

Sensory stimulation for people with dementia

The effect of the Sonas
programme on communication

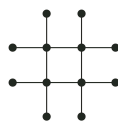
**Sensory stimulation for people with dementia:
The effect of the Sonas programme on communication**

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Dissertation Submitted
in Partial Fulfilment of the Requirements
for the Degree of Philosophiae Doctor (Ph.D)

VID Specialized University

2017



VID

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ISBN: 978-82-93490-16-6

ISSN: 2535-3071

*Dissertation Series for the Degree of Philosophiae Doctor (Ph.D.)
at VID Specialized University, Volume no. 6*

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Cover: Dinamo

Printed in Norway: F.J. Stenersen AS, 2017.

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In loving memory of
Inger Elisabeth Sørensen Doksrud (1940-2007)
og
Tormod Strøm (1937-2009)

“Communication becomes the crucial difference between isolation and social connectedness, between dependence and independence, and between withdrawal and fulfilment”.

Lubinski, 1981. p 339

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Acknowledgements

First of all I wish to thank VID Specialized University and the pro-dean Liv Thorhild Undheim at the Faculty of Health and Nursing, for giving me the position of a research fellow. I would also like to thank my two supervisors Professor Ellen-Karine Grov and Professor Knut Engedal for their guidance and support during the PhD process. Their knowledge and availability have been most valuable and of importance to be able to complete this work. My thanks to Professor Siri Ytrehus for her valuable guidance at the beginning of the project, to Professor Hans Stifoss-Hanssen for his support and to Jurate Saltyte Benth for her help with statistics. I am grateful to the librarian Hilde Trygstad and her staff who helped me to find books and articles for the PhD.

I express my sincere gratitude to Sr. Mary Threadgold, the foundress of the Sonas programme, for providing me with valuable information concerning the background and knowledge of her brainchild and for all her great and valuable support.

My gratitude to the management of the seven included nursing homes in Ireland and to the nurses who helped with data collection. I am also grateful to the Sonas aPc for providing free Sonas training for staff in the included nursing homes and for helping out with providing necessary information.

A special thanks to the Sisters of St. Joseph of Cluny and the Province of Ireland and Great Britain who gave me the opportunity to do the PhD, to Sr. Morag Collins for her proof reading of both the articles and thesis. Also a thank to Sr. Bernadette Pinto and Sr. Susanne Hoyos for all their support and encouragement during these four years.

My thanks also to all my co-research fellows, and especially Åse Holmberg, Hilde Frøkedal, Ingerbjørg Haugen and Hilde Lausund for time spent in discussions and sharing about our projects.

A special thanks to my sister and co-research fellow, Hanne Maria Bingen, for all the support and encouragement and to my niece Therese and nephew Andreas for their help with copying and numbering all the assessment forms for the research.

To all my other friends who were directly or indirectly involved, I say thank you.

Abstract

Background

The increase in communication difficulties among people living with dementia and their reduced ability to interpret sensory stimulation, emphasize the need to find appropriate interventions to overcome these challenges. A variety of sensory stimulation interventions has been developed; however, neither the effect of these interventions nor their characteristics are clear. In addition, strategies developed to improve communication in people with dementia are limited, as well as psychometrically tested communication scales to assess their communication ability.

Aims

The thesis has three aims

- Provide an overview of available sensory stimulation interventions and their effect on persons with dementia and to present theoretical and methodological characteristics of the studies included (sub-study 1).
- Investigate the psychometric properties of the Holden Communication Scale and the association between scores on the Holden Communication Scale and cognitive function among persons with dementia (sub-study 2).
- Examine the effect of the Sonas programme on communication ability for people with moderate to severe dementia living in nursing homes and to explore if any effect could be related to cognitive function and different aspects of communication (sub-study 3).

Design

In order to achieve the above aims of the study, three sub-studies were conducted. The first sub-study was a literature review of sensory stimulation for people with dementia, whereas sub-study two was a psychometric evaluation of the Holden Communication Scale. The third sub-study was a randomized controlled trial, conducted over a period of 24 weeks.

Methods

Three different methods were used in the study. First, a search for available sensory stimulation interventions was performed, using CINAHL, PubMed (Medline), The Cochrane library and PsycINFO. The 55 studies included were subject to a quality assessment by means of the Critical Appraisal Skills Programme.

The psychometric evaluation of the Holden Communication Scale included 128 participants. Internal consistency was assessed by Cronbach's alpha coefficient and inter-item correlations. To test the instrument's stability a test-retest was carried out. An exploratory factor analysis with principal components extraction method and oblimin rotation was performed to evaluate construct validity. To explore associations between the scores on Holden Communication Scale and cognitive function, Pearson's correlation coefficients were calculated.

The three-armed (Sonas, reading and control group) randomized controlled trial, which included a sample of 120 people with dementia was performed. The study was conducted over a period 24 weeks and 105 completed follow-up assessments. The main outcome was change in communication abilities measured by the Holden Communication Scale (Appendix 1).

Results

The literature review (sub-study 1), including 55 studies, revealed that even though more than half of the studies referred to a theoretical foundation, several had methodological limitations. The variation in sample size, length of interventions, different treatment approaches and outcomes made it difficult to compare the studies. The majority of the studies used negative outcome such as aggression, whereas only one of the included studies used communication ability as the primary outcome. Even though it is difficult to make an overall conclusion of the effect of using different sensory stimulation approaches, the majority of the music interventions reported a positive effect. However, whether receiving multi-sensory or single-sensory stimulation or attending a group session compared with individual sessions, the possible effect on communication was not sufficiently explored.

The psychometric evaluation of the Holden Communication Scale (sub-study 2) revealed that the Holden Communication Scale is a reliable and valid instrument for assessing communication ability in persons with dementia. Even though the factor analysis revealed a one-component structure, a forced three-factor analysis was performed based on the original subgrouping, which resulted in a different distribution of the subgrouping, with a higher explained variance.

Even though no overall significant effect of the Sonas programme was found, there was an intervention effect between the Sonas group and the reading and control group, respectively. The Sonas group also demonstrated a significant improvement during the 24 week period, whereas the reading group showed an almost unchanged communication ability and the control group a decrease. Some of the aspects of communication, such as showing

interest in past events, humour and having general knowledge, showed effect. A significant improvement in communication ability was found among those with severe dementia when stratified on cognitive function.

Conclusion

These findings indicate that the Sonas programme has an intervention effect on some aspects of communication and that the programme is most suitable for people with severe dementia.

The present study has also overcome some of the methodological weaknesses found in previous research on the Sonas programme.

Sammendrag

Bakgrunn

Økningen i kommunikasjonsvansker hos personer som lever med demens og deres nedsatte evne til å fortolke sanseinformasjon understreker behovet for å finne passende intervensjoner som kan overvinne disse utfordringene. En rekke sansestimulerende intervensjoner har blitt utviklet, men verken virkningene av eller kjennetegn ved disse intervensjonene har imidlertid blitt klarlagt. I tillegg er det utviklet få strategier for forbedret kommunikasjon med personer med demens, og få psykometrisk testede kommunikasjonskalaer for vurdering av deres kommunikasjonsevne.

Mål

Avhandlingen har tre mål:

- Å gi en oversikt over tilgjengelige intervensjoner for sansestimulering og deres effekt på personer med demens, og presentere teoretiske og metodologiske kjennetegn ved de inkluderte studiene (delstudie 1).
- Å studere de psykometriske egenskapene av Holdens kommunikasjonskala og sammenhengen mellom skår på Holdens kommunikasjonskala og kognitiv funksjon hos personer med demens (delstudie 2).
- Å undersøke virkningen av Sonas-programmet på kommunikasjonsevnen hos personer med moderat til alvorlig demens i sykehjem, og utforske hvorvidt en eventuell effekt kan relateres til kognitiv funksjon og ulike aspekter av kommunikasjon (delstudie 3).

Design

For å nå målene med studien ble det gjennomført tre delstudier. Den første delstudien besto i en gjennomgang av litteratur om sansestimulering av personer med demens, mens delstudie 2 omfattet en psykometrisk vurdering av Holdens kommunikasjonskala. Den tredje delstudien omfattet en randomisert, kontrollert studie gjennomført over en periode på 24 uker.

Metoder

I avhandlingen er det benyttet tre ulike metoder. For det første ble det foretatt søk i CINAHL, PubMed (Medline), Cochrane Library og PsychInfo etter tilgjengelige studier av intervensjoner for sansestimulering. De 55 studiene som ble inkludert ble kvalitetskontrollert ved hjelp av Critical Appraisal Skills-programmet.

Den psykometriske vurderingen av Holdens kommunikasjonsskala omfattet 128 deltakere. Intern konsistens ble vurdert ved hjelp av Cronbachs alfa-koeffisient og inter-item-korrelasjoner. Det ble foretatt en test-retest for å teste instrumentets stabilitet. En eksplorerende faktoranalyse med metode for uttrekk av prinsipalkomponenter og oblimin-rotasjon ble gjennomført for å vurdere konstruktvaliditet. Pearsons korrelasjonskoeffisient ble beregnet for å undersøke sammenhenger mellom skår på Holdens kommunikasjonsskala og kognitiv funksjon.

Det ble gjennomført en trearmet (Sonas, lesegruppe og kontrollgruppe) randomisert, kontrollert studie som omfattet et utvalg på 120 personer med demens. Studien ble gjennomført over en periode på 24 uker med 105 fullførte oppfølgingsvurderinger. Hovedutfallet besto i endring i kommunikasjonsevne målt ved hjelp av Holdens kommunikasjonsskala.

Resultater

Litteraturgjennomgangen (delstudie 1) omfattet 55 studier og viste at selv om mer enn halvparten av studiene henviste til et teoretisk grunnlag, var det mange som hadde metodologiske begrensninger. Variasjoner i utvalgsstørrelse, lengden på intervensjonene, ulike tilnærminger til behandling og ulike utfall gjorde det vanskelig å sammenligne studiene. Flertallet av studiene brukte negativt utfall, slik som aggresjon, mens bare én av de inkluderte studiene brukte kommunikasjonsevne som primærutfall. Selv om det er vanskelig å trekke en generell konklusjon om effekt av bruken av ulike strategier for sansestimulering, rapporterte flertallet av de musikkbaserte intervensjonene en positiv effekt. Imidlertid ble det ikke tilstrekkelig studert hvorvidt mottak av enten multisensorisk eller monosensorisk stimulering, eller deltakelse i gruppeintervensjoner sammenlignet med individuelle møter, hadde noen mulig effekt på kommunikasjon.

Den psykometriske vurderingen av Holdens kommunikasjonsskala (delstudie 2) viste at skalaen er et pålitelig og valid instrument for vurdering av kommunikasjonsevne hos personer med demens. Selv om faktoranalysen viste at strukturen besto av en enkelt komponent, ble det gjennomført en tvungen trefaktoranalyse på basis av den opprinnelige undergrupperingen, noe som resulterte i en fordeling som avvek fra undergrupperingen, med høyere forklart varians.

Selv om det ikke ble funnet noen overordnet signifikant effekt av Sonas-programmet, var det en intervensjonseffekt mellom henholdsvis Sonas-gruppen, lesegruppen og kontrollgruppen. Sonas-gruppen oppviste også en signifikant forbedring over den 24 uker

lange perioden, mens lesegruppen hadde en nesten uendret kommunikasjonsevne og kontrollgruppen oppviste en nedgang. Det ble funnet en effekt på enkelte aspekter av kommunikasjon, slik som interesse for tidligere hendelser, humor og allmennkunnskap. En signifikant forbedret kommunikasjonsevne ble funnet blant deltakere med alvorlig demens ved stratifisering etter kognitiv funksjon.

Konklusjon

Disse funnene antyder at Sonas-programmet har en intervensjonseffekt på enkelte aspekter av kommunikasjon, og at programmet er mest egnet for personer med alvorlig demens. Den foreliggende avhandlingen har dermed overvunnet noen av de metodologiske svakhetene ved tidligere forskning om Sonas-programmet.

Abbreviations

AD	Alzheimer's dementia
ADL	Barthel Activity of Daily Living Index
APC	Attention placebo control
BPSD	Behavioural and psychological symptoms of dementia
CASP	Critical Appraisal Skills Program
CBS	Communication Problems Scale
CDR	Clinical Dementia Rating Scale
CLB	Core Linguistic Battery
DON	Director of Nursing
EEA	European Economic Area
FTD	Frontotemporal Dementia
GDS	Geriatric Deterioration Scale
HCS	Holden Communication Scale
HIQA	Health Information and Quality Authority
ITT	Intention-to-treat
LBD	Lewy body dementia
MMSE	Mini-Mental State Examination
NH	Nursing Home
NPS	Neuropsychiatric symptoms
P-CAT	Person-centred Care Assessment Tool
QoL	Quality of Life
REK	Regional Committees for medical and health research Ethics
RCT	Randomized controlled trial
SAS	Statistical Analysis Software
SLP	Sonos licensed practitioner
SPSS	Statistic Program for Social Sciences
TCT	Threadgold Communication Tool
TAU	Treatment as usual
T0	Baseline
T1	After 12 weeks
T2	After 24 weeks
VaD	Vascular Dementia
WHO	The World Health Organization

List of papers

- I. Strøm BS., Ytrehus S., Grov E-K. (2016). Sensory stimulation for persons with dementia: a review of the literature, *Journal of Clinical Nursing* 25 (13-14), 1805-1834.
- II. Strøm BS., Engedal K., Saltyte Benth J., Grov E-K. (2016). The psychometric properties of the Holden Communication Scale *BMJ Open* 6 (12), 1-7.
- III. Strøm BS., Engedal K., Saltyte Benth J., Grov E-K. (2017). Effect of the Sonas Programme on Communication in People with Dementia: A Randomized Controlled Trial, *Dementia and Geriatric Cognitive Disorders Extra* 7 (1), 122-135.

1 Introduction

Most countries throughout the world have an aging population, which leads to an increase in number of people with dementia (Plassman et al., 2007). Dementia is a life changing condition and a diagnosis of dementia is often very distressing for the individual and for immediate family members. It affects the memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment (World Health Organization, 2012). Even though no further deterioration of the senses than what is seen in normal aging is documented, there is a reduced ability to interpret what they see, hear, feel, taste and smell due to dementia (Bakker, 2003; National Institutes of Health, 2002).

An increase in communication difficulties is common in people with dementia, especially at a later stage of the various dementia disorders (Engedal, Haugen, & Brækhus, 2009). Even though word retrieval worsens (Cummings, Benson, Hill, & Read, 1985), the persons' ability to express their needs and emotions by the use of non-verbal communication is maintained longer. Therefore, improving the communication ability can prevent the person from being isolated (Acton, 1999; Acton, Yauk, Hopkins, & Mayhew, 2007; Kitwood, 1997). An early recognition of communication difficulties can help practitioners to explore ways of maintaining social communication and thereby prevent isolation as well as adapting the environment according to the person's needs. However, there are a limited number of tools to assess communication ability in people living with dementia. The Holden communication Scale (HCS) has been used in different studies; however, to our knowledge no psychometric evaluation has been performed. Nevertheless, such an evaluation would be necessary to be able to use the HCS as an outcome measure.

So far there is no cure for dementia, and therefore psychosocial interventions are recommended (Gauthier, Leuzy, Racine, & Rosa-Neto, 2013), with the main focus on improving quality of life (QoL). The importance of providing meaningful activities is one of the important aspects of the person-centred approach, developed by Kitwood (1997) and is recommended by the NICE guidelines (NICE, 2012) and The Norwegian Directorate of Health (2016). Even though several psychosocial interventions have been developed, some of them focusing on sensory stimulation, their methodological and theoretical characteristics are unclear.

One form of psychosocial interventions is a multi-sensory stimulation approach, the Sonas programme which involves cognitive, sensory, and social stimulation, including all five senses; touch, smell, taste, hearing and sight. The purpose of the Sonas programme is to

activate whatever potential for communication there is (Sonas aPc, 2011), based on Kitwood's idea of person-centred care: maximizing each person's potential, rather than focusing on limitations (Edvardsson, Winblad, & Sandman, 2008). Despite the Sonas programme being widely used in Irish nursing homes, little evidence of effect have been documented.

The main aim of this doctoral thesis is therefore to explore the effect of the Sonas programme on communication among people living with dementia. Investigating the effect of the Sonas programme according to the aim of the programme is important for further implementation of the programme. However, exploring the effect on the different aspects of communication and the level of dementia and investigating who the programme is most suitable for, is examined as well (sub-study 3).

In addition, an overview of available sensory stimulation interventions and their methodological and theoretical characteristics are presented in sub-study 1. Based on the importance of using psychometric tested tools when assessing communication ability, the psychometric evaluation of the HCS is presented in sub-study 2.

2 Background

2.1 Dementia

Dementia, which is recognized by the World Health Organization (WHO) as a public health priority (World Health Organization, 2012), is a clinical syndrome and not a simple disease. Dementia can be caused by various brain disorders, where the most common are Alzheimer's disease, vascular dementia, frontotemporal dementia and dementia with Lewy bodies (Engedal et al., 2009). These will be further described in 2.1.5.

2.1.1 Prevalence and incidence

Approximately 46.8 million persons worldwide are estimated to live with dementia and, in accordance with Alzheimer's Disease International (Prince et al., 2015) these numbers will nearly double every 20 years, especially in Asia, to an estimation of 74.7 million in 2030, and 131.5 million in 2050. Most countries throughout the world have an aging population, which leads to an increase in the number of people with dementia (Plassman et al., 2007) with an estimate of 9.9 million new cases of dementia every year, with the highest incidence rate seen in the group over 90 years of age.

As for Norway, 78.000 people were calculated to have dementia in 2013 (Vossius et al., 2015) and it is expected to reach to around 140.000 in 2050 (Ferri et al., 2005). Pierce, Cahill, and O'Shea (2014) report much lower figures for Ireland where approximately 41.740 people were likely to have dementia in 2006. This could be due to the relatively low proportion of older people (11%) as well as dementia being an under-prioritised issue in Ireland. However, this number is estimated to reach around 140,000 in 2041 in Ireland (Pierce et al., 2014).

Even though dementia is one of the leading causes of disability and admission to nursing homes in Ireland (Alzheimer's Society, 2007), only 38% was reported to be formally diagnosed with dementia in an Irish study of 2010 (Nursing Home Ireland, 2010). Therefore it is estimated that approximately as many as 89% of nursing home residents in Ireland have dementia (Cahill, O'Shea, & Pierce, 2012).

2.1.2 The symptoms of dementia

Most brain diseases leading to dementia are of a progressive nature and incurable and they are characterized by a chronic and irreversible cognitive decline, lack of ability to perform

activities of daily living (ADL) and change in social behaviour. Dementia is characterized by cognitive, motoric, behavioural and psychological symptoms (Engedal et al., 2009).

Cognitive symptoms

There are several symptoms of cognitive decline, such as reduced awareness, which leads to difficulties in interpreting stimuli. This reduced ability to interpret stimuli affects the capacity to learn as well as to remember. The ability to identify stimuli, new or old, is reduced with dementia and could lead to restlessness and insecurity. Short-time memory like difficulties with remembering names and recent events is present already in the early stage of dementia disorders. The ability to remember what has happened in the past (retrospective) as well as planning for the future (prospective) is part of long-term memory and are affected already at an early stage. However, long-term memory is not affected to the same degree and will differ depending on the type of dementia (Engedal et al., 2009).

A reduced sense of orientation, where the person might get lost while driving or have difficulties recognizing objects seen from different angles, is common in dementia, often at an early stage of the disease. The navigation in unfamiliar places is often severely disturbed, whereas the navigation (to find the way) in familiar surroundings are better preserved (ibid).

Language problems due to aphasia is common in dementia and are expressed by difficulties with talking (word findings) and understanding. The use of proper words can be difficult, where the person often rewrites by using nouns (ibid). Language problems are normally more often seen in younger people in an early phase of dementia. However, in late stages of dementia language is mostly affected in all (ibid). Communication difficulties will be further described in 2.3.3.

Apraxia, agnosia and visual-spatial problems are seen in many persons as dementia progresses. A person with apraxia knows what to do, but is not able to put different sequences together in the right order. Agnosia, which is reduced ability to process sensory information, is expressed by difficulties in recognising items or the inability to use them in the right way. Another form of agnosia is a deficit in recognising sounds, which could lead to insecurity and fear. Impairment in visual-spatial function leads to problems in calculating distances and placing the body in the correct spatial situation (climbing a step, dressing etc.). The person becomes less flexible and finds abstract thinking difficult (ibid).

As a result of the various cognitive impairments the activities of daily living (ADL) become difficult because of a lack of ability to perform practical actions (ibid).

Motoric symptoms

Persons with dementia also have motoric symptoms like problems with balance, difficulties with coordination of movements (Engedal et al., 2009), where all aspects of balance control deteriorates with the increase of cognitive severity (Tangen, Engedal, Bergland, Moger, & Mengshoel, 2014). Further, some become incontinent, especially at the more severe stage of dementia (Engedal et al., 2009).

Behavioural and psychological symptoms

Behavioural and psychological symptoms in dementia (BPSD), also called neuropsychiatric symptoms (NPS), is reported to be present in at least 82% of all people with dementia (Selbaek, Engedal, & Bergh, 2013), and is significant higher in people with more severe cognitive impairment compared to those with less impairment (Bjork et al., 2016). The causes of BPSD can among others be related to neuropathological changes, and severity and type of dementia (Veerhuis, Nielsen, & Tenner, 2011). Other factors which could explain this behaviour could be delirium due to severe physical disorders or the side effect of drugs, anxiety, personality, physical environment, lack of understanding of their own situation and interaction with others (Engedal et al., 2009). The unmet need model is one of several models which have been developed to explain BPSD. Behaviour is, according to this model a result of an increased difficulty to communicate needs (Hancock, Woods, Challis, & Orrell, 2006). This might be connected to pain, discomfort, social contact or an imbalance in level of stimulation (Cohen-Mansfield, 2001). In other words, several factors, both biological and psychological, can interact.

In a longitudinal study conducted in Norway over a period of 53 months, the most prevalent and persistent symptoms were reported to be: agitation/aggression, irritability, disinhibition, and apathy. As the disease progressed, depression and anxiety decreased, whereas agitation, disinhibition, irritability and apathy increased. Other symptoms like euphoria, hallucinations, and change in eating habits were reported as well, although not that frequently (Selbaek, Engedal, Benth, & Bergh, 2014). These findings are consistent with a recent study (Brodaty, Connors, Xu, Woodward, & Ames, 2015) where it was found that the symptoms increased over a three year period and that the severity of dementia was associated with greater levels of BPSD at baseline. Delusions, hallucinations, agitation, anxiety, apathy, disinhibition, irritability, and aberrant motor behaviour increased most, whereas depression, euphoria, night time behaviour, and appetite did not increase significantly over the same period.

