with their family caregiver, but these talks do not always take place.<sup>26,43,44</sup> Dickinson et al.<sup>22</sup> noted that life-long conversations led to a confidence in unspoken knowledge to help inform future decision-making. However, according to research, family caregivers may lack full comprehension of what people with dementia see as important and how it relates to care.<sup>43,52</sup>

The optimal structure for discussions of future care has been seen as the person with dementia–family caregiver dyad working as a team, supported by the work of e.g. Wilson,<sup>53</sup> Kitwood,<sup>54</sup> and Keady and Nolan.<sup>55</sup> Harrison Dening<sup>9</sup> suggests that, in dementia care, a person-centered approach is not enough as it may cause conflict with the perspectives and preferences of a family caregiver and vice versa. Harrison Dening<sup>9</sup> goes on to suggest that a relationship-centered approach may be more appropriate.

In a relationship-centered approach, the whole family may be included. Nolan et al.<sup>56</sup> suggest a relationship-centered dementia care model where the nurse works together with the person with dementia and the family caregiver in a triad, in order to promote senses of belonging, security, continuity, purpose, achievement, and significance. A relationship-centered ACP intervention is also supported by the results of the Advanced Care Planning in Early Dementia (ACP-ED) intervention study by Poppe et al.<sup>44</sup>

Research has looked into various tools to be used in ACP in order to assist facilitators in achieving the optimal ACP structure. In their report, Butler et al.<sup>57</sup> describe ACP decision aids as supportive of certain key components of the process, such as learning about what to expect, care options, reflecting on care options, and communicating preferences for future care. Butler et al.<sup>57</sup> call for easily accessible, understandable, readable tools appropriate for patients working across various settings and with various facilitators. Volandes et al.<sup>45</sup> conducted ACP research with the help of video images; a tool often conveying more understanding than a text describing the same phenomena. In the study which evaluated the video support tool, patients who viewed the video were more likely to choose a comfort-oriented approach compared to patients in the control group who received a verbal description instead. The participants also indicated that the video support tool was highly acceptable.<sup>45</sup>

There are several ethical challenges in in the ACP process for people with early-stage dementia. In March 2015, during the First WHO Ministerial Conference on Global Action Against Dementia, the importance of paying attention to people with dementia from a human rights perspective was emphasized. The dignity, needs, and wishes of people with dementia are to be respected in all phases of the illness.<sup>58</sup> One of the ethical challenges is overcoming the traditionally paternalistic attitudes of healthcare workers. Community expectations for increased community care and improved palliative care for patients with chronic conditions have grown, leading to shifts in general ethical principles underlying healthcare decision-making. There is an increased respect for patient autonomy when it comes to making decisions about medical treatment and healthcare.<sup>59</sup> However, Gastmans<sup>23</sup> argues for an approach that goes beyond the principles of autonomy, nonmaleficence, beneficence, and justice, principles that are dominant model in medical ethics. Gastmans<sup>23</sup> introduces a dignity-enhancing ethical framework where the vulnerability of people with dementia is seen as an extraordinary vulnerability, requiring carers to have the ethical attitudes of responsibility and competency.

Studies indicate that nurses and nurse practitioners are well positioned to initiate and lead ACP discussions as well as suited to participate in the development of ACP processes and models. In two of the studies included in this scoping review, it was suggested that outpatient memory clinics with properly trained and resourced staff were suitable for the initiation of ACP discussions.<sup>42,44</sup> However, the role of nurses and nurse practitioners was not explicated. In a scoping review of experiences of ACP for people

with dementia conducted by Jones et al.,<sup>18</sup> it was found that community nurses and palliative care specialists had the most experience of discussing and developing ACP and were therefore the most confident in initiating ACP. Yeun-Sim Jeong, Higgins and McMillan<sup>60</sup> highlight the role of the nurse in ACP when describing the clinical nurse consultant role as a broker who acts as an intermediary in decision-making (between family and doctors), collects information, initiates interventions, educates clients and peers, and acts as client advocate. Cotter et al.,<sup>14</sup> in turn, state that nurse practitioners have a responsibility to facilitate the ACP discussion with people in the early phase of dementia. However, a recent systematic review by Blackwood et al.<sup>61</sup> found that there is a need for increased focus on the training and education required for both nurses and other healthcare staff for ACP to become a routine part of clinical practice.

A challenge in dementia care is the lack of continuity in the contact with care professionals. As the dementia progresses and the care needs of the person with dementia increases, the place of care changes from outpatient memory clinics to assisted-living facilities and nursing homes. In this type of dementia care structure, the person with dementia and his/her family caregiver will encounter many nurses and doctors along the illness trajectory who are not necessarily familiar with the person with dementia and his/her family and their care preferences and wishes for end-of-life care. A focus on the re-structuring of dementia care to ensure care contact continuity is essential.

In summary, initiatives to develop a standardized, semi-structured, and simple tool for systematic ACP discussions with this patient group and their family caregivers are required. Furthermore, the professional group responsible for these discussions should be explicated. The number of studies identified that have included feedback from people with dementia was low. This indicates the need for further studies that include people with dementia in the early phase of the illness trajectory. The gaps also include a lack of validated tools to evaluate ACP intervention feasibility and acceptability from the perspective of the people with dementia themselves. Studies that focus on outcome and process evaluations are equally essential; however, there is a lack of validated evaluation tools. Examples of ACP outcome evaluation studies include a randomized controlled trial where Detering et al.<sup>62</sup> investigated the impact of ACP on end-of-life care in legally competent elderly patients. The primary outcome measure was whether the patient's end-of-life wishes were known and respected. Other outcome evaluations such as monitoring emergency admissions to hospital after ACP in a nursing home setting have been conducted as well.<sup>63</sup> Klingler et al.<sup>64</sup> studied the cost implications of ACP and the associated ethical conflicts. In dementia care, ACP outcome evaluations which focus on the satisfaction of the family caregiver should be emphasized as the person with end-stage dementia is no longer able to communicate his or her satisfaction with the care.



The current study's strengths are the description of ACP interventions aimed at older people with early-stage dementia as well as its focus on the experience of the person with dementia and, in extension, his/her family caregiver. The number of included studies was low due to the stringent inclusion criteria, which limited the studies to those where the feedback from the people with dementia themselves was reported. The studies were also limited to English-speaking, Western countries. The number of participants in the identified studies was low as most were qualitative studies. Pilot interventions were tested and evaluated. Only one of the studies had a randomized controlled trial design,<sup>45</sup> while another had a two-group comparison design.<sup>41</sup>

## Conclusion

There is a general consensus that ACP in dementia care can be a valuable way to alleviate suffering for both people with dementia and family caregivers. ACP for dementia patients provides an opportunity for relationship-centered triad care that includes the person with dementia, the family caregiver, and professional care staff. Staff competence is of great significance in ACP for all patient groups; even more so in dementia care where the diminishing cognition, reduced decision capacity, and extraordinary vulnerability associated with the illness provide significant ethical challenges. The ACP process should be organized as a continuous collaboration between care professionals, people with dementia and their family caregiver. The ethical challenges, the complexity of ACP program or intervention implementations in early-stage dementia care, and the development of process and outcome evaluation measures need further study. The results of the scoping review provide a starting point for healthcare organizations, such as memory clinics, to develop a structure for ACP discussions with people with dementia and their family caregivers.

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## Author contribution

All authors, Annika Tetrault, Maj-Helen Nyback, Heli Vaartio-Rajalin, and Lisbeth Fagerström meet the criteria for authorship. All authors contributed to the conception and the design of the study, acquisition of data, and the selection of studies. All authors participated in the review of data, analysis and interpretation of data, and critical reading and revision of the article. Annika Tetrault wrote the first draft of the manuscript. All authors have read and approved the final manuscript.

## Conflict of interest


The authors declare that there is no conflict of interest.

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## Supplemental material

Supplemental material for this article is available online.

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# Advance care planning in dementia care: Wants, beliefs, and insight

Nursing Ethics

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## Abstract

**Background:** Advance care planning gives patients and their family members the possibility to consider and make decisions regarding future care and medical procedures.

**Aim:** To explore the view of people in the early stage of dementia on planning for future care.

**Research design:** The study is a qualitative interview study with a semistructured interview guide. The data were analyzed according to the Qualitative Analysis Guide of Leuven.

**Participants and research context:** Dementia nurses assisted in the recruiting of people with dementia for participation in the study. Study information was mailed to 95 people with early stage dementia. Ten people with dementia and eight caregiver spouses participated in the study.

**Ethical considerations:** People with dementia belong to a vulnerable patient group, and care was taken in the areas of informed consent and accessible information.

**Findings:** The views of people with dementia are characterized by a complex storyline involving tensions and movement within the themes of wants, beliefs, and levels of insight. Participants wanted to think about the future but also wanted to live in the here and now.

**Discussion:** High demands are placed on the advance care planning process for people with dementia and their family caregivers. A dignity-enhancing approach in dementia care emphasizes the dignity of and respect for this vulnerable and care-dependent patient group.

