Locus of Control among People with Dementia -

associations with dementia severity, cognitive function and depressive symptoms

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Summary

Background

Dementia is a syndrome characterized by cognitive dysfunction and behavioural and psychological changes, and the ability to perform everyday activities independently is impaired. It is usually progressive and uncurable. Dementia is associated with several psychiatric disorders, and depression is among the most common. Effective psychosocial interventions are necessary to help this patient group cope with their difficulties. Perceptions of control is associated with a person's ability to cope with stress, and locus of control is one of several constructs that may affect the coping process. Knowledge on locus of control among people with dementia may increase the understanding for how people with dementia cope with their challenges.

Aim

The aim of this thesis was to examine locus of control among people with dementia and whether it is associated with dementia severity, cognitive function, or depressive symptoms. The following specific aims were investigated in four papers: 1) to synthesize the present knowledge regarding locus of control and other perceived control belief constructs among people with dementia; 2) to examine the applicability and usefulness of a specific locus of control measurement scale for people with dementia and examine the association between locus of control, depressive symptoms, and cognitive function; 3) to examine association between locus of control and depressive symptoms among people with dementia, both cross-sectionally and prospectively; and 4) to examine whether locus of control changes over time in relation to dementia progression and whether demographic and clinical characteristics are associated with this change.

Method

The thesis includes four substudies. Paper 1 is a systematic review focusing on studies using quantitative, self-reported measures of a control belief construct. Paper 2 is a cross-sectional study examining the applicability of the Locus of Control of Behaviour Scale (LoCB) for people with dementia. Paper 3 is a longitudinal study examining the association between locus of control orientation and severity of depressive symptoms. Paper 4 is a longitudinal study examining one-year changes in locus of control orientation.

Results

Paper 1: We found 18 eligible papers, of which 14 examined self-efficacy, three examined mastery and only one examined locus of control (our own, Paper 2). The studies varied in design, methodology, and whether the control belief was an outcome variable or a covariate. The cross-sectional studies included found support for associations between control belief and the target of interest. The longitudinal and intervention studies varied in their results, and no conclusion can be drawn. However, none of the studies reported difficulties with using a self-reported scale to measure control belief among people with dementia.

Paper 2: Age, education, and cognitive function affected the ability to complete the LoCB. However, cognitive function did not appear to affect the reliability of the scale. The principal component analysis revealed three components as best fitting the data. Locus of control was associated with depression defined as > 7 on the Montgomery-Aasberg Depression Rating Scale.

Paper 3: Locus of control, general health, and insight into dementia disorder were associated with depressive symptoms at baseline. Locus of control and depressive symptoms measured at baseline were also associated with depressive symptoms measured one year later.

Paper 4: After one year, most participants in this study became either more or less externally oriented, using > 5% change as an indication of a clinically meaningful change. Locus of control was the only variable associated with this change. Those participants who became more external showed negative developments on more variables related to dementia progression compared to those who became more internal. However, the severity of depressive symptoms decreased in the group that became more external.

Conclusion

It appears feasible to examine control beliefs among people with dementia using quantitatively self-reported measures, but formal validation for this population is lacking. The LoCB provided reliable results even among those with reduced cognitive function; however, the completion percentage was lower with reduced cognitive function. The LoCB may benefit from a reduction of number of items and more concise wording.

Apart from completion rate, dementia severity and cognitive function were not associated with locus of control. However, more external orientation was associated with more severe depressive symptomatology. The findings support the thesis hypotheses.

Sammendrag

Bakgrunn

Demens er kjennetegnet ved kognitiv dysfunksjon, atferdsmessige og psykologiske endringer, og forstyrrelser av en persons evne til selvstendig å utføre livets daglige aktiviteter. Den er vanligvis progressiv og uhelbredelig. Demens er forbundet med flere psykiatriske lidelser, og depresjon er en av de vanligste. Effektive psykososiale intervensjoner er nødvendig for å hjelpe denne pasientgruppen med deres utfordringer. Opplevelsen av kontroll er assosisert med hvordan en person mestrer stress, og kontrollorientering (locus of control) er en av flere kontrollkonstruksjoner som påvirker mestringsprosessen. Kunnskap kontrollorientering hos personer med demens kan øke forståelsen for hvordan personer med demens mestrer deres utfordringer.

Mål

Målet med denne avhandlingen var å undersøke kontrollorientering hos personer med demens, og om kontrollorientering var forbundet med alvorlighetsgrad av demens, kognitiv funksjon eller depressive symptomer. Dette ble ble undersøkt i fire artikler med følgende mål: 1) Å sammenfatte dagens kunnskap om kontrollorientering og andre kontrollkonstruksjoner blant personer med demens. 2) Å undersøke anvendbarheten av et spesifikt instrument til å måle kontrollorientering hos personer med demens, samt å undersøke sammenhengen mellom kontrollorientering, depressive symptomer og kognitiv funksjon. 3) Å undersøke assosiasjoner mellom kontrollorientering og depressive symptomer blant personer med demens, både tverrsnitt og prospektivt. 4) Å undersøke om kontrollorientering endres over tid i forhold til demensprogresjon, og om demografiske og kliniske variabler var forbundet med denne endringen

Metode

Avhandlingen omfatter fire delstudier. Artikkel 1 er en systematisk oversikt med fokus på studier ved hjelp av kvantitative, selvrapporterte skalaer på opplevelsen av kontroll. Artikkel 2 er en tverrsnittsstudie som undersøkte anvendelsen av Locus of Control of Behaviour-skalaen (LoCB) for personer med demens. Artikkel 3 er en longitudinell studie som undersøker sammenhengen mellom kontrollorientering og alvorlighetsgraden av depressive symptomer. Artikkel 4 er en longitudinell studie som undersøker ettårig endring i kontrollorientering.

Resultater

Artikkel 1: Vi fant 18 kvalifiserte artikler, hvorav 14 undersøkte mestringstro (self-efficacy), tre undersøkte opplevelse av mestring (mastery) og kun en som undersøkte kontrollorientering (vår egen artikkel 2). Artiklene beskrev studier som varierte i design, metodikk og om hvorvidt opplevelsen av kontroll var brukt som en utfallsvariabel eller en annen type variabel. Tverrsnittsstudiene som ble inkludert fant assosiasjoner mellom opplevelse av kontroll og de respektive utfallsmålene. De longitudinelle studiene og intervensjonsstudiene varierte vedrørende assosiasjon mellom utfallsmål og opplevelse av kontroll, og ingen konklusjon kunne trekkes. Ingen av studiene rapporterte imidlertid om vanskeligheter med å bruke en selvrapportert skala for å måle opplevelse av kontroll hos personer med demens.

Artikkel 2: Alder, utdanning og kognitiv funksjon påvirket evnen til å fullføre LoCB. Kognitiv funksjon så imidlertid ikke ut til å påvirke evnen til å svare pålitelig på skalaen. Hovedkomponentanalysen (Principal Component Analysis) avdekket at tre komponenter passet best til dataene. Kontrollorientering var assosiaert med depresjon definert som >7 på Montgomery Aasberg Depression Rating skala.

Artikkel 3: Kontrollorientering, generell helse og innsikt i demenssykdommen var assosiaert med grad av depressive symptomer ved baseline. Kontrollorientering og grad av depressive symptomer målt ved baseline var også forbundet med grad av depressive symptomer målt ett år senere.

Oppgave 4: I løpet av ett år ble de fleste deltakerne i denne studien enten mer eller mindre eksternt orientert. Vi brukte endring på >5% som indikasjon på en klinisk meningsfull endring. Kontrollorientering var den eneste variabelen assosiaert med denne endringen. De som ble mer eksterne viste negativ utvikling på flere variabler knyttet til demensprogresjon sammenlignet med de som ble mer interne. Imidlertid ble alvorlighetsgraden av depressive symptomer redusert i gruppen som ble mer ekstern.

Konklusjon

Det synes mulig å undersøke opplevelsen av kontroll hos personer med demens ved bruk av kvantitative selvrapporterende skalaer, men formell validering for denne populasjonen mangler. LoCB ga pålitelige resultater selv blant de med redusert kognitiv funksjon, men fullføringsprosenten var lavere jo dårligere kognitive fungerende deltakerne var. LoCB kan dra nytte av en reduksjon i antall elementer og av en mer konsis ordlyd.

Bortsett fra fullføringsprosent, var hverken kognitiv funksjon eller alvorlighetsgrad av demens forbundet med kontrollorientering. Mer ekstern orientering var imidlertid forbundet med mer alvorlig depressiv symptomatologi. Funnene støtter således avhandlingens hypoteser.

List of papers

1. Halse I, Bjørkløf GH, Engedal K, Selbæk G, Barca ML. Control Beliefs among People with Dementia: A Systematic Review. Dementia and Geriatric Cognitive Disorder. 2021;50(3):205-223. doi: 10.1159/000516789. Epub 2021 Jun 21.
2. Halse I, Bjørkløf GH, Engedal K, Rokstad AMM, Persson K, Eldholm RS, Selbaek G, Barca ML. Applicability of the locus of control of behaviour scale for people with dementia. Aging and Mental Health. 2020 Dec;24(12):2111-2116. doi: 10.1080/13607863.2019.1652244. Epub 2019 Aug 12.
3. Halse I, Bjørkløf GH, Engedal K, Selbæk G, Barca ML. Locus of Control and Its Associations with Depressive Symptoms amongst People with Dementia. Dementia and Geriatric Cognitive Disorder. 2021;50(3):258-265. doi: 10.1159/000517936. Epub 2021 Aug 12.
4. Halse I, Bjørkløf GH, Engedal K, Selbæk G, Barca ML. One-Year Change in Locus of Control among People with Dementia. Dementia and Geriatric Cognitive Disorder Extra. 2021 Dec 7;11(3):298-305. doi: 10.1159/000520248.

Abbreviations

ACE The Addenbrooke's Cognitive Examination

AD Dementia by Alzheimer's Disease

BPSD Behavioural and Psychological Symptoms of Dementia

bvFTD Behavioural variant of FTD

CDR The Clinical Dementia Rating scale

CSE The Coping Self-Efficacy scale

DLB Dementia with Lewy body disease

DSM-5 Diagnostic and Statistical Manual of Mental disorders, 5th edition

ECOD Effects and Cost of Day Care Centre Program Designed for People with Dementia – A 24-Month Controlled Study

FTD Frontotemporal dementia

GMHR The General Medical Health rating scale

GSES The Generalized Self-Efficacy scale

IADL The Instrumental Activities of Daily Living Scale

ICD-10 International Statistical Classification of Diseases and Related Health Problems, 10th edition

LoCB The Locus of Control of Behaviour scale

lvFTD Language variant of FTD

MADRS The Montgomery Aasberg depression rating scale

MCI Mild cognitive impairment

MMSE-NR The Mini-Mental Status Examination- Norwegian Revised

MoCA The Montreal Cognitive Assessment scale

PADR The Progression of Alzheimer's Disease and Resource Use Study

PCA Principal Component Analysis

PDD Parkinson's Disease with Dementia

PSMS The Physical Self-Maintenance scale

RCT Randomized Controlled Trial

REED Anosognosia Rating Scale

SCI Subjective Cognitive Impairment

SLT Social Learning Theory

TIME Targeted Interdisciplinary Model for Evaluation and Treatment of Neuropsychiatric Symptoms

VaD Vascular Dementia

VIPS Value Individualized Perspective Social

WHO World Health Organization

1 Introduction

Dementia is a syndrome characterized by cognitive deficits and behavioural and psychological symptoms that interfere with a person's ability to live life independently. Most people in the early and moderate stages of dementia are aware of the changes they are experiencing (Starkstein, 2014), meaning that they continually need to manage the loss of functions and abilities (Bjørkløf et al., 2019). It is unsurprising that dementia is associated with many adverse consequences, such as reduced quality of life and depression. Dementia profoundly affects both the person with the diagnosis as well as family and friends, and it has become one of the most feared syndromes of old age (Bystad et al., 2016; Cutler, 2015). Because there is still no cure for dementia, effective psychosocial interventions for helping this patient group cope are essential.

This thesis aims to contribute to a better understanding of perception of personal control, specifically locus of control, among people with dementia. Locus of control is the extent to which a person feels in control over what happens as opposed to external influences determining what happens and is considered an influential part of coping. Locus of control orientation is examined in relation to dementia severity, cognitive function, and depressive symptomatology with a special focus on community-dwelling people with dementia. Hopefully, increased knowledge about the associations among locus of control, depressive symptoms, and dementia can be of value in the understanding of how people with dementia cope with their disorder.

2 Background

2.1 Dementia

2.1.1 Prevalence

Worldwide, it is assumed that 55 million people live with dementia today, with 10 million new cases yearly (WHO, 2021). The prevalence rate is expected to increase substantially to 139 million in 30 years due to the aging population (WHO, 2021). In Norway, the present estimated 101,000 people with dementia will more than double to 236,000 by 2050 (Gjøra et al., 2021). A recent study found a higher prevalence rate than previously assumed, with 14.6% of those aged 70 years or older having dementia (Gjøra et al., 2021). The prevalence rate increased steadily with age; 5.6% of those aged 70 to 74 had dementia compared to 48.1% of those aged 90 and older, and women had a 1.3% higher prevalence rate than men. Due to the aging population, the numbers found in Norway resonate with worldwide estimations (WHO, 2021).

2.1.2 Diagnostic Criteria

The two most commonly used criteria for diagnosing dementia and the aetiological dementia diseases are the International Classification of Diseases 10th edition (ICD-10) (WHO, 1993) and the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) (APA, 2013). Other diagnostic criteria also exist for the etiological dementia diagnoses, such as the criteria for dementia by Alzheimer's disease defined by the National Institute on Aging (McKhann et al., 2011), the criteria for vascular cognitive disorders defined by the International Society for Vascular Behavioral and Cognitive Disorders (Sachdev et al., 2014; Sachdev et al., 2019), the criteria for frontotemporal dementia (FTD) by the International Behavioural Variant FTD Criteria Consortium (Rascovsky et al., 2011), and the criteria for Lewy body dementia by the Dementia with Lewy Body Consortium (McKeith et al., 2005).

As presented in Table 1, both the ICD-10 criteria for dementia and DSM-5 criteria for 'major neurocognitive disorder' focus on a cognitive decline that affects a person's ability to perform activities of daily living (ADL) independently and require that the cognitive decline cannot be explained by reduced consciousness due to conditions such as delirium or psychosis. A major difference between the two sets of diagnostic criteria is that according to the DSM-5, cognitive decline can be in any one or more domains, while according to the ICD-10, memory

must be one of at least two impaired domains. This will change in the upcoming ICD-11, where memory impairment as one of at least two impaired domains will no longer be a requirement. Both the ICD-10 and DSM-5 have criteria for diagnosis of dementia type or aetiology; however, these are not listed in this thesis. The clinical symptoms are the basis for diagnosing dementia, but biomarkers can now be used for confirming the disease aetiology of some dementia types (McKhann et al., 2011).

Table 1: Diagnostic Criteria for Dementia

ICD-10	Dementia 1. Evidence of each of the following: -A decline in memory, which is most evident in the learning of new information from both verbal and nonverbal material. -A decline in other cognitive abilities characterized by deterioration in judgement and thinking and in the general processing of information. The severity of the decline is specified according to the following: **Mild**. The decline in cognitive abilities causes impaired performance in daily living, but not to a degree that makes the individual dependent on others. **Moderate**. The decline in cognitive abilities makes the individual unable to function without the assistance of another in daily living. **Severe**. The decline is characterized by an absence or virtual absence of intelligible ideation. 2. Preserved awareness of the environment 3. A decline in emotional control or motivation or a change in social behaviour manifest as at least one of the following: emotional lability, irritability, apathy, coarsening of social behaviour. 4. For a confident clinical diagnosis, criteria 1 should have been present for at least six months. The diagnosis is further supported by evidence of damage to other higher cortical functions, such as aphasia, agnosia, and/or apraxia.
DSM-5	Major Neurocognitive Disorder

	A. Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual-motor, or social cognition) based on 1. Concern of the individual, a knowledgeable informant, or the clinician that there has been a significant decline in cognitive function, and 2. A substantial impairment preferably documented by standardized neuropsychological testing. B. The cognitive decline interferes with independence in everyday activities. C. The cognitive decline does not occur exclusively in the context of a delirium. D. The cognitive decline is not better explained by another mental disorder. The severity of decline is specified according to the following: **Mild:** Difficulties with instrumental activities of daily living **Moderate:** Difficulties with basic activities of daily living **Severe:** Fully dependent Specify: **Without behavioural disturbance:** If the cognitive disturbance is not accompanied by any clinically significant behavioural disturbance. **With behavioural disturbance** *(specify disturbance)*: If the cognitive disturbance is accompanied by a clinically significant behavioural disturbance (e.g., psychotic symptoms, mood disturbance, agitation, apathy, or other behavioural symptoms).

Criteria modified from the ICD-10 (WHO, 1993) and DSM-5 (APA, 2013).

In Norway, the Norwegian Directorate of Health has developed a standardized procedure for diagnosing dementia, and the following is a shortened version of this (Helsedirektoratet, 2017): The diagnosis is based on clinical presentations of symptoms, the history of symptoms' debut, and assessment of how the symptoms interfere with activities of daily living. An anamnestic history and symptoms description should also be provided by someone who knows the patient well, such as a family member. In addition, the patient should undergo somatic examinations and neuropsychological tests, both of which may support or contradict the clinical presentation. People with suspected dementia are either diagnosed by their primary physician or can be referred to a geriatric, psychiatric, or neurological hospital clinic. Referral is done when the symptoms presented are atypical or show a rapid progression, if the

patient is younger than 65 years old, if there are psychiatric comorbidities or developmental disorders, or if the patient is from a cultural minority group or speaks a different language.

2.1.2.1 After Diagnosis

Because there is no cure for dementia, treatment after diagnosis primarily consists mainly of provision of care. The WHO has referred to the principles of person-centred care in their recommendations for a global dementia care strategy, and Norway adheres to these principles (Helsedirektoratet, 2017; Kitwood, 1997). Indeed, since 2015, Norway has had a particular care and prevention guideline for dementia, and this is currently in its third version (Norwegian Ministry of Health and Care Services, 2021). Despite loss of cognitive and functional abilities, people with dementia are to be viewed as individuals with the right to their own perception of their situation and this perception should influence care options. According to Brooker (2003), the four main principles of person-centred care are the inherent value of all human beings, the need for individualized approaches, taking into account the perspective of the person with dementia, and a focus on positive social psychology. This was developed into a in a framework called the VIPS model, which is used as a means of exemplifying the essence of person-centred care (see Table 2) (Brooker, 2003; Røsvik et al., 2011).

Table 2 The VIPS Model of Person-Centred Care

V	A VALUE base that asserts the absolute value of all human lives regardless of age or cognitive ability
I	An INDIVIDUALIZED approach recognising uniqueness
P	Understanding the world from the PERPECTIVE of the person living with dementia
S	Positive SOCIAL psychology in which the person living with dementia can experience relative well-being

In Norway, most older people live in their own homes. Municipal services are in place to encourage continued home dwelling for older people with a variety of disabilities, and these also relate to people with dementia (Helsedirektoratet, 2017). As such, people with dementia can receive in-house care and assistance such as help with medication, dressing, and personal care as well as practical help such as house cleaning and grocery shopping. Furthermore, people with dementia are eligible for day care services, and all counties in Norway are required to have day care services designed particularly for those with dementia (Helsedirektoratet, 2017). At the severe stage of dementia or if home dwelling is no longer

possible even with municipal assistance, the person with dementia moves to a nursing home (Helsedirektoratet, 2017).

Still, despite the lack of a cure for dementia, there are some recommendations regarding pharmacological options that may delay further development of cognitive deficits or ease behavioural and psychological symptoms, however, these options have only produced modest effects (Helsedirektoratet, 2017). Pharmacological treatment options are mentioned where relevant in the description of the individual dementia types in Section 2.1.4.

2.1.3 Risk Factors

Known nonmodifiable risk factors for dementia are age and certain genetic variabilities such as the presence of the ApoE type 4 allele (Scheltens et al., 2021). Fortunately, however, recent reports have concluded that there are 12 important modifiable risk factors and that effective management of these could reduce the incidence of dementia in as many as 40% of all cases (Livingston et al., 2020; Livingston et al., 2017). The 2020 Lancet Commission on Dementia Prevention, Intervention and Care listed the following 12 modifiable risk factors: low education, hearing loss, depression, high blood pressure, diabetes, obesity, physical inactivity, smoking, social isolation, excessive alcohol consumption, head injury, and air pollution. Addressing these factors is expected to be effective by either reducing neuropathological damage or increasing and maintaining the individual's cognitive reserve. Indeed, there are already indications that dementia incidence rates are

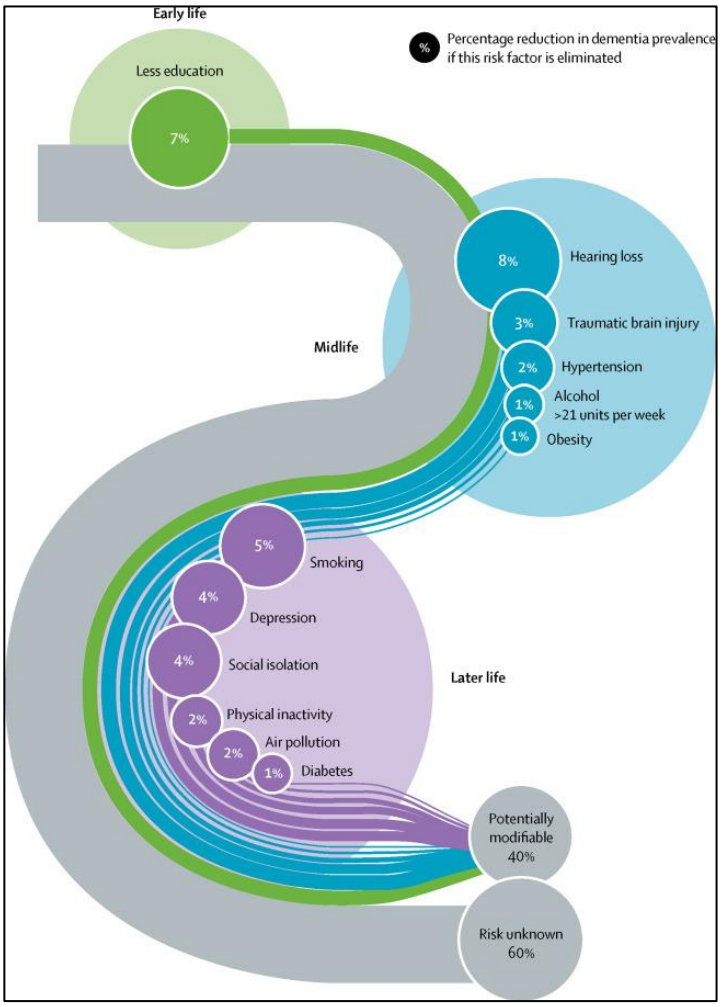

Figure 1: Potentially Modifiable Risk Factors for Dementia and Time Periods in Which They Should Optimally Be Targeted. The illustration is reprinted with permission.

decreasing in several Western countries, which could be attributable to better management of cardiovascular diseases and better education (Roehr et al., 2018; Stephan et al., 2018). This shows how even addressing only a few of the modifiable risk factors may have a positive effect on the prevention or delayed development of dementia. However, as seen in Figure 1, these factors need to be addressed at what appear to be different time periods during life (Livingston et al., 2020).

Before a dementia diagnosis, many people experience conditions called subjective cognitive impairment (SCI) and mild cognitive impairment (MCI). SCI (also called subjective cognitive decline or subjective memory complaints) is used to describe experiences of cognitive decline that cannot be verified by objective measures (Engedal & Haugen, 2018). A meta-analysis found that experiencing SCI doubled the risk of developing dementia compared to control groups without SCI (Mitchell et al., 2014). MCI is used to describe cognitive deficits that are measurable but do not interfere significantly with independent functioning in activities of daily living (Petersen et al., 2018). MCI may have a variety of causes, such as delirium, depression, alcohol abuse, psychiatric illness, stroke, or cerebrovascular diseases (Roberts & Knopman, 2013), many of which also can cause dementia. Some individuals with MCI remain stable at this level of impairment, and some reverse to become cognitively healthy (Petersen et al., 2018). The risk of developing dementia varies between studies and populations but is reported to have an annual conversion rate of between 5 and 20% (Langa & Levine, 2014). However, in a study of MCI patients recruited from memory clinics, as many as 71% had been diagnosed with dementia within seven years (Engedal et al., 2020).

Both the DSM-5 and the ICD-10 have criteria for diagnosing MCI, but there are no diagnostic criteria for SCI in either of the major diagnostic manuals (APA, 2013; WHO, 1993). However, a consensus group has developed a set of criteria for use in research (Jessen et al., 2014). Figure 2 is a simplified illustration of changes in cognitive function in people with normal

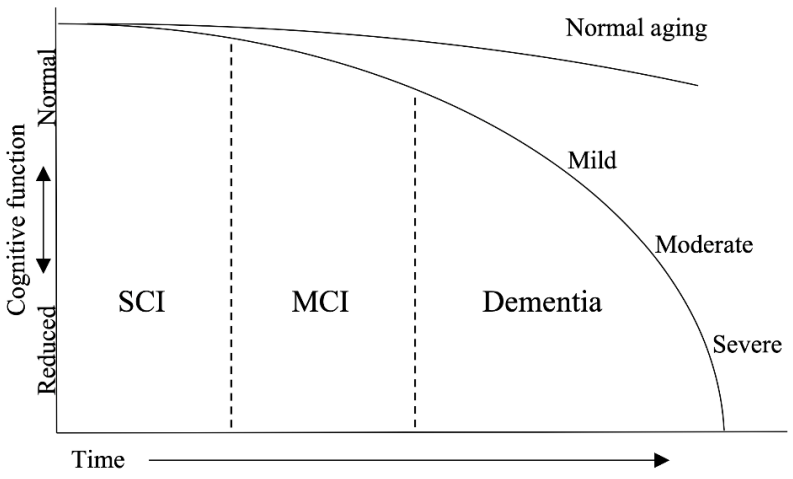

Figure 2: An Illustration of Cognitive Decline in Normal Aging Versus Aging with Subjective Cognitive Impairment, Mild Cognitive Impairment, or Dementia. The illustration is adapted from Sperling et al. (2011) and Jessen et al. (2014).

aging versus people with SCI, MCI, or dementia.

2.1.4 Diagnoses

In the following sections, the most common types of dementia are presented. Importantly, however, many of the below-mentioned dementias may co-occur and confuse the clinical manifestations, particularly among the oldest (Gale et al., 2018).

2.1.4.1 Dementia by Alzheimer's Disease

For many people, Alzheimer's disease has become synonymous with dementia, and the two terms are often used interchangeably among non-professionals. Alzheimer's disease is characterized by the accumulation of beta-amyloid plaque located outside the neurons and neurofibrillary tangles inside the neurons in the brain, which causes neurodegeneration (Engedal & Haugen, 2018). It is possible to have Alzheimer's disease without dementia and thus be either asymptomatic or showing symptoms of MCI. It is assumed that Alzheimer's disease begins in the brain 10 to 15 years before the clinical signs of dementia are present (Scheltens et al., 2021). However, the progressive neurodegeneration leads to what is called dementia by Alzheimer's disease (AD). Among the many different types of dementia, AD represents the majority (i.e., between 57 and 80% of all cases; (Gjøra et al., 2021)). The mean survival is 10 to 12 years after symptom onset (Gale et al., 2018). The cause(s) of AD are unknown, but as mentioned in Section 2.1.3, many risk factor have been identified (Scheltens et al., 2021). In Norway, it is recommended that a person with mild to moderate AD be treated with cholinesterase inhibitors (Helsedirektoratet, 2017).

The neurodegeneration in AD usually starts in the hippocampal areas, explaining why memory difficulties are the hallmark of this type of dementia (Engedal & Haugen, 2018). This is called the amnestic variant of AD (Knapskog et al., 2021). However, in the non-amnestic variant of AD the disease may manifest itself in behaviour changes, language difficulties or impairment in orientation for space (Knapskog et al., 2021). In the non-amnestic variant the frontal or parietal lobes are the first parts of the brain that are affected (Engedal & Haugen, 2018). As the disease progresses, the degeneration spreads to other parts of the cortex and the subcortex, causing more global cognitive dysfunction (Engedal & Haugen, 2018). Even with a gradual onset and slow symptom progression, a person with AD will eventually become unable to perform any activities independently and will require continual care (Engedal & Haugen, 2018).

2.1.4.2 Vascular Dementia

Vascular dementia (VaD) is the second most common dementia type, accounting for 15 to 35% of all dementias (Gale et al., 2018). VaD is a nondegenerative type of dementia caused by cerebrovascular diseases such as stroke, brain infarct, or haemorrhage after which the primary symptoms of dementia become manifest (O'Brien & Thomas, 2015). When diagnosing VaD, it is important to adhere to the criteria of a temporal relationship between stroke or cerebrovascular events and development of dementia symptoms (Sachdev et al., 2014), and the onset of dementia symptoms is often sudden (Gale et al., 2018; O'Brien & Thomas, 2015). The primary clinical symptoms of VaD will vary according to which areas of the brain were affected first. However, the predominant deficits are in information processing speed, attention, and executive function, while there are more variable deficits in memory, language, and apraxia (O'Brien & Thomas, 2015; Sachdev et al., 2014). As a nondegenerative disease, the symptom severity does not automatically progress; however, new cerebrovascular incidents are common and may thereby cause a step-wise worsening of the dementia severity (Gale et al., 2018). AD and VaD have several overlapping risk factors, and a mixture of AD and VaD is common among older people with dementia, especially those 85 years old and older (Gale et al., 2018; O'Brien & Thomas, 2015)). Treating VaD with dementia medication is not recommended; however, medication and life-style changes are recommended for preventing future vascular incidents. Mixed AD and VaD may be treated with memantine (Helsedirektoratet, 2017).

2.1.4.3 Lewy Body Dementias

Dementia with Lewy body disease (DLB) and Parkinson's disease with dementia (PDD) are together the second most common type of neurodegenerative dementia (Hogan, Fiest, et al., 2016). They are both defined by the accumulation of Lewy bodies, which constitutes an alpha-synuclein protein disease that leads to neurodegeneration (Gale et al., 2018; Walker et al., 2015). The two types of dementia differ in whether their primary symptoms are indicative of dementia or Parkinson's disease. However, they become clinically and biologically similar as the neurodegeneration progresses (Walker et al., 2015). Both DLB and PDD are characterized by symptoms of fluctuation of cognitive dysfunction and arousal, visual hallucinations, Rapid Eye Movement sleep behaviour disorder, and muscle rigidity and slowness (Gale et al., 2018; McKeith et al., 2017; Walker et al., 2015). In the early phases, DLB can often be difficult to differentiate from delirium because both are characterized by fluctuation of awareness and visual hallucinations (Engedal & Haugen, 2018; Walker et al.,

2015). It is furthermore hypothesized that DLB is underdiagnosed because it may be misdiagnosed as AD (McKeith et al., 2017; Walker et al., 2015). For a diagnosis of PDD, Parkinson's disease must already have been determined, and the motor symptoms must have started more than one year ahead of the cognitive impairment (Emre et al., 2007; Gale et al., 2018). PDD is found among approximately 50% of people with more than 10 years of Parkinson's disease (Walker et al., 2015). Persons with mild to moderate DLB or PDD may be treated with cholinesterase inhibitors; however, this is not a firm recommendation (Helsedirektoratet, 2017).