Even though there is a growing awareness of symptoms and causes of BPSD, an unsolved challenge is the lack of effective and well tolerated treatments for dealing with BPSD in people with dementia (Forlenza, Loureiro, Pais, & Stella, 2017).

2.1.3 The diagnosis of dementia

There are several ways of defining the dementia syndrome. The criteria developed by the International Classification of Diseases, version 10 (ICD-10) consists of four criteria, where all the four criteria have to be met in order to establish a dementia diagnosis (World Health Organization, 1993). These criteria are frequently used in Norway, either for diagnostic use or for use in research (table 1).

Table 1: Research criteria for dementia according to ICD-10

I	A decline in memory, especially learning of new information A decline in other cognitive abilities (e.g. judgement, and thinking, and general processing of information) <i>Mild:</i> Affects the persons performance of daily living <i>Moderate:</i> The person needs assistance to perform activities of daily living <i>Severe:</i> An absence of intelligible ideation
II	Preserved awareness of the environment
III	A decline in emotional control, motivation or social behaviour in relation to at least one of the following: emotional liability, irritability, apathy and coarsening of social behaviour.
IV	The presence of cognitive decline for six months or more.

Another way is to use the widely accepted Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013), which uses the term “neurocognitive disorder”, although “dementia” still can be used.

2.1.4 Assessing cognitive function

Part of the process of diagnosing dementia is to assess cognitive function. Many simple screening instruments can be applied, the most often of which is the Mini-Mental State Examination (MMSE) (Robert et al., 2010). The questionnaire comprises 11 questions that cover orientation, memory, attention and calculation, recall, and language. Each question is scored with 30 as the highest score (Folstein, Folstein, & McHugh, 1975). Even though the

MMSE is reported to be a valid and reliable instrument it is important to assess the person's physical disabilities beforehand since this can affect performance on the MMSE (Pangman, Sloan, & Guse, 2000). Other aspects, which could affect the performance, is language, any sensory impairments, skills, psychiatric illness or physical/neurological problems, and above all educational level and age (NICE, 2012; O'Bryant et al., 2008). The instruments do not take into consideration persons with motor dysfunction (O'Bryant et al., 2008).

It is emphasized that the MMSE first of all is a scale to assess cognitive function and not suitable for staging - or diagnosing dementia (Engedal et al., 2009). However, the MMSE can be used as a surrogate measure for the Global deteriorating scale (GDS) or the Clinical dementia rating scale (CDR), which is used to stage dementia (Pernecky et al., 2006).

2.1.5 Types of dementia and related symptoms

Dementia is an umbrella term, which can be divided into three groups according to the aetiologies: degenerative brain diseases, vascular diseases and secondary dementias (Engedal et al., 2009).

Degenerative brain diseases

Approximately 60% of all people with dementia have Alzheimer's dementia (AD), which is a chronic neurodegenerative disease with a gradual progression, usually divided into different stages. AD is characterized by loss of synapses and neurons in the cerebral cortex in the early phase (in a later stage also in other parts of the brain), which results in atrophy of the affected areas. Neurofibrillary tangles and amyloid plaques are visible by microscopic observations (Engedal et al., 2009).

At an early stage of AD one of the first symptoms is the problem with episodic memory like forgetting where the glasses have been placed or not remembering having taking the medication, or forgetting an appointment with the dentist, and so on. In the middle stage of AD, the person might become restless and the episodic memory worsens. In addition, the person will have difficulties with attention and will have encoding and retrieval deficits. At this stage the semantic memory, which has to do with the understanding of general information and word knowledge, will be affected. Even though the speech usually is fluent at the early stage, the person has difficulty finding words. At a later stage of AD the speech might still be fluent (or not), however, it is usually slower and more halting. Some might become mute, whereas others use repetitive phrases. They are unable to express themselves in writing or verbally and have difficulties with reading (Bayles & Tomoeda, 2014).

AD is associated with lower levels of neuropsychiatric symptoms than other types of dementia at the early stage (Brodaty et al., 2015), but depression has been reported to be the same whatever the severity of dementia (Verkaik, Nuyen, Schellevis, & Francke, 2007). However, the strongest significant factor associated with depression in people with AD is reported to be the history of depression (Barca, Engedal, Laks, & Selbaek, 2012).

Lewy Body Dementia (LBD) is characterized by an abnormal amount of Lewy bodies in the neurons of both substantia nigra as well as in the cortex of the brain. The disease is often combined with AD and is present in 10-15% of persons with dementia (Beasley & Davis, 1981; Engedal et al., 2009). Persons with LBD have fluctuating attention and alertness, visual hallucinations and loss of appetite as well as depression and anxiety, and they have motor symptoms like the ones seen in Parkinson's disease (Engedal et al., 2009). The working memory is impaired and the episodic memory is affected, but less than in persons with AD, especially for verbal information. The speech and grammatical aspects of language are relatively preserved (Bayles & Tomoeda, 2014).

Frontotemporal Dementia (FTD) is an overarching concept of several degenerative brain diseases. This type of dementia is a result of a neurodegeneration of the anterior temporal and/or frontal lobes and is the third most common form of dementia (Bayles & Tomoeda, 2014; Engedal et al., 2009). Lack of initiative, deficit in attention, impaired problem-solving ability and, difficulty organizing, leads to executive problems. Further, lack of interest, loss of inhibition, anxiety, restlessness and change in eating and drinking habits are seen as well. Some impairment in memory at an early stage is reported, however less than in AD (Engedal et al., 2009). Persons with FTD have good understanding and intact visuo-spatial function, but have greater levels of neuropsychiatric symptoms at an early stage of the disease (Brodaty et al., 2015). The speech is also relatively intact at this early stage; however, motoric deficit such as lack of fluency, control of speech and difficulties with completing sentences, is seen. At a later stage of dementia the person might become mute (Engedal et al., 2009).

Vascular dementia

The second most common cause of dementia is vascular dementia (VaD). Even though pure VaD is rare, the cause is first of all problems in the supply of blood to the brain after a stroke (Engedal et al., 2009). The episodic memory function is less impaired in persons with VaD compared to people with AD, and the memory problem is secondary to attention and executive function deficit (Bayles & Tomoeda, 2014). The person with VaD is usually aware

of their situation and able to orient themselves in time and place. However, difficulties with direction and the placing in the room, is reduced. Other symptoms like depression, apathy and emotional instability is also common (Engedal et al., 2009).

Secondary dementias

There are also several other more rare causes of dementia such as: alcohol related brain damages, Creutzfeld-Jacobs disease, Hunting's disease, normal pressures hydrocephalus, syphilis, subdural haematoma, HIV, cerebral tumours and many others (Engedal et al., 2009). However, this thesis is considering the most common types and symptoms of dementia. Therefore, these more rare causes of dementia will not be described.

2.2 The human senses

The average person uses his or her five primary senses (smell, taste, touch, hearing and vision) to interact with and respond to the environment (Kovach, 2000). Sensory deficit can be described by reduced ability to detect, discriminate and identify either smell, tastes, touch, sound or visual objects (figure 1).

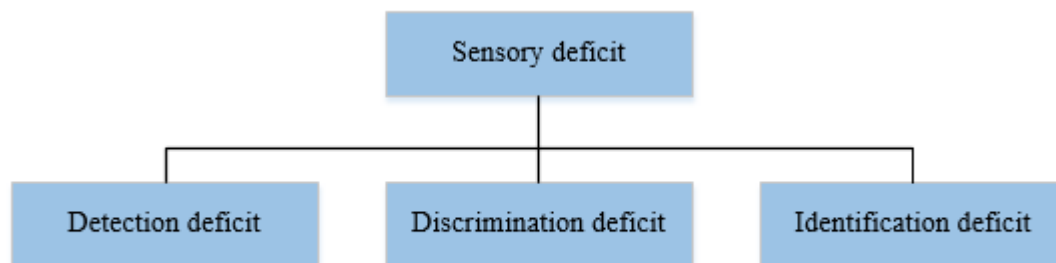


Figure 1 Sensory deficit

2.2.1 Sensory deficit due to age

Olfactory (smell) deficit

It is reported that more than 75% of people over the age of 80 years have olfactory deficit (Murphy et al., 2002). Age-related olfactory deficit could be explained by structural changes in the nose and changes in the nasal airflow patterns and mucous composition. Atrophy of the nasal epithelium and decrease in its mucosal blood flow and reduced elasticity, is reported, as well as a thinning of the epithelium and reduced size of the olfactory bulbs and numbers of its laminae (Doty & Kamath, 2014).

Olfactory deficit can be expressed by reduced ability to detect, discriminate and identify odour (Doty & Kamath, 2014). Olfactory detection represent the lowest detectable concentration of odours, while olfactory discrimination is the ability to differentiate between odours. Olfactory identification is the ability to identify odours (Eibenstein et al., 2005). In old people both detection and identification of olfactory information is reported to be impaired (Larsson, Finkel, & Pedersen, 2000) and this increases with age (Murphy et al., 2002). Altered olfactory function has been reported to affect the person's quality of life as well as their nutritional status (Wittmann-Price, 2012).

Gustatory (taste) deficit

Gustation is closely linked to the sense of olfaction due to its approximation where olfactory receptors are stimulated from both the nostrils and nasopharyngeal passages (Wittmann-Price, 2012). Taste deficit is less prevalent than smell as part of the aging process (Bartoshuk, 1989) and what is considered as a problem with taste is truly a problem with smell (Boyce & Shone, 2006). A reduction in saliva production and changes in taste cell membranes involving altered function of ion channels and receptors is reported (Mistretta, 1984), however, more common is regional taste deficit (Boyce & Shone, 2006). It is especially the ability to detect smell that declines with age and such deficit could result in reduced appetite (Murphy, 2008) and thereby weight loss.

Auditory (hearing) deficit

The Global Burden of Disease Study 2015 (GBD, 2016) refer to hearing loss as the second leading cause of disability by number of individuals. Approximately one-third of the world's elderly population above 65 years are affected by disabling hearing loss (WHO, 2012), caused by changes in the nervous system (Dawes et al., 2015). Consequences of hearing impairment have been reported as increasing the levels of anxiety and depression (Carlsson et al., 2015), social isolation (Strawbridge, Wallhagen, Shema, & Kaplan, 2000), impairing the person's ability to communicate (Brabyn, Schneck, Haegerstrom-Portnoy, & Lott, 2007) and making it difficult to take part in daily activities such as walking (Crews & Campbell, 2004). A significant association between hearing loss and life satisfaction has been reported as well (Solheim, Kvaerner, & Falkenberg, 2011) as affecting the person's self-reported health (Crews & Campbell, 2004; Solheim et al., 2011).

Visual (sight) deficit

Vision loss is the third leading cause of disability in the world (GBD, 2016) and the prevalence increases with age (Jee et al., 2005). The changes in vision can be caused by age-related macular degeneration, glaucoma, cataracts or diabetic retinopathy (Rosenberg & Sperazza, 2008). Difficulties to see fine details and the need for more light is seen in macular degeneration, whereas people with cataracts get blurred vision. Blurred vision is seen in diabetic retinopathy also, however, these people are also more sensitive to glare (Saunders & Echt, 2007). Jacobs, Hammerman-Rozenberg, Maaravi, Cohen, and Stessman (2005) found that people with impaired vision have poorer self-rated health and greater dependency in ADL. An increased loneliness and less ability to rely on friends, as well as more frequent hospitalisation, was also reported.

The biological clock is controlled by the endogenous circadian rhythm generated by the suprachiasmatic nuclei (SCN) which is linked to the light–dark cycle. Functional deterioration of the SCN is part of the aging process, leading to among others altered sleep patterns such as difficulties in sleeping (Forbes et al., 2009).

Tactile (touch) deficit

As part of the aging process, the sense of touch often declines due to reduced ability to detect, encode and transmit stimuli, as well as changes in the skin and nervous system (Decorps, Saumet, Sommer, Sigauco-Roussel, & Fromy, 2014). Even though touch is seen as a non-verbal aspect of communication, no studies describing the use of touch in older people in long-term facilities, have been found (Gleeson & Timmins, 2004b). Nevertheless, this review reported that nursing home residents expressed that touch gave them comfort, warmth and security and had a calming effect.

2.2.2 Sensory deficit due to dementia

Sensory discrimination disorder involves the incorrect processing of sensory information. Even though no documentation of any further sensory loss in persons living with dementia is documented other than what is seen due to age, a reduced ability to interpret what they see, hear, taste, feel and smell due to dementia, is reported (Bakker, 2003; National Institutes of Health, 2002). It is unclear if these changes are risk factors for developing dementia or more age-related degeneration (Behrman, Chouliaras, & Ebmeier, 2014), or either factors or consequences of dementia (Kenigsberg et al., 2015).

Even though there is some evidence that sensory impairment and dementia are associated, a recent study reports that hearing, sight and smell impairment in individuals with dementia is not associated with risk of cognitive impairment and conclude that sensorineural health may be a marker of brain aging (Fischer et al., 2016).

Olfactory (smell) deficit

Olfactory deficit has a high prevalence in dementia, estimated to be as high as 100% in AD and 15% in VaD (Duff, McCaffrey, & Solomon, 2002). A deficit in olfactory discrimination and identification is seen already in the early stage of AD, whereas less difficulties are seen in odour detection (Alves, Petrosyan, & Magalhaes, 2014). Odour identification impairment can be an early biomarker as well (Devanand et al., 2015; Kjellvik et al., 2014). These findings are consistent with the findings from a meta-analysis (Rahayel, Frasnelli, & Joubert, 2012) where it is shown that persons with AD are more impaired on odour identification than detection. This deficit in identification might be due to the lack of possibility to present odour verbally or visually (Richardson & Zucco, 1989).

Gustatory (taste) deficit

There is limited evidence that there exists an association between taste and dementia (Behrman et al., 2014) as well as limited studies exploring such an association, especially on taste discrimination (Aliani et al., 2013). In a review conducted by Aliani et al. (2013) no significant difference was found in taste detection between persons with AD and normal aging, and no studies were found on taste discrimination. Regarding taste identification ability in persons with familial risk for AD no differences were reported compared with normal aging over a period of one and a half years, whereas taste detection and discrimination worsened over the same period for those with familial risk of AD.

Auditory (hearing) deficit

Although hearing impairment does not worsen as part of the dementia process (C. J. Hardy et al., 2016), it has been reported as being associated with an increased risk of developing dementia (Deal et al., 2016). However, what we know is that persons living with dementia have difficulties with the identification of sounds as well as the ability to distinguish between them (Engedal et al., 2009). Such problems with both identification and discrimination of sounds might cause fear and the risk of being isolated.

Hallucinations might appear, caused by cognitive decline and postponing of time (Engedal et al., 2009), where the person hear sounds or voices. Nevertheless, it is important to distinguish this from the problem the person often has with the interpretation of sensory input.

Visual (sight) deficit

Several visual problems for people living with dementia have been described, even though some of the findings are controversial (Armstrong & Kergoat, 2015). The review (ibid) found studies reporting higher prevalence of impairment in near-and far-vision, reduced visual field, problems with detecting distance differences, reduced contrast detection and deficit in colour vision. However, the deficit in colour vision is controversial and less studied in dementia and seems to be more age-related than dementia related. Further, problems with eye movements is a well-known problem for people with dementia, especially for those living with Parkinson's disease dementia.

Visual agnosia where the person has reduced ability to recognise tools used in daily life and often uses them inappropriately, is common and the person might also have difficulties recognising faces (Engedal et al., 2009).

It is still unclear if visual impairment precedes dementia onset (Behrman et al., 2014), but what we know is that visual impairment affects physical and cognitive functions in old people (Hajek et al., 2016). As functional deterioration of the SCN is part of the aging process (Forbes et al., 2009), individuals with dementia lose the ability to maintain stable circadian rhythmicity (Nowak & Davis, 2011) and therefore might stay awake at night and sleep during the day.

Tactile (touch) deficit

As already mentioned touch is seen as a non-verbal aspect of communication (Gleeson & Timmins, 2004b). In a review by Gleeson and Timmins (2004a) where the aim was to explore the use of touch with older people with dementia, they found that the concept has been described since the 1970s. Physical touch was described as an aspect of nursing practice and could prevent the person living with dementia becoming depersonalised. The same review also describes the importance of being aware of the way touch is used, by using "gentle, soothing, supportive touch and a firm grasp". Even though the need for touch is a basic human need, a Cochrane review found that there was limited amount of reliable evidence in favour of touch interventions (Hansen, Jørgensen, & Ørtenblad, 2006). However, no further

tactile deficit is documented in persons with dementia, except a deficit in the interpretation of stimuli.

2.3 Communication

The need to communicate and interact with others is considered as basic for humans, only the need of survival being more important (Beck & Heacock, 1988). Bayles and Tomoeda (2014, p. 1) describe communication as “the sharing of information by means of a symbol system”. It serves several critical roles like maintaining a sense of identity, relieving loneliness, depression, or anxiety (Lubinski, 1995) and helps to build relationship (Kitwood, 1997)

2.3.1 Linear and circular models of communication

Several different communication theories and models have been developed. The first major communication model in modern time was developed by Shannon and Weaver in 1949. In this model, which was designed for telephone technology, communication is understood as a linear process, consisting of sender, channel, and receiver. However, communication is more complex and dynamic (Wogn-Henriksen, 2008) and in 1960 Berlo expanded this model to “The Sender-Message-Channel-Receiver Model” (SMCR) of communication. When adapting such a linear model to a patient-carer relationship, the *source* can be seen as the carers’ ability to communicate and their knowledge about the receiver (patient), influenced by the person’s values, beliefs, culture, religion and general understanding of society. The verbal and non-verbal language is the *message* and its content, and whatever is communicated will reach one or more of the five human senses, which are the channels of communication. However, the way the message is received depends on the capacity of the receiver (ibid).

There have been several criticisms of the linear communication model (Miller, 2005). First of all the assumption that there is a clear cut at the beginning and at the end of the communication. Additionally, we need elucidations on the complexity of the model and its lack of emphasis on non-verbal communication. The barrier to communication or the effect and impact on the person involved, is not mentioned either.

Bateson (2000) suggested changing the theoretical way of understanding communication, from a linear to a circular model. In this way of thinking, we search to understand to find new ways of acting, rather than looking for the cause. He emphasized the importance of transferring from looking at the characteristic of the individuals to the relationship. For Bateson, communication is about how we understand the reality, the perception and interpretation. How we interpret stimuli depend on previous experiences:

smell might for some awaken positive memories while for others negative feelings might be evoked. Watzlawick, Bavelas, and Jackson (1967) developed the circular model further, describing the “interactional view”. This refers to five different axioms necessary to have a functioning communication process. The model can be used to explain how miscommunication can occur. First of all, *we cannot not communicate* and all behaviour, verbal or non-verbal, is a way of communication. A patient who turns his or her back to the nurse is communicating something. However, the challenge with this view is that non-verbal communication can be understood as a one-way process rather than relational. The second axiom states that “*every communication has a content and relationship aspect such that the latter classifies the former and is therefore a metacommunication*”. This axiom emphasises the relationship, describing how the person who sends the message wants to be understood and how the person who sends the communication sees the relationship with the receiver of communication.

In the third axiom, “*The nature of a relationship is dependent on the punctuation of the partners’ communication procedure*”, he explains that the sender as well as the receiver interpret their behaviour as a reaction to the other’s behaviour. In order to prevent misunderstandings if a resident expresses aggression it is to use punctuation to prevent misunderstanding by assessing the situation from two angles: e.g. is she aggressive because she is alone, or is she alone because she is aggressive? The axiom “*Human communication involves both digital and analog modalities*”, refers back to the first axiom and the importance of verbal, as well as non-verbal communication in a relationship. The fifth, and last axiom, refers to the use of equality or differences in the power between communicators, stating that the “*inter-human communication procedures are either symmetric or complementary*”.

There is some criticism regarding the challenge of applying the entire theory as well as the difficulties of applying all the five axioms at the same time, however, the axioms are helpful in the sense of explaining communication problems, which might arise.

2.3.2 Speech and language

As mentioned above, communication depends on speech and language, which is in accordance with new literature on this topic (Klimova & Kuca, 2016). However, it is important to differentiate the two communication dimensions from each other (Bayles & Tomoeda, 2014; Tang-Wai & Graham, 2008). Language is seen as the ability to encode ideas into words (Tang-Wai & Graham, 2008) in order to communicate ideas, feelings and

thoughts, while speech is the “motor production of sounds” (phonation, articulation, fluency and voice) (Bayles & Tomoeda, 2014) (figure 2).

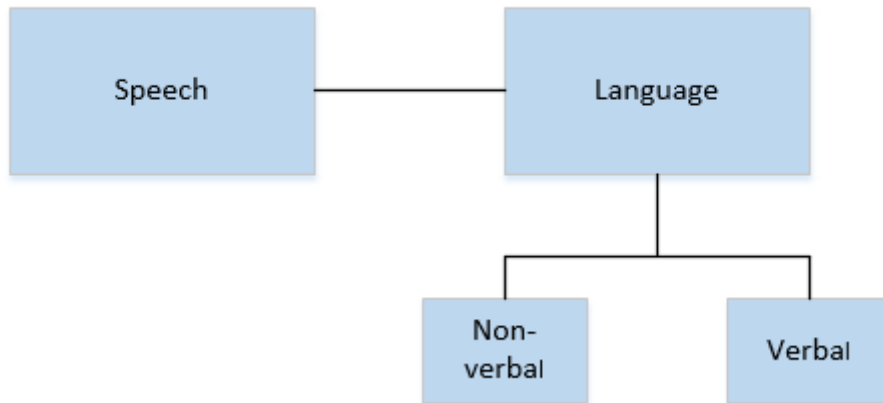


Figure 2 Speech and language

Non-verbal and verbal communication

The first form of communication a human being uses is non-verbal, also called extra-linguistic (Klimova & Kuca, 2016). This can be expressed by gestures, tone of voice, face expressions etc. and is, according to Watzlawick et al. (1967), part of the analogue level of communication. Further, verbal communication, where words are used to communicate, also called linguistic communication (Bayles & Tomoeda, 2014), is part of what Watzlawick et al. (1967) call the digital level of communication (figure 2).

2.3.3 Communication deficit in dementia

One of the most common symptoms of dementia is speech and language impairment, depending on type and degree of dementia (Klimova & Kuca, 2016). Nevertheless, the majority of people with dementia have impairments due to language rather than speech deficits (Kempler & Goral, 2008), where control of phonation, articulation, and resonance remains intact until the latest stage (Kempler, 1991). Both verbal and non-verbal language are impaired in persons with dementia, since “both are cognitive processes for sharing information” (Bayles & Tomoeda, 2014, p. 2). “Communication is affected because the pathophysiologic processes of dementia that disrupt multiple cognitive functions and produce dementia disrupt information generation and processing” (Bayles & Tomoeda, 2014, p. 21). This problem will change over time and with the degenerative process of dementia (Engedal et al., 2009).