**Conclusion:** The process of advance care planning in dementia care needs to go beyond person-centered care to a relationship-centered process. The illness trajectory and the impact on autonomy need to be taken into consideration.

## Keywords

Advance care planning, autonomy, dementia, relationship-centered care, the qualitative analysis guide of Leuven

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## Introduction

Supporting autonomy and engagement in care are at the core of ethical values in healthcare<sup>1</sup> and important concepts in person-centered care. The person is to be treated as a unique individual and his or her preferences to be taken into consideration. The recommended treatments, risks and benefits, available alternatives, and likely outcomes of no treatment need to be known to the patient.<sup>2</sup> Life-prolonging care at the end of life is not always in harmony with the needs and intents of the patient.<sup>3,4</sup> An important way to alleviate this discrepancy is to engage the patient in care decisions,<sup>4,5</sup> including end-of-life care decisions.

Advance care planning (ACP) is a means of extending patient autonomy to a phase of life where patients are no longer capable of making their own care decisions.<sup>4,6</sup> It can be described as a process of discussion about the goals for care<sup>4</sup> and gives patients and their family members the possibility to consider the kind of care and medical procedures that are acceptable or not acceptable in the future.<sup>4,6</sup> Person-centered care is also a process in which the patient's life experiences, wishes, and interests are sought as a basis for a care plan<sup>7,8</sup> and the inclusion of family members is part of the process.<sup>9</sup> Within dementia care, the challenges of the ACP process reach another dimension as the person with dementia (PWD) will gradually lose cognitive and functional abilities.<sup>2,10–12</sup> Capability for autonomy should not be seen as the capability to make rational decisions.<sup>13</sup> Ethical challenges arise when trying to balance a need of PWD for independence and autonomy with the degree to which lost abilities affect decision-making capacity.<sup>14</sup>

This study is part of a project which aims to develop a model for a relationship-centered ACP process in dementia care. The objective of the current study is to explore the view of people in the early stage of dementia on planning for future care. How do they describe and understand their current circumstances and their ability to affect their future situation?

## Background

Dementia is a global issue of concern with the number of people living with dementia expected to double every two decades.<sup>15</sup> In recent years, ACP in dementia care has received attention with a number of studies exploring barriers and facilitators as well as subsequent effects on end-of-life care.<sup>6,16,17</sup> A challenge in the ACP process is the need for guidance pertaining to the timing of ACP as well as to the approach chosen when introducing the ACP concept to patients and their family members.<sup>10</sup> A survey of general practitioners' perceptions on ACP for people with dementia (PWDs) indicated that most respondents agreed that discussions in the early stages would make decision-making easier during the advanced stage of the disease. However, many were reluctant to holding these discussions at the time of diagnosis. The optimal timing was viewed as being determined by the readiness of the patient and family to acknowledge the end-of-life considerations.<sup>18</sup>

Many ACP programs and interventions have been developed as evidenced by the results of a recent scoping review.<sup>19</sup> There is a general lack of dementia-specific components in a number of the identified ACP programs and interventions. A low number of published ACP intervention studies include feedback on the interventions from the people with dementia themselves.<sup>19</sup>

In Finland, palliative care has received attention during the last two decades with reports and recommendations produced by the Ministry of Social Affairs and Health.<sup>20</sup> Concepts related to ACP, such as advanced directives, advance decisions to refuse treatment, and lasting power of attorney, have been in use for a long time.<sup>21</sup> However, ACP has not received attention in Finland until fairly recently,<sup>20,21</sup> and thus, there are few relevant studies.<sup>21</sup>



## Methodology

### Research setting

The context is dementia care in the Finnish welfare society. Finland is a developed country with an established home-nursing and long-term care infrastructure according to the “Nordic model,” characterized by strong institutionalized care for older people.<sup>22,23</sup> In a society with a government-financed healthcare and social care system, the population lives with the beliefs, hopes, and expectations that society will take care of the ill and the older people, and that family members and relatives will not be expected to provide and finance long-term care.<sup>24</sup>

### Design

The study is a qualitative interview study with an inductive approach and a semistructured interview guide (Supplemental file 1). The interview guide was constructed by two of the research team members and evaluated and approved by the remaining two team members. The general area of inquiry revolved around the wishes of the PWD since being diagnosed with dementia and views on planning for future care in general. The interview guide consisted of open-ended key questions with optional and flexible follow-up questions to elicit descriptive answers to the main inquiry. Care was taken to use language that the participants could easily understand. The dementia nurses from memory clinics in four municipalities were asked to assist in the recruiting of PWDs, as they know their clients well. Before recruitment started, one dementia nurse was asked to evaluate the recruitment form.

### Inclusion criteria

Study information and recruitment forms were mailed to 95 people in four municipalities. The recipients were all living in their own homes as opposed to assisted living facilities. None of the participants had regular home care services at the time of the study. Due to confidentiality reasons, the research team did not have access to the client registers. The dementia nurse determined which of her clients would receive the study information and recruitment form. The decision was based on the nurses’ own assessment of the cognitive abilities and illness insight of the PWD, as understanding of the purpose of the interview and the ability to give informed consent were necessary. The dementia nurses were asked to keep careful records of the number of recruitment forms mailed out as well as the age span of the recipients. A certain minimum number of points achieved in Mini Mental State Examination or Consortium to Establish a Registry for Alzheimer’s Disease testing were not set as a criterion as there is disagreement about whether these fully indicate and assess the capabilities of the PWD to understand and participate in an interview situation.<sup>25–27</sup> A limit was not set on time since diagnosis as the progress of dementia is highly individual and time since diagnosis is not an indicator of ability to participate in a study.<sup>28</sup>

### Participants

Ten people, aged 65–85 (mean age 76.6 years), accepted the invitation to participate and were equally distributed in gender. The interviews took place in participants’ homes. The researcher was contacted by three PWDs themselves and by caregiver spouses on behalf of the remaining PWDs. At first contact with the spouse, it was emphasized that the PWD him/herself had to be able to give informed consent. Two of the participants and their caregivers were not sure of which type of dementia they had been diagnosed with. The characteristics of the participants are presented in Table 1.

**Table 1.** Participants' information.

Participant	Gender	Age, years	Time since diagnosis	Diagnosis	CG present	CG gender	Age, years
1	Female	85	1 year	Alzheimer's	X	Male	89
2	Male	79	6 months	Unknown	X	Female	71
3	Male	82	3.5 years	Alzheimer's	X	Female	79
4	Male	71	3 years	Alzheimer's	X	Female	67
5	Female	76	1 month	Unknown		–	–
6	Male	82	2 years	Alzheimer's	X	Female	80
7	Female	83	5 months	Alzheimer's		–	–
8	Female	75	1 year	Alzheimer's	X	Male	81
9	Female	65	3 months	Alzheimer's	X	Male	69
10	Male	68	4 years	Benson's syndrome	X	Female	65

CG: caregiver spouse.

During eight of the interviews, the PWD was accompanied by his or her caregiver spouse as per the wishes of the PWDs and the spouses, making the interviews dyadic in nature. The caregiver spouses sometimes expressed their own views on ACP and supported the PWDs by at times clarifying statements. However, precedence was given to the PWD responses as the primary source of information. Two PWDs were interviewed without a caregiver spouse as they were both widowed. Data were collected from July 2018 to April 2019. The interviews lasted between 28 and 85 min with the average interview lasting about 60 min. The interviews were recorded with the permission of the PWD and the caregiver spouse (when present), and transcribed verbatim. Immediately after each interview, the interviewer recorded field notes, observations, and reflections on the interview. Field notes were also transcribed verbatim.

