

From The Department of Clinical Sciences, Danderyd Hospital
Division of Rehabilitation Medicine
Karolinska Institutet, Stockholm, Sweden

**MANAGING TIME WITH DEMENTIA:
ASSESSMENT AND EARLY DETECTION
OF THE NEED FOR TIME-RELATED
INTERVENTIONS AND EXPERIENCES OF
TIME ASSISTIVE TECHNOLOGY**

Ann-Christine Persson



**Karolinska
Institutet**

Stockholm 2022

All previously published papers were reproduced with permission from the publisher.

Published by Karolinska Institutet.

Printed by Universitetservice US-AB, 2022

© Ann-Christine Persson, 2022

ISBN 978-91-8016-700-0

Cover illustration by Stefan Arousell

MANAGING TIME WITH DEMENTIA: ASSESSMENT AND EARLY DETECTION OF THE NEED FOR TIME-RELATED INTERVENTIONS AND DIFFERENT EXPERIENCES OF TIME ASSISTIVE TECHNOLOGY

THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

Ann-Christine Persson

The thesis will be defended in public at The Lecture Hall at Danderyd Hospital, on October 28, 2022, at 09.00

Principal Supervisor:

Associate Professor Monika Löfgren
Karolinska Institutet
Department of Clinical Sciences
Division of Rehabilitation Medicine

Co-supervisor(s):

Associate Professor Lena Dahlberg
Dalarna University
School of Health and Welfare,
Karolinska Institutet
Department of Neurobiology, Care Sciences and Society,
Aging Research Center

PhD Gunnel Janeslätt
Uppsala University
Department of Public Health and Caring Sciences
Center for Clinical Research Dalarna

Associate Professor Marika Möller
Karolinska Institutet
Department of Department of Clinical Sciences
Division of Rehabilitation Medicine

Opponent:

Professor Louise Nygård
Karolinska Institutet
Department of Neurobiology, Care Sciences and Society
Division of Occupational Therapy

Examination Board:

Professor Johan Sanmartin Berglund
Blekinge Institute of Technology
Department of Health

Professor Ingrid Hellström
Marie Cederschiöld University
Department of Health Care Sciences

Professor Ingeborg Nilsson
Umeå University
Department of Community Medicine and Rehabilitation
Division of Occupational Therapy

POPULAR SCIENCE SUMMARY OF THE THESIS

How we experience and manage our time is essential for our independence, participation, and well-being. Dementia often affects time-related functions and skills, and when persons with dementia need support in daily time management, it is usually provided by significant others, such as spouses, children, or friends.

Today, there is no medical cure for dementia, and thus there is an urgent need for additional solutions to support persons with dementia in managing their time in daily life for as long as possible. A common intervention for support in daily time management is time assistive technology (AT), which can be prescribed by occupational therapists. Examples of time AT are devices that display time and date or the remaining time of an activity. They can also give support in time management. Previous research has shown that persons with dementia can benefit from time AT. However, there is a lack of knowledge concerning occupational therapists' experiences of prescribing time AT and the assessment methods that form the basis of the prescription. There are instruments that assess the cognitive functions of time (time processing ability) and daily time management that have been developed for other patient groups, but they have not been tested for use in persons with dementia. Moreover, there is a need to further understand how time processing ability, daily time management, and dementia severity are related. Early interventions, such as the prescription of time AT, increases the possibility that the persons with dementia can learn how to use and implement a device. Thus, it is important to increase the knowledge on how to detect early time-related problems in persons with dementia. Considering this, it is also very important to increase the understanding of how both persons with dementia and significant others experience the person with dementia's daily time management and the support the significant other provides in that daily time management, including the use of time AT. Thus, the overall aim of this thesis is to explore persons with dementia's daily time management. More specifically, it focuses on assessments of daily time management and time processing ability and the prescription and use of time assistive technology from the perspectives of persons with dementia, significant others, and occupational therapists.

In study I, interviews with occupational therapists show that they have limited resources and access to instruments when assessing time-related problems and prescribing time AT for persons with dementia. This leads to high demands on participation and support from a significant other during intervention with time AT. However, occupational therapists' lack of time resulted in limited opportunities to conduct follow ups. Study II and III were based on an

objective measure and questionnaires completed by persons with dementia and significant others. In study II, three instruments that assess time processing ability and daily time management, KaTid-Senior, Time-S Senior, and Time-Proxy, were for the first time evaluated for persons with dementia. The results show that these instruments are appropriate for persons with dementia. Nevertheless, more challenging items should be added to KaTid-Senior to better target persons with mild symptoms of dementia. Furthermore, additional response alternatives for the self-ratings could further improve the instruments. In study III, the most important finding was the significant relationship between time processing ability and dementia severity, especially with respect to visuospatial functions. Finally, in study IV, interviews with persons with dementia and significant others showed that significant others start providing time management support at an early stage of dementia. The responsibility for daily time management is gradually transferred to the significant other, often imbedded in other kinds of support. Even though time AT can support orientation to time, significant others still need to place time in context. However, the person with dementia's participation and engagement in daily time management can be supported using time AT and calendars.

Taken together, support from significant others is important in all aspects of daily time management in persons with dementia. It is thus essential that significant others are well supported and trained so that they, in turn, can support persons with dementia in their use of time AT. Importantly, there is also a risk that persons with dementia living alone and without support from significant others will not receive such interventions as time AT or subsequent support in using the device. Specific forms of support need to be developed and directed at those individuals to ensure that they have fair opportunities to obtain and benefit from time AT.

When assessing time-related problems in persons with dementia, KaTid-Senior, Time-S Senior, and Time-Proxy can be used by health care professionals both clinically and in research. The instruments might increase the possibility of an early detection of time-related problems, in turn facilitating early, timely interventions to enhance daily time management for persons with dementia. Knowledge of the relationships between time processing ability, daily time management, and dementia severity can further increase the possibility of the early identification of time-related problems. However, for a thorough assessment of time-related problems in persons with dementia, objective measures should be used together with self-ratings and proxy-ratings.

The findings in study II and III can be used to promote methods to compensate for time-related problems with dementia. Since the responsibility for time management is transferred

to significant others at an early stage of dementia, time-related assessments and interventions should be provided at the onset to increase the possibility to maintain daily time management skills. Even when not used independently by persons with dementia, time AT and calendars can be used to involve the person with dementia in the time management or inform them about the time management carried out by others, by providing an overview of forthcoming and past activities. Thus, when supporting persons with dementia in time-related problems, collaboration and communication between persons with dementia, significant others and occupational therapists are essential at all stages, from the assessment of needs to the implementation of interventions such as assistive technology. Central to all this is the involvement of persons with dementia in their daily time management.

ABSTRACT

Background: Dementia is one of the most common global diseases. One frequently occurring consequence of dementia is time-related problems, and persons with dementia often need support from significant others to manage time in daily life. With no medical cure available, non-pharmacological interventions, such as the prescription of time assistive technology (AT), become important. Previous research has shown that persons with dementia can benefit from using AT. However, there is a knowledge gap regarding how occupational therapists assess the time processing ability and daily time management of persons with dementia and their experiences of prescribing time AT. Furthermore, while valid and reliable instruments assessing all three levels of time processing ability and daily time management are available for other patient groups, none have yet been evaluated for persons with dementia. Orientation to time and experience of time are known to be linked to dementia; however, expanded knowledge of associations between time processing ability, daily time management, and dementia severity could enhance the comprehension of time-related problems in dementia and further contribute to the identification of time-related problems and the need for time-related interventions. Considering this, it is also important to enhance the body of knowledge on how persons with dementia manage time in daily life and receive support from significant others in their daily time management, as well as examine the experience of time AT from the perspectives of both persons with dementia and significant others.

Aim: The overall aim of this thesis is to explore daily time management in persons with dementia, with a focus on assessments of daily time management and time processing ability, and the prescription and use of time AT from the perspectives of persons with dementia, significant others, and occupational therapists. The specific aims for the four studies are as follows:

- (I) To explore occupational therapists' experiences of assessing the need for and prescribing time AT for persons with dementia
- (II) To evaluate the psychometric properties of KaTid-Senior, Time-S Senior, and Time-Proxy when used with persons with dementia
- (III) To investigate the associations between time processing ability, daily time management, and dementia severity
- (IV) To explore the experiences of persons with dementia and significant others regarding daily time management and their perceptions on how time AT affects their everyday life

Methods: This thesis contains two studies where qualitative methods were applied (study I and IV) and two studies that used quantitative methods (study II and III). In study I, focus group interviews with occupational therapists ($n=17$, in total) who prescribe time AT for persons with dementia were analysed via qualitative content analysis. In study II and III, persons with dementia ($n = 53$) and their significant others ($n = 49$) participated. In study II, Rasch analyses were used to evaluate KaTid-Senior, Time-S Senior, and Time-Proxy regarding the following aspects: rating scale functioning; internal scale validity; person-response validity; unidimensionality; person-separation reliability; and internal consistency. In study III, bivariate analyses were used to investigate associations between time processing ability, daily time management and dementia severity. Linear regression models were used to further predict the role of the subtests in the Mini Mental State Examination (MMSE) for the time processing ability results. In study IV, semi-structured interviews with persons with dementia ($n=6$) and significant others ($n=9$) were carried out three months after obtaining the prescribed time AT. Qualitative content analysis was used for the analysis of interviews.

Results: The focus group interviews revealed that the prescription of time AT was a multiplex and time-consuming process that required support from significant others. Due to organisational limitations and time constraints, the occupational therapists were often impeded in following the national prescription guidelines. They also had to take responsibility for keeping up to date with existing time AT and commercial alternatives. The Rasch analyses demonstrated appropriate psychometric properties for KaTid-Senior, Time-S Senior, and Time-Proxy. However, in order to also target persons with mild symptoms of dementia, more challenging items should be added in KaTid-Senior. Moreover, the person-response validity parameters in Time-S Senior need to be remedied. The bivariate analyses showed significant correlations between time processing ability and dementia severity, where the strongest correlation occurred with visuospatial functions. Time processing ability also demonstrated a significant correlation to proxy-rated daily time management. Moreover, proxy-rated daily time management was significantly correlated with dementia severity and persons with dementia's self-ratings of daily time management. Finally, the interviews with persons with dementia and significant others found that the significant others provided support for daily time management at all stages of dementia. The responsibility for time management, the top level of time processing ability, was successively transferred to the significant others, and the support in time management was often integrated with other kinds of support. Time AT supported time orientation but did not enable independent time management for the persons with dementia; however, it could enhance involvement.

Conclusion: Support from significant others is important in all aspects of daily time management for persons with dementia. This also includes support from significant others during the whole prescription process and implementation of time AT. Thus, there is a risk that persons with dementia without support from significant others do not receive time AT interventions or subsequent support in using the device. Specific forms of support need to be developed directed at those individuals to ensure that they have fair opportunities to obtain and benefit from time AT.

When assessing time-related problems in dementia, KaTid-Senior, Time-S Senior, and Time-Proxy can validly and reliably be used to assess time processing ability and daily time management, both in clinical research and healthcare settings. The assessments can also increase the possibility of early detection of impaired time processing ability and daily time management problems, facilitating early, timely interventions to enhance occupational performance.

Knowledge of the association between time processing ability, dementia severity, and visuospatial functions can further increase the possibility of early identification of time processing ability impairments. However, for a thorough assessment of time-related problems in persons with dementia, objective measures should be used together with self-ratings and proxy-ratings. These findings can be used in clinical research and healthcare settings to promote methods to compensate for time-related problems in dementia.

Since support in time management is transferred to significant others at an early stage of dementia, time-related assessments and interventions should be provided at onset to increase the possibility to maintain daily time management skills. Even when not used independently by persons with dementia, time AT and calendars can be used to inform about time management carried out by others, which can increase agency and occupational participation for persons with dementia. As persons without support from significant others comprise an extra vulnerable group, it is important that society has adequate resources to also meet their need of support in daily time management.

LIST OF SCIENTIFIC PAPERS

- I. **Persson A-C**, Boman I-L, Dahlberg L, Janeslätt G, Möller MC, Löfgren, M. Lack of time and dependence on significant others: Occupational therapists' experiences of prescribing time assistive technology for persons with dementia. *Scand J Occup Ther.* 2020;27(8):614-24.
- II. **Persson A-C**, Möller MC, Dahlberg L, Löfgren M, Janeslätt G. Assessing time processing ability and daily time management in persons with dementia: Psychometric properties of three instruments. *Aust Occup Ther J.* 2022; n/a(n/a).
- III. **Persson A-C**, Janeslätt G, Dahlberg L, Löfgren M, Möller M. Associations between Time Processing Ability, Daily Time Management, and Dementia Severity. *Int J Environ Res Public Health.* 2022;19(7):3928.
- IV. **Persson A-C**, Dahlberg L, Janeslätt G, Möller MC, Löfgren M. Time assistive technology can support time orientation for persons with dementia, while significant others place time in context. Submitted.

CONTENTS

1	INTRODUCTION.....	1
2	LITERATURE REVIEW	3
2.1	Dementia.....	3
2.1.1	Prevalence and management.....	3
2.1.2	Dementia disorders and common symptoms	3
2.2	Theoretical frameworks.....	4
2.2.1	International Classification of Functioning, Disability and Health	4
2.2.2	Canadian Model of Occupational Performance and Engagement.....	5
2.3	Time concepts.....	6
2.3.1	Time processing ability and daily time management.....	6
2.4	Persons with dementia and time-related problems in daily life	8
2.5	Diagnostic assessments of dementia.....	9
2.5.1	Basic memory assessment	9
2.5.2	Extended memory assessment	10
2.6	Assessments of time processing ability and daily time management.....	10
2.7	Time-related interventions for persons with dementia.....	11
2.7.1	Occupational therapy approaches	11
2.7.2	Assistive technology	12
2.8	Provision of support for persons with dementia.....	13
2.8.1	Formal and informal caregiving	13
2.8.2	Supporting the use of assistive technology	14
2.9	Rationale for the thesis	14
3	RESEARCH AIMS	17
4	MATERIALS AND METHODS	19
4.1	Study context and designs	19
4.1.1	The Managing Time with Dementia project	19
4.1.2	The impact of COVID-19 on recruitment	20
4.1.3	The single randomised controlled trial	20
4.1.4	Inclusion criteria and participants.....	21
4.2	Measures	22
4.2.1	Semi-structured interview guides	22
4.2.2	KaTid-Senior®	22
4.2.3	Time-S Senior®	22
4.2.4	Time-Proxy®	23
4.2.5	Mini Mental State Examination (MMSE).....	23
4.3	Data collection.....	23
4.4	Data analyses	24
4.4.1	Qualitative analyses	24
4.4.2	Statistical analyses.....	25
4.5	Ethical considerations.....	27
4.5.1	Including persons with dementia in research	27

4.5.2	Ethical considerations regarding the data collection.....	28
5	RESULTS.....	29
5.1	Participants	29
5.2	Assessing the need for and prescription of time assistive technology for persons with dementia (Study I)	30
5.3	Psychometric properties of KaTid-Senior, Time-S Senior, and Time- Proxy when used with persons with dementia (Study II)	31
5.4	Associations between time processing ability, daily time management, and dementia severity (Study III)	32
5.5	Experiences of persons with dementia and significant others on daily time management and time assistive technology (Study IV).....	33
6	DISCUSSION	35
6.1	Main findings.....	35
6.2	Early detection of time-related problems in persons with dementia.....	35
6.3	The timing of interventions.....	37
6.4	The role of time assistive technology	38
6.5	The engagement of significant others	39
6.6	Methodological considerations	41
7	CONCLUSIONS AND IMPLICATIONS.....	43
8	FUTURE PERSPECTIVES.....	45
9	SVENSK SAMMANFATTNING	47
10	ACKNOWLEDGEMENTS.....	49
11	REFERENCES.....	51

LIST OF ABBREVIATIONS

AT	Assistive technology
ATMS	The Assessment of Time Management Skills
CMOP-E	The Canadian Model of Occupational Performance and Engagement
ICF	The International Classification of Functioning, Disability and Health
KaTid	The Kit for Time-Processing Ability
LGO	Let's Get Organized
MMSE	The Mini Mental State Examination
MMSE-SR	The Mini Mental State Examination, Swedish Revision
MoCA	The Montreal Cognitive Assessment
RUDAS	The Rowland Universal Dementia Assessment Scale
SPSS	Statistical Package for the Social Sciences
Time-S	The Time-Self-Rating
TOPS	The Time Organization and Participation Scale
WCPA-SE	The Swedish version of Weekly Calendar Planning Activity

1 INTRODUCTION

Daily occupations usually take place within a timeframe. The ability to manage time in daily life is of great importance for independence, participation in society, and well-being.

Dementia often affects the ability to perform desired daily occupations, which are often dependent on daily time management skills. When persons with dementia need help in daily time management, it is often significant others, such as partners, family members or friends, who provide the support. Subsequently, interventions targeting occupational performance affected by an impaired time processing ability should be given high priority among occupational therapists. As a compensatory intervention, occupational therapists can prescribe time assistive technology (AT) that might facilitate the daily time management and thus enable time-dependent occupations.

Although many symptoms of dementia, such as memory and reasoning impairments, behavioural changes, and inactivity can also affect occupational performance, the focus of this thesis will be on time processing ability and daily time management. The aim of the thesis is to add to the knowledge on how persons with mild to moderate dementia manage time and how time AT can support their daily living, as investigated from the perspectives of occupational therapists, persons with dementia and significant others.

2 LITERATURE REVIEW

2.1 DEMENTIA

2.1.1 Prevalence and management

Dementia is a global disease with approximately 50 million persons diagnosed with dementia worldwide, a quantity that is expected to increase to 82 million by 2030 and 153 million by 2050 (1). In Sweden, there are 130 000–150 000 persons living with dementia, and roughly estimated, 20 000–25 000 new cases of dementia are discovered each year. The incidence of dementia increases exponentially in older ages, and the number is expected to increase significantly the coming years when the large number of persons born in the 1940s achieve older age (2).