2.1.4.4 Frontotemporal Dementias

FTD is caused by various degenerative brain disorders and has a prevalence rate of 2.7% of all dementias (Hogan, Jetté, et al., 2016). However, it is far more common among those with early onset dementia (those diagnosed before the age of 65), where prevalence rates may be as high as 20 to 26% (Bang et al., 2015; Gale et al., 2018). FTD can be caused by several diseases that have in common that they primarily affect either the prefrontal or temporal cortex or both (Engedal & Haugen, 2018). The causes of the various brain disorders causing FTD are largely unknown but in contrast to the other types of dementia genetic factors are more common. It is assumed that approximately 25% of the cases can be explained by genetics (Warren et al., 2013). Treating FTD with dementia medications is not recommended (Helsedirektoratet, 2017).

FTD exists in two variants: the behavioural variant (bvFTD), accounting for 55% of FTD, and the language variant (lvFTD), accounting for 45% (Engedal & Haugen, 2018; Gorno-Tempini et al., 2011; Rascovsky et al., 2011). A person with bvFTD may at first show symptoms such as a lack of concentration, initiative, and ability to plan a course of action. This can manifest itself as apparent personality changes with disinhibited or compulsive behaviours and mental rigidity (Engedal & Haugen, 2018; Gale et al., 2018). Since memory and speech are intact in the early stages of the disease, the primary symptoms may be difficult to differentiate from psychiatric disorders such as depression, mania, or psychosis (Bang et al., 2015; Rascovsky & Grossman, 2013). A person with lvFTD will primarily show symptoms of language difficulties, and lvFTD can be further subdivided into three variants: nonfluent/agrammatical, semantic, or logopedic (Gorno-Tempini et al., 2011). While the bvFTD and lvFTD have characteristic features, these are primarily detectable in the early stages because disease progression leads to a global cognitive impairment (Bang et al., 2015; Gale et al., 2018).

The abovementioned list of dementia types is far from exhaustive. Dementia can also be caused by long-term excessive alcohol consumption, infections such as meningitis, immune deficiency conditions such as multiple sclerosis, and many other biological and neurological conditions (Engedal & Haugen, 2018). However, these types of dementia are considered beyond the scope of this thesis.

In sum, the symptomatic differences between the different types of neurodegenerative dementia are mostly present in the early phases of the disease. In the severe stages of most common types of dementia (except for VaD), persons with various neurodegenerative brain diseases will have clearly impaired memory; reduced awareness; and difficulty with logical reasoning, comprehension, and production of language and will have become dependent in activities of daily living with gait and motor disturbances.

2.1.5 Symptoms

In this section, the symptoms of dementia are described in more detail. These symptoms are the hallmarks of a dementia diagnosis, and they help define the dementia severity. Monitoring the symptoms of dementia is essential for continually providing the best possible treatment for the individual. Additionally, the symptoms of dementia are manifestations of the losses and changes that the person with dementia cannot control and must learn to cope with. Control and coping are described in more detail in Section 2.2.

2.1.5.1 Cognitive Symptoms of Dementia

Cognition is an overarching term for the many mental processes humans rely on to understand and interact with the world. It is defined as 'the mental action or process of acquiring knowledge and understanding through thought, experience, and the senses (Press, 2021). Cognition encompasses processes such as perception, memory, attention, learning, orientation, language, and problem solving. Some processes are considered simple, whereas others are complex in that they incorporate several processes at one time (Harvey, 2019). The processes are typically classified into domains of cognitive performance.

Memory deficits are in most cases one of the first symptoms of all brain disorders causing AD, and because AD is the most common form of dementia, this explains the emphasis on memory deficits in various definitions of dementia in the past and today (ICD-10). Memory consists of multiple processes (i.e., short term and long term) and types (episodic, semantic, and procedural), and it is closely related to learning (Engedal & Haugen, 2018). Deficits in

memory can be in any one or several of these processes, making memory one of the more complex cognitive domains (Harvey, 2019). Long-term, episodic memory deficits are the hallmark of AD.

Language is often affected by dementia, and the processes that are commonly affected are word fluency, word understanding, and word naming (Engedal & Haugen, 2018). The affected processes differ according to dementia type and dementia severity, as presented in the description of different language variants of FTDs. Language difficulties are also common in AD. In the early stage, they manifest as difficulties with naming, and in the moderate and severe stages, they manifest as dysfunction in verbal fluency, comprehension, and semantics (Ferris & Farlow, 2013).

Visuospatial perception and visuospatial function are closely linked processes that are related to people's understanding of objects and space and their body in relation to these (Cronin-Golomb, 2011). Deficits in these functions may explain why people with dementia may become lost in familiar places and struggle with using common and familiar home appliances (Cronin-Golomb, 2011). These types of deficit affects are seen in all types of dementias but are early symptoms among people with DLB, who early in the disease development experience hallucinations and visual misconceptions (Cronin-Golomb, 2011).

Executive function is the domain involved in reasoning and problem solving (Engedal & Haugen, 2018; Harvey, 2019). It is considered the most evolved domain because it is needed in complex tasks. Executive functions include planning, cognitive flexibility, and restraint, and closely related processes are processing speed, working memory, and attention (Harvey, 2019). Dysfunctions in executive processes at an early stage of dementia are often indicative of FTD (Rascovsky & Grossman, 2013). Finally, deficits in executive functions along with memory and language are hypothesised to be what lead to anosognosia (lack of insight in cognitive impairment) in dementia because the integration of information from different brain regions is disconnected (Rosen, 2011). This is most prevalent in FTDs but is also common in other dementias (Rosen, 2011).

2.1.5.2 Motor Symptoms of Dementia

The motor symptoms of dementia are perhaps the lesser-known symptoms associated with this syndrome. Motor symptoms commonly seen among people with dementia are Parkinsonistic or extrapyramidal such as tremor and rigidity, low gait speed, and reduced balance (Allan et al., 2005; Engedal & Haugen, 2018). Many of these symptoms are common

for Lewy body dementias, which are defined by their Parkinsonistic features, but these symptoms are also found in other types of dementia. There are even indications that motor symptoms may be used for differential diagnosis of dementia types (Mitchell, 1999; Scherder et al., 2007). Low gait speed, step length, and postural stability, for example, are associated with AD, and wide gait steps, rigidity, and disturbance in initiation of gait are associated with VaD (Scherder et al., 2007).

2.1.5.3 Activities of Daily Living

A defining feature of dementia is difficulties with activities of daily living that were previously easily manageable, and such difficulties may often be the first sign for the person with dementia or those around that something is wrong (Desai et al., 2004). It is common to differentiate between instrumental and physical self-maintenance activities. At first, so-called higher-order ADLs such as managing one's everyday economy become difficult, but gradually, more automatized and less complex ADLs such as getting dressed increase in difficulty (Desai et al., 2004). Common cognitive causes for ADLs are executive, memory, and/or visuospatial deficits (Desai et al., 2004).

2.1.5.4 Behavioural and Psychological Symptoms of Dementia

In this section, behavioural and psychological symptoms of dementia (BPSD) are first described in general followed by a particular focus on depression.

BPSD, also called neuropsychiatric syndromes, are psychiatric or behavioural symptoms frequently observed in people with dementia (Lyketsos et al., 2002). The symptoms that constitute BPSD are varied, may fluctuate and co-occur, and are associated with a faster disease progression if left untreated (Cerejeira et al., 2012; Defrancesco et al., 2020; Edwin et al., 2021; Rabins et al., 2013). They are considered biopsychosocial, meaning that factors related to the person with dementia, the environment, and social surroundings are all likely to contribute to the development of these symptoms (Engedal & Haugen, 2018; Kales et al., 2015). The cause of BPSD is therefore likely multifactorial, and BPSD may thus be difficult to both understand and treat (Lichtwarck et al., 2018).

The typical symptoms of BPSD are listed in Table 3. A Norwegian study found that 72.1% of the sample with dementia receiving domiciliary care exhibited symptoms of BPSD, and of these 21.1% had symptoms rated as clinically significant (Wergeland et al., 2014). Longitudinal studies of both community-dwelling people with dementia and nursing home residents with dementia have reported cumulative prevalence rates for BPSD symptoms as

high as 77% and 97%, respectively (Selbæk et al., 2014; Steinberg et al., 2008). Depression and anxiety are often reported as most prevalent in the earlier stages of the dementia disease; apathy is more evenly reported across all stages; and more severe dementia is more often associated with agitation, disinhibition, psychosis, and irritability (Kales et al., 2015; Selbæk et al., 2014). For many formal and informal caregivers, BPSD represents the most challenging part of caring for a person with dementia (Kales et al., 2015). The symptoms are associated with increased caregiver burden and negative mood as well as earlier institutionalization (Brodaty et al., 2014; Feast et al., 2016).

Table 3: Symptoms of Behavioural and Psychological Symptoms of Dementia

- Delusions (distressing beliefs)
- Hallucinations
- Agitation: easily upset; repeating questions; arguing or complaining; hoarding; pacing; inappropriate screaming, crying out, or disruptive sounds; rejection of care (e.g., bathing, dressing, grooming); leaving home
- Aggression (physical or verbal)
- Depression or dysphoria
- Anxiety: worrying, shadowing (following caregiver)
- Apathy or indifference
- Disinhibition: socially inappropriate behaviour, sexually inappropriate behaviour
- Irritability or lability
- Motor disturbance (repetitive activities without purpose): wandering, rummaging
- Night-time behaviours (waking and getting up at night)

List adapted from Kales et al. (2015).

It has been suggested that individual symptoms are best understood as parts of clusters or subsyndromes, such as the psychotic cluster, the behavioural or hyperactive cluster, the affective cluster, or the apathy cluster. The cluster understanding is based on the belief that groups of symptoms have the same underlying cause and can thereby be treated similarly (Connors et al., 2018; Selbæk & Engedal, 2012). However, the stability of such clusters has been questioned because studies have found differences in factor loadings when comparing samples and when comparing the same sample over time (Connors et al., 2018).

Because the causes of BPSD are likely multifactorial, careful considerations regarding the target of treatment of BPSD are needed. If the person with dementia is the primary receiver of treatment, a person-centred focus using nonpharmacological interventions is recommended as

a first line approach because such interventions are considered minimally invasive (Helsedirektoratet, 2017; Kales et al., 2014). There are many types of nonpharmacological treatment interventions, and in a comprehensive systematic review, Abraha et al. (2017) categorized the different types into the following categories: sensory stimulation interventions, cognitive-emotion-oriented interventions, behaviour management interventions, multicomponent interventions, and others. Examples of each are listed in Table 4.

Table 4 Examples of Behavioural and Psychological Symptoms of Dementia Interventions Divided by Target Focus

Sensory Stimulation	Cognitive-Emotion	Behaviour Management	Multicomponent	Others
Acupressure, aromatherapy, massage/touch therapy, light therapy, sensory garden	Cognitive stimulation, music/dance therapy, Snoezelen, transcutaneous electrical nerve stimulation, reminiscence therapy, validation therapy, simulated presence therapy	Cognitive behaviour therapy, functional analysis of specific behaviour, individual behavioural reinforcement strategies, communication training, habit training, progressive muscle relaxation	Combinations of psychosocial, nursing, medical, and pharmacological interventions	Exercise therapy, animal-assisted therapy, special care unit and dining room environment-based interventions

List adapted from Abraha et al. (2017)

In addition to the type of interventions available, the modes of implementing them can vary. For example, interventions can be implemented as individual therapy, in group settings, in dyads with the person with dementia and a family caregiver, or as case management interventions in which those involved in the care for an individual person are included (Regan & Varanelli, 2013). The latter is particularly applicable in nursing homes, where the person with dementia is presumably in the severe stage of the disorder and thereby less likely to be able to clearly communicate the origin of their BPSD. In Norway, a recently developed example is the Targeted Interdisciplinary Model for Evaluation and Treatment of Neuropsychiatric Symptoms (TIME). Using TIME has resulted in positive effects on agitation for people with dementia living in nursing homes (Lichtwarck et al., 2018).

In some instances, however, medical treatment of BPSD is warranted. This can be when nonpharmacological approaches have failed or if the symptoms are severe and/or acute (Helsedirektoratet, 2017). Psychotic symptoms and aggressive agitation may be treated with antipsychotics for people with AD, VaD, or mixed dementia. People with FTD or DLBs should not receive antipsychotics due to potentially adverse side effects (Helsedirektoratet, 2017). Benzodiazepines are not recommended for people with dementia due to both potential adverse side effects and addiction development (Helsedirektoratet, 2017). On a final note, evidence of effectiveness of psychopharmacological treatment is low, further increasing the importance of using nonpharmacological interventions as first-line approaches (Dyer et al., 2018; Kales et al., 2015; Wang et al., 2015).

2.1.5.4.1 Depression in Dementia

Of the individual BPSD symptoms, depression is one of the more prevalent (Barca, Engedal, & Selbæk, 2010; Enache et al., 2011; Lyketsos et al., 2002). Depression in the general population is characterized by low mood or sadness, lack of interest, and lack of energy (APA, 2013; WHO, 1993). It has a gradual onset, and the small but incremental changes in behaviour may be difficult to detect. A person with depression often avoids social meetings and instead isolates at home. Hobbies and other interests are neglected, and sleep rhythm is disturbed. Loss of appetite is common, resulting in even less energy. The ability to concentrate is affected, and depressive thoughts, low self-esteem, increased rumination, and feelings of guilt are common, as are suicidal ideation and sometimes action.

As can be inferred from the above description, differential diagnosis between depression and dementia can be difficult. Diagnosing depression among people with a confirmed dementia diagnosis may be even more challenging because many of the symptoms overlap. It is possible that depression in dementia is underreported, particularly in the severe stages of dementia (Starkstein et al., 2005). Because studies have found that the DSM-5 criteria may underrepresent the actual prevalence rates, the use of a different set of diagnostic criteria for depression in AD has been proposed (Barca, Engedal, & Selbæk, 2010; Olin et al., 2002; Sepehry et al., 2017). According to research on the proposed Provisional Diagnostic Criteria for depression in Alzheimer's disease defined by Olin et al. (2002), depression in AD is generally milder than depression among people without dementia, indicating that only three, not five, of the DSM-5 criteria may be necessary for a diagnosis (Sepehry et al., 2017).

Even with the possibility of underreporting, depression prevalence rates among people with dementia are high (Barca, Engedal, & Selbæk, 2010; Enache et al., 2011; Kitching, 2015;

Knapskog et al., 2014). A review and meta-analysis found prevalence rates ranging from 19 to 78% with a pooled prevalence of 42% (Zhao et al., 2015). Another review and meta-analysis found a similar pooled prevalence rate to remain consistent across dementia stages and dementia type (Leung et al., 2021).

Several studies indicate that depression can lead to or exacerbate cognitive decline (Barca et al., 2017; Fritze et al., 2011; Rapp et al., 2011). Furthermore, depression among people with dementia is associated with reduced quality of life (Barbe et al., 2018; Naglie et al., 2011; Winter et al., 2011), reduced independence in daily life activities (Knapskog et al., 2014), earlier admission to a nursing home (Starkstein et al., 2005), suicidal ideation (Draper et al., 1998; Kiosses et al., 2015), and higher morbidity and mortality (Barca, Engedal, Laks, et al., 2010). Treating depression or depressive symptoms is essential because of the association with adverse outcomes. Pharmacological treatment of depression using selective serotonin reuptake inhibitors may be conducted, but is likely most effective if depression is moderate to severe (Helsedirektoratet, 2017). Regardless of degree of depression, however, nonpharmacological interventions should be the first choice (Helsedirektoratet, 2017).

The nonpharmacological treatment interventions for depression in dementia are many of the same as mentioned for BPSD in general, such as emotion-oriented and sensory-stimulation therapies. Additionally, people with mild to moderate dementia have been included in studies with traditional psychological interventions also used for people without cognitive deficits, such as variants of cognitive-behavioural therapy and problem-solving therapy (Kiosses et al., 2015; Spector et al., 2015; Teri et al., 1997; Tonga et al., 2021). While it has been viewed as too cognitively demanding for people with dementia, cognitive-behavioural therapy is now being performed, but with assistive techniques such as involvement of a family caregiver and the use of structured formats, repetitions, and notes. Several reviews have concluded that studies targeting depression using nonpharmacological interventions appear effective, but firm conclusions remain elusive due to small studies and the heterogeneity of study designs and intervention types (Noone et al., 2019; Orgeta et al., 2015; Regan & Varanelli, 2013; Tay et al., 2019).

As with all types of BPSD, no single factor causes depression. Instead, depression should be understood as caused by interconnections between biological, psychological, and social or environmental factors. Studies have found several biological and social risk factors for depression among people with dementia, such as the degree of cognitive decline, dementia disease insight, prior depressive disorder, general health, and residing in an assisted-living

facility (Barca et al., 2012; Fritze et al., 2011; Harwood et al., 2000; Lyketsos & Olin, 2002; Rosness et al., 2010; Steck et al., 2018; Stroud et al., 2008). More knowledge is needed about how depression in people with dementia is associated with psychological risk factors such as perceptions of control.

2.2 Locus of Control

Control became an influential topic in psychology in the mid-20th century. The allure of control as a psychological phenomenon was the idea that all humans strive to interact effectively with the environment, meaning that they wish to obtain positive outcomes and avoid negative ones. In essence, humans want to feel competent. With the cognitive revolution in psychology came the distinction of objective and subjective experiences of control, with the latter referred to as beliefs or perceptions of control (Chipperfield et al., 2012). An idea evolved that humans do not need to objectively interact effectively with their environment; for a person's well-being, it appeared sufficient for individuals to perceive themselves as being in control.

One of the first and most influential control belief[1] constructs is locus of control (Rotter, 1966). In 1966, Julian Rotter presented this construct as an integral part of his social learning theory (SLT). In contrast to understanding behaviour as a reflexive reaction to stimuli or as motivated by unconscious drives, as was common in the dominant understandings in behaviourist and psychoanalytic traditions of the time, Rotter explained behaviour as resulting from an interaction of a person's history of learning through life experiences and stimuli that occur both inside and outside of awareness. He described four components that in combination predicted behaviour: behaviour potential (the likelihood that a behaviour will occur), expectancy (the subjective belief that a behaviour will lead to a specific outcome), reinforcement value (the subjective valence placed on an outcome), and psychological situation (the subjective interpretation of the situation) (Rotter, 1975). Thus, the potential for a behaviour to occur is the function of the subjective value of the outcome and the subjective expectancy that, if the behaviour is performed, it will lead to the desired outcome (Nowicki &

[1] In this thesis, 'perceived control' and 'control belief' are used synonymously as overarching terms for all constructs referring to a personal perception or expectancy of control.

Duke, 2016). Put more simply, the likelihood that one will act increases if what is obtainable is considered meaningful and one's efforts are assumed to be productive.

Though Rotter presented a complete theory for explaining behaviour, the locus of control construct gained the most recognition (Rotter, 1975). Locus of control is an expectancy variable in the SLT, and Rotter defined expectancy as 'a subjective probability or contingency held by the individual that any given specific reinforcement or group of reinforcements will occur due to a certain response' (Strickland, 2016, p. 24). Rotter (1966) considered a person's locus of control to be on a continuum ranging from internal to external and that one's expectancy generalizes between similar situations. A person with an internal locus of control expectancy, often called an internal orientation, is more likely to think that reinforcements or outcomes would be dependent upon his or her own behaviours. Conversely, a person with an external orientation is more likely to expect reinforcements to be contingent upon luck, chance, or fate or under the control of powerful others (Rotter, 1966). These different ways of placing control over outcomes are learned through experiences and are most likely to be influential in determining behaviour in situations that are experienced as novel or ambiguous (Rotter, 1975). In order to measure locus of control, Rotter (1966) developed a measure called the internal-external (I-E) scale.

Locus of control quickly ignited an immense number of academic discussions, research, and development of general and specific locus of control scales (Lefcourt, 1981, 1992). Between 1965 and 1975, Rotter's 1966 publication became the third most cited in the Social Science Citation Index (Furnham & Steele, 1993). One of the major discussions was whether locus of control is a unidimensional or multidimensional construct. Rotter advocated the former, but Levenson (1973) argued that locus of control multidimensional and that the external orientation could be dichotomised into orientation towards powerful others and orientation towards fate, luck, or chance.

The interest in locus of control led to a range of areas in which this construct was deemed applicable and informative (Furnham & Steele, 1993). However, many researchers argued that the I-E scale produced inconsistent and unreliable results due to either the attributes of the scale itself, such as its unidimensionality and forced choice format, or it being situationally unspecific. Rotter claimed that his scale was intended to capture a general tendency that people would trend towards either internality or externality across situations. He therefore recognized that the scale had low predictability of behaviour and the need for other scales to measure situation-specific locus of control, allowing for higher behaviour predictability. Thus,

in addition to the development of new generalized measures, a plethora of new situation-specific scales such as the Multidimensional Health Locus of Control scale (Wallston et al., 1978) and the Locus of Control Scale for Children (Nowicki & Strickland, 1973) were produced. Lesser-known situation-specific scales can be found in areas such as aviation safety, for children ages three to eight years (Hunter, 2002; Mischel et al., 1974), for tenants (LeBrasseur et al., 1988), and for parents (Furnham, 2010), to mention a few. However, to this day, Rotter's I-E scale is used in research across situations, age groups, and cultures (Afrasiabi et al., 2020; Kurtović et al., 2018).

The discussion of generality versus specificity also led to debates regarding whether locus of control is a personality trait or should be understood as a cognitive process (Infurna & Reich, 2016). Personality traits can be defined as 'enduring, automatic patterns of thoughts, feelings, and behaviours that tend to manifest in certain ways under certain circumstances' (Jackson et al., 2012). Rotter viewed locus of control as a personality trait, and locus of control has been hypothesized to be part of a higher-order personality construct together with self-esteem, self-efficacy, and neuroticism (Judge & Bono, 2001). However, other scholars have argued that its learned origin and situation-specific influence are precisely what distinguish it from fixed personality traits (Lachman et al., 2011).

In addition to locus of control, several other control belief constructs were soon developed, including self-efficacy, learned helplessness, and mastery (Skinner, 2016). Table 5provides definitions of the most common constructs. How a construct was labelled and defined could vary, giving rise to a myriad of other terms that perhaps only differed slightly from one another. In an attempt to gather and categorise the many control belief constructs, Skinner (1996) identified more than 100 terms, which is a testament to the inherent value of perceived control but also indicative of the research difficulties this could entail.

Table 5: Definitions of the Most Well-Known Control Belief Constructs

Control Belief Constructs	Definition
Self-efficacy (Bandura, 1978)	A judgement of whether one has the skills to do the necessary specific actions in a specific situation
Mastery (Pearlin & Schooler, 1978)	An overall sense of being able to perform intended actions
Learned helplessness (Abramson et al., 1978)	The belief that having control over a situation is impossible, resulting from continuous situations in which control has been experienced as nonexistent

Locus of control and other control belief constructs are believed to affect how people cope. One of the most commonly used understandings of coping is the transactional model of stress and coping developed by Lazarus and colleagues (Lazarus & Folkman, 1984). Without stress, there is nothing to cope with, so the two concepts are intertwinedFigure 3: A Simplified Illustration of the Transactional Model of Stress and Coping by Lazarus and Folkman (1984). Figure 3 presents an illustration of the stress and coping model. Primary appraisal is what occurs when a person determines whether the event is experienced as a threat (or loss/harm/challenge) or as benign (or positive/irrelevant). If viewed as anything but benign, the process continues to secondary appraisals. Here the person determines the potential efficacy of his or her psychological resources and coping strategies. Based on the secondary appraisals, a coping response is applied that either focuses on changing the stressor or one's reaction to it. Such responses are called problem-focused or emotion-focused response styles (Folkman, 1984). The outcome of the coping response can be positive or negative and affects the appraisal of similar events.

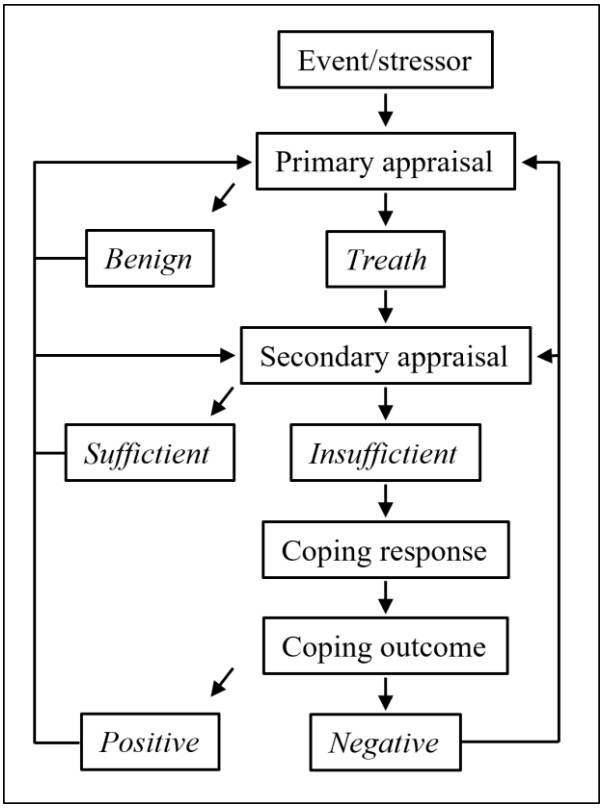

Figure 3: A Simplified Illustration of the Transactional Model of Stress and Coping by Lazarus and Folkman (1984).

Locus of control is perhaps most influential in the primary appraisal processes, during which a person ascribes meaning to an event and assesses whether it has the potential to affect that person's well-being (Folkman, 1984). For example, when appraising an ambiguous event, a person with an internal locus of control would potentially view the situation as controllable (i.e., benign), while a person with an external locus of control would view it as uncontrollable (i.e., threatening;) (Folkman, 1984). The entire process of the transactional model of stress and coping is a continual cycle of transactions between the individual and the environment. In its essence, it resembles Rotter's SLT in that people learn and modify their beliefs based on their experiences of undergoing ambiguous or stressful events. This can in turn lead to a change in behaviour and thereby new ways of coping.

Having an internal locus of control, or perceived personal control, has generally been found to be beneficial. Indeed, a sense of perceived control has consistently been associated with being 'happy, healthy, wealthy, and wise' (Lachman, 2006, p. 283), as would be expected based on the theories of both control belief constructs and coping. With regards to health, an internal perception of control has been associated with better treatment adherence, healthy behaviours, and better adaptation to chronic illness conditions (Choi & Twamley, 2013; Robinson & Lachman, 2017; Wallston, 2015). The positive effects of perceived control are further cemented by findings of associations between adverse health and an absence of perceived control. An external locus of control, for example, has been associated with symptoms of depression both among adults in general and among older people with depression (Benassi et al., 1988; Bjørkløf et al., 2013; Bjørkløf et al., 2015).

Among people with dementia, however, there is a lack of knowledge about perceptions of personal control in general and locus of control in particular. In general, an internal locus of control orientation is seen as more adaptive and has to a greater extent than an external orientation been associated with healthy and adaptive behaviours in relation to chronic illness, pain, and diseases (Robinson & Lachman, 2017). However, how do perceptions of control affect a person who has been diagnosed with dementia, a chronic and usually progressive disease that leads to a gradual increase in symptoms negatively affecting the ability to live life independently? To the best of our knowledge, no studies had examined locus of control in people with dementia prior to the beginning of this PhD project. There is a need for knowledge about if and how locus of control is associated with depressive symptoms in this population and whether is it affected by cognitive decline. Information about this could help

health practitioners understand the circumstances that may lead to depression and its maintenance and help inspire how to help people with dementia cope with their situation.

3 The Thesis

Based on the background presented in the previous sections, the aim of this thesis is to investigate locus of control among people with dementia by examining its associations with dementia severity, cognitive function, and depressive symptoms. We hypothesised that locus of control is not associated with dementia severity or cognitive function but that more external locus of control is associated with more severe depressive symptomatology. Of essence in this respect was the need to investigate the feasibility of measuring locus of control using a rating scale in this population.

3.1 Aims

In accordance with the thesis' aim and hypotheses, the following aims were investigated and reported in four papers:

I. To synthesize the present knowledge regarding locus of control and other perceived control belief constructs among people with dementia (Paper 1)
II. To examine the applicability and usefulness of a specific locus of control measurement scale for people with dementia and to examine the association among locus of control, depressive symptoms, and cognitive function (Paper 2)
III. To examine associations between locus of control and depressive symptoms among people with dementia both cross-sectionally and prospectively (Paper 3)
IV. To examine whether locus of control changes over time in relation to dementia progression and whether demographic and clinical characteristics are associated with this change (Paper 4)

3.2 Study Design

This thesis comprises four quantitative substudies among people with dementia using both cross-sectional and longitudinal designs. Paper 1 is a systematic review of research studies reporting quantitative measures of perceived control. Paper 2 is a cross-sectionally designed study that examined the applicability of the Locus of Control of Behaviour Scale (Craig et al., 1984) for this population. Paper 3 uses both cross-sectional and longitudinal designs to examine whether depressive symptoms were associated with locus of control. In Paper 4, a prospective design was used to investigate change in locus of control over 12 months.

3.3 Method Used for the Systematic Literature Review

3.3.1 Inclusion Criteria

The first paper presented in this thesis is a systematic review with a synthesis of the present knowledge on control beliefs among people with dementia. For this review, studies were included if they met the following criteria:

- The participants had a confirmed dementia diagnosis of any type
- A quantitative measure of perceived control was used which the participants with dementia responded to themselves
- The study was original research with a quantitative design
- The study was peer-reviewed, published in a journal, and written in English

Studies were excluded if they mixed participants with dementia and MCI or if they were dissertations, reviews, protocols, posters, congress disseminations, or theoretical studies. Studies were also excluded if they had been published before 2000 because it was viewed as unlikely to find studies published before this time in which participants themselves responded to such questionnaires.

3.3.2 Search Process

A research librarian performed systematic searches at three timepoints between April 2019 and January 2021 on the following databases: MEDLINE, CINAHL, PsychINFO, AgeLine, Embase, and the Cochrane Library databases. The search strategy included medical subject headings (MeSH), keywords, and text words for the following constructs: dementia, control, and coping. Table 6 and Table 7 provide overviews of the applied search terms.