At the early stage of dementia, language deficit can be expressed by mild word retrieval difficulties, use of semantically empty or substitute words, and use of contextually appropriate language (Klimova & Kuca, 2016). However, it is suggested that semantic memory remains intact whereas the access is disrupted (Kemper, 1994). In middle stage dementia, word retrieval worsens the person uses more substitutions of empty words as well as related words. Poor topic maintenance and overuse of pronouns is also reported. The ability of turn-taking in conversation remains intact, whereas the comprehension is affected (Cummings et al., 1985). At late stage, where word and sound substitutions are used, verbal production becomes more difficult to interpret (Mayhew, Acton, Yauk, & Hopkins, 2001) and as cognitive impairment increases, so too does displayed agitation (Vance et al., 2003). At this stage the person's ability to build relationship and make their needs known, is affected (Kitwood, 1997). Disruptive vocalizations (screaming, repetitive vocalization) is also seen at this stage (Souder, Rapp, Davis, Beck, & Liem, 2004). Vocalizing has been considered BPSD, described as loud and/or repetitive communication, such as screaming, moaning, nonsensical sound and requests for attention (Yusupov & Galvin, 2014). However, it could also be seen as a mean of communicating unsatisfied needs or desires like pain or emotional discomfort (Matteau, Landreville, Laplante, & Laplante, 2003).

People with dementia, even at a late stage of the disease where they have lost the ability to use words as a mean of communication, are able to produce meaningful communication by expressing their needs, wants and, desires through non-verbal behaviours (Acton, 1999). A relatively preserved identification of non-verbal emotional facial expression and recognition of differences in emotion has been found as well (Bucks & Radford, 2004). Even though BPSD, like vocalization, is seen as something negative, the ability to use non-verbal behaviours can be exploited to keep the person involved in the social world (Astell & Ellis, 2006). A singing-like type of vocalization, which is different from the negative vocalization has been described as a meaningful way of communication (Samuelsson & Hyden, 2011).

Powell, Hale, and Bayer (1995) studied the association between breakdown in communication skills and cognitive-communication deficit in people with dementia. Carers of 79 community-living people with dementia and family/close friends of 76 people who served as a control were asked about their perceptions of 32 symptoms of communication breakdown. The greatest discrepancy between the two groups was found in: asking the same question, difficulties keeping and following conversation, remembering people's names and name of places, trouble following TV programmes, calling people by the wrong name,

starting to say something and then forgetting and, telling the same story a number of times. People with dementia were also reported to be significantly more sensitive to sounds than the control group.

2.3.4 The impact of communication deficit

Heidegger, Macquarrie, and Robinson (1962) claim that human beings are fundamentally considered relational and that they depend on each other. However, meaningful communication requires that the person have comprehension of ideas as well as a symbol system where the ideas are expressed.

It is well known that people living with dementia are at risk of being marginalized by society (T. Bush, 2003) and depersonalized (Acton et al., 2007) due to communication difficulties. Such difficulties can affect their ability to interact with others (ibid.) and is even said to result in “social death” (Spicker, 2000). The ability to have a conversation will also be affected, since the ability to sustain a topic and maintain its coherence is impaired (Bayles, 1985). As Lubinski (1981, p. 339) states: “communication becomes the crucial difference between isolation and social connectedness, between dependence and independence, and between withdrawal and fulfilment”.

In a review conducted by Snyder and Drego (2006) people living with dementia reported that cognitive and functional losses had an impact on language and thereby diminished their ability to communicate. They also experienced a sense of lack of connectedness with family and friends and the ability to join in activities, due to communication difficulties.

2.3.5 Factors facilitating communication

In order to help the person remain part of the society and maintain the person’s dignity and well-being, Mayhew et al. (2001) emphasize the importance of trying to interpret and understand the communication. Satisfaction of basic human needs can only be satisfied within the framework of the individual and this is why the interpretation of their communication, often expressed non-verbally, is essential in order to be able to meet their needs (Acton, 1999).

Kitwood (1988) suggests that well-being could be increased by successful collaborative communication, where e.g. the carer provides extra time to give the person the possibility to communicate in a meaningful way. Use of semantic memory where the emphasis is on general knowledge, is reported to be more successful than using questions

which require episodic memory (Small & Perry, 2005). In a study conducted by Stanyon, Griffiths, Thomas, and Gordon (2016) of how healthcare workers facilitate what they perceive to be effective communication, they found four main themes. First, the attribute of a care worker, where having knowledge and skills about dementia and their personal characteristics, was emphasized. A more realistic expectation of the resident and getting to know them better might be helpful in building the relationship. The second theme was the use of communication strategies. This can be done by reducing the speech complexity; use shorter sentences and avoid using abstract ideas. Use of non-verbal communication like eye contact can prevent withdrawal and help the person to communicate emotions, where touch can help to initiate and maintain attention. Organisational factors are also mentioned as important factor to facilitate communication. The importance of encouraging staff to sit down and chat with residents is emphasized as well as making sure that the staffing level is sufficient and that staff have suitable training. The physical characteristics of the care environment is the last theme. Adequate space, suitable level of auditory and visual stimulation, where the emphasis is on not overloading the premises.

2.3.6 Assessing communication

Several instruments to assess the care and research outcome in relation to people with dementia have been developed, however, few are developed specifically to assess communication. In a review by Robert et al. (2010) of available Alzheimer's disease scales only two assessment scales related to communication were included: the Core Linguistic Battery (CLB) (Bayles, Tomoeda, & Trosset, 1992) and the Communication Problems Scale (CBS) (Powell et al., 1995). While the CLB assess the profile of deficits in linguistic communication, the CBS was developed to assess possible communication breakdowns in people with dementia. Nevertheless, the scales have not been psychometrically tested and aspects of communication such as "responsiveness, correct use of interpretation of gestures and facial expressions" are not present in these scales (Robert et al., 2010). Whereas the above assessment tools have been developed to monitor changes in the person's daily life, other tools are developed to assess changes within an activity session.

The Threadgold communication Tool (TCT) is such a tool, used to assess communication ability during the multisensory programme, Sonas. This tool is demonstrated to be a reliable and valid instrument, suitable for measuring communication among people with dementia (Strøm, Engedal, & Grov, 2016).

The Holden Communication Scale (HCS) is an instrument developed by Una Holden to assess communication ability in persons with dementia, initially in connection with reality orientation approaches and reminiscence programmes (Holden & Woods, 1995). The HCS includes 12 items assessing conversation, awareness, humour and responsiveness. The score range from 0-48 and the higher score denotes more difficulties with communication. Even though the instrument is widely used, it has not been previously psychometrically tested.

3.0 Person-centred approach

The philosopher and theologian Martin Buber suggested an alternative in medical practice where the patient first of all must be seen as a whole person, not as a disease (Buber & Smith, 1958). He further developed the concept of relationship and dialogue to provide insight into the person-to-person encounter between physician and patient (Cohn, 2001). Then, in the 1940s and 1950s the American psychologist, Carl Rogers developed his own unique approach to understanding personality and human relationships, described as a person-centred approach.

Tom Kitwood applied, in the late 1980s the Rogerian model to caring for older adults with dementia as a response to what was seen as a reductionist biomedical view of dementia (Kitwood, 1997) to a phenomenological understanding of people's subjective experience of having dementia (Dewing, 2004; McCormack, 2004). Kitwood challenged the view that the behaviour of people with dementia was entirely due to neuropathological processes, yet he accepted this as an important aspect as well. Instead, the persons were considered to be the expert in their life history and needs, with the helper as a facilitator, and where the aim is to preserve the person's personhood. In this, the attention was moved away from focusing on the bio-medical aspects of dementia on to people's subjective experience of living with dementia. With such an understanding behaviour can be interpreted as ways of communicating unmet basic needs as a response to non-adapted environment (Edvardsson et al., 2008) and as ways of coping (Ridder, Stige, Qvale, & Gold, 2013). It could be an expression of pain, discomfort, need for social contact, or an escape from boredom and inactivity (Cohen-Mansfield & Werner, 1997).

Kitwood focuses on the need to preserve personhood throughout the dementia process, defining "personhood" as "a position or social relationship that is bestowed upon one human being by others', in the context of relationship and social being" (Kitwood, 1997, p. 8). If the personhood is maintained, the person living with dementia can achieve "a state of at least relative well-being" (Kitwood & Bredin, 1992, p. 270). However, although Kitwood emphasised the term "personhood", defining "personhood" in the way he does, means people living with dementia often are given a secondary status (Dewing, 2008). Another challenge is that by discussing criteria for being or not being a person, a value-based hierarchy is already built (Dewing, 2008), often depending on cognition functioning. Therefore, using the term "person" will not necessarily ensure a holistic approach: it is more a question of how we relate to the person.

There is no consensus on how to define the concept person-centred, however, “the aim of person-centred care is to acknowledge the personhood of people with dementia in all aspects of their care” (Edvardsson et al., 2008, p. 362) and is characterized by Kitwood (1997) as:

- The individual is a person that can experience life and relationships
- Offering and respecting choices
- The inclusion of the person’s life and history in their care
- The focus on what the person can do (abilities).

Most of the above aspects by Kitwood were also identified by care staff when asked to describe the characteristic of person-centred communication: incorporation of life history, preferences, and the person’s feelings (Savundranayagam, Sibalija, & Scotchmer, 2016). The importance of relationships were described in a review conducted by Eriksen et al. (2016) where people living with dementia experienced a change in relations like being disconnected and with a feeling of loss of social function due to reduced cognitive function. Particularly important was contact with family and friends and being part of a spiritual community, where being together with peers reduced their experience of being isolated. Striving to maintain personhood in spite of cognitive decline could help to prevent isolation and the experience of being disconnected and by prioritizing the relationship with the persons with dementia as much as care tasks (Edvardsson et al., 2008), involving family members in care and offering shared decision making (Sabat, 2005) and valuing all people (Woods, 2001).

3.1 The impact of person-centred approach

Apart from the need to clarify what is meant by person-centredness (Dewing, 2004) there is a need to investigate whether person-centred care has an effect on health outcomes such as quality of life (QoL) (Edvardsson et al., 2008).

Even before Kitwood introduced his philosophy, several attempts had been made to develop positive interventions in order to improve the life of persons with dementia such as: reality orientation (Taulbee & Folsom, 1966), validation therapy (Feil, 1982), reminiscence (Butler, 1964) and the Sonas programme (Threadgold, 1995). However, (Kitwood, 1997, p. 55) questioned the theoretical foundation in some of these interventions and emphasized that the aim to stimulate well-being is provided by meeting the person’s psychological needs for comfort, occupation, attachment, inclusion and identity.

Terada et al. (2013) investigated the relationship between person-centred care and proxy-rated QoL in nursing home residents and found that aspects of QoL like positive affect,

ability to communicate, spontaneity and activity, and attachment to others had a significant relationship with person-centred care, independent of cognitive function and ADL level. Although not significant, the same relationship between person-centredness and QoL was also found by Sjogren, Lindkvist, Sandman, Zingmark, and Edvardsson (2013), while a significant correlation was found between person-centredness and the person's ability to perform ADL.

Rokstad et al. (2013) used the Person-centred Care Assessment Tool (P-CAT) to examine whether the use of Dementia Care Mapping (DCM) or the VIPS practice model was more effective than educating nursing home staff about dementia, in preventing agitation and QoL in persons with dementia. Even though no positive differences were reported on agitation, an improvement was found on QoL for both interventions compared with the control group. These findings are consistent with a cross-sectional study conducted in Sweden by Edvardsson, Petersson, Sjogren, Lindkvist, and Sandman (2014) who found significantly higher QoL among nursing home residents who lived in more person-centred units, with everyday activities like outdoor walks, excursions, parlour games, church visits and housing-related activities. However, the number of residents participating in these activities was low (18%).

The inconsistency in the above three studies might be due to the use of different outcome measures for both ADL and person-centred care and additionally the tool for measuring person-centred care in the first study (Terada et al., 2013) has not been psychometrically tested. Even though several tools have been developed to measure person-centred care of older people living with dementia they are generally of low methodological quality (Wilberforce et al., 2016), and therefore a need for psychometric evaluation of these tools has been emphasized (Edvardsson & Innes, 2010). Another challenge when comparing studies is the difficulty to distinguish between good quality of care and person-centred care, where the question is if these might be the same (McCormack, 2004).

The philosophy of personhood has "either been uncritically accepted or rejected as having limited relevance for practice" (Dewing, 2008), arguing that it has primarily been focusing on the personhood of the person being cared for and not the importance of the relationships (Nolan, Brown, Davies, Nolan, & Keady, 2006) and that Kitwood's work is unfinished and not refined (Dewing, 2008). However, despite some of the criticism of Kitwood's concept of person-centred care, this philosophy forms the basis for dementia care in the NICE Guidelines (NICE, 2012), the Norwegian guideline for dementia (The Norwegian Directorate of Health, 2016) and the National Standards for Older People in Ireland (HIQA, 2016).

3.2 Pharmacological interventions

Use of pharmacological interventions for cognitive as well as non-cognitive symptoms and behaviour that challenges people living with dementia, is described by NICE (2012) and The Norwegian Directorate of Health (2016).

3.2.1 Pharmacological interventions for cognitive symptoms

There is an ongoing research to find medication to prevent further brain damage due to Alzheimer's disease, and medication to help maintaining cognitive function. However, so far only medication used to relieve dementia symptoms are available (Engedal et al., 2009). The three acetylcholinesterase (AChE) inhibitors donepezil, galantamina and rivastigmine are recommended for treatment of Alzheimer's disease and dementia with Lewy bodies in a mild to moderate stage of the disease. However, this treatment should not be prescribed for people with VaD or mild cognitive impairment (MCI). In a moderate to severe stage of AD, Memantin is recommended if the person has intolerance to Cholinesterase inhibitors, and in AD of moderate to severe degree (NICE, 2012; The Norwegian Directorate of Health, 2016).

3.2.2 Pharmacological interventions for non-cognitive symptoms

A cohort study conducted in Norwegian nursing homes between 1997 and 2009 reported an increased prevalence of prescription of psychotropic drugs from 57.6% to 70.5%, including anti-depressants that increased from 31.5% to 50.9% (Ruths et al., 2013). This class of drugs is used to treat BPSD, including depression in people with dementia. However, it is emphasized that pharmacological interventions (except for depression) should only be offered in the first instance if the symptoms are severe and the person is an immediate risk to themselves or others (NICE, 2012). It is further emphasized that anti-psychotic drugs should not be prescribed for people with LBD because they are at risk of unwanted reactions. Persons with psychosis due to LBD could be treated with Acetylcholinesterase inhibitors (ibid).

Even though psychotropic drugs are frequently used among residents in Norwegian nursing home (Helvik, Saltyte Benth, Wu, Engedal, & Selbaek, 2017), there are still concerns about their side-effects on people with dementia (Seitz et al., 2013). Therefore, psychosocial interventions should be the first choice (Fossey et al., 2006; Kolanowski, Fick, Frazer, & Penrod, 2010).

3.3 Psychosocial interventions

For many persons with chronic diseases, such as advanced dementia there is a treatment goal shift, from prolonging life, toward optimizing QoL, dignity, and comfort (Heggestad, Nortvedt, & Slettebo, 2013b; Rabins, Lyketsos, & Steele, 2006; Volicer & Hurley, 2003). So far there is no cure for dementia, and therefore psychosocial interventions are recommended in order to help the person living with dementia to cope with BPSD and improve their QoL (NICE, 2012; The Norwegian Directorate of Health, 2016). There are several psychosocial interventions and Douglas, James, and Ballard (2004) and O'Neil et al. (2011) divide these methods into four broad categories: behaviour-oriented, emotion oriented, cognitive-oriented and, sensory-stimulation-oriented (figure 3).

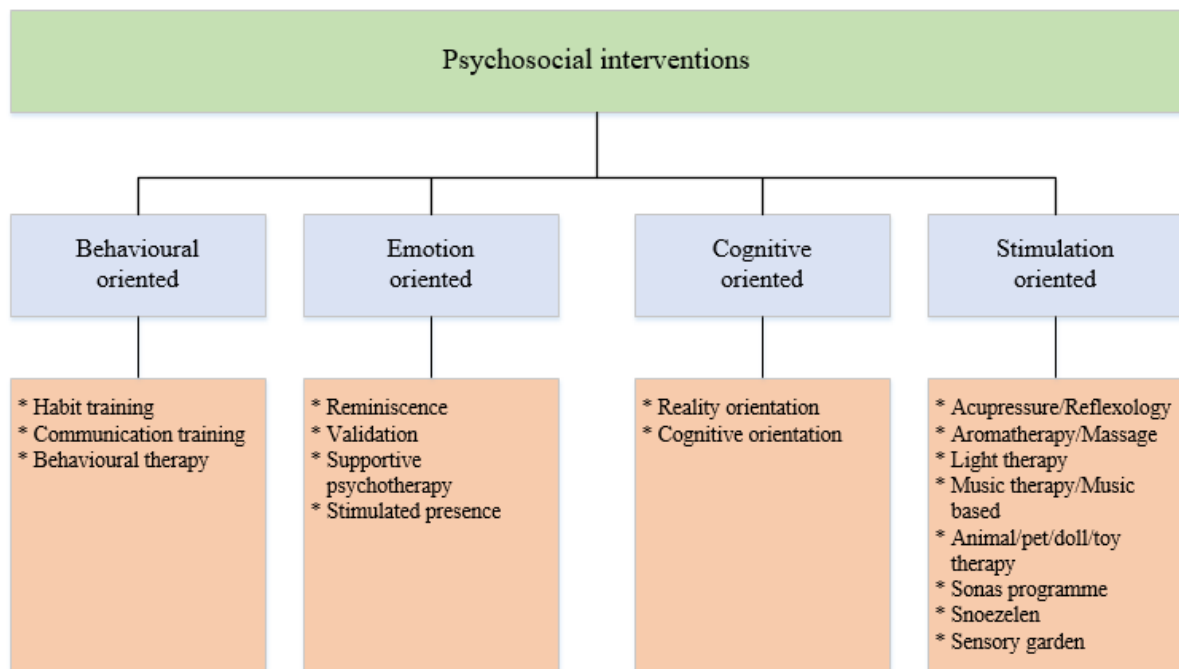


Figure 3 Psychosocial interventions

The importance of offering meaningful psychosocial interventions is confirmed both by people living with dementia and their family and care staff as a way of providing person-centred care (Edvardsson, Fetherstonhaugh, & Nay, 2010).

3.4 Group engagement

Their incapacity to occupy themselves is linked with a decline in the person's physical, behavioural, and cognitive functioning (Kolanowski, Buettner, Litaker, & Yu, 2006) and people with severe cognitive impairment are at risk of being more disengaged (Nolan, Grant,

& Nolan, 1995) and disconnected (Eriksen et al., 2016). Even though most people with dementia can be engaged with some stimulus, one of the challenges is to find appropriate sensory stimulation in order to awaken latent memories and abilities (Bakker, 2003).

Cohen-Mansfield, Hai, and Comishen (2017) developed the “Comprehensive Process Model of Group Engagement” (figure 4), which is an expansion of the “Comprehensive Process of Engagement”, asserting that “engagement with a stimuli is affected by environmental attributes, personal attributes, and stimuli attributes – group activity (Cohen-Mansfield, Dakheel-Ali, & Marx, 2009). Engagement, which is understood as “the act of being occupied or involved with an external stimulus”, is a necessary aspect for the development of psychosocial interventions for people with dementia” (Cohen-Mansfield, Dakheel-Ali, et al., 2009).

3.4.1 Environmental attributes

Several elements in a person’s environment, such as setting characteristics, presentation and timing, might influence the level of attention to stimulus (Cohen-Mansfield, Thein, Dakheel-Ali, & Marx, 2010a). It could be the location of activity, time of the day, same day versus a different day of the week, light, noise level, number of people in the group, modelling, order of presentation (Cohen-Mansfield, Dakheel-Ali, et al., 2009), seating comfort (Cohen-Mansfield et al., 2017) and temperature (Trahan, Kuo, Carlson, & Gitlin, 2014). Other environmental attributes could be the cognitive level and behaviour of the other group members (Cohen-Mansfield et al., 2017)

3.4.2 Stimuli attributes – group activity

Even though we know that stimuli have an effect on the level of engagement (Cohen-Mansfield, Dakheel-Ali, et al., 2009), “the amount, type, and variety of stimuli really matter; both under- and overstimulation cause confusion, illusions, frustration, and agitation” (Bakker, 2003).

3.4.3 Personal attributes

The characteristics of the person, such as cognitive function, past interest (Cohen-Mansfield, Dakheel-Ali, et al., 2009), apathy, propensity for enjoying social activities and hearing and vision (Cohen-Mansfield et al., 2017), are likely to influence the person’s ability to engage with stimuli.