Dementia has physical, psychological, social, and economic impacts, not only for the persons with dementia, but also for their significant others and society. Currently, there is no medical cure for dementia. Existing medical treatments seem to have a limited effect and mainly target Alzheimer's disease, although there are several ongoing clinical trials that could offer further medical treatments for dementia. However, health care services can offer support and improve the situation for persons with dementia and their significant others through early diagnosis, which can advance timely and adequate management, thereby optimising physical health, cognition, activity, and well-being; promoting an understanding and handling of behaviour changes; and offering information and support to carers. Identifying and addressing the complex needs of persons with dementia entails organised efforts across public and commercial sectors at the local, regional and national level (1, 3).

2.1.2 Dementia disorders and common symptoms

Dementia, sometimes referred to as a 'major neurocognitive disorder', is not a specific disease but a syndrome of cognitive impairment that significantly affects the ability to perform daily occupations. Dementia affects individuals in various ways, depending on the cause of the disease, other health conditions and the person's previous cognitive functioning (1). Known risk factors are, for example, hypertension, obesity, and dyslipidaemia during midlife. Low education can also increase the risk of early cognitive decline (4).

Alzheimer's disease is the most frequent type of dementia in persons older than 65 years, even if persons older than 80 years often have additional causes of dementia, such as minor strokes or neurological diseases (3). The second most common form is vascular dementia. Other frequently occurring forms are dementia with Lewy bodies and frontotemporal dementia. Dementia may also be related to specific infections such as human immunodeficiency virus (HIV); harmful use of alcohol; or chronic traumatic encephalopathy. The distinctions between the different types of dementia are not always evident, and mixed forms often exist. Young-onset dementia occurs in persons under the age of 65 years and might be caused by any of the diseases mentioned above. Although symptoms vary across the different diseases, memory loss, disorientation, confrontational behaviour, language

problems, and physical problems occur to various degrees across all types of dementia, with an impact on daily occupations and autonomy (1-3).

The progress of dementia can be divided into three levels. In the early, or mild, stage the onset is gradual and the person with dementia can carry out their daily living with minor support (1, 2, 5). According to the World Alzheimer report 2021 (3), there are several early signs of dementia indicating an urgent need to seek medical care and receive an adequate assessment: memory loss; searching for words; errors with directions; significant changes in mood and behaviour, such as anxiety, social withdrawal and depression; problems performing familiar activities; language problems; disorientation of time and place; misplacing things; and problems understanding visual and spatial information. In the middle, or moderate, stage, the symptoms become more evident, and the person with dementia might forget names and recent events, becoming confused even in the home environment, having increasing communication problems, being of need of support with personal care, and experiencing behavioural changes, which includes wandering and repetitive questions (1, 2, 5). The late, or severe, stage of dementia is characterised by increasing dependence and inactivity. Symptoms such as unawareness of time and place, problems in recognising significant others, an increasing need for support in self-care activities, walking difficulties, and behavioural changes that may worsen, including aggression (1, 2, 5). However, for a dementia diagnosis, functional impairments need to have an impact on daily living. A predominant characteristic of dementia is a decreased ability to perform daily occupations (3).

2.2 THEORETICAL FRAMEWORKS

The International Classification of Functioning, Disability and Health (ICF) is an internationally used classification system that facilitates communication across different professionals by proposing a standardised language and structure for describing health and health-related conditions (2, 6). In this thesis, ICF is mainly used for describing time-related concepts of body function, and activity and participation levels. The Canadian Model of Occupational Performance and Engagement (CMOP-E) (7) focuses on the enablement of occupation through a client-centred approach, and in this thesis the model is used to provide a deeper understanding of the role of the dynamic interaction between person, occupation and engagement and its impact on occupational performance and occupational engagement related to daily time management.

2.2.1 International Classification of Functioning, Disability and Health

The ICF consists of two parts. The first part, *Functioning and disability*, includes (a) body functions and body structures, and (b) activities and participation. *Body functions* (a) are the physiological functions of body systems (including psychological functions, e.g., orientation to time) while *body structures* are anatomical parts of the body such as organs, limbs, and their components. Impairments are problems in body function or structure as a result of significant deviation or loss. *Activities and Participation* (b) describes the execution of a task

or action when participating in an activity, for example, managing one's time. Activity limitations are individual difficulties in executing activities, whereas participation restrictions are problems an individual may experience with involvement in life situations.

The second part of ICF, *Contextual factors*, includes (a) environmental factors and (b) personal factors. *Environmental factors* (a) comprise the physical, social, and attitudinal environment in which people live and work, including products and technology; natural environment and human-made changes to the environment; support and relationships; attitudes; services; systems; and policies. The environmental factors are described as facilitators or barriers. *Personal factors* (b) consist of personal characteristics that do not belong to health status but are not classified in the ICF due to the large associated social and cultural variations.

2.2.2 Canadian Model of Occupational Performance and Engagement

The CMOP-E, illustrated in Figure 1, describes occupational performance and occupational engagement as the effect of a dynamic, interwoven interaction between the person, the occupation, and the environment, where spirituality is an over-arching concept for the person's "self", formed and expressed through occupations. *The person* encompasses three performance components: physical, affective, and cognitive. The person exists in a unique *environmental* context (physical, social, cultural, and institutional), which implies different occupational circumstances. *Occupation*, classified in the three categories (self-care, productivity, and leisure), links the person and the environment by suggesting that the individual acts in the environment through occupation. The CMOP-E distinguishes between and defines occupations, activities, and tasks like this: "Performance of a task includes a set of purposeful movements and mental processes, for example, cutting vegetables for dinner. An activity is defined as a wider concept that includes performing a set of combined tasks, for example, cooking. Occupation would then be an even greater concept that includes a set of activities, for example, making dinner for your family. Occupation could include anything that people do in their everyday lives such as self-care, leisure, and productivity" (7). Occupational performance refers to the active participation in occupation while occupational engagement refers to broader emotional and cognitive factors associated with occupation. Occupational participation is defined as "involvement in a life situation through occupation", that is, when the performance has personal significance and is part of a social role (7, 8). In contrast to the concept participation in ICF, occupational participation in CMOP-E may also be a result of, or a context for, occupational performance (7).

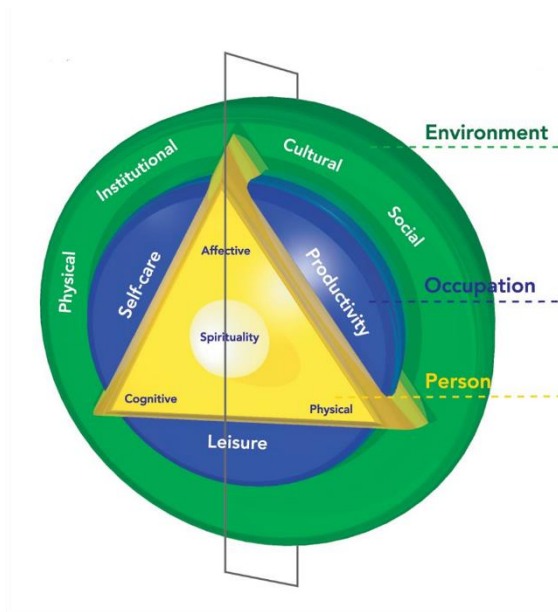


Figure 1. The Canadian Model of Occupational Performance and Engagement (9).

In this thesis, the focus will be on the cognitive performance component of time processing ability in older adults with dementia and how this component relates to and affects occupational performance and engagement in situations affected by daily time management.

2.3 TIME CONCEPTS

2.3.1 Time processing ability and daily time management

In the ICF (10), concepts delineating body functions related to time are comprised within the Mental functions (Table 1), whereas *Experience of time* is the subjective experiences related to the length and passage of time (10-12). Difficulties in estimating the time duration might lead to sudden experiences of time shortage or a surplus of time (13, 14). Moreover, research has shown that impaired experience of time can be linked to a sense of social exclusion and the meaning of life (15). *Orientation to time* includes awareness of clock time, today's date, month and year (10), and understanding how to use clocks, calendars or other devices is necessary for keeping track of time (11, 16). *Time management*, on the other hand, is one of the higher-level cognitive functions and covers the organisation of events in chronological order with enough time allocated (10, 17, 18), which requires the ability to know when to do an activity and for how long (10). Importantly, effective time management is also involved in the meta-cognitive processing of several executive functions, such organising and planning (16), and knowing when to stop ongoing tasks and perform the intended one (18, 19). Time management has a positive relation to experienced control of time and health, and a negative relation to stress (19).

Together, the experience of time, the orientation to time and time management form one construct, *Time processing ability*, with increasing levels of complexity. Both the experience of time- and orientation to time functions are required for the ability to manage time (11, 12).

The time-based prospective memory, that is, the ability to remember to carry out something at a certain time in the future, is also important for the planning and organising of daily occupations (20-22).

Research has shown that the time processing ability is connected to the *daily time management*, but whereas the time processing ability refers to the knowledge and cognitive capacity that provides the fundamentals for daily time management, daily time management represents how time is managed in daily life (23). In the ICF, daily time management is part of activity and participation within *General tasks and demands* (Table 1) (10, 24). The codes *Managing one's own activity level*, *Adapting to changes in daily routine*, and *Managing one's time* include time-related skills that are required to “carry out simple or complex and coordinated actions in order to plan, manage and complete the requirements of day-to-day procedures or duties, such as budgeting time and making plans for separate activities throughout the day” (24).

Table 1. Time concepts in the International Classification of Functioning, Disability and Health.

Component	Code	Description
Body functions	b1 Mental functions	
	<i>b1802 Experience of time</i>	Specific mental functions of the subjective experiences related to the length and passage of time
	<i>b1140 Orientation to time</i>	Mental functions that produce awareness of time of the day, day of the week, date, month, and year
	<i>b1642 Time management</i>	Mental functions of ordering events in chronological sequence, allocating amounts of time to events and activities
Activities and participation	d2 General tasks and demands	
	<i>d2303 Managing one's own activity level</i>	Carrying out actions and behaviour to arrange the requirements in energy and time day-to-day procedures or duties
	<i>d2304 Adapting to changes in daily routine</i>	Interrupting and shifting tasks and actions in response to new situational and/or time requirements or making a transition from a usual pattern of activities to a new set of activities as a means of fulfilling daily tasks.
	<i>d2305 Managing one's time</i>	Managing the time required to complete usual or specific activities, such as preparing to depart from the home, taking medications, and accessing assistive technology and supports.

Daily time management can also be placed in a social context. As a part of social structures and societies, time aspects affect the individual's relation to occupational performance and occupational participation, for example, if time is related to clock-time or events (25). In addition, the daily time management is influenced by the occupational environment by, for instance, clocks, daylight, or other persons (26, 27).

Time is usually associated with the clock, but the concept *temporality* primarily involves subjective, perceived time, with regard to the relation among past, present and future. (28).

2.4 PERSONS WITH DEMENTIA AND TIME-RELATED PROBLEMS IN DAILY LIFE

Since early-stage time processing ability impairments are common in persons with dementia (29-31), there is an increased risk of time-related problems in daily life. Depending on previous habits and routines; which activities the person wants, or needs, to perform; and the demands the specific environment places on the individual, the impact on independence and well-being might vary across individuals.

In the literature, there are several examples of time-related problems in dementia and their impact on daily occupations. Missed appointments, incorrect notes in calendars, insecurity about when something will happen, uncertainty about whether it is time to get dressed or if it is in the middle of the night, or how to dress if unsure of season, are examples of how time orientation impairments affect daily life (31). Moreover, impaired orientation to time and place might lead to unsafe situations, for example, if the person with dementia leaves the home during night-time (14).

Impairments regarding the experience of time might cause problems for persons with dementia in terms of a sudden lack of time, late or early arrivals at appointments, or uncertainty with respect to how much time has passed when waiting. These kinds of problems often create feelings of anxiety and stress (13).

Persons with dementia can experience problems with time management in the form of difficulty knowing how many activities they can perform during a certain time interval, the time required to complete different activities in a time-specific order, or how to perform activities at the right time in relation to each other (2, 17, 18). Reduced work pace and time-consuming problems related to dementia might result in more time than usual being required for different activities, which in turn complicates time estimation when planning for daily activities (32). Examples of common time problems affecting daily routines for persons with dementia are eating regularly and paying bills on time (33). It might also be necessary to implement new routines for certain tasks, such as taking medication regularly, which can be difficult when experiencing problems with time management (33, 34).

In the early stages of the disease, persons with dementia often use strategies in their daily time management, for example, checking today's date on newspapers or in smartphones, making notes or marking today's date in calendars, or asking others for help. It is also common to compensate for these shortcomings by making sure there is plenty of time at one's disposal to avoid a sudden time shortage. However, previous strategies might begin to no longer work as intended. For instance, the person with dementia might not remember when the marking in the calendar was made, calendars and smart phones could be mislaid or become difficult to handle, and constant questions could be perceived as tiresome by others (13, 35).

Effective daily time management is dependent on the ability to use environmental support, such as clocks, calendars, and smart phones, which often becomes more and more difficult

when the dementia progresses (36). Person with dementia might also be in environments ruled by the clock, for example, day care centres, hospitals, or subject to visits by home care staff under strict time pressures, which increases the demands on adequate time management (37).

Consequently, time processing ability impairments and daily time management problems are often present in persons undergoing memory assessments (2).

2.5 DIAGNOSTIC ASSESSMENTS OF DEMENTIA

2.5.1 Basic memory assessment

An older person with suspected dementia usually undergoes a basic dementia assessment in primary health care. The basic assessment aims to establish if the person has a cognitive impairment, whether it is caused by dementia or other diagnoses, and if so, which type, stage, disabilities and implications of the dementia persist, as well as which interventions can minimise or compensate for them (2, 3). A dementia diagnosis is based on anamnesis, interviews with significant others, assessments of physical and mental conditions, cognitive tests, and assessment of activities in daily living. Thus, a multi-professional team-based approach is necessary to gain a comprehensive picture (2).

In interviews with significant others, it is often possible to receive information regarding the person with dementia's previous illnesses and drug treatment. Furthermore, the significant other has frequently observed changes in the person with dementia over a long period, both in terms of cognitive impairments and how those impairments affect daily occupations. The assessment of the physical condition usually includes blood tests and brain imaging with computed tomography or magnetic resonance imaging (3). For cognitive testing, the Swedish National Board of Health and Welfare (2) recommends the Mini Mental State Examination, Swedish Revision (MMSE-SR) (38), together with a clock test, in addition to the Montreal Cognitive Assessment (MoCA) (39). For target groups with a native language other than Swedish, a non-Swedish cultural background or a low level of education, the Rowland Universal Dementia Assessment Scale (RUDAS) is used (40). MMSE-SR is an instrument for cognitive assessments of spatial and temporal orientation, attention, memory, language, and visuospatial ability. The clock test measures, among other things, construction, and executive functioning, and can be used as a complement to MMSE-SR in the basic dementia investigation. MoCA evaluates attention and concentration, executive functions, memory, linguistic ability, visual constructive abilities, abstract thinking, numeracy and time and space orientation. RUDAS measures cognitive functions such as memory, visuospatial orientation, ability to perform intentional movements and actions (practice), visual construction, judgement, and language.

When assessing activities in daily living, previous functional level and comorbidity are also considered. Interviews with both the person with dementia and the significant others, as well as functional assessments and observations of the person with dementia performing relevant tasks and activities, for example, making a meal, or handling everyday technology, are also

included. These results provide relevant information in relation to the cognitive test results and are part of the estimation of the degree of dementia and the basis for the planning of further interventions (2, 3).

2.5.2 Extended memory assessment

Referral to a memory clinic for an extended memory assessment may be required. An extended investigation is used to establish a diagnosis in cases where a basic dementia examination has not been sufficient or when there are complicating circumstances. For example, it is common for a younger person with suspected dementia only to undergo an extended dementia investigation. The extended memory assessment includes structural imaging of the brain with magnetic resonance imaging and a lumbar puncture for analysis of biomarkers. In some cases, the measurement of glucose metabolism and single photon emission computed tomography to measure dopamine transport and blood flow in the brain is also conducted (2).

Neuropsychological tests covering several cognitive domains such as episodic memory, executive functions, attention/working memory, visuospatial/visuoconstructive functions and language (41) are also included in the extended memory assessment, as well as measures of occupational performance in activities that are vital for independent living, for example, dressing, bathing and eating, and instrumental activities such as managing finances, managing medication, cooking or other household routines (3, 42).

Although both basic and extended memory assessments include measures with questions of orientation to time (38, 39), there is a lack of instruments assessing all three levels of time processing ability (orientation to time, experience of time and time management) and daily time management targeting persons with dementia.

2.6 ASSESSMENTS OF TIME PROCESSING ABILITY AND DAILY TIME MANAGEMENT

The occupational performance for persons with dementia can be evaluated through various methods, such as performance-based assessments and/or self- and proxy-reported measures (3, 42). Performance-based assessments provide a more objective measurement, although time-consuming application and predetermined activities are possible limitations. Self-rated questionnaires are easy to administer and enable the assessment of a broad variety of activities, but it may be problematic if the awareness of one's own abilities is impaired due to disease progression. To determine the most suitable measures to use in clinical practice, attention should be paid to the purpose and targeting of the measures. The psychometric properties of the measures should also be considered (3).

Even if there is a lack of instruments measuring all three levels of time processing ability and daily time management evaluated for persons with dementia, such instruments are validated for other target groups. The Kit for Time-Processing Ability (KaTid[®]) is an objective, performance-based test that operationalises the ICF concepts' experience of time, orientation

to time, and time management. It was developed and evaluated for children and youth with and without neurodevelopmental disorders (11, 12, 16, 43). Another objective instrument, the Swedish version of the Weekly Calendar Planning Activity (WCPA-SE), encompasses time management measuring the ability to carry out cognitive planning tasks including organisation, planning, and use of strategies. The WCPA-SE is intended from twelve years old to adulthood for those who experience subtle difficulties due to impaired executive functions (44, 45). Regarding daily time management, the Time-Self-Rating (Time-S[®]) and Time-Proxy[®] have been developed and evaluated for self-ratings and proxy-ratings of daily time management in children (12, 23, 46). In comparison, the Time-S[®] Adult version has been evaluated for adults (46). The Time-S aims at guiding interventions with time AT (46). The Assessment of Time Management Skills (ATMS) is a self-rating questionnaire on how a person utilises tools and strategies for time use, and self-awareness regarding time management (18). ATMS-S is validated in Swedish and contains three subscales measuring time management skills, organisation and planning, as well as the regulation of emotions (47). The Time Organization and Participation Scale (TOPS) is another self-rating questionnaire for the estimation of time allocation to daily activities, time planning, and feelings of failure connected to time management (47, 48). The instrument has been translated into Swedish but has not yet been evaluated. None of the instruments mentioned have been evaluated for persons with dementia.