Table 6: Search Terms for Dementia Applied in Different Databases

Database	Dementia Terms
EMBASE	dementia/ OR Alzheimer disease/ OR parkinsonism/ OR (lewy adj1 bod*).ab,kw,ti. OR (parkinson* adj1 dementia).ab,kw,ti. OR (dementia* or alzheimer*).ab,kw,ti. OR (frontotemp* adj1 dementia).ab,kw,ti. OR (vascul* adj1 dementia).ab,kw,ti.
MEDLINE	dementia/ or alzheimer disease/ or dementia, vascular/ or frontotemporal lobar degeneration/ or lewy body disease/ OR (dementia* or alzheimer* or (lewy adj1 bod*) or (parkinson* adj1 dementia*)).ab,kf,kw,ti. OR parkinsonism.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
CINAHL	TI dement* OR AB dement* OR SU dement* OR TI alzheimer* OR AB alzheimer* OR SU alzheimer* OR (MH "Lewy Body Disease") OR TI parkinson* N1 dement* OR AB parkinson* N1 dement* OR SU parkinson* N1 dement* OR (MH "Dementia+") OR (MH "Alzheimer's Disease")
PSYCHINFO	dementia/ or dementia with lewy bodies/ or presenile dementia/ or semantic dementia/ or senile dementia/ or vascular dementia/ OR alzheimer's disease/ OR "alzheimer*".ab,mh,sh,ti. OR "dement*".ab,mh,sh,ti. OR (lewy adj1 bod*).ab,mh,sh,ti. OR (parkinson* adj1 dement*).ab,mh,sh,ti.
AGELINE	DE "Dementia" OR DE "Alzheimers Disease" OR DE "Early Onset Dementia" OR DE "Frontotemporal Dementia" OR DE "Lewy Body Dementia" OR DE "Vascular Dementia" OR DE "Vascular Dementia" OR DE "Lewy Body Dementia" OR DE "Frontotemporal Dementia" OR DE "Early Onset Dementia" OR DE "Alzheimers Disease" OR AB (dementi* or alzheimer*) OR TI (dementi* or alzheimer*) OR SU (dementi* or alzheimer*) OR TI parkinson* N1 dementi* OR AB parkinson* N1 dementi* OR SU parkinson* N1 dementi* OR AB lewy N1 bod* OR TI lewy N1 bod* OR SU lewy N1 bod*
COCHRANE	MeSH descriptor: [Dementia] explode ORMeSH descriptor: [Alzheimer Disease] explode OR (dementi* OR alzheimer* OR lewy OR parkinsonism):ti,ab,kw

Table 7: Search Terms for Control and Coping Applied in Different Databases

Database	Coping Terms
EMBASE	coping behavior/ OR (coping adj1 (strateg* or style* or mechanism* or behavio* or way*)).ab,ti,kw. OR "locus of control assessment"/ or internal-external control scale/ or "multidimensional health locus of control scale"/ OR "locus of control"/ OR "locus of control".ab,kw,ti. OR control/ OR *self concept/ OR (control adj1 (personal or subjectiv* or belief* or perceived or orientation or sense or expectancy)).ab,kw,ti. OR self-efficacy.ab,kw,ti. OR "sense of coherence scale"/ OR "sense of coherence"/ OR "sense of coherence".ab,kw,ti. OR learned helplessness.ab,kw,ti. OR learned helplessness/ OR personal causation.ab,kw,ti. OR situation appraisal.ab,kw,ti. OR perceived competence.ab,kw,ti. OR efficacy expectancies.ab,kw,ti. OR "agency belief*".ab,kw,ti. OR ways of coping.ab,kw,ti. OR mastery.ab,kw,ti.
MEDLINE	(coping adj1 (strateg* or style* or mechanism* or behavio* or way*)).ab,ti,kw,kf. OR Internal-External Control/ OR "locus of control".ab,kw,ti,kf. OR (control adj1 (personal or subjectiv* or belief* or perceived or orientation or sense or expectancy)).ab,kw,ti. OR self-efficacy.ab,kw,ti,kf. OR "sense of coherence".ab,kw,ti,kf. OR learned helplessness.ab,kw,ti,kf. OR personal causation.ab,kw,ti,kf. OR situation appraisal.ab,kw,ti,kf. OR perceived competence.ab,kw,ti,kf. OR efficacy

	expectancies.ab,kw,ti,kf. OR "agency belief*".ab,kw,ti,kf. OR ways of coping.ab,kw,ti,kf. OR mastery.ab,kw,ti,kf. OR Internal-External Control/ OR Helplessness, Learned/ OR Self Efficacy/ OR "Sense of Coherence"/ OR Adaptation, Psychological/
CINAHL	(MH "Coping+") OR TI ((coping w1 (behavio** OR style* OR strateg* OR mechanism* or way*))) OR AB ((coping w1 (behavio* OR style* OR strateg* OR mechanism* or way*))) OR SU ((coping w1 (behavio* OR style* OR strateg* OR mechanism* or way*))) OR (MH "Locus of Control") OR (MH "Self Regulation") OR TI ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR AB ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR SU ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR (MH "Helplessness, Learned") OR sense of coherence OR "mastery" OR TI (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy) OR AB (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy) OR SU (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy) OR TI locus of control OR AB locus of control OR SU locus of control
PSYCHINFO	(coping adj1 (strateg* or style* or mechanism* or behavio* or way*)).ab,ti,sh. OR "internal external locus of control"/ OR "locus of control".ab,ti,sh. OR (control adj1 (personal or subjectiv* or belief* or perceived or orientation or sense or expectancy)).ab,sh,ti. OR self-efficacy.ab,sh,ti. OR "sense of coherence".ab,ti,sh. OR learned helplessness.ab,ti,sh. OR personal causation.ab,sh,ti. OR situation appraisal.ab,sh,ti. OR perceived competence.ab,ti,sh. OR efficacy expectancies.ab,ti,sh. OR "agency belief*".ab,ti,sh. OR ways of coping.ab,ti,sh. OR mastery.ab,ti,sh. AND Helplessness, Learned/ OR Self Efficacy/ OR "sense of coherence"/ OR coping behavior/ OR *self-control/ OR helplessness/ or learned helplessness/ OR exp Self-Perception/
AGELINE	DE "Coping Behavior" OR TI ((coping w1 (behavio* OR style* OR strateg* OR mechanism* or way*))) OR AB ((coping w1 (behavio* OR style* OR strateg* OR mechanism* or way*))) OR SU ((coping w1 (behavio* OR style* OR strateg* OR mechanism* or way*))) OR TI ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR AB ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR SU ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR DE "Learned Helplessness" or DE "Locus of Control" or DE "Self Efficacy" OR TI (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy or sense of coherence) OR AB (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy or sense of coherence) OR SU (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy or sense of coherence) OR TI locus of control OR AB locus of control OR SU locus of control
COCHRANE	MeSH descriptor: [Adaptation, Psychological] explode OR MeSH descriptor: [Self Concept] explode (coping):ti,ab,kw OR (locus of control):ti,ab,kw OR ("control orientation" or "sense of control" or "control expectancy" or "control belief*" or "personal control" or "perceived control" or "perception of control" or "self-efficacy" or "sense of coherence" or "personal causation" or "learned helplessness" or "situation appraisal" or "perceived competence" or "efficacy expectanci*" or "agency belief*" or "way* of coping" or mastery):ti,ab,kw

3.3.3 Selection Process

The searches yielded a total of 7,005 studies which were transferred into EndNote version 20.2. First, we used EndNote to eliminate duplicates. Next, we examined the papers for eligibility. To reduce the risk of oversight or wrongful eliminations, all papers were reviewed by two authors at all stages of the elimination process. To ensure consistency, I (IH) was one member in each of these pairs. The elimination process is presented in Figure 4, and was as follows: 1) All titles were divided into three parts and delegated at random to three pairs of the coauthors (pair 1: IH and coauthor Maria Lage Barca [MLB], pair 2: IH and coauthor Guro Hanevold Bjørkløf, pair 3: IH and coauthor Knut Engedal). Article titles that clearly did not meet the inclusion criteria were rejected. 2) All remaining abstracts were divided and delegated at random to the three pairs. Abstracts that did clearly not meet the inclusion criteria were discarded. 3) All remaining articles were thereafter divided and delegated at random to the three pairs for full text reading. Disagreements were resolved by consulting all coauthors. 4) Finally, IH conducted a search through the reference lists of already eligible papers.

Once the paper selection process was completed, we found that 18 papers could be included. They were appraised for research quality. Because we had included studies with any kind of quantitative design, even pilot studies, we needed a critical appraisal tool that would accommodate such vast design differences. We used an assessment tool developed for any type of research, quantitative or qualitative, that suited our purpose. The tool developed by Hawker et al. (2002) is applicable to all study designs and comprises nine areas for review: abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, results, transferability and generalizability, and implications and usefulness. Each area is given a score between 1 and 4 based on a set of guiding criteria, and the total score possible is 36. A higher total score indicates better quality within the type of study design. The tool does not differentiate on study design, and a randomized controlled study (RCT) can therefore receive an identical score to a cross-sectional pilot study. Two of the authors (IH and MLB) separately assessed the 18 studies included in the review. Minor discrepancies of a single point were averaged, and major discrepancies were to be discussed. No major discrepancies occurred between the assessments. We did not define any cut-off points for exclusion from the review.

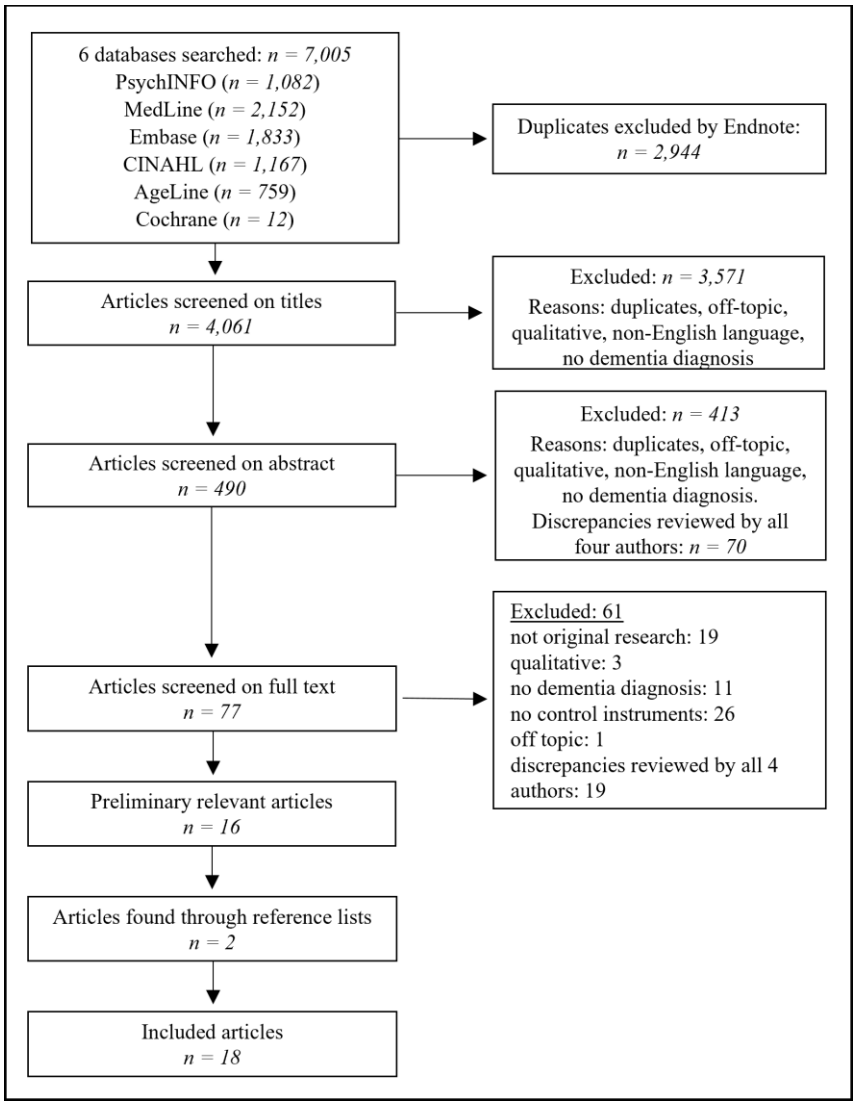

Figure 4: Flow chart of the Article Selection Process

3.4 Methods Used in the Three Clinical Studies

Paper 2 was based on data from two clinical studies: 'Effects and Cost of Day Care Centre Program Designed for People with Dementia – A 24-Month Controlled Study' (ECOD) (Rokstad et al., 2014) and follow-up data from 'Progression of Alzheimer's Disease and Resource Use Study' (PADR) (Barca et al., 2017). ECOD was a quasi-experimental study with assessments at baseline and 12 and 24 months. PADR was a longitudinal observation study with assessments at baseline and at follow-up after a mean of 24 months. In total, ECOD included 261 participants and PADR 273 participants, of whom a total of 534 were included in Paper 2. Further details of the two studies and what data was used in the individual papers in this thesis are presented below. Papers 3 and 4 were based on data solely from ECOD. The number of participants included in Paper 3 was 138 and 54 in Paper 4.

3.4.1 Inclusion Criteria

In Paper 2, participants were included in the study if they had a dementia or MCI diagnosis due to AD and had completed the LoCB scale without missing items. Eligible participants were extracted from both ECOD and PADR. Table 8 provides an overview of inclusion and exclusion criteria for the ECOD and PADR studies.

In Paper 3, we included all participants from the ECOD study. In Paper 4, we included participants from the ECOD study who had responded to at least 50% of the items on the LoCB scale at both baseline and the 12-month follow-up.

Table 8: Overview of Inclusion and Exclusion Criteria for ECOD and PADR studies

	ECOD	**PADR**
	Inclusion criteria	
Type of dementia	AD, VaD, DLB, PDD, or a mix of these types of dementia	AD or MCI due to AD
Participating proxy/caregiver	Yes	Yes
Age	65 years or older	No limit
Living situation	Live at home	Live near test centres to allow for reassessments
Cognitive function	MMSE-NR score ≥ 15	No limit
Capacity to give participation consent	Yes	Yes
Other	Additional criteria for those with day care: has attended day care for ≥ 4 weeks and ≤ 12 months and attends day care ≥ 2/week	Being fluent in Norwegian
	Exclusion criteria	
	Having applied for permanent nursing home placement Having a serious comorbidity with life expectancy ≤ 6 months	Having serious comorbidities

Abbreviations: AD: dementia by Alzheimer's disease; VaD: vascular dementia; DLB: dementia with Lewy body disease; PDD: Parkinson's disease with dementia; MCI: mild cognitive impairment; MMSE-NR: Mini-Mental Status Examination – Norwegian Revised

3.4.2 Recruitment

Recruitment for the ECOD study was conducted from 2013 to 2015. Participants were recruited from all four health regions in Norway and from small, medium, and large municipalities. The participants were recruited from day care centres designed for people with dementia and from local authority dementia teams and in-home care services. Due to ethical restrictions, defining who was qualified for inclusion and the primary contact were done by care workers with knowledge of the eligible participants. Contact was organized between those who were interested in participating in the study and research assistants in the ECOD project, after which a meeting was arranged where formal consent was obtained.

Recruitment for the PADR study was conducted from 2010 to 2014. Participants were recruited from three memory clinics in different parts of Norway, namely Oslo University Hospital in Oslo, Innlandet Hospital in Sanderud, and St. Olav's Hospital in Trondheim. At Oslo University Hospital and Innlandet Hospital, participants with baseline data already collected for the Norwegian Registry of Persons Assessed for Cognitive Symptoms were contacted by phone and asked if they were willing to participate in a follow-up study (PADR). In Trondheim, participants were recruited for PADR at baseline and contacted later for the follow-up data collection.

3.4.3 Data Collection

In the ECOD study, a total of 13 assessors collected the data. The assessors were nurses, occupational therapists, and one psychologist. All assessors participated in two joint information and training sessions. The participants could choose whether they wanted the data collection to occur at a day care centre or in their own home. Participating caregivers completed parts of the data collection by themselves and the remainder with an assessor either at the participant's day care centre or home or over the phone.

In the PADR study, three medical doctors participated in the data collection. The data collection was conducted at memory clinics and was performed as an extension of the regular basic diagnostic assessment and follow-up after an AD diagnosis.

3.4.4 Attrition

The ECOD study suffered from a substantial attrition rate, and this affected the number of eligible participants in Papers 3 and 4. At the 12-month follow-up, only 138 (53.7%) of the

original participants remained, and at 24 months only 54 (21%) remained. The most common reason for attrition was movement to a long-term nursing home facility. Figure 5 presents a flow chart of the attrition. Potential attrition from the PADR study was irrelevant for the current thesis because these subjects were only included in Paper 2, which used cross-sectional data only.

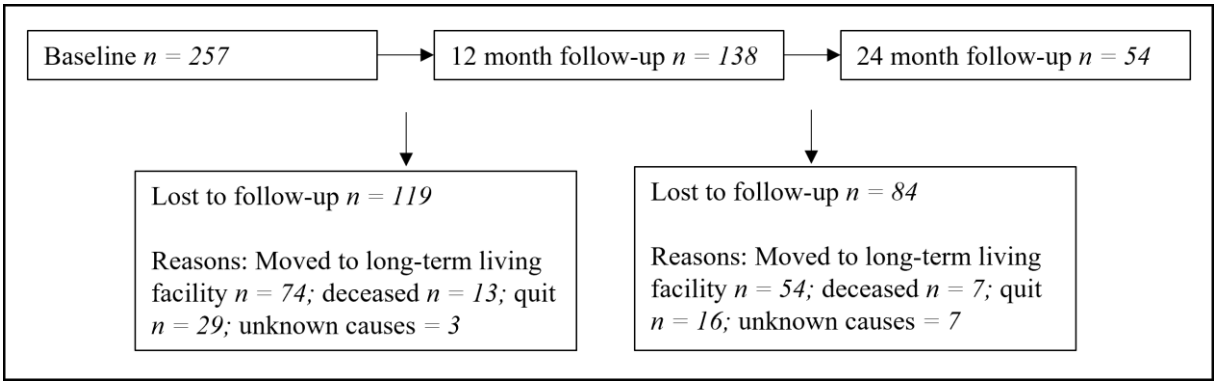

Figure 5. Flow Chart of Participants in the ECOD Study at Baseline and 12 and 24 Months.

3.4.5 Measures

The ECOD and PADR study protocols gathered many demographic and clinical data. The following were used in the clinical studies in this thesis:

3.4.5.1 Demographics

The background variables were age, sex, marital status, years of education, day care attendance, number of prescription medications, and having depression previously in life. These data were collected from the PADR and ECOD data collection protocols.

3.4.5.2 Assessment Instruments

An overview of which instruments were used in the individual papers can be found in Table 10.

To assess locus of control, the LoCB was used. This scale is a self-report questionnaire (Craig et al., 1984). It consists of 17 Likert-style items ranging from 0 to 5 or 'I disagree very much' to 'I agree very much'. Seven items measuring internal dispositions are inverted, and the total score varies between 0 and 85; higher scores indicate a higher degree of external LoC orientation. The original English version is presented in Table 9. The LoCB has been translated to Norwegian and back-translated (Nordtug et al., 2011), and the Norwegian

version has been applied in several studies including studies with older participants (Bruvik et al., 2013; Helvik et al., 2016) and studies with older people with depression (Bjørkløf et al., 2015).

Table 9: The Locus of Control of Behaviour Scale

	Directions: Below are a number of statements about how various topics affect your personal beliefs. There are no right or wrong answers. For every item there are a large number of people who agree and disagree. For each item, please indicate the choice you believe to be true: Strongly disagree 0 · Generally disagree 1 · Somewhat disagree 2 · Somewhat agree 3 · Generally agree 4 · Strongly agree 5
1*	I can anticipate difficulties and take action to avoid them
2	A great deal of what happens to me is probably just a matter of chance
3	Everyone knows that luck or chance determines one's future
4	I can control my problem(s) only if I have outside support
5*	When I make plans, I am almost certain that I can make them work
6	My problem(s) will dominate me all my life
7*	My mistakes and problems are my responsibility to deal with
8*	Becoming a success is a matter of hard work, luck has little or nothing to do with it
9	My life is controlled by outside forces and events
10	People are victims of circumstances beyond their control
11	To continually manage my problem(s) I need professional help
12	When I am under stress, the tightness in my muscles is due to things outside my control
13*	I believe a person can really be master of his fate
14	It is impossible to control my irregular and fast breathing when I am having difficulties
15	I understand why my problem(s) varies so much from one occasion to the next
16*	I am confident of being able to deal successfully with future problems
17	In my case maintaining control over my problem(s) is due mostly to luck

Notes: * = items relating to internality that are inverted before summation of total scale scores.

The revised Norwegian version of the Mini Mental Status Examination (MMSE-NR) was used to assess cognitive function. The MMSE-NR is often used as a screening tool for dementia and cognitive impairment. It consists of 20 items covering a broad set of cognitive functions: orientation for time and place, memory (short term and postponed), attention, language (reading, production, and understanding), and understanding of space. Total scores vary between 0 and 30, with a higher score indicating better cognitive function (Engedal et al., 1988; Folstein et al., 1975; Strobel & Engedal, 2008).

The Clinical Dementia Rating Scale (CDR) was used to measure dementia severity. The research assistants scored it based on information collected from both participants and

participating caregivers. The CDR comprises six items covering cognitive functions and daily activities often impaired in AD and other forms of dementia, namely memory, orientation, judgement and problem solving, community affairs, home and hobbies, and personal care. There are two ways to score the CDR. The original scoring, CDR Global, is based on an algorithm in which memory difficulties are considered the primary outcome and thus weighted more heavily than the other scored domains (Hughes et al., 1982). A later developed scoring system and the one used in the present studies, Sum of Boxes, adds all domains without weighting and has proven a good comparison to the global method while also having the advantage of easier monitoring of potential changes in CDR. The CDR Sum of Boxes total score ranges from 0 to 18, with 0 indicating no impairment and 18 indicating severe impairment (O'Bryant et al., 2008).

The Instrumental Activities of Daily Living Scale (IADL) was used to assess ability to perform instrumental activities of daily life. This scale comprises eight items examining ability to use the telephone, manage grocery shopping, cook, clean the house, do laundry, use transportation, manage medications, and manage finances. Total scores range between 8 and 31, and a higher score indicates poorer independent functioning (Lawton & Brody, 1969). The IADL was proxy rated by a family caregiver.

The Physical Self-Maintenance Scale (PSMS) was used to assess ability to independently perform personal activities of daily life. The PSMS has six items examining ability to independently manage toilet visits, eating, dressing, personal maintenance, movement, and bathing. Total scores range between 6 and 30, and a higher score indicates poorer independent functioning (Lawton & Brody, 1969). The PSMS was proxy rated by a family caregiver.

The Montgomery-Aasberg Depression Rating Scale (MADRS) was used in an interview with the participants to measure the severity of depressive symptoms. The questionnaire consists of 10 items covering the most common symptoms of depression corresponding to the criteria for depression in ICD-10: visible sadness, subjective sadness, inner tension, reduced sleep, reduced appetite, difficulties concentrating, lack of initiative, reduced emotional reactions, depressive thoughts, and suicidal thoughts. Possible scores range between 0 and 60, with higher scores indicating more severe symptomatology (Montgomery & Asberg, 1979). The Norwegian version has been validated for use among people with dementia, and the best cut-off indicating depression in this population was 7 points or higher (Knapskog et al., 2011) compared to 16 points or higher among older people without dementia (Engedal et al., 2012).

The MADRS has been reported to be able indicate depression in AD patients independent of their dementia severity (Müller-Thomsen et al., 2005).

The Anosognosia Rating Scale (REED) was used to judge insight into the degree of memory loss. The scale consists of a single item with four categories scored between 1 and 4 (full awareness, shallow awareness, no awareness, and denies impairment). The score is set by the research assessor based on the complete interview with the participants and cognitive test performance (Reed et al., 1993).

The General Medical Health Rating scale (GMHR) was used to evaluate general health. This scale consists of a single item with four categories (poor, fair, good, and excellent scored 1–4, respectively). Scoring is based on assessments of sickness and number of prescription medications. This scale was developed for use with people who have dementia (Lyketsos et al., 1999).

Table 10: Overview of Variables Included in Papers 2, 3, and 4

	Paper 2	Paper 3	Paper 4
Primary interest	LoCB	MADRS	LoCB
Covariates	Age, sex, civil status, education, LoCB, MMSE-NR, MADRS, IADL	Age, sex, civil status, education, attendance in day care, number of prescription medications, history of prior depression, dementia disease insight, LoCB, CDR, MMSE-NR, IADL, GMHR, REED	Age, sex, civil status, education, attendance in day care, number of prescription medications, history of prior depression, LoCB, CDR, MMSE-NR, MADRS, IADL, PSMS

Abbreviations: CDR: Clinical Dementia Rating Scale; LoCB: Locus of Control of Behavior Scale; MMSE-NR: The Mini Mental Status Examination – Norwegian Revised; IADL: Instrumental Activities of Daily Living Scale; PSMS: Physical Self-Maintenance Scale; MADRS: Montgomery-Aasberg Depression Rating Scale; GMHR: General Medical Health Rating scale; REED: Anosognosia Rating Scale.

3.4.6 Analyses

In Papers 2, 3, and 4, all statistical analyses were performed using the Statistical Package for the Social Sciences. In Paper 2, version 21.0 was used, and in Papers 3 and 4, version 27 was used. To determine the use of parametric or nonparametric tests, distribution of continuous data was assessed by examining the histograms and the Kolmogorov-Smirnov statistics. The level of statistical significance was set at $p < 0.05$. Table 11 provides an overview of the statistical tests used in Papers 2, 3 and 4.

Statistics used for comparisons between groups were defined based on whether the data was continuous or categorical, on the normality distribution, and on whether the groups were independent or paired. For categorical data, we used an X^2 test. For continuous data with normal distribution, we used an independent samples t-test or paired samples t-test. For continuous data with skewed distribution, we used a Mann–Whitney/Kruskal–Wallis test or Wilcoxon singed-rank test for paired data.

A principal component analysis (PCA) was performed on the LoCB in Paper 2. A PCA is a type of factor analysis in which the aim is to reduce the items of a larger scale into fewer components while retaining as much of the variance as possible. Because there is theoretical disagreement as to whether dimensions in locus of control are correlated or not, we performed two set of PCA analyses; first, we conducted an unforced PCA using varimax rotation, and then we gradually enforced fewer components until we reached just one. Loadings greater than or equal to 0.4 were judged to be significant. The entire process was then repeated using oblimin rotation. A varimax rotation is used when it is assumed that the components are uncorrelated while oblimin rotation is used when components are assumed to be correlated. We determined the number of components best fitting the data by evaluating the criterion of eigenvalues ≥ 1, examining the scree plot, and performing a Monte Carlo PCA for parallel analysis.

We used the following procedure for both logistic and linear regression analysis in the papers: First, we performed unadjusted regression analyses of each individual variable. Variables with a p-value < 0.2 together with the patients' age and sex were then included in the adjusted analysis. This method makes it possible to reduce the number of variables in a multiple regression analysis, which has a recommended ratio of 1 to 10 between number of variables included in the analyses compared to the number of participants. Thus, in papers with few participants, this method is useful for deciding which variables to focus on in the multivariate model. Finally, both unadjusted and adjusted models were assessed for multicollinearity, normality, and outliers.

Where applicable, imputation of missing items was performed by a statistician if cases had at least a 50% item response. Items were imputed by random numbers drawn from an empirical distribution generated for each item of interest.

Level of education was dichotomized (< 10 vs > 10 years), as was marital status (married and de facto vs divorced, single, and widowed).

Table 11: Overview of Methods of Analysis in the Three Papers

Paper 2	Paper 3	Paper 4
Principal component analysis; logistic regression; group comparisons using either independent samples t-test, X^2 test, or Mann–Whitney/Kruskal–Wallis test	Linear regression; group comparisons using either independent samples t-test, X^2 test, or Mann–Whitney test	Linear regression; group comparisons using either X^2 test, independent samples t-test, paired samples t-test, Mann–Whitney test, or Wilcoxon signed-rank test

3.4.6.1 Paper 2

To examine the applicability of the LoCB for people with dementia, we first measured the proportion of complete responses in predefined groups according to the participants' MMSE-NR scores. The groups were based on the following MMSE-NR sum scores: 0 to 4, 5 to 9, 10 to 14, 15 to 19, 20 to 24, 25 to 27, and 28 to 30. Furthermore, we calculated the internal reliability of the LoCB in the seven groups using Cronbach's α.

Second, we examined differences between those with complete LoCB versus incomplete LoCB using the independent sample t-test and the Mann–Whitney U test/Kruskal–Wallis test for normally distributed and skewed continuous data, respectively. For categorical data, we used the X^2 test. We used logistic regression analysis to examine factors associated with completion or incompletion of the LoCB.

Third, we examined the LoCB scale using a PCA on complete data. We did this to further examine the applicability of the scale for people with dementia. We hypothesized that a PCA item distribution, like a distribution found in other populations, would further indicate the scale's applicability among those with dementia. The sample size was determined as sufficient, and the appropriateness of a PCA was examined using the Kaiser–Meyer–Olkin measure of sampling adequacy and Bartlett's test of sphericity. Both results indicated a PCA as appropriate.

Finally, we examined whether LoCB sum scores and the sum scores of the LoCB subscales (as found through the PCA component analysis) were associated with depressive symptomatology and a degree of cognitive impairment as measured by MMSE-NR scores. Associations between assumed depression or not (dichotomized at seven points on the MADRS scale; (Knapskog et al., 2011) and LoCB sum score and subscale sum scores were

examined using the Mann–Whitney U test. Associations between cognitive impairment (based on the predefined MMSE-NR groups) and LoCB sum and subscale sum scores were examined using the Kruskal–Wallis test.

3.4.6.2 Paper 3

To examine associations between depressive symptoms as measured by MADRS at baseline and at 12 months (the dependent variables), we performed linear regression analyses with the following independent variables registered at baseline: age, gender, marital status, education, day care attendance, general health, number of prescription medications used (maximum nine), history of prior depression (yes vs no), cognitive function (and change in cognitive function from baseline to follow-up), dementia severity, degree of insight into the dementia disorder, independent functional ability in everyday activities, and locus of control.

The sociodemographic and clinical characteristics of the participants were examined by comparing men and women using the independent samples t-test, X^2 test, or Mann–Whitney test as applicable. We examined the relationship between locus of control and the included variables using an independent samples t-test, analysis of variance, or correlation analysis. Differences between those with complete versus incomplete LoCB and between those who remained or were lost to follow-up were assessed using an X^2 test, independent samples t-test, or Mann–Whitney test. In this study, missing data were imputed on the LoCB (the method for imputation is described in section 3.4.6.

3.4.6.3 Paper 4

To find whether locus of control changes over time in relation to dementia progression, we first examined the difference in mean at baseline versus at 12 months using an independent samples t-test. Next, we dichotomized the group into those who showed an increase in LoCB mean score and those who showed a decrease in LoCB score. A cut-off for what constituted a clinically significant change in score either way was set at 5% as suggested by the developers of the LoCB scale (Craig & Andrews, 1985; Craig et al., 1984). In their study, a change of ≥ 5% towards internality (i.e., a decreased LoCB score) was associated with both clinical improvement and reduced risk of relapse after treatment. Differences between the two groups, both at baseline and at 12 months, were analysed using an independent samples t-test, X^2 test, or Mann–Whitney U test, as appropriate. Changes from baseline to follow-up within the dichotomized groups were analysed using a paired samples t-test or Wilcoxon signed-rank test.

To examine whether change in LoCB scores was associated with any of the baseline variables, we performed a multiple linear regression analysis. Change in LoCB score was calculated (measure at 12 months – measure at baseline) and used as the dependent variable in the regression analyses. The following variables were included in the analyses: age, gender, marital status, education, day care attendance, number of prescription medications used (maximum nine), history of prior depression, current depressive symptoms, cognitive function, dementia severity, independent functional ability in everyday activities and physical self-maintenance, and locus of control.

In addition to the main analyses, we also examined the differences between those with baseline only (N = 130) versus baseline and follow-up measures of LoCB (N = 52) using a chi-square test, independent samples t-test, or Mann–Whitney U test as appropriate. In this study missing items were imputed on the LoCB at baseline and at 12 months and on the IADL (the method for imputation is described on page 35).

3.5 Ethical Considerations

We performed data collection in accordance with the Helsinki declaration. After being given written and oral information about the study, participants with dementia and their participating family caregivers gave written consent. Only participants with the capacity to give consent were included in the study. Partaking in the study was deemed unlikely to inflict any harm on the participants. Both ECOD and PADR were approved by the Regional Committee in Ethics in Medical Research in South-East Norway.