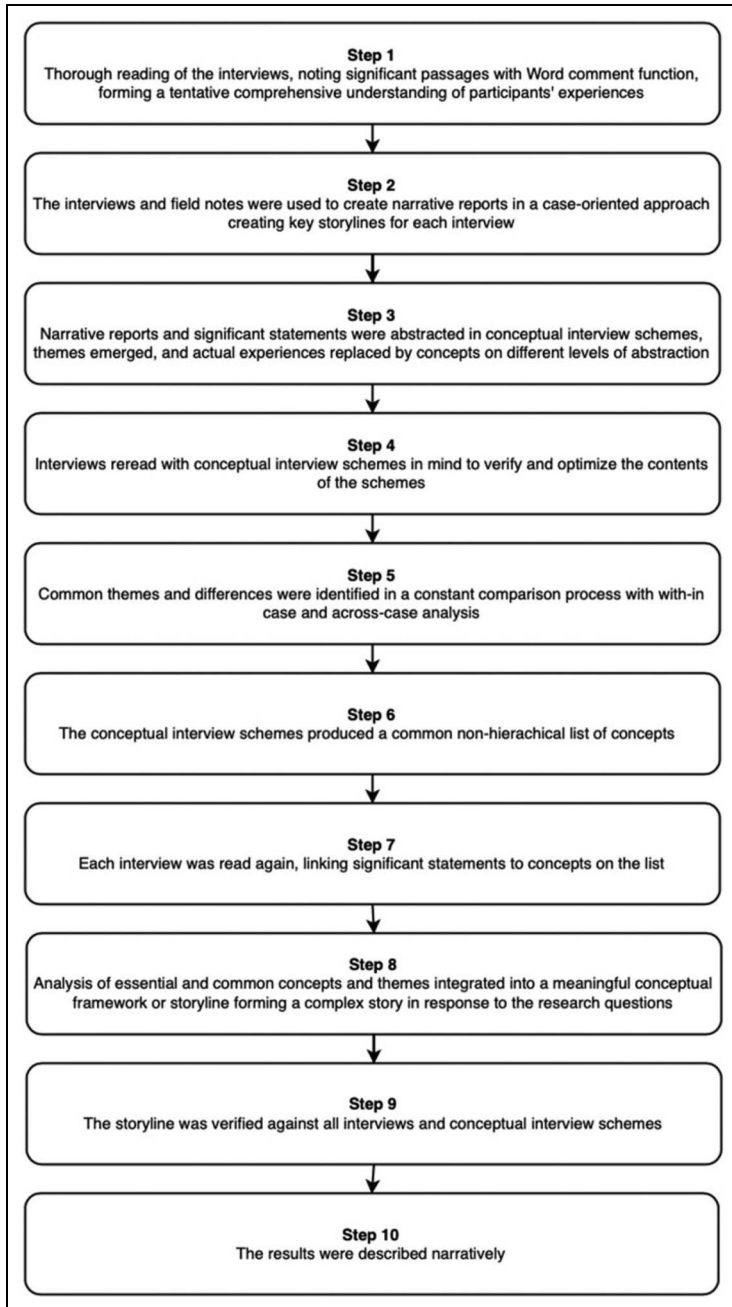
### Data analysis

The current study used a modified version of the Qualitative Analysis Guide of Leuven (QUAGOL).<sup>29,30</sup>

QUAGOL presents a multifaceted, comprehensive, and systematic approach to the analysis of complex qualitative data without being rigid. A systematic analytical approach is combined with a case-oriented narrative approach.<sup>30</sup> The analysis was performed in interconnected stages described in Figure 1. The analysis process was a team activity where forthcoming results were discussed continuously within the research team. Common themes and differences between emergent findings were explored. An example of a conceptual interview scheme can be found in Supplemental file 2.

### Ethical considerations

This study is ethically challenging as PWDs belong to a vulnerable patient group where heightened sensitivity is required. The researcher needs good understanding of guidelines with regards to informed consent, the balance of risk and benefits, and insight into acceptable procedures for such patient groups.<sup>31</sup> An approved application for permission to conduct the study was obtained from the ethics committee of Åbo Akademi University and from the healthcare committee of each municipality participating in the study. Participants were recruited specifically among people in the early stage of dementia that the dementia nurse deemed capable of understanding the purpose of the study and participating. The researchers consciously used plain language in the consent form and the interviewer reviewed the consent form with each participant and their caregiver spouse before the interview. Participants were informed of their right to withdraw at any time, interview confidentiality, and how their identity would be protected. They were told about the potential discomfort experienced when discussing illness progression and end-of-life care. At the end of



**Figure 1.** Stages of the analysis.

the interview, the participants were told they could contact the researcher with further questions or concerns. They were also reminded of the local memory clinic and dementia nurse as support systems.

## Results

The results are presented in the form of a narrative storyline. The participants gave an account of their views on ACP as well as of their fears and hopes for the future. The views of the PWDs and their caregiver spouses are characterized by a complex dialectic tension between and within the three main themes of the conceptual framework created in the analysis: wants, beliefs, and levels of insight. Within this storyline, there is tension and movement between the poles.

### *Wants: to plan for the future or to live for today*

Participants fell mainly into two groups, one that thought ahead by anticipating future needs and possible consequences of illness progression and one that did not want to think about or be reminded of what the future might hold. This latter group wanted to live day by day and not worry too much about the future. Some participants vacillated between the viewpoints by understanding the need to think about the future but making a conscious decision to live in the present and not worry about the future. Most participants felt positively about ACP in general while expressing preference for living day by day. Some expressed the view that since their illness was progressing slowly, they did not feel an urgent need to plan for or think about the future. A few PWDs and caregiver spouses noted the importance of planning sooner rather than later and were willing to accept help with planning for the future.

PWD3: *No, one doesn't want to dwell on it, how things may become and so on.*

Two of the PWDs disclosed other health conditions which they felt would lead to death before the dementia would. They expressed the wish that they would indeed die from the other illness before the dementia worsened. Participants did not want life-prolonging care if there were no hope for improvement.

PWD4: *I haven't been able to decide how I would want this but-but for sure it's the way that . . . if the cancer doesn't progress fast enough, it means that I will get more and more memory problems . . . and-and that's something that I don't want. My memory would become really bad that way . . . so in that sense you could say that I actually would rather die from cancer . . . and as quickly as possible then, if it . . . then when it becomes difficult.*

Almost all of the participants had completed legal documents such as continuing power of attorney where the adult children were assignees. In all of the PWD-caregiver spouse dyads, the spouse had taken over management of household finances as well as contact with healthcare organizations. In three of the dyads, a wish to avoid family conflicts caused by inheritance issues was mentioned as a motivating factor in drawing up legal documents. Few of the participants had completed living wills or advance directives. One of the dyads had obtained living will forms but found them too complicated to complete and wished for a simpler document to be made available. Some expressed the view that it was enough to have talked to their spouse and/or children about end-of-life care and stated that as a reason for not having completed a living will. They trusted their spouse or children to make good choices for them. When asked about how they would feel about a nurse visiting them in their homes to inform them about living wills, most participants were positive to the suggestion while a few said they were not interested in such an arrangement.

PWD4: *I do want that on paper, in the way that one shouldn't be tortured until the end, always to the end in that way.*

Participants who took the view that they wanted to live for today expressed a desire to not burden themselves and their spouses with worry about the future. They wanted to enjoy the present moments and not feel stressed about the future. The view that anything might happen in the future was expressed, and thus planning for it is pointless. Others again expressed a desire to feel some sort of control over the future.

CG10: *No, we haven't thought about it. Someone gets to, someone gets to decide that later. No, that [end-of-life] is so, it's so dismal somehow since we've always felt ourselves to be so youthful and thought that we have so much left . . . somehow one wants to sweep it under the rug and just enjoy the sun today and simply not care about it.*

Half of the PWD–caregiver spouse dyads had simplified their living arrangements by moving from single-family homes to easier to care for apartments. The widowed participants felt stressed about the future in anticipation of worsening illness. Both had made plans for future living arrangements in nearby assisted living facilities.

### **Beliefs: to be cared for with love or to be a burden**

The PWDs were in most cases aware of the difficulties they would have if their spouse would not be there to help them. They expressed their gratitude while also seeming to take for granted that the spouse would be there for them. One PWD did not even want to think about the possibility that the caregiver spouse would be the first to die, thereby leaving the PWD behind.

PWD4: *I don't know . . . no, I can't really imagine that-that it would be that way that you wouldn't be . . . I don't know what I'd do if something were to happen so that you were not here, I don't know. I haven't thought about it that way. For sure I don't want to think about it . . . consciously at least.*

A few acknowledged that they would feel like a burden for their caregiver spouse if or when their condition worsened and expressed a wish to move to a nursing home in such circumstances. Some of the dyads had talked to each other about end-of-life care while others had not. In several instances, the couples assumed the other would know without needing to discuss it. The participants had experienced the creation of the welfare state during their lifetime. The participants trusted healthcare in general and did believe that there will be enough nursing home places for everyone as needed.

CG3: *We kind of trust society, we have tried to be a part of building our society . . . we trust our society . . . that there will be people who want it to function.*

PWD8: *[when I become really ill] it'll be the bed ward then and I'll lay there until I get to go to some other place.*

Most of the participants had personal experiences of their loved ones or friends becoming ill and dying from dementia. The experience influenced some of the participants, particularly in the way they viewed nursing homes and where they wanted to live and be cared for in the future. The ones who had visited loved ones in nursing homes had strong opinions about what a good nursing home and care received is like. Recent national nursing home scandals did, however, affect the participants. They expressed doubts and fears that there may not be nursing home vacancies when needed and that the care received would not be of high quality.

### *Insight: to be aware of progressing illness or to think things will stay the same*

While some participants had educated themselves about dementia, others were less knowledgeable about the illness. Most of the PWDs seemed to have trouble imagining a future where their condition had worsened. Several of the PWDs used the phrase “IF it gets worse” rather than “WHEN it gets worse.” Some of the caregiver spouses also seemed to have difficulties imagining a worsening condition. The slowness of the illness progression was mentioned as a factor in this. The caregiver spouses also tended to use the term “if” instead of “when.” Two of the PWDs had professionally cared for patients with dementia in nursing homes or mental institutions, but did not seem to connect those experiences to their own illness and possible illness trajectory.