2.7 TIME-RELATED INTERVENTIONS FOR PERSONS WITH DEMENTIA

There is still no pharmacological cure for dementia. Risk reduction and prevention of dementia through lifestyle-based interventions (4, 49) and cognitive rehabilitation (50-52) are therefore important research areas and intervention approaches for persons with dementia.

2.7.1 Occupational therapy approaches

The aim of occupational therapy interventions is to promote occupational performance, prevent occupational performance problems, and/or resolve occupational performance problems by different approaches, such as training, adaptation, compensation, prevention, consultation, and/or education (53, 54).

“Let’s Get Organized” (LGO) is an example of group intervention training time management skills (55). The Swedish version LGO-S has been evaluated for persons with mental or neurodevelopmental disorders with promising results regarding improved time management, organisation and planning, emotional regulation, executive functioning, and satisfaction with daily occupations (45, 56). Another example is an occupational time-use intervention, Action Over Inertia, that has been evaluated for persons with mental illness, suggesting evidence of efficacy and clinical utility (57, 58).

However, for persons with dementia, compensatory interventions are important in order to maintain desired occupations for as long as possible. A systematic review divided occurring compensatory intervention strategies into four parts: home environmental modifications, task adaptations or task simplifications, use of sensory cues, and promotion of daily routines,

often combined in multifaceted interventions targeting both persons with dementia and significant others (59). As an example of a compensatory intervention, occupational therapists can use technological solutions to facilitate daily time management and thus promote time-dependent occupations for persons with dementia. This also entails the consultation and education of caregivers and significant others, which are also important occupational therapy interventions to support the daily living of persons with dementia (60).

2.7.2 Assistive technology

Technological interventions aiming at compensating for existing cognitive impairments is a highly current topic in research and clinical contexts. A recent review about dementia and support by technology found that the most commonly cognitive functions targeted by such interventions were time and place orientation, sequencing complex actions, memory, and communication (52). Another systematic review of interventions for persons with dementia showed that recent studies increasingly reported on interventions that include wearable and environmental digital AT, usually including multiple functions such as prompting and reminding the persons with dementia of activities; monitoring the persons with dementia at home with environmental sensors; and supporting safety outdoors. However, the authors concluded that technologies need to be further developed and adapted in order to be dementia-friendly (61). This also applies to everyday technologies, whose functions can be a support in daily occupations as well as a hindrance. Today, the society depends on various technical functions from smart phones, computers, remote controls and household electronics to automatic telephone services, cash machines and electronic purchases of products or tickets. Two qualitative studies exploring the experiences of persons with dementia using everyday technology found that it could provide daily support in different ways (62), but that there were difficulties related to a lack of knowledge about the technology and problems in following instructions for the devices. This applied when using both familiar and new technology (63). Moreover, research has shown that it can be challenging for persons with cognitive impairments and dementia to handle everyday technologies not only in the home environment but also in public spaces (64, 65).

Although technological development entails many commercial alternatives for technology support, occupational therapists working with persons with dementia often prescribe specifically developed AT. AT is part of a global approach to non-drug interventions in dementia care (66) and could be defined as “any device or system aimed at maintaining or improving an individual’s function and participation” (67). AT for cognition aims at supporting daily occupations by compensating for cognitive impairments, for example, memory impairments or time processing ability impairments. Complex attention, executive reasoning, prospective memory and self-monitoring for the enhancement or inhibition of specific behaviour are examples of higher cognitive functions that could also be targeted (68, 69). In this thesis, the term time AT will be used for the types of AT for cognition that aim at supporting daily time management by compensating for impairments in orientation to time, experience of time, and time management. For example, an easy-to-use device displaying

today's date can support orientation to time, while an easy-to-use device showing how much time of an activity has been spent can compensate for the experience of time. More advanced time AT, such as electronic calendars, can support time management and provide reminders for when activities should be performed. According to the Swedish National Board of Health and Welfare's national guidelines, individually adapted AT for cognition should be offered to persons with dementia (2).

Previous studies have found that AT has the potential to promote independence, well-being, safety, and quality of life for persons with dementia (33, 63, 70-73). Persons with dementia can also benefit from time AT (33, 36, 64, 74, 75), especially if the AT is provided in an early phase (76) and if the implementation of the device is supported by professionals or significant others (77, 78). The use of AT supporting orientation to time could, for example, lead to increased independence, less anxiety, and fewer questions about time of the day (14). Time reminders have also proved to be effective in supporting persons with cognitive impairments (69, 79). However, an intervention study where persons with dementia received training in using AT (a clock showing day and date, post-it notes, pen and notepad, and a calendar) found that the persons with dementia did not improve or maintain independence in daily occupations (80). A qualitative study exploring the experiences of persons with dementia living alone when using time AT and spontaneous time strategies also found limited beneficial results, especially if there was a lack of motivation and insight (13). Another qualitative study found that AT, including time AT, could positively affect the occupational performance of persons with Alzheimer's disease if the person with dementia was motivated to use the device and if it was possible to receive support from another person (36).

2.8 PROVISION OF SUPPORT FOR PERSONS WITH DEMENTIA

2.8.1 Formal and informal caregiving

In Sweden, home care is provided via primary health care and home help in regions and municipalities. Home help and care homes are the two main forms of social care for older persons. Home help services aim to support older adults in daily life and to enable ageing in place (81, 82). Aging in place is a guiding principle in Swedish care for older persons, implying that older persons should be able to remain in their homes as long as possible with support from formal care instead of moving to care homes (83). In more than eight out of ten municipalities, there are also day care centres with activities targeted at persons with dementia (84). Formal care for older persons is based on individual needs and is formally assessed (83).

Whereas most persons with dementia in Sweden live in ordinary housing, half of them do not obtain home care services (85, 86). However, persons with cognitive impairment receive more informal care (that is, home care provided by family and friends) than persons without cognitive impairment (5, 86). Persons with dementia receiving formal care often receive informal care as well (87). Due to considerable cutbacks in the Swedish provision of care for older adults over the last decades, more responsibility for care has been transferred to significant others (81, 88). In this thesis, the term significant others will be used for partners, family members or friends that support the person with dementia in their home environment. When significant others support persons with dementia in daily occupations, it can lead to

both positive and negative outcomes (89-92). Feelings of accomplishment and meaning concerning the caregiver role and the sustaining of important relationships are examples of positive outcomes (89, 93, 94). On the other hand, caring for persons with dementia might affect the significant others' own occupational balance due to continuous changes, adjustments and a disruption of roles and routines (91). There is a risk of a negative impact on work, health and family concerns that might lead to health problems, financial challenges, and social isolation for significant others (95-97). Spouse caregivers have also been identified as a vulnerable group as they are often older than other informal caregivers and usually provide more comprehensive care (98). On the other hand, it also poses a risk to persons with dementia, whereas not all relationships are sound and supportive (135, 136).

2.8.2 Supporting the use of assistive technology

Consequently, it is often significant others that provide the support when persons with dementia have problems in daily time management (14, 70). Moreover, significant others are vital in facilitating the implementation of AT into the daily routines of the person with dementia by providing guidance and reminders (36, 99-102). Significant others must often support even easy-to-use technologies by routinely reminding them to look at the device instead of just answering on what time it is (99).

However, qualitative research suggests that significant others are generally positive towards using AT as support for persons with dementia (103, 104). A systematic review (104) found that AT in general, when enabling independence and participations in meaningful occupations for the persons with dementia, also had a positive effect on the significant others. Whether the person with dementia used the AT independently or with support, the significant others considered the AT as reducing worries and improving well-being. However, the same study also reported findings suggesting that AT could increase the significant others' burden and stress. Adapting and maintaining the use of AT for persons with dementia often involves learning, problem-solving, and seeking support resources (89). Significant others may acquire problems due to poor comprehension, poor design of the AT or a lack of support from occupational therapists (104). Another issue might be that significant others who assist persons with dementia in using AT do this from their own viewpoint (36), and that their needs, wishes, attitudes, knowledge, expectations, and experiences might differ from those of the person with dementia (76, 101, 102, 105).

According to the Swedish National Board of Health and Welfare's guidelines for dementia, education for significant others should be offered by formal caregivers as there is scientific support for the positive effects of education on perceived burden and depression (84). Widehammar et al. (106) recommend education for significant others in supporting the daily use of AT. Thus, it is important that occupational therapy interventions are directed towards both persons with dementia and significant others (107).

2.9 RATIONALE FOR THE THESIS

Persons with dementia often experience time-related problems in daily life. When they need support in time-dependent occupations, it is usually significant others that give the support. A common, compensatory intervention provided by occupational therapists is time AT prescription. There is, however, a lack of knowledge on how occupational therapists assess

time processing ability and daily time management for persons with dementia, and on the occupational therapists' experiences of prescribing time AT. Furthermore, valid and reliable instruments assessing all three levels of time processing ability and daily time management for persons with dementia is lacking. Orientation to time and experience of time are known to be associated with dementia; however, increased knowledge of associations between time processing ability, daily time management, and dementia severity could enhance the understanding of time-related problems in relation to dementia, and further contribute to identification of time-related problems, thereby facilitating the timely introduction of interventions, such as time AT. There are a few previous qualitative studies on the experiences of time AT by persons with dementia, (13, 14, 36); nevertheless, the perspectives of significant others are dominant (76). However, the importance of also including persons with dementia in research has been emphasised (36, 108). Thus, it is important to further explore how persons with dementia manage time in daily life, support from significant others in daily time management, and the experience of time AT, from the perspectives of both persons with dementia and significant others.

3 RESEARCH AIMS

The general aim of this thesis was to explore daily time management in persons with dementia, with focus on assessments of daily time management and time processing ability and the prescription and use of time AT from the perspectives of persons with dementia, significant others, and occupational therapists.

The specific aims for the studies were as follows:

- (I) To explore occupational therapists' experiences of assessing the need for and prescribing time AT for persons with dementia
- (II) To evaluate the psychometric properties of KaTid-Senior, Time-S Senior, and Time-Proxy when used with persons with dementia
- (III) To investigate the associations between time processing ability, daily time management, and dementia severity
- (IV) To explore the experiences of persons with dementia and significant others regarding daily time management and their perceptions on how time AT affects their everyday life

4 MATERIALS AND METHODS

4.1 STUDY CONTEXT AND DESIGNS

This thesis is based on four studies that use qualitative and quantitative methods to investigate how persons with mild to moderate dementia manage time and how time AT can support their daily living, investigated from the perspectives of occupational therapists, persons with dementia and significant others. The two different research approaches complement each other by broadness and depth, description and interpretation of statistics and exploration of areas with limited knowledge. An overview of study aims, study designs, participants and methods in the PhD project is provided in Table 2.

Table 2. Summary of the aim, design, number of participants and methods in the four studies.

	Study I	Study II	Study III	Study IV
Aim	To explore occupational therapists' experiences of assessing the need for and prescribing time assistive technology for persons with dementia	To evaluate the psychometric properties of KaTid-Senior, Time-S Senior, and Time-Proxy when used with persons with dementia	To investigate the associations between time processing ability, daily time management, and the dementia severity	To explore the experiences of persons with dementia and significant others regarding daily time management and their perceptions on how time assistive technology affects their everyday life
Design	Qualitative, descriptive	Cross-sectional	Cross-sectional	Qualitative, descriptive, emergent
Participants	Occupational therapists (n=17)	Persons with dementia (n=53) Significant others (n=49)	Persons with dementia (n=53) Significant others (n=49) The same cohort as in study II	Persons with dementia (n=6) Significant others (n=9)
Data collection	4 focus group interviews with 3-6 participants each Interview guide with open questions	<u>Persons with dementia:</u> Demographics (questionnaire) MMSE (objective measure) KaTid-Senior (objective measure) Time-S Senior (self-rating questionnaire) <u>Significant others:</u> Demographics (questionnaire) Time-Proxy (proxy-rating questionnaire)	<u>Persons with dementia:</u> Demographics (questionnaire) MMSE (objective measure) KaTid-Senior (objective measure) Time-S Senior (self-rating questionnaire) <u>Significant others:</u> Demographics (questionnaire) Time-Proxy (proxy-rating questionnaire)	Semi-structured interviews (face-to-face, via video call or telephone) Interview guides with open questions
Data analysis	Content analysis	Descriptive analysis Rasch analysis Cronbach's α	Descriptive analysis Spearman's Rho Linear regression analysis	Content analysis

4.1.1 The Managing Time with Dementia project

The four studies were conducted within a main project, Managing Time with Dementia, which is a FORTE-funded international research project based on collaboration between Sweden, India, and Japan. The aim of the project is to a) investigate and model the relationship between the use of time AT by older persons with mild or moderate dementia, their daily time management, and their well-being, and to b) devise strategies for the acceptance and use of such products by older persons with dementia and their significant others (Clinicaltrials.gov, reg no. NCT03677284). In the Swedish part of the project, thirteen registered occupational therapists on eleven memory clinics in eleven different regions

recruited the participants and conducted the baseline data collection for the quantitative studies.

4.1.2 The impact of COVID-19 on recruitment

The Managing Time with Dementia project started in 2018 and was initially expected to last for three years. However, COVID-19 restrictions from March 2020 until the beginning of 2022 had a significant impact on the possibility to recruit participants. Several of the memory clinics were periodically closed. The health care professionals were largely decimated, and some of the occupational therapists were temporally relocated to other wards. When the memory clinics opened in 2021, many patients cancelled their visits. External visits, including follow-up assessments by the present PhD student and research assistants, were not permitted. Despite these conditions, some recruitment and data collection were possible to carry out during the pandemic, enabling the four studies introduced above. However, the data collection for a single randomised controlled study that was previously planned to be a part of this thesis could not be carried out as intended. To be able to recruit enough participants, the data collection period had to be extended until end of May 2022, with follow-up assessments until end of August 2022. Thus, the study will not be a part of this thesis, although some information about the study will be included in the next section.

4.1.3 The single randomised controlled trial

The aim of this study, to be finalised outside the framework of this thesis, was to investigate to what extent time AT can support persons with mild to moderate dementia to achieve their activity goals regarding the performance of daily activities and satisfaction with the performance. The Canadian Occupational Performance Measure (COPM) (109) was used to identify one to three activities in which the participants should use prescribed time AT as support in daily time management. The COPM is a client-centred measure to detect change in the self-perception of occupational performance over time. COPM was used at baseline before randomisation and intervention and after three months for both intervention and control group (Figure 2). All participants received a brochure developed for the study, including common difficulties to manage time due to dementia, e.g., how long it takes to carry out familiar activities or to pay a bill in time. The brochure also provided examples of strategies to handle the problems. In addition, the intervention group received an individually prescribed time AT as support for daily time management, including instructions and training in using the device. The control group that only received the brochure was offered individually prescribed time AT three months after inclusion.

A power calculation based on the primary outcome measure in the study (COPM) showed that 74 participants should be included. In April 2021, preliminary analyses were performed including assessments at baseline and after three months for 35 participants ($n = 16$ in the intervention group and $n = 19$ in the control group). The preliminary results indicated that the intervention group was supported by the time AT in carrying out the specified time-related activities; after three months the intervention group rated the performance higher than that of

the control group without time AT. However, more participants had to be included for reliable analyses, and the data collection for the RCT study lasted until end of August 2022.

4.1.4 Inclusion criteria and participants

In study I, participants were occupational therapists ($n=17$) with more than two years' experience of prescribing time AT for persons with dementia. The participants worked in memory clinics or primary care in five different regions encompassing urban and rural areas in Sweden. During 2018-2019 they were recruited via professional networks of occupational therapists working with persons with dementia. The participants in study II and III, persons with dementia older than 60 years and who had daily time management problems identified by occupational therapists through memory assessments ($n=53$), along with their significant others ($n=49$), are the same cohort recruited within the main project between 2018-2021. For study III, a power analysis with the purpose to use a multiple regression analysis including three independent variables and an assumption of an adjusted R square of 20% showed that a group of at least 36 persons is needed in the study to have 80% power and a 5% significance level. A subsample of persons with dementia ($n=6$) and significant others ($n=9$) participating in study II and III were recruited by the PhD student for study IV between 2019-2021. An overview of the inclusion criteria for the studies is provided in Table 3.

Table 3. Inclusion criteria in the four studies.

Inclusion criteria	Study I	Study II	Study III	Study IV
Occupational therapists:				
More than two years' experience of prescribing time AT for persons with dementia	x			
Persons with dementia:				
Diagnosed dementia		x	x	x
Daily time management problems identified by occupational therapists in memory assessments		x	x	x
Age ≥ 60 years		x	x	x
No mental illness unrelated to dementia		x	x	x
Mini-Mental State Examination (MMSE) results ≥ 11		x	x	x
Receipt of time AT prescribed for at least three months ago				x
Ability to communicate in Swedish		x	x	x
Significant others:				
Knowledge about the person with dementia's daily life and daily time management		x	x	x
Knowledge about the person with dementia's usage of time AT for at least three months				x
Ability to communicate in Swedish		x	x	x

4.2 MEASURES

4.2.1 Semi-structured interview guides

A semi-structured interview guide with open-ended questions was used in the focus group interviews with occupational therapists in study I, covering the following topics: assessment and selection of time AT; introduction, education, and follow-ups of time AT; the roles of significant others; facilitating and hindering factors for using time AT; information and education; and organisational factors.

In study IV, separate semi-structured interview guides with open-ended questions for persons with dementia and significant others were used to be able to direct questions to each of them and to use questions that were easy to understand for the person with dementia. Follow-up questions on the informants' answers were also prepared for further exploration. However, both interview guides included the same topics: daily time management problems; daily time management strategies; prescription; implementation and follow-ups of time AT; experiences of using/supporting the use of time AT; and the impact of time AT use on everyday life. A pilot interview with a significant other was conducted to evaluate and revise an early version of the interview guide.