3.6 My contribution

In this section, I provide a short overview of my personal contribution of data collection and data analysis. I was hired as a research assistant for the ECOD project in 2013. At that time, I participated in the pilot study data collection, examining the feasibility of the study protocol for both the participants with dementia and their participating family caregivers. Beginning in 2014, I continued in the project as a PhD student. I helped recruit participating day care centres and met and collected data from participants and their family caregivers. For the individual studies included in this thesis, I performed the qualitative assessments and statistical analyses with guidance and assistance from my co-authors, particularly my main supervisor MLB. I drafted all manuscripts, which were then reviewed and edited to their final version in collaboration with my co-authors.

3.7 Results

3.7.1 Paper 1

The systematic search yielded 4,061 individual studies to be assessed for eligibility. After the elimination process was complete, 16 studies remained. Two additional studies were found through examination of reference lists. The 18 studies included in the review examined the constructs of self-efficacy, personal control/mastery, and locus of control. Self-efficacy was the most frequently examined control belief construct and was applied in 14 studies using seven different scales (Clare et al., 2019; Clare et al., 2020; Fankhauser et al., 2014; Fitzsimmons & Buettner, 2003; Hindle et al., 2018; Lamont et al., 2019; Leroi et al., 2020; Logsdon et al., 2010; Quinn et al., 2016; Regan et al., 2019; Roberts & Silverio, 2009; Schmitter-Edgecombe et al., 2008; Stockwell-Smith et al., 2018; Werheid et al., 2020). Personal control/mastery was examined in three studies (Burgener & Twigg, 2002; Burgener & Berger, 2008; Burgener et al., 2015), and locus of control was examined in one study (Halse et al., 2019). None of the studies reported methodological difficulties with the use of the control belief instruments, and internal consistency or scale reliability (Cronbach's α) of the control instruments was reported in six articles (Burgener & Twigg, 2002; Burgener & Berger, 2008; Burgener et al., 2015; Halse et al., 2019; Lamont et al., 2019; Roberts & Silverio, 2009).

Five studies examined control beliefs using cross-sectional data. Self-efficacy was reported as being associated with an experience of discontinuity in the subjective experience of one's self (Clare et al., 2020). As part of what was labelled as motivational processes, self-efficacy was associated with depression and was also found to predict depression in a regression analysis (Fankhauser et al., 2014). High self-efficacy was found to be associated with increases on three different scales measuring the subjective experience of living well, but the effect sizes were reduced when accounting for shared variance with optimism and self-esteem (Lamont et al., 2019). Personal control was found to be lower among those with AD compared to PDD and only associated with stigma among those with PDD (Burgener & Berger, 2008). Finally, a more external locus of control was found to be associated with more severe depressive symptomatology, while no association was found between locus of control and cognitive function (Halse et al., 2019).

Two descriptive longitudinal studies examined perceived personal control as part of a composite measure of quality of life. These studies found indicators of both change over time and associations with experienced stigma (Burgener & Twigg, 2002; Burgener et al., 2015). The 11 intervention studies reported overall positive effects of the various interventions, and they all included a measure of self-efficacy. Three studies reported on the effects of cognitive rehabilitation (Clare et al., 2019; Hindle et al., 2018; Schmitter-Edgecombe et al., 2008) and five on a variety of support and self-management interventions (Fitzsimmons & Buettner, 2003; Logsdon et al., 2010; Quinn et al., 2016; Roberts & Silverio, 2009; Stockwell-Smith et al., 2018). One study translated a cognitive stimulation therapy manual and performed a pilot intervention examining effectiveness (Werheid et al., 2020). The final intervention study examined the effect of an exercise and mental activity program (Regan et al., 2019).

Changes in self-efficacy were found in five of the intervention studies (Hindle et al., 2018; Logsdon et al., 2010; Quinn et al., 2016; Schmitter-Edgecombe et al., 2008; Werheid et al., 2020). The remaining six studies reported effective interventions but found no changes in self-efficacy (Clare et al., 2019; Fitzsimmons & Buettner, 2003; Leroi et al., 2020; Regan et al., 2019; Roberts & Silverio, 2009; Stockwell-Smith et al., 2018).

3.7.2 Paper 2

A total of 234 participants from ECOD and PADR completed the LoCB. Completion percentages ranged from 74% in the group with an MMSE-NR score between 28 and 30 to 0% in the two groups with MMSE-NR scores of 0 to 9. Internal reliability measured by Cronbach's α was between 0.80 and 0.72 in groups with a MMSE-NR score > 9, while in groups with an MMSE-NR score of 20 to 24, the internal reliability was 0.52. Those in the group with complete responses were younger, had more education, had better cognitive function, and had better function in the activities of daily living compared to the noncompleters (see Table 12).

Table 12: Demographic and Clinical Characteristics in Groups with and Without a Complete Locus of Control Behavior Scale

Characteristics	All (n = 534)	Complete LoCB (n = 234)	Incomplete LoCB (n = 300)	p-Value
Age, mean (sd) (n = 534)	78.43 (8.1)	77.3 (SD 8.2)	79.3 (7.8)	0.003[1]
Female, n (%) (n = 534)	311 (58.2)	125 (53.4)	186 (62.0)	0.057[2]
Education, < 10 yrs, n (%) (n = 524)	263 (50.2)	91 (39.7)	172 (58.3)	< 0.001[2]
Unmarried, n (%) (n = 531)	242 (45.6)	102 (44.0)	140 (46.8)	0.570[2]
LoCB, mean (sd) (n = 234)	NA	30.8 (10.5)	NA	
MMSE-NR, mean (sd) (n = 520)	19.8 (5.6)	22.2 (3.7)	17.9 (6.2)	< 0.001[3]
MADRS, mean (sd) (n = 483)	4.6 (5.1)	4.8 (5.4)	4.5 (4.8)	0.672[3]
IADL, mean (sd) (n = 417)	21.0 (6.5)	19.4 (6.2)	22.2 (6.4)	< 0.001[3]

[1] Independent sample t-test [2] Chi-square test for independence [3] Mann–Whitney test. NA = not applicable.
Abbreviations: LoCB: Locus of Control of Behavior Scale; MMSE-NR: Mini Mental Status Examination – Norwegian Revised; IADL: Instrumental Activities of Daily Living Scale

As seen in Table 13, age, MMSE-NR score, and education were also associated with completion in the multiple logistic regression analysis.

Table 13: Logistic Regression Predicting Likelihood of Locus of Control of Behavior Completion

Variable	Unadjusted Regression Analysis			Adjusted Regression Analysis		
	OR	95% C.I.	p-value	OR	95% C.I.	p-value
Gender	1.42	1.00–2.01	0.046	1.21	0.73–2.02	0.453
Age	0.97	0.97–0.99	0.003	0.96	0.93–0.99	0.007
Education	2.12	1.49–3.01	< 0.001	1.59	1.01–2.49	0.044
Married	1.12	0.80–1.58	0.512			
MADRS	1.01	0.98–1.05	0.444			
MMSE-NR	1.22	1.16–1.27	< 0.001	1.21	1.14–1.29	< 0.001
I-ADL	0.93	0.91–0.96	< 0.001	1.01	0.97–1.05	0.732

Abbreviations: LoCB: Locus of Control of Behavior Scale; MMSE-NR: Mini Mental Status Examination – Norwegian Revised; IADL: Instrumental Activities of Daily Living Scale

The component correlation matrix from the oblimin PCA revealed low correlations between the variables, indicating that the components were not related. The varimax rotation procedure was therefore determined to best fit the data. The PCA with three components produced the best results (see Table 14). The three components were labelled ‘powerful others’, ‘luck/fate’, and ‘internal’ and explained 41.3% of the variance. The Cronbach’s α of the full scale was 0.69. The powerful others, internal, and luck/fate subscale scores had a Cronbach’s α of 0.47, 0.67, and 0.65, respectively.

Table 14: Principal Component Analysis of the Locus of Control of Behavior Scale

Item #	Statement	Component Distribution		
		Powerful others	Internal	Luck/fate
12	When I am under stress, the tightness in my muscles is due to things outside my control.	0.635		
15	I understand why my problem(s) varies so much from one occasion to the next.	-0.593		
6	My problem(s) will dominate me all my life.	0.585		
11	To continually manage my problem(s) I need professional help.	0.517		
14	It is impossible to control my irregular breathing when I am having difficulties.	0.506		
10	People are victims of circumstances beyond their control.	0.505		0.428
4	I can control my problem(s) only if I have outside support.	0.413		
13*	I believe a person can really be the master of his fate.		0.742	
8*	Becoming a success is a matter of hard work, luck has little or nothing to do with it.		0.649	
16*	I am confident of being able to deal successfully with future problems.		0.593	
5*	When I make plans, I am almost certain that I can make them work.		0.575	
7*	My mistakes and problems are my responsibility to deal with.		0.517	
1*	I can anticipate difficulties and take action to avoid them.		0.439	
3	Everyone knows that luck or chance determines one's future.			0.817
17	In my case maintaining control over my problem(s) is due mostly to luck.			0.728
2	A great deal of what happens to me is probably just a matter of chance.			0.579
9	My life is controlled by outside actions and events.			0.528
Eigenvalue		3.3	2.2	1.5
Explained variance		19.3	13.0	9.0
Cronbach's α		0.47	0.67	0.65
Extraction method: principal component analysis. Rotation method: varimax with Kaiser normalization.[a]				

Notes: * Items relating to internality that are transposed before summation of total scale scores.

Participants with a MADRS score ≥ 7 scored higher on the LoCB sum score, powerful others, and internal subscale scores but not the luck/fate subscale. The score on the MMSE-NR did not affect LoCB scores.

3.7.3 Paper 3

Of 257 participants in this study, 182 had a complete response on the LoCB at baseline after imputation. Those without a complete LOCB score (and less than 50% item completion allowing for imputation) had more severe dementia, had worse cognitive function, were more dependent in daily activities, and had less education (data not shown). The 138 participants that were lost to follow-up were at baseline older than those who remained, but no other differences were found.

The MADRS score at baseline was associated with a higher LoCB sum score, poorer general health, using a higher number of prescription medications, having more dementia disease insight, and having previous depression in the unadjusted analyses. In the adjusted analysis, only LoCB sum score, poorer general health, and having more insight remained significantly associated with the MADRS score at baseline, with the LoCB sum score being most strongly associated (standardized $\beta = 0.396$). The model accounted for 28% of the variance of MADRS scores at baseline ($F(8, 161) = 7.825$, $p < 0.001$). Table 15 presents the details.

Table 15: Linear Regression Analyses Showing Associations Between Baseline Montgomery-Aasberg Depression Rating Scale Score and Sociodemographic and Clinical Variables

Characteristics at Baseline	**Unadjusted Regression Analysis**		**Adjusted Regression Analysis**		
	B (95% CI)	p-value	*B* (95% CI)	β	p-value
Age	−0.056 (−0.156, 0.044)	0.269	−0.062 (−0.170, 0.046)	−0.078	0.260
Gender (female = 0, male = 1)	−0.985 (−2.317, 0.348)	0.147	−0.998 (−2.440, 0.444)	−0.094	0.174
Marital status (unmarried = 0, married = 1)	0.238 (−1.074, 1.549)	0.722			
Education (< 10 years = 1, >10 years = 2)	−0.538 (−1.837, 0.762)	0.416			
Attends day care (no = 0, yes = 1)	−1.155 (−2.548, 0.237)	0.104	−0.278 (−1.802, 1.246)	−0.025	0.719
LoCB sum score	0.181 (0.120, 0.241)	< 0.001	0.175 (0.115, 0.234)	0.396	< 0.001
MMSE-NR	0.082 (−0.100, 0.265)	0.377			
CDR	0.104 (−0.148, 0.357)	0.415			
GMHR	−1.711 (−2.592, −0.830)	< 0.001	−1.565 (−2.599, −0.531)	−0.225	0.003
IADL	−0.10 (−0.131, 0.112)	0.879			
N of prescription medications[1]	0.249 (0.011, 0.487)	0.040	–0.062 (−0.344, 0.220)	−0.032	0.666
Prior depression (no = 0, yes = 1)	2.996 (1.131, 4.862)	0.002	1.546 (−0.533, 3.626)	0.102	0.144
Dementia disease insight	−1.414 (−2.470, −0.357)	0.009	–1.503 (−2.649, −0.357)	−0.179	0.010

[1]Potential ceiling effect because the maximum number reported was restricted to nine different prescription medications. Abbreviations: CDR: Clinical Dementia Rating Scale; LoCB: Locus of Control of Behavior Scale; MMSE-NR: Mini Mental Status Examination – Norwegian Revised; IADL: Instrumental Activities of Daily Living Scale; MADRS: Montgomery-Aasberg Depression Rating Scale; GMHR: General Medical Health Rating scale

MADRS score at 12 months was associated with higher LoCB sum score, more severe depressive symptomatology, and poorer general health at baseline in the unadjusted analyses. In the adjusted analysis, only the LoCB sum score and MADRS score at baseline remained significant predictor variables. The model accounted for 56.3% of the variance of MADRS scores at 12 months ($F(8, 92) = 14.791$, $p < 0.001$; see Table 16 for details).

Table 16: Linear Regression Analyses Showing Associations Between Montgomery-Aasberg Depression Rating Scale Scores at 12 Months and Baseline Sociodemographic and Clinical Variables

Characteristics at Baseline	**Unadjusted Regression Analysis**		**Adjusted Regression Analysis**		
	B (95% CI)	p-value	*B* (95% CI)	β	p-value
Age	0.008 (−0.156, 0.172)	0.925	0.031 (−0.103, 0.164)	0.032	0.649
Gender (female = 0, male = 1)	0.468 (−1.715, 2.651)	0.672	1.266 (−0.520, 3.053)	0.100	0.162
Marital status (unmarried = 0, married = 1)	0.435 (−1.714, 2.583)	0.690			
Education (< 10 years = 1, >10 years = 2)	−0.822 (−2.948, 1.304)	0.446			
Attends day care (no = 0, yes = 1)	−1.885 (−4.148, 0.378)	0.102	−0.807 (−2.690, 1.075)	−0.061	0.397
LoCB sum score	0.235 (0.141, 0.329)	< 0.001	0.088 (0.008, 0.168)	0.167	0.032
MADRS	0.857 (0.709, 1.004)	< 0.001	0.768 (0.580, 0.956)	0.645	< 0.001
MMSE-NR	−0.088 (−0.387, 0.210)	0.560			
One-year change in MMSE-NR	−0.007 (−0.338, 0.324)	0.966			
CDR	0.069 (−0.346, 0.484)	0.742			
GMHR	−1.992 (−3.418, −0.567)	0.007	−0.374 (−1.671, 0.922	−0.045	0.568
IADL	0.100 (−0.095, 0.295)	0.313			
N of prescription medications[1]	0.321 (−0.067, 0.709)	0.104	0.019 (−0.328, 0.366)	0.008	0.568
Prior depression (no = 0, yes = 1)	2.188 (−0.896, 5.271)	0.163	−0.050 (−2.613, 2.513)	−0.003	0.913
Dementia disease insight	−0.914 (−0.2645, 0.817)	0.298			

[1]Potential ceiling effect because the maximum number reported was nine different prescription medications.
Abbreviations: CDR: Clinical Dementia Rating Scale; LoCB: Locus of Control of Behavior Scale; MMSE-NR: Mini Mental Status Examination – Norwegian Revised; IADL: Instrumental Activities of Daily Living Scale; MADRS: Montgomery-Aasberg Depression Rating Scale; GMHR: General Medical Health Rating scale.

3.7.4 Paper 4

The LoCB mean score for the total sample of 52 participants did not change from baseline (mean = 29.33, SD = 11.97) to follow-up (mean = 30.33, SD = 11.25), p = 0.553. However,

further examinations showed that the LoCB score remained stable for only four participants, while 21 reduced and 27 increased their LoCB scores.

The group with the reduced LoCB score had a higher baseline LoCB score (mean = 33.81, SD = 12.18) than the group with the increased LoCB score (mean = 24.56, SD = 10.27), p = 0.006. At follow-up, the group with the reduced LoCB score had a lower LoCB score (mean = 23.57, SD = 9.57) than the group with an increased LoCB score (mean = 34.41, SD = 10.03), p = 0.001. No other differences between the two groups were found at baseline or at follow-up.

From baseline to follow-up, both groups had an increase in dementia severity (CDR) and dependence in physical self-maintenance (PSMS). Additional findings among the group with the increased LoCB score were an increase in the number of prescribed medications, greater dependence in instrumental activities of daily living (IADL), a decline in cognitive function (MMSE-NR), and a decrease in the severity of depressive symptomatology (MADRS). Table 17 provides details in this regard.

Table 17: Changes from Baseline to Follow-Up Among Those with Reduced or Increased Locus of Control of Behavior Scale in 12 Months

Variables	**Group with Reduced LoCB (N = 21)**			**Group with Increased LoCB (N = 27)**		
	Baseline	12 months	p-value	Baseline	12 months	p-value
Number of medications,[3] mean (sd) **Group that reduced N = 19**	4.89 (2.96)	5.74 (2.92)	0.149[1]	5.00 (2.56)	6.13 (2.44)	0.033[1]
CDR, mean (sd) **Group that increased N = 25**	5.14 (2.57)	6.36 (2.72)	0.003[1]	5.02 (2.14)	6.80 (2.56)	0.001[1]
MADRS, mean (sd) **Group that reduced N = 20** **Group that increased N = 25**	3.85 (3.94)	3.43 (4.70)	0.488[2]	4.64 (5.05)	3.30 (4.61)	0.003[2]
MMSE-NR, mean (sd)	21.95 (2.96)	21.14 (3.42)	0.163[1]	23.22 (3.13)	21.30 (3.62)	0.002[1]
PSMS, mean (sd) **Group that increased N = 25**	7.86 (1.56)	8.76 (2.30)	0.040[2]	8.63 (3.73)	9.28 (3.65)	0.007[2]
IADL, mean (sd) **Group that increased N = 25**	19.48 (5.48)	20.05 (6.30)	0.649[1]	19.20 (5.80)	21.36 (6.07)	0.003[1]

[1]Paired samples t-test; [2]Wilcoxon signed-rank test. Abbreviations: CDR: Clinical Dementia Rating Scale; LoCB: Locus of Control of Behavior Scale; MMSE-NR: Mini Mental Status Examination – Norwegian Revised; IADL: Instrumental Activities of Daily Living Scale; PSMS: Physical Self-Maintenance Scale; MADRS: Montgomery-Aasberg Depression Rating Scale. [3]Potential ceiling effect because the maximum number reported was nine different prescription medications.

The baseline LoCB score and MMSE-NR were associated with LoCB changes in the unadjusted analyses. In the adjusted analysis, only baseline LoCB was associated with LoCB changes (standardized β = –0.435, p = 0.001). The model accounted for 27.5% of the variance of change in LoCB scores (F (4, 46) = 4.365, p = 0.004; see Table 18).

Table 18: Multiple Linear Regression Analyses of Associations Between Changes in Locus of Control of Behavior Scale Score and Baseline Patients' Characteristics

Characteristics at Baseline	**Unadjusted Regression Analysis**		**Adjusted Regression Analysis**		
	B (95% CI)	p-value	*B* (95% CI)	β	p-value
Age	-0.251 (-0.805, 0.103)	0.127	-0.223 (-0.649, 0.202)	-1.138	0.425
Gender (female = 0, male = 1)	1.525 (-4.561, 7.612)	0.617	2.185 (-3.274, 7.644)	0.103	0.425
Marital status (unmarried = 0, married = 1)	1.963 (-4.027, 7.952)	0.513			
Education (< 10 years = 1, > 10 years = 2)	-1.942 (7.876, 3.991)	0.513			
Attends day care (no = 0, yes = 1)	3.639 (-2.675, 9.953)	0.252			
LoCB	-0.428 (-0.657, -0.199)	< 0.001	-0.394 (-0.628, -0.160)	-0.435	0.001
MADRS	0.177 (-0.519, 0.872)	0.611			
MMSE-NR	0.694 (-0.255, 1.642)	0.148	0.533 (-0.325, 1.391)	0.158	0.217
CDR	-0.316 (-1.481, 0.848)	0.587			
IADL	-0.117 (-0.648, 0.414)	0.660			
PSMS	0.241 (-0.736, 1.218)	0.622			
N of prescription medications[1]	0.345 (-0.719, 1.408)	0.518			
Prior depression (no = 0, yes = 1)	-2.773 (-9.818, 4.273)	0.433			

Abbreviations: CDR: Clinical Dementia Rating Scale; LoCB: Locus of Control of Behavior Scale; MMSE-NR: Mini Mental Status Examination – Norwegian Revised; IADL: Instrumental Activities of Daily Living Scale; PSMS: Physical Self-Maintenance Scale; MADRS: Montgomery-Aasberg Depression Rating Scale. [1]Potential ceiling effect because the maximum number reported was nine different prescription medications.

4 Discussion

The aim of this thesis was to investigate how locus of control among people with dementia is associated with dementia severity, cognitive function, and depressive symptoms. Through four papers, these aims were investigated in different manners as presented in the previous method and result sections. In this section, the findings from the four individual papers are discussed. I begin by discussing the review findings and continue with a discussion of similarities and contradictions between the findings from the three clinical studies.

4.1 The Review

The goal of the first paper in this thesis was to synthesize the current knowledge of control beliefs among people with dementia. We wanted to know what constructs had been examined, who the participants were in terms of dementia type and dementia severity, and whether using a quantitative measure of perceived control was feasible. Through a comprehensive search of six relevant databases, we found only 18 studies that had used a quantitative measure of perceived control in this population. The studies examined self-efficacy, mastery, or locus of control and varied greatly in aims, design, and number of participants. Two new cross-sectional studies have since been published examining self-efficacy in relation to awareness or illness representation (Alexander et al., 2021; Clare et al., 2022). In this section, some of the findings are discussed as they relate to the aims of this thesis.

We found that self-efficacy was the control belief construct most frequently investigated among people with dementia followed by mastery and then locus of control. The newly published studies also examined self-efficacy (Alexander et al., 2021; Clare et al., 2022), and data came from the same cohort used in two previous studies (Clare et al., 2020; Lamont et al., 2019). All three control belief constructs are some of the most researched in general (Skinner, 1996), and Wallston (2017) has argued that the use of any control belief construct could give a good indication of perceived control because they are likely to correlate significantly. This is presumably because they are related to one another within the coping process as defined by Folkman (1984). When stated in the individual studies, reasons for including a measure of perceived control were based on its relation to coping with the dementia disorder in various ways (Fitzsimmons & Buettner, 2003; Logsdon et al., 2010; Quinn et al., 2016; Roberts & Silverio, 2009; Stockwell-Smith et al., 2018; Werheid et al., 2020).

Another aspect of interest for conducting the review was whether control beliefs differed in relation to dementia type and severity. Most studies included participants with AD, VaD, or a mixture of these two dementia types. Some studies restricted inclusion to these types, while others included all types but mostly ended up with these dementia variants. This is natural because it represents reported prevalence rates as seen in Section 2.1.4. However, when including people with different types of dementia in one group, potentially dementia-specific differences that could be informative are lost. One could speculate that different types of dementia could affect perceptions of control differently. For example, it is difficult to predict if and how VaD will further develop, while AD has a more commonly known progression. In FTD, personality type changes are often seen early, while LDB may have early physical dysfunctions and hallucinations. Do such differences affect perceptions of control differently? This was not addressed in any of the studies included in the review, but two studies compared participants with a specific dementia diagnosis to groups without dementia (Burgener & Berger, 2008; Fankhauser et al., 2014).

It is possibly of more clinical value to study control beliefs in relation to dementia severity than dementia type. There are two main arguments for this: First, regardless of dementia diagnosis, everyone will have an idiosyncratic progression. Second, it is not uncommon to have more than one type of dementia simultaneously, particularly the older one is (Gale et al., 2018). Using dementia type as an inclusion criterion may set unnecessary restrictions that may cause difficulties in recruiting participants. Inclusion based on dementia severity is probably a better criterion. Severity indicates to what degree a person with dementia has difficulties with cognitive, functional, motoric, social, behavioural, or psychological aspects that interfere with activities of daily living. These are likely to be topics of interest in psychosocial interventions where perceptions of control could be important information for evaluating intervention efficacy.

Knowledge about dementia severity is also important in terms of feasibility. Feasibility cut-off scores are helpful in research and practice when deciding whether a specific scale is applicable. Apart from our own study examining applicability of the LoCB, none of the self-efficacy and mastery scales were reported to have investigated feasibility cut-offs or been validated for people with dementia, neither were there reports of other reliability tests such as test-retest reliability or comparisons between self and proxy ratings. Reliability should be examined to increase the trustworthiness of the findings.

Though Moniz-Cook et al. (2008) present concerns regarding the measure of self-efficacy, none of the studies relevant for our review reported difficulties with quantitatively measuring perceptions of control in this population. This is important information for future research and practice. A few studies reported having reduced the number of items in the applied scale. In the study by Roberts and Silverio (2009), 21 out of an original 43 items were retained because only these were assumed relevant to coping with dementia. The internal reliability score with the reduced number was 0.9, which is considered excellent. Regan et al. (2019) also reduced the number of items from nine to four but did not indicate why this was done or present any psychometrics related to the reduced scale. Of the studies that investigated the internal reliability of the scales, Cronbach's α was between 0.70 and 0.77 (Mastery scale), between 0.7 and 0.88 (GSES), 0.9 (CSE), and 0.69 (LoCB).[2] It is generally accepted in psychological research that scores of 0.7 and above are acceptable. Furthermore, it is a testament to the scales' validity that all the observational studies included in the review found that perceptions of control were associated as expected with the target of interest in the individual studies.

Deciding which construct to investigate is one aspect to consider in research. Another is which scale to use to measure it. Scales measuring control beliefs examine either a general or overall perception of control or a perception of control related to a very specific situation or task. Both scale types may present difficulties for people with dementia. Thinking generally about how one tends to react may be too abstract for people with cognitive deficits, while maintaining focus on one specific situation may be difficult due to decreased ability to maintain attention over time. We still do not know whether control belief questionnaires that relate to a specific issue could yield more valid results.

An additional finding from the systematic review was the indication of an increased interest in how people with dementia experience personal control. As mentioned in the review, most of the studies were from after 2010, and 11 of 18 were from after 2015. Added to these are the two new articles recently published (Alexander et al., 2021; Clare et al., 2022). It is uplifting to see increased interest in assessing the subjective experience of the person with dementia when evaluating the effects of a psychosocial intervention. Kitwood (1997) introduced a revolution in how to perceive a person with dementia as a whole person through the dementia

[2]Mastery scale (Pearlin & Schooler, 1978); GSES: General Self-Efficacy Scale (Schwarzer & Jerusalem, 1995); CSE: Coping Self-Efficacy Scale (Merluzzi & Martinez Sanchez, 1997); LoCB: Locus of Control of Behavior Scale (Craig, Frankling & Andrews, 1984).

progression. Prior to Kitwood's and his idea of person-centred care gaining momentum, a person with dementia was merely 'a demented', indicating that the disease had become the person's defining characteristic. This reductionist understanding is likely part of what made researchers less interested in the perspective of people with dementia, because they were not assumed able to communicate a relevant perspective or understanding. The increase in research using self-report questionnaires with people with dementia is a testament to the belief that they can contribute to research with valuable subjective information.

Self-efficacy was the construct most often researched in this population, and the GSES was used in 9 of 16 studies found that measured self-efficacy, including the two newly added. Though arguably all control belief constructs add valuable information about how people cope, reducing the number of scales used to measure control would likely increase knowledge on perceptions of control more quickly. The GSES appears the most popular, has already gathered the most data, and should for this reason be considered in future research. However, validation of the scale for people with dementia appears nonexistent and should be performed. Indeed, this has previously been advocated by the European network of researchers collaborating on research on psychosocial interventions in dementia (i.e., INTERDEM; (Moniz-Cook et al., 2008)) and more recently in a feasibility study for a psychosocial intervention for people with DLB (Killen et al., 2022).

4.2 The Clinical Studies

In Papers 2 and 3, we found that a more external locus of control orientation at baseline is associated with more severe depressive symptoms measured both at baseline and one year later. In Paper 4, we found that 92.3% of the 51 participants had a clinically significant change in their orientation, with 21 participants becoming more internal and 27 more external. Neither cognitive function nor dementia severity were associated with locus of control, but cognitive function was associated with the ability to complete the LoCB. The discussion begins with a focus on the applicability of the LoCB for people with dementia followed by discussions on locus of control and depressive symptoms, dementia severity, and cognitive function.

4.2.1 On the Feasibility of Measuring Locus of Control

In Paper 2 of this thesis, we examined whether the LoCB was applicable for a population with dementia. This feasibility study primarily intended to examine comprehension and completion

ability at different stages of cognitive impairment (measured by the MMSE-NR). This study used data from participants with a 100% response on the LoCB in order to increase the trustworthiness of the PCA. However, the overall completion percentage was lower than hoped for. In total, 44% of participants completed the full scale, with a gradual decrease from 74% among those with an MMSE-NR score between 28 and 30 to 14% among those with an MMSE-NR score between 10 and 14. The studies included in the review did not report difficulties with low completion rates.

We speculated that the low completion percentage could be due to the length of the scale or complex item formulations. When measuring general perceptions of control, such as with the LoCB and GSES, the items to which the participants must agree or disagree are not related to specific situations or tasks but rather to problems in general. This makes the items abstract and thereby more cognitively demanding. In addition, some of the items are complex, such as item 9: 'My life is controlled by outside forces and events'. What does it mean to be controlled, and are outside forces and events the same and influential to the same degree? Another difficulty with the LoCB is having to rate an item that has an uncertainty in it with a six-point Likert scale. For example, item 5: 'When I make plans, I am almost certain that I can make them work.' What does it mean when a participant answers 'I somewhat disagree' to a statement about being almost certain? It is therefore possible that a more precise wording would be easier to answer and thus could have led to a larger response rate.

Additionally, we found that although degree of cognitive impairment appears to affect response rates, it does not necessarily affect response reliability. Cronbach's α remained good even among those with substantial cognitive impairment (MMSE-NR scores of 10–14 and 15–19), which is comparable to many other studies using similar questionnaires on samples without cognitive deficits. The low response rate could also be due to the LoCB being the second to last questionnaire in the ECOD data collection procedure. The data collection interview generally lasted 1 to 2 hours starting with general questions regarding demographic details followed by several measures of cognitive function. Then came questionnaires regarding general health and quality of life before the LoCB and MADRS. Fatigue may therefore explain some of the low response rate.

It is valuable for practitioners to know whether there is a cut-off level where people with dementia would no longer be expected to provide reliable answers to self-report questionnaires. We investigated this regarding the LoCB in Paper 2 by examining completion percentages in relation to degree of cognitive impairment. We saw that no participant with an

MMSE score below 10 (N = 28) completed the scale, and only with a score of minimum 20 did we see a completion rate above 50%. However, two aspects are relevant to mention here. First, the LoCB is long with 17 items. A shorter scale such as the GSES or the Mastery scale could have allowed for a higher completion rate. Second, we chose a strict definition for completion because we wanted to use only complete responses in the PCA analysis. Nevertheless, it is likely that an LoCB with a few missing items would yield a reliable score for use in research. Indeed, in the studies reported in Papers 3 and 4, we used imputation if a participant had answered at least 50% of all items, which is a cut-off for imputation defined by a contributing statistician.

It could also be that the MMSE-NR is not the best instrument to use when measuring the cut-off for reliability of the LoCB measured on people with dementia. The MMSE-NR provides an indication of cognitive deficits, but for many with mild dementia, it may not detect the extent of impairment because it does not differentiate well among those with small cognitive deficits, which is a so-called ceiling effect. Furthermore, the MMSE-NR is intended to measure impairment across a range of cognitive functions, but some only have impairments on a few functions. Thus, a person could earn a low score by only struggling with, for example, short-term memory and orientation of time and space because these items constitute 13 out of 30 possible points. Difficulties with these two cognitive functions may be debilitating in everyday life and enough to constitute a dementia diagnosis but may not affect ability to reason or reflect on one's personality and behavioural tendencies. The internal reliability scores for each group reported in Paper 2 may be taken to support this. Thus, there is little indication that a lower MMSE score is automatically associated with less reliable results.