Interviewer: *What do you think the future could be like?*

PWD8: *Exactly the way it is now*

CG8: *Well, no*

PWD8: *if we both live*

CG8: *yes, but it can*

PWD8: *(raising her voice) yes but I said for as long as we both are alive and I'm healthy then it will be like it is today but we don't know anything about it when that day comes, it can come tomorrow*

Some PWDs were reluctant to acknowledge any difficulties or lost functions, while others were very much aware of losses. One identified irritation as well as increased anxiety associated with being confronted with unfamiliar things. One of the widowed participants worried about the illness progressing and not knowing the speed of progression.

PWD7: *... but I don't know how it will progress and how fast it will go and that's why I worry so much about why it's taking such a long time [to get an appointment for a follow-up], ... I know that I have a terrible time with collecting myself and to discuss and I forget all kinds of things, not just names but ... words ... that's the worst, not knowing how long I can be at home for, when will I have to go there [nursing home] and I don't want to go there ...*

In two of the care dyads, the relationships were complicated by the PWD's lack of insight into the help they needed and how much effort was made by the spouse. The PWD even bristled at times at the suggestion that they would not be able to, for example, live at home on their own or partake in travel on their own.

None of the participants felt that it was a negative or burdening experience to talk about ACP and end-of-life care. Some of the caregiver spouses expressed gratitude for the opportunity to talk about their situation and for the attention they felt dementia patients were given throughout this study.

## **Discussion**

Dementia care is a complicated process, with policies and care plans often guided by our ethical values. While participants in the current study acknowledged a need to plan for the future, they also expressed a wish to live in the present and not bother themselves too much with gloomy thoughts. While thinking about the future elicited worries and fears, there was simultaneously hope that the illness would somehow not progress. There were also thoughts about other illnesses leading to death before the dementia worsened, thereby eliminating the need to plan for future care. PWDs wanted and trusted their spouse to care for them, but did not want to be or become a burden. They believed and trusted that society would take care of them if needed while harboring doubts about the quality of older people care in general and future access to a place in a nursing home. Most of the PWDs were aware of lost functions, but were at times not aware of how the

illness affected them and their caregiver spouse. Such powerful dialectic tensions between and within wants, beliefs, and insight place high demands on the ACP process for PWDs and their family caregivers.

Timing is of importance in ACP discussions and even more so in dementia care as the PWD will progressively lose cognitive and functional abilities.<sup>10–12</sup> Time is required to come to terms with the diagnosis, but is also important when discussing future care decisions in the early stages of the disease.<sup>32,33</sup> A few of the PWDs showed signs of anosognosia, lacking insight into their illness. All seemed to have difficulties imagining a future where the illness had progressed and what it would mean for themselves and their caregiver spouse. Similar results have been found in previous studies with PWDs.<sup>16,34,35</sup> Most study participants did not seem to recognize dementia as a life-limiting illness. Some seemed to view dementia as a normal part of aging, especially when reflecting over the illness trajectories of their own parents or older relatives with dementia. These barriers to ACP have been identified in other studies as well.<sup>36,37</sup>

To enable PWDs to make informed decisions about care, they need information about the possible illness trajectory, different care alternatives, and the consequences of these alternatives. Informative discussions can take place as part of a systematic, person-centered ACP process in the early stage of dementia while the PWD has the necessary capacity to partake in decision-making about future care. The term “person-centered” care was first used by Kitwood in the context of dementia care,<sup>38,39</sup> emphasizing the lived experience of PWDs along with the importance of communication and relationships.<sup>38,40</sup> This carries over to Gastmans’s<sup>41,42</sup> foundational ethical framework for dignity-enhancing nursing care, where lived experience and the dialogical-interpretative process are two of the framework’s pillars. Gastmans argues for a move from principlism where respect for an autonomy that is cognitive-oriented is one of the cornerstones. Dignity-enhancing care for PWDs offers an alternative, with an emphasis on the respect for and dignity of vulnerable and care-dependent people in their full reality. Care practices have to be situated in a relational and dialogical context.<sup>42</sup> When this frame of mind is brought to the ACP process in dementia care, it opens up for a dialogical-interpretative process based on lived experience with the aim of protecting and maintaining the dignity of the PWD. The ethical challenges in dementia care move to the forefront when it comes to illness trajectory—do PWDs want information about illness progression and about what can be expected in the late stages? Such information can aid in decision-making about future care, but also promote a sense of hopelessness and despair.

The place of care for PWD transitions from out-patient memory clinics to assisted living facilities and nursing homes as the dementia progresses and the PWD’s care needs increase. A challenge in dementia care is this lack of continuity in contact with care professionals. In this type of dementia care structure, the PWD and his or her family caregiver will encounter many nurses and doctors along the illness trajectory who are not necessarily familiar with the PWD and his or her family, their care preferences, and their wishes for end-of-life care. A focus on the restructuring of dementia care to ensure care continuity, staff competency, and responsibility is essential. Knowing the patient<sup>43</sup> becomes of utmost importance in the dementia care ACP process when striving to maintain dignity and protect this vulnerable patient group. A relationship-centered dementia care model where the nurse works together with the PWD and the family caregiver in a triad, to promote senses of continuity, security, purpose, achievement, and significance is ideal.<sup>44,45</sup>

PWDs account for a large minority group within all populations worldwide and need to be treated as citizens with personhood<sup>46</sup>; however, persons with diminishing cognition were rarely heard from in research despite the growth in size of this group.<sup>47,48</sup> In the late 1990s and early 2000s, with the increased interest in person-centered care came a growing recognition in the research community that PWDs should be included in the research as participants and not merely as subjects or objects. It is possible to include PWDs in research and it is important to do so.<sup>49</sup>

### **Strengths and limitations**

There are several limitations in this study. One of the challenges in involving PWDs in research pertains to reaching a wider range of participants, such as people who do not have family caregivers and people who lack illness insight. The sample is limited in size and does not reflect the full range of PWDs, as the recruitment of enough participants for the study was challenging. Therefore, the findings cannot be generalized to the study population. It should additionally be noted that the findings were potentially biased. The people who contacted the researcher were aware of their diagnosis and possibly already interested in planning for future care. Furthermore, the presence and participation of the caregiver spouse and how this might have affected the responses needs to be noted as well.<sup>50</sup> The interviews conducted jointly resulted in a shared narrative,<sup>51</sup> where there is the risk that the voice of the PWDs is overpowered.<sup>52</sup> Other disadvantages may include the interviewer only getting the “public” story.<sup>50</sup> However, dyadic interviewing is also considered a method of triangulation and as an accommodation for PWDs.<sup>50</sup>

QUAGOL<sup>29,30</sup> was used as the guiding tool it is intended for. The potential stumbling blocks of the method include information overload, losing track of the research question, and the focus on intuition and creativity.<sup>29,30</sup> The trustworthiness of the analysis process was enhanced by the documentation of reflections and field notes which were used in the narrative reports and conceptual interview schemes. Continuous research team discussion about data analysis and emergent results affirm credibility.

### **Conclusion**

The process of ACP in dementia care needs to extend beyond person-centered care to a relationship-centered process, and it needs to consider the illness trajectory as well and the impact of the illness on autonomy. To take willingness as well as reluctance to plan for the future into account is possible for a nurse who knows the patient. Promoting the sense that society can be trusted to care for PWDs is essential for the well-being of PWDs and perhaps even more so for family caregivers.

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All authors meet the criteria for authorship. All authors contributed to the conception and the design of the study, acquisition of data, and the selection of studies. All authors participated in the review of data, analysis and interpretation of data, and critical reading and revision of the article. Annika Tetrault wrote the first draft of the manuscript. All authors have read and approved the final manuscript.

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## Ethical approval

An approved application for permission to conduct the study was obtained from the ethics committee of Åbo Akademi University and from the healthcare committee of each municipality participating in the study.

## Supplemental material

Supplemental material for this article is available online.

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RESEARCH

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# 'A perfect storm' or missed care? Focus group interviews with dementia care professionals on Advance Care Planning



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## Abstract

**Background** Dementia is one of the leading causes of dependency and disability among older people and currently the seventh leading cause of death among all diseases. In recent years, healthcare research in Advance Care Planning in dementia care has received increased attention. Advance Care Planning is a discussion process conducted in anticipation of future deterioration of a person's health condition. The purpose of the study was to investigate the views of dementia nurses and geriatricians on Advance Care Planning in dementia care.

**Methods** The study design is a qualitative study using semi-structured focus group interviews with dementia care professionals in a region in Western Finland. A total of seventeen dementia care professionals participated. A modified version of the Qualitative Analysis Guide of Leuven was used for the data analysis.