4.2.2 KaTid-Senior®

KaTid® is an instrument measuring three levels of time processing ability: experience of time, orientation to time and time management. KaTid is previously validated for patient groups with cognitive and physical impairments and can also be used when evaluating interventions (11, 12, 17, 43, 110). The version used in study II and III, KaTid-Senior, was based on KaTid-Youth which contains 59 items and has been evaluated with Rasch analyses showing good psychometric properties (11). According to the principal component analysis (PCA), variance explained by measures was 81.5%; unexpected variance in first contrast was 1.5%, providing support for validity and unidimensionality. Person separation was 2.11 and reliability 0.82. KaTid-Senior included 29 items estimated to fit the ability of persons with mild to moderate dementia. Twenty-five of the items are scored Can (1), or Cannot (0), and four items are scored Can (2), On the way (1), and Cannot (0). KaTid was chosen for study II and III as it encompasses all three levels of time processing ability in one instrument.

4.2.3 Time-S Senior®

Time-S® is a self-rating instrument of daily time management that has been evaluated for adults with and without mental health problems (46). The principal component analysis (PCA) of 68.9% and the unexplained variance in first contrast of 3% indicated that Time-S measures one construct: daily time management. The person separation was 2.75 and reliability 0.88. In study II and III, an adapted version of Time-S for persons with mild to moderate dementia was used. Items that were not relevant for older adults with dementia, e.g., items specific to still working adults, were exchanged to new relevant items. This version is called Time-S Senior. Time-S Senior contains 21 items with four response alternatives on a Likert scale: Never (1), Sometimes (2), Often (3), and Always (4). Time-S Senior was selected for self-ratings of the persons with dementia in study II and II because of

the possibility to guide and evaluate interventions, and for providing specific activities for the ratings.

4.2.4 Time-Proxy[®]

Time-Proxy[®] is an instrument for proxy-rating a person's daily time management. Time-Proxy is based on the Time-Parent scale, which has been evaluated for children and adolescents with and without disabilities, with a Cronbach alpha of 0.79–0.86 (12, 16). In Time-Proxy, items that were relevant for adolescents but not for persons with dementia were exchanged to items relevant for adults. Significant others' ratings of the person with dementia's daily time management on 13 items with five response alternatives on a Likert scale ("I don't know" (0), Never (1), Sometimes (2), Often (3), and Always (4)) were used in study II and III. The use of Time-Proxy entailed comparable ratings with Time-S Senior.

4.2.5 Mini Mental State Examination (MMSE)

The Mini Mental State Examination (MMSE) is a commonly used screening tool for cognitive level identification for persons with cognitive impairments and dementia (25). In study II and III, the results of the Swedish version of the MMSE-SR were used to approximate the cognitive level in the persons with dementia. The MMSE has a total score of 30 and includes the following sub-items: orientation (10), registration (3), attention and calculation (5), recall (3), language (8), and figure copying (1).

4.3 DATA COLLECTION

The focus groups interviews with occupational therapists in study I were carried out in the initial part of the Managing Time with Dementia project (Figure 2). Four focus group sessions were held at Danderyd University Hospital. Each focus group met once and lasted between 1.5-2 hours. The focus groups interviews were moderated by the PhD student and one of the supervisors took notes and asked additional questions. All focus group sessions were digitally recorded and transcribed verbatim.

All data for studies II-III were collected at baseline from participants recruited within the main project Managing time with Dementia during 2018–2021. Twelve registered occupational therapists working at the memory clinics conducted the data collection using the demographic questionnaire, KaTid-Senior form, and Time-S Senior form for the persons with dementia ($n=53$). The assessments were carried out in clinical settings or in the participants' homes. At the same time, a significant other of the person with dementia answered the demographic questionnaire and the Time-Proxy form ($n=49$). Information of dementia diagnoses and MMSE results were received from medical records. All occupational therapists on the memory clinics involved in the project were trained in using the instruments before the data collection started. In addition to the initial education, the project principal investigator and the PhD student held network meetings for the occupational therapists from the memory clinics 2-3 times a year with an opportunity to discuss issues related to the data collection.

The persons with dementia and significant others participating in study IV were interviewed individually or together depending on their wishes. The present PhD student carried out the interviews. In total, twelve interviews lasting between 15 and 60 minutes were conducted

with 15 participants. Based on prevailing COVID-19 restrictions and the participants’ preferences, the interviews were carried out individually or in dyads via phone ($n=9$), video calls ($n=2$) or face-to-face ($n=1$). Demographic data for persons with dementia and significant others was collected within the main project. The interviews were digitally recorded and transcribed verbatim.

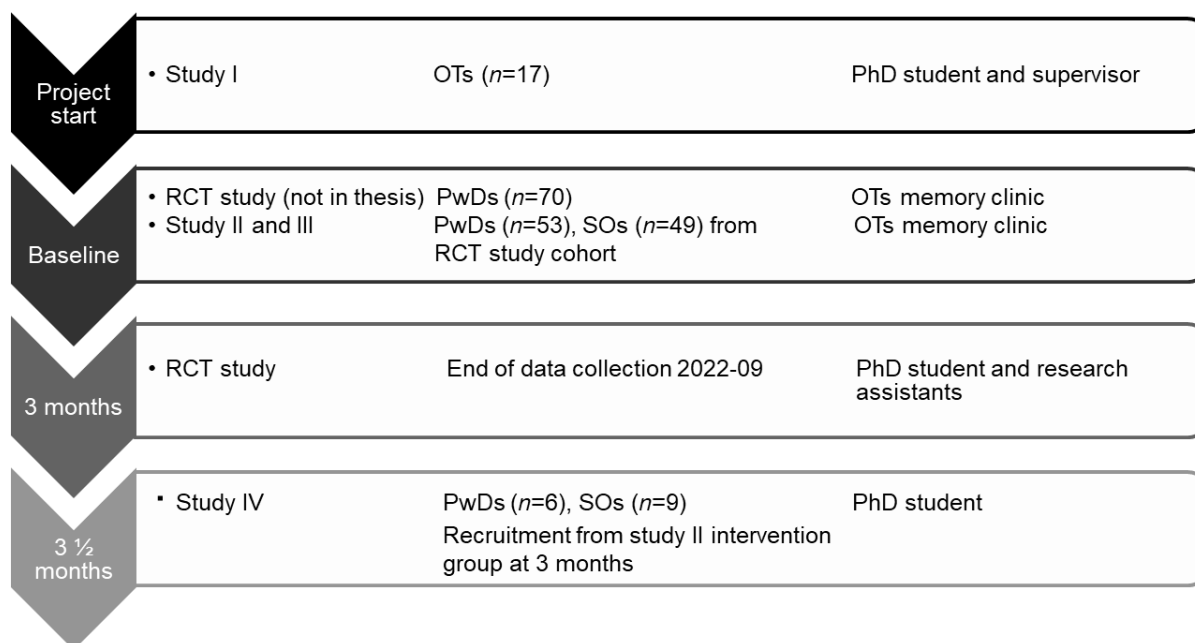


Figure 2. Study population (occupational therapists (OTs), persons with dementia (PwDs), and significant others (SOs)), and data collectors for the studies in the thesis and the randomised controlled trial (RCT) study.

4.4 DATA ANALYSES

4.4.1 Qualitative analyses

In study I and IV, content analyses were used to analyse the focus group interviews and individual interviews, respectively (111). The procedures were similar in both studies, although an emergent design was applied in study IV. The verbatim transcribed interviews were read through several times for an overall comprehension of the material. In the next step, coding of data that could be linked to the aim of the studies were carried out. Thereafter, comparisons and groupings of the codes were made to find preliminary subcategories and categories, based on similarities and differences. This process was carried out for each interview separately before merging the findings from all interviews in the study. The analyses continued according to constant comparisons until no further new insights could be obtained. Finally, the results were compared with the interviews.

To increase trustworthiness, several measures were taken (112). Credibility was ensured by the following aspects: Triangulation by use of researchers with different areas of expertise

(neuropsychology, cognitive rehabilitation, qualitative research in rehabilitation, aging and informal care); and peer debriefing by discussing the findings with a skilled clinician and in seminars with occupational therapists experienced in the field of dementia. Citations were used to report findings and increase the transparency of the original data. Regarding confirmability, the present PhD student that conducted the interviews is an occupational therapist with extensive experience of cognitive rehabilitation. Prolonged engagement by previous knowledge might be considered a strength as it can deepen the understanding of the interviews. The authors' pre-understandings were continuously discussed to ensure neutrality. Neutrality during data collection and analysis was also ensured by the fact that none of the researchers were involved in the participants' care. Adding to transferability, accurate descriptions of the settings and the participants were provided (112).

In study IV, the text was coded in the Open Code software programme (<https://www.umu.se/en/department-of-epidemiology-and-global-health/research/open-code2>).

4.4.2 Statistical analyses

Study I-IV:

Descriptive statistics for sample characterisation was calculated with Statistical Package for the Social Sciences (SPSS) v.25.

Study II:

Rasch analyses were used to examine the psychometric properties of KaTid-Senior, Time-S Senior, and Time-Proxy when used with persons with dementia. The Rasch partial credit model was used to evaluate KaTid-Senior because it allows for items with more than two response options with different scoring criteria. The Rating Scale Model was used to evaluate Time-S Senior and Time-Proxy as these instruments use Likert scale types for all response options (113).

First, the *rating scale functioning* was examined by checking that the average calibration for the rating categories advanced monotonically, and that the z-values in Outfit MnSq were less than 2 for each rating category (113). In general, at least 10 answers for each category and item are recommended (114, 115), but as this was not applicable in this study, rating scale analyses of all items together using the Rating Scale model were carried out for each instrument (116).

The *internal scale validity* and *person-response validity* were evaluated with goodness-of-fit statistics (117-119). The criteria for acceptable goodness-of-fit for both items and persons were set at a *Infit MnSq* ≤ 1.4 with an associated standardised $z \leq 2.0$ (23, 120). For acceptable person-response validity, no more than 5% of the sample can demonstrate poor goodness of fit (117-119).

To examine *unidimensionality* and possible additional explanatory factors in the measures, a principal component analysis of the residuals was carried out. The Eigenvalue of the first

contrast was set to ≤ 3 , and at least 50% of the total variance should be explained by the first latent dimension (in these cases, time processing ability and daily time management) (23, 118, 119).

The *person-separation reliability* was evaluated. The person-separation index approximates the spread or separation of persons on the measured variable. A person-separation index of ≥ 1.5 is regarded as acceptable, ≥ 2 is good, and ≥ 3 is excellent. The person-reliability index approximates the replicability of the ordering of persons that can be expected if a specific sample of persons were to be given another set of items measuring the same construct. The person-reliability index should be ≥ 0.80 (114, 118).

The match of item difficulty to person ability was examined via person-item maps displaying both persons and items along the same linear continuum. The mean values from item and person measures were also compared. Preferably, the mean values should not differ more than 0.5 logits (113).

The *internal consistency* was evaluated for each instrument using Cronbach's alpha, with values of > 0.80 considered acceptable (117, 121).

Thereafter, a step-by-step process was conducted by which items failing to meet the criteria were removed one at a time. Person misfits were also analysed. Omitting a person with misfit did not significantly affect the test values, and when the misfit might be explained by reasons other than random responses, no removal was done (119).

The WINSTEPS analysis software, version 4.5.1, was used to conduct the Rasch analyses (119).

Study III:

Pearson's r or Spearman's rho were used to examine bivariate associations between the time processing ability (KaTid-S Senior), self-rated daily time management (Time-S Senior), proxy-rated daily time management (Time-Proxy), and dementia severity (MMSE-SR). T-tests were used to control for gender differences concerning potential associations between outcomes and demographic data. To further explore the association between TPA and dementia severity, MMSE subitems correlating with the KaTid-Senior with $r \geq 0.30$ were selected for multiple linear regression analysis. Assumptions of linearity, independence, normality, and equal variance were checked for violations before the regression analyses. Outliers were evaluated for any potential impact on each model by removing outliers before running the regression analysis again, and then comparing the models. Model fit was evaluated with Adjusted R^2 . The level of significance was set at $p < 0.05$. Statistical analyses were calculated with IBM SPSS Statistics for Windows, Version 27.0. Armonk, NY, USA. No adjustment to experimental alpha was made for multiple testing, and therefore, caution should be added for the risk of an inflated Type I error rate.

4.5 ETHICAL CONSIDERATIONS

The studies in the project were conducted with ethical permission from the Regional Ethical Review Board in Uppsala (reg. no. 2018/059) and adhered to the ethical principles according to the Declaration of Helsinki (World Medical Association, 2018). The following supplementary applications were approved by The Ethical Review Agency: inclusion of an additional memory clinic (reg. no. 2018/059/1); inclusion of five additional memory clinics and change of inclusion criteria from ≥ 65 years to ≥ 60 years for persons with dementia (reg. no. 2020–00064); revised interview guide for study IV (reg. no. 2019–04531); and the inclusion of persons with dementia in study IV (reg. no 2020-02877).

Informed, written consent was received from all participants in the studies. All participants were given the following oral and written information about the respective study: the data is protected by the Public Access to Information and Secrecy Act (2009:400); no unauthorised persons will have access to individual responses; the results will be presented on the group level in scientific reports, such as journal articles and conference presentations; and participation in the study is completely voluntary and can be withdrawn at any time without further explanation and without any impact on future care or support.

4.5.1 Including persons with dementia in research

The ethical principles include respect for autonomy and personal integrity, which becomes especially critical when persons with dementia are included in studies as they may have a reduced ability to protect their integrity. The persons with dementia that participated had been diagnosed with mild to moderate dementia and were regarded able to understand the study information and autonomously make a decision concerning their participation. In addition, they were included and participated together with a significant other, which further increased the possibility of drawing attention to problems in understanding what participation in the studies entailed.

Taking ethical considerations into account, it is valuable to allow persons with dementia to be heard and included in research. A systematic review found that many persons with dementia were well able to communicate their needs and desires in words (122). The importance of gaining insights into individual experiences concerning what it means to live with dementia requires the involvement of persons with dementia in research, both regarding subjective experiences in qualitative studies, and, for example, self-ratings in quantitative research designs (122). Other studies have also pointed out the importance of including persons with dementia's perspectives in research (123, 124), and the benefit of participation usually exceeds the risks if safe environments are created (125). Moreover, interviews can be experienced as positive events both by persons with dementia and their spouses, providing a possibility to discuss and validate feelings and experiences with another person (125). Nevertheless, attention to the vulnerable situation that cognitive impairments might entail was given, and the greatest possible sensitivity was sought after in the communication with the participants both before and during the data collection.

4.5.2 Ethical considerations regarding the data collection

To promote the participation of persons with dementia, the data collection was adapted based on the participants' conditions and needs. The time of day and length of test situations and interviews adapted the questions, and the way in which the interviews were conducted (with or without significant others, face-to-face, via telephone or via videocalls) were flexible and based on the preferences of the individuals.

The most important ethical consideration in this context was the risk of violence towards the participants' integrity and their sense of self. The use of KaTid-Senior and Time-S Senior implied a focus on time processing ability impairments and daily time management problems, issues that persons with dementia might not be fully aware of or might experience as troublesome and embarrassing. Research has shown that professionals' attention to impairments and problems can lead to a negative impact on the person with dementia's sense of self (126, 127). Thus, it is important that solution-focused interventions related to the results of the assessments are offered to the participants. During this project, the participants had ongoing contacts with the occupational therapists on the memory clinics or were referred to occupational therapists in primary care for time-related interventions.

This project was taken on with the general aim to explore daily time management in persons with dementia, with a focus on assessments of daily time management and time processing ability and the prescription and use of time AT. By means of this research, health care professionals meeting persons with dementia with time-related problems, along with researchers, might gain access to valid and reliable instruments for assessing time processing ability and daily time management in dementia, which can contribute to the development of improved and more effective time-related assessments and interventions. Regarding the interests of the participants in this research, the possible advantages could be assumed to outweigh the potential risks.

5 RESULTS

5.1 PARTICIPANTS

In study I, sixteen women and one man in total participated in four focus group interviews, with each focus group including between three and six participants. The participants worked in memory investigation units ($n = 13$), a municipality unit ($n = 1$), and in primary care ($n = 3$).

In study II and III, a total of 53 persons with dementia and 49 significant others participated. The characteristics of the participants are presented in Table 4, whereas the characteristics of the subsample of persons with dementia ($n=6$) and significant others ($n=9$) that participated in study IV are presented in Table 5.

Table 4. Basic characteristics of participants with dementia and significant others in study II and III.

Persons with dementia ($n = 53$)		Significant others ($n = 49$)	
Gender n (%)		Gender n (%)	
Women	25 (47.2)	Women	28 (57.1)
Men	28 (52.8)	Men	21 (42.9)
Age, years (<i>mean, SD</i>)	74.9 (6,9)	Age, years (<i>mean, SD</i>)	67.1 (9.7)
Diagnosis n (%)		Relation to participant n (%)	
Alzheimer's disease	38 (71.7)	Spouse	41 (83.7)
Vascular dementia	6 (11.3)	Child	7 (14.3)
Dementia with Lewy bodies	4 (7.5)	Missing information	1 (2.0)
Dementia (other)	3 (5.7)	Support given (days/week) n (%)	
Alcohol dementia	1 (1.9)	≤1	6 (12.2)
MMSE (<i>mean, SD</i>)	22.4 (4.0)	2-3	6 (12.2)
Family situation n (%)		Daily	35 (71.4)
Single, living alone	7 (13.2)	Missing information	2 (4.1)
Partner, not living together	3 (5.7)		
Partner/family, living together	43 (81.1)		
Region (%)		Region (%)	
Dalarna	7.6	Dalarna	6.1
Gävleborg	9.4	Gävleborg	10.2
Stockholm	16.9	Stockholm	14.3
Sörmland	9.4	Sörmland	10.2
Uppsala	18.9	Uppsala	20.4
Värmland	15.1	Värmland	14.3
Västmanland	1.9	Västmanland	2.0
Örebro	20.8	Örebro	22.4
Missing information	1 (1.9)		

Table 5. Basic characteristics of participants with dementia and their significant others in study IV.