A more sensitive test with a deeper investigation of the different cognitive domains could have resulted in a better differentiation regarding cut-offs. In addition, it could have yielded information about which cognitive domains affect completion and which do not. The Addenbrooke's Cognitive Examination (ACE) has the MMSE embedded but with added test items for investigating language, attention, memory, and comprehension more thoroughly (Mathuranath et al., 2000). The ACE has a possible high score of 100 compared to 30 on the MMSE. Another possible test is the Montreal Cognitive Assessment scale (MoCA) (Nasreddine et al., 2005). This instrument is also on a scale from 0 to 30 like the MMSE but covers more cognitive domains and is considered more challenging (Engedal et al., 2021). Both the ACE and the MoCA are useful for detection of MCI and could potentially be more

informative for determining a cut-off or indicating which domains are necessary for completion of control belief questionnaires.

The PCA revealed three components as best fitting the data. These were labelled ‘powerful others’, ‘internal’, and ‘luck/fate’. Apart from item 15, the internal items as indicated by Craig et al. (1984) were clustered in the internal component. Item 15 was clustered within the powerful others component; however, it was the only item of all 17 with a negative value. Item 15 was excluded in another Norwegian study, resulting in an increased internal reliability score (Nordtug et al., 2011).

Despite not having performed a standardized validation study for the LoCB in a population with dementia, we found indications of face validity. Locus of control is well known to be associated with depression, with general tendencies showing that more severe depression is associated with greater external locus of control orientation (Benassi et al., 1988; Bjørkløf et al., 2013). This tendency was also found among people with dementia in Papers 2 and 3, though when measuring the severity of depressive symptoms rather than depression per se. The associations between locus of control and depressive symptoms, the internal reliability scores, and the PCA results indicate that the LoCB is valid for use in this population. However, the likelihood of completion is reduced with a lower MMSE-NR score. A shorter and more concise version of the LoCB could enhance the completion rate.

4.2.2 Relationship Between Locus of Control and Depressive Symptoms

In Paper 2, we compared the locus of control orientation between those with a MADRS score > 7 and ≤ 7, which is a cut-off indicative of depression among people with dementia (Knapskog et al., 2011). On average, the participants with assumed depression had a 10-point higher mean score on the LoCB. When examining the component scores, it is interesting to note that results on the luck/fate subscale did not differ significantly between the two MADRS groups. In Paper 3, locus of control was also found to be associated with severity of depressive symptoms one year later, though the measure of depressive symptoms at baseline was the variable most strongly associated with later depressive symptoms.

Surprisingly, in Paper 4 we found that those who became more externally oriented at the one-year follow-up had a decrease in depressive symptomatology while no change was found among those who became more internally oriented. The group that became more external also showed negative developments on more measures related to dementia progression than those

who became more internal over the year. We speculated that allowing oneself to feel less personal responsibility for what happens and placing control externally instead of internally may be beneficial for some experiencing decline due to dementia. Studies considered comparable, such as studies on chronic illness and severe cancer diagnoses, have produced similar results (Eccles & Simpson, 2011). The potential value of a shift from internal to more external is important to be aware of when planning psychosocial interventions for chronically ill people, including people with dementia. Coping is an individual process, and some people with dementia may benefit from experiencing less responsibility for what happens in life by placing control externally.

As the dementia disorder progresses, the need for assistance begins. In the ECOD project, we collected data on a variety of municipal resource uses, but for the present thesis, we only examined whether the participants had a day care service. In retrospect, further analyses on whether increased use of formal and informal services was related to changes in locus of control orientation would have been interesting. Perhaps the knowledge of accessible support or an actual increase in support allows a person with increased dementia severity to feel supported and secure. In a situation in which one has little control, becoming more externally oriented could be advantageous. This could explain the finding of increased external orientation and decreased depressive symptomatology.

As seen in Paper 1, to our knowledge, only one study apart from ours has examined the association between a control belief construct and depression in a sample with people with dementia. Fankhauser et al. (2014) examined whether motivational processes mediated the relationship between social support and depression among AD, MCI, or unimpaired individuals. Motivational processes were a composite variable in which self-efficacy was one of four components together with decision regulation, activation regulation, and motivation regulation. Fankhauser et al. (2014) found that motivational processes were indeed associated with depression in all three groups, while social support lost significance in the groups with MCI or dementia. Quinn et al. (2016) did not look directly at associations between self-efficacy and depression but found small effect sizes indicating increased self-efficacy and less severe depression at three and six months after a self-management intervention. They did not use statistics to examine whether the effect was of significance because this was a small pilot study with only 13 participants receiving the intervention and 11 controls receiving treatment as usual.

Even though we found significant associations between locus of control and depressive symptoms in Paper 2 and 3, it is important to note that the degree of depressive symptoms was low. In all three clinical studies of this thesis, the average MADRS score was below 6 points. This makes the clinical relevance of the results weaker. The difference between a statistically meaningful difference and clinically meaningful difference is relevant here. A clinically meaningful difference is understood as the point difference in improvement that the patient or clinician regards as significant regardless of statistically significant differences (Copay et al., 2007). For the clinician, this is a useful addition to statistical analyses because statistically significant changes can be affected by, for example, sample size; thus, a large sample may make clinically unimportant changes significant.

Though Paper 4 revealed an increase in the external locus of control based on the criteria of $\geq$ 5% change as clinically significant as well as a statistically significant decrease in depressive symptoms, the mean MADRS score decreased 1.3 points on average. A threshold for clinically significant changes in MADRS scores among people with dementia has to our knowledge not been investigated. Intervention studies on other populations have reported meaningful differences between intervention and control groups to be from 1.6 to 1.9 points (Duru & Fantino, 2008). A statistically significant change in the MADRS of only 1.3 points may thus not be clinically significant. However, it could also be that the 1.3-point change is clinically relevant because people with dementia report less symptoms of depression compared to cognitively healthy individuals (Knapskog et al., 2011; Olin et al., 2002; Sepehry et al., 2017). Furthermore, because the MADRS is not a diagnostic instrument, a high or low score on the MADRS is not equivalent to having depression or not, though it can provide a trustworthy indication.

When using the MADRS to assess the severity of depressive symptoms, the recommendation in Norway is to asks the person interviewed to reflect on the last three days. This was also specified when interviewing the participants with dementia in the ECOD project. However, thinking back on the last few days may be one of the more difficult tasks for a person suffering from memory problems. This potentially makes data gathered when the person is asked to look back in time less reliable and can be part of the explanation for why the cut-off for indicating depression is lower for this group. A person with dementia may have scored lower on the MADRS during the interview than he or she would the very same evening when alone at home.

4.2.3 Locus of Control, Dementia Severity, and Cognitive Impairment

We examined the potential association between locus of control and cognitive impairment (MMSE-NR) using both cross-sectional and longitudinal data, and there was no significant association in neither. We also examined the potential association between locus of control and dementia severity (CDR) with both cross-sectional and longitudinal data and again could not find any association. However, Paper 2 showed that the LoCB completion rate was at its highest at 74% and less than 50% among those with MMSE-NR< 20. This indicates that cognitive function affects the ability to complete the LoCB. As mentioned earlier, a shorter and more concise scale could have increased the completion rate and thus given us more reliable information.

Though we did not find any associations between dementia severity and cognitive function in the present sample, we did find indications of change in locus of control from baseline to 12 months later. In the small study reported in Paper 4, the locus of control orientation changed for 92.3% of the 52 participants in this study. Using the criteria of a minimum 5% change in orientation as clinically meaningful, 21 participants became more internally oriented and 27 more externally oriented. Rotter viewed locus of control as most likely to change in situations that are novel. Over the course of one year, it is likely that most participants would have experienced some changes in abilities as a consequence of the dementia diagnosis, so why did we not find any association between locus of control and dementia severity or cognitive impairment?

One reason could be that the consequences of dementia were simply not causing the one-year change in orientation. The participants may already have become adjusted to experiencing loss of functions due to dementia and thereby had found ways of coping with these. Other changes in life may explain the change in orientation. Locus of control is of course equally affected by any other events that may have occurred in the participants' lives, such as health issues and losses not related to dementia. The lack of knowledge about this unfortunately leaves a great knowledge gap in our data but is a consequence of using quantitative measures for data collection. Adding qualitative measures of perceptions of control could adjust for this weakness.

However, there are several reasons to be cautious of the findings reported in Paper 4. First, the sample size in Paper 4 was small. A small sample may camouflage a finding, meaning that the change in orientation could indeed have been even larger, or it could exacerbate a finding if,

for example, the sample we used was not representative of the larger population. The sample size was small due to a substantial attrition rate in the ECOD study and missing data on the LoCB. Second, it is possible that the cut-off of 5% change as meaningful is inaccurate. In many types of scales, assessments of clinically meaningful changes are difficult, and there are several ways in which they can be calculated (Copay et al., 2007). The developers of the LoCB argued the change based on percentage calculations to be most fitting because it is to a lesser degree affected by where on the scale change occurs (Craig, 1984). In sum, the findings from Paper 4 need to be replicated with a larger sample to gain power and thus representativeness. With regards to dementia severity, cognitive function, and its association with locus of control, the most robust finding is the relation between MMSE-NR score and completion ability.

5 Methodological Considerations

The goal when conducting research is to produce trustworthy results than can be applied to the relevant population, meaning research with high internal and external validity. In the present section, these aspects are discussed separately for the review and the clinical studies.

5.1 The Review

5.1.1 Search Terms

The goal of the systematic review was to examine the current knowledge of control beliefs among people with dementia. The reason for including all types of control beliefs was simply the prevalence in preliminary searches, indicating the lack of studies on locus of control among this population and the need to broaden our research focus. This led to the inclusion of a myriad of control belief constructs in the search strategy based on Skinner (1996) findings. Search terms referring to coping were also included because control beliefs can be considered part of the coping process, and it was presumed that titles and abstracts could refer to coping when using a control belief questionnaire. Thus, regarding search terms, we believe that we have included most of what could have been relevant for an increased understanding of perceived control among people with dementia.

5.1.2 Inclusion Criteria

Limitations have been set that may have restricted the inclusion of relevant articles. For example, we decided to only include original research studies that had been peer reviewed, were written in English, and had been published after 2000. Regarding the first limitation, we wanted to ensure a certain quality of the studies included in the review. By only including articles that had undergone a peer review before publication as opposed to so-called 'grey' literature, dissertations, and conference poster presentations, we may have lost breadth but gained quality. Through peer review, a study is scrutinized for its theoretical basis and methodology as well as results and subsequent conclusions. By only including such articles, we could begin the process of analysing the findings with a trust in their quality.

Limiting the search to articles in English is not uncommon for reviews because most international research is published in this language, meaning we may have missed valuable research in other languages. However, all reference lists in included articles were also examined, and we could not find any reference to eligible studies in other languages there

either. Therefore, we believe that we have managed to include most of the relevant studies. With regards to excluding studies from before 2000, this was based on a historical understanding of how people with dementia have been understood and included in prior research. It is presumably partly due to Kitwood's efforts that people with dementia gradually became included in research as active participants with their own voice being heard. They went from being included as passive subjects to being considered people with competence regarding their own needs and the ability to express those needs. This did not change overnight, however, and as seen from the results of the included review, most of the included articles are from after 2010.

5.1.3 Quality Assessment

Two of the review authors examined all of the included articles for their methodological quality. Because we had included only 18 articles and both research methods and outcome measures were very homogenous, we decided that all articles should be included in the review despite potential research weaknesses. Though the goal was to examine current knowledge, it was quickly decided that this would be done in a descriptive manner, not by meta-analysis. Thus, the need for a quality assessment tool that included all types of studies was deemed appropriate. The choice fell on the method developed by Hawker et al. (2002). This quality assessment tool can be used on all types of study designs, and the results thus refer to a score within the specific design. The tool does not differentiate between design hierarchy such that a RCT may score equal to a case study. This has its limitations because the amount of generalizable information one can deduce from an RCT and a case study is of course extremely different. However, the tool does have the advantage of scoring a study based on its own right, meaning that it makes it possible to compare different type of studies to each other.

5.1.4 Review Synthesis

It is possible to synthesize review findings in several ways, and meta-analysis is the most common statistical method. However, a meta-analysis requires the included studies to have used the same outcome measure and is usually used when studies aim to examine the same thing, such as the effect of a pharmacological intervention. Given the indications that there had been little research on control beliefs among people with dementia, we were open to the use of control belief as any type of variable in all types of research designs. The topics extracted for the review synthesis were defined based on our review goal. We wanted to learn

about perceptions of control in people with dementia, and as such, we needed to know what constructs had been examined and who the participants were in terms of dementia type and severity. Thus, although the search was systematic, the synthesis resembled a literature review.

5.2 The Clinical Studies

5.2.1 Study Design

Research designs are often considered in a hierarchical manner due to the degree to which one can rely on their results to be valid and generalizable. RCTs are considered the most informative, but particularly in social science studies, RCTs may be difficult and even unethical to implement.

The clinical studies in this thesis had both cross-sectional and longitudinal designs. Cross-sectional design can often recruit more participants than in longitudinal designs, because the participants need not commit themselves to several data collection points. However, the results from a cross-sectional study will always have a certain insecurity around them because they can only present a situation at one specific time. As such, cause and effect cannot be determined, only correlations. Longitudinal studies, on the other hand, can have the potential to inform about cause and effect between measured variables. However, observational studies such as ours still lack certainty about cause and effect because we did not manipulate any variables.

5.2.2 The Study Sample

Our aim was to learn more about locus of control among people with dementia with a particular focus on those who are still community dwelling. The research was conducted within the framework of the ECOD project, which included participants across most of Norway and in both cities and rural areas. However, certain limitations were set from the beginning of the study because ECOD aimed to examine the effects of attending day care on people with dementia, however it appeared the participants often first start using day care when their dementia has become moderate to severe (Rokstad et al., 2018). This may indicate that participants from the ECOD project were quite far into their dementia progression. Compared to other community-dwelling older people with dementia, our sample may have been skewed towards those being institutionalized.

The inclusion process in ECOD was dependent upon help from practitioners in the day care centres and municipal in-house services. The inclusion criteria stated that all eligible participants should be asked to participate; however, it is possible that knowledge the practitioners had about the potential participant or the family caregiver prevented potential participants from being asked. Furthermore, the fact that to be eligible for inclusion a family caregiver also needed to participate meant that those without this possibility could not participate. This means that we may have missed those who are the loneliest; however, it was also possible to participate with a close friend.

The ECOD exclusion criteria may also have had an effect due to the fact that participants could not have other serious medical issues or a short life expectancy. Older people with dementia often have additional medical issues and excluding them for this reason offers a narrow picture of the group as a whole. At the same time, a too-heterogeneous group of participants could have made it difficult to produce any statistically significant and meaningful results.

The ECOD excluded participants with MCI. However, in Study 2, in which we examined the applicability of the LoCB for people with dementia, a small percentage of participants with amnestic MCI were included because they were part of the PADR study. This means that the PCA was not performed exclusively on people with dementia; however, those diagnosed with amnestic MCI are at a higher risk of developing dementia (Langa & Levine, 2014). Still, we believe that there are potential differences in how a person cope with having either dementia or MCI. First, the degree of deficits interfering in everyday life is less for people with MCI as per the MCI definition. Second, dementia is definite, and most types are progressive. This means knowing that impairments will get worse, while people with MCI can remain hopeful that they may remain at the present stage. These distinctions could affect the degree to which a person experiences control, so this was unfortunate.

5.2.3 Assessment Scales

In general, the ECOD project used sound measurements scales with good validity and reliability. Most have been used in plenty of Norwegian and international studies, making comparisons across samples possible. However, the LoCB had never been used in research on people with dementia in Norway. Although findings indicate that those who managed to complete the scale gave reliable answers, a revised LoCB or another locus of control scale could have yielded more robust results. The review and subsequent relevant studies also

indicate that self-efficacy is more commonly examined in this type of research, and particularly by using the GSES by Schwarzer and Jerusalem (1995). It may be worth continuing research on perceived control using this scale instead to increase the current knowledge base, though validation is needed.

On the other hand, compromises will always be made when assessing a perception of control using a standardized scale. It has become more common to conduct studies using both quantitative and qualitative methods, and this is perhaps particularly important among people with reduced ability to express themselves, remain concentrated, and remember without cues from their conversation partner. The review included in this thesis also found studies reporting discrepancies between results on quantitative control belief measures and the qualitative perceptions of control. Including both types of research, particularly while still examining the validity and reliability of control belief scales in this population, would yield important information.

5.2.4 Missing Data and Attrition

Missing values is a common problem in research using large datasets and human participants, as it was in the present studies. There may be many reasons for missing values on a questionnaire, such as oversights, wrongful markings, and participants' reluctance to answer. With regards to participants with dementia, there is also the possibility that the person may not have had the cognitive capacity to answer. For example, the person may not have comprehended the question or remembered or understood how to answer. More concise wordings and answers could have increased the response rate, and the scale could probably benefit from a revision. In the ECOD project, we tried to prevent many of these possible causes of missing data by presenting all of the questionnaires in an interview format. The researcher led the participants through all of the questionnaires and recorded the responses. Background information was collected from the participating family caregiver. Despite these precautions, there was missing data in the ECOD project that affects the studies in the current thesis.

6 Conclusion and Implications for Future Research

The present thesis has presented the current knowledge about perceptions of control in people with dementia with a particular focus on the construct of locus of control. A primary aim was to examine the feasibility of using quantitative measures of control beliefs completed by the person with dementia. This appears feasible as found in both the review and the clinical studies. However, the clinical studies indicate that cognitive function affects the ability to complete a complex measurement scale such as the LoCB. Future studies should consider reducing the number of items and the complexity of this scale to enhance completion probability.

Other than completion rate, dementia severity and cognitive function were not associated with locus of control in this sample. This underscores the likelihood of obtaining reliable answers from those with dementia who manage to reply. With regards to depressive symptoms, we found that a more external locus of control was associated with more severe depressive symptomatology. This is in accordance with studies of the general population as well as studies of older people with depression. This finding adds support to the increased interest in nonpharmacological interventions for treating depression in people with dementia. More longitudinal studies, preferably starting at an early stage after receiving a dementia diagnosis, could help us identify who is at greater risk of developing depression and what kind of support they may need to overcome depression.

Finally, despite the feasibility of using a quantitative measurement scale to examine perceptions of control in people with dementia, there is great value to adding qualitative measures. Qualitative measures allow researchers to obtain a deeper understanding of what the person with dementia needs to feel in control of and what can be left to others.

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Dementia and Geriatric Cognitive Disorders

Systematic Review

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Control Beliefs among People with Dementia: A Systematic Review

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Dementia · Control beliefs · Self-efficacy · Coping · Psychosocial interventions

Abstract
Introduction: Dementia diseases are still incurable, and in order to assist in living well with the disease, researchers are increasing their attention to the value of control beliefs. Control beliefs are associated with coping and psychological well-being; however, knowledge on how they relate to well-being outcomes in people with dementia is limited. This review aimed to synthesize knowledge about control beliefs in this group to guide future interventions and research. ***Method:*** A systematic search of 6 databases (MEDLINE, CINAHL, PsychINFO, AgeLine, Embase, and the Cochrane Library) with broad search terms related to dementia, control, and coping was conducted. Studies that investigated people with a confirmed dementia diagnosis and that used a questionnaire to measure control beliefs quantitatively were included. ***Results:*** Eighteen studies were identified, examining self-efficacy, personal control/mastery, or locus of control. The studies varied in aim and design, with fair to good methodological quality. However, 10 studies included <50 participants with dementia, leaving findings unreliable due to low power. Participants with dementia in the mild to moderate stages were included, with average age in the seventies. Except for one validation study, the control belief questionnaires had not been validated for people with dementia. ***Conclusion:*** There is a lack of knowledge about control beliefs among people with dementia, due to few and low-powered studies. Although we cannot conclude regarding control beliefs, our findings support the feasibility of quantitative research on control beliefs among people with dementia and we recommend that they be included in this type of research.

Introduction

No cure or treatment that can delay the progression of any dementia disorders are yet available, and due to an increase of older adults worldwide, the number of people with dementia will rise substantially in the years to come [1]. Over time, dementia leads to decreased ability to function cognitively, socially, and independently in everyday life. A growing interest regarding how to live and

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cope with dementia is emerging [2]. Knowledge about how people cope with dementia has value for implementing interventions that target adaptive coping strategies for activities of daily living as well as behavioral and psychological symptoms due to the disease.

Control beliefs has been an area of research for more than half a century in social, personality, and clinical psychology. Experiencing a sense of control has repeatedly been shown to be beneficial when coping with a variety of health problems [3, 4]. Many control constructs have been developed [5], and the most prominent are locus of control, learned helplessness, mastery, and self-efficacy. Although defined as distinct constructs, each definition attempts to explain how a person views his/her abilities, effort, or expectations of realizing an outcome. Indeed, several constructs and definitions have been proposed as indicators of the same underlying personality construct [6].

Studies have shown control beliefs to be beneficial for coping [7, 8]. In health research, for example, perception of control has been found to affect one's ability to engage in positive health behaviors and adjust to a demanding situation [9]. In the 1970s, Langer and Rodin [10] demonstrated how a perception of control can positively impact upon well-being among nursing-home residents. In their intervention study, residents who were given more responsibilities in daily decision-making reported to be happier and appeared more active than that of a comparison group given the same activities but with a fixed time schedule. A positive difference was measurable even 18 months after the intervention. In addition, the study reported that the persons in the intervention group tended to live longer than those in the control group [11]. This study bridged the research on control among older people and control in health-related situations and helped shape subsequent gerontological research [8].

Control beliefs among older adults have been associated with the same tendencies as found among younger adults; less perceived control negatively affects well-being, and more perceived control leads to positive outcomes and overall successful aging [4, 8]. In addition, among healthy older people, more perceived control has been associated with greater use of effective strategies to improve memory and to maintain cognitive functioning [4, 7, 12]. According to Bandura [13], a person will invest more effort in a task when the outcome is believed to be attainable. As control beliefs are important to both mental well-being and cognition, they are likely important elements of psychosocial interventions for people with dementia. Knowledge about how control beliefs function among people with dementia could assist informal caregivers and health-care personnel in helping this group to cope with their progressive disease.

Research Aim

The aim of the present review was to synthesize knowledge on control beliefs among people with dementia by performing a systematic search of relevant quantitative research studies. By doing so, we wished to illuminate the present knowledge base and help guide future research on this topic.

Methods

Selection of Eligible Studies

A systematic, computerized search of quantitative research literature was conducted in the MEDLINE, CINAHL, PsychINFO, AgeLine, Embase, and the Cochrane Library databases. The search was conducted by a research librarian at 3 time points, April 2019, October 2019, and January 2021. The second and third searches were restricted to articles published after January 2019.

The search strategy included Medical Subject Headings (MeSH), keywords, and text words for the following constructs: *dementia*, *control*, and *coping*. Perceived control can be viewed as an aspect of coping, and it is possible that some researchers have examined coping with the use of a control instrument; hence, *coping* was included in order to increase the likelihood of incorporating all relevant research. Control beliefs have been defined in numerous ways [5]; thus, we performed a search with a variety of search terms in order to encompass relevant studies (see Appendix 1 for an overview of *dementia* search terms and Appendix 2 for *control* and *coping* search terms).

The inclusion criteria in this review were research conducted by including persons with a confirmed dementia diagnosis, who had responded to a control belief instrument. Additionally, the research had to be original and peer-reviewed, have a quantitative design, and published after the year 2000. Reviews, protocols, conference abstracts, posters, or theoretical research were excluded as were articles in a language other than English. We also excluded articles that studied persons with dementia and mild cognitive impairment (MCI) as a single group, since we wished to have a clear focus on dementia.

The selection of relevant articles was performed in dyads to reduce the risk of oversights. One author was a member of every dyad throughout the selection process to ensure consistency. After an initial elimination of duplicates by EndNote, the selection procedure was performed as follows: First, all titles were divided into 3 parts and delegated at random to the 3 pairs (of the co-authors). Article titles that clearly did not meet the inclusion criteria were discarded. Disagreements within the dyads were resolved by consulting the other co-authors. The procedure was repeated when delegating and reading the abstracts, skimming the full articles, and, finally, when comprehensibly reading the remaining articles. Last, a search for additional articles was conducted by examining the reference lists of all included articles.

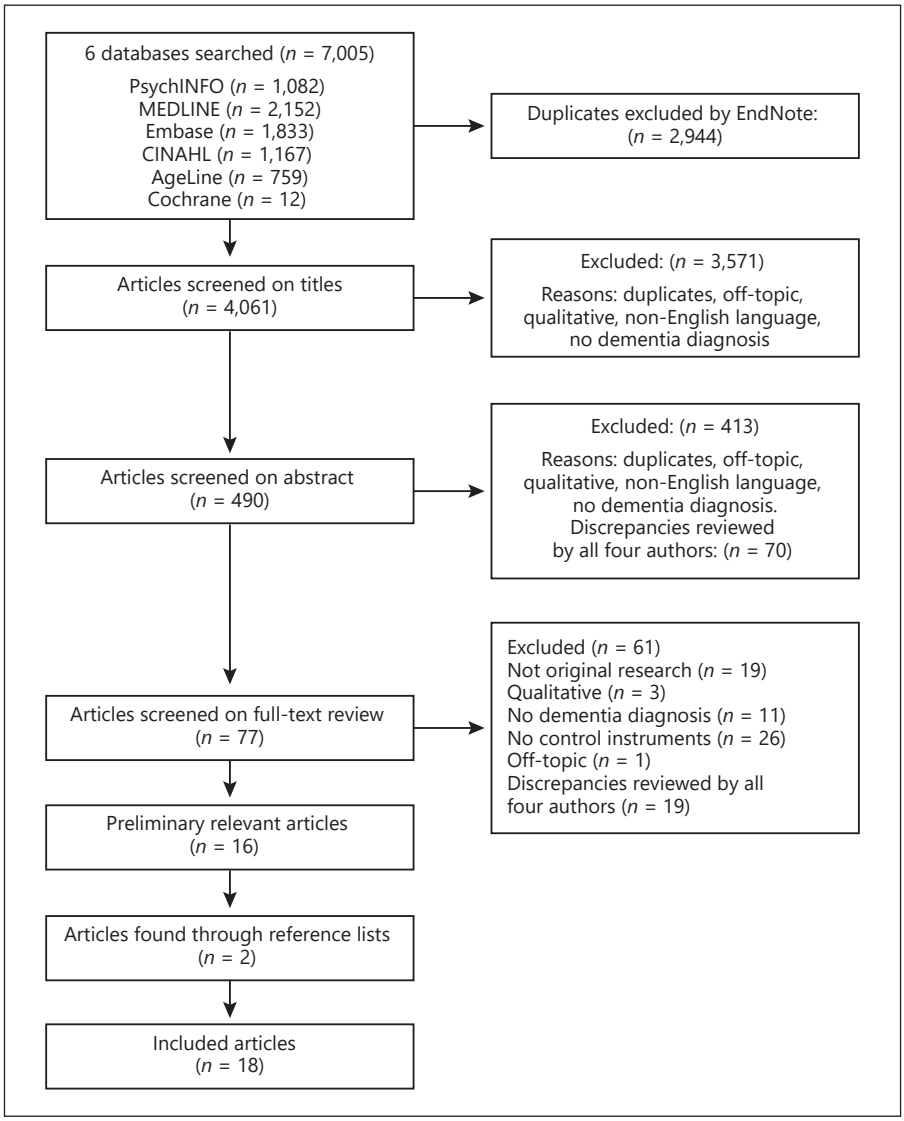

Fig. 1. Overview of the review process.

Quality Assessment

A quality assessment of each article was performed using the critical appraisal tool developed by Hawker et al. [14]. This tool is applicable to all study designs and comprises 9 areas for review: Abstract and Title; Introduction and Aims; Method and Data; Sampling; Data Analysis; Ethics and Bias; Results; Transferability and Generalizability; and Implications and Usefulness. Each area is given a score between 1 and 4 based on a set of guiding criteria; the minimum sum score is 9 and the maximum is 36. A higher total score indicates better quality. Two authors scored the articles separately, and minor disagreements of one point were averaged. No articles were excluded based on their quality assessment. The appraisal tool by Hawker et al. [14] allows for an assessment that focuses on the quality of each research article regardless of study design, meaning that a cross-sectional study can receive a score equal to a randomized controlled trial.

Results

The 3 electronic searches yielded a total of 7,005 articles (final search performed in February 2021). EndNote was used to eliminate duplicates, resulting in 4,061 articles to be assessed for eligibility by the authors. After elimination first by a review of titles, then by abstracts followed by full-text readings, 16 articles remained. Two additional articles were found through examination of reference lists; thus, 18 articles were included in this review. Figure 1 shows the review process.

Methodological Quality of the Studies

As shown in Table 1, the studies had good methodological quality, with 12 studies receiving a score above

Table 1. Quality assessment of studies

Authors	Abstract and title	Introduction and aim	Method and data	Sampling	Data analysis	Ethics and bias	Results	Transferability/ generalizability	Implications/ usefulness	Total (36)
Burgener and Twigg [19]	3	3.5	4	3	3.5	3	4	3.5	3	30.5
Burgener and Berger [21]	3	3.5	4	2.5	3.5	2.5	4	2.5	3	28.5
Burgener et al. [26]	3	3.5	4	2.5	4	2	4	2.5	3.5	29.0
Clare et al. [18]	4	3	3	4	4	3.5	4	4	4	33.5
Clare et al. [30]	3	4	3	3	4	2.5	4	3	4	30.5
Fankhauser et al. [25]	4	3	3.5	3	4	2.5	4	3	3.5	30.5
Fitzsimmons and Buettner [20]	2	2.5	2.5	2.5	2	1	3	2.5	2.5	20.5
Halse et al. [27]	4	3.5	3.5	3.5	4	4	4	3.5	3.5	33.5
Hindle et al. [17]	4	4	4	4	4	4	4	4	3.5	35.5
Lamont et al. [28]	3.5	4	4	4	4	2.5	3.5	3.5	4	33.0
Leroi et al. [31]	3.5	3.5	3.5	3	4	3	3.5	3	3.5	30.5
Logsdon et al. [24]	4	4	4	3	4	1	4	3	3	30.0
Quinn et al. [15]	4	4	4	4	3.5	3.5	4	3	4	34.0
Regan et al. [29]	3.5	3.5	3.5	3	4	3.5	4	3	3.5	31.5
Roberts and Silverio [23]	3	3.5	3	3	3.5	1.5	3.5	3	3	27.0
Schmitter-Edgecombe et al. [22]	2.5	2	3	3	2.5	1	2.5	3	2	21.5
Stockwell-Smith et al. [16]	3.5	3.5	3.5	3	4	2.5	4	3.5	3.5	31.0
Werheid et al. [32]	3	3.5	3	3	2	3.5	3	2.5	3.5	27.0

Assessment done using the appraisal tool by Hawker et al. [14]. 1, very poor; 2, poor; 3, fair; 4, good.

30, and no studies below 20. The studies were, in general, well-justified with good methodological considerations, clear results and discussion sections, and appropriate conclusions regarding implications and usefulness. However, only one study used a control belief questionnaire validated for people with dementia and 10 included <50 participants with dementia.