**Results** The data analysis identified one main theme and three sub-themes describing the views of dementia nurses and geriatricians on Advance Care Planning in dementia care. The main theme was the 'perfect storm' with sub-themes relating to the person with dementia, the care process, and the care professional. The unfavorable circumstances creating a 'perfect storm' are related to the nature of the illness and the associated stigma, to the unclarity in the suggested care path with inadequate guidelines for Advance Care Planning, and to the demands placed on dementia nurses and geriatricians, as well as to insufficient resources.

**Conclusions** Dementia nurses and geriatricians acknowledge the importance of advance directives and express a generally positive view of Advance Care Planning in dementia care. They also hold views on a number of factors which affect the conditions for conducting Advance Care Planning. The lack of Advance Care Planning in dementia care can be seen as a form of missed care caused by multiple forces coming together simultaneously.

**Keywords** Dementia, Advance care planning, Missed care

## Background

Dementia is a global issue of concern. Worldwide, more than 55 million people live with dementia and the number of people living with dementia is expected to increase to 152 million by 2050 [1]. Every year there are close to 10 million new cases with Alzheimer's disease which accounts for 60–70% of overall cases. Dementia is one of the leading causes of dependency and disability among older people and is currently the seventh leading cause of death among all diseases. Dementia is usually progressive

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in nature, with cognitive decline affecting orientation, thinking, memory, comprehension, language, learning capacity, and judgement. Mood and behavior changes, emotional control, and/or motivation commonly accompany or precede deterioration in cognitive function [2].

In recent years, healthcare research in Advance Care Planning (ACP) in dementia care has received increased attention. ACP is a discussion process conducted in anticipation of future deterioration of a person's health condition [3]. A definition of ACP as proposed by a multi-disciplinary Delphi panel is provided in Table 1 [4].

Recent healthcare research in ACP has focused on different areas, including the roles of nurses [5, 6], doctors [6–8], family members [9–12] and the person with dementia [9, 10, 12, 13]. Other studies have focused on the effects and feasibility of different approaches [14, 15] and have described ACP and the dementia approach of different interventions [16]. Factors that facilitate or hinder ACP in dementia care have been explored [17–19] and resulting insights and increased knowledge have led to the creation of guidelines [20, 21] and educational programs [5]. The consensus seems to be that ACP should be initiated as soon as possible [22] as decision-making capacity and illness awareness diminish as the illness progresses [19, 23, 24]. However, one of the questions that remain largely unanswered and challenging concerns the timing of ACP in dementia care as confirmed by a recent narrative review [25]. Additionally, ACP is rarely conducted with dementia patients [26] despite ACP being seen as especially important for people living with dementia as self-determination capacity and abstract thinking ability diminish with illness progression [14, 19, 27]. While research in dementia care ACP has often focused on the advanced stage of illness [28, 29], research involving the person with dementia in the early phase of illness is needed [30].

Finnish laws about patient rights state that healthcare services and care should be arranged together with the patients and that everyone has the right to refuse care [31–33]. In Finland palliative care in general has received increased attention during the last two decades [34–36]. In 2016, the Finnish Ministry of Social Affairs and Health appointed a national group to work on uniform criteria for access to care. Part of that work focused on drafting a proposal for the provision of end-of-life and palliative care. The objective of this proposal is to ensure equal

access to palliative and end-of-life care throughout the country [36, 37]. ACP evolved from and includes such concepts as living wills, advance directives, advance decisions to refuse treatment, and lasting power of attorney [38]. These concepts have been in use for a long time in Finland [39], however, ACP as a systematic process in itself has not received attention in Finland until fairly recently [37, 39] and there are few relevant studies in the literature [39]. Several international studies have indicated that nurses and nurse practitioners are well suited to participate in ACP process development and well positioned to initiate and lead ACP conversations [9, 23, 40–43]. Nurses' experiences of ACP have been explored [6], their understanding of ACP has been examined [44], and their confidence levels and motivation for ACP have been described [45]. A training needs analysis of Admiral Nurses in the United Kingdom showed that the skills and confidence of nurses would benefit from combining communication training with supervised practice, shadowing, and access to materials that facilitate discussion [46]. As ACP in general is not a well-known concept in Finland, studies exploring ACP in the Finnish healthcare context are needed. A study focusing on nurses in Finnish dementia care is relevant for the development of ACP in this context.

## Methods

This study is part of a PhD project, which aims to develop a model for a relationship-centered ACP process in early-phase dementia care. The aim of the current study is to investigate the views of dementia nurses and geriatricians on ACP in dementia care. The objective of the study was kept non-specific to obtain as many viewpoints as possible from the study participants on the many aspects of ACP, including when to initiate the process, whose responsibility it is to take the initiative, and the ethical aspects of conducting or refraining from ACP.

## Design and method of data collection

The approach of the current study is a qualitative study with semi-structured focus group interviews conducted with dementia care professionals. In the last decades, the use of focus group interviews in qualitative health research has been increasing. Focus groups have the potential to provide in-depth information in a relatively short period of time [47, 48]. The participants are

**Table 1** Advance Care Planning definition

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*Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions [4]*

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selected based on their experience with and/or knowledge of the specific matter at hand [49]. The Standards for Reporting Qualitative Research (SRQR) have been used to report the study [50].

### Context and participants

In the European Dementia Monitor report of 2020, Finland was ranked sixth in care availability, first in care affordability, and as number eight in overall ranking out of the 36 countries and regions evaluated. The Finnish dementia service structure provides a wide range of services and services are available to all [51]. In Finland, memory clinics are often situated within a larger primary care clinic. In memory clinics, registered nurses (RNs) work together with physicians. Memory clinics are easily accessible. Individuals or their family members who suspect the onset of dementia can contact the dementia nurse directly without the referral of a physician. Home care nurses can also contact the memory clinic if they suspect the onset of dementia in their client. The investigation and path to a diagnosis are conducted according to national guidelines [52]. Memory clinics in their current form were initiated in primary care in the late 1990s [53] and the first version of national guidelines for dementia care published in 2005 [52].

The dementia nurse invites the client to participate in an initial assessment of the situation. Testing of cognitive function is conducted using the Mini-Mental State Examination [54] (MMSE) and the Consortium to Establish a Registry for Alzheimer's Disease [55] (CERAD) test. A standard series of blood tests are conducted as well as a magnetic resonance imaging (MRI) or computerized tomography (CT) scan of the brain. The combined results of the investigation are evaluated by the memory clinic geriatrician who then meets with the patient in order to communicate the diagnosis and possibly prescribe medication. After meeting with the geriatrician, the patient sees the dementia nurse to clarify potential misunderstandings and to go through the information received as required. Follow-up visits at the clinic and in the home are scheduled according to a timetable which varies from municipality to municipality depending on resources available. The mean length of time from problems being noticed to diagnosis, was found to be 2,24 years as noted

by a 2018 survey of family carers' experiences [56], a survey in which Finland was included.

An invitation to participate in the study was sent via e-mail to a total of 29 dementia care professionals within a Finnish wellbeing services county in Western Finland. Seventeen of the invitees participated in the study. In the invitation to participate, introductory questions and themes were listed as outlined in Table 2. Researcher networking was utilized to identify interviewees; therefore, recruitment was purposeful. The participants worked within a primary care area with a wide geographical spread. The interviews were arranged in the participants' own settings. The inclusion criteria for participants were experience in out-patient dementia care and willingness to participate in the interview. The majority of participants were registered nurses ( $n=13$ ). The remaining participants consisted of two geriatricians, one social worker, and one professional of applied gerontology. All participants were female and had worked with dementia clients in memory clinics and/or a home care setting. Work experience in dementia care ranged from 20+ years to 1,5 years. Nine of the nurses had continuing education in dementia care.

### Data collection

Data were collected by two researchers (the first and the second author) in August 2022 via three semi-structured focus group interviews. The focus groups included 4, 5, and 8 participants respectively. The two geriatricians who participated were included in the group with 8 participants. All interviews followed a protocol starting with a description of the PhD project and proceeding to open-ended questions. The first author, who possesses extensive ACP knowledge, functioned as moderator posing questions and moving the discussion forward while the second author observed, took notes, at times asked follow-up questions, and in conclusion presented a summary of the interview. After each session, the second author debriefed with the moderator and gave feedback on the session [47]. Each focus group interview was digitally recorded. Verbatim transcription of the interview recordings was performed by a research assistant. Participants were highly involved in the interview situation and gave a rich account of their views on and experiences with planning for future care with their patients,

**Table 2** Focus group interview introductory questions

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- *In what phase of dementia illness should ACP be initiated?*
  - *Whose responsibility is it to initiate ACP in dementia care?*
  - *What are the ethical aspects in conducting ACP as well as in refraining from doing so?*
  - *How could ACP be organized to be beneficial for the person living with dementia and his/her family caregiver?*
-

resulting in sessions that lasted an average of 1 h 5 min and totaled 57 pages of text with a word count of 28,728. Data sources also include the field notes of the second author as well as the post-interview debriefing notes of the first author.