	Persons with dementia (<i>n</i> =6)	Significant others (<i>n</i> =9)
Gender (<i>n</i>)		
Women	3	6
Men	3	3
Age, years (<i>mean, SD</i>)	74.7 (2.4)	63.4 (12.3)
Region (<i>n</i>)		
Gävleborg	1	1
Dalarna	1	1
Stockholm	1	2
Sörmland	2	2
Uppsala		1
Värmland	1	1
Västmanland		1
Family situation (<i>n</i>)		
Spouse, living together	6	8
Parent/child, not living together		1

5.2 ASSESSING THE NEED FOR AND PRESCRIPTION OF TIME ASSISTIVE TECHNOLOGY FOR PERSONS WITH DEMENTIA (STUDY I)

In study I, the analysis of the focus group interviews with occupational therapists revealed one main category, *A complex prescription process in need of support from significant others*, and four categories: *Assessment of TPA and DTM*, *Facilitating and hindering factors during implementation*, *Follow-ups – a question of time*, and *Need of professional knowledge and information*. Each category included between two and four subcategories. The main category stressed the importance of support from significant others in all phases of the prescription process, including the preceding need assessment. Thus, occupational therapists argued that significant others had a key role not only for persons with dementia but also for occupational therapists in a multifaceted and time-consuming prescription process that was often affected by organisational constraints.

The occupational therapists reported that assessments of time processing ability and daily time management in persons with dementia were conducted by means of interviews, cognitive instruments, occupational performance assessments and home visits. Which assessments were carried out depended on structural conditions in different regions and workplaces. The occupational therapists also pointed out that there was a need for instruments assessing time processing ability and daily time management. According to the occupational therapists, persons with dementia often had problems with daily time management. As a basis for further interventions, the occupational therapists paid attention to whether the persons with dementia were using strategies in their daily time management.

Prescription of easy-to-use time AT was a frequently occurring intervention, whereas advanced time AT was considered too difficult to use in general for persons with dementia, particularly when the persons with dementia had no support from a significant other.

Timing was an important but complex factor when implementing time AT; early introduction was advantageous while it could be difficult to introduce the device at an early stage if the person with dementia, for example, was not motivated to use the device or did not foresee a future need. However, when prescribing time AT, it was important that both persons with dementia and significant others were motivated to use it, as support from a significant other was generally needed for a successful implementation of the device. Organisational factors often affected the occupational therapists' opportunities to provide support. Moreover, possibilities for occupational therapists to follow-up prescribed devices varied considerably across workplaces. However, the occupational therapists that conducted follow-ups experienced that persons with dementia and significant others were usually positive towards time AT, as it often provided support in daily time management and prolonged the ability for the person with dementia to manage time.

Professional knowledge was important, and the occupational therapists had to stay informed of time AT on prescription as well as commercial alternatives, such as smart phones and electronic calendars. However, the occupational therapists reported that smart phones and technology were often too difficult to use for persons with dementia, and they frequently needed to inform persons with dementia and significant others of possible alternatives and the provision of technological support on the right level, for example, easy-to-use time AT.

5.3 PSYCHOMETRIC PROPERTIES OF KATID-SENIOR, TIME-S SENIOR, AND TIME-PROXY WHEN USED WITH PERSONS WITH DEMENTIA (STUDY II)

In study II, the Rasch analysis showed that KaTid-Senior has sound psychometric properties when used with persons with dementia. In the principal component analysis (PCA), the first component explained $\geq 50\%$ of the total variance, and the Eigenvalue of the first contrast was ≤ 3 , providing support for validity and unidimensionality, understood to be time processing ability. Person separation was 0.77 and reliability 1.82. The Cronbach's alpha coefficient was 0.81. Due to the low value of person separation, the results suggest that there is a need to add more challenging items to match the ability of persons with mild to moderate dementia.

For Time-S Senior, the PCA of the first component explained $\geq 50\%$ of the total variance, and the Eigenvalue of the first contrast was ≤ 3 , suggesting that Time-S Senior measures one construct, understood to be daily time management. The person-separation index was 2.70 and person-reliability index 0.88, indicating separation of individuals into three different levels of daily time management. The Cronbach's alpha coefficient was 0.92. However, the Rasch analysis revealed person-response validity issues, and further analyses indicated a need for additional response alternatives.

Time-Proxy had a PCA that explained $\geq 50\%$ of the total variance, and an Eigenvalue of the first contrast was ≤ 3 , indicating unidimensionality, assumed to measure proxy-rated daily

time management. The person separation was 2.93 and reliability 0.90. The Cronbach’s alpha coefficient was 0.93.

5.4 ASSOCIATIONS BETWEEN TIME PROCESSING ABILITY, DAILY TIME MANAGEMENT, AND DEMENTIA SEVERITY (STUDY III)

In study III, the results demonstrated a significant positive correlation between time processing ability (KaTid-Senior) and dementia severity (MMSE, total score). Furthermore, analyses of time processing ability in relation to MMSE subitems showed significant but weak correlations between time processing ability and orientation; attention and calculation; and language; in addition to a moderate correlation between time processing ability and figure copying.

No significant correlation was found between time processing ability and self-rated daily time management (Time-S Senior), but significant correlations were found between time processing ability and proxy-rated daily time management (Time-Proxy), and proxy-rated and self-rated daily time management. Proxy-rated daily time management was also correlated with dementia severity. The correlations are illustrated in Figure 3.

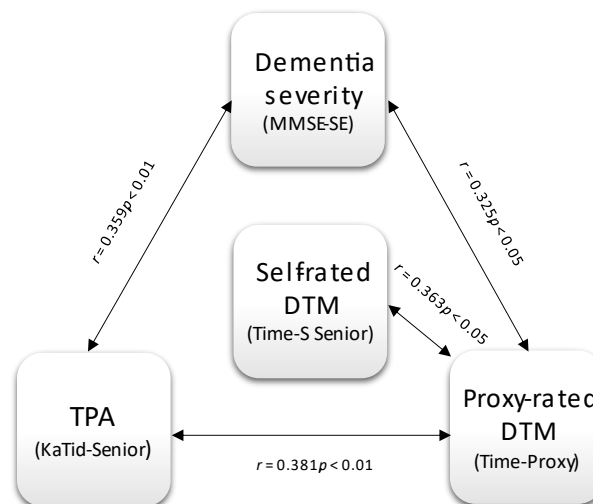


Figure 3. Associations between time processing ability (KaTid-Senior, self-rated daily time management (Time-S Senior), proxy-rated daily time management (Time-P), and dementia severity (MMSE). Correlations performed with Pearson’s r or Spearman’s ρ .

In a multiple regression model of MMSE sub-items, orientation ($p = 0.050$), attention and calculation ($p = 0.047$), and, specifically, figure copying ($p = 0.002$), turned out to be significant predictors of time processing ability. To investigate which functions contributed to the different levels of time processing ability, we performed multiple linear regression analyses between the dependent time processing ability variables (KaTid-Senior subgroups) *time orientation/time concepts*, *time orientation/objective time*, and *time management* and the independent cognitive variables (MMSE sub-items), *orientation*, *attention and calculation*, and *figure copying*. Visuospatial function measured with the Figure copying sub-test was the

most significant predictor of all the above-mentioned time processing ability variables: time orientation/time concepts ($p = 0.014$), time orientation/objective time ($p = 0.008$), and time management ($p = <0.001$). The MMSE subitem attention and calculation was a significant predictor of time orientation/objective time ($p = 0.009$) and time management ($p = 0.020$).

5.5 EXPERIENCES OF PERSONS WITH DEMENTIA AND SIGNIFICANT OTHERS ON DAILY TIME MANAGEMENT AND TIME ASSISTIVE TECHNOLOGY (STUDY IV)

In study IV, the analysis of the interviews with persons with dementia and significant others revealed one main category, *Support of significant others is always part of daily time management*, and three categories: *Facing new challenges*, *Using strategies to handle changes*, and *Time AT matters*, each including two or three subcategories. The main category illustrated that significant others provided varying grades of support in daily time management during all phases of dementia, from the emergence of time-related problems. Increasingly, the overall responsibility for the daily time management was transferred to the significant other. Easy-to-use time AT provided support in orientation to time for the persons with dementia, but it did not replace the support from significant others as significant others had to put the time in a context. Such information could be provided via calendars and advanced time AT, but apart from the need of support to carry out the time planning and handle the device, the persons with dementia also experienced a need to confirm the scheduled information with their significant other.

The persons with dementia and the significant others described how they, together, faced the new challenges, namely a variety of emerging problems caused by the dementia, including time-related problems in daily life. The persons with dementia experienced that it was difficult to acknowledge and adapt to the emerging problems and to no longer being able to perform previous occupations. The significant others described that the persons with dementia needed support in carrying out time management, although it varied whether the significant others considered it to be a significant problem or not. They also described feelings of loss when the person with dementia started losing interests, initiative, and independence. In light of the emerging challenges, both significant others and persons with dementia expressed concern for each other.

The persons with dementia and the significant others used different strategies to handle the changes. Both parts stressed maintenance and the impact of old habits and routines, for example, the continuous use of calendars with an increasing level of support. Activities at set times, which the person with dementia wanted to continue carrying out, also affected the person with dementia's relation to time. Based on previous habits and routines, new strategies were developed to deal with the new challenges and the person with dementia's growing need for support in daily time management, such as the use of checklists or the involvement of the person with dementia in time planning. However, the most common strategy described by the persons with dementia and the significant others was to ask the significant other about time, upcoming events, etcetera. The persons with dementia relied on their significant other to be in

control of everything in daily life, and the significant others described that they had increasingly taken over the control of the common daily life, including the daily time management. Furthermore, as the persons with dementia, for example, often needed to be accompanied during most activities outside the home, it implied that the support in daily time management was embedded in another kind of support.

Knowledge about time AT and the possibility of the prescription of the device was sparse amongst persons with dementia and significant others before contact with health care services. When in contact with health care professionals, the level of information, support, and follow-ups of time AT varied from case to case, and so did the need from persons with dementia and significant others. Even if hesitant at first, the persons with dementia were motivated to use the prescribed easy-to-use time AT and reported that such devices supported orientation to time. The significant others appreciated that the person with dementia benefited from the time AT but did not think that their own situation was facilitated to any great extent. The persons with dementia did not see a need for advanced time AT to support time planning and scheduling as the responsibility for such matters had already been transferred to the significant others. However, advanced time AT could provide visual information of the planning made, which gave the persons with dementia a feeling of security. The significant others benefited from advanced time AT as a tool to communicate and remind the person with dementia of the time planning. All participants recommended the use of time AT for persons in a similar situation like theirs, and it was the mutual experience of persons with dementia and significant others that meant time AT still mattered.

6 DISCUSSION

6.1 MAIN FINDINGS

The general aim of this thesis was to explore daily time management in persons with dementia, with a focus on assessments of daily time management and time processing ability, and the prescription and use of time AT from the perspectives of persons with dementia, significant others, and occupational therapists. The main findings in the separate studies are theoretically linked to the CMOP-E model as follows: time processing ability (person, cognitive component) in study I, II and III; daily time management (occupation) in study I, II, III and IV; and support from significant others and time assistive technology (environment) in study I and IV. The results in study IV show how time processing ability, daily time management and support from significant others and assistive technology can be related to and affect occupational performance and occupational participation.

The main results in the four studies were as follows. Study I found that there were high demands on significant others' participation during the prescription process of time AT. This also means that persons with dementia with no support from significant others are at risk of not obtaining or benefitting from such intervention. Another important finding was that the occupational therapists reported a need for instruments assessing time processing ability and daily time management in memory assessments. In study II, three instruments assessing time processing ability, self-reported daily time management, and proxy-reported daily time management were respectively validated for persons with dementia. These assessments might enhance the possibility of the early identification of impaired time processing ability and daily time management problems, thereby facilitating timely interventions and the improvement of occupational performance. In study III, the results showed significant correlations between time processing ability and dementia severity, especially visuospatial functions. This finding might contribute to the early detection of time processing ability impairments by indicating a need for in-depth assessments of time-related functions. Furthermore, for a comprehensive assessment of time processing ability and daily time management, objective measures should be used in combination with self-ratings and proxy-ratings. Finally, study IV found that time AT could support time orientation for persons with dementia, whereas significant others supported daily time management and carried out the time planning. However, time AT and paper calendars could still increase the occupational participation for persons with dementia by providing an overview of future and past events by facilitating involvement in time management or by being a tool for significant others to communicate time management already planned.

6.2 EARLY DETECTION OF TIME-RELATED PROBLEMS IN PERSONS WITH DEMENTIA

It is well-recognised that early and timely interventions for persons with dementia increase the possibility for successful outcomes (76). Research has also shown that time disorientation and impaired experience of time are common symptoms of dementia (29, 30), and thus,

attention must be paid to time-related assessments. In memory assessments, questions of orientation to time are often included in tests, as well as items assessing visuospatial functions (2).

However, up to the present there has been a lack of valid and reliable instruments for assessing all three levels of time processing ability and daily time management for persons with dementia, which was requested by the occupational therapists in study I. In study II, KaTid-Senior, Time-S Senior, and Time-Proxy were validated for clinical use and research for persons with dementia. The current version of KaTid-Senior is a useful instrument in assessing time processing ability in persons with dementia. In initial stages where little is known about problems in daily occupations, a structure for what to look for as well as what to report is helpful (128). KaTid-Senior measures all three levels of time processing ability, not just orientation to time, which might be easiest to detect in other contexts. However, to also target persons with mild symptoms of dementia, the KaTid-Senior needs to be further developed with more challenging items targeting time management. Also, Time-S Senior needs alternative response options to better fit persons with dementia, such as “non-applicable” or “together with another person”. The results underscore the importance of evaluating instruments for different target groups. Time-S Senior and Time-Proxy can capture the perceptions of persons with dementia and significant others regarding daily time management.

However, when a person lacks awareness of impairments, the reliability and validity of self-reporting is diminished. Likewise, the information obtained through a significant other depends on knowledge about the person, the time spent together and the type of activities that are carried out during that time (129-131). This could also be a dilemma for persons with dementia without support from significant others or formal care, where nobody has the possibility to notice time-related problems. This was also brought up by the occupational therapists in study I. Understanding awareness may be important to caregivers, and while it could be inappropriate to force persons with dementia to confront and dwell upon their impairments, other ways to support awareness could be useful, for example, a comparison of self-ratings with proxy-ratings and objective measures (50, 132). This is in line with the results in study III suggesting that KaTid-Senior, Time-S Senior, and Time-Proxy used in combination can give a broad picture of time-related issues for the persons with dementia and provide a basis for further investigations or interventions.

Importantly, the results in study III also showed a correlation between visuospatial functions and time processing ability (especially time management), which could be valuable information for health care professionals and enable early assessments of time processing ability and daily time management. Hence, when visuospatial impairments are observed in screening tests, occupational therapists should be prompted to do an in-depth assessment of time processing ability and daily time management.

Even if instruments play an important role in the detection of time-related problems, the context of the individual must be considered in relation to the results. In CMOP-E (7),

impaired time processing ability is related to the *person* (cognitive component), daily time management to *occupation*, and support from significant others and/or time AT to *environment*. Are there time processing ability impairments affecting daily time management? Is this an issue for the person with dementia? Which occupations does the person want and need to perform, and which daily time management skills are required to perform those occupations? Furthermore, the interaction with the environment needs to be considered regarding demands and support, for example, from technology and social environments (7, 130). This applies to the results in study II, III and IV, showing that persons with dementia often have impaired time processing ability and problems in daily time management. However, according to the results in study IV in relation to environmental support, it seems like the responsibility for the time management has already been transferred to the significant others before the person with dementia visits the memory clinics. Similar findings have been described in other studies (13, 125). Deterioration caused by the dementia occurs earlier in more complex instrumental activities as they make higher demands on cognitive skills (3). Study IV found that the support for daily time management was often imperceptibly embedded in support for other daily instrumental activities. Thus, KaTid-Senior could be useful in detecting time processing ability impairments, where the development of the instrument by adding more challenging items could be useful in identifying problems on the highest level of time processing ability, that is, time management.

6.3 THE TIMING OF INTERVENTIONS

Early investigation and early, timely interventions are needed to increase the possibility for the person with dementia to prolong the maintenance of daily time management, for example, by support from time AT, before the full responsibility has been transferred to the significant other. The importance of timing for a successful implementation of AT has also been highlighted in previous research (133). Implementation of an AT early in the disease trajectory enhances the possibility for the person with dementia to learn how to use the device. On the other hand, AT could be introduced too early if the persons with dementia, or the significant others, do not experience such a need or perceive the AT as stigmatising (133). Moreover, the person with dementia and the significant other must be motivated to use the AT (13, 134). In study IV, the participants had already established their own routines for daily time management and the persons with dementia saw no need for other solutions.

Furthermore, problems in time management were not always experienced as a major issue in relation to other consequences of the dementia. Focusing on the assessments and identification of impairments and limitations might also negatively influence the person with dementia's agency (127), and, thus, the assessments must be conducted for legitimate reasons and entail possible interventions to support the persons with dementia and the significant others in their desired occupations in daily life. Agency has been described as an individual's capacity to initiate social action and to participate actively in making decisions or, at least, influence their personal circumstances, and that persons with dementia can demonstrate

creative capacity for agency (135). Interventions and approaches aiming at maintaining the participation of the persons with dementia are important to sustaining their sense of agency (127). This could also be related to occupational performance (active participation in occupations) and occupational participation (when performance has personal meaning and is part of a social role) (7).

6.4 THE ROLE OF TIME ASSISTIVE TECHNOLOGY

A common compensatory intervention provided by occupational therapists is the prescription of time AT. Study I showed that the prescription of time AT is a frequently occurring intervention, although everyday technology, such as smart phones, provides similar functions for support in daily time management. Previous research has, however, found that experienced difficulty in using everyday technology enhances in persons with mild cognitive impairment to become more tangible in mild-stage dementia (63, 64). In study I and IV, the result showed that smart phones often became too difficult to use for the persons with dementia. At the same time, the ability to use clocks, calendars and everyday technology is fundamental for effective daily time management. The importance of making everyday technology inclusive and dementia-friendly has been underscored (136). Thus, time AT can be a useful alternative by making information about time, days of the week, etc., easily accessible.