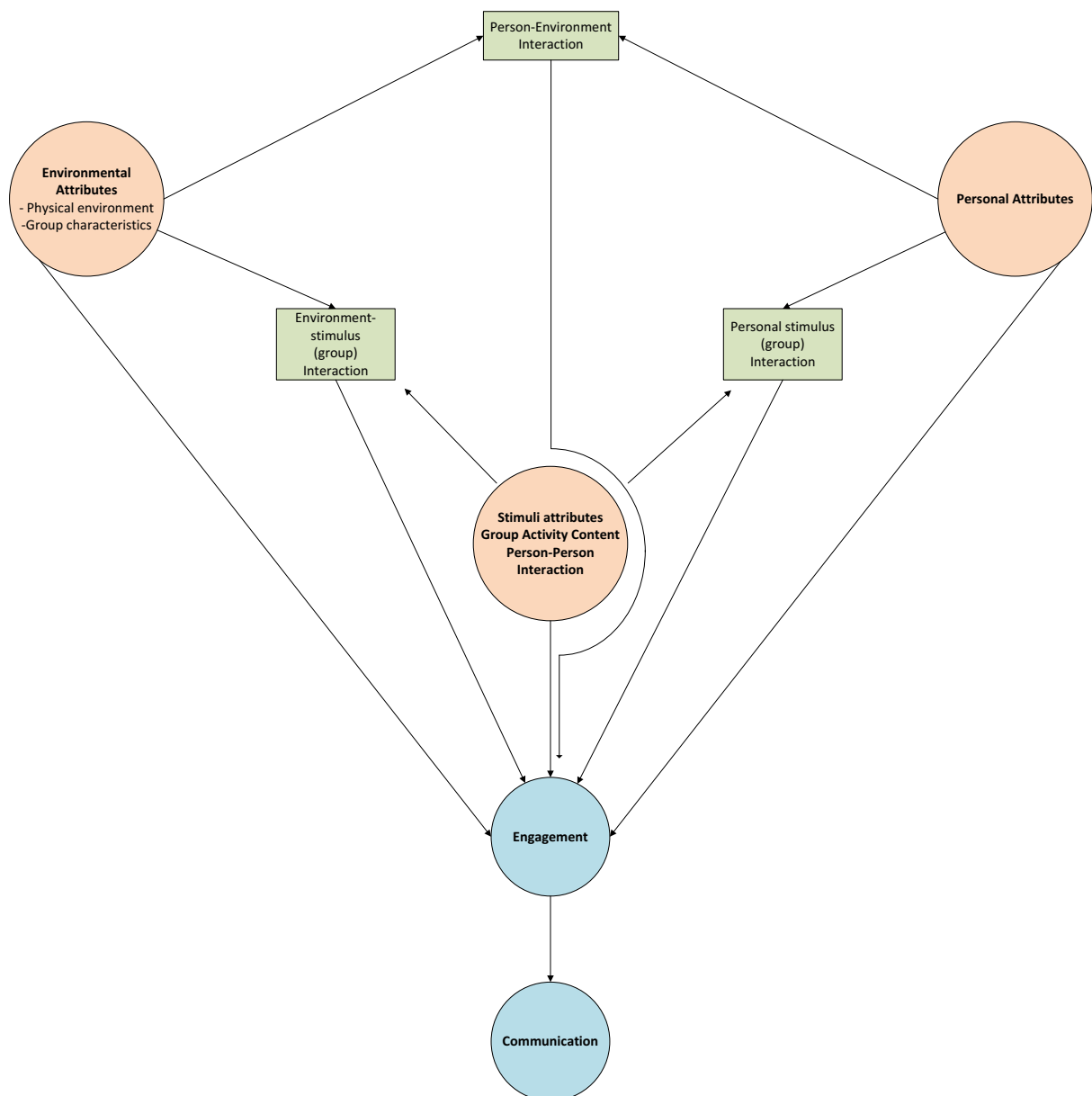


Figure 4: A modified version of “The comprehensive Process Model of Group Engagement” after Cohen-Mansfield et al., 2017, with permission from the author.

3.5 Sensory stimulation

Sensory stimulation refer to different techniques or interventions used to stimulate one or more of the five human senses with the overall aim of increasing alertness and reducing agitation (Gammeltoft, 2011).

3.5.1 The rationale for using sensory stimulation

Various theoretical models are used to explain the possible effect of sensory stimulation: physiological, neurological and psychological models (Bayles & Tomoeda, 2014). However, the rationale for providing sensory stimulation is that, regardless of cognitive stage, consistent use of retained skills and knowledge helps maintain them. The human brain is plastic and therefore stimulation is needed to trigger neuroplasticity, where the goal is to strengthen residual knowledge and skills. Some of the factors which are known to be influential in recovery of function are: attention, stimulation, use or loss, repetition and duration (ibid). As previously described, sensation is received through our eyes, ears, skin, nose and tongue, and then interpreted in sensory cortices (Bayles & Tomoeda, 2014), and since people living with dementia still perceive the world around them through their senses “appropriate sensory stimulation is a main avenue to awakening latent memories and abilities” (Bakker, 2003).

Olfactory (smell) and gustative (taste) stimulation

As previously mentioned, smell and taste are closely connected (Wittmann-Price, 2012). Pleasant smell is reported to increase oxygenated haemoglobin (HbO₂) over the frontal brain region (Harada, Tanaka, & Kato, 2006). However, the response depends on previous experiences because the stimulation, which is brought to consciousness, must be interpreted: some smell might trigger positive emotions, while others negative, depending on the person’s previous experiences. Elsner (2001) reported that memory formed through smell usually last longer than memories formed through other sensory modalities and have more emotional value. A study on animals even suggests that the olfactory sense has an importance for the awakening of childhood memories, especially stress and trauma (Sevelinges et al., 2007). Aromatherapy, where pure essential oils from fragrant plants (such as Peppermint, Sweet Marjoram, and Rose) is reported to relieve health problems and improve QoL in general (Forrester et al., 2014). In a review carried out by Gonzalez and Kirkevold (2013) the use of a sensory garden, which also stimulates the sense of smell, has been reported to improve well-being, sleep pattern as well as reduce disruptive behavior.

Tactile (touch) stimulation

Massage and touch, such as different forms of massage and types of stroking like slow-stroke massage are common interventions used in dementia care. The possible calming effect of these interventions could be explained by the production of oxytocin when providing massage

(Fritschy & Sarter, 2009). Further, providing touch can be a way of improving comfort and communication (E. Bush, 2001) and to “activate non-verbalized patterns of memories and meaning” (Opie, Rosewarne, & O'Connor, 1999). However, a review conducted by Hansen et al. (2006) reported limited reliable evidence of these interventions, the majority targeting on agitated behavior as outcome measure.

Auditory (hearing) stimulation

Music therapy seek to “optimize the quality of life of the person and improve their physical, social, communicative, emotional, intellectual, and spiritual health and wellbeing” (WFMT, 2011). Some of the key elements are the use of live music, client participation, stimulation and the use of preserved skills/abilities (Sherratt, Thornton, & Hatton, 2004). A Cochrane review of music therapy (Vink, Bruinsma, & Scholten, 2003) concluded that the results could not be validated or further analyzed due to poor methodological quality. However, a recent review (Peck, Girard, Russo, & Fiocco, 2016) reported that music can activate and improve the interaction between systems in the brain and thereby enhance memory. The authors refer to three possible underlying mechanisms: the regulation of the autonomic nervous system, enhanced dopaminergic projections and enhanced default network connectivity.

Visual (sight) stimulation

Our biological clock is controlled by the endogenous circadian rhythm generated by the suprachiasmatic nuclei (SCN) which is linked to the light–dark cycle. As functional deterioration of the SCN is part of the aging process (Forbes et al., 2009), individuals with dementia lose the ability to maintain stable circadian rhythmicity (Nowak & Davis, 2011). A consequence, sleep disturbance has been reported to have an association with agitation in individuals with dementia (Skjerve, Bjorvatn, & Holsten, 2004). However, a Cochrane review (Forbes et al., 2009) concludes that there is insufficient evidence that providing light therapy has an effect on cognition, sleep, function, or BPSD in people with dementia.

3.5.2 The need for sensory stimulation

The life in an institution becomes easily boring and passive, and as the memory is getting worse and the daily activities become difficult to carry out the need for stimulation increases (Vozzella, 2007). However, too much stimuli can result in exceeding the person’s stress threshold (Kovach, 2000). An appropriate level of stimuli could be influenced by the person’s circadian rhythm, which is, as already mentioned, often disturbed in people with dementia.

Further, changes in neurophysiological status due to the disease where the motivation for participating in activities changes, or environmental factors such as noise level and room temperature, could have an impact on the stimulus balance (Kovach, 2000). This is consistent with Cohen-Mansfield “Comprehensive Process Model of Engagement” described in 3.4 (Cohen-Mansfield, Dakheel-Ali, et al., 2009), and is essential for the development or implementation of sensory stimulation.

It is emphasized that as “verbal communication becomes increasingly difficult, supplementing the care with other non-verbal methods of interaction becomes necessary” (Furesund, Wogn-Henriksen, Lykkeslet, & Skrondal, 2007). Despite this, research reports that residents are not engaged the majority of the time they spend in the nursing home (Harper Ice, 2002). Such lack of stimulation can lead to sensory deprivation (Kovach, 2000), which can be expressed by apathy, boredom, depression and loneliness (Cacioppo, Hughes, Waite, Hawkey, & Thisted, 2006). A positive association has been found between activity engagements and thriving, where spending time together with somebody they liked and participating in activity programs, were reported to have the strongest positive association with residents thriving (Bjork et al., 2017). Nevertheless, it was reported that nursing home residents rarely visited a cinema, took part in educational programs or did everyday chores.

Although several studies have been conducted to measure the effect of different sensory stimulation interventions, Kenigsberg et al. (2015, p. 9) emphasize the need for more research “to understand the most efficient procedures for psychosocial intervention, their mechanisms of efficacy, and the modulating factors”.

3.6 The Sonas programme

A multi-sensory stimulation programme has been developed which involves cognitive, sensory, and social stimulation, including all five senses; touch, smell, taste, hearing and sight, called Sonas, which is a Gaelic word and means well-being, joy and contentment. The programme was developed by Sr. Mary Threadgold in 1990 as a therapeutic activity for people who have significant communication impairment, primarily as a result of dementia.

The aim of the Sonas programme is:

1. to activate whatever potential for communication has been retained by an older person with communication impairment
2. to encourage the creation of an environment which will facilitate communication

3. to have activation of potential for communication recognized and accepted as an essential part of care planning for older people.

(Sonas aPc, 2011)

The aims of the Sonas programme is consistent with Kitwood's idea (1997) of person - centeredness and focuses on the person's abilities rather on limitations. The programme is delivered at least twice a week in groups of eight residents and follows the same structure each time, believing that repetition is a way of helping the individual to remember. Each session takes 45 minutes and is led by a person who is trained in how to perform the Sonas programme. The intervention is described in more detail in chapter 5.3.4.

3.6.1 Previous research on the Sonas programme

The focus of this review is to give an overview of published and unpublished studies and to explore possible effects of the Sonas programme. All available studies of the Sonas programme were included: studies, reports and dissertations. However, studies, which did not report on the effect of the Sonas, programme, were not included.

To identify these studies of the Sonas programme a review was conducted in November 2016 in four databases; CINAHL, PubMed (Medline), PsycINFO and PubPsych. The search terms Sonas OR Sonas programme, were used. A hand-search was also conducted in order to find unpublished results, since the tendency is to publish studies reporting significant effect whereas non-significant findings might be rejected by reviewers and editors, leading to publication bias (Polit & Beck, 2012). Even though primary sources are the first choice when conducting a review (Polit & Beck, 2012), secondary sources were used since some studies were not accessible. Five published and four unpublished studies were identified according to the inclusion - and exclusion criteria (figure 5). No new studies after the previous research conducted in 2013, were found.

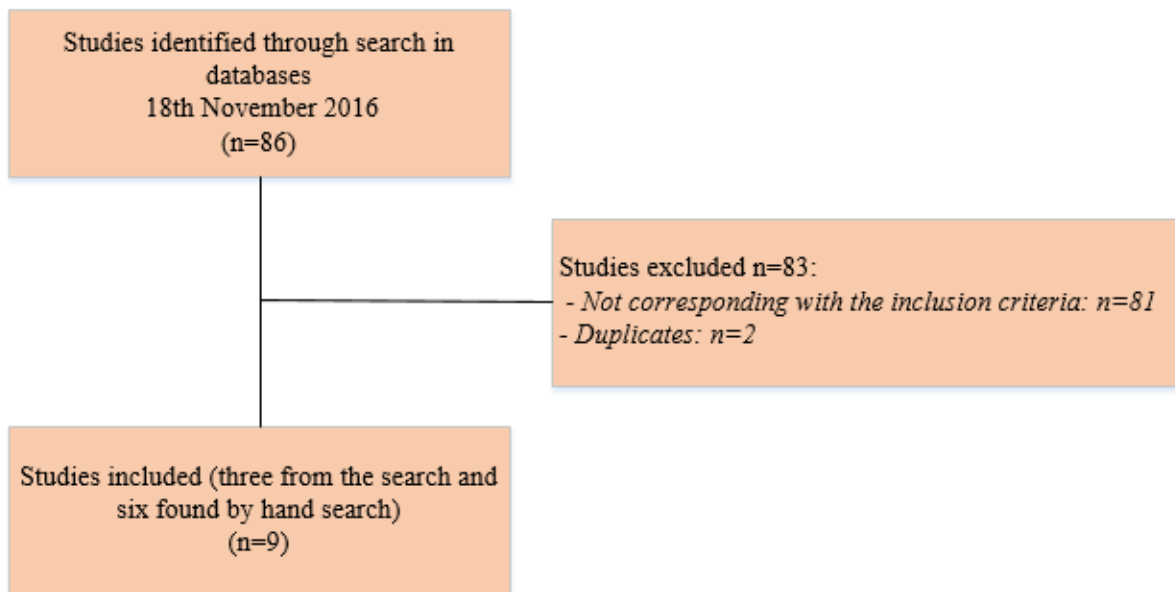


Figure 5 Flow diagram of studies on the Sonas programme

The Critical Appraisal Skills Program (CASP) (CASP, 2014) was used to assess the quality of the studies: one for the quantitative studies and one for the qualitative studies. This is a tool developed to assess the quality of studies (CASP, 2014). However, this was not used for exclusion of articles. There are two tools, one for quantitative studies and one for qualitative studies, consisting of 11 and 10 items, respectively. The tools are evaluating the following properties of the studies: valid result of the review, what the findings are and if the result will have an impact clinically. Each item was rated potentially at low risk of bias (“Yes=1”), high risk of bias (“No=0) or unclear (“Can’t tell=X). We set the cut-off to ≥ 9 , representing high quality. There was a strong evidence of heterogeneity across studies, which can involve a risk of bias when reporting the result. The quality assessments of the individual studies, assessed by CASP, are presented in table 2 and 3, respectively.

Table 2 Quality assessments of quantitative studies on the Sonas programme

First author, year	CASP criteria for quantitative studies											Total
	1	2	3	4	5	6	7	8	9	10	11	
Linehan (1996)	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	0
Connors (2000)	+	÷	+	÷	÷	÷	+	÷	+	+	+	6
Connors (2001)	+	+	+	+	÷	÷	+	÷	+	+	+	8
Jackson (2003)	+	+	+	÷	+	+	+	÷	+	+	+	9
Hutson (2014)	+	+	+	÷	+	+	+	+	+	+	+	10

Table 3 Quality assessments of qualitative studies on the Sonas programme

First author, year	CASP criteria for qualitative studies										Total
	1	2	3	4	5	6	7	8	9	10	
Brown (1997)	÷	÷	÷	÷	÷	÷	÷	÷	÷	÷	0
Hamill (1998)	+	÷	÷	÷	÷	÷	÷	÷	÷	÷	1
Parrish (2005)	+	÷	÷	÷	+	÷	÷	÷	+	+	4
Dugmore (2012)	+	+	+	+	+	+	+	+	+	+	10

Published and unpublished studies on the Sonas programme are presented in table 4.

Table 4. Published and unpublished studies on the Sonas programme

Published studies					
Author(s) Year Country	Design	Sample	Intervention	Outcome	Main findings
<i>Quantitative studies</i>					
Jackson 2003 UK	RCT	75 nursing home residents with dementia	42 participated in one Sonas session per week for eight weeks. 33 in the control group received informal conversation, with similar degree of social contact.	<ul style="list-style-type: none"> • CMAI (short version) • RAGE • Cognitive Performance Scale • Depressive Signs Scale • Additional observations during the sessions. 	<p>No overall statistically significant effect between groups were found.</p> <p>In the Sonas group a significant increase in depressive signs were found, while no change in cognitive performance. However, an increase on aggression and verbally-agitated behaviour and decrease in non-aggressive physical agitation, were found, although not significant.</p> <p>In the control group no significant differences were found on any outcome.</p> <p>Qualitative data showed that attending the Sonas session was an enjoyable activity for most participants.</p>
Hutson (2014) UK	Pilot RCT	39 nursing home residents with moderate to severe dementia	21 participated in two Sonas sessions per week for seven weeks. 18 in the control group received care as usual.	<ul style="list-style-type: none"> • RAID • CSDD • NPI-Q • QoL-AD • HCS 	<p>No overall statistically significant effect between groups were found.</p> <p>Some improvement for both groups in relation to depression, anxiety, behaviour and mood.</p> <p>Quality of life increased for the Sonas group whereas this decreased for the control group. The Sonas group showed less deterioration in communication than the control group.</p>

<i>Qualitative studies</i>					
Brown (1997) UK	Observation study	Groups of eight confused or socially isolated clients	Attended weekly <i>Sonas</i> sessions, some up to 18 months.	<ul style="list-style-type: none"> Behavioural signs of well-being 	A general improvement in alertness, happiness, relaxation and <i>QoL</i> was observed in some participants.
Parrish, Wilshaw, and Baker (2005) UK	Evaluation study	51 residents with dementia in two care facilities: 31 in the day hospital and 20 in a ward.	All attended a 45 minutes <i>Sonas</i> sessions up to one year.	<ul style="list-style-type: none"> DCM (observation every 2 ½ minute for 45 minutes before each <i>Sonas</i> session and continue for 30 minutes afterwards) WIB 	<p>A significant number of participants in all settings showed a positive change in well-being</p> <p>Day hospital: 84% showed improvement in WIB scores during the sessions</p> <p>Care wards: 80% showed improvement in WIB</p>
<i>Dugmore</i> 2012 UK	Semi-structured interviews	17 care home staff			<p><i>Impact on residents</i></p> <p>Staff expressed that the <i>Sonas</i> programme can have a number of positive, predominantly short-term, effects on participants: mood, cognition, communication and interaction, and levels of participation.</p> <p><i>Impact on staff</i></p> <p>Found the session enjoyable and an improved job satisfaction.</p> <p>The <i>Sonas</i> programme could help staff to get to know their residents better and improve their interaction with residents.</p>

Unpublished studies <i>Quantitative studies</i>					
Linehan and Birkbeck (1996) Ireland	Repeated measure design	24 participants	Participants attended weekly Sonas sessions delivered over a three-month period.	<ul style="list-style-type: none"> • MMSE • Confusion Symptoms Checklist • The adaptive Behavior Scale • HCS • 2 observational scales to assess potential change. 	Significant increase in purposeful activity, social interaction, verbal communication, and independent functioning. However, no significant improvement were reported in affect, interaction, or cognition.
Connors (2000) Ireland	Experimental cross-over design	32 patients with dementia in three hospitals	Three groups of eight patients attended Sonas sessions once a week for six months. A control group of eight patients attended an informal chat for three months and then attended the Sonas sessions for three months.	<ul style="list-style-type: none"> • Assessed at three times points: at baseline (T0) 3 months (T1) and 6 months (T2) • MMSE • GDS • The Baumgarten Dementia Rating Scale • The Blessed-Roth Scale • HCS • Communication behaviour • Video 	<p>No significant effect was shown between groups, except an improvement in ADL.</p> <p>The results show a significant improvement in the Sonas group regarding: cognition, depression, communication.</p> <p>The control group showed a significant improvement regarding depression.</p>

Connors (2001) Ireland	RCT Cross-over design	64 patients with dementia and other communication difficulties, in three hospitals	48 participated in <u>Sonas</u> sessions twice a week for six months. 16 in the control group received informal chat in groups of eight for three months and then the <u>Sonas</u> sessions twice a week for three months.	<ul style="list-style-type: none"> • MMSE • GDS • The <u>Baumgarten</u> Dementia Rating Scale • The Blessed-Roth Scale • HCS 	<p><i>Between groups</i> No significant difference between groups on any outcome variable at any time.</p> <p><i>Within groups</i> Significant increase in the <u>Sonas</u> group regarding cognition and reduction in behaviour disturbances and ADL whereas no significant changes were reported in the control group.</p>
<i>Qualitative studies</i> Hamill (1998) Ireland	Qualitative pilot project	Four residential care units Number of participants unknown	<u>Sonas</u> sessions twice a week for 10 weeks	<ul style="list-style-type: none"> • Observation 	<p><i>Staff</i> observed improvement in communication skills, and an increase in self-confidence.</p> <p><i>Relatives</i> reporting; taking initiative in conversation, asking the odd question and more bubbly.</p> <p><i>SLP</i> reported some more use of words.</p>

ADL (Activity of Daily Living); **CMAI** (Cohen-Mansfield Agitation Inventory); **CSDD** (Cornell Scale for Depression in Dementia); **DCM** (Dementia care mapping); **GDS** (Geriatric Depression Scale); **HCS** (Holden Communication Scale); **MMSE** (Mini-Mental State Examination); **NPI-Q** (Neuropsychiatric Inventory); **QoL** (Quality of life); **QoL-AD** (Quality of life in Alzheimer's Disease); **RAGE** (Rating Scale for Aggressive Behaviour in the Elderly); **RAID** (Rating Anxiety in Dementia); **WIB** (Well-or-Ill-Being).

3.6.1.1 Published studies

Of the five published studies identified, two were quantitative and two qualitative. The sample size varied from 75 to 36 participants and the length of intervention period varied from seven weeks to 18 months. Some had one session a week some had two. The outcome differed between the studies; most used more than one outcome and a range of different scales were used (table 5). None of the published studies reported a significant effect on either of the outcomes (table 4).

Table 5 Targeted outcomes for published studies

Studies	Communi- -cation	Aggression/ Agitation	Depression/ Mood	Anxiety	QoL/ Well being	ADL	Cognition
Brown (1997)					x		
Parrish (2005)					x		
Dugmore (2012)	x		x				x
Jackson (2003)		x	x				x
Hutson (2014)	x	x	x	x	x		

The first known study on the Sonas programme is an observation study carried out by Brown (1997). Behavioural signs of well-being were used as the outcome. Some positive changes in well-being, self-confidence, self-esteem and trust as well as improved alertness, happiness and relaxation were observed in the participants. QoL was reported to improve during sessions, whereas no benefit was found on agitation and aggression. However, the quality of this study was poor, with an unknown number of persons with dementia attending the Sonas sessions. No information was given regarding frequency of attendance of the Sonas sessions.

The second qualitative study was conducted in day hospitals and care wards by Parrish, Wilshaw, and Baker (2005), including 51 participants with dementia. A significant number of participants showed a positive change in well-being: 84% in day hospitals and 80% in care wards. This improvement in well-being sustained for around 50% of the participants in each group, 30 minutes after the Sonas session. They became more animated, initiated conversation and sang after attending the Sonas sessions. A strength with this study is that evidence was gathered from the perspective of the persons with dementia by using dementia care mapping (DCM). However, a limitation is the lack of a control group, and that the participants were only assessed once.

Dugmore (2012) assessed the effect of the Sonas programme from the perspective of seventeen Sonas Licenced Practitioners (SLP's) and other care home staff. Staff expressed that the Sonas programme had a number of positive, predominantly short-term, effects on the

participants. Positive effects were reported in relation to mood, cognition, communication, interaction and activity. These positive effects were explained through the creation of a sense of familiarity, explicitly valuing each resident's personhood and gaining and maintaining participants' attention. Another important aspect of the Sonas programme was the impact on staff. They found the sessions enjoyable and gave them an improved job satisfaction. Further, it was reported that it could help staff get to know their residents better and improve their interaction with residents. The study demonstrated a strong methodological quality.