### Data analysis

A modified version of the Qualitative Analysis Guide of Leuven (QUAGOL) [57, 58] was used for the two-step analysis. In this modified version, a software program for analysis was not used. As the interviews were conducted in both Finnish and Swedish, the use of a software program for coding was deemed inappropriate. QUAGOL provides a systematic, comprehensive, and multifaceted approach to the analysis of complex qualitative data. A case-oriented narrative approach is combined in a systematic analytical process [58]. Figure 1 describes the interconnected stages of the analysis. All authors participated in the data analysis, continuously discussing emerging results.

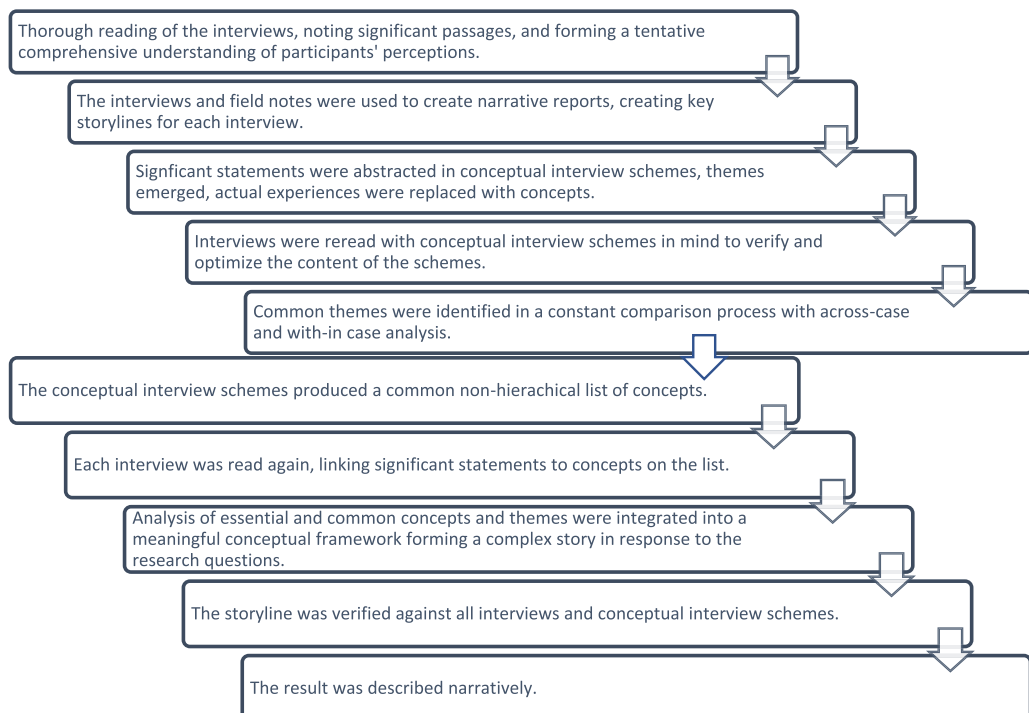
An example of a narrative report can be found in Supplemental file 1. An example of the analysis path for sub-theme 1 is presented in Table 3.

### Ethical considerations

The ethical principles of The Finnish Advisory Board on Research Integrity have guided the current study [59]. The study was granted research permission by the Board for Research Ethics (FEN) at Åbo Akademi University as well as by the Research, development and innovation department of the Wellbeing services county in which the study took place. All participants received both written and oral information about the aim of the study. They were informed of the voluntary nature of participation, that the interviews would be recorded, and that results would be presented on a group level so that individual participants could not be identified. Participants gave their written informed consent before the interviews. The data were stored in password protected computer files. In the transcripts, any personally identifiable information was removed. Only the researcher group had access to the files.

### Results

The data analysis identified one main theme with three sub-themes describing the views of dementia nurses and geriatricians on ACP in dementia care



**Fig. 1** The stages of the data analysis

**Table 3** An example of the analysis path

Significant statements	Key elements	Sub-theme
<p>Stage 3 on the Global Deterioration Scale/Functional Assessment Staging latest, it's been too late for care planning</p> <p>All clients don't understand the diagnosis and what it means</p> <p>During subsequent home visits by the nurse, the progression can sometimes be talked about</p> <p>There are clients who don't understand that they have a dementia illness, they lack illness insight and even deny illness</p> <p>When clients come in for assessment, they're already in stage 3 or 4</p> <p>At stage 4 you no longer have the capacity to make your own decisions</p> <p>Such clients don't want to think about the future or a living will as they perceive themselves to be young and healthy</p> <p>Clients ought to come for assessment in an earlier stage</p> <p>When the client comes for assessment the illness can have progressed far</p> <p>Not everyone is interested in an assessment</p> <p>Barriers to contact the clinic can be challenging</p> <p>Sometimes the client's illness has progressed far</p> <p>Single clients often come to assessment late in the trajectory</p>	Delayed diagnosis	The person with dementia: losing capacity for self-determination, losing oneself

and the factors that affect the ACP process. The main theme is the 'perfect storm' caused by multiple forces and circumstances coming together and affecting the ACP process in dementia care. The unfavorable circumstances creating this 'perfect storm' consist of the nature of the illness, the demands placed on the care professional, as well as insufficient resources. The sub-themes are:

- 1) The person with dementia: losing capacity for self-determination, losing oneself with the key elements being delayed diagnosis, client illness trajectory and illness insight.
- 2) The person with dementia and the care professional: Building a trusting relationship where the dementia care process is the key element
- 3) The care professional: skimming the surface or diving into the ACP conversation where the professional carer is the key element.

The sub-themes are presented in the form of a narrative storyline.

- 1) *The person with dementia: losing capacity for self-determination, losing oneself*

The study participants were concerned with the delay in investigation and late diagnosis of dementia. When people get in touch with the memory clinic due to a concern with their own health or with the health of a loved one, the dementia has often reached a moderate stage.

*They [patients] have a 15 [points] on the MMSE test, I would say, about, and actually, already at the first or second visit, we've had to start thinking about a nursing home. And it's not supposed to be that way. (Focus group 1, (FG1), dementia nurse 1 (DN1)).*

People are also at times reluctant to be assessed and the perceived barrier to the memory clinic can feel challenging. Once the diagnosis is communicated, the person with dementia and their family caregiver (the dyad) might lack understanding for and knowledge about dementia, its consequences, and the illness trajectory. Some people with dementia lack illness insight altogether and even deny being ill. People with dementia react in their own way to the diagnosis. Some people with dementia do not want to talk about the illness or future care at all as the situation can get too emotional and anxiety filled. The diagnosis often comes as a shock.

*We would like them to get in touch earlier so that the dementia diagnosis could be made as early [in the illness trajectory] as possible. But if no one reacts to it nor gets in touch. Or we get a referral, well, we don't go investigating anyone just like that. (FG1, DN3).*

While the study participants agree ACP should be introduced as soon as possible in the care path, they also state the first time one meets with the person with dementia is not the right time due to the information overload, sensitivity, and sometimes shock of the situation. The first follow-up visit after 4–6 months is seen as a better time to introduce ACP. However, due to care contact often being established relatively late in the

illness trajectory, the dementia nurses sometimes experience that it is too late for ACP involving the person with dementia during the follow-up visit.

2) *The person with dementia and the care professional: building a trusting relationship*

While the participants viewed ACP as something that is or ought to be part of the care process, ACP is often a conversation that does not take place, as participants felt it was important to build a trusting relationship before introducing more sensitive topics. As noted in the first theme, time of diagnosis is viewed as the wrong time for discussing future care. There is a great deal of information shared during the diagnosis visit with the geriatrician. After seeing the geriatrician, the dyad meet with the dementia nurse who tries to ensure the dyad has understood the diagnosis, discusses medication if it has been prescribed, and informs the dyad about the future care pathway. At this point, illness trajectory, prognosis, living wills, and lasting power of attorney are not discussed unless the person with dementia and/or their family caregiver initiates such discussions.

*It's good to do [ACP] in the early phase of the illness, when you find it, so that it won't be too late, which it often gets to be, but you can't do it the first time you meet a patient, not even when the diagnosis has been communicated at an earlier visit [by someone else]. You have to create trust and a rapport with the patient before you can start talking about these kinds of difficult things, and that's why it often gets pushed to a later stage. (FG2, geriatrician 1(G1)).*

During the first or second follow-up visit at the home of the person with dementia, a lasting power of attorney form is often introduced along with a form for a living will. There are several different forms for living wills in circulation in Finland and the nurses have specific ones they prefer to use.

*Yes, sometimes we just give [the form] to them, sometimes they are the kind that don't really want to, they don't even want to take it with them, and sometimes we review it together, the city of Sibbo and the Alzheimer's Society have co-created the living will form, and it's the kind I like to use, it's clear, it tells a bit more about such things. (FG3, DN2).*

However, the living will form is not always reviewed and completed together with the person with dementia unless he/she requests it. The person with dementia is asked to fill out the form by them self with the help of family and to turn it in during their next visit or register the form at the general health clinic. In the patient

journal systems used, there is no easy way to document the wishes of the person with dementia in a clear manner which is quickly visible to other professional care staff.