An easy-to-use electronic calendar is a relatively simple time AT intervention that can support orientation to time according to the results in study I and study IV. The persons with dementia experienced a feeling of security when being able to keep track of time. A strategically placed device with clear information about time, day, and date easily became a natural part of the person with dementia's environment. The ability to keep track of time and to manage time affects well-being (19). The results in study IV suggest that when time AT supports the person with dementia to stay informed about time and daily time management, it can increase occupational engagement and occupational participation, as well as preserve agency and diminish the need for asking questions about time. Questions not only affected the significant others, as the persons with dementia reported that the need to ask questions was troublesome and uncomfortable for themselves as well. According to the occupational therapists in study I, advanced time AT was not often prescribed to persons with dementia. The results in study IV indicated that calendars and advanced time AT was not independently used by the persons with dementia for time management but served as a method to keep track of scheduled events, sometimes with active reminders, which increased the participation in the daily time management.

However, the occupational therapists in study I reported that they, due to organisational factors, had limited resources to follow all steps in the prescription process for AT recommended by the Swedish National Board of Health and Welfare: (1) Selection of device; (2) Adaptations if needed; (3) Information; (4) Education and training; and (5) Follow-up and evaluation of function and utility (137). In addition, the assessment of needs is an important step preceding the prescription. The results showed that the significant others were engaged

during all steps of the prescription process, and that the occupational therapists did not always have time for education, training and follow-ups. These results were confirmed in study IV. Consequently, the occupational therapists in study I conveyed that the persons with dementia living alone without support from significant others had minor chances to receive and benefit from time AT. This result is in accordance with a previous study reporting that persons with dementia living alone have more unmet needs and are more isolated than those living together with someone (138). From a wider perspective, the policy of aging in place entails that many persons with dementia remain in their homes, with decreasing formal care leading to higher demands of support from significant others (81, 88). Thus, it is essential that policymakers and formal service providers recognise the vulnerable situation of persons with dementia, especially for those without support from significant others.

6.5 THE ENGAGEMENT OF SIGNIFICANT OTHERS

It is well known that significant others are important for the implementation of AT in the daily lives of persons with dementia (36, 100, 103, 133). In addition, the results in study I showed that significant others were important at all stages in the prescription process of time AT, both for the persons with dementia, and for the occupational therapists' potential to implement AT. Significant others have often inherited the main responsibility for supporting persons with dementia at home (139), including the provision of support in daily time management and the use of time AT as reported in study I. Study IV found that even if time AT could support orientation to time for the persons with dementia, significant others still had to place time in context, take responsibility for time management and monitor what was going to happen when. The responsibility for daily time management had been gradually transferred to the significant others. When the person with dementia had received easy-to-use time AT, the significant others sometimes needed to provide reminders, but for advanced time AT the significant others carried out the time management and maintenance of the device. Sometimes, the significant others tried to enhance the person with dementia's participation by involving the person with dementia in the time management or by using the device to visualise and communicate scheduled events.

Previous research has shown that significant others, as part of the social environment, play an important role in forming the occupational lives of the persons with dementia (140). Heading for the right balance between taking over daily occupations, and maintaining or adapting activities, significant others try to preserve the person with dementia's skills, identity, and dignity (139). Another study found that the significant others were trying to confirm and promote the agency of the persons with dementia when they provided support (141). Collaboration between the person that provides support and the person with dementia has been reported as a key to maintaining agency (132). However, the significant other's own perception of occupation and participation has an impact when they try to involve the person with dementia in daily occupations (140). Our results in study IV showed that it was the significant others that, on their own, took the initiative and found approaches to involve the persons with dementia in the time management.

Dementia also affects the significant others' daily living (142). Studies have found that significant others' own occupations and roles become affected, and they must adapt to a new occupational life (107, 139). For spouses, the daily lives often become intertwined with the life of the person with dementia, and one way of supporting persons with dementia in occupations is to do things together (143, 144). A reported positive aspect of caring for a person with dementia is feelings of mutuality (92, 145). These findings are coherent with the result of study IV, where the daily lives of the participants had changed, occupations were intertwined, and the spouses conveyed concern and respect for the other one. Time AT did not seem to affect the significant others' situation to great extent but was still one facilitator in daily life for them, which was reported in both study I and IV. Furthermore, both studies showed that significant others needed information and support from formal care and occupational therapists regarding time AT. Follow-ups were also requested on how to use advanced time AT or altered interventions when the need was changing. Thus, assessments and interventions must be directed to both significant others and persons with dementia. Active involvement of the significant other in the intervention process has proven to be an effective strategy for positive intervention outcomes (146).

In summary, this thesis has shown that occupational therapists have limited resources and instruments for assessing time processing ability and daily time management. Thus, when prescribing time AT for persons with dementia, high demands are made on significant others' participation during the whole prescription process. Commonly, the occupational therapists lack time to implement the prescribed device and follow-ups. For the contribution of valid and reliable time-related assessments, three instruments assessing time processing ability and daily time management have been evaluated for persons with dementia. In this research, additional knowledge about the associations between time processing ability, daily time management and dementia severity has been acquired, where the significant correlations between time processing ability and dementia severity, visuospatial functions, and attention and calculation were the most important findings. Thus, it is important to also investigate the time processing ability early in memory assessments. Furthermore, significant others start providing support in daily time management at an early stage of the dementia, often imbedded in other kinds of support. The significant others are also very important for the persons with dementia to benefit from time AT. Even though time AT can support orientation to time, significant others still need to place time in context. The responsibility for time management is gradually transferred to the significant other. However, the person with dementia's sense of agency, occupational participation and occupational engagement can be enhanced by involving the person with dementia in the time management, and that involvement can be supported by using calendars and time AT. Consequently, persons with dementia can benefit from time AT by reducing the need to ask questions about time as well as helping them stay informed about the time management carried out by the significant others. Furthermore, time AT can assist significant others by diminishing questions of time and functioning as a tool to provide information and engage the person with dementia in the time management.

6.6 METHODOLOGICAL CONSIDERATIONS

This thesis used both qualitative and quantitative methodologies to address the overall aim to explore daily time management in persons with dementia, with a focus on assessments of daily time management and time processing ability and the prescription and use of time AT. The use of both qualitative and quantitative methodologies in triangulation has the potential to uncover unique features and important information that might not have been discovered with the use of only one approach (147). While quantitative studies are hypothesis testing, qualitative studies explore areas lacking knowledge, where there are no hypotheses and the knowledge needs to be generated. Qualitative studies can also contribute with a deeper and more nuanced understanding. Study I captured occupational therapists' subjective experiences of assessing the need and prescribing time AT for persons with dementia, illustrating a complex and time-consuming prescription process that was facilitated if the person with dementia was supported by a significant other. Study II evaluated the psychometric properties of three instruments assessing time processing ability and daily time management in persons with dementia for use in clinical settings to inform intervention and in research. Study III provided increased knowledge of the associations between time processing ability, daily time management, and dementia severity, and demonstrated the importance of using objective measures in combination with self-ratings and proxy-ratings for a comprehensive assessment of time processing ability and daily time management. Finally, study IV broadened the picture of daily time management in dementia by exploring the experiences of persons with dementia and significant others regarding daily time management and their perceptions of how time AT affects everyday life.

The original plan for the thesis included a randomised controlled trial to evaluate the effect of time AT on the person with dementia's activity goals regarding the performance of daily activities and their satisfaction with the performance. Thus, the focus on time AT influenced the whole PhD project from beginning to end, but when there were not enough participants, the affected randomised controlled trial had to be excluded from the thesis. However, with the broader focus in study IV, a further understanding of daily time management in daily life was gained, and the meaning of time AT could be highlighted in relation to other needs.

An important strength of this thesis is the inclusion of persons with dementia, significant others, and professionals in the qualitative studies, allowing for different perspectives on daily time management. Earlier qualitative studies have most often focused on the experiences of significant others only. All three perspectives are also included in the quantitative studies in this thesis. However, the reliability of answers given by persons with dementia varies (148, 149). Another possible limitation is that only persons with 'mild to moderate' dementia were included in the studies in this thesis. If persons with mild cognitive impairments had also been included, the findings would have covered another target group for which this type of research could be useful. Such inclusion would also have facilitated the recruitment of participants, where a larger sample size would have allowed for analyses of different needs for persons with different dementia diagnoses.

A further strength was that the recruitment of persons with dementia and significant others were conducted by occupational therapists from eleven memory clinics in different regions, covering urban and rural areas in Sweden. However, the sample sizes in the studies are rather small. The COVID-19 pandemic restrictions had a considerable impact on the possibility for the memory clinics to recruit new participants (as described in section 4.1.3). However, one advantage of using Rasch analysis in study II is that it can also be used for validating measures with small sample sizes (119). In study III, a larger sample size might have presented more reliable estimates, even though the power estimation showed that the current sample would be sufficient for the analyses. Although there was a relatively small sample in study IV as well, especially regarding persons with dementia, many participants openly shared their experiences on emerging problems in daily life, including daily time management problems, resulting in rich data. However, a limitation might be that the data collection was carried out during the COVID-19 pandemic, which had a restrictive impact on the participants' daily occupations and social contacts.

In study IV, most participants were spouses, and it is likely that the circumstances are different when the significant other is a child, neighbour, or friend not living together with the person with dementia. This limits the transferability of the results for persons with dementia in general, but the high level of support from significant others in daily time management found in study IV highlights the need for exploring the situation for persons with dementia living alone. Also, there are differences between the cognitive functioning in early-onset and late-onset dementia (150), which might limit the generalisation across age groups.

7 CONCLUSIONS AND IMPLICATIONS

The findings in this thesis expand the understanding of how persons with dementia manage time in daily life and on how significant others play a crucial role in supporting daily time management from the onset of dementia. Furthermore, this thesis generates an increased understanding of the prescription and use of time AT as support in daily time management in dementia from the perspectives of persons with dementia, significant others, and occupational therapists. The evaluation of three instruments enables valid and reliable assessments of time processing ability and daily time management in persons with dementia. An investigation of the associations between time processing ability, daily time management and dementia severity further adds to the body of knowledge. Thus, despite the exploratory nature of the thesis and the limited study sample sizes, new insights have been obtained that may have both clinical and policy implications.

Based on the results, some clinical implications for time-related assessments are suggested. Occupational therapists need instruments to assess time processing ability and daily time management that are evaluated for persons with dementia. This thesis has shown that KaTid[®]-Senior can validly and reliably assess time processing ability in dementia, and Time-S[®] Senior and Time-Proxy[®] can validly and reliably assess daily time management in dementia for use in clinical research and healthcare settings. Time processing ability is linked to the severity of dementia and visuospatial functions, which can indicate a need for an extended investigation of time processing ability and daily time management, especially when visuospatial impairments are observed. Importantly, objective measures should be used together with self-ratings and proxy-ratings for a comprehensive assessment of time processing ability and daily time management. Taken together, this knowledge increases the possibility of early detection of time-related problems in dementia, thereby facilitating adequate timing of interventions, such as implementation of time AT, to enhance occupational performance and occupational participation in daily time management. Thus, the results suggest that greater focus needs to be placed on investigating the time processing ability and daily time management in persons with dementia. Moreover, increased resources are needed for occupational therapists to be able to implement and carry out follow ups of interventions, also for the support of significant others in this process.

Regarding support in daily time management for persons with dementia, including support from significant others and the prescription and use of time AT, there are implications on both clinical and policy levels. This thesis shows that significant others were always a part of the support in daily time management for persons with dementia throughout the whole prescription process and use of time AT. This poses a risk that persons with dementia without significant others have limited possibilities to receive support or interventions in daily time management. Thus, resources are needed to develop specific varieties of support targeted at persons with dementia without significant others. Furthermore, health care professionals should target specific information and guidance to individual significant others, so that they can optimally assist the person with dementia in their daily time management but also to facilitate the significant other's situation.

8 FUTURE PERSPECTIVES

Significant others have a very important role in supporting persons with dementia in daily time management, including the use of time AT. Therefore, further research on how persons with dementia without support from significant others manage time in daily life, and to what extent they receive time AT, would be valuable. It would also be of interest to investigate to what extent time AT supports persons with dementia in the performance of desired time-dependent daily occupations.

Another theme in this thesis was the importance of the early detection of time processing ability impairments and daily time management problems for the provision of early, timely interventions. Thus, further development and evaluation of KaTid-Senior to improve the targeting of persons with mild symptoms of dementia is needed. Moreover, further studies to strengthen the knowledge on correlations between time processing ability and visuospatial functions could generate increased knowledge supporting early identification of time-related impairments. In addition, if the timing is right and time AT is successfully implemented, how long will the benefit last in relation to the progression of the dementia? In such research, it would also be of interest to include persons with early-onset dementia.

In the Managing time with dementia project, the participating persons with dementia already had an identified need of time AT before inclusion. Therefore, another area of interest in further studies is to explore the prevalence of early time processing ability impairments and daily time management problems amongst persons undergoing memory assessments. It would also be of interest to further explore time management in persons with dementia and the support given at an early stage. As organisation and planning skills are connected time management skills (10), both concepts should also be considered together.

9 SVENSK SAMMANFATTNING

Hur vi uppfattar och hanterar vår tid har stor inverkan på självständighet, delaktighet och välbefinnande. Demenssjukdomar påverkar ofta tidsrelaterade funktioner och förmågan att hantera tid, och när personer med demenssjukdom behöver stöd i den dagliga tidshanteringen är det oftast närstående, såsom makar, barn eller vänner, som tillgodoser behovet av stöd.

Idag finns det inget medicinskt botemedel mot demenssjukdomar och därför finns det ett stort behov av andra åtgärder för att stödja personer med demenssjukdom i den dagliga tidshanteringen. En vanlig åtgärd för stöd i daglig tidshandling är användning av tidshjälpmiddel som kan förskrivas av arbetsterapeuter. Tidshjälpmiddel kan exempelvis visa tid och datum, hur mycket tid som är kvar av en aktivitet eller ge stöd i tidshandling. Tidigare forskning har visat att personer med demenssjukdom kan ha nytta av tidshjälpmiddel. Det saknas dock kunskap om arbetsterapeuternas erfarenheter av att förskriva tidshjälpmiddel och om vilka bedömningsmetoder som ligger till grund för förskrivningen. Det finns instrument som bedömer tidsuppfattning och daglig tidshandling, men de är utvecklade för andra patientgrupper och har inte utvärderats för användning för personer med demenssjukdom. Dessutom finns det ett behov av utökad kunskap om sambanden mellan tidsuppfattning, daglig tidshandling och graden av demens. Tidiga åtgärder med exempelvis förskrivning av tidshjälpmiddel ökar möjligheten att personer med demenssjukdom kan lära sig att använda hjälpmedlet. Det är därför viktigt att öka kunskapen om hur man tidigt upptäcker tidsrelaterade problem vid demenssjukdom. Det är också mycket viktigt att öka förståelsen för de erfarenheter både personer med demenssjukdom och närstående har av personen med demenssjukdoms dagliga tidshandling, det stöd som ges från närstående i daglig tidshandling och användningen av tidshjälpmiddel. Det övergripande syftet med denna avhandling var därför att utforska daglig tidshandling för personer med demenssjukdom. Mer specifikt fokuserar den här avhandlingen på bedömningar av daglig tidshandling och tidsuppfattning, och på förskrivning och användning av tidshjälpmiddel ur personer med demenssjukdoms, närståendes och arbetsterapeuters perspektiv.

I studie I intervjuades arbetsterapeuter som förskriver tidshjälpmiddel till personer med demenssjukdom, och resultaten visade att de har begränsade resurser och begränsad tillgång till instrument som kan bedöma tidsrelaterade problem. Detta leder till höga krav på delaktighet och stöd från en närstående under hela förskrivningsprocessen för tidshjälpmiddel. Brist på tid leder också till begränsade möjligheter för arbetsterapeuterna att göra uppföljningar. I studie II och III användes ett objektiva instrument samt frågeformulär för självskattning som fylldes i av personer med demenssjukdom och närstående. I studie II utvärderades tre instrument för bedömning av tidsuppfattning och daglig tidshandling, KaTid-Senior, Tid-S Senior och Tid-Proxy för personer med demenssjukdom. Resultaten visade att dessa instrument var lämpliga att använda även för personer med demenssjukdom. Mer utmanande uppgifter bör dock läggas till KaTid-Senior för att bättre motsvara förmågan hos personer med lindriga symtom på demenssjukdom, och fler svarsalternativ vid självskattningarna av daglig tidshandling skulle förbättra instrumenten ytterligare. I studie III

var det viktigaste resultatet det statistiskt säkerställda sambandet mellan tidsuppfattning och svårighetsgrad av demens, särskilt vad gällde visuospatiala funktioner. Slutligen, i studie IV, visade intervjuer med personer med demenssjukdom och närstående att närstående börjar ge stöd i tidsplanering i ett tidigt skede av demenssjukdomen. Ansvar för den dagliga tidshandlingen överförs gradvis till den närstående, och stöd för daglig tidshandling ges ofta i samband med andra typer av stöd. Även om tidshjälpmiddel kan stödja tidsorientering för personen med demenssjukdom behöver närstående placera tiden i ett sammanhang. Personen med demenssjukdoms delaktighet och engagemang i den dagliga tidshandlingen kan dock ökas med stöd av tidshjälpmiddel och kalendrar.

Sammantaget är stöd från närstående väsentligt för alla aspekter av daglig tidshandling hos personer med demenssjukdom. Det är därför angeläget att även närstående får ett bra stöd och utbildning så att de i sin tur kan stödja personer med demenssjukdom i till exempel användningen av tidshjälpmiddel. Det är också viktigt att uppmärksamma att det finns en risk att personer med demenssjukdom som lever ensamma och utan stöd från närstående inte får likvärdiga insatser, som exempelvis tillgång till eller efterföljande stöd vid användning av tidshjälpmiddel. Specifika former av stöd måste därför utvecklas och riktas till dessa individer, för att säkerställa att de har rättvisa möjligheter att få tillgång till och ha nytta av tidshjälpmiddel.