Study Designs of the Articles

Of the 18 included articles, 11 were intervention studies, of which 7 were pilot studies. The remaining 7 articles were observational studies, of which 2 focused on scale psychometrics. Only 2 intervention studies examined control belief as the primary outcome [15, 16] and another 2 as part of the secondary outcomes [17, 18]. The remaining intervention and observational studies included control beliefs as exploratory outcome measures or as dependent measures without further specifications [19–32].

Heterogeneity in terms of aim, study design, sample size and outcome measures deemed a non-statistical synthesis of the results appropriate. Table 2 shows an overview of the study details.

Study Settings

The participants' home was the research setting in 9 studies [16–19, 21, 23, 28, 30, 31], while 3 were performed in recreational facilities, adult day care or senior centers, or in an assisted living facility [20, 24, 29]. One study was performed in a memory clinic [15], one allowed participants to choose between home or memory clinic [26], and another collected data at participants' home, day care, or memory clinic [27]. Finally, 3 studies did not specify research setting [22, 25, 32].

Participants

Although the age range of the participants with dementia varied from 52 to 96 years, mean age in all studies was in the 70s. Four studies had an age specification as part of their inclusion criteria, with a minimum age varying between 55 and 65 years [16, 17, 25, 27]. See Table 3 for an overview of demographics regarding participants with dementia. Demographics of participating caregivers or comparison groups are not presented in this review.

Dementia Diagnosis

All studies in this review included participants with a confirmed dementia diagnosis; however, only 10 reported which diagnostic criteria had been used [15–18, 22, 25, 27, 28, 30, 32]. Five studies [15, 18, 27, 28, 30] diagnosed dementia according to the International Statistical Classification of Diseases and Related Health Problems, 10th revision (ICD-10) criteria [33], one study [32] used the Diagnostic and Statistical Manual of Mental Disorders,

Table 2. Overview of aims, control belief constructs, and study findings

Authors	*N*	Aim and study design	Outcome and dependent measures	Control belief construct and questionnaire details	Study findings
Burgener and Twigg [19]	191	To examine associations between caregiver factors and Quality of Life (QoL) outcomes in care recipients with dementia; descriptive longitudinal study	Well-being dimension of QoL (defined as depression and psychological well-being). Behavioral competence dimension of QoL (defined as physical impairment, functional ability of daily life, productive behaviors, and personal control)	Personal control measured 3 times with the Mastery Scale [44]: 7 items are rated on a 5-point scale, ranging from 1 (not at all true) to 5 (exactly true). Total score ranges from 7 to 35, with a higher score indicating more personal control. Cronbach's α was 0.77. Participants with dementia mean baseline score: 21.52 (4.7)	From baseline to 18 months, care recipients significantly declined in mental status, productive behaviors, and functional ability, while depression scores improved. If controlling for 12-month mental ability, quality of relationship, and activity participation predicted psychological well-being at 18 months. Depression was predicted by activity participation, and functional ability was predicted by activity participation and caregiver role stress. Quality of relationship predicted productive behaviors, and caregiver role stress combined with total social contacts predicted care recipient social behaviors. Personal control showed a significant increase from baseline to 18 months, and at 18 months was correlated to the personal distress subscale on caregiver role stress. However, personal control was not predicted by any of the studied variables
Burgener and Berger [21]	40	To examine the psychometric properties of 2 stigma measures, Stigma Impact Scale (SIS) and Stigma Experience Scale, and to determine differences in perceived stigma in persons with Alzheimer's Disease (AD) and Parkinson's Disease (PD); cross-sectional comparison study	Perceived stigma, cognitive function, disease severity, self-esteem, depression, and personal control	Personal control measured once with the Mastery Scale [44]: 7 items are rated on a 5-point scale, ranging from 1 (not at all true) to 5 (exactly true). Total score ranges from 7 to 35, with higher score indicating more personal control. Cronbach's α was 0.70. Participants with dementia mean baseline score: 23.5 (5.9)	The SIS was found to have better reliability and validity for both the AD and PD groups. Cognitive function was related to stigma for both groups, but self-esteem, depression, and personal control were only related to stigma in persons with PD. However, personal control was related to the social rejection subscale (1 of 4 subscales) of the SIS in both groups. No difference between AD and PD was found on total SIS scores, but AD participants scored higher on the internalized shame subscale. Personal control was lower in the AD group, but no difference between the groups was found on measures of self-esteem or depression
Burgener et al. [26]	97	To examine if QoL varies in the early dementia disease stages and to examine associations between perceived stigma and quality of life in persons with dementia; descriptive longitudinal study	QoL (defined as depression, anxiety, behavioral symptoms, personal control, physical health, self-esteem, social support, and activity participation)	Personal control measured 4 times with the Mastery Scale [44]: 7 items are rated on a 5-point scale, ranging from 1 (not at all true) to 5 (exactly true). Total score ranges from 7 to 35, with higher score indicating more personal control. Cronbach's α was 0.70 at baseline and 0.77 at 12 months. Participants with dementia mean baseline score: 25.5 (4.8)	Over the 18-month study, anxiety and social support and activity participation significantly decreased, while behavioral symptoms significantly increased. No changes were found on depression, personal control, self-esteem, or physical health scores Stigma was examined at the subscale level (social isolation, internalized shame, and social isolation). Social rejection was associated with anxiety, behavioral symptoms, health, and activity participation. Internalized shame was associated with personal control, health, self-esteem, social support understanding and assistance, and activity participation. Social isolation was associated with depression, anxiety, personal control, health, self-esteem, social support understanding, and activity participation

Table 2 (continued)

Authors	*N*	Aim and study design	Outcome and dependent measures	Control belief construct and questionnaire details	Study findings
Clare et al. [18]	475	To determine whether individual goal-oriented cognitive rehabilitation (CR), compared to treatment as usual (TAU), improves everyday functioning for people with mild to moderate dementia; randomized controlled trial	Primary outcome was self-reported goal attainment at 3 months. Secondary outcomes were informant-reported goal attainment, QoL, mood, self-efficacy, and cognition, as well as partner stress and QoL	Self-efficacy measured 3 times with the General Self-Efficacy Scale (GSES) [43]: 10 items are rated on a 4-point scale, ranging from 1 (not at all true) to 4 (exactly true). Total score ranges from 10 to 40, with higher score representing more self-efficacy. No psychometrics for present sample were presented. Participants with dementia mean baseline score: 30.94 (5.09)	Compared to TAU, self-reported goal attainment increased significantly in the group receiving CR, measured at both 3 and 9 months. No significant differences were found on secondary outcomes at either measuring point, including self-efficacy
Clare et al. [30]	2,748	To explore the extent to which people with dementia experience discontinuity of their subjective experience of themselves and factors associated with this experience; cross-sectional study (the IDEAL study)	Cognitive function, ability to function independently, neuropsychiatric symptoms, psychological well-being indicators (self-acceptance, self-esteem, self-efficacy, aging attitudes, optimism, loneliness, and depression), measures of living well (quality of life and life satisfaction), and caregiver stress	Self-efficacy measured once with the GSES [43]: 10 items are rated on a 4-point scale, ranging from 1 (not at all true) to 4 (exactly true). Total score ranges from 10 to 40, with higher score representing more self-efficacy. No psychometrics for present sample were presented. Participants with dementia mean score: discontinuity group 27.04 (5.85), continuity group 29.86 (5.23)	A fifth of the participants described an experience of discontinuity. Participants in the discontinuity group were younger, with slightly more neuropsychiatric symptoms. There were no other differences between the groups on participant- or dementia-related characteristics. The discontinuity group scored lower on self-acceptance, self-esteem, self-efficacy, attitudes toward own aging, and optimism. They scored significantly higher on loneliness and depression. On living well measures, the discontinuity group scored lower on quality of life, well-being, and satisfaction with life. Caregivers in the discontinuity group reported greater distress due to neuropsychiatric symptoms, and higher levels of caregiver stress
Fankhauser et al. [25]	229	To investigate the role of motivational processes as a mediator of the relationship between social support and depression in participants with dementia, those with mild cognitive impairment (MCI), or unimpaired participants; cross-sectional comparison study	Primary outcome was depression. Explanatory variables were measures of motivational processes (a composite measure based on self-efficacy, activation regulation, motivation regulation, and decision regulation) and social support	Self-efficacy measured once with the GSES [43]: 10 items are rated on a 4-point scale, ranging from 1 (not at all true) to 4 (exactly true). Total score ranges from 10 to 40, with higher score representing more self-efficacy. Cronbach's α was 0.70. Mean baseline score not reported, as self-efficacy was examined as part of a composite measure	In the total sample, both social support and motivational processes were correlated with depression. Only motivational processes predicted depression in a regression analysis, where social support lost its significance. The association between motivational processes and depression remained significant in regression analysis controlling for age, sex, education, MMSE, cognitive impairment, and activities. In the 3 groups, the association between motivational processes and depression was stronger among cognitively unimpaired participants than among dementia and MCI participants. Predictive ability was higher with less impairment

Table 2 (continued)

Authors	*N*	Aim and study design	Outcome and dependent measures	Control belief construct and questionnaire details	Study findings
Fitzsimmons and Buettner [20]	7	To report on results from an experimental college course for older adults with early-stage dementia; pilot intervention study, pretest/posttest	Depression, self-esteem, self-efficacy, and stress	Self-efficacy measured twice with the GSES [43]: 10 items are rated on a 4-point scale, ranging from 1 (not at all true) to 4 (exactly true). Total score ranges from 10 to 40, with higher score representing more self-efficacy. No psychometrics for the present sample were presented. Participants with dementia mean baseline score: 33.17	Differences between pretest and posttests indicate a reduction in depression and perceived stress scores, an increase in self-esteem scores, and stable self-efficacy scores. Statistical analysis not performed due to small sample size
Halse et al. [27]	534	To investigate the applicability of the Locus of Control of Behavior Scale for people with dementia; psychometric evaluation, cross-sectional data	Cognitive function, depressive symptoms, and ability to function independently	Locus of control (LoC) was measured once with the Locus of Control of Behavior Scale [45]: 17 items are rated on a 6-point scale, ranging from 0 to 5. Total score ranges from zero to 85, with higher score representing more external LoC. Cronbach's α was 0.69. Participants with dementia mean baseline score: 30.8 (10.5)	Older age, less education, and poorer cognitive function decreased likelihood of scale completion. Cronbach's α remained relatively stable, despite degree of cognitive impairment, and at an acceptable level. Locus of control was associated with depressive symptoms, but not with degree of cognitive impairment
Hindle et al. [17]	55	To examine the appropriateness and feasibility of CR compared to TAU or relaxation therapy (RT) for people with dementia due to PD and Lewy body disease, and to assess usefulness of outcome measures and obtain effect sizes to guide future RCTs; pilot randomized controlled trial	Primary outcomes were rating of goal attainment and satisfaction with goal attainment. Secondary outcomes were quality of life, mood, cognition, health status, and everyday functioning. Secondary outcomes for carers were ratings of person with dementia's goal attainment, own quality of life, and stress levels	Self-efficacy was measured 3 times with the GSES [43]: 10 items are rated on a 4-point scale, ranging from 1 (not at all true) to 4 (exactly true). Total score ranges from 10 to 40, with higher score representing more self-efficacy. No psychometrics for present sample were presented. Participants with dementia mean baseline score: 29.45 (4.35)	Compared to TAU and RT, effect size estimates showed that CR was superior on both primary outcomes at the 2-month follow-up and partially superior at the 6-month follow-up. Furthermore, CR was superior to TAU and/or RT at 2 months on mood, self-efficacy, social domain of quality of life, and carer ratings of participants' goal attainment. At 6 months, CR was superior on delayed recall, health status, quality of life, and carer ratings of goal attainment
Lamont et al. [28]	1,547	To examine the associations between psychological resources and the ability to live well with dementia; cross-sectional study (the IDEAL study)	Primary outcome was living well (defined as quality of life, life satisfaction, and mental well-being). Explanatory variables were self-efficacy, optimism, and self-esteem	Self-efficacy was measured once with the GSES [43]: 10 items are rated on a 4-point scale, ranging from 1 (not at all true) to 4 (exactly true). Total score ranges from 10 to 40, with higher score representing more self-efficacy. Cronbach's α was 0.88. Participants with dementia mean baseline score: 29.26 (5.49)	High self-efficacy (compared to low) was associated with meaningful increases on quality of life, life satisfaction, and mental well-being. Optimism and self-esteem were also associated with significant increases on each of the 3 living-well scales. In a multivariable model, the results continued to be significant, but effect sizes were reduced Comparing standardized scores, high self-efficacy (compared to low) was still associated with increased quality of life, life satisfaction, and mental well-being, with little variation between the constructs. Optimism similarly showed little variation based on the living-well measure, but self-esteem showed greater variation

Table 2 (continued)

Authors	*N*	Aim and study design	Outcome and dependent measures	Control belief construct and questionnaire details	Study findings
Leroi et al. [31]	38	To evaluate the feasibility, acceptability, and tolerability of a new sensory intervention to support hearing and vision, and to identify the key variables for a cost-effectiveness evaluation; pilot intervention study, pretest/posttest	Persons with dementia were assessed on cognition, behavior, mental well-being, and self-efficacy. Study partners were assessed on physical and mental well-being, and caregiver burden. Both were assessed on relationship satisfaction and quality of life	Self-efficacy was measured twice with the Generalised Self-Efficacy Scale [56]: 8 items are rated on a 5-point scale, ranging from 1 (strongly disagree) to 5 (strongly agree). Item responses are averaged, and total score ranges from 1 to 5, with higher score representing greater self-efficacy. No psychometrics for the present sample were presented. Participants with dementia mean baseline score: 2.85 (0.54)	Mean score increases indicated that people with dementia felt an improvement in quality of life and in hearing and vision functional abilities. Proxy rating indicated a decrease in quality of life. Measures on physical and mental functioning, neuropsychiatric symptoms, self-efficacy, and functional ability indicated only slight changes. Indications that relationship satisfaction improved according to the person with dementia but decreased according to study partners. Statistical analysis not performed due to small sample size
Logsdon et al. [24]	284	To compare a time-limited early-stage memory loss group program to wait list control; randomized controlled trial	Primary outcome was quality of life; secondary outcomes were mood, communication and interpersonal relationships, and stress; self-efficacy and memory-related behavior problems were exploratory outcomes	Self-efficacy was measured twice with the Self-Efficacy Scale [57]: 7 items are rated on a 4-point scale, ranging from strongly agree to strongly disagree. No psychometrics for present sample were presented. Participants with dementia mean baseline score: 7.92 (1.32)	The treatment group showed significant increases on measures of participant QoL, depression, and family communication. No differences were found among caregivers in the 2 groups. For the treatment group, those whose quality of life improved reported more depressive symptoms, more stress, and more distress on several health-related quality of life subscales at baseline. They also showed greater increases in mood, family communication, and self-efficacy than non-improvers. For those who showed improvements in the waitlist group, no baseline associations were found
Quinn et al. [15]	48	To develop and evaluate a self-management intervention compared with TAU for people with early-stage dementia; pilot randomized controlled trial	Primary outcome was self-efficacy. Secondary outcomes were anxiety and depression, well-being, social functioning, problems and risks to self, health-related QoL, and a person's sense of capability-related well-being	Self-efficacy measured twice with the GSES [43]: 10 items are rated on a 4-point scale, ranging from 1 (not at all true) to 4 (exactly true). Total score ranges from 10 to 40, with higher score representing more self-efficacy. No psychometrics for the present sample were presented. Participants with dementia mean baseline score: 28.36 (4.82)	Compared to TAU, intervention participants indicated gains in self-efficacy with small effect sizes at both 3 and 6 months. The intervention participants also showed improved effect sizes for depression after 6 months and on capability-related well-being after 3 and 6 months. They had lower QoL scores at 3 months but higher scores at 6 months. At both 3 and 6 months, the intervention group had higher anxiety scores. Statistical analysis not performed due to small sample size

Table 2 (continued)

Authors	*N*	Aim and study design	Outcome and dependent measures	Control belief construct and questionnaire details	Study findings
Regan et al. [29]	661	To evaluate changes in physical function, physical activity, exercise self-efficacy, and well-being; pilot intervention study, pretest/posttest	Physical function, physical activity, exercise self-efficacy, and mental well-being	Exercise self-efficacy was measured twice with the Self-efficacy of Exercise Scale [58]: original scale consists of 9 items rated on a 11-point scale, ranging from 0 (not confident) to 10 (confident). Total score ranges from 0 to 100, with higher score representing greater self-efficacy. In the present study, only 4 items were used, and rated on a 3-point scale. No psychometrics for present sample were presented. Mean baseline score not reported	For participants with dementia, most physical function measures improved, and there was also an increase in frequency, duration, and intensity of physical activity after the program. Mental well-being increased, while exercise self-efficacy did not change
Roberts and Silverio [23]	74	To evaluate a 4-session education and support program for persons with early-stage dementia and their care-partners; intervention study, pretest/posttest	Participant satisfaction, improvements on AD knowledge, coping self-efficacy, and adjustment to illness, and using more support services and coping strategies were main outcomes	Coping self-efficacy was measured twice with the Illness Coping Self-efficacy Scale [59]. Original scale consists of 43 items rated on a 5-point scale, ranging from 1 to 5. In the present study, only 21 items were used, with a Cronbach's α of 0.9. Mean baseline score not reported	No significant changes were found regarding AD knowledge, coping self-efficacy, or psychosocial adjustment to the illness. Participants reported a high degree of satisfaction with the program, and at the 3-month follow-up, they had significantly increased their use of 7 out of 11 measures of coping and health behaviors
Schmitter-Edgecombe et al. [22]	9	To examine the efficacy of a group memory notebook intervention for people with very mild dementia; pilot intervention study, pretest/posttest	Cognitive performance, cognitive function, objective and subjective memory measures, and measure of independent functioning. Psychological measures of depression, anxiety and stress, and coping self-efficacy	Coping self-efficacy was measured twice with the Coping Self-Efficacy Scale [60]: 26 items are rated on a 11-point scale, ranging from 0 (cannot do at all) to 10 (certain I can do). No psychometrics for present sample were presented. Participants with dementia mean baseline score: 74.20 (19.19)	Mean increases reported by persons with dementia were found regarding use of memory strategies and all 4 measures on the daily checklist. Coaches (spouses) reported mean increases on memory ability, memory strategy use, ADL, use of techniques, use of notebook, and activity engagement. Regarding coping self-efficacy, all 5 participants reported feeling more confident that they could get support from family or friends, with mean score increases from pre- to posttreatment. No changes were seen in the use of problem-focused coping or stopping unpleasant thoughts nor on mental health

Table 2 (continued)

Authors	*N*	Aim and study design	Outcome and dependent measures	Control belief construct and questionnaire details	Study findings
Stockwell-Smith et al. [16]	166	To evaluate the effect of a targeted community-based psychosocial intervention on self-efficacy outcomes for care recipient/carer dyads living with early-stage dementia; intervention study, pretest/posttest with comparison group	Primary outcomes were self-efficacy, stress from the perspective of dyadic strain, and well-being (QoL and depression). Secondary outcomes were dyads' uptake and awareness of available support services	Self-efficacy was measured 3 times with the Self-Efficacy Questionnaire [61]: 10 items are rated on a 10-point scale, ranging from 1 (not at all certain) to 10 (very certain). The scale was developed for caregivers, but minor changes in wording were done to support completion by people with dementia. No psychometrics for present sample were presented. Participants with dementia mean baseline scores: symptom management 37.38 (9.44); support service 31.58 (7.26)	No significant between-group differences in either symptom management self-efficacy or support service self-efficacy. At baseline, the comparison group had higher use of education/training/support groups, with 40% compared to 16% stating they had access to such services. At T1, this had changed to 61% in the intervention group versus 30% in control, but at T2 there was no longer a difference between the groups. Finally, the intervention group's use of social support services for families dealing with memory loss was higher at T2, with 41 versus 13%. No difference was found regarding remaining service types (such as home help/social support services)
Werheid et al. [32]	13	To report on the cultural adaptation and translation of the English Cognitive Stimulation Therapy (CST) manual into German Pilot study, pretest/posttest	Cognitive function, quality of life, depressive symptoms, and self-efficacy	Self-efficacy was measured twice with the GSES [43]: 10 items are rated on a 4-point scale, ranging from 1 (not at all true) to 4 (exactly true). Total score ranges from 10 to 40, with higher score representing more self-efficacy. No psychometrics for present sample were presented. Participants with dementia mean baseline score: 27.23 (6.08)	The German version of the CST manual appears applicable. Measures of effect sizes showed participants had an increase in cognitive function on 1 of 2 scales, and an increase in self-efficacy. No changes were found on quality of life or depressive symptoms. Eight participants additionally completed a maintenance program, and results indicated no changes 6 months later

GSES, General Self-Efficacy Scale; SIS, Stigma Impact Scale; AD, Alzheimer's disease; PD, Parkinson's disease; CR, cognitive rehabilitation; TAU, treatment as usual; RT, relaxation therapy; CST, Cognitive Stimulation Therapy.

Table 3. Demographics of participants with dementia

Authors and country	Participants with dementia (other)	Age mean (SD), range	% Male	Education	Married	Degree of impairment mean (SD), range	Dementia subtype, %
Burgener and Twigg [19], USA	96 (95 caregivers)	77.3 (7.8), 55–96	43	13.4 yr (SD 3.3)	–	MMSE 21.5 (SD 4.7), 10–29	AD, VD, or mixed
Burgener and Berger [21], USA	26 (14 with PD)	77.2 (6.5)	62	12.2 yr (SD 3.5)	–	MMSE 21.8 (5.6) CDR 0.5–2.0	AD or mixed
Burgener et al. [26], USA	50 (47 caregivers)	78.3 (8.3)	–	13.3 yr (SD 4.0)	–	CDR 0.86	AD, VD, or mixed
Clare et al. [18], England and Wales	475	78.6 (7.1), 53–95	52.3	12.6 yr (SD 3.4)	70%	MMSE 23.8 (SD 3.0), 18–30	AD: 59.9 VD: 15.6 Mixed 24.5
Clare et al. [30], UK	1,465 (1,283 caregivers)	76.2 (8.5)[a]	56.4[a]	University: 20.6%[a]	–	ACE-III: 69.6 (13.1)[a]	AD:55.5 VD: 10.9 Mixed: 21.2 Other: 12.4
Fankhauser et al. [25], Switzerland	47 (64 with MCI, 118 controls)	78.0 (7.5)	34.0	11.7 yr (SD 3.0)	–	MMSE 22.9 (SD 3.0)	AD: 20.5
Fitzsimmons and Buettner [20], USA	7	77.9 70.7–85.5	29	–	–	MMSE 21.7	–
Halse et al. [27], Norway	534	78.4 (8.1)	41.8	>10 yr: 49.8	54	MMSE-NR 19.8 (5.6)	AD: 81.1 VD: 8.1 Mixed, LDB, PDD, FLD, or other: 10.9
Hindle et al. [17], Wales	29	76.3 (6.42) 61–85		10.97 yr (SD 1.55)		ACE-III: 71.3 (7.5) 52–81	PDD or LBD
Lamont et al. [28], England, Scotland, and Wales	1,547	76.4 (8.6)	56.4	–	–	ACE-III 69.3 (SD 13.2)	AD: 55.5 VD: 11.1 Mixed: 21.1 Other: 12.4
Leroi et al. [31], France, England, and Cyprus	19 (19 caregivers)	76 63–88	63	–	–	MOCA 17.3 (3.7) 12–23	AD: 47.3 VD: 47.3 Mixed: 5.3
Logsdon et al. [24], USA	142 (142 caregivers)	74.9[a]	50.7[a]	College: 47.2%[a]	72%[a]	MMSE 23.4 (4.4),[a] CDR between 0 and 1	–
Quinn et al. [15], Wales	24 (24 caregivers)	75.6 (8.4),[a] 52–88	75.0	College/university: 62.5%	83%	MMSE 23.6 (SD 2.1),[a] 20–29	AD, VD, or mixed
Regan et al. [29], Canada	343 (318 caregivers)	77.3 (7.8)	60.9	–	–	–	–
Roberts and Silverio [23], USA	37 (37 caregivers)	74.4 (7.2), 55–89	73	College: 75%	81%	23.8 (3.9)	AD: 89% Other: 11%
Schmitter-Edgecombe et al. [22], USA	5 (4 caregivers)	76.0 (9.1), 63–85	20	18 yr (SD 1.41)	≥80%	RBANS 80.4 (SD 9.6)	–
Stockwell-Smith et al. [16], Australia	88 (88 caregivers)	77.8 (7.1)[a]	57.0	≤Grade 10: 46.0% ≥Grade 11: 54.5%	68%	CDR 0.5–1 (as inclusion criteria)	–

Table 3 (continued)

Authors and country	Participants with dementia (other)	Age mean (SD), range	% Male	Education	Married	Degree of impairment mean (SD), range	Dementia subtype, %
Werheid et al. [32], Germany	13	78.8 (12.7)	46.2	–	–	ADAS-COG: 22.0 (8.02) MMSE: 21.9 (5.09)	–

MCI, mild cognitive impairment; MMSE, Mini-Mental State Examination; CDR, Clinical Dementia Rating; ACE-III, Addenbrooke's Cognitive Examination-III; ADAD-COG, Alzheimer's Disease Assessment Scale; MCI, mild cognitive disorder; AD, Alzheimer's disease; VD, vascular dementia; Mixed, combination of AD and VD; PD, Parkinson's disease; PDD, Parkinson's disease dementia; LBD, dementia with Lewy body; FTD, frontal lobe dementia; MOCA, Montreal Cognitive Assessment. [a] Mean originally listed according to treatment groups, but combined for this review.

4th edition (DSM-IV) criteria [34], and 2 studies [16, 22] based the dementia diagnosis on the Clinical Dementia Rating Scale (CDR) [35, 41]. Two studies based the dementia diagnosis on consensus criteria. One [25] used the criteria established by the National Institute of Neurological and Communicative Disorders and Stroke/Alzheimer's Disease and Related Disorders Association [36], and the other study used the criteria established by the Movement Disorder Society [37, 38] and by the Dementia with Lewy Bodies consortium [39].

Where reported, the percentage of participants diagnosed as having Alzheimer's disease (AD) ranged from 47 to 89% [18, 23, 25, 27, 28, 30, 31]. See Table 3 for overview of prevalence of diagnoses in individual studies. If specific dementia diagnoses were among the inclusion criteria, AD, vascular dementia (VD), or mixed AD/VD were the most commonly used diagnoses [15, 18, 19, 21, 25, 26, 28, 31]. One study only included participants with dementia due to Parkinson's disease (PD) or Lewy body disease [17]. The remaining studies either included all types of dementia [23, 27, 30] or did not specify the etiological dementia diagnosis [16, 20, 22, 24, 29, 32].

Dementia Severity

Degree of dementia severity was an inclusion criterion in 11 studies, all of which recruited participants with mild to moderate dementia severity [15, 16, 18, 21–23, 25, 28, 30–32]. A definition of mild to moderate severity was presented in 9 studies, using 8 different types of criteria. Mini-Mental State Examination (MMSE) score [40] was used in 4 studies, and mild to moderate dementia was defined as either ≥15 [28, 30] or ≥18 [18], or ≥20 [15]. The CDR [35, 41] was used in 3 studies, indicating either very mild dementia with a score of 0.5 [22], mild dementia with a score of 0.5–1.0 [16], or mild to middle stage dementia with a score of 0.5–2.0 [21]. One study used a score of ≥12 on the Montreal Cognitive Assessment (MOCA) scale [42] to indicate mild to moderate dementia [31], and the final study used the DSM-IV to define mild to moderate dementia [32]. A further 3 studies also had cognitive assessment requirements as part of their inclusion criteria, but without indicating their purpose [17, 24, 26].

Constructs of Control Beliefs

Although many control constructs are described in the literature [5], self-efficacy [13] was most frequently applied in the included studies of this review. In all, 7 different scales measuring self-efficacy were used in 14 studies. Eleven studies measured self-efficacy at 2 or more time

points [15–18, 20, 22–24, 29, 31, 32]. The General Self-Efficacy Scale (GSES) [43] was used in 8 studies and the remaining 6 self-efficacy scales [56–61] in one study each (see Table 2). The Mastery scale developed by Pearlin and Schooler [44] was used in 3 studies to examine personal control [19, 21, 26]. One study examined locus of control using the Locus of Control of Behavior scale developed by Craig et al. [45].

As seen in Table 2, internal consistency/scale reliability (Cronbach's α) of the control instruments was reported in 6 articles [19, 21, 23, 26–28]. One study's primary aim was to assess the applicability of the control belief scale for use among persons with dementia [27], while no other studies reported or did any validation of the control belief scales for the included study population. However, no studies reported methodological difficulties with the use of the control belief instruments.

Findings Regarding Control Beliefs

Five studies examined control beliefs using cross-sectional data. Clare et al. [30] examined the experience of discontinuity in the subjective experience of one self and found that this was associated with lower scores on self-efficacy. Fankhauser et al. [25] found that motivational processes (self-efficacy and activity, motivation, and decision regulation) were associated with depression and furthermore that motivational processes, not degree of social support, predicted depression in a regression analysis. In the study by Lamont et al. [28], high self-efficacy was found to be associated with increases on 3 different living-well scales. However, the effect sizes were reduced when accounting for shared variance with optimism and self-esteem, considered by the authors to be 2 related concepts. Burgener and Berger [21] examined differences in experiences of stigma among participants with AD and PD. They found that personal control was lower among those with AD and only associated with stigma among those with dementia due to PD. Finally, Halse et al. [27] found more external locus of control to be associated with more depressive symptoms, but no association between locus of control and cognitive function.

Two descriptive longitudinal studies examined personal control as one of several quality of life variables for participants with dementia. Burgener and Twigg [19] found improvements in personal control over an 18-month period; however, the main hypothesis that such a change could be predicted by caregiver factors was not supported. Burgener et al. [26] examined effects of perceived stigma on quality of life variables and found that personal control was associated with both the social isolation and internalized shame stigma subscales. This was more prominent among participants living in urban areas in the USA and those of African American decent.

The 11 intervention studies reported overall positive effects of the various interventions; however, only 5 found these effects to be potentially associated with changes in control beliefs. Examining the efficacy of an early stage memory loss support group, Logsdon et al. [24] found that the intervention was associated with increased quality of life and that this increase was associated with improved self-efficacy. Quinn et al. [15] found that self-efficacy effect sizes increased in the group receiving a self-management intervention compared to that in a group receiving treatment as usual. This increase persisted 6 months post-intervention, along with improved effect size increases in depression and well-being scores. Statistical analysis was not performed due to small sample size. Hindle et al. [17] found that goal-oriented cognitive rehabilitation was superior regarding self-efficacy at 2 months to both relaxation therapy and treatment as usual, but the effect was not sustained at the 6-month follow-up. Two small pilot studies also reported on improved self-efficacy after interventions [22, 32]. In their process of translating and validating a cognitive stimulation therapy manual using 13 participants with dementia, Werheid et al. [32] found that self-efficacy increased from pretest to posttest. Schmitter-Edgecombe et al. [22] found that their 5 participants with dementia showed an increased self-efficacy regarding beliefs about obtaining support from family or friends, one of 3 subscales on the Coping Self-Efficacy Scale.