*Well, I always think that sometimes, well, these forms they are of course different, but sometimes there are such medical words and terms, that an ordinary person, an ordinary person doesn't know, what it's like, what it's like to have a peg [percutaneous endoscopic gastrostomy] (FG3, DN4).*

The national guidelines for dementia care provide a clear, generic path for dementia nurses and geriatricians but no detailed checklist, tool, recommendations, or model for ACP. The majority of participants stated that a checklist would not work as each person with dementia is an individual and every care situation unique. However, some form of structure or support was viewed as having the potential to be useful, especially for new dementia nurses.

*It would be pretty difficult to have a certain kind of conversation model... it's little by little... (FG2, DN4).*

*Yes, when everyone is so... it's so individual... but of course conversation technique is very important, in my experience, so if it doesn't come naturally, it's probably good to take some classes. (FG2, DN3).*

Making ACP into a natural and routine part of the dementia care path was seen as an essential facilitating factor. The current process limits number of visits with a doctor or geriatrician to one or two visits total which means that the responsibility for ACP conversations falls to the dementia nurse who may follow-up, care for, and support the person with dementia and their family for many years.

Lack of time and resources were often highlighted as barriers to introducing ACP. The dementia nurses mentioned having too many clients which prevented them from visiting their clients more often and reduced time for deeper conversations. Time for reflection in an undisturbed environment and the support of co-workers were seen as important in facilitating ACP conversations. A trusting relationship and the time to build such a rapport were seen as necessary prerequisites for introducing conversations about sensitive issues such as illness trajectory, lost function, and end-of-life care.

*Well, anyway, I think that one has to get quiet time at work, it is very stressful to have difficult things, if you at the same time feel that you don't really have the time, because it gets hard for oneself, we're only human. One needs to talk to one's colleagues, do a bit of briefing... and then some processing in your own*

head. (FG1, DN1).

3) *The care professional: skimming the surface or diving into the ACP conversation*

The study participants spoke of intuition around and sensitivity to the emotions of the person with dementia and their family caregivers when approaching sensitive issues. Intuition was described as a type of undervalued silent knowledge acquired through work and crisis handling experience. However, intuition was also compared and contrasted to evidence-based practice and mentioned as something decisions could not be based solely upon. The participants spoke of their own feelings as something which could potentially lead to conscious or unconscious avoidance of difficult conversation topics when caring for people with dementia.

*I'm thinking that one uses feeling and intuition a lot. And with more work experience and life experience, it awakens, wakes up, the intuition grows, so that you can better choose to do or not to do. But in some ways, it's then on pretty thin ice, when it's like this, yes... what is it that makes us avoid this kind of conversation, is it our own baggage, our own fear, yes... it's really a difficult question, when do you cause more good and when more harm, that's the question we need to activate more. (FG2, G1).*

When reflecting on the challenges of ACP in dementia care, the consensus was that dementia is different than other illnesses. According to the participants' experiences, there is still a stigma attached to dementia and the associated loss of cognitive abilities. ACP and illness trajectory was viewed as easier to discuss in cases of, for example, incurable cancer where there is a more predictable illness trajectory and time frame. A person can live with dementia for many years which contributes to people with dementia occasionally feeling that planning for future care is not an immediate concern.

*Is it in sense then a societal challenge, this illness? (Moderator).*

*Yes, very much so, there's still that shame, it's still like that, [the illness], it's not understood... (FG3, DN1).*

The insecurity felt by the participants is related to role confusion, to the lack of knowledge about ACP, and to the lack of support and the lack of a strong foundation to stand on for ACP. There was some confusion when it came to the roles and responsibilities of the dementia nurse versus the geriatrician. Dementia nurses felt the doctor at times pushed the responsibility of explaining

the diagnosis onto the nurse as well as failed to properly inform the dyad about the life-limiting nature of dementia.

*I think that it's good that the doctor introduces [a living will] in that stage when the diagnosis comes, the doctor is in a way the authority so that perhaps in that stage a memory of it remains, that this is something we have talked about and that the nurse gives the brochures and the doctor, they don't need to review it, but the nurse goes through it. (FG3, N2).*

Some of the nurses drew a distinct line between formal decisions and treatment restrictions made and documented by the doctor, the living will document completed by the person with dementia, and the more informal discussions about wishes for future care conducted by the dementia nurses. The nurses also felt they did not have enough training to manage dementia patients in acute psychological crisis caused by being diagnosed with dementia. While having identified critical moments, such as hospitalization or a move to an assisted-living facility, as opportunities to initiate ACP, they wished for more support and training in general on how to approach and introduce ACP and when to do so, especially when caring for a patient who is reluctant to talk about the future. A fear of saddening their patients with ACP conversations at times contributed to the insecurity felt.

*It's not so difficult to talk about, no, I don't feel that it's hard to talk about, but at what point, sort of... (FG3, DN3) Right, and then you still have to be... even though you can manage talking about it, you always have to sort of try to suss out the situation, when [to talk] (FG3, DN2).*

*I don't feel that I have [tools for ACP], but I really would like to have some, I have the facts knowledge but precisely that, how to approach and how to raise the issue, and [to know] what do I say now... and how to get the other one to listen, the message, when the person is not very receptive, but needs to be... (FG3, DN4).*

While generally acknowledging the positive aspects of ACP in dementia care, the participants emphasized a strong focus on positivity, the maintenance of hope, and support for a good quality of life for people with dementia and their family caregivers. Some of the study participants expressed the view that ACP conversations could potentially remove hope and throw a person with dementia into despair.

*Well, I think it's good there after 6 months, to discuss and give, bring up both [lasting power of attorney and living will], but to start discussing the end of*

*life then, it's of course... we're still supposed to give them hope and try to strengthen them and their self-esteem, a lot of it is based on their self-esteem, that they can actually think that they can manage and feel well. So, it would actually be like pulling the rug from under them. (FG2, DN4).*

The study participants wanted to strengthen the self-esteem of their clients and focus on the possibilities of maintaining hope and a good quality of life despite the illness. Speaking about the end of life and living wills too soon felt wrong to the majority of participants as they felt such conversations would lower the quality of life of their patients. However, study participants vacillated on their views at times, stating that a living will can be a positive thing as well and can be completed in a positive manner. A majority of the participants expressed the view that a living will and lasting power of attorney should be a natural part of every person's life and something that everyone, whether ill or not, should complete and document, preferably before reaching old age.

The participants reflected on the self as an instrument and tool when caring for people with dementia and their family caregivers. Strong and sometimes difficult emotions arise in dementia nurses and geriatricians when working in challenging situations and with people who are in shock, at times depressed, and/or in denial. Difficult situations also arise in the later stages of illness when the family caregiver may express different wishes for care than the person with dementia has previously expressed. Participants saw it as necessary to have worked through one's own issues and fear of death to be able to talk about death with their patients. The nurses and geriatricians felt the need to be grounded in themselves to find the courage to initiate such conversations. If a nurse or geriatrician is not grounded in this sense, the choice to steer away from such talks is easier made and the topic often avoided altogether.

## Discussion

The purpose of the study was to investigate the view of dementia nurses and geriatricians on ACP in dementia care. The results of the current study demonstrated that dementia nurses and geriatricians express a generally positive view of ACP in dementia care, but simultaneously hold a number of views about factors which affect the conditions for conducting ACP. The questions of timing and responsibility remain unclear.

The ACP conversation is hampered by people and family caregivers contacting the memory clinic late in the illness trajectory which may give the dementia nurse and the geriatrician the perception that it is already too late to introduce planning for end-of-life care. In a 2018 survey

of family carers' experiences in five European countries [56] in which Finland was included, a high prevalence of the person with dementia refusing to seek help was reported by 46,3% of carer respondents. Another cause for the delay was the first professional seen not considering anything to be wrong, as reported by 26,3% of respondents. Referrals to diagnostic services taking a long time were reported by 15,4%. The view that it is already too late to introduce ACP is deepened by the long intervals between follow-up visits. In our study dementia nurses and physicians also reported a lack of knowledge among people with dementia and their family caregivers about illness trajectory, prognosis, and dementia in general. These views are supported by the aforementioned survey [56] and other studies as well [60, 61]. Moore, Goodison, and Sampson noted in a 2018 study [30] that dementia clinics have mixed views about the appropriateness of disclosing the terminal nature of dementia to people with dementia. The mixed emotions about informing people with dementia and their family caregivers about potential illness progression has been well documented [6] and was noted in the current study.

As ACP has not received much attention in everyday healthcare work in Finland [37, 39], there is a general lack of knowledge of the ACP process and an ACP conversation is often reduced to the completion of Advance Directives through different forms provided by the Alzheimer's Society, for example. There is a lack of distinct guidelines and tools for ACP in dementia care adapted to the Finnish care context which further challenges the initiation of ACP conversations. In Finland in general, documentation of healthcare and care decisions are fragmented in many different journal systems which do not communicate with each other, making the identification of critical decisions difficult. Dementia nurses and physicians report a shortage of staff which increases the number of clients to dementia nurse as well as the amount of time between follow-up visits. As allotted time per person with dementia becomes increasingly pressured, ACP conversations tend to be left undone or to take a back seat to matters that are considered more urgent, such as medication reviews and the challenges of living at home with a caregiver spouse.