Vid bedömning av tidsrelaterade problem vid demenssjukdom kan KaTid-Senior, Tid-Senior och Tid-Proxy användas både kliniskt av vårdpersonal och inom forskning. Instrumenten kan öka möjligheten att tidigt upptäcka tidsrelaterade problem, vilket kan möjliggöra tidiga insatser med rätt timing för att stödja dagliga tidshandling. Kunskap om sambanden mellan tidsuppfattning, daglig tidshandling och graden av demens kan ytterligare öka möjligheten till tidig upptäckt av tidsrelaterade problem. För en noggrann bedömning av tidsrelaterade problem hos personer med demenssjukdom bör dock objektiva mått användas tillsammans med självskattningar och närståendes skattningar.

Resultaten i studie II och III kan användas för att främja metoder för att kompensera för tidsrelaterade problem vid demens. Eftersom ansvaret för den dagliga tidshandlingen överförs till närstående i ett tidigt stadium av demenssjukdomen, bör tidsrelaterade bedömningar och insatser ges så tidigt som möjligt för att öka möjligheten att upprätthålla förmågan till dagliga tidshandling. Och även om tidshjälpmiddel och kalendrar inte används självständigt av personer med demenssjukdom, kan de vara ett stöd för att involvera personen med demenssjukdom i tidshandlingen och ge en översikt över kommande och tidigare aktiviteter. För att stödja personer med demenssjukdom i tidsrelaterade aktiviteter är samarbete och kommunikation mellan personer med demenssjukdom, närstående och arbetsterapeuter viktigt i alla skeden, från bedömningar av behov till genomförande av åtgärder såsom förskrivning av tidshjälpmiddel. Centralt för insatserna är att involvera personerna med demenssjukdom i den dagliga tidshandlingen.

10 ACKNOWLEDGEMENTS

Without the support from so many persons, this thesis would not have been written. I want to express my deep gratitude to all of you. Only a few can be mentioned here, but no one is forgotten.

First of all, I want to thank the persons with dementia, significant others and occupational therapists that participated in the studies and so generously shared your experiences and patiently responded to my questions.

My sincere gratitude also goes to:

My main supervisor Monika Löfgren. Thank you for being positive, helpful, and encouraging, and for sharing your great expertise of qualitative methodology. Thanks also for always being available for big and small issues.

My co-supervisor and project investigator for “Managing time with dementia”, Gunnel Janeslätt. Thank you for sharing your great knowledge about time and for your ability to see the possibilities in every situation. And last but not least, thank you for your kindness during those nice summer days at WFOT in Paris.

My co-supervisor Lena Dahlberg. Thank you for your helpfulness, sharp-wittedness, and always valuable points of view, with an eye for important details.

My co-supervisor Marika Möller. Thank you for fast, constructive feedback on my work, and for making me begin to appreciate statistical methodology. I also value your straightforward communication and humorous approach.

A special thanks goes to Inga-Lill Boman, who was my main supervisor when the PhD project started. You have paved the way and created opportunities to develop my interest in research and development. I have benefited a lot from the knowledge you shared both before and during my time as a PhD student.

Professor Kristian Borg, head of the Division of Rehabilitation Medicine, Department of Clinical Sciences, Danderyd Hospital, Karolinska Institutet. Thank you for providing research facilities and encouragement.

My home department at Karolinska Institutet, the Department of Clinical Sciences, Danderyd Hospital (KIDS) with Håkan Wallén, Nina Ringart and colleagues, who gave me the opportunity to become a PhD student. Thank you for your kind and immediate support in all types of questions.

My mentor Camilla Walles Malinowsky. Thank you for your everlasting kindness, calm and wise reflections, and for inviting courage and inspiration.

The University Department of Rehabilitation Medicine, Stockholm at Danderyd Hospital, Sweden for giving me the opportunity to work on this PhD project, and to all persons in the staff who helped me with all kinds of matters.

Maria Johansson, Unit manager of the Section for Specialized Brain Injury Rehabilitation Inpatient, the University Department of Rehabilitation Medicine, Stockholm at Danderyd Hospital, Sweden. Thank you for your support and encouragement throughout the years, and not least for your patience and flexibility when combining research with a clinical employment.

Christian Andersen, Manager of the University Department of Rehabilitation Medicine, Stockholm at Danderyd Hospital, Sweden. Thank you for providing me with possibilities to complete my research.

All current and past fellow PhD students at The Rehabilitation Medicine Clinic for encouragement, discussions and sharing of experiences: Märta Berthold, Natascha Ekdahl, Karolina af Ekenstam, Malin Einarsson, Anna Holmqvist, Gaia Pennati, Karin Uhlin, and Anneli Wall. A special thanks to Jeanette Plantin and Helena Hybbinette, my forerunners that have inspired and supported me, and who generously shared their knowledge and experiences.

To all researchers in the “Management time with dementia” in Sweden, India and Japan for the possibility to learn from your expertise.

To the occupational therapists that recruited the participants and collected the data: Marie Edqvist, Pernilla Engström, Anita Gustafsson, Kristin Gylén, Eva Hallin Busk, Elisabeth Henley, Terése Kans, Kerstin Kåwe, Anna Lindqvist, Riitta Montgomery, Lena Nilsson, Anna Oldebring, and Afat Sharify. I have really enjoyed working with you, and I am grateful for your sharing of valuable knowledge on dementia.

My family and friends, who did not fully understand what I was doing during these years, but who always believed in me, supported me, and reminded me of the rest of life. I am so happy and grateful for you and look forward to being a little bit more present in the future.

Per-Anders, Ida, and Sofia, who supported me through ups and downs during these years and reminded me of what is important. Thank you for being there.

The organizations who kindly provided grants to support this thesis project:

The Swedish Research Council for Health Working Life and Welfare (FORTE), the Promobilia Foundation, Demensfonden, Thureus siftelse, the University Department of Rehabilitation Medicine, Danderyd University Hospital, and the Department of Clinical Sciences, Karolinska Institutet, Danderyd Hospital.

11 REFERENCES

1. Towards a dementia plan: a WHO guide. Geneva: World Health Organization; 2018.
2. Socialstyrelsen. Nationella riktlinjer för vård och omsorg vid demenssjukdom. Stöd för styrning och ledning 2017 [2022-05-16]. Available from: <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/nationella-riktlinjer/2017-12-2.pdf>.
3. Gauthier S, Rosa-Neto P, Morais J, Webster C. World Alzheimer Report 2021: Journey through the diagnosis of dementia. Alzheimer's Disease International. 2021.
4. Kivipelto M, Mangialasche F, Ngandu T. Lifestyle interventions to prevent cognitive impairment, dementia and Alzheimer disease. *Nature Reviews Neurology*. 2018;14(11):653-66.
5. Winblad B, Amouyel P, Andrieu S, Ballard C, Brayne C, Brodaty H, et al. Defeating Alzheimer's disease and other dementias: a priority for European science and society. *The Lancet Neurology*. 2016;15(5):455-532.
6. Internationell klassifikation av funktionstillstånd, funktionshinder och hälsa (ICF) - Svensk version. Socialstyrelsen; 2022.
7. Townsend EA, Polatajko HJ. Enabling occupation II : advancing an occupational therapy vision for health, well-being & justice through occupation : 9th Canadian occupational therapy guidelines. Ottawa, Ontario: Canadian Association of Occupational Therapists; 2013.
8. Larsson-Lund M, Nyman A. Participation and occupation in occupational therapy models of practice: A discussion of possibilities and challenges. *Scand J Occup Ther*. 2017;24(6):393-7.
9. Polatajko HJ, Townsend EA, Craik J. Canadian model of occupational performance and engagement (CMOP-E). *Enabling occupation II: Advancing an occupational therapy vision of health, well-being & justice through occupation*. 2007;23.
10. WHO. International Classification of Functioning, Disability and Health (ICF) Geneva: World Health Organization; 2017 [20190709]. Available from: <https://apps.who.int/classifications/icfbrowser/>.
11. Janeslatt G. Validity in assessing time processing ability, test equating of KaTid-Child and KaTid-Youth. *Child Care Health Dev*. 2012;38(3):371-8.
12. Janeslatt G, Granlund M, Kottorp A. Measurement of time processing ability and daily time management in children with disabilities. *Disabil Health J*. 2009;2(1):15-9.
13. Nygård L, Johansson M. The Experience and Management of Temporality in Five Cases of Dementia. *Scand J Occup Ther*. 2001;8(2):85-95.
14. Topo P, Saarikalle K, Begley E, Cahill S, Holthe T, Macijauskiene J. "I don't know about the past or the future, but today it's Friday"—Evaluation of a time aid for people with dementia. *Technology and Disability*. 2007;19(2-3):121-31.
15. Vasile C. Time perception, cognitive correlates, age and emotions. *Procedia-Social and Behavioral Sciences*. 2015;187:695-9.

16. Janeslätt G, Granlund M, Alderman I, Kottorp A. Development of a new assessment of time processing ability in children, using Rasch analysis. *Child Care Health Dev.* 2008;34(6):771-80.
17. Janeslätt G, Kottorp A, Granlund M. Evaluating intervention using time aids in children with disabilities. *Scand J Occup Ther.* 2014;21(3):181-90.
18. White SM, Riley A, Flom P. Assessment of Time Management Skills (ATMS): A Practice-Based Outcome Questionnaire. *Occupational Therapy in Mental Health.* 2013;29(3):215-31.
19. Aeon B, Faber A, Panaccio A. Does time management work? A meta-analysis. *PLoS One.* 2021;16(1):e0245066.
20. Mioni G, Santon S, Stablum F, Cornoldi C. Time-based prospective memory difficulties in children with ADHD and the role of time perception and working memory. *Child Neuropsychol.* 2017;23(5):588-608.
21. Mioni G, Stablum F. Monitoring behaviour in a time-based prospective memory task: The involvement of executive functions and time perception. *Memory.* 2014;22(5):536-52.
22. Mioni G, Stablum F, McClintock SM, Cantagallo A. Time-based prospective memory in severe traumatic brain injury patients: The involvement of executive functions and time perception. *J Int Neuropsychol Soc.* 2012;18(4):697-705.
23. Sköld A, Janeslätt GK. Self-rating of daily time management in children: psychometric properties of the Time-S. *Scand J Occup Ther.* 2017;24(3):178-86.
24. ICF Update Platform <https://extranet.who.int/icfrevision/nr/loginICF.aspx>2020: World Health Organization; 2020 [2020-11-15]. Available from: <https://extranet.who.int/icfrevision/nr/loginICF.aspx>.
25. Pemberton S, Cox DL. Synchronisation: Co-ordinating Time and Occupation. *Journal of Occupational Science.* 2015;22(3):291-303.
26. Janeslätt G. Time for time: assessment of time processing ability and daily time management in children with and without disabilities: Institutionen för neurobiologi, vårdvetenskap och samhälle/Department of ...; 2009.
27. Wennberg B, Janeslätt G, Gustafsson PA, Kjellberg A. Occupational performance goals and outcomes of time-related interventions for children with ADHD. *Scand J Occup Ther.* 2021;28(2):158-70.
28. Thoft DS, Ward A. “Just ask me what it means to live with dementia” – people with mild dementia’s strategies and techniques shared through in-depth qualitative interviews. *Journal of Clinical Nursing.* 2020;n/a(n/a).
29. Dumurgier J, Dartigues JF, Gabelle A, Paquet C, Prevot M, Hugon J, et al. Time Orientation and 10 Years Risk of Dementia in Elderly Adults: The Three-City Study. *J Alzheimers Dis.* 2016;53(4):1411-8.
30. El Haj M, Gandolphe MC, Wawrziczny E, Antoine P. Flashbulb memories of Paris attacks: Recall of these events and subjective reliving of these memories in a case with Alzheimer disease. *Medicine (Baltimore).* 2016;95(46):e5448.
31. Evans D. An exploration of the impact of younger-onset dementia on employment. *Dementia.* 2016;18(1):262-81.

32. Liu L, Bulley A, Irish M. Subjective Time in Dementia: A Critical Review. *Brain Sciences*. 2021;11(11):1502.
33. Cahill S, Begley E, Faulkner J, Hagen I. "It gives me a sense of independence"—Findings from Ireland on the use and usefulness of assistive technology for people with dementia. *Technology and Disability*. 2007;19(2):133-42.
34. Wherton JP, Monk AF. Technological opportunities for supporting people with dementia who are living at home. *Int J Hum Comput Stud*. 2008;66(8):571-86.
35. Nygård L, Ryd C, Astell A, Nedlund A-C, Boger J, Mäki Petäjä Leinonen A, et al. Self-initiated management approaches in everyday occupations used by people with acquired cognitive impairment. *Scand J Occup Ther*. 2022;29(2):139-51.
36. Lindqvist E, Nygård L, Borell L. Significant junctures on the way towards becoming a user of assistive technology in Alzheimer's disease. *Scand J Occup Ther*. 2013;20(5):386-96.
37. Eriksen S, Bartlett RL, Grov EK, Ibsen TL, Telenius EW, Mork Rokstad AM. The Experience of Lived Time in People with Dementia: A Systematic Meta-Synthesis. *Dement Geriatr Cogn Disord*. 2020;49(5):435-55.
38. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975;12(3):189-98.
39. Nasreddine ZS, Phillips NA, Bédirian V, Charbonneau S, Whitehead V, Collin I, et al. The Montreal Cognitive Assessment, MoCA: A Brief Screening Tool For Mild Cognitive Impairment. *J Am Geriatr Soc*. 2005;53(4):695-9.
40. Storey JE, Rowland JTJ, Conforti DA, Dickson HG. The Rowland Universal Dementia Assessment Scale (RUDAS): a multicultural cognitive assessment scale. *Int Psychogeriatr*. 2004;16(1):13-31.
41. Ekman U, Ferreira D, Muehlboeck JS, Wallert J, Rennie A, Eriksson M, et al. The MemClin project: a prospective multi memory clinics study targeting early stages of cognitive impairment. *BMC Geriatr*. 2020;20(1):93.
42. Martyr A, Nelis SM, Clare L. Predictors of perceived functional ability in early-stage dementia: self-ratings, informant ratings and discrepancy scores. *Int J Geriatr Psychiatry*. 2014;29(8):852-62.
43. Janeslätt G, Granlund M, Kottorp A, Almqvist L. Patterns of time processing ability in children with and without developmental disabilities. *J Appl Res Intell Disab*. 2010;23(3):250-62.
44. Toglia J. *Weekly calendar planning activity: AOTA PRESS*; 2015.
45. Wingren M, Lidström-Holmqvist K, Roshanai AH, Arvidsson P, Janeslätt G, White S, et al. One-year follow-up after the time management group intervention Let's Get Organized. *Scand J Occup Ther*. 2022;29(4):305-14.
46. Janeslätt G, Lindstedt H, Adolfsson P. Daily time management and influence of environmental factors on use of electronic planning devices in adults with mental disability. *Disabil Rehabil Assist Technol*. 2015;10(5):371-7.
47. Janeslätt GK, Holmqvist KL, White S, Holmefur M. Assessment of time management skills: psychometric properties of the Swedish version. *Scand J Occup Ther*. 2018;25(3):153-61.

48. Rosenblum S. Validity and reliability of the Time Organisation and Participation Scale (TOPS). *Neuropsychol Rehabil.* 2012;22(1):65-84.
49. Rydström A, Darin-Mattsson A, Kåreholt I, Ngandu T, Lehtisalo J, Solomon A, et al. Occupational complexity and cognition in the FINGER multidomain intervention trial. *Alzheimer's & Dementia.*n/a(n/a).
50. Clare L, Evans S, Parkinson C, Woods R, Linden D. Goal-setting in cognitive rehabilitation for people with early-stage Alzheimer's disease. *Clin Gerontol.* 2011;34(3):220-36.
51. Clare L, Linden DE, Woods RT, Whitaker R, Evans SJ, Parkinson CH, et al. Goal-oriented cognitive rehabilitation for people with early-stage Alzheimer disease: a single-blind randomized controlled trial of clinical efficacy. *The American journal of geriatric psychiatry.* 2010;18(10):928-39.
52. Fabricatore C, Radovic D, Lopez X, Grasso-Cladera A, Salas CE. When technology cares for people with dementia: A critical review using neuropsychological rehabilitation as a conceptual framework. *Neuropsychol Rehabil.* 2020;30(8):1558-97.
53. Christiansen C, Baum CM, Bass-Haugen J. *Occupational therapy: Performance, participation, and well-being:* Slack Thorofare, NJ; 2005.
54. Cohen ML, Ryan AC, Lanzi AM. Prevention of and Early Intervention for Cognitive Decline Due to Alzheimer's Disease and Related Disorders. *Delaware Journal of Public Health.* 2021;7(4):118.
55. White S. Let's Get Organized: An Intervention for Persons With Co-occurring Disorders. *Psychiatr Serv.* 2007;58(5):713-.
56. Holmefur M, Lidstrom-Holmqvist K, Roshanay A, Arvidsson P, White S, Janeslatt G. Pilot Study of Let's Get Organized: A Group Intervention for Improving Time Management. *Am J Occup Ther.* 2019;73(5):73052050201-730520502010.
57. Edgelow M, Krupa T. Randomized Controlled Pilot Study of an Occupational Time-Use Intervention for People With Serious Mental Illness. *Am J Occup Ther.* 2011;65(3):267-76.
58. Krupa T, McLean H, Eastabrook S, Bonham A, Baksh L. Daily Time Use as a Measure of Community Adjustment for Persons Served By Assertive Community Treatment Teams. *Am J Occup Ther.* 2003;57(5):558-65.
59. Raj S, Mackintosh S, Fryer C, Stanley M. Home-Based Occupational Therapy for Adults With Dementia and Their Informal Caregivers: A Systematic Review. *Am J Occup Ther.* 2021;75(1):75012050601-750120506027.
60. Collins ME. Occupational Therapists' Experience with Assistive Technology in Provision of Service to Clients with Alzheimer's Disease and Related Dementias. *Phys Occup Ther Geriatr.* 2018;36(2-3):179-88.
61. Holthe T, Halvorsrud L, Lund A. Digital Assistive Technology to Support Everyday Living in Community-Dwelling Older Adults with Mild Cognitive Impairment and Dementia. *Clin Interv Aging.* 2022;17:519-44.
62. Nygård L. The meaning of everyday technology as experienced by people with dementia who live alone. *Dementia.* 2008;7(4):481-502.
63. Nygård L, Starkhammar S. The use of everyday technology by people with dementia living alone: Mapping out the difficulties. *Aging Ment Health.* 2007;11(2):144-55.