The first quantitative study was published by Jackson, Sterling, Russell, and Templeton (2003). Seventy-five participants in eleven different nursing homes were randomly selected to attend the Sonas group or a control group who received treatment as usual, for eight weeks. No overall statistically significant results were found between groups. An average decrease in non-aggressive physical agitation, as well as an increase in average aggression and verbally-agitated behaviour, was reported, although not statistically significant. However, a significant increase in depressive signs were found in the Sonas group. For the control group, no statistically significant differences between the pre- and post-test assessments were found. However, a slight decrease in aggressive behaviour and non-aggressive physically agitated behaviour, and a slight increase in cognitive deficit, verbally agitated behaviour and depressive signs, were reported. Based on observation notes it was reported that most participants found that attending the Sonas programme was an enjoyable activity.

Hutson, Orrell, Spector, and Dugmore (2014) conducted a randomized controlled trial (RCT) including 39 nursing home residents, of which 21 participated in the Sonas sessions twice a week over a period seven weeks and 18 in a control group, receiving treatment as usual (TAU). There were no statistically significant differences between the groups in relation to depression, anxiety, communication, QoL or behavioural disturbances at the end of the study period. However, there was some improvement for both the TAU and Sonas groups in relation to depression and anxiety, and interestingly the TAU group showed greater improvement than the Sonas group. The study revealed that behaviour and mood also improved for both groups: the Sonas groups reported a greater improvement regarding negative behaviour than the TAU group. In relation to QoL, the mean Sonas scores improved whereas the TAU scores deteriorated during the eight weeks. Finally, the Sonas group showed less deterioration in communication compared with TAU group. The strength of this study was the inclusion of a control group and a relatively large sample size. However, some of the

sessions were facilitated by only one member of staff, which could influence the outcome. The lack of adaptation of choice of music is another limitation.

3.6.1.2 Unpublished studies

Four unpublished studies of the Sonas programme were found, of which three were quantitative and one qualitative. The sample size varied from 24 to 64 participants with a length of the intervention period from ten weeks to six months; using different outcome measures (table 6). One or two sessions were held weekly.

Table 6 Targeted outcomes for unpublished studies

Studies	Communi- -cation	Aggression/ Agitation/	Depression/ mood	Anxiety	QoL/ Well being	ADL	Cognition
Linehan (1996)	x	x					x
Hamill (1998)	x						
Connors (2000)	x	x	x			x	x
Connors (2001)	x	x	x			x	x

A significant increase in purposeful activities, social interaction, verbal communication and independent functioning was reported in Linehan and Birkbeck (1996) study of 24 participants attending the Sonas sessions once a week over a three months period. However, no significant effect was reported on affect, interaction and cognition. The problem with this study is all the limitations: no control group, no blinding, missing data, no information about when the assessment was carried out and the sessions facilitated by staff without training in the Sonas programme. There is an absence of pre-defined criteria to guide sample selection and an inconsistency in how the sessions were delivered and it is not clear if the participants had dementia or not.

In a qualitative study conducted by Hamill (1998) staff observed improvement in communication skills and an increase in self-confidence, whereas relatives reported that the person with dementia took more initiative in conversation and asked the odd question and was more bubbly. The Sonas Licensed Practitioner (SLP) even reported some more use of words. However, this study has some serious methodological problems such as unknown number of participants and lack of information about research design and analysis.

Some of these limitations were overcome in Connors (2000) study which included thirty-two persons with dementia or Parkinson's disease. Three groups of eight participants were planned to attend a weekly Sonas sessions for six months facilitated by staff trained in

the Sonas programme and, one group of eight served as a control group by having an informal chat. However, in three locations, the experiment group only received the Sonas programme for the first 3-4 weeks of the second period and the control group experienced several disruptions in the last three months due to a national strike, which might explain the outcome. No significant effect was reported between groups, except from ADL. The result showed a significant improvement in the Sonas group in relation to cognition, depression and communication. Improved mood was reported in the control group, which might be due to the attention they received through the informal chat. Although having overcome some of the limitations of previous research, this study had a relatively small sample size and the participants were not randomized into groups. Further, there was no direct statistical comparison between the experimental and the control groups.

In order to overcome some of the above limitations, Connors (2001) conducted another study where sixty-four participants were included: forty-eight assigned to experimental groups and sixteen to control groups. Although twenty-seven residents in the Sonas group had a diagnosis of dementia, none of the residents in the control group had a dementia diagnosis. The Sonas sessions were delivered twice a week over a six-month period. The overall result showed that those attending the Sonas sessions improved in ADL, behaviour and cognition. Sonas had the greatest effect on those with dementia: improving cognition, activity of daily living and communication. No effect was observed on mood. The strengths of this study were: the larger sample, the fact that the researchers were blinded and the inclusion of a control group. However, the use of outcome measures with unknown psychometric properties and unclear randomisation is a clear limitation with the study. People without dementia were included and no direct statistical comparison between the experimental and the control groups was used. In addition, an unclear method of randomization, gives the study some limitations.

3.6.2 Summary

This review found no evidence of a significant effect of the Sonas programme of any of the outcome measures, the majority focusing on negative outcomes. It is difficult to compare the outcome of the studies since they vary regarding sample size, length of intervention period and frequency. Some did include persons without dementia. A comparison is also difficult because several of the studies have methodological weaknesses and no measure of adherence to the Sonas intervention was used. Even though some of the studies measured the effect of communication, which is the overall aim of the Sonas programme, they used the HCS, which

is not psychometrically tested. With only a few published studies investigating the effectiveness of the Sonas programme there is a need for more studies in order to overcome some of the above mentioned limitations.

4 Study aims and philosophical positioning

With just five published studies examining the effect of the Sonas programme, three of them showing methodological limitations, the overall aim of this thesis was to measure the effect of the Sonas programme on communication for people with moderate to severe dementia.

4.1 Study aims

The importance of developing a protocol with main aims, clear research questions and details about search strategy is emphasized (Denison et al., 2013). Based on the overall aim of the thesis, the following three specific aims were to:

- Provide an overview of available sensory stimulation interventions and their effect on persons with dementia and to present theoretical and methodological characteristics of the studies included (sub-study 1).
- Investigate the psychometric properties of the Holden Communication Scale (HCS) and the association between scores on HCS and cognitive function among persons with dementia (sub-study 2).
- Examine the effect of the Sonas programme on communication ability for people with moderate to severe dementia living in nursing homes and to explore if any effect could be related to cognitive function and different aspects of communication (sub-study 3).

4.2 Philosophical positioning

A paradigm, also referred to as philosophical positioning, is a worldview that takes a stand on questions about ontology, epistemology, axiology and methodology (Polit & Beck, 2012, p. 13). These are either explicit or implicit but will undoubtedly influence the choices made in the practical positioning of the research (Pearce, 2015). Worldview, which can be defined as “a basic set of beliefs that guide action” (Guba, 1990, p. 17), can be described within a post positivistic and naturalistic paradigm (Polit & Beck, 2012). In the following, the ontological, epistemological, and axiological questions will be discussed.

4.2.1 Ontology

Ontology, which is the nature of reality is understood differently within paradigms. Within the naturalistic tradition reality is understood as multiple and subjective, whereas within a positivistic tradition there is an assumption that reality is found in the real world. This view of

total objectivity is modified in the post-positivistic paradigm where the impossibility of total objectivism is recognized (Polit & Beck, 2012).

In recent years more emphasis has been on the persons' experience of living with dementia rather than the diagnosis. Even though the reality to some degree is subjective and multiple, this thesis' ontological approach is placed within the post positivistic tradition, where the focus is on observation of communication ability rather than the person's own experience. Including data about the person's personal experience would have strengthened the thesis. Nevertheless, because of the fact that several of the participants were unable to express themselves verbally, this approach was not considered as suitable.

4.2.2 Epistemology

How we understand ontology will also influence the choice of an epistemological approach. The research questions and methodology set the conditions for the epistemological standpoint, where the question is how information is collected and how to justify what we know (Pearce, 2015). The overall research question for the thesis was: "what is the effect of the Sonas programme on communication among people with moderate and severe dementia"? Therefore, an epistemological post positivistic approach was considered appropriate, where the researcher is not directly involved with the participants. This is different from the naturalistic paradigm where the interaction between the researcher and those being researched, is emphasized (Polit & Beck, 2012).

In the thesis, staff who knew the participants well led the Sonas and reading groups in order to make them feel safe. Using staff who know the residents in carrying out interventions were considered to be more ethically appropriate since this prevented the participants from having to deal with new people just for a short time of the sake of research. Otherwise it would have been difficult for the project leader to run the Sonas and reading groups in six different nursing homes twice a week, over a period of 24 weeks.

4.2.3 Axiology

Axiology is understood as the role of values in research. Research questions asked or not asked and type of data collected or not collected, are important aspects of the axiology (Polit & Beck, 2012). It is impossible, and not even desirable, for the researcher to be completely free of personal values, nevertheless, the types of questions asked will have an implication on the choice of method for collecting data.

The fact that people with moderate and severe dementia were included in the study resulted in questions around the ethical consideration of involving them in research. The ethical considerations are further described in chapter 6.

Asking question about effect places the thesis, as already mentioned, within a post-positivistic tradition, where objectivity is sought, even though there is a recognition that total objectivity is impossible (Polit & Beck, 2012). The need for developing knowledge as well as evaluating the effect of interventions in health care practice has been emphasized (Richards & Hallberg, 2015). As already mentioned, the need for stimulation will increase for the person living with dementia as the disease progresses. Providing empirical evidence would be preferable before implementing the Sonas programme in other settings to ensure the value of the programme on people living with dementia. However, empirical evidence requires quantitative data where one of the aims is to generalize and therefore a quantitative approach was chosen.

5 Study design, material and methods

Methodology is a question about how evidence is best obtained. Depending on the nature of the research questions, a qualitative or quantitative study design will be chosen as an approach. Qualitative and quantitative refers to distinctions about the nature of knowledge but also to research methods (Polit & Beck, 2012). Another way of thinking about these terms is by defining them as type of data with corresponding analysis (O'Leary, 2004, p. 99).

To achieve the aims of the study, a design with three sub-studies were chosen (table 7). The first sub-study reviewed the research literature of sensory stimulation for people with dementia (sub-study 1), whereas sub-study two was a psychometric evaluation of the HCS (sub-study 2). Finally, the third sub-study was a randomized controlled trial (RCT), conducted over a period of 24 weeks (sub-study 3). Sub-study two and three were based on the same sample of nursing home residents with dementia.

Table 7: Study design

	Sub-study 1	Sub-study 2	Sub-study 3
Strategies of inquiry	Literature review	Psychometric evaluation	RCT
Participants		128 nursing homes residents	120 nursing homes residents*
Data collection	Research articles from selected data bases	HCS MMSE	HCS MMSE
Analysis	Descriptive statistics Content analysis	Descriptive statistics Inter-item correlation Cronbach's alpha coefficient and corrected item-total correlation Exploratory factor analysis Inter-item reliability	Descriptive statistics Linear mixed model analysis Explorative statistics

* One nursing home with eight residents was excluded from sub-study 3 due to lack of randomisation.

Holden Communication Scale (HCS): Mini-Mental State Examination (MMSE).

5.1 Sub-study 1

Before deciding to conduct a review, a literature search was performed to explore the existing reviews about sensory stimulation. Several literature reviews of different sensory stimulation

interventions for persons with dementia have been conducted during the recent years. However, most report on single interventions such as light therapy, massage and touch, acupuncture and music therapy (Forbes et al., 2009; Hansen et al., 2006; Peng, Zhao, Liu, & Wang, 2007; Vink et al., 2003).

5.1.1 Research questions

Three research questions were defined to reach the aims for sub-study one:

1. At present, what kind of sensory stimulation interventions are used for persons with dementia?
2. What theoretical and methodological characteristics, e.g. specific study design and measures, do the available studies incorporate?
3. What is the effect of the different interventions?

5.1.2 Strategy of inquiry

A literature review is an objective, thorough summary and critical analysis of available research relevant to a chosen topic (Hart, 1998). However, a variety of different types of reviews exist, and even though they have a lot in common, the choice of type will depend on the aim of the specific view. Since the aim of sub-study 1 was to provide an overview of available sensory stimulation interventions and their effect on persons with dementia, as well as giving an overview of the theoretical and methodological characteristics, including different targeted outcomes of the studies, a “systematic search and review”, was chosen. This type of review “combines the strengths of a critical review with a comprehensive search process” (Grant & Booth, 2009, p. 102). The strength of a “systematic search and review” is that it allows incorporating multiple study types and therefore provides a more complete picture of the area of research. However, a weakness might be that it is prone to some of the limitations of the traditional review where explicit inclusion and exclusion criteria and a clear process of synthesis is required (Grant & Booth, 2009). To overcome some of these weaknesses, explicit inclusion and exclusion criteria were developed. Although these criteria were established beforehand, there was a need for some amendment during the review process to include all available sensory interventions. The final list is presented in table 8.

Even though this was not a systematic review, the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA statement) was used as a guideline for reporting the review. It is not a quality assessment instrument, but a help to perform and improve the reporting of systematic reviews (Moher, Liberati, Tetzlaff, & Altman, 2009). The

PRISMA statement consists of a 27-item checklist and a four-phase flow diagram. The checklist was used as a guide to organise the article, however, some of the items were not included. One of the first items in the guide is about protocol and registration. Although no formal review protocol or registration number (item 5) is available, all the different steps of the review process are documented and can be made available on request. Items 16 and 23, both describing additional analysis, were not carried out, whereas item 13, summary measure and item 21, synthesis of results, were not applicable.

Table 8: Inclusion and exclusion criteria for sub-study 1

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • Randomised controlled trials (RCT) • Controlled clinical trials (CCT) • Crossover design • Pre-post studies with control • Participants having a diagnosis of dementia (including Alzheimer disease, frontotemporal dementia, vascular dementia and mixed Alzheimer’s disease) • Main intervention to be sensory based • Delivered to individuals or in a group performed by staff members or researchers (not family caregivers) at a day hospital or long-term care home • Using standardized instruments to measure the outcomes/effect • English language • Peer-reviewed 	<ul style="list-style-type: none"> • Dissertations • Interventions aimed for the caregiver • Interventions carried out in persons’ homes • Studies measuring the effect of pharmacological treatment or combination of pharmacological and sensory stimulations • Studies measuring the effect on staff or family

5.1.3 The search process

The search was performed in August 2014 in accordance with the inclusion and exclusion criteria (table 8). Available sensory stimulation interventions published between 2003-2014, were included. The search terms were identified by first searching concepts describing the same, like nonpharmacological - and psychosocial methods or interventions. An additional search was conducted to get an overview of available sensory stimulation interventions used for persons with dementia. The same search terms were used in all four databases: CINAHL, PubMed (Medline) and the Cochrane library and PsycINFO. The search terms are listed in table 9. To expand or narrow the search the Boolean operators (OR, AND) were used. Where possible, the truncated search term, ending with * was used as well.

Table 9: Search terms for sub-study 1

• Dement*	• music
• Alzheimer*	• massage
• sensor stimul*	• touch
• multi-sensor stimul*	• aromatherap*
• multisensory	• relexolog *
• stimul multi-sensor*	• Sonas
• environ*	• Snoezelen
• multisensory environ*	• sensory garden
• psychosocial method	• acupressure
• psychosocial intervent*	• light therap*
• non-pharmacologic	• bright light therap*
• intervent*	• doll therap*
• nonpharmacologic	• toy therap *
• non-pharmacologic therap*	• pet therap*
• nonpharmacologic therap*	

5.1.4 Data selection

The first search to identify available sensory stimulation interventions was conducted by the first author, which gave a total of 2495 hits. A screening process where all titles and abstracts were read, was done thereafter, leaving 119 studies to be assessed for eligibility. All 119 articles were printed and divided among the three authors where the first author assessed all for eligibility by reading the full-text, and the second and third author assessed half the number each. Any discrepancies were discussed and a consensus was reached regarding inclusion of articles. A further deduction was made according to the inclusion and exclusion criteria, resulting in 55 included studies for review (figure 6).

5.1.5 Analysis

First, all three authors with the purpose of answering the three research questions read the included studies. The studies were read several times to get an overview. The next step was to identify categories. The first research question of identifying available sensory stimulation interventions for people with dementia was relatively easy to answer, as this was usually described even in the title of the articles. Sensory stimulations were limited to interventions that stimulates one or more of the five human senses. Regarding theoretical characteristics of the interventions, a thorough analysis of each study, searching for a description of the theoretical foundation of the intervention, was performed. Further, all three authors used the Critical Appraisal Skills Program (CASP) (CASP, 2014) to assess the methodological

characteristics and the risk of bias in the included studies. The CASP is further described in chapter 3.6.1.

The third research question about the effect of the different interventions were grouped into two main categories and seven sub-categories:

1. Single sensory stimulation included music, light therapy, acupressure/reflexology, massage/aromatherapy and doll therapy/pet therapy/toy therapy.
2. Multi-sensory stimulation included Snoezelen and the Sonas programme.

The findings were presented in a data extraction form, which was piloted on the first five studies, including: study, setting, country, purpose, study design, sample, intervention, duration and frequencies, target, outcome measure, type of intervention, theoretical foundation, main findings, length of intervention and strength/quality.

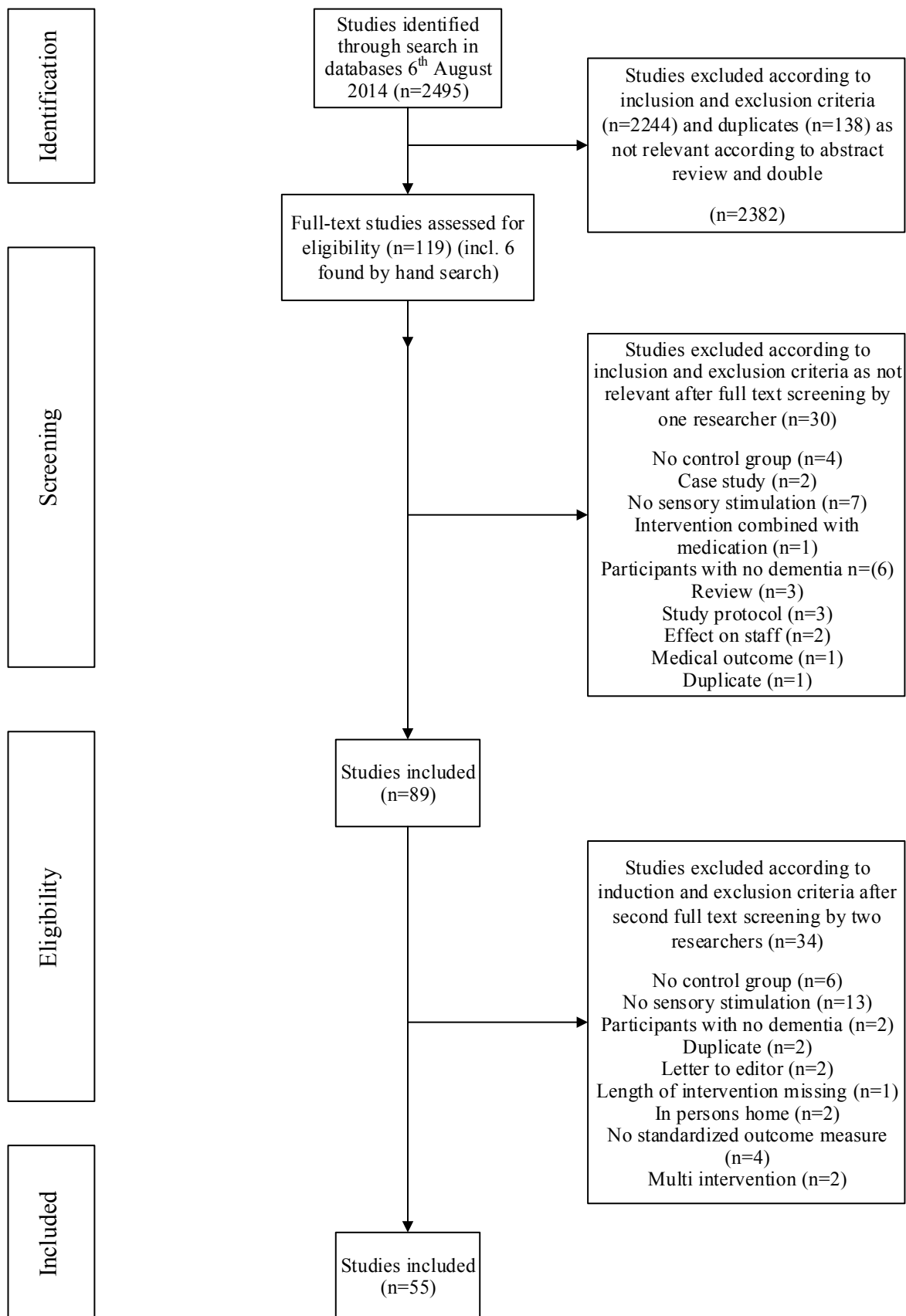


Figure 6: PRISMA 2009 Flow diagram of the selection process

5.2 Sub-study 2

The overall aim of sub-study 2 was to investigate the psychometric evaluation of the HCS.

5.2.1 Research questions

Two research questions were defined:

1. What are the psychometric properties of the English version of the Holden Communication Scale (HCS) in a sample of persons with moderate to severe dementia living in nursing homes in Ireland?
2. What is the association between the ability to communicate and cognitive function, measured by the means of HCS and Mini-Mental State Examination (MMSE), respectively?

5.2.2 Strategy of inquiry

To answer the two research questions a psychometric evaluation of the HCS was performed.

5.2.3 Participants and procedure

Participants

The recruitment process took place between January and March 2014. A convenience sample of 128 persons in seven different nursing homes in Ireland were included and assessed at baseline, whereas 88 of the same sample (the control group was not included) were included in the test-retest reliability study. The recruitment process is further described in 5.3.3.

Table 10 Participants characteristics in sub-study 2 ($n=128$)

Variabel	n	%
Gender		
- male	27	21
- female	101	79
	Mean	SD
Age, years	85.2	7.2
MMSE score	8.9	7.0
HCS score	22.3	12.0

Data collection

Two to three nurses in each nursing home received two hours training in how to carry out the assessments. The HCS (Holden & Woods, 1995) was used to assess communication ability,

further described in 2.3.4, whereas the Mini-Mental State Examination (MMSE) was used to assess cognitive performance (Folstein et al., 1975), further described in 2.1.4

All the participants included in sub-study 2 and 3 had a dementia diagnosis; however, no information about dementia stage was available other than the MMSE. Even though the MMSE is not meant to distinguish between dementia stages, Perneczky et al. (2006) found that the MMSE discriminated well between all CDR stages and therefore can be used as a surrogate measure for the CDR for the staging of dementia in AD. Based on this, MMSE 0-10 was considered as severe dementia (CDR 3), whereas 11-20 as moderate dementia (CDR 2).

5.2.4 Analysis

Data were analysed using the Statistic Program for Social Sciences (SPSS), version 22.0 and Statistical Analysis Software (SAS), version 9.4. An overview of statistical analysis used in sub-study 2 is presented in table 11.