Dementia nurses and physicians indicate that an undisturbed environment and time are factors that facilitate discussions about and planning for future care. Time with individual clients would increase if the client to nurse ratio was increased so that each nurse would have fewer clients to follow-up and attend to. Developing and building relationships with clients in dementia care was seen as key in enabling ACP discussions, a key factor noted in other studies as well [19]. Dementia nurses also stated that support from the physician is often necessary and

indeed mandatory when it comes to decisions such as palliative care decisions or medication decisions. While the dementia nurses feel knowledgeable about forms relating to Advance Directives, illness trajectory, and the care path recommended by national dementia care guidelines, it was noted that more distinct ACP guidelines and clearer role distribution between nurses and physicians would facilitate ACP in dementia care. The detailed checklist approach is not seen as helpful, which is a notion supported by a 2017 editorial discussing ACP and Advance Care Directives in which Komesaroff states what is needed is not complicated and refined protocols and checklists, but a “continuing awareness of the key role of open ethical dialogue in the practice of all aspects of clinical care” [62].

Trying to normalize ACP conversations and making them part of routine care as well as using critical moments or key triggers to initiate the ACP process are seen as other facilitators. Critical moments can include the termination of mitigating medication, the need for home care services, or contemplating moving to a nursing home [17, 21]. In our study, dementia nurses note that in caring professions, one uses the self as a tool in the care situation and process. Using one’s intuition honed through many years of working with dementia patients and their family caregivers is seen as a strength in the balancing act between enabling hope and maintaining realistic expectations.

Dementia nurses and geriatricians highlight wanting to do good and to act in the best interests of the patient. Dementia nurses and geriatricians state they know what ought to be done, but planning for future care with their patients and family caregivers does not at times take place. To talk about death and end-of-life care is seen as potentially anxiety-inducing and the thought of one’s own death avoided. Not having come to terms with one’s own mortality and lacking the time and the support to dive into challenging conversations, as well as diverting from the sorrow, grief, and anxiety of the person with dementia by focusing on a positive attitude contribute to the absence of ACP or, in a sense, to “skimming the surface” of the ACP process. An important ethical question to address is: can hope and ACP exist side by side? The feeling that discussing the progressive and terminal nature of dementia is contradictory to focusing on living well with dementia has been found in other studies [30, 63]. A recent meta-review identifying moral barriers and facilitators encountered by physicians in ACP discussions with people with dementia described moral dilemmas that can lead to avoidant behavior concerning ACP [64]. The burden of a high patient to nurse ratio reduces time available with each patient and the weariness of a heavy workload contributes to an avoidance of sensitive and

emotionally challenging subjects. The dementia nurses in the current study felt a need to function as advocates and to protect their patients from feelings of hopelessness and anxiety, similar to nurses in an oncological context [65].

In the Finnish national guidelines for post-diagnosis dementia care, some of the best care practice steps are listed as follows: 1) the dementia diagnosis should be explained to both PWD and family caregiver, 2) a care plan should be made after diagnosis, 3) symptom-based medication for progressive dementia needs follow-up, 4) expertise is needed for anticipation and treatment of behavioral symptoms, 5) there needs to be a holistic approach to the general health of the person with dementia, including an assessment of nutritional status, 6) the following documents should be part of the care; guardianship and lasting power of attorney as well as a living will [52]. The national guidelines give no further instructions on when, how, and who should conduct ACP. The living will discussion is often the part omitted from the care process for reasons discussed in previous paragraphs. It can be argued that omitting the living will part of the care path is a form of missed care. Studies show that ACP interventions for people with dementia can have positive effects and have the potential to provide a sense of relief [16]. For family carers, ACP for older people can have a stress, anxiety, and depression reducing effect [66].

Any aspect of nursing care that is delayed or altogether omitted in whole or in part is referred to as missed care or care left undone [67]. According to Suhonen and Scott (2018), missed care can be seen as “an outcome of activities and processes performed (or not performed), consciously or unconsciously, by professional nurses” [68]. Inadequate time, skill mix, and staffing level contribute to the failure to carry out or withholding of necessary nursing tasks [69]. The topic of missed care has been studied most in acute care hospitals but has been found to be a common issue in nursing contexts [68]. A recent study focusing on missed care in community and primary care settings found that there is a high prevalence of understaffing in community nursing, making missed care more likely to occur [70]. Suhonen and Scott (2018) suggest considering the ethical basis for resource allocation and highlight resource constraints on available nursing time as a necessary and urgent public, national and international discussion [68].

The argument that everyone should have a living will no matter what health issues and diagnoses has been suggested in other studies as well [71]. How to educate the general public about dementia, lasting power of attorney, and living wills, in short Advance Care Planning, remains a complex subject to be further studied.

### Strengths and limitations

The preparation, data collection, and analysis stages were documented and performed with care to enhance the trustworthiness of the research. The Standards for Reporting Qualitative Research (SRQR) [50] were followed. The sampling method chosen ensured that knowledgeable participants were recruited. The study participants were engaged in the focus groups interviews, producing a large amount of meaningful data. The knowledge and experience of the study's participants provided a diverse and deep understanding of the research phenomena which has previously not been extensively explored in the Finnish context. These findings provide important information for the development of ACP in dementia care in this context as well as in other regions with similar dementia care processes. The first author's knowledge about ACP guidelines, jurisdiction, and terminology may be considered both a strength and a weakness of the study. There might be a risk of "blindness" to certain aspects of ACP. However, ongoing reflection and sensitivity to the material, the participation of the second author in the focus group interview sessions, and all authors participating in the data analysis provided opportunities to consider any presuppositions during the interviews and analysis stages. Limitations associated with small data samples are present in the current study as well, including limited generalizability. Therefore, the main findings need to be further explored in related settings.

There are possible stumbling blocks connected to the QUAGOL analysis method [57, 58], including losing track of the research question, information overload, and focusing on creativity and intuition. The use of field notes and the documentation of reflections in the analysis process have enhanced trustworthiness. Credibility was affirmed by continuous research team discussions about the emergent results.

### Conclusion

In our study, dementia nurses and geriatricians acknowledge the importance of advance directives and hold a generally positive view of ACP in dementia care. A number of factors affect the conditions for conducting ACP. The lack of ACP in dementia care can be seen as a form of missed care caused by multiple forces coming together simultaneously. The unfavorable circumstances creating this 'perfect storm' consist of the nature of the illness and the associated stigma, unclarity in the suggested care path with inadequate guidelines for ACP, the demands placed on dementia nurses and geriatricians, as well as insufficient resources. Creating a trusting and caring relationship, getting to

know the person with dementia and their family, using intuition and sensitivity in the timing of the ACP conversation, as well as receiving support in the form of coaching and time to reflect with co-workers are all prerequisites for a relationship-centered ACP process, a process with the potential to be rewarding for both care professionals and the person with dementia and their family caregiver.

### Abbreviations

ACP	Advance Care Planning
CERAD	Consortium to Establish a Registry for Alzheimer's Disease
CT	Computerized Tomography
DN	Dementia Nurse
FG	Focus Group
G	Geriatrician
MMSE	Mini-Mental State Examination
MRI	Magnetic Resonance Imaging
QUAGOL	Qualitative Analysis Guide of Leuven
PhD	Doctor of Philosophy
RN	Registered Nurse
SRQR	Standards for Reporting Qualitative Research

### Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12877-023-04033-7>.

**Additional file 1:** Focus group interview 1 Narrative report (page 1 of 4).

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### Authors' contributions

AET: Conception, design, data acquisition and interpretation, drafting the article, all revisions and final approval. M-HN: Conception, design, data acquisition and interpretation, all revisions and final approval. LF: Conception, design, interpretation, all revisions and final approval. HV-R: Conception, design, interpretation, all revisions and final approval.

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### Availability of data and materials

The data generated and analyzed during the current study are not available for public use, due to confidentiality, but are available from the corresponding author on reasonable request.

### Declarations

#### Ethics approval and consent to participate

The Board for Research Ethics (FEN) at Åbo Akademi University approved the PhD project in April 2018. The study was conducted following the ethics principles of the Declaration of Helsinki and the Finnish National Board of Research Integrity (TENK). Approval for the current study was given by the Research, development and innovation department of the Wellbeing services county in which the study took place. All participants received both written and oral information about the aim of the study. They were informed about the voluntary nature of participation, that the interviews would be recorded, and that results would be presented at group level so that individual participants would not be possible to identify. Participants gave their written



informed consent before the interviews. Detailed background data was not collected due to the small sample size.

#### Consent for publication

Not applicable.

#### Competing interests

The authors declare no competing interests.

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