64. Rosenberg L, Kottorp A, Winblad B, Nygård L. Perceived difficulty in everyday technology use among older adults with or without cognitive deficits. *Scand J Occup Ther.* 2009;16(4):216-26.
65. Gaber SN, Nygård L, Brorsson A, Kottorp A, Malinowsky C. Everyday technologies and public space participation among people with and without dementia. *Canadian Journal of Occupational Therapy.* 2019;86(5):400-11.
66. Kenigsberg PA, Aquino JP, Berard A, Bremond F, Charras K, Denning T, et al. Assistive Technologies to Address Capabilities of People with Dementia: From Research to Practice. *Dementia (London).* 2019;18(4):1568-95.
67. ISO 21802:2019. Assistive products, Guidelines on cognitive accessibility, Daily time management. 2019.
68. Frank Lopresti E, Mihailidis A, Kirsch N. Assistive technology for cognitive rehabilitation: State of the art. *Neuropsychol Rehabil.* 2004;14(1-2):5-39.
69. Gillespie A, Best C, O'Neill B. Cognitive function and assistive technology for cognition: A systematic review. *J Int Neuropsychol Soc.* 2012;18(1):1-19.
70. Boger J, Quraishi M, Turcotte N, Dunal L. The identification of assistive technologies being used to support the daily occupations of community-dwelling older adults with dementia: a cross-sectional pilot study. *Disability and Rehabilitation: Assistive Technology.* 2014;9(1):17-30.
71. Daly Lynn J, Rondón-Sulbarán J, Quinn E, Ryan A, McCormack B, Martin S. A systematic review of electronic assistive technology within supporting living environments for people with dementia. *Dementia.* 2019;18(7-8):2371-435.
72. Klimova B, Valis M, Kuca K. Exploring assistive technology as a potential beneficial intervention tool for people with Alzheimer's disease—a systematic review. *Neuropsychiatr Dis Treat.* 2018;14:3151-8.
73. Lenker JA, Harris F, Taugher M, Smith RO. Consumer perspectives on assistive technology outcomes. *Disability and Rehabilitation: Assistive Technology.* 2013;8(5):373-80.
74. King AC, Dwan C. Electronic memory aids for people with dementia experiencing prospective memory loss: A review of empirical studies. *Dementia.* 2019;18(6):1994-2007.
75. Meiland F, Innes A, Mountain G, Robinson L, van der Roest H, García-Casal JA, et al. Technologies to Support Community-Dwelling Persons With Dementia: A Position Paper on Issues Regarding Development, Usability, Effectiveness and Cost-Effectiveness, Deployment, and Ethics. *JMIR Rehabilitation and Assistive Technologies.* 2017;4(1):e1.
76. van Boekel LC, Wouters EJ, Grimberg BM, van der Meer NJ, Luijkx KG, editors. Perspectives of stakeholders on technology use in the care of community-living older adults with dementia: A systematic literature review. *Healthcare; 2019: Multidisciplinary Digital Publishing Institute.*
77. Olsson A, Persson A-C, Bartfai A, Boman I-L. Sensor technology more than a support. *Scand J Occup Ther.* 2017:1-9.
78. Bartfai A, Boman I-L. A multiprofessional client-centred guide to implementing assistive technology for clients with cognitive impairments. *Technology and Disability.* 2014;26(1):11-21.

79. de Joode E, van Heugten C, Verhey F, van Boxtel M. Efficacy and usability of assistive technology for patients with cognitive deficits: a systematic review. *Clin Rehabil.* 2010;24(8):701-14.
80. Clarkson P, Pitts R, Islam S, Peconi J, Russell I, Fegan G, et al. Dementia Early-Stage Cognitive Aids New Trial (DESCANT) of memory aids and guidance for people with dementia: randomised controlled trial. *Journal of Neurology, Neurosurgery & Psychiatry.* 2021:jnnp-2021-326748.
81. Dahlberg L, Berndt H, Lennartsson C, Schön P. Receipt of Formal and Informal Help with Specific Care Tasks among Older People Living in their Own Home. National Trends over Two Decades. *Soc Pol Admin.* 2018;52(1):91-110.
82. Genet N, Boerma WGW, Kringos DS, Bouman A, Francke AL, Fagerström C, et al. Home care in Europe: a systematic literature review. *BMC Health Serv Res.* 2011;11(1):207.
83. Dahlberg L, Ahlström G, Bertilsson G, Fahlström G. Kunskapsläget för bedömning och insatser inom äldreomsorgen [Social care and services for older adults. An evidence map addressing assessment and interventions]. Report 306/2019. Stockholm: Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU), 2019. Stockholm: Swedish Agency for Health Technology Assessment and Assessment of Social Services [Statens beredning för medicinsk och social utvärdering, SBU]. 2019.
84. Socialstyrelsen. Nationella riktlinjer – Utvärdering 2018. Vård och omsorg vid demenssjukdom 2018. Indikatorer och underlag för bedömningar. 2018 [200203]. Available from: <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/nationella-riktlinjer/2018-3-2.pdf>.
85. Odzakovic E, Hydén L-C, Festin K, Kullberg A. People diagnosed with dementia in Sweden: What type of home care services and housing are they granted? A cross-sectional study. *Scand J Public Health.* 2018;47(2):229-39.
86. Wimo A, Elmstahl S, Fratiglioni L, Sjolund BM, Skoldunger A, Fagerstrom C, et al. Formal and Informal Care of Community-Living Older People: A Population-Based Study from the Swedish National Study on Aging and Care. *J Nutr Health Aging.* 2017;21(1):17-24.
87. Szebehely M, Trydegård G-B. Home care for older people in Sweden: a universal model in transition. *Health & Social Care in the Community.* 2012;20(3):300-9.
88. Ulmanen P, Szebehely M. From the state to the family or to the market? Consequences of reduced residential eldercare in Sweden. *Int J Soc Welfare.* 2015;24(1):81-92.
89. Hwang AS, Rosenberg L, Kontos P, Cameron JI, Mihailidis A, Nygard L. Sustaining care for a parent with dementia: an indefinite and intertwined process. *Int J Qual Stud Health Well-being.* 2017;12(sup2):1389578.
90. Van der Roest HG, Wenborn J, Pastink C, Droes RM, Orrell M. Assistive technology for memory support in dementia. *Cochrane Database Syst Rev.* 2017;6(6):CD009627.
91. Yong ASL, Price L. The human occupational impact of partner and close family caregiving in dementia: a meta-synthesis of the qualitative research, using a bespoke quality appraisal tool. *Br J Occup Ther.* 2014;77(8):410-21.

92. Johansson MF, McKee KJ, Dahlberg L, Summer Meranius M, Williams CL, Marmstål Hammar L. Negative Impact and Positive Value of Caregiving in Spouse Carers of Persons with Dementia in Sweden. *International Journal of Environmental Research and Public Health*. 2022;19(3).
93. Roth DL, Fredman L, Haley WE. Informal caregiving and its impact on health: A reappraisal from population-based studies. *The Gerontologist*. 2015;55(2):309-19.
94. Pysklywec A, Plante M, Auger C, Mortenson WB, Eales J, Routhier F, et al. The positive effects of caring for family carers of older adults: a scoping review. *International Journal of Care and Caring*. 2020;4(3):349-75.
95. Prince M, Wimo A, Guerchet M, Ali GC, Wu YT, Prina M. The global impact of dementia. *World Alzheimer Report*. 2015:1-82.
96. Lethin C, Hanson E, Margioti E, Chiatti C, Gagliardi C, Vaz de Carvalho C, et al. Support Needs and Expectations of People Living with Dementia and Their Informal Carers in Everyday Life: A European Study. *Social Sciences*. 2019;8(7):203.
97. Hiel L, Beenackers MA, Renders CM, Robroek SJW, Burdorf A, Croezen S. Providing personal informal care to older European adults: Should we care about the caregivers' health? *Prev Med*. 2015;70:64-8.
98. Johansson MF, McKee KJ, Dahlberg L, Williams CL, Summer Meranius M, Hanson E, et al. A comparison of spouse and non-spouse carers of people with dementia: a descriptive analysis of Swedish national survey data. *BMC Geriatr*. 2021;21(1):338.
99. Gibson G, Dickinson C, Brittain K, Robinson L. Personalisation, customisation and bricolage: how people with dementia and their families make assistive technology work for them. *Ageing and Society*. 2018:1-18.
100. Holthe T, Halvorsrud L, Karterud D, Hoel K-A, Lund A. Usability and acceptability of technology for community-dwelling older adults with mild cognitive impairment and dementia: a systematic literature review. *Clin Interv Aging*. 2018;13:863.
101. Riikonen M, Paavilainen E, Salo H. Factors supporting the use of technology in daily life of home-living people with dementia. *Technology and Disability*. 2013;25:233-43.
102. Rosenberg L, Nygård L. Persons with dementia become users of assistive technology: A study of the process. *Dementia*. 2011;11(2):135-54.
103. Rosenberg L, Kottorp A, Nygård L. Readiness for Technology Use With People With Dementia: The Perspectives of Significant Others. *J Appl Gerontol*. 2011;31(4):510-30.
104. Sriram V, Jenkinson C, Peters M. Informal carers' experience of assistive technology use in dementia care at home: a systematic review. *BMC Geriatr*. 2019;19(1):160.
105. Evans N, Collier L. An exploration of the experience of using calendar reminders for people with dementia and family carers. *Dementia (London)*. 2019;18(5):1912-33.
106. Widehammar C, Lidström H, Hermansson L. Environmental barriers to participation and facilitators for use of three types of assistive technology devices. *Assist Technol*. 2017:1-9.
107. Persson M, Zingmark K. Living with a person with Alzheimer's disease: Experiences related to everyday occupations. *Scand J Occup Ther*. 2006;13(4):221-8.

108. Nygård L. How can we get access to the experiences of people with dementia? Suggestions and reflections. *Scand J Occup Ther.* 2006;13(2):101-12.
109. Canadian Occupational Performance Measure (COPM). Svensk version, Femte upplagan. 2016.
110. Persson M, Janeslatt G, Peny-Dahlstrand M. Daily time management in children with spina bifida. *J Pediatr Rehabil Med.* 2017;10(3-4):295-302.
111. Elo S, Kyngäs H. The qualitative content analysis process. *Journal of advanced nursing.* 2008;62(1):107-15.
112. Lincoln YS, Guba EG. *Naturalistic inquiry.* Beverly Hills, Calif.: Sage; 1985.
113. Linacre JM. Optimizing rating scale category effectiveness. *Journal of applied measurement.* 2002;3(1):85-106.
114. Bond TG, Fox CM. *Applying the Rasch model : fundamental measurement in the human sciences.* London: Routledge; 2015.
115. Boone WJ, Noltemeyer A. Rasch analysis: A primer for school psychology researchers and practitioners. *Cogent Education.* 2017;4(1):1416898.
116. Holmefur MM, Krumlinde-Sundholm L. Psychometric properties of a revised version of the Assisting Hand Assessment (Kids-AHA 5.0). *Dev Med Child Neurol.* 2016;58(6):618-24.
117. Bonsaksen T, Kottorp A, Gay C, Fagermoen MS, Lerdal A. Rasch analysis of the General Self-Efficacy Scale in a sample of persons with morbid obesity. *Health Qual Life Outcomes.* 2013;11(1):202.
118. Fan CW, Yazdani F, Carstensen T, Bonsaksen T. Rasch analysis of the Self-Efficacy for Therapeutic Use of Self questionnaire in Norwegian occupational therapy students. *Scand J Occup Ther.* 2020:1-11.
119. Linacre JM. *Winsteps® Rasch measurement computer program user's guide.* Beaverton, Oregon: Winsteps com. 2020.
120. Fallahpour M, Kottorp A, Nygård L, Lund ML. Perceived difficulty in use of everyday technology in persons with acquired brain injury of different severity: a comparison with controls. *J Rehabil Med.* 2014;46(7):635-41.
121. Scanlan JN. Evaluation of the construct and internal validity of the Professional Identity Questionnaire: A Rasch analysis. *Aust Occup Ther J.* 2018;65(5):395-404.
122. von Kutzleben M, Schmid W, Halek M, Holle B, Bartholomeyczik S. Community-dwelling persons with dementia: what do they need? What do they demand? What do they do? A systematic review on the subjective experiences of persons with dementia. *Aging Ment Health.* 2012;16(3):378-90.
123. Martyr A, Clare L. Awareness of functional ability in people with early-stage dementia. *Int J Geriatr Psychiatry.* 2018;33(1):31-8.
124. Öhman A, Josephsson S, Nygaard L. Awareness through interaction in everyday occupations: experiences of people with Alzheimer's disease. *Scand J Occup Ther.* 2008;15(1):43-51.
125. Hellström I, Nolan M, Lundh U. Sustaining 'couplehood': Spouses' strategies for living positively with dementia. *Dementia.* 2007;6(3):383-409.

126. Hedman R, Norberg A, Hellström I. Agency and Communion in People with Alzheimer's Disease, as Described by Themselves and their Spousal Carers. *Dementia*. 2017;18(4):1354-72.
127. Merrick K, Camic PM, O'Shaughnessy M. Couples constructing their experiences of dementia: A relational perspective. *Dementia*. 2013;15(1):34-50.
128. Stigen L, Bjork E, Lund A. The power of observation. Occupational therapists' descriptions of doing observations of people with cognitive impairments in the context of community practice. *Scand J Occup Ther*. 2020:1-13.
129. Bielsten T, Hellström I. A review of couple-centred interventions in dementia: Exploring the what and why – Part A. *Dementia*. 2017;18(7-8):2436-49.
130. Romero-Ayuso D, Castellero-Perea Á, González P, Navarro E, Molina-Massó JP, Funes MJ, et al. Assessment of cognitive instrumental activities of daily living: a systematic review. *Disabil Rehabil*. 2021;43(10):1342-58.
131. Curnow E, Rush R, Maciver D, Górska S, Forsyth K. Exploring the needs of people with dementia living at home reported by people with dementia and informal caregivers: a systematic review and Meta-analysis. *Aging Ment Health*. 2021;25(3):397-407.
132. Bosco A, Schneider J, Coleston-Shields DM, Jawahar K, Higgs P, Orrell M. Agency in dementia care: systematic review and meta-ethnography. *Int Psychogeriatr*. 2019;31(5):627-42.
133. Gibson G, Dickinson C, Brittain K, Robinson L. The everyday use of assistive technology by people with dementia and their family carers: a qualitative study. *BMC Geriatr*. 2015;15(1):89.
134. Nishiura Y, Nihei M, Nakamura-Thomas H, Inoue T. Effectiveness of using assistive technology for time orientation and memory, in older adults with or without dementia. *Disabil Rehabil Assist Technol*. 2019:1-7.
135. Boyle G. Recognising the agency of people with dementia. *Disability & Society*. 2014;29(7):1130-44.
136. Wallcook S, Nygård L, Kottorp A, Malinowsky C. The use of everyday information communication technologies in the lives of older adults living with and without dementia in Sweden. *Assist Technol*. 2021;33(6):333-40.
137. Förskrivning av hjälpmedel. Stöd vid förskrivning av hjälpmedel till personer med funktionsnedsättning.: Socialstyrelsen; 2021 [Available from: <https://www.socialstyrelsen.se/>].
138. Miranda-Castillo C, Woods B, Orrell M. People with dementia living alone: what are their needs and what kind of support are they receiving? *Int Psychogeriatr*. 2010;22(4):607-17.
139. Yong ASL, Price L, Napier F, Matthews K. Supporting sustainable occupational lives for partner caregivers of people with dementia. *Br J Occup Ther*. 2020;83(9):595-604.
140. Tsunaka M, Chung JCC. Care-givers' perspectives of occupational engagement of persons with dementia. *Ageing and Society*. 2012;32(4):543-60.
141. Chung PYF, Ellis-Hill C, Coleman P. Supporting activity engagement by family carers at home: maintenance of agency and personhood in dementia. *International Journal of Qualitative Studies on Health and Well-being*. 2017;12(1):1267316.

142. Chiao CY, Wu HS, Hsiao CY. Caregiver burden for informal caregivers of patients with dementia: A systematic review. *International Nursing Review*. 2015;62(3):340-50.
143. Hellström I, Nolan M, Lundh U. 'We do things together': A case study of 'couplehood' in dementia. *Dementia*. 2005;4(1):7-22.
144. Vikström S, Josephsson S, Stigsdotter-Neely A, Nygård L. Engagement in activities: Experiences of persons with dementia and their caregiving spouses. *Dementia*. 2008;7(2):251-70.
145. Yu DSF, Cheng S-T, Wang J. Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *Int J Nurs Stud*. 2018;79:1-26.
146. Piersol CV, Canton K, Connor SE, Giller I, Lipman S, Sager S. Effectiveness of Interventions for Caregivers of People With Alzheimer's Disease and Related Major Neurocognitive Disorders: A Systematic Review. *Am J Occup Ther*. 2017;71(5):7105180020p1-p10.
147. Thurmond VA. The Point of Triangulation. *J Nurs Scholarsh*. 2001;33(3):253-8.
148. Clare L, Whitaker CJ, Nelis SM. Appraisal of Memory Functioning and Memory Performance in Healthy Ageing and Early-Stage Alzheimer's Disease. *Aging, Neuropsychology, and Cognition*. 2010;17(4):462-91.
149. Hill NL, Mogle J, Whitaker EB, Gilmore-Bykovskyi A, Bhargava S, Bhang IY, et al. Sources of Response Bias in Cognitive Self-Report Items: "Which Memory Are You Talking About?". *The Gerontologist*. 2019;59(5):912-24.
150. Velayudhan L, Baillon S, Daby L, Suntharamoorthy P, Kablan A, Tromans S, et al. Predictors of Disease Progression in Early-Onset Alzheimer's Dementia: A Retrospective Cohort Study. *J Am Med Dir Assoc*. 2020;21(11):1735-9.