No deviation from normality was found when inspecting the distribution of data. An inter-item correlation analysis, using Pearson's correlation coefficient was performed to explore if all items of the HCS were measuring the same underlying characteristics. The Cronbach's alpha coefficient and corrected item-total correlation were used to analyse internal consistency reliability. The criterion function for acceptable reliability was set to $\alpha \geq .7$ (M. A. Hardy & Bryman, 2004, p. 23). Pearson correlation coefficient (r) was used to examine the test-retest reliability, and criterion function for acceptable reliability was set to $r \geq 0.7$. A paired samples Student's test was applied to assess bias and 95% limits of agreement between test and re-test measurements were constructed. The limit of agreement might be useful even though a priori width for the limits was specified.

An exploratory factor analysis (FA) with principal components extraction method was performed, including all 12 items of the HCS to explore the component structure and construct validity. Prior to the FA, Bartlett's test of sphericity (significance better than 0.05) and the Kaiser-Meyer-Olkin (KMO) test (higher than 0.60), were carried out. To allow for correlated factors, an oblimin rotation was applied. First, by inspection of the scree plot and the Kaiser criterion (eigenvalue ≥ 1), the number of components retained for extraction was revealed. Then a factor analysis with three components was carried out since the original version of the HCS suggests three subgroups. The concurrent validity between the HCS and MMSE was examined using Pearson's correlation coefficient, stratified by MMSE score of 0-10 (severely impaired, $n=67$) and MMSE score 11-20 (moderately impaired, $n=61$). An inter-

rater reliability was not performed since the assessments were carried out by the same nurses in each of the nursing homes.

Table 11: Statistical analysis in sub-study 2

	Statistical analysis
Inter-item correlation	Pearson's correlation coefficient (r)
Internal consistency reliability	Cronbach's alpha coefficient (α) Corrected item-total correlation
Test-retest reliability	Pearson correlation coefficient (r)
Assess bias	Paired samples Student's t-test 95% limits of agreement
Checking for appropriateness for factor analysis	Bartlett's test of sphericity Kaiser-Meyer-Olkin (KMO) test
Component structure and construct validity	An exploratory factor analysis (FA)
Concurrent validity	Pearson's correlation coefficient (r)

5.3 Sub-study 3

The overall aim of sub-study 3 was to test the hypothesis that the Sonas programme is more effective than attending a reading - or control group to improve communication ability in persons with moderate to severe dementia.

5.3.1 Research questions

Three research questions were defined:

1. What effect does the Sonas programme have on communication among people with moderate to severe dementia?
2. Can the effect be related to cognitive function when stratified on moderate and severe dementia?
3. Can the effect be related to the different aspects of communication?

The CONSORT 2010 Statement (Schulz, Altman, & Moher, 2010) and the extended version of the CONSORT Statement for non-pharmacological treatment which consists of a 22 points

check list (Boutron, Moher, Altman, Schulz, & Ravaud, 2008), was used to report the findings.

5.3.2 Strategy of inquiry

The study was a multi-centred randomized controlled trial (RCT), with participants assigned to one of the three groups: 1) Sonas group, 2) a reading group, or 3) a control group. The advances of conducting a RCT is that it is considered to be well suited to draw conclusion of effect (Polit & Beck, 2012). The control group received standard care and attended usual activities in the nursing home (NH), the reading group was considered as an attention control group. This is used when one wants to “rule out the possibility that intervention effects are caused by the special attention given to the people receiving the intervention, rather by the actual content” of the intervention (Polit & Beck, 2012, p. 253). In this study, this was not possible to follow to the same extent since it would entail leaving the participants on their own in order to exclude attention from human beings. However, leaving them alone was considered unethical even though it implied some limitations. Therefore, reading was chosen as an attention placebo control (APC).

An intention-to-treat (ITT) approach, where participants are considered in the way they were randomized, was chosen (Armijo-Olivo, Warren, & Magee, 2009). Even though none of the participants changed the group they originally had been assigned to, those who chose to leave the study after randomization were included in the analysis as well (Armijo-Olivo et al., 2009).

5.3.3 Recruitment process

The Consort Statement suggests that the eligible criteria for participants as well as for the setting and those who perform the interventions, are presented (Boutron et al., 2008 §3).

Setting

In all, 168 nursing homes (NH's) in Dublin and five surrounding counties in Ireland, all registered with the independent authority, “Health Information and Quality Authority” (HIQA), were considered eligible. The goal of HIQA is to perform continuous improvement in Ireland's health and social care services (HIQA, 2016). The reason for limiting to NH's registered with HIQA was that this gave access to inspection reports with information whether the Sonas programme was provided in the NH's or not. Only long-term facilities registered with HIQA, with at least 40 beds that did not use the Sonas programme at present or

previously, were initially chosen. The counties were chosen because of the logistic considerations like travel distance.

Of the 168 NH's, 47 had less than 40 beds, 18 were not NH's but hospitals and 78 were already using the Sonas programme according to the last inspection report carried by HIQA, and therefore not considered to fulfil the inclusion criteria. The remaining 25 NH's received an e-mail with information about the project and a question if they were using or had used the Sonas programme. They were also asked if they had at least 16 potential participants with dementia who could be eligible for the study. Nine of the 25 NH's used the Sonas programme, six did not answer the e-mail and two did not agree to participate, which left us with eight NH's. However, one NH withdrew after one week due to change in leadership and therefore two more counties were included in the search. In this round, one of the nine eligible NH's accepted to participate, but withdrew before baseline data was collected because of heavy work load in the NH. This left us with seven nursing homes, but when the time came to collect baseline data it showed that one NH did not have enough participants for two groups. However, eight residents from this NH were randomly chosen among 10 to be included in sub-study 2, which left us with six NH's for this RCT: three NH's from the counties Dublin, and one from county Laois, Louth and Meath, respectively (figure 7).

Participants

The participants were recruited between January - March 2014 and the Director of Nursing (DON) in each NH identified potential male and female residents. A total of 147 persons were considered eligible for the study and informed consent was obtained from the next-of-kin. Persons > 65 years of age, who had a dementia diagnosis and a moderate to severe stage of dementia as classified by pre-trial MMSE scores of 0–20, spoke English and were living in the NH, were considered suitable for participation in the study. Persons were not included if they were in the palliative stage, not expected to live longer than six months or able to attend a Sonas session, had major depression, current or partial remission, had severe pain or had been exposed to previous Sonas sessions. Three NH's had enough participants for three groups, while the other three were randomized for two groups. We ended up with 120 participants, leaving 27 out of the study due group size of eight (figure 7). Participants characteristics are presented in table 12.

Table 12: Participants characteristics in sub-study 3

Characteristics	Total (n=120) n (%)	Sonas group (n=48) n (%)	Reading group (n=32) n (%)	Control group (n=40) n (%)
Gender				
Women	93 (77.5)	40 (83.3)	25 (78.1)	28 (70)
Men	27 (22.5)	8 (16.7)	7 (21.9)	12 (30)
Marital status				
Single	36 (30)	12 (25.0)	11 (34.4)	13 (32.5)
Married	22 (18.3)	8 (16.7)	6 (18.8)	8 (20.0)
Widowed	61 (50.8)	27 (56.3)	15 (46.9)	19 (47.5)
Divorced	1 (0.8)	1 (2.1)	0 (0)	0 (0)
Degree of cognitive function				
Severe (MMSE 0-10)	63 (52.5)	29 (60.4)	15 (46.9)	19 (47.5)
Moderate (MMSE 11-20)	57 (47.5)	19 (39.6)	17 (53.1)	21 (52.5)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Age	84.8 (7.0)	86.1 (6.6)	84.9 (7.2)	83.3 (7.1)
MMSE	9.0 (7.1)	7.7 (6.7)	10.0 (7.2)	9.7 (7.5)
HCS	22.0 (11.9)	24.7 (12.1)	18.2 (12.0)	21.9 (10.9)

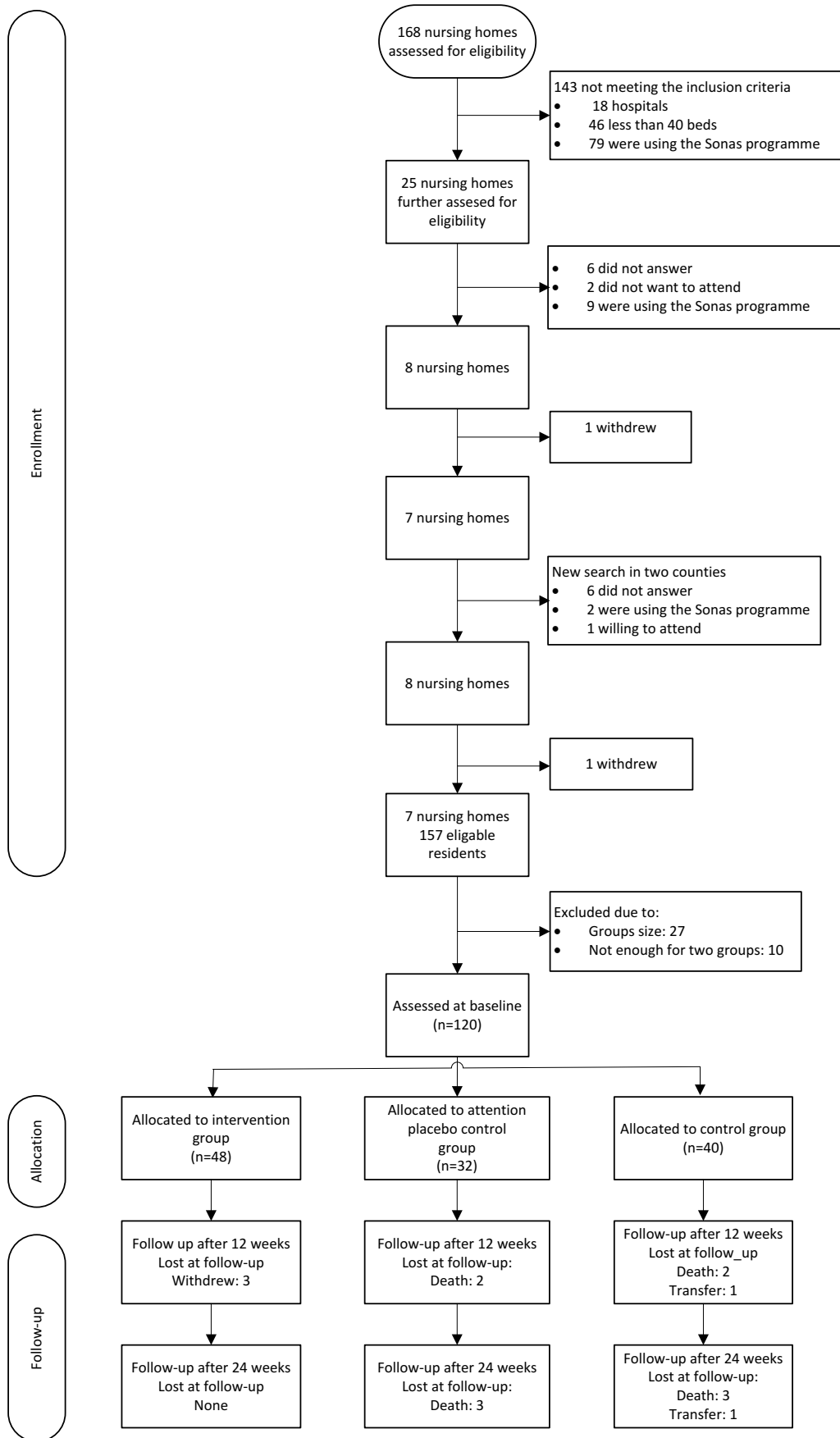


Figure 7 Consort flow

Randomization

Randomization, which is important because it eliminates most other sources of systematic variation where variation is due to the manipulation of the independent variable (Field, 2013), was carried out according to recommendations from the Consort Statement (Boutron et al., 2008 § 8). The randomisation was performed separately in each NH by the DON and the project leader after collection of baseline data. Due to ethical considerations, it was decided beforehand that all NH's would have one Sonas group, which would give each nursing home the possibility to offer a new intervention.

The names of the participants were placed in a container and study participants were drawn. For the NH's with less than 24 eligible participants, eight participants were randomly assigned to the Sonas group, whereas the remaining eight were randomly allocated to the reading- or control group, respectively. The randomisation process resulted in: Sonas programme (n=48), reading group (n=32) and control group (n=40). The recruitment process is presented in table 7 according to the recommendation from the Consort Statement (Boutron et al., 2008 § 13)

5.3.4 Intervention

A detailed presentation of the interventions and how they are administered, is recommended (Boutron et al., 2008 § 4). Based on this, the Sonas group, reading group and control group are presented as followed.

Preparation

The Sonas Licenced Practitioners (SLP's) attended a three days training in the Sonas programme conducted by the Sonas apc, whereas the project leader provided an additional information about the Sonas programme to the nursing staff as well. Those who facilitated the reading group were instructed how to lead the group whereas no additional training was given to the remaining staff.

The Sonas group

The Sonas session was carried out twice a week over a period of 24 weeks, led by a SLP and an assistant. Each group had eight participants and the session lasted 45 minutes. The programme follows a fixed structure each time, believing that repetition can help the person to remember (Sonas aPc, 2011). The programme consisted of the following 11 elements shown in table 13.

Table 13: The 11 elements of the Sonas programme and stimulation of the senses

The Sonas programme	Stimulation of senses
Signature tune and greeting song	Hearing, sight and touch
Exercises to music	
Smell	Smell
A “sing-along” which includes three familiar songs	Hearing
Relaxing music/massage and tasting	Touch and taste
Music with percussion instruments	Hearing
Joining in proverbs	
Listening to poetry	Hearing
Contribution	
Second “sing-along”	Hearing
Closing song and signature tune	Hearing, sight and touch

The participants are seated in a semi-circle so everybody can see each other and keep eye contact during the session. During the greeting song, the SLP goes around, make sure to have eye contact and be at the same eye level and welcome each participant by name, and shake their hand. The same is done at the end of the session where each one is wished good-bye. During the session, the participants are presented with a smell and something to taste and offered relaxing massage while music is played. Two sing-alongs and use of percussion instruments are also used, as well as an invitation to join in proverbs and listening to poetry (table 13).

The reading group

The reading group attended a reading group for 45 minutes twice a week, where one member of staff read from a newspaper for 45 minutes. In addition, they attended the daily activities provided in the nursing home.

The control group

The control group did not join the Sonas group or the reading group, but continued with their daily routines, e.g. attending the daily activity programme set up by the nursing home.

5.3.5 Data collection and outcome measures

Demographic data were collected from medical and nursing home records. Two to three nurses in each of the six nursing homes collected data about cognitive functioning and

communication ability. The assessments were based on observations done during two weeks, carried out by nurses who knew the resident well. The nurses who assessed the participants did not take part in the interventions. They were blinded to group assignment at baseline but not at follow-up.

The main outcome was communication, as measured with the Holden Communication Scale (HCS), which measures communication ability, whereas the secondary outcome was the degree of cognitive functioning, assessed by the Mini-Mental State Examination (MMSE). The data were collected at baseline (T0), and then again after 12 weeks (T1) and 24 weeks (T2).

5.3.7 Analysis

The statistical analyses were conducted using SPSS version 22 and SAS version 9.4. Results with p-values below 0.05 were considered statistically significant.

Power calculation

The main aim of the sub-study was to compare the HCS score between the Sonas and the reading group as the primary analysis. Although a previous pilot study of the Sonas programme found that a total sample size of 40 would be sufficient to detect an effect size of .80 (Hutson et al., 2014), a new power calculation was performed, assuming Cohen's $d= 0.80$ as the effect size. With the significance level of 5% and power of 80%, a minimum sample size of 24 in each group, was required. Based on an assumed dropout rate of 30%, a required sample size was therefore adjusted to 32 persons per group.

Resident's characteristics

At baseline, each participant's characteristics were summarized as frequencies and percentages for the categorical variables and as means and standard deviations (SD) for the continuous variables (table 12). Testing for baseline differences was not made since this is considered not to be appropriate when reporting a RCT (Boutron et al., 2008; Schulz et al., 2010). The normality of the continuous variables was assessed by inspecting the histograms.

Resident's outcomes

In order to assess differences in HCS total scores between the intervention group, the reading group and the control group a linear mixed-model with fixed effects for a time component up to second-order and group variable, was estimated. In addition, the interaction between the two was included since a significant interaction term would suggest differences between the

three groups during the 24 week period. Included in the model were also random effects for participant nested within nursing homes. Using such a model will account for intra-participants correlations due to repeated measurements for each participant. The model also accounts for cluster effect within each nursing home. The advantages of using a linear mixed model is that it handles unbalanced data by including all available information, including that from drop-outs. In an exploratory analysis, the same model for each component of HCS was estimated.

To assess changes among those with moderate and severe dementia measured by MMSE, a similar model as above was estimated. An extra fixed effect for level of cognitive decline, the interaction between the level and time, and the interaction between the level and the group with moderate and severe cognitive decline, respectively, was included. Using such an analysis will help to explore if those with moderate or severe cognitive decline benefit most from the Sonas programme compared with the reading and control group. This is consistent with Polit and Beck (2012) who emphasise the importance of not only understanding what is working, but what works for whom.

Table 14: Statistical analysis in sub-study 3

<i>Resident's characteristics</i>	Statistical analysis
Descriptive statistics of categorical variables	Numbers (n) Percentages (%)
Descriptive statistics of continuous variables	Mean (SD)
<i>Resident's outcomes</i>	
Between-group comparison for change over time for continuous variables (HCS)	Linear mixed model analyses
An exploratory analysis – between-group comparison for change over time for items of HCS	Linear mixed model analyses
Additional comparison between two groups with respect to cognitive decline	Linear mixed model analyses

Missing values

One of the strengths about mixed models, applied in this study, is that the models are very flexible in handling unbalanced data sets in a way that they utilize all available data, including those from drop-outs and from participants with one or more missing data points.

6 Ethical considerations

The aim of the Health Research Act (2008 §1) is to “promote good and ethically sound medical and health research”, and to achieve this there is a need for people who are willing to participate in research projects, including people with dementia. Even though it is more common to include people with dementia in research, only 1.9% of studies performed to find interventions to reduce challenging behaviour in people with dementia included persons with severe dementia (Gruneir, Lapane, Miller, & Mor, 2008). One reason might be that it is difficult to find appropriate interventions for this group, or the ethical challenges in relation to obtaining voluntary, informed consent. The consequences could be that one must sacrifice the value of including people with dementia due to considerations from ethical committees with the risk that this population is excluded from research (Dewing & Pritchard, 2008). Despite this challenge, Hellström, Nolan, Nordenfelt, and Lundh (2007) claim that it would be unethical and a threat to their dignity to exclude people with dementia from research.

6.1 Prior approval

The Health Research Act (2008 §9) states that all medical and health research that involves humans beings must have prior approval from the regional committees for medical and health research ethics (REK). REK perform a quality assurance by evaluating the objectives of the project and its safety by looking at potential risks and benefits and whether privacy is assured. Even though the present study was carried out in Ireland and not on Norwegian territory, there was a need to obtain approval from REK since a person established in Norway conducted the study (The Health Research Act, 2008 §3). Before the submission, a research protocol was developed as required by the The Health Research Act (2008 §6), and the question of whether it would be ethically acceptable to include people with moderate and severe dementia in the research as well as an assessment of the balance between benefit and risk, was carried out as suggested by Ruyter (2010). The risk of attending the Sonas programme was considered minimal, whereas receiving multi-sensory stimulation was considered being beneficial. The study was approved by REK under the registration number IRB 0000 1870 (Appendix 2).

6.2 Consent

The requirement that “consent must be informed, voluntary, express and documented”, and related to a specific research project, is emphasized in the Health Research Act (2008, §13). This requirement has its origin in the Nuremberg Code of 1947 where it is determined that "the voluntary consent of the human subject is absolutely essential" (Ruyter, Førde, &

Solbakk, 2000). The requirement that it is "absolutely", is waived in the declaration of Helsinki (World Medical Association, 2013).

One of the biggest challenges in the thesis is the question of competence to give consent since the persons included have moderate to severe dementia. It is also important to underline not to take for granted that persons with dementia are not able to make decisions, but that they deserve a fair assessment of their ability to provide a voluntary choice in relation to participation (Heggstad, Nortvedt, & Slettebo, 2013a). To say that a person is not competent to give consent based on a diagnosis of dementia would be to exclude them (Heggstad et al., 2013a). An important question is whether it is an either or, or a both and, since the boundary between competence and lack of competence is unclear (Kim, 2011). However, the Health Research Act (2008 §18) emphasise that "it is a requirement that there is no reason to believe that the person concerned would have been averse to participating in the research project if they had the capacity to give their consent".

The use of assessment tools such as the MMSE to determine whether a person is competent or not is debated in the literature (O'Bryant et al., 2008). The problem with such a test is that it does not take the person's situation into the full picture and do not say anything about their ability to express emotions or experiences. Meanwhile, studies show that the MMSE corresponds with clinical assessments and therefore could be useful in identifying those with doubtful capacity to consent (Raymont et al., 2004). Even though the importance of assessing the competence of persons with dementia in providing consent is suggested, this might not be possible. Nevertheless, the most important thing would be to make sure that the person is provided with information that is relevant in order to make an informed consent (Appelbaum, 2007).

In the present study, after the NH had accepted to participate in the study, they received a letter with information about the organisation and aim of the study, the intervention and absence of risk involved. Even though an initial consent was obtained, Dewing (2007) emphasises the importance of revising the consent during the research period. Therefore, a letter with almost the same information as for the nursing home was attached for residents who were considered eligible for the study and for their next-of-kin. Apart from information about the study, it was emphasized that they could withdraw at any time, which is one of the requirements of the The Health Research Act (2008 §16). The staff received the same information where it was emphasised that even if the participants were not able to express themselves verbally, it was important to observe if they expressed any discomfort, which would be regarded as a wish to withdraw.

6.3 Use of health data

It is a requirement that all personal health data is treated with confidentiality and adequately anonymized so that privacy is assured (The Health Research Act, 2008). The confidentiality was safeguarded by de-identifying the data where name, date of birth etc. was removed and replaced with a code key attached to the resident. The code keys, collected in a codebook, was kept with the DON in each nursing home. To ensure anonymity, the codebook, which links the data to the respective respondent, was not accessible for the project leader. The anonymization of the data made it possible to transfer the data from Ireland to Norway since both countries belong to the European Economic Area (EEA) (The Health Research Act, 2008 §37).