Finally, 6 studies reported effective interventions, but found no changes in control beliefs. Clare et al. [18] found that goal-oriented cognitive rehabilitation was effective with regard to improved everyday functioning; however, self-efficacy did not change. In a large study evaluating effect of an exercise intervention of physical function, activity, well-being, and exercise self-efficacy, Regan et al. [29] reported increases on all outcomes except self-efficacy. Stockwell-Smith et al. [16] examined effectiveness of a psychosocial intervention for care recipients and carer dyads using both quantitative and qualitative methods. Statistical differences on self-efficacy were not found; however, qualitative reports postintervention indicated increased self-efficacy regarding identifying and accessing community support. Roberts and Silverio [23] examined a 4-session educational and support program. Although the 37 participants with dementia increased their use of several measured coping and health behaviors, no statistical changes were found regarding coping self-effi-

cacy or psychosocial adjustment to the illness. In a small study including 19 participants with dementia, Leroi et al. [31] examined effectiveness of a sensory intervention to improve quality of life for participants with hearing and/or vision impairment. Mean increases in quality of life were reported as clinically significant, but only slight changes were found regarding self-efficacy. Finally, Fitzsimmons and Buettner [20] concluded that their group interventions target health promotion as a success, but mean self-efficacy scores remained stable.

Discussion

To the best of our knowledge, this is the first systematic review conducted of scientific studies investigating constructs of control beliefs among people with dementia. We found 18 studies that met our inclusion criteria, examining a total of 3 different constructs using 9 different control belief scales. The studies had a wide variety of research aims and designs, with good methodological quality. However, 7 studies were pilots, and as many as 10 studies included <50 participants with dementia. Low-powered studies reduce the possibility of detecting effects, increase possibility of false positives, or may inflate effects sizes of valid effects.

Most of the included studies examined control beliefs in relation to an intervention. Knowledge about perceived control is valuable when designing and implementing psychosocial interventions to support and enhance coping with a dementia disorder. Regardless of the idiosyncratic ways dementia can evolve, there is inevitably a fall in functioning in daily activities, in social activities, and in autonomy. A common coping mechanism is withdrawal from that which has become difficult, leading to reduced social network, increased isolation, and increased feelings of helplessness. Some become overwhelmed and experience symptoms of anxiety and depression [46]. Intervention programs should preferably be offered before this happens.

The interventions reported in this review were diverse, aiming to examine feasibility of cognitive rehabilitation, effectiveness of physical exercise, or effectiveness of addressing hearing and vision difficulties [17, 18, 22, 29, 31]. Other interventions aimed to improve a variety of quality of life variables [15, 20, 23, 24, 32] or to increase the use of support services [16]. Two studies had control beliefs as a primary outcome [15, 16]. Both considered their intervention effective, and one found indication of increased self-efficacy [15].

Five studies had follow-up measures after 6 or more months from baseline. One study reported an increase in personal control over an 18-month period [19], while the other 4 with a timespan of 6 months or more did not find control belief changes [16–18, 26]. However, most studies had a shorter time frame with measures done at baseline and again typically after 2 or 3 months. Dementia progresses differently for all individuals, but in the mild stages of the disease, it can be assumed that the changes are slow and minor. More longitudinal data on the associations between cognitive status and control beliefs are thus needed to examine whether cognitive decline affects a person's perception of control. The included studies could not answer this question because of too short follow-up time and being low-powered.

By observing baseline data, it appears that level of perceived control among people with dementia is comparable to other populations without dementia. The GSES was used in 7 studies, with mean baseline scores ranging from 27.2 to 33.2 [15, 17, 18, 20, 28, 30, 32]. Though not comparable in age, a similar GSES mean of 29.46 (SD 5.33) was reported in a large study with 19,120 participants from 25 countries [47]. Furthermore, the descriptive longitudinal studies measuring personal control with the Mastery scale found mean baseline scores ranging from 23.5 to 25.5. Similar means have been reported among middle-aged adults [48] and older adults without dementia [49]. Although caution is needed in interpreting the results of the included studies due to small sample sizes, it indicates that self-efficacy and personal mastery levels among people with dementia resonate other populations. This is encouraging, from both methodological and coping perspectives.

Studies reporting cross-sectional results found several important associations of control beliefs in people with dementia that are useful for our understanding of coping with the diseases. Two studies examining self-efficacy found that a higher level was associated with less depression and better quality of life [25, 28], resonating findings among older people with depression [8, 50]. Compared to people with PD, people with AD reported less personal control and scored higher on the internalized shame subscale of a stigma measure [19]. Finally, low self-efficacy was associated with experiencing a discontinuity in their sense of self because of the dementia disease [30]. This feeling of discontinuity was associated with several negative measures, such as higher scores on loneliness and depression and lower scores on quality of life.

The results found in this review support conclusions made by others, for example, that persons with demen-

tia are prone to thoughts of helplessness, loss of identity, and embarrassment, particularly in the mild stages of the disease process [46, 51]. People with dementia may also be prone to lowered expectations and prejudice by those in their surroundings, and so-called *dementia-ism* can be a source of stigma and negative self-stereotypes [52]. Addressing low control expectations has been shown to positively affect memory training among older adults with cognitive deficits [53, 54]. Health-care personnel and informal caregivers assisting people with dementia should focus on control beliefs to enhance coping. Supporting people with dementia to reach own goals by focusing on increasing their perception of control could lead to empowering effects and may thereby reduce some of the negative psychological effects of the disease.

Apart from the study by Halse et al. [27] that validated the Locus of Control of Behavior Scale for people with dementia, none of the studies reported having validated the control belief questionnaire for the current population. Still, the studies did not report difficulties with the use of such questionnaires. Depending on the degree of cognitive deficit, people with dementia may be expected to struggle with questions that require judgments on a Likert-type scale, which is commonly used in such questionnaires. One could speculate that they would answer arbitrarily if they did not understand the questions or how to respond. This should be detectable in an internal reliability analysis, and 7 studies reported a Cronbach's alpha score ranging from 0.69 to 0.90. This indicates that reliable data regarding control beliefs using quantitative measures can be acquired in this manner, which is supported by the study of Halse et al. [27]. Therefore, we suggest that persons with dementia should be included in this type of research as their voices are important and informative.

Notably, the 18 studies tended to include participants with mild to moderate dementia, and most of those included had either AD, VD, or a mix of these diseases. Although there is an overall lack of knowledge regarding control beliefs among persons with dementia, studies should also include participants in the severe stages of the disease and with other dementia diagnoses. Furthermore, studies focusing specifically on subgroups with comorbidities such as depression or anxiety would likely give further knowledge on who and how a person with dementia could benefit from a focus on control beliefs to increase coping effectiveness.

This review applied a broad search strategy regarding terms to cover both dementia and control beliefs, and thereby, it should capture most of what has been published in English and in peer-reviewed journals. Furthermore, we applied a strict definition of dementia, meaning that studies mixing our target group with people with mild cognitive impairment were excluded. This was done in order to promote the generalizability of our findings, a necessity also advocated by others [55]. However, particularly due to the exclusion of non-English articles, there may exist additional research on the topic that is missing in this review.

Conclusion and Future Directions

Understanding how experiences of control influences coping can make it easier for informal caregivers and health-care personnel to give effective support to the person with dementia, allowing them to live independently longer and thereby prevent premature burden on society. This systematic review revealed that too few and small studies exist to conclude on the relations between perceived control and dementia; thus, there is a need for more robust studies. However, our findings support that quantitative research on control beliefs among people with dementia is feasible, and people with dementia are recommended to be included in this type of research. The rising interest in this field of knowledge is encouraging, as it may enlighten best practice and help in the development of effective interventions so that people with dementia can cope and live well with their disease.

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Statement of Ethics

The study is exempt from Ethical Committee approval as it is a review based on already published research data.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

I.H., K.E., G.H.B., G.S., and M.L.B. contributed to the design and/or analysis and/or interpretation of data and have contributed in the drafting, revising, and final version of the manuscript. They all agree to be held accountable for the content of the manuscript and have signed an Author Submission Statement declaring this.

Appendix 1

Search words for dementia in different databases

Database	Dementia terms
EMBASE	Dementia/OR Alzheimer disease/OR parkinsonism/OR (lewy adj1 bod*).ab,kw,ti. OR (Parkinson* adj1 dementia).ab,kw,ti. OR (dementia* or alzheimer*).ab,kw,ti. OR (frontotemp* adj1 dementia).ab,kw,ti. OR (vascul* adj1 dementia).ab,kw,ti.
MEDLINE	Dementia/or alzheimer disease/or dementia, vascular/or frontotemporal lobar degeneration/or lewy body disease/OR (dementia* or alzheimer* or (lewy adj1 bod*) or (parkinson* adj1 dementia*)).ab,kf,kw,ti. OR parkinsonism.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
CINAHL	TI dement* OR AB dement* OR SU dement* OR TI alzheimer* OR AB alzheimer* OR SU alzheimer* OR (MH "Lewy Body Disease") OR TI parkinson* N1 dement* OR AB parkinson* N1 dement* OR SU parkinson* N1 dement* OR (MH "Dementia+") OR (MH "Alzheimer's Disease")
PSYCHINFO	Dementia/or dementia with lewy bodies/or presenile dementia/or semantic dementia/or senile dementia/or vascular dementia/OR alzheimer's disease/OR "alzheimer*".ab,mh,sh,ti. OR "dement*".ab,mh,sh,ti. OR (lewy adj1 bod*).ab,mh,sh,ti. OR (parkinson* adj1 dement*).ab,mh,sh,ti.
AGELINE	DE "Dementia" OR DE "Alzheimers Disease" OR DE "Early Onset Dementia" OR DE "Frontotemporal Dementia" OR DE "Lewy Body Dementia" OR DE "Vascular Dementia" OR DE "Vascular Dementia" OR DE "Lewy Body Dementia" OR DE "Frontotemporal Dementia" OR DE "Early Onset Dementia" OR DE "Alzheimers Disease" OR AB (dementi* or alzheimer*) OR TI (dementi* or alzheimer*) OR SU (dementi* or alzheimer*) OR TI parkinson* N1 dementi* OR AB parkinson* N1 dementi* OR SU parkinson* N1 dementi* OR AB lewy N1 bod* OR TI lewy N1 bod* OR SU lewy N1 bod*
COCHRANE	MeSH descriptor: [Dementia] explode ORMeSH descriptor: [Alzheimer Disease] explode OR (dementi* OR alzheimer* OR lewy OR parkinsonism):ti,ab,kw

Appendix 2

Search words for control and coping in different databases

Database	Coping terms
EMBASE	Coping behavior/OR (coping adj1 (strateg* or style* or mechanism* or behavio* or way*)).ab,ti,kw. OR "locus of control assessment"/or internal-external control scale/or "multidimensional health locus of control scale"/OR "locus of control"/OR "locus of control".ab,kw,ti. OR control/OR *self concept/OR (control adj1 (personal or subjectiv* or belief* or perceived or orientation or sense or expectancy)).ab,kw,ti. OR self-efficacy.ab,kw,ti. OR "sense of coherence scale"/OR "sense of coherence"/OR "sense of coherence".ab,kw,ti. OR learned helplessness.ab,kw,ti. OR learned helplessness/OR personal causation.ab,kw,ti. OR situation appraisal.ab,kw,ti. OR perceived competence.ab,kw,ti. OR efficacy expectancies.ab,kw,ti. OR "agency belief*".ab,kw,ti. OR ways of coping.ab,kw,ti. OR mastery.ab,kw,ti.
MEDLINE	(Coping adj1 (strateg* or style* or mechanism* or behavio* or way*)).ab,ti,kw,kf. OR Internal-External Control/OR "locus of control".ab,kw,ti,kf. OR (control adj1 (personal or subjectiv* or belief* or perceived or orientation or sense or expectancy)).ab,kw,ti. OR self-efficacy.ab,kw,ti,kf. OR "sense of coherence".ab,kw,ti,kf. OR learned helplessness.ab,kw,ti,kf. OR personal causation.ab,kw,ti,kf. OR situation appraisal.ab,kw,ti,kf. OR perceived competence.ab,kw,ti,kf. OR efficacy expectancies.ab,kw,ti,kf. OR "agency belief*".ab,kw,ti,kf. OR ways of coping.ab,kw,ti,kf. OR mastery.ab,kw,ti,kf. OR Internal-External Control/OR Helplessness, Learned/OR Self Efficacy/OR "Sense of Coherence"/OR Adaptation, Psychological/
CINAHL	(MH "Coping+") OR TI ((coping w1 (behavio** OR style* OR strateg* OR mechanism* or way*))) OR AB ((coping w1 (behavio* OR style* OR strateg* OR mechanism* or way*))) OR SU ((coping w1 (behavio* OR style* OR strateg* OR mechanism* or way*))) OR (MH "Locus of Control") OR (MH "Self Regulation") OR TI ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR AB ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR SU ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR (MH "Helplessness, Learned") OR sense of coherence OR "mastery" OR TI (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy) OR AB (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy) OR SU (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy) OR TI locus of control OR AB locus of control OR SU locus of control
PSYCHINFO	(Coping adj1 (strateg* or style* or mechanism* or behavio* or way*)).ab,ti,sh. OR "internal external locus of control"/OR "locus of control".ab,ti,sh. OR (control adj1 (personal or subjectiv* or belief* or perceived or orientation or sense or expectancy)).ab,sh,ti. OR self-efficacy.ab,sh,ti. OR "sense of coherence".ab,ti,sh. OR learned helplessness.ab,ti,sh. OR personal causation.ab,sh,ti. OR situation appraisal.ab,sh,ti. OR perceived competence.ab,ti,sh. OR efficacy expectancies.ab,ti,sh. OR "agency belief*".ab,ti,sh. OR ways of coping.ab,ti,sh. OR mastery.ab,ti,sh. AND Helplessness, Learned/OR Self Efficacy/OR "sense of coherence"/OR coping behavior/OR *self-control/OR helplessness/or learned helplessness/OR exp Self-Perception/
AGELINE	DE "Coping Behavior" OR TI ((coping w1 (behavio* OR style* OR strateg* OR mechanism* or way*))) OR AB ((coping w1 (behavio* OR style* OR strateg* OR mechanism* or way*))) OR SU ((coping w1 (behavio* OR style* OR strateg* OR mechanism* or way*))) OR TI ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR AB ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR SU ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR DE "Learned Helplessness" or DE "Locus of Control" or DE "Self Efficacy" OR TI (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy or sense of coherence) OR AB (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy or sense of coherence) OR SU (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy or sense of coherence) OR TI locus of control OR AB locus of control OR SU locus of control
COCHRANE	MeSH descriptor: [Adaptation, Psychological] explode OR MeSH descriptor: [Self Concept] explode (coping):ti,ab,kw OR (locus of control):ti,ab,kw OR ("control orientation" or "sense of control" or "control expectancy" or "control belief*" or "personal control" or "perceived control" or "perception of control" or "self-efficacy" or "sense of coherence" or "personal causation" or "learned helplessness" or "situation appraisal" or "perceived competence" or "efficacy expectanci*" or "agency belief*" or "way* of coping" or mastery):ti,ab,kw

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III

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Locus of Control and Its Associations with Depressive Symptoms amongst People with Dementia

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Keywords
Dementia · Locus of control · Depression · Coping · Psychosocial interventions

Abstract
Introduction: Depression is common amongst people with dementia. This study examines whether locus of control (LoC), a perceived control construct influential in the coping process, is related to depressive symptoms in this population. ***Methods:*** In this prospective observational study, 257 community-dwelling older adults with a confirmed dementia diagnosis were included. At baseline, measures of depressive symptoms, LoC, cognition, independent functional ability, general health, dementia severity, and dementia disease insight were collected. At follow-up, measures of depressive symptoms and cognition were collected. Multiple linear regression using degree of depressive symptoms as measured with Montgomery-Asberg Depression Rating Scale as a dependent variable was applied to assess whether LoC was associated with depressive symptoms at baseline and follow-up while controlling for covariates. ***Results:*** LoC ($p < 0.001$), general health ($p = 0.003$), and insight ($p = 0.010$) were associated with severity of depressive symptoms at baseline, accounting for 28% of the variance. LoC ($p = 0.025$) and depressive symptoms ($p < 0.001$) at baseline were associated with severity of depressive symptoms at follow-up, accounting for 56.3% of the variance. ***Conclusion:*** LoC was significantly associated with severity of depressive symptoms in people with dementia at baseline and at follow-up. Attention to LoC may be valuable for our understanding of depression in people with dementia, and interventions targeting depression could benefit from including a focus on internalizing perceived control. However, these findings are novel, and more research is needed.

Introduction

The number of people with dementia is increasing globally, and a recent population study in Norway has found a 14.6% prevalence rate amongst those aged 70 years or older [1]. As no cure is imminent, supporting people to live well with dementia should be a priority for health-care and social service providers. Depression is common amongst people with dementia [2–4] and can lead to or exacerbate cognitive decline [5–7], reduced

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quality of life [8–10], and reduced functioning in daily living [3]. As in the general population, depression amongst people with dementia is a disorder that can be related to biopsychosocial risk factors, such as the degree of cognitive decline and insight into this decline, prior depression disorder, general health, and residing in an assisted-living facility, all factors that are difficult to modify [5, 11–15]. However, little is known about psychological risk factors and, especially, how depression amongst people with dementia is associated with the perception of control.

Perceived control is recognized as a fundamental human goal because people want to interact effectively in any situation [16]. For decades, studies have shown perceived control to be an influential aspect of the coping process affecting how individuals appraise stressful situations and the available resources for managing them [16]. In relation to health issues, greater perceived control is associated with better treatment adherence, healthy behaviours, and better adaptation to chronic conditions [17–19].

Self-efficacy, mastery, learnt helplessness, and locus of control (LoC) are examples of the most commonly studied constructs of perceived control [20–23]. LoC is defined as the degree to which a person expects occurrences in life to be due to his or her own actions, considered internal control, or due to actions of others or chance, both considered external control [20]. In general, people tend to cope more efficiently with stress they perceive as controllable, which also prevents stress from becoming overwhelming and potentially triggering symptoms of depression and anxiety [24].

LoC has repeatedly been linked to depression among older persons and persons coping with chronic illness, and findings from both cross-sectional and prospective studies show external LoC to be associated with increased severity of depressive symptoms [25–28]. Even though dementia profoundly affects cognition, independent functional ability, and autonomy, perceived control beliefs remain largely unexamined in the scientific literature focussing on people with dementia. A systematic review of research conducted with people with dementia using a control belief questionnaire revealed 18 eligible studies [29]. None of the studies reported methodological difficulties with using such questionnaires, and internal reliability was reported as ranging from acceptable to good [29].

Depressive symptoms were measured in 10 of the studies in the review, but only 2 looked at the association with control beliefs. Fankhauser et al. [30] measured self-efficacy as part of a composite measure that also included decision regulation, activation regulation, and motivation regulation. They found that the composite measure predicted depression, also when controlling for variables such as age, gender, cognition, and dementia severity. Halse et al. [31] found more external LoC as being associated with more depressive symptoms but no association between cognition and LoC. In addition, a pilot intervention study examining feasibility of a self-management course resulted in mean increases in self-efficacy and decreases in depression; however, neither a direct association was examined nor a statistical significance was found due to a small sample size [32]. In summary, regardless of a growing interest in examining perceived control amongst people with dementia, little is known about its relationship with depression in this group.

Aims and Hypotheses

The present study aimed to examine the degree to which LoC is associated with depressive symptoms when controlling for sociodemographic and clinical variables related to depression in a sample of persons diagnosed with dementia. We hypothesized that more external LoC is associated with increased severity of depressive symptoms at baseline and, furthermore, that more external LoC is associated with increased severity of depressive symptoms at a 12-month follow-up.

Methods

Design

This is a prospective observational study with a 12-month follow-up. It is part of a larger project called "Effects and Cost of a Day Care Centre Program Designed for People with Dementia" (ECOD), which studies the effectiveness of the Norwegian day service programme for people with dementia. The project recruited participants from 2013 to 2015. For more details about the project, see Rokstad et al. [33].

Participants

All 257 participants in the ECOD project were included in the current study. The inclusion criteria for the project were being 65 years of age or older, having a dementia diagnosis and a Mini-Mental Status Examination-Norwegian Revised (MMSE-NR) minimum score of 15, residing at home, and having the ability to give informed consent for participation. Participants were recruited from day care centres designed for people with dementia and by in-home nursing service providers. To ensure all participants had a dementia diagnosis, 2 specialists in geriatric psychiatry (authors K.E. and M.B.) used baseline information to confirm dementia diagnoses as defined by the research criteria of ICD-10 [33, 34].

Table 1. Description of participants' sociodemographic and clinical characteristics at baseline

Characteristic (assessed subjects, *n*)	Baseline		*p* value
	female (*n* = 168)	male (*n* = 89)	
Age, mean (SD), (*n* = 257)	81.54 (6.6)	81.48 (6.0)	0.950[1]
Married (or de facto married), *N* (%), (*n* = 255)	37 (22.0)	62 (71.3)	**<0.001**[2]
Education >10 years, *N* (%), (*n* = 249)	67 (41.1)	45 (52.3)	0.119[2]
Attendance at day care, *N* (%), (*n* = 257)	111 (66.1)	71 (78.9)	**0.031**[2]
Good or very good physical health, *N* (%), (*n* = 240)	123 (78.9)	63 (75.0)	0.697[2]
N of prescription medications, mean (SD)[4], (*n* = 257)	4.73 (2.74)	4.88 (2.50)	0.670[1]
Has had prior depression, *N* (%), (*n* = 257)	28 (16.7)	5 (5.6)	**0.020**[2]
Full/partial insight of dementia disease, *N* (%), (*n* = 252)	150 (90.9)	80 (92.0)	0.938[2]
LoC, mean (SD), (*n* = 182)	30.8 (11.15)	31.15 (12.12)	0.837[1]
Depressive symptoms, mean (SD), (*n* = 246)	5.5 (4.98)	4.5 (5.17)	**0.024**[3]
Cognitive function, mean (SD), (*n* = 256)	20.55 (3.50)	20.19 (3.44)	0.397[3]
Dementia severity, mean (SD), (*n* = 253)	5.93 (2.35)	7.30 (2.67)	**<0.001**[1]
Functional ability, mean (SD), (*n* = 251)	20.68 (5.31)	24.38 (4.41)	**<0.001**[3]

LoC, locus of control. [1] Independent samples *t* test. [2] χ^2 test for independence. [3] Mann-Whitney test. [4] Potential ceiling effect, as maximum number reported was restricted to 9 different prescription medications.

Most of the participants had Alzheimer's disease (78.6%), followed by vascular dementia (8.6%), mixed Alzheimer's/vascular (5.4%), Lewy Body or Parkinson's disease with dementia (5.1%), frontotemporal dementia (0.8%), and other dementias (1.6%). The mean age was 81.5 years (SD 6.4), and 168 (65.4%) participants were women. After 12 months, 138 participants remained in the study. Reasons for attrition were admittance to a long-term living facility, withdrawal from the study, or death.

Assessments

The participants were interviewed either at home or at a day care centre. At baseline, sociodemographic and clinical characteristics were recorded. The participants were assessed with the instruments listed below both at baseline and at 12 months. For the present study, only measures of depressive symptoms and cognitive function were used of the follow-up data.

The Locus of Control of Behavior Scale (LOCB) was used to measure LoC orientation [35]. It consists of 17 items, with a total score ranging from zero to 85. Higher scores indicate a higher degree of external orientation. The scale has been translated to Norwegian and back-translated [36] and has been applied in several Norwegian studies with older participants [37–39]. In a study examining its applicability to people with dementia, Cronbach's alpha (internal reliability) was at a satisfactory level of 0.69 and remained at 0.73 even among those with MMSE-NR score between 15 and 19 [31]. The Cronbach's alpha in the present study was 0.70.

The Montgomery-Asberg Depression Rating Scale (MADRS) was used to measure depressive symptoms. It consists of 10 items, with possible scores ranging from zero to 60 and higher scores indicating more severe symptomatology [40]. The Norwegian version has been validated for use with people diagnosed with dementia, and the best cutoff indicating depression was 6/7 points [41].

The revised Norwegian version of the MMSE-NR was used to measure global cognition. It consists of 20 items, and the total score ranges from 0 to 30, with higher scores indicating better cognitive function [42, 43].

The Clinical Dementia Rating scale was used to assess dementia severity. It consists of 6 items to assess severity of dementia, and the total score ranges from zero to 18 (sum of boxes method), with zero indicating no impairment and 18 indicating severe impairment [44, 45].

The Instrumental Activities of Daily Living Scale was used to measure the ability to perform activities of daily life independently. It consists of 8 items, and the total score ranges from 8 to 31. Higher scores indicate poorer functional ability [46].

The General Medical Health Rating scale was used to measure physical health. It consists of a single item with 4 categories (poor, fair, good, and excellent [scored 1–4, respectively]). It was developed for use with people who have dementia [47].

The Anosognosia Rating Scale was used to rate the patients' degree of awareness of memory loss. It consists of a single item with 4 categories (full awareness, shallow awareness, no awareness, and denies impairment [scored 1–4, respectively]). The scoring is set based on an interview usually in combination with tests of cognition. Inter-rater reliability has been reported as high (0.91) [48].

Statistics

The data were analysed using Statistical Package for the Social Sciences, version 27.0. Missing items were imputed if cases had an item response of at least 50%. The missing values were imputed by random numbers drawn from an empirical distribution generated for each item of interest. The imputation was performed by a biostatistician. We assessed variables for normality, and a *p* value of <0.05 was used as the statistical level throughout.

We first examined the sociodemographic and clinical characteristics of the participants using the independent samples *t* test, χ^2 test for independence, or Mann-Whitney test as applicable. The level of education was dichotomized (<10 vs. >10 years). We examined the relationship between LoC and the included variables using the independent samples *t* test, ANOVA, or correlation analysis. Differences between those with complete versus incomplete LOCB and those who remained or were lost to follow-up were as-

Table 2. Linear regression analyses showing associations between baseline MADRS scores and sociodemographic and clinical variables

Characteristics at baseline	Unadjusted reg. analysis		Adjusted reg. analysis		
	B (95% CI)	*p* value	*B* (95% CI)	β	*p* value
Age	−0.056 (−0.156, 0.044)	0.269	−0.062 (−0.170, 0.046)	−0.078	0.260
Gender (female = 0; male = 1)	−0.985 (−2.317, 0.348)	0.147	−0.998 (−2.440, 0.444)	−0.094	0.174
Civil status (unmarried = 0; married = 1)	0.238 (−1.074, 1.549)	0.722			
Education (<10 years = 1; >10 years = 2)	−0.538 (−1.837, 0.762)	0.416			
Attends day care (no = 0; yes = 1)	−1.155 (−2.548, 0.237)	0.104	−0.278 (−1.802, 1.246)	−0.025	0.719
LoC	0.181 (0.120, 0.241)	**<0.001**	0.175 (0.115, 0.234)	0.396	**<0.001**
Cognitive function	0.082 (−0.100, 0.265)	0.377			
Dementia severity	0.104 (−0.148, 0.357)	0.415			
Physical health	−1.711 (−2.592, −0.830)	**<0.001**	−1.565 (−2.599, −0.531)	−0.225	**0.003**
Functional ability	−0.10 (−0.131, 0.112)	0.879			
prescription medications[1], *n*	0.249 (0.011, 0.487)	**0.040**	−0.062 (−0.344, 0.220)	−0.032	0.666
Prior depression (no = 0; yes = 1)	2.996 (1.131, 4.862)	**0.002**	1.546 (−0.533, 3.626)	0.102	0.144
Dementia disease insight	−1.414 (−2.470, −0.357)	**0.009**	−1.503 (−2.649, −0.357)	−0.179	**0.010**

The model explains 28% of the variance of depressive symptoms at baseline (F [8, 161] = 7.825, $p < 0.001$). LoC, locus of control; MADRS, Montgomery-Asberg Depression Rating Scale; CI, confidence interval. [1] Potential ceiling effect, as maximum number reported was restricted to 9 different prescription medications.

sessed using the χ^2 test for independence, independent samples *t* test, or Mann-Whitney test.

Secondly, we performed unadjusted linear regression analyses to examine the associations between the dependent variables (severity of depressive symptoms as measured by MADRS at baseline and at 12 months) and the following independent variables measured at baseline: gender, age, marital status, educational level (<10 vs. >10 years), day care attendance, general health, number of prescription medications used (max 9), history of prior depression, cognition (and change in cognition from baseline to follow-up), dementia severity, degree of insight into dementia disorder, functional ability, and LoC. Gender, age, and variables with a *p* value of <0.2 were examined further in adjusted multiple regression analyses. The models were assessed for multicollinearity, normality, and outliers.

Ethics

The ECOD project was reviewed and approved by the Regional Committee for Ethics in Medical Research in South-East Norway; REK South-East case number 2013/1020. After receiving written and oral information about the study, participants signed a written consent form. Only those with the capacity to give their consent were included in the study.

Results

Table 1 shows the baseline sociodemographic and clinical characteristics. Women had higher MADRS scores and were more likely to have had depression previously in life but had less severe dementia and were less dependent on others in daily activities. Men were more likely to be married and to attend day care.

A total score on LOCB was obtained for 182 participants. The 75 participants that did not complete the LOCB had more severe dementia, worse cognition, were more dependent in daily activities, and had less education (data not shown). LoC was positively correlated with MADRS measured at baseline (rs [175] = 0.405 and $p < 0.001$), but not associated with any other variable (data not shown). The 119 participants who were lost to follow-up were at baseline significantly older (mean 82.5 and SD 6.24) than those who remained (mean 80.67 and SD 6.37), but no other differences were found (data not shown).

Table 2 displays the baseline characteristics associated with MADRS scores at baseline. At baseline, more external LoC, poorer general health, using a higher number of prescription medications, having more disease insight, and having previous depression were associated with higher MADRS scores in the unadjusted analysis. In the adjusted analysis, only more external LoC, poorer general health, and having more insight remained significantly associated to the MADRS score at baseline, with LoC being most strongly associated (standardized β = 0.396). The model accounted for 28% of the variance of MADRS scores at baseline (F [8, 161] = 7.825 and $p < 0.001$).

Table 3 displays the baseline characteristics associated with MADRS scores at 12 months. More external LoC, more depressive symptoms, and poorer general health at baseline were associated with higher MADRS scores at 12

Table 3. Linear regression analyses showing associations between MADRS scores at 12 months and baseline sociodemographic and clinical variables

Characteristics at baseline	Unadjusted reg. analysis		Adjusted reg. analysis		
	B (95% CI)	*p* value	*B* (95% CI)	β	*p* value
Age	0.008 (−0.156, 0.172)	0.925	0.031 (−0.103, 0.164)	0.032	0.649
Gender (female = 0; male = 1)	0.468 (−1.715, 2.651)	0.672	1.266 (−0.520, 3.053)	0.100	0.162
Civil status (unmarried = 0; married = 1)	0.435 (−1.714, 2.583)	0.690			
Education (<10 years = 1; >10 years = 2)	−0.822 (−2.948, 1.304)	0.446			
Attends day care (no = 0; yes = 1)	−1.885 (−4.148, 0.378)	0.102	−0.807 (−2.690, 1.075)	−0.061	0.397
LoC	0.235 (0.141, 0.329)	**<0.001**	0.088 (0.008, 0.168)	0.167	**0.032**
Depressive symptoms	0.857 (0.709, 1.004)	**<0.001**	0.768 (0.580, 0.956)	0.645	**<0.001**
Cognitive function	−0.088 (−0.387, 0.210)	0.560			
One-year change in cognitive function	−0.007 (−0.338, 0.324)	0.966			
Dementia severity	0.069 (−0.346, 0.484)	0.742			
Physical health	−1.992 (−3.418, −0.567)	**0.007**	−0.374 (−1.671, 0.922	−0.045	0.568
Functional ability	0.100 (−0.095, 0.295)	0.313			
prescription medications[1], *n*	0.321 (−0.067, 0.709)	0.104	0.019 (−0.328, 0.366)	0.008	0.568
Prior depression (no = 0; yes = 1)	2.188 (−0.896, 5.271)	0.163	−0.050 (−2.613, 2.513)	−0.003	0.913
Dementia disease insight	−0.914 (−0.2645, 0.817)	0.298			

The model explains 56.3% of the variance of depressive symptoms at follow-up (F [8, 92] = 14.791, $p < 0.001$). LoC, locus of control; MADRS, Montgomery-Asberg Depression Rating Scale; CI, confidence interval. [1] Potential ceiling effect, as maximum number reported was 9 different prescription medications.

months in the unadjusted analysis. In the adjusted analysis, only more external LoC and MADRS scores at baseline remained significant predictor variables. The model accounted for 56.3% of the variance of MADRS scores at 12 months (F [8, 92] = 14.791 and $p < 0.001$).

Discussion

In the present study, we examined whether LoC in people with dementia measured at baseline was associated with severity of depressive symptoms at baseline and at follow-up. Our analyses showed support for both hypotheses. LoC was the independent variable most strongly associated with depressive symptoms at baseline. Also, LoC continued to be associated with depressive symptoms at follow-up, but baseline degree of depressive symptoms was the stronger predictor. In both analyses, there was a positive association between severity of depressive symptoms and more external LoC. To our knowledge, this is the first study to examine the relationship between LoC and depressive symptoms in people with dementia, making comparisons difficult [29]. However, the results are in accordance with findings from systematic reviews and studies on older people with depression [25, 27, 28].

Regardless of how dementia develops, there is inevitably a fall in function across several domains, and many persons with dementia feel increasingly out of control in their daily life and strive to cope with things they are used to manage [49]. Supporting people to cope with the cognitive, functional, and social consequences of dementia may have positive effects on quality of life and depression [32, 50]. Successful coping is what prevents stressors from developing into adverse effects such as depression [24]. LoC is one of the several internal resources contributing to the coping process, and our findings indicate that assessing LoC may give additional understanding of depressive symptoms among people with dementia.

Psychosocial interventions for people with dementia are increasing in popularity [51]. Though not necessarily targeting depression, a measure of psychological well-being is usually included as a mean to examine intervention efficacy. A synthesis of 22 systematic reviews examining a variety of psychosocial interventions for people with dementia could not conclude regarding their effects on mood, but several of the included reviews indicated positive effects on depression [52]. Furthermore, group-based cognitive stimulation therapy was found to positively affect quality of life, a construct associated with depression. As depression has been found to be a persistent comorbidity in people with dementia [5], knowledge about cop-

ing resources such as LoC, and how it relates to both depression and is affected by interventions, is of interest. Indeed, the interest in examining control beliefs among people with dementia appears also to be increasing [29].

To better understand LoC in people with dementia, we examined whether LoC was associated with any of the covariates included in this study. It was interesting to find that the degree of depressive symptoms was the only variable associated with LoC, with a positive correlation of medium strength. In combination with the findings from the regression analyses, this indicates that LoC is a coping resource making independent contributions to depressive symptoms. Few studies have examined LoC or other perceived control beliefs in people with dementia, and the results regarding depression and control beliefs such as self-efficacy, mastery, and LoC remain indicative [30–32, 53–55]. The present findings and those of the review by Halse et al. [29] support a continued focus on control beliefs in this type of research.

Knowledge of which mechanisms lead to effective interventions in people with dementia is relevant to both formal and informal caregivers, and policymakers. Helping people with dementia cope with their disease and live independently longer could prevent premature burden on people with dementia, their families, and society. Increasing the perception of internal control could be 1 such mechanism, potentially leading to empowering effects in the individual. Even the slightest increase in control can make a profound difference in general well-being, as shown in a simple but effective manner in the, now classic, study by Langer and Rodin [56]. The degree to which events are perceived as being a consequence of one's own actions (internal LoC) is part of what motivates a person to feel in control of the situation and thereby act in one's best interest. Indeed, low perception of control has been linked to reduced treatment adherence and a reduced belief in the potential efficacy of an intervention [17]. Conversely, addressing low control expectations of treatment efficacy has been shown to positively affect memory training among older adults with cognitive deficits [57].

As found in other studies, worse physical health and a higher degree of insight into the dementia disease were also associated with more depressive symptoms [11, 12]. However, we did not find any association between the severity of depressive symptoms and dementia severity, cognition, or independent functional ability, as found by others [15]. A potential reason for this could be that LoC moderates the stress due to dementia. This was found to be the case in a study investigating mastery as a stress moderator buffering the effects of disability on depression in elderly without cognitive deficits [58]. Those who experienced more personal control were less likely to experience depressive symptoms, despite their disabilities.

A limitation of this study is that we were not able to analyse LoC at follow-up due to a low response rate. A potential reason for this may be that the length and complexity of the scale becomes a barrier when cognitive decline has progressed. As Halse et al. [31] found in their study, dementia severity appears to affect response rates, but not necessarily response reliability. It is possible therefore that a less complex control belief instrument could have led to a larger response rate and thereby more information regarding potential changes associated with depression and dementia severity. Finally, it is important to emphasize that we measured degree of depressive symptoms, not depression. Depressive symptoms may overlap with symptoms of dementia; however, the applied instrument for assessing depressive symptoms (MADRS) has been validated for use in dementia with a cutoff of 6/7 indicating depression [41].

Conclusion

This is the first study to investigate the association between LoC and severity of depressive symptoms amongst people with dementia. We found that LoC was associated with severity of depressive symptoms at baseline and that LoC at baseline predicted depressive symptoms after 12 months. As with adults and older people in general, our findings indicate that attention to LoC may be valuable when understanding depressive symptoms in people with dementia. Interventions that aim to prevent or treat depression in this population may benefit from including a focus on internalizing perception of control. Therefore, further research is needed regarding the relationship between LoC and depression, especially intervention studies that examine the potential amenability of this relationship.

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Statement of Ethics

The project has been accepted by the Regional Committee in Ethics in Medical Research in South-East Norway; REK southeast case numbers 2013/1020 and 2011/531. After written and oral information about the project, the participants were asked to give written informed consent. Only participants with the capacity to give consent were included.

Author Contributions

I.H., G.H.B., K.E., G.S., and M.L.B. jointly designed the study and participated with the statistical considerations and discussion of results. I.H. performed the statistical analysis and wrote the manuscript, with input and revisions from G.H.B., K.E., G.S., and M.L.B. All the authors approved the final version of the manuscript.

Conflict of Interest Statement

The authors declare no conflict of interest.

Data Availability Statement

The data that support the findings of this study are available upon request from the corresponding author.

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IV

Dementia and Geriatric Cognitive Disorders Extra

Research Article

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One-Year Change in Locus of Control among People with Dementia

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Keywords
Dementia · Locus of control · Coping

Abstract
Introduction: Knowledge of how perceptions of personal control change over time may provide valuable insights into how people cope with having dementia. The present study aimed to examine change in locus of control over a 12-month period in persons with dementia. ***Method:*** The study included 52 participants with dementia. Locus of control was measured with the Locus of Control of Behavior Scale (LoCB), with higher scores indicating a more external locus of control, interpreted as perceiving less personal control. A ≥5% change on the LoCB was considered clinically meaningful. We recorded sociodemographic characteristics and assessed dementia severity, cognition, ability to function independently in daily activities and physical self-maintenance, depressive symptomatology, and number of prescribed medications. Analyses were performed to examine differences between those with increases (more external) or decreases (less external) in the LoCB score after 12 months and to examine associations between baseline variables and change in the LoCB score. ***Results:*** The mean LoCB score for the total sample did not change after 12 months (baseline mean 29.33 vs. follow-up mean 30.33, $p = 0.553$); however, 2 subgroups emerged. Using the ≥5% cutoff revealed that the LoCB score changed for 92.3% of the sample, becoming less external (lower LoCB) for 21 participants and more external (higher LoCB) for 27 participants. At baseline, the mean LoBC score was higher in the group that became less external (33.81 vs. 24.56), $p = 0.006$, while this was reverse at follow-up (23.57 vs. 34.41), $p = 0.001$. Dementia severity and dependence in physical self-maintenance increased during the 12 months in both groups. Among those becoming more external, we also found a decline in cognition ($p = 0.002$), an increase in dependence in daily activities ($p = 0.003$), an increase in the use of prescribed medication, and a decrease in depressive symptomatology ($p = 0.003$). The baseline LoCB score was the only variable associated with 12-month change in LoCB scores ($p = 0.001$). ***Conclusion:*** Most participants showed a clinically meaningful change in locus of control after 12 months. Those with more signs of dementia progression reported a decrease in personal control but also a decrease in depressive symptoms. These findings are interesting for our understanding of coping but must be replicated with a larger sample.

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Introduction

Coping is affected by how much a person feels in control of a situation. Having dementia means experiencing a decline in cognitive, instrumental, and social abilities, and these changes may require an almost ongoing coping response [1]. Information about how health practitioners can best assist in this coping process is important for enabling people with dementia to continue functioning in daily life. Knowledge about perceptions of control, regardless of actual control, may provide valuable information about how people with dementia cope with their challenges.

Perceived control is related to how we interpret a situation and our abilities to handle it and is thereby part of what motivates us to act [2–4]. It has been widely studied in health science, for example, among patients with depression, cancer, chronic illnesses, and pain, and is associated with treatment adherence, health behaviors, and adaptation to chronic diseases [5–8]. Studies have generally found that perceiving yourself to be in control of a situation is advantageous [9].

The concept of perceived control has also been studied among older people. Associations between coping and illness, cognitive decline, and mental health have been identified, with better health associated with greater perceptions of personal control [10]. The degree to which people perceived to be in control has been found to change in a curvilinear way with age, with a peak in midlife [9, 11, 12]. Decreases in perceptions of personal control with age could imply that older people may be more vulnerable when faced with adversities such as health problems [11].

Little research has been done on perceived control among people with dementia, however. A recent review reported on 18 studies investigating perceived control beliefs in this population, but still, only 6 studies examined change with a time span of at least 6 months [13]. Using the Pearlin Mastery scale [14], Burgener and Twigg [15] reported an increase in personal control over an 18-month period, while the remaining 5 studies did not report any statistically significant within-group changes [16–20].

Perceived control is an umbrella term that has been defined and operationalized in many ways [21], but one of the initial and most widely studied constructs is locus of control [22]. Locus of control is defined as the degree to which an individual expects what happens in life to be due to either internal or external causes. In other words, a person who expects things to happen in life because of himself or herself has an internal locus of control, and if the person expects things to happen in life because of powerful others or chance, fate, or luck, he or she has an external locus of control [22]. Thus, more external locus of control indicates less personal control. The aim of the present study was to examine if locus of control among people with dementia changes over a 1-year period, as well as which sociodemographic or clinical variables may be associated with such changes.

Materials and Methods

Design

The present prospective observational study is part of a larger study on the effectiveness and cost of the Norwegian day service program for people with dementia (ECOD). The ECOD study recruited 257 participants from 2013 to 2015, and they were followed up for 2 years. The participants were interviewed annually either at home or at a daycare center. The study had substantial participant attrition from baseline to the 12-month follow-up, with 119 participants reaching either a study endpoint (N = 74 moved to a long-term nursing facility, N = 13 deceased), withdrawing (N = 29), or were lost due to unknown causes (N = 3). For more details about the ECOD study, see the Rokstad et al. [23].

Participants

Participants with dementia were included if they were 65 years of age or older, had the revised Norwegian version of the Mini Mental Status Examination-NR (MMSE-NR) score of 15 or above, and resided at home. The dementia diagnosis was confirmed by 2 psychiatrists (coauthors K.E. and M.L.B.) using the ICD-10 criteria [24]. The current study reports on the participants who completed the Locus of Control of Behavior Scale (LoCB) at baseline and at the 12-month follow-up, or who responded to enough of the items to allow for statistical imputation. This resulted in LoCB data from 182 participants at baseline, 58 participants at follow-up, and a total of 52 participants with LoCB data at both timepoints (see flowchart, Figure 1).

Of the 52 participants included in this study, most were diagnosed with dementia due to Alzheimer's disease (71.2%), followed by vascular dementia (13.5%), mixed Alzheimer's/vascular dementia (5.8%), Lewy body disease with dementia (3.8%), Parkinson's disease with dementia (1.9%), and other dementia diseases (3.8%). The mean age was 80 years (SD 6.3), and 65.4% were women.

Assessments

Sociodemographic and clinical data such as age, sex, marital status, education, daycare attendance, use of prescription medication, and history of depression were recorded at baseline, and the participants were evaluated with the following instruments at both baseline and follow-up:

The LoCB is a self-reported questionnaire used to measure locus of control [25]. It consists of 17 Likert-style items, with a total score between 0 and 85; higher scores indicate a higher degree of external locus of control, interpreted as perceiving less personal control. The scale has been translated to Norwegian [26], and has been applied in several Norwegian studies with older participants [27, 28] and in studies with older people with depression [29] and dementia [30, 31].

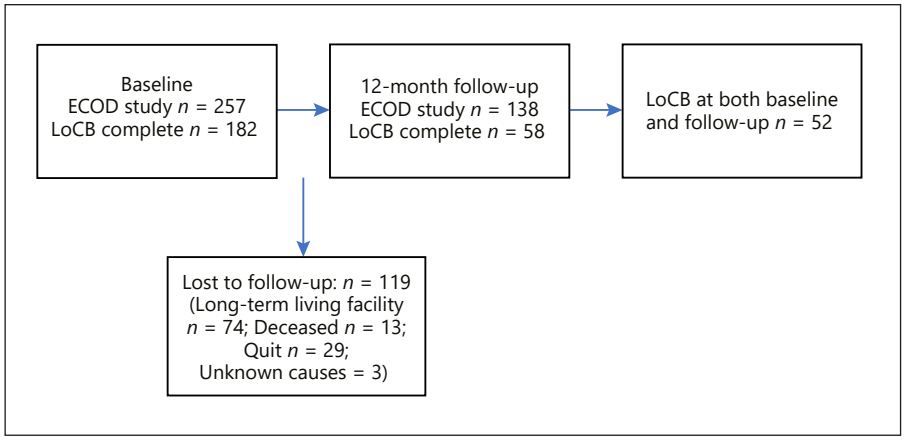

Fig. 1. Flowchart of included participants and those lost to follow-up. LoCB, Locus of Control of Behavior Scale.

The MMSE-NR was used to measure global cognitive function. It consists of 20 items, and total scores vary between 0 and 30, with a higher score indicating better cognitive function [32, 33].

The Clinical Dementia Rating Scale (CDR) was used to assess dementia severity based on data collected from participants and contributing family carers. It comprises 6 items that assess severity of dementia, and the total score ranges from 0 to 18 (using the sum of boxes method), with 0 indicating no impairment and 18 indicating severe impairment [34, 35].

The Instrumental Activities of Daily Living Scale (IADL) and the Physical Self-Maintenance Scale (PSMS) were used to measure the ability to perform activities of daily life independently [36]. The IADL comprises 8 items, with a possible score between 8 and 31. The PSMS has 6 items, with a possible score between 6 and 30. For both scales, a higher score indicates poorer independent functioning [36]. IADL and PSMS were proxy rated by a family caregiver.

The Montgomery-Aasberg Depression Rating Scale (MADRS) was used in an interview with the participant to assess the degree of depressive symptoms. It consists of 10 items, with possible scores ranging between 0 and 60, with higher scores indicating more severe symptomatology [37]. The Norwegian version has been validated for use among people with dementia, and the best cutoff indicating depression was 7 points or higher [38].

Statistics

Statistical analyses were performed with the Statistical Package for the Social Sciences, version 27. The level of statistical significance was set at $p < 0.05$. Missing values were imputed if cases had at least a 50% item response (relevant for LoCB and IADL). Missing values were imputed by random numbers drawn from an empirical distribution generated for each item of interest. Differences between those with baseline only ($N = 130$) versus baseline and follow-up measures of LoCB ($N = 52$) were assessed using χ^2 test, independent samples *t* test, or Mann-Whitney U test as appropriate.

We first examined the overall change in LoCB scores over 12 months among the 52 participants. Next, we dichotomized the participants into groups based on whether their LoCB score had increased or decreased 5% or more from baseline to follow-up. The developers of the LoCB suggested a ≥5% change as clinically significant because a change of this size toward internality was associated with both clinical improvement and reduced risk of relapse after treatment for a behavioral problem [39]. Based on dichotomization, we analyzed differences between those who became either more or less externally oriented at both baseline and follow-up, using independent samples *t* test, χ^2 test, or Mann-Whitney U test as appropriate. Changes from baseline to follow-up within the groups were analyzed using paired samples' *t* test or the Wilcoxon signed-rank test.

Finally, we conducted multiple linear regression analyses with 1-year changes in LoCB scores (measure at 12 months – measure at baseline) as the dependent variable and baseline sociodemographic variables, number of prescribed medications, and scores on LoCB, CDR, MMSE-NR, IADL, PSMS, and MADRS as independent variables. First, unadjusted analyses were performed. Then, variables with a *p* value of <0.2, together with the patients' age and sex, were included in the adjusted analysis. The model was assessed for multicollinearity, normality, and outliers.

Results

The 130 participants with only baseline LoCB response, compared to the 52 with a follow-up response, had at baseline more severe dementia (CDR score, median 6 [Q1:4.5–Q3:8] vs. 4.5 [Q1:4–Q3:7], $U = 2{,}453.5$, $p = 0.011$), had worse cognitive functioning (MMSE-NR score, median 20.5 [Q1:18–Q3:23] vs. 22.5 [Q1:20–Q3:25], $U = 4{,}568$, $p < 0.001$), and were more dependent in regard to both physical self-maintenance (PSMS score, median 9 [Q1:7–Q3:11] vs. 7 [Q1:6–Q3:9], $U = 2{,}358.5$, $p = 0.001$) and instrumental activities of daily living (IADL score, median 22 [Q1:19–Q3:26] vs. 20 [Q1:16–Q3:24.75], $U = 2{,}452.5$, $p = 0.008$). Nonsignificant findings are not reported.

The mean LoCB score for the 52 participants did not change from baseline (mean 29.33, SD 11.97) to follow-

Table 1. Patients' characteristics at baseline, and follow-up of those who became more or less externally oriented in 12 months

Characteristics	Groups at baseline			Groups at 12 months		
	less external (n = 21)	more external (n = 27)	p value	less external (n = 21)	more external (n = 27)	p value
Age, mean (SD)	81.33 (6.09)	79.33 (6.01)	0.261[1]	–	–	
Female, *n* (%)	16 (76.2)	16 (59.3)	0.355[2]	–	–	
Education (>10 years), *n* (%)	13 (65.0)	13 (50.0) (N = 26)	0.473[2]	–	–	
Prior depression, *n* (%)	6 (28.6)	5 (18.5)	0.634[2]	–	–	
Married, *n* (%)	8 (38.1)	12 (46.2) (N = 26)	0.796[2]	8 (38.1)	13 (50) (N = 26)	0.602[2]
Attends day care, *n* (%)	13 (61.9)	21 (77.8)	0.379[2]	14 (73.7) (N = 19)	21 (84.0) (N = 25)	0.643
Medications, *n*, mean (SD)	4.52 (3.06)	5.22 (2.58)	0.395[1]	5.74 (2.92)(N = 19)	6.13 (2.44) (N = 23)	0.637[1]
CDR, mean (SD)	5.14 (2.57)	5.21 (2.31)	0.924[1]	6.36 (2.71)	6.85 (2.52)	0.526[1]
MADRS, mean (SD)	3.85 (3.94)	4.64 (5.05)	0.669[3]	3.43 (4.70)	3.30 (4.61)	0.915[3]
LoCB, mean (SD)	33.81 (12.18)	24.56 (10.27)	**0.006**[1]	23.57 (9.57)	34.41 (10.03)	**0.001**[3]
MMSE-NR, mean (SD)	21.95 (2.96)	23.22 (3.13)	0.160[1]	21.14 (3.42)	21.30 (3.62)	0.882[1]
PSMS, mean (SD)	7.86 (1.56)	8.63 (3.73)	0.848[3]	8.76 (2.30)	9.28 (3.65) (N = 25)	0.875[3]
IADL, mean (SD)	19.48 (5.48)	19.59 (5.77)	0.944[1]	20.05 (6.30)	21.36 (6.07) (N = 25)	0.476[1]

CDR, Clinical Dementia Rating Scale; LoCB, the Locus of Control of Behavior scale; MMSE-NR, the revised Norwegian version of the Mini Mental Status Examination; IADL, the Instrumental Activities of Daily Living scale; PSMS, The Physical Self-Maintenance scale; MADRS, the Montgomery-Aasberg Depression Rating Scale. [1] Independent sample t test. [2] χ^2 test for independence. [3] Mann-Whitney U test.

Table 2. Changes from baseline to follow-up among those becoming more or less externally oriented in 12 months

Variables	Less external (N = 21)			More external (N = 27)		
	baseline	12 months	p value	Baseline	12 months	p value
Number of medications, mean (SD)[Group that decreased (N = 19)]	4.89 (2.96)	5.74 (2.92)	0.149[1]	5.00 (2.56)	6.13 (2.44)	**0.033**[1]
CDR, mean (SD)[Group that increased (N = 25)]	5.14 (2.57)	6.36 (2.72)	**0.003**[1]	5.02 (2.14)	6.80 (2.56)	**0.001**[1]
MADRS, mean (SD)[Group that decreased (N = 20)/Group that increased (N = 25)]	3.85 (3.94)	3.43 (4.70)	0.488[2]	4.64 (5.05)	3.30 (4.61)	**0.0032**
MMSE-NR, mean (SD)	21.95 (2.96)	21.14 (3.42)	0.163[1]	23.22 (3.13)	21.30 (3.62)	**0.0021**
PSMS, mean (SD)[Group that increased (N = 25)]	7.86 (1.56)	8.76 (2.30)	**0.0402**	8.63 (3.73)	9.28 (3.65)	**0.0072**
IADL, mean (SD)[Group that increased (N = 25)]	19.48 (5.48)	20.05 (6.30)	0.649[1]	19.20 (5.80)	21.36 (6.07)	**0.0031**

CDR, Clinical Dementia Rating Scale; MMSE-NR, the revised Norwegian version of the Mini Mental Status Examination; IADL, the Instrumental Activities of Daily Living scale; PSMS, the Physical Self-Maintenance scale; MADRS, The Montgomery-Aasberg Depression Rating Scale. [1] Paired samples' t test. [2] Wilcoxon signed rank test.

up (mean 30.33, SD 11.25), p = 0.553. However, further examinations identified 2 subgroups with distinct changes. Using the criteria set by Craig et al. [25] to examine clinically meaningful changes in externality, the LoCB score remained stable for 4 participants, while 21 became less external (lower LoCB), and 27 became more external (higher LoCB). Participants in the group that became less external had a higher baseline LoCB score (mean 33.81, SD 12.18) than participants who became more external (mean 24.56, SD 10.27), p = 0.006. At the follow-up, the participants who had become less external now had a lower LoCB score (mean 23.57, SD 9.57) than participants who had become more external (mean 34.41, SD 10.03), p = 0.001. No other differences were found at baseline or at follow-up between the 2 groups (see Table 1). LoCB reliability analyses revealed a Cronbach's alpha value of 0.74 at baseline and 0.77 at follow-up.

From baseline to follow-up, both groups had an increase in dementia severity (CDR) and dependence in physical self-maintenance (PSMS). Those who became less external after 12 months had a CDR mean of 5.14 (SD = 2.57) at baseline compared to 6.36 (SD = 2.72) at follow-up, p = 0.003, and a PSMS mean of 7.86 (SD = 1.56) at baseline compared to 8.76 (SD = 2.30) at follow-up, p = 0.040. Similarly, those who became more external after 12 months had a CDR mean of 5.02 (SD = 2.14) at

Table 3. Multiple linear regression analyses of associations between changes in LoCB and baseline patients' characteristics

Characteristics at baseline	Unadjusted reg. analysis		Adjusted reg. analysis		
	B (95% CI)	*p* value	*B* (95% CI)	β	*p* value
Age	−0.251 (−0.805, 0.103)	0.127	−0.223 (−0.649, 0.202)	−1.138	0.425
Gender (female = 0; male = 1)	1.525 (−4.561, 7.612)	0.617	2.185 (−3.274, 7.644)	0.103	0.425
Civil status (unmarried = 0; married = 1)	1.963 (−4.027, 7.952)	0.513			
Education (<10 years = 1; >10 years = 2)	−1.942 (7.876, 3.991)	0.513			
Attends day care (no = 0; yes = 1)	3.639 (−2.675, 9.953)	0.252			
LoCB	−0.428 (−0.657, −0.199)	**<0.001**	−0.394 (−0.628, −0.160)	−0.435	**0.001**
MADRS	0.177 (−0.519, 0.872)	0.611			
MMSE-NR	0.694 (−0.255, 1.642)	0.148	0.533 (−0.325, 1.391)	0.158	0.217
CDR	−0.316 (−1.481, 0.848)	0.587			
IADL	−0.117 (−0.648, 0.414)	0.660			
PSMS	0.241 (−0.736, 1.218)	0.622			
Prescription medications,[1] *n*	0.345 (−0.719, 1.408)	0.518			
Prior depression (no = 0; yes = 1)	−2.773 (−9.818, 4.273)	0.433			
R^2 27.5% (F 4, 46) = 4.365, p = 0.004					

CDR, Clinical Dementia Rating Scale; LoCB, the Locus of Control of Behavior scale; MMSE-NR, the revised Norwegian version of the Mini Mental Status Examination; IADL, the Instrumental Activities of Daily Living scale; PSMS, the Physical Self-Maintenance scale; MADRS, the Montgomery-Aasberg Depression Rating Scale. [1] Potential ceiling effect, as maximum number reported was 9 different prescription medications.

baseline compared to 6.80 (SD = 2.56) at follow-up, p = 0.001, and a PSMS mean of 8.63 (SD = 3.73) at baseline compared to 9.28 (SD = 3.65) at follow-up, p = 0.007. Additional findings among those who became more external were an increase in the number of prescribed medications (baseline mean 5.00 [SD = 2.56] compared to follow-up mean 6.13 [SD = 2.44]), p = 0.033, greater dependence in instrumental activities of daily living (baseline mean 19.20 [SD = 5.80] compared to follow-up mean 21.36 [SD = 6.07]), p = 0.003, a decline in cognitive function (baseline mean 23.22 [SD = 3.13] compared to follow-up mean 21.30 [SD = 3.62]), p = 0.002, and a decrease in depressive symptomatology (baseline mean 4.64 [SD = 5.05] compared to follow-up mean 3.30 [SD = 4.61]), p = 0.003 (see Table 2).

Finally, we investigated predictors of LoCB change (see Table 3). One participant with an extreme change in LoCB (−45 points) was excluded from the regression analyses. LoCB at baseline (p < 0.001), age (p = 0.127), sex (p = 0.617), and MMSE-NR (p = 0.148) were included in the adjusted analysis. The adjusted model accounted for 27.5% of the variance of change in LoCB scores (F 4, 46) = 4.365, p = 0.004, and LoCB at baseline was the only independent variable associated with change in LoCB (standardized β = −0.435, p = 0.001).

Discussion

To the best of our knowledge, this study is the first to examine change in locus of control among people with dementia. On average, LoCB sum scores did not change from baseline to follow-up; however, further examinations revealed substantial changes within the group. Using the criteria of ≥5% change as clinically meaningful showed that 48 participants (92.3%) became either less (n = 21) or more (n = 27) externally oriented. Baseline LoCB was the only variable associated with a 12-month change in the LoCB sum score, and those becoming more externally oriented showed increases on more factors associated with dementia disease progression. Although the sample size was small, the findings suggest that locus of control among people with dementia varies across time and possibly in relation to dementia progression.

Adapting to the progression of a dementia disease aligns well with the theoretical notion that changes in locus of control are most likely to occur in novel situations [22]. Age-related findings suggest a general tendency toward feeling less personal control in old age [9, 11, 12]; however, approximately half of the current study sample showed the opposite. Our findings indicate that it is a faster progression of dementia, as indicated by worsening on several measures of dementia-related factors (CDR,

MMSE-NR, IADL, and PSMS), that is related to experiencing loss of personal control, not age. Still, whether it is the speed of progression or the severity of the symptoms that is associated with loss of personal control remains unknown.

A consequence of dementia progression is to become more dependent on others to manage everyday activities. Thus, we suggest that those who reported less personal control after 12 months may have experienced more challenges as a result of their disease. However, shifting one's expectation of who is in control from oneself and instead place it externally, such as to family members and healthcare systems, may be a resourceful strategy for adaptive coping. The decrease in symptoms of depression observed in the group that became more externally oriented may support this, although a small sample size hinders early conclusions. Furthermore, we suggest that those who became less externally oriented managed to cope with living with the dementia disease, perhaps because of less challenges or experiences of mastery, and thereby gained an increased feeling of personal control. Though opposite, both ways agree with findings identified by Bjørkløf et al. [1], who reported in a review that reconstructing a sense of self and accepting support from family and friends were common coping strategies for people with dementia.

In Western societies, it is generally assumed that more personal control is associated with a healthier mental life, and studies have repeatedly found that having a more external locus of control is associated with adverse outcomes such as depression, anxiety, and decreased quality of life [10, 40]. However, if objective control is indeed absent, then allowing oneself to not be responsible for what happens, such as with an external locus of control, can potentially be adaptive. Support for this is reported in studies examining chronic diseases such as cancer [41, 42]. Allowing oneself in such situations to trust others to make good decisions for oneself may be better than assuming all the responsibility alone.

There are limitations in this study, and the small number of participants is the most important. The present results must, therefore, be interpreted with caution. Because of this small number, we could not perform multiple regression analyses with the 2 groups separately. Finally, as the participants showed progression of dementia severity, one could potentially question the validity of the LoCB results at follow-up. However, as shown by Halse et al. [30], increases in dementia severity as indicated by the MMSE-NR affected the ability to complete the LoCB but not the reliability of the responses.

The major strengths of this study are the prospective design, the use of well-established assessment scales, and the fact that participants were diagnosed with dementia using standardized clinical criteria by 2 experts. Furthermore, the study examined clinically meaningful changes in the LoCB in addition to statistically significant changes. Statistical significance is vulnerable to both small and large sample sizes, and, arguably, can be less relevant for practitioners than reporting clinically meaningful results.

Conclusion

Most participants had a change in their locus of control, and those who became more external showed more signs of dementia disease progression. The findings may indicate that when the dementia progresses, shifting toward a greater trust in others or other external factors may allow for adaptive coping. However, the low number of participants prevents us from concluding based on the present data, and more research examining changes in locus of control in relation to dementia is needed.

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Statement of Ethics

The project has been accepted by the Regional Committee in Ethics in Medical Research in South-East Norway, REK South-East case No. 2013/1020. After being provided with written and oral information about the project, the participants were asked to give their written informed consent. Only participants with the capacity to give informed consent were included.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

All authors jointly designed the study and participated in the statistical considerations and discussions of the results. I.H. performed the statistical analyses and wrote the manuscript, with continual input from the coauthors. All authors approved the final version of the manuscript.

Data Availability Statement

The data that support the findings of this study are available upon request from the corresponding author.

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Errata

Navn på kandidat: Ingeborg Halse
Avhandlingstittel: Locus of Control among People with Dementia -
associations with dementia severity, cognitive function and depressive symptoms

Sidetall	Linje	Fotnote	Originaltekst	Type rettelse	Korrigert tekst
ix	28		...langsgående..	Korrektur	longitudinell
ix	29		..locus av kontrollorientering	Slette overflødig ord	..kontrollorientering..
ix	31		..locus av kontrollorientering	Slette overflødig ord	..kontrollorientering..
ix	30		langsgående	Korrektur	longitudinell
59	7		>	Korrektur	<
59	14		48	Korrektur	52