For the first part of the study, data was collected from the regular documentation, whereas the second part collected data that fell outside the everyday documentation. When deciding on the use of proxy or not, the stress this might cause on the person with dementia was considered. Even though the use of proxy would not give the person's personal view or experience, based on the nature of communication as outcome and the fact that participants had moderate and severe dementia, which would make verbal communication difficult, meant that proxy was considered to cause less strain on the person. Staff who had the daily responsibility for the resident carried out the assessments, since bringing people in who are not known to the participants, might cause stress.

6.4 The use of attention placebo control

In order to minimize the challenge with clinical equipoise, which means that there is a genuine uncertainty whether one intervention has more effect than an other (Binik et al., 2011), a reading group was chosen as the attention placebo control (APC). The reason was, first of all, that reading is not part of the Sonas programme and that previous studies have reported that reading has an effect on agitation in people living with dementia (Craig, 2014), and therefore it was considered ethically acceptable to be used as APC. In this way the risk of potential harm was minimized, as emphasized by the Helsinki declaration (2000).

7 Main findings

7.1 Sub-study 1

The first sub-study is a literature review of sensory stimulation for persons living with dementia (Strøm, Ytrehus, & Grov, 2016). Of the 2495 studies found in the literature search, 119 were assessed for eligibility, whereas 55 were included in the literature review. The different sensory stimulation interventions were organised into eight categories: music, light therapy, acupressure/ reflexology, massage/aromatherapy and doll therapy/pet therapy/ toy therapy, the Sonas programme, Snoezelen and sensory garden. However, no clinical trials were found on sensory garden (table 15).

Table 15: Targeted outcomes in sub-study 1

Outcome	Music	Light therapy	Acupressure/ reflexology	Massage /aromatherapy	Doll therapy/ animal assisted therapy/ toy therapy	Snoezelen	The Sonas programme	Total
Agitation/aggression	11	4	1	4	3	1	1	25
BPSD	8	1	0	1	2	3	1	16
Depression/mood	4	2	0	1	2	2	2	13
Sleep	0	4	0	1	0	0	0	5
Quality of life/ well being	1	0	0	0	2	1	1	5
Anxiety	3	0	0	0	0	0	1	4
Affect	0	0	2	1	1	0	0	4
Psychological stress	2	0	1	1	0	0	0	4
Cognition	1	1	0	0	0	1	0	3
Functioning performance	1	0	0	1	0	1	0	3
Nutrition and food intake	2	0	0	0	0	0	0	2
Fall and balance	0	0	0	1	0	1	0	2
Pain	0	0	1	0	0	0	0	1
Communication	0	0	0	0	0	0	1	1

Even though 67% of the studies referred to a theoretical foundation, several had methodological limitations. All interventions using light therapy referred to a solid theoretical foundation. Nevertheless, only one of the eight studies included, documented an effect, which was on agitation/aggression, depression/dysphoria, aberrant motor behaviour and appetite/eating disorders.

The majority of the studies used agitation, aggression and BPSD as outcome, but otherwise a wide variety of outcomes were studied, which made it difficult to compare the studies. The variation in sample size, length of sessions, different treatment approaches and the relatively short intervention period used in some studies were other aspects that made comparison difficult.

Whereas a theoretical foundation was absent in the studies on doll therapy/animal assisted therapy/toy therapy, two of the four studies included, reported an improvement in QoL and an increase in pleasure and interest. Interestingly, only one study used communication as a primary outcome. The majority of the music interventions referred to a theoretical foundation where as many as 76% of the music interventions reported an effect. The effect did not differ between those who attended group sessions compared with individual sessions (table 16).

Receiving multi-sensory stimulation compared with single stimulation did not seem to have any significant effect. None of the two studies included in the multisensory programme Sonas reported any effect, whereas Snoezelen, which is also multi-sensory, did report an effect in three of the seven studies included.

Table 16: Theoretical and methodological characteristics, effect of interventions and study quality

	Sessions				Targeting level of dementia					Studies with quality score ≥ 9	
	Total studies n=55	Theoretical foundation	Group	Individual	Documented effect n=50	Severe	Moderate to severe	Mild to severe	Mild to moderate		No specific
Music	12	9	7	5	10	2	3	2	1	4	10
Music therapy											
Music based											
a. Use of instruments	2	0	2	0	2	1	0	0	0	1	2
b. Singing	1	1	1	0	0	0	0	0	0	1	1
c. Movements	1	1	1	0	1	0	0	0	0	1	1
d. Listening	9	5	2	7	6	0	2	0	5	2	9
Light therapy											
Light in common area	4	4	4	0	0	1	0	0	0	3	3
Use of light box	4	4	0	4	1	1	0	0	0	3	4
Acupressure/reflexology											
Acupressure	1	0	0	1	1	0	0	0	0	1	1
Reflexology	1	1	0	1	1	0	0	0	1	0	1
Aromatherapy/massage											
Aromatherapy											
a. Spray into patient's chest	1	1	0	1	0	0	0	0	0	1	1
b. Aroma diffuser on pillow	1	1	0	1	1	0	0	0	0	1	1
c. Lavender patch attached to patient's clothes	1	1	0	1	1	0	0	0	0	1	1
d. Massage of forearms with lavender oil	1	1	0	1	0	0	0	0	0	1	1
Massage	3	0	0	3	1	0	1	0	0	2	3
Doll therapy/animal assisted therapy/toy therapy											
Animal assisted therapy	3	0	1	2	1	0	0	0	1	2	2
Toy therapy	1	0	0	1	1	0	0	0	0	1	0
Snoezelen	7	7	0	7	3	0	3	1	0	3	5
The Sonas programme	2	1	2	0	0	0	1	0	0	1	2

7.2 Sub-study 2

Sub-study 2 is a psychometric evaluation of the Holden Communication Scale (HCS) for people with dementia (Strøm, Engedal, Benth, & Grov, 2016). A total of 128 persons living in seven nursing homes in Ireland, mean age 85.2 (SD 7.2), of whom 101 (79%) were women, were recruited. The mean MMSE score for the entire group was 8.9 (SD 7.0) and the mean HCS score was 22.3 (SD 12.0) (table 10).

Internal consistency

The Cronbach's alpha for the total HCS score was 0.94 and an inter-item correlations above 0.37, all positive. The corrected item-total correlations ranged from 0.63 to 0.79, with the highest correlations between: success in communication and attempts to communicate (0.79), speech and attempts to communicate (0.76), success in communication and speech (0.73), humour and pleasure (0.71) and speech and response (0.70). The lowest correlations were observed between pleasure and remembering names (0.37) and remembering names and the ability to join in games (0.44). The corrected item-total correlations had an acceptable range from 0.63 to 0.79.

Test-retest reliability

There was no significant difference between the HCS score at baseline and after 1-week, (22.6 (SD 12.5) and 22.2 (SD 12.1)), respectively, and the paired sample Student's t-test showed $p=0.35$. When assessing the individual items a small bias was revealed in one of the items, "the ability to join in games" ($p=0.04$). There are indications that the HCS is a reliable measurement since the 95% limits of agreement interval was rather narrow for each item as well as for the total HCS score.

Factor analysis

Bartlett's test of sphericity was significant ($p<0.001$), and the Kaiser-Meyer-Olkin (KMO) measure was 0.94, indicating appropriateness for performing a factor analysis. A one-component structure accounting for 63% of the variance was revealed when the factor analysis used a criterion of eigenvalue ≥ 1 and when the scree plot was inspected. However, a forced three-factor analysis which was performed to assess the original three subgroups structure of the HCS, revealed a total explained variance of 76%. Most of the items loaded substantially on one factor, most of them having a strong loading (table 17). However, a clear break was found after the first component when inspecting the scree-plot.

Table 17: Three-component structure of the HCS

Holden	Comp 1	Comp 2	Comp 3
3 Pleasure	0.970	0.051	0.041
8 Ability to join in games etc.	0.689	0.135	0.056
4 Humour	0.615	0.155	0.212
11 Interest and response to objects	0.553	0.095	0.307
2 Interest in past events	0.407	0.378	0.206
6 General orientation	0.156	0.907	0.152
5 Names	0.190	0.792	0.307
7 General knowledge	0.354	0.503	0.085
10 Attempts at communication	0.022	0.059	0.896
12 Success in communication	0.076	0.005	0.858
9 Speech	0.064	0.029	0.841
1 Response	0.479	0.056	0.521
Explained variance	62.1%	7.3%	6.6%
Cronbach's alpha	0.89	0.81	0.91

Relationship between the ability to communicate and cognitive function

A relationship was, as expected, found between the ability of the people living with dementia to communicate as measured by the HCS and the cognition function as measured by the MMSE (-0.67), suggesting that the lower the level of cognitive functioning, the more difficulties there are with communication. However, when those who have moderate and severe cognitive impairment due to dementia are separated into two groups, a moderate correlation (-0.61) was found for those with severe cognitive impairment (MMSE 0-10) whereas this correlation was low (-0.06) among those with a moderate cognitive impairment (MMSE 11-20).

The strongest correlation was found between cognitive dysfunction and *speech* (-0.59) among those with severe cognitive impairment, whereas for those with moderate cognitive impairment the strongest correlation was between cognitive function and *interest in past events* (-0.30). The ability to express *humour* was also strongly correlated with cognitive function (-.56), where those with moderate cognitive decline only exhibited a low correlation (-0.06). Further, the ability to *respond* (-0.55), express *attempts at communication* (-0.52) and *having success in communication* (-0.52) was strongly correlated among those with severe cognitive decline, indicating difficulties. Nevertheless, the ability to express *pleasure* and have *general orientation* do not seem to be affected by cognitive function to the same degree (table 18).

Table 18: Pearson’s correlations between communication (HCS) and cognitive function (MMSE) ($n=128$)

Holden / MMSE	MMSE score 0-10 (n=67)	MMSE score 11-20 (n=61)
Conversation		
1 Response	-0.55	-0.10
2 Interest in past events	-0.49	-0.30
3 Pleasure	-0.31	-0.18
4 Humour	-0.56	-0.06
Awareness and knowledge		
5 Names	-0.30	-0.04
6 General orientation	-0.16	-0.22
7 General knowledge	-0.42	-0.10
8 Ability to join in games etc.	-0.46	-0.07
Communication		
9 Speech	-0.59	-0.13
10 Attempts at communication	-0.52	-0.09
11 Interest and response to objects	-0.47	-0.13
12 Success in communication	-0.52	-0.03
Total Holden	-0.61	-0.06

7.3 Sub-study 3

Sub-study 3 is a randomized control trial (RCT) where the effect of the Sonas programme on communication in people living with dementia is measured (Strøm, Engedal, Benth, & Grov, 2017). All participants had dementia and the mean age of the participants was 84.8 ± 7.0 years (range: 67-100 years), the majority were women (77.5%). The mean MMSE score of 9.0 ± 7.1 indicates that the participants had severe cognitive impairment, whereas a mean HCS score 22.0 ± 11.9 indicates a moderate degree of communication difficulties (table 12).

Drop-outs and attendance

Of the 120 assessed at baseline, a total of 105 residents completed the study, which gave a drop-out rate of 12.5%. Two decided to leave the Sonas group and one withdrew because of serious illness. In the reading group five dropped out, while seven left the control group, five died and two were transferred to another nursing home. Those who participated in the Sonas group attended an average of 39.8 ± 11.8 (range 1-48) sessions, whereas the reading group had an average attendance rate on 42.1 ± 6.9 (range 1-48).

Effect of intervention

We found no overall effect of the Sonas programme on communication. However, a significant change in communication ability between the Sonas versus reading group ($p=0.019$) and Sonas versus control group ($p=0.001$) was found throughout the whole study period. As illustrated in figure 8, the score on the HCS decreased in the Sonas group from 24.7 at T0 to 23.6 at T1 ($p=0.014$) and 24.7 at T0 to 22.3 at T2 ($p=0.002$), indicating that the communication ability improved significantly. In the control group the HCS score increased from 21.9 at T0 to 23.5 at T2, while the mean score in the reading group was almost unchanged (from 18.2 at T0 to 18.8 at T2). The number of sessions attended did not affect the outcome of the HCS.

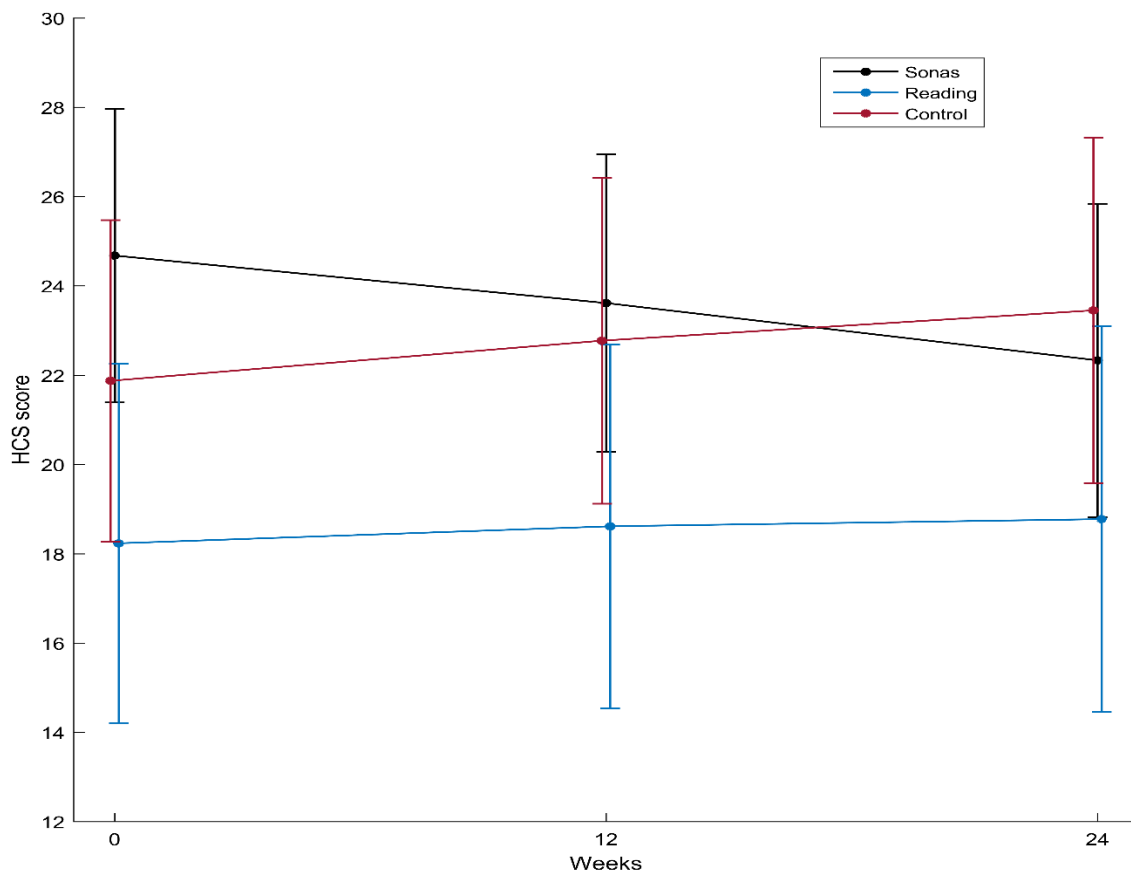


Figure 8 Mean HCS score at baseline, 12 weeks and 24 weeks (without adjusting for MMSE).

When inspecting the sub-items in the HCS, an overall effect was demonstrated in *interest in past events*, *humour* and having *general knowledge*, between the Sonas group and reading group and between the Sonas group and the control group, respectively. No significant effect was found between either groups regarding *remembering names*, *speech*, *showing interest and*

response to objects and having *success in communication*. The Sonas group demonstrated a significant improvement in *response* compared with the control group, but not with the reading group. An unexpected significant improvement in *pleasure* in relation to the reading group but not the control group was demonstrated. The same was seen in relation to *attempts at communication* where the Sonas group demonstrated a significant effect compared with the reading group, but not the control group.

Stratifying the participants using the MMSE score (moderate and severe; cut off 10 point) revealed a significant reduction in mean HCS score between the Sonas group versus reading group among those with severe dementia (MMSE 0-10) at T0 (p=0.011) and at T1 (p=0.044). However, this difference ceased at T2 (p=0.156). Among those with moderate dementia (MMSE 11-20) a significant difference in HCS mean score was found between the Sonas versus reading group at baseline (p=0.026). No significant difference was found between the Sonas group and the control group at any time points, either for those with severe dementia or those with moderate dementia. Inspecting the three groups separately, a significant reduction in mean HCS score was only found in the Sonas group at the three time points (table 19).

Table 19: The ability to communicate ratings across time by groups stratified on level of cognition (MMSE)

Time	Sonas group	Reading group	Control group	Sonas vs Reading	Sonas vs Control
	MMSE 11-20				
	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	p-value	p-value
Baseline	23.9 (20.6; 27.3)	18.0 (14.0; 22.0)	20.4 (16.8; 24.1)	0.026	0.380
12 weeks	22.7 (19.3; 26.1)	18.1 (14.0; 22.2)	20.9 (17.1; 24.6)	0.092	0.325
24 weeks	21.5 (17.9; 25.1)	18.3 (13.9; 22.8)	21.4 (17.4; 25.4)	0.267	0.301
MMSE 0-10					
	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	p-value	p-value
Baseline	25.2 (22.0; 28.5)	18.6 (14.5; 22.6)	23.3 (19.7; 27.0)	0.011	0.081
12 weeks	24.1 (20.8; 27.4)	18.8 (14.8; 22.8)	23.9 (20.3; 27.5)	0.044	0.061
24 weeks	23.0 (19.5; 26.5)	19.1 (14.8; 23.3)	24.6 (20.7; 28.4)	0.156	0.057
MMSE 11-20					
0 vs 12	0.015	0.867	0.411		
0 vs 24	0.009	0.792	0.319		
12 vs 24	0.015	0.867	0.411		
MMSE 0-10					
0 vs 12	0.017	0.698	0.283		
0 vs 24	0.008	0.608	0.194		
12 vs 24	0.017	0.698	0.283		

Figures in bold indicate significant effect.

8 Discussion

Sensory deficit is reported to be common in people over the age of 80 years (Decorps et al., 2014; Jee et al., 2005; Murphy, 2008; Murphy et al., 2002; WHO, 2012). Although no further deficit is found in people with dementia, a reduced ability to interpret sensory stimuli is reported (Bakker, 2003; National Institutes of Health, 2002). While the detection ability seems to be intact, difficulties with the discrimination and identification of stimuli, is reported in relation to smell (Alves et al., 2014), taste (Aliani et al., 2013), hearing (Engedal et al., 2009) and touch (Hansen et al., 2006). In addition language impairment is common in people with dementia, especially verbal language impairment (Kempler & Goral, 2008). However, the impairment will change with the degenerative process of dementia (Engedal et al., 2009) where a reduced ability to interpret sensory stimuli and difficulties with verbal communication could lead to frustration as well as isolation. Therefore, it is important to remember that people living with dementia have the same need of belonging and connectedness than everybody else (Edvardsson et al., 2008; Engedal et al., 2009)

Whereas the overall aim of using sensory stimulation is to increase alertness and reduce agitation (Gammeltoft, 2011), the rationale for using it is that it might awaken latent memories and abilities (Bakker, 2003). There is no doubt that people living with dementia have an increased need of stimuli since the ability to be occupied becomes difficult due to a decrease in physical, behavioural, and cognitive functioning (Kolanowski et al., 2006; Vozzella, 2007). This need of engagement was supported in a study by Cooney, Murphy, and O'Shea (2009), where 101 people with dementia living in residential care reported that being connected to others and being involved in meaningful activities were some of the factors which had an impact on their QoL. Kenigsberg et al. (2015) support this view by emphasizing that the science of sensory impairment and social engagement in people with dementia needs to be developed and seen as an investment in QoL.

As already mentioned, the overall aim of the thesis was to measure the effect of the Sonas programme on communication for people with moderate and severe dementia. Even though no overall effect was found, there was a significant effect between groups in aspects of communication. Further, when stratifying on the cognitive level, a significant effect was found for those with severe dementia, between T0 and T1 (sub-study 3).

The HCS was found to be a reliable and valid scale for assessing communication ability in people with dementia. A moderate correlation was found between communication

ability and cognitive function for those with severe dementia, whereas this was low among people with moderate dementia (sub-study 2).

As described in sub-study 1, even though the majority of the studies included in the review based their intervention on a theoretical foundation, most of them showed methodological limitations. The outcome mainly reported on negative behaviour, only one using communication as outcome. About half of the included studies reported a significant effect. Based on these findings, further studies are needed to clarify the appropriate background for the specific intervention and the effect on communication, as well as to investigate whether the effect depends on the stage of dementia.

In the following, the need of communication as primary outcome measure (sub-study 1) and the psychometric evaluation of the HCS (sub-study 2), will be discussed. The need of communication as a primary outcome is discussed according to Watzlawick et al. (1967) using his five axioms of what is needed for a functioning communication process. Further, the effect of the Sonas programme on communication (sub-study 3) is discussed based on the modified version of the Cohen-Mansfield engagement model (Cohen-Mansfield, Dakheel-Ali, et al., 2009), “The comprehensive Process Model of Group Engagement”, followed by methodological considerations.

8.1 The need of communication as primary outcome

The increase in communication difficulties seen in people with dementia (Engedal et al., 2009) emphasises the need of using communication as an outcome for research, as well as investigating the relationship between communication ability and dementia severity. The importance of measuring communication problems in daily life is supported by Lomas et al. (1989), however, standard language assessments do not indicate the use of language in everyday communication (Irwin, Wertz, & Avent, 2002). Since the ability to express needs and emotions depend on verbal as well as non-verbal communication (Haberstroh et al., 2013), there is a need for outcome measures to assess these aspects of communication. However, as already mentioned only one of the studies included in the review (sub-study 1) did use communication as an outcome measure.

The first axiom in Watzlawick’s (1967) “interactional view” emphasize that “we cannot not communicate”. All behavior, verbal and non-verbal is considered as communication. It becomes more difficult for the person with dementia to communicate as the disease progresses (Engedal et al., 2009), but the person will, based on Watzlawick’s understanding, still be able to express their needs and emotions. The understanding of

behavior as a way of communicating unmet basic needs (Edvardsson et al., 2008) or as a way of coping (Ridder et al., 2013) is consistent with Kitwood's (1997) person-centred approach where behavior is considered not entirely due to the neuropathological processes.

One of the characteristics of a person-centred approach is the ability to experience life and relationship with others (Kitwood, 1997). How the person wants to be understood by those who receive the message, and how the person sees him/her self in relation with the receiver, is by Watzlawick et al. (1967) described as meta-communication. This form of communication is about how information is meant to be interpreted. Nevertheless, since people living with dementia have difficulties interpreting sensory stimulation (Bakker, 2003), there is a question about how conscious they are of how they want their communication to be interpreted.

Another challenge regarding relationship is the deficit in verbal communication seen in people with dementia. Relationship, which is needed in order to interact with others (Beck & Heacock, 1988), is often built on verbal communication; therefore, people who have communication difficulties might be at risk of being marginalized (T. Bush, 2003) and depersonalized (Acton et al., 2007). This is supported in Snyder and Drego's study (2006) where people living with dementia reported that they had less connectedness with family and friends due to communication difficulties. Therefore, maintaining communication can prevent isolation, strengthen the persons' identity and decrease depression and anxiety (Lubinski, 1995). Even though people with severe dementia appear to have a reduced transaction ability, the ability to retain interaction seems to be intact (Hamilton, 1994). Difficulties with transaction can be expressed as problems with giving specific information, while interaction includes eye contact, the ability to use turn taking and embodied behaviour. Focusing on not only transaction ability but also interaction can provide important ways of enhancing social contact (Kindell, Keady, Sage, & Wilkinson, 2016).

The above mentioned difficulties with interpretation can lead to misunderstandings and therefore to what Watzlawick et al. (1967) describes as "punctuation". By using "punctuation", both sender and receiver interpret their behaviour as a reaction to the other's behaviour. Even though this could be an important aspect in preventing communication difficulties, it would not be applicable when the person has severe dementia where the interpretation ability is reduced. However, such an approach used by the staff could help them to understand the communication, and what may cause of the communication difficulties.

As described by Klimova and Kuca (2016) the ability to communicate will depend on speech as well as language, where language is divided into verbal and non-verbal

communication. These two forms of communication, verbal and non-verbal, are consistent with what Watzlawick et al. (1967) describes as digital and analog modalities in his fourth axiom. Digital modality refers to verbal communication, whereas analog refers to non-verbal communication such as eye contact, gestures, singing, tone of voice etc. Even though people with dementia have difficulties with verbal as well as non-verbal communication (Bayles & Tomoeda, 2014), non-verbal communication, such as facial expression and differences in emotions seem to be preserved longer (Bucks & Radford, 2004).

The fifth, and last of Watzlawick's (1967) axioms describes the symmetric and complementary inter-human communication procedures. This refers to how the communication process could be affected by the relationship between the communicators, and whether it is equal or unequal. The relationship between staff and the person with dementia, especially when the person is in a later stage of the disease, will often be unequal due to the person's cognitive decline. Nevertheless, even though the person has cognitive decline, using a person-centered approach where the personhood is acknowledged, may help to respond to the persons' needs. Using an assessment tool could be one way of collecting information about the person's communication ability.

8.1.1 Assessing communication ability

Even though the importance of assessing communication ability in people with dementia, is obvious, there are, to the best of our knowledge only two dementia-specific tools available, the Threadgold Communication Tool (TCT) (Sonas aPc, 2011) and the Holden Communication Scale (HCS) (Holden & Woods, 1995). The TCT was developed to assess communication during the Sonas sessions and was found to be a reliable and valid instrument (Strøm, Engedal, & Grov, 2016). However, even though the HCS has been used in several studies, no psychometric evaluation has been performed. The need of using "appropriate" outcome measures is emphasized by Haberstroh et al. (2013) who refer to clinical/ practical outcome measures relevant for the patients and the importance of strong psychometric properties.

The psychometric evaluation of the HCS performed in sub-study 2 reported a high Cronbach's α of 0.94, with an inter-item correlation above 0.37, which indicates a satisfactory internal consistency. Nevertheless, such a high Cronbach's α could indicate that some of the items are measuring the same construct. When performing a corrected item-correlation, the highest correlation was found between *success in communication* and *attempts at communication* (0.79), *speech* and *attempts to communicate* (0.76) and *success in*

communication and *speech* (0.73). Since the speech ability depends on ability to produce verbal language (Klimova & Kuca, 2016), the correlation between *success in communication* and *speech* was as expected. Reasonably, the other two items were not correlated because the persons' attempts to communicate are not necessarily related either to how he/she succeeds in communication or is able to use speech. The strong correlation between *speech* and *response* (0.70) was as expected since response is, according to the HCS, a question of initiating conversation, which requires verbal language like speech.

The strong correlation between *humour* and *pleasure* (0.71) was not expected even though they are closely connected. While pleasure is considered to be subjective and to be one of the core dimensions of emotions, humour is seen to be a more complex phenomenon, which has been thought to be synonymous with “joke”, “laughter” and “wit” (Tanay, Roberts, & Ream, 2013). The ability to understand a joke or a witticism would require a certain level of cognitive function whereas this is not the case with pleasure. Laughter has even been described as a compensatory strategy during conversation as a way of dealing with communication difficulties (Lindholm, 2008). The concept of *pleasure* is challenging since it measures the ability to communicate, based on the degree of smiling (Holden & Woods, 1995), whereas in the QUALID it is one aspect of QoL (Weiner et al., 2000). Nevertheless, the inter-item correlations showed that all items were positive and above 0.37, which is an indication that they are measuring communication but different aspects of communication.

The factor analysis reported a one-component structure, however, since the HCS constructed by Holden and Woods (1995) consists of three sub-scales: conversation, awareness and knowledge, and communication, a forced three-factor solution was performed. The new subscales had a slightly different component structure where three of the items moved to another sub-scale and will be discussed according to this new structure.

The terminology used to describe the three sub-scales can be challenging since it is difficult to differentiate between communication and conversation. These two concepts are often used interchangeably in the literature. While “communication” is defined as “the sharing of information by means of a symbol system” (Bayles & Tomoeda, 2014, p. 1), “conversation” is described as a “form of interactive, spontaneous communication between two or more people and occurs in verbal communication” (Thornbury & Slade, 2006).

Conversation

The understanding of conversation as an interactive process, requiring verbal communication, would mean that people with severe dementia, where verbal communication becomes difficult

(Bayles & Tomoeda, 2014), would not be able to participate in conversation. However, persons with severe dementia have been observed using agreements, minimal response, formulaic (prefabricated) comments and general remarks as a resource to participate in the conversation (Guendouzi & Pate, 2014). One explanation could be that this is a way of compensating for communication difficulties by using retained socially accepted communicative behaviour (ibid). Even though this most probably is non-volitional behaviour, it could be a way for the person to maintain personhood, which is described by Kitwood (1997) as the aim of person-centred care.

Inspecting all the five items in the revised sub-scale *conversation*, the majority would not require verbal communication skills, except the first, *interest in past events*, which is described as giving an account of past events. Being able to show interest in past events is connected to the episodic memory, which is one of the first difficulties reported among people with AD (Bayles & Tomoeda, 2014). Even though the *ability to join in games* and express *interest and response to objects* do not depend on the ability to communicate verbally, they would require a certain level of cognitive function. This is confirmed by Cohen-Mansfield, Marx, Regier, and Dakheel-Ali (2009) where the cognitive level is reported to have an impact on the person's ability to be engaged with stimuli. Based on the above definition of conversation where the use of verbal communication is emphasized, naming this sub-scale as *conversation* is questionable and could be considered changed to "non-verbal communication".

Awareness and knowledge

All the aspects of communication in the second sub-scale *awareness and knowledge*, require a certain degree of semantic memory as well as speech. Speech, as well as semantic memory is maintained at the early stage of dementia (Bayles & Tomoeda, 2014), nevertheless, all aspects of communication in this sub-scale are more linked to knowledge and memory and also similar to some of the questions in the MMSE (Folstein et al., 1975). Therefore, assessing these aspects of communication might rather be considered as a way of assessing the person's memory rather than communication.

Communication

As already described. communication is the sharing of information by means of a symbol system (Bayles & Tomoeda, 2014), including both verbal and non-verbal communication. Most of the items in the revised sub-scale require verbal communication ability, except for

attempts at communication, which is an aspect of non-verbal communication. Since three of the four items in the sub-scale describe verbal communication could the sub-scale be renamed “verbal communication”.

8.2 The effect of the Sonas programme on communication

Cohen-Mansfield et al. (2017) describe different attributes, which affect the person’s ability to engage with stimuli: personal attributes, stimulus attributes – group activity and environmental attributes. Since the ability to engage with the stimuli might have an impact on the outcome, the effect of the Sonas programme on communication will be discussed based on these three attributes.

8.2.1 Personal attributes

Even though it is “important to discuss the preserving of the person’s capacities rather than the sole biological aspect of the disease” (Kenigsberg et al., 2015), the person’s cognitive function will have influence on how they engage with the stimuli. According to Bowly (1993) sensory stimulation is most appropriate for persons with moderate to severe dementia since the ability to attend other activities becomes more difficult as the disease progresses.

Cohen-Mansfield, Marx, et al. (2009) found that the impact of personal attributes on engagement had a significant correlation with the length of the engagement duration for those with higher cognitive function, but also the highest refusal rates. There is also evidence that interventions work best when they are tailored to the resident’s background and preferences (Cohen-Mansfield, Marx, Thein, & Dakheel-Ali, 2010) and when it is experienced as meaningful (Cohen-Mansfield, Thein, Dakheel-Ali, & Marx, 2010b).

The mean MMSE score for the participants in sub-study 3 was 9.0 (± 7.1), indicating severe dementia. Therefore, we would assume this to have an impact on the outcome since communication difficulties change as part of the degenerative process of dementia (Engedal et al., 2009). The relationship between dementia severity and the ability to communicate was also confirmed in sub-study 2, where a moderate correlation was found for those with severe dementia and a low one for those with moderate dementia.

The challenge with expecting an improvement in communication ability among people who at the same time are expected to have a decline in their cognitive ability due to dementia, could be one way of explaining the lack of an overall effect. Nevertheless, a significant improvement in communication ability was reported in the Sonas group compared with the control group, where the results show decline in communication ability during the 24 weeks.

There could be several reasons behind such an intervention effect. First, receiving extra multi-sensory stimulation during the Sonas sessions might have greater impact on communication ability than just continuing with ordinary activities provided in the nursing home. The extra attention received by attending the Sonas sessions could also be part of the explanation. In order to control the possible effect of attention, the reading group was included. However, the almost unchanged communication ability reported in the reading group might be explained by the fact that some stimulation is better than nothing, which is supported by the decrease in communication ability reported in the control group. The significant improvement in the Sonas group might therefore be due to the programme rather than the extra attention received by being in the reading group.

The significant effect found among those with severe dementia and not among those with moderate dementia is consistent with Joranson, Pedersen, Rokstad, and Ihlebaek (2016) who investigated the effect of robot-assisted group activity with Paro, where a significant improvement in QoL was reported for those with severe dementia. However, the latter mentioned study used QoL as an outcome measure, while the Sonas study used communication as outcome. Olsen et al.'s (2016) study of the effect of animal-assisted interventions reported a significant effect on QoL as well, but also on depression. An explanation might be that people with severe dementia have more potential for improvement than those with moderate dementia. Nevertheless, it is interesting to see an improvement in both QoL and communication despite the decline in cognitive functioning. A suggested explanation could be the fact that cognitive function does not have the same impact neither on communication nor on QoL.

While speech becomes less efficient as a communication tool, the question is if some aspects of communication remain intact and could be used to keep the person involved in the social world despite the decline in cognitive function. Inspecting the effect of the Sonas programme related to different aspects of communication showed a significant effect between the Sonas group versus the reading and control on the ability to express *humour*, *interest in past events* and *general knowledge* (sub-study 3). The improvement in *humour* was not expected since an altered sense of humour is reported in people with dementia, independently of type of dementia (Clark et al., 2015). These findings were supported in sub-study 2 where a moderate correlation was found between humour and dementia severity, indicating that the response to humour decreases with the dementia severity. A way of explaining the effect could be how the nurses interpreted humour. Holden describes it as enjoying comic situations

and the way this is observed can be questionable. Some might report a smile in the resident as an expression of enjoying humour, whereas others expect a clear understanding of humour. The significant effect on *interest in past events* was not expected since recalling past events requires episodic memory, which is reported to be one of the first symptoms of AD (Bayles & Tomoeda, 2014). One explanation of this effect could be due to the type of dementia. People with VaD would not have the same problems with the episodic memory as those with AD. Nevertheless, in this study we have no information of which type of dementia the participants had. The significant effect found in *general knowledge* was more expected since this aspect of communication is depending on semantic memory, which is intact longer than episodic memory (ibid).

The aspect of communication which correlated strongest with dementia severity, was *speech, attempts at communication* and *success in communication* (sub-study 2), therefore, no significant effect was expected for these aspects of communication. Even though lack of effect was found in relation to *speech* and *success in communication*, a significant difference was found in the *attempts at communication* between the Sonas and reading group (sub-study 3). The improvement in the Sonas group versus the reading group and not between the Sonas group and control is difficult to explain. One explanation that the Sonas group showed a significant effect versus the reading group could be that regular stimulation of the five senses improves the attempts at communication, whereas the attention received by attending a reading group does not have the same effect. However, why no effect was revealed between the Sonas group and the control group is unclear. The disease severity and a possible ceiling effect might be one explanation.

The ability to *respond*, which showed a moderate correlation with dementia severity in sub-study 2, reported a significant effect in the Sonas group versus the control group, and not versus the reading group. One explanation of the lack of effect in the Sonas group versus the reading group could be that the attention given in both groups might be enough to stimulate response, which in the HCS is described as initiating conversation.

Further, the ability to express *pleasure* reported a significant improvement for the Sonas group versus the reading group, whereas this was not found between the Sonas group and the control group (sub-study 3). The improvement in the Sonas group versus the reading groups was expected since a low correlation between *pleasure* and dementia severity was found in sub-study 2. As already mentioned *pleasure* is based on the degree of smiling, according to Holden and Woods (1995), and reported to be an expression of comfort and well-being in people with dementia (Kaufmann & Engel, 2016). However, the lack of

significant change between the Sonas group and the control group is difficult to explain, but might be due to the way the nurses interpret *pleasure*.

One aspect of the person-centered approach is to offer and respect individual choices (Kitwood, 1997) and to tailor the intervention according to the person's preferences and abilities (Lawrence, Fossey, Ballard, Moniz-Cook, & Murray, 2012). Determining a person's stimuli preference has been found to predict responsiveness when it comes to music, art and pets (Cohen-Mansfield, Marx, Thein, et al., 2010). Despite this, the individual preferences of the participants in this study were not identified, partly because the Sonas programme is multi-sensory and follows the same structure each time, and partly because of the severity of the dementia. Based on the difficulties of adapting the programme according to individual choices, the staff conducting the sessions were informed of the importance of observing if the participants looked content during the sessions and if some of them expressed that they wanted to leave the group.

8.2.2 Stimuli attributes – group activity

Sensory deficit, which is described as a reduced ability to detect, discriminate and identify one or more of the five human senses (Kovach, 2000), is reported in people with dementia. However, people with dementia are not reported to have any further sensory loss than what is due to the normal aging process. While the ability to detect is probably less affected as part of the dementia process, the ability to interpret what they see, hear, taste, smell and feel is reduced (Bakker, 2003; National Institutes of Health, 2002). Nevertheless, even if their ability to interpret the stimuli is reduced, the need for stimuli is still present (Bayles & Tomoeda, 2014).

According to Bakker (2003) the amount, type and variety of stimuli are important aspects to take into account when choosing a stimuli. Cohen-Mansfield, Thein, Dakheel-Ali, et al. (2010b) included 69 nursing home residents with dementia in their study, and found that work-related stimuli like folding towels and stuffing and folding envelopes resulted in more engagement than non-work stimuli like manipulative block stimuli. In a larger study (Cohen-Mansfield, Thein, Dakheel-Ali, Regier, & Marx, 2010) 193 persons with dementia were presented with 25 different stimuli during a period of three weeks in order to assess for duration, attention and attitude. Presentation with social stimuli rather than non-social stimuli, having a life-like baby doll rather than a childish looking doll and being presented with a robotic animal rather than a plush animal, showed significant longer duration and higher attention and attitude. Being engaged with a real baby or one-to-one socializing with a

research assistant, showed higher attention as compared with a dog (ibid). The importance of social interaction, which is also used in the Sonas programme, is supported by Kaufmann and Engel (2016) who found that people with dementia were looking for real human contact. The significant improvement in communication in the Sonas group and not in the reading group and control group, might be explained by the close relationship between the SLP and the participants.

Even though focusing on more than one thing over time or relating to more than one stimulus at a time is difficult for people with dementia (Engedal, 2009), the importance of stimulating all the five human senses during the Sonas sessions is emphasized (Sonas aPc, 2011). Based on this assumption, the senses are not stimulated simultaneously during the Sonas sessions, but one at the time. Stimulation of the different senses is supposed to have different impact, where e.g. olfactory memories usually last longer and have more emotional influence than memories formed through other sensory modalities (Elsner, 2001). The majority of the sensory stimulation interventions presented in sub-study 1 used single sensory stimulation approach, however whether using single – or multi-sensory stimulation did not seem to have any significant implication of the effect on the outcome.

In a review by Peck et al. (2016) they found that the use of familiar music appeared to be superior in order to create the most effective interventions. This is consistent with the underlying philosophy of the Sonas programme where music and songs used during the sessions are familiar to the participants. However, whether this had any influence on the outcome is difficult to know.

8.2.3 Environmental attributes

The importance of the physical environment is described as a provision of person-centred care by personalising the surroundings (Edvardsson et al., 2008). The physical environment, such as sound level, light, the size and layout of the unit as well as creating a homelike atmosphere, are reported to influence behaviour and the experience of well-being in people with dementia (Chaudhury, Cooke, Cowie, & Razaghi, 2017). These findings are consistent with the Cohen-Mansfield, Thein, Dakheel-Ali, et al. (2010a) study where a moderate level of sound and light reportedly increased the duration of attention and engagement. It is emphasized that the Sonas sessions are conducted in a separate, quiet room and that no other staff or residents are allowed into the room during the session.

The number of people in the room is another factor, which might influence the person's ability to engage with a stimulus. Even though presenting the stimuli on an

individual level rather than in a group is reported to affect the level of engagement (Cohen-Mansfield, Marx, Dakheel-Ali, Regier, & Thein, 2010), Cohen-Mansfield, Thein, Dakheel-Ali, et al. (2010a) found that the participants showed a significantly higher attention to the engagement stimuli with four to nine people in the room than being alone or being in a crowd of people. The Sonas sessions are carried out in groups of eight and one way of explaining the significant improvement in communication ability found in the Sonas group might be that they feel secure in the group with appropriate social relations and have the right balance of stimuli.

One of the goals of sensory stimulation is, according to Bayles and Tomoeda (2014) repetition, which has been reported to be appropriate for residents with moderate as well as severe cognitive decline (Cohen-Mansfield, Thein, Dakheel-Ali, et al., 2010a). These findings support the philosophy of the Sonas programme where the same structure is followed each time since repetition is believed to evoke memory (Sonas aPc, 2011). The unexpected findings of the significant improvement in *general knowledge* and *general orientation*, which would depend on memory, might be explained by repetition and recognition.

The time of the day is reported to influence the engagement duration and attention (Cohen-Mansfield, Thein, Dakheel-Ali, et al., 2010a), whereas having the stimuli at the same time everyday did not show any significant difference. The SLP's were instructed to choose a time for the Sonas sessions where the residents would be rested and most alert. However, there was no consistency in the timing even though most of the groups met around 11 am.

8.3 Methodological considerations

Randomised controlled trials (RCT) are considered the golden standard for intervention and treatment studies. Nevertheless, several threats to a RCT could occur. In the following, possible threats will be discussed according to Shadish, Cook, and Campbell (2002) such as typology of validity (statistical conclusion validity, construct validity, internal validity and external validity). In addition, possible threats concerning reliability will be discussed.

8.3.1 Design

The overall design of the thesis is an RCT, which is considered the most powerful method for testing hypothesis (Polit & Beck, 2012). To strengthen the RCT design a literature review was conducted to get an overview of available sensory stimulation interventions. In addition, since no previous psychometric evaluation of the primary outcome measure HCS was available, this was performed in sub-study 2.

Although the literature review aimed to include all available sensory stimulation interventions used for people living with dementia, the search terms used did not include studies conducted on the robotic seal, Paro. Another limitation is that only quantitative studies were included, because including qualitative studies would have been too comprehensive to include in one article.

A cluster randomized controlled trial, where each nursing home would have been seen as a cluster, was first considered. Even though assigning each nursing home to one study arm might have reduced the risk of contamination, this approach would have required more participants (Polit & Beck, 2012). In addition, there is a risk of a recruitment bias when using cluster randomised trials since consent usually is obtained after randomization and therefore it increases the risk that participants would refuse to participate due to the awareness of allocation to a specific group (Hahn, Puffer, Torgerson, & Watson, 2005). Taking into consideration the challenge of recruiting six nursing homes with at least two groups of eight, an RCT with one intervention group in each nursing home was chosen. Another reason for this was the assumption that it might be easier to get nursing homes to participate if a new intervention was offered.

By including the eight participants who had been excluded from the RCT due to lack of randomisation, a convenience sample of 128 participants was chosen for the psychometric evaluation of the HCS. However, 128 is a relatively small number. Nevertheless, Pett, Lackey, and Sullivan (2003) refer to a number of at least 10 to 15 subjects per initial item in order to conduct a psychometric evaluation, and since the HCS has 12 items, 128 participants were considered to be sufficient.

The consideration of including an APC when doing psychosocial interventions is emphasized (Vickers & Craen, 2000), even though an appropriate APC is rarely used (Popp & Schneider, 2015). The intention of including a reading group in the study was to rule out the possibility that an effect of the Sonas programme was caused by the special attention given to the participants, rather than by the actual content of the intervention. However, offering human presence without any other stimuli was considered unethical. The ethical considerations regarding the challenge of including an APC were discussed in chapter 6.

8.3.2 Recruitment

External validity, which is a question about generalization of the research results where findings from one setting can be transferred to various populations, settings and epochs (Taylor & Asmundson, 2008), was brought up in relation to the recruitment.

All NH's in eight counties in Ireland and those who met the inclusion criteria, were invited to participate in the study. One weakness is that no systematic information about those refusing to participate or withdrawing was obtained. However, we know that the NH's were from different counties, some private and some public, and based on this there is no indication of recruitment bias. Since participation was voluntary, it might be that those accepting to participate were more positive towards activities. Offering training in the Sonas programme for free might be one explanation for compliance. Nevertheless, reading the HIQA reports on those NH's not accepting to participate did not reveal any major differences from the included NH's. Based on this information, a probability for selection bias was not likely.

The fact that the DON in each NH chose eligible participants based on their personal judgement, could have been a risk regarding selection bias. A risk could be that the selection of eligible participants was based on whom they found most suitable for intervention in terms of possible benefit. This selection bias could have been a threat to external validity. Nevertheless, an advantage was that the DON knew the residents well and in this way made sure that the inclusion and exclusion criteria were met. Inspecting the demographic data did not give any indication of any selection bias since these were consistent with similar studies, which to a certain degree ensure representativeness and thereby strengthened external validity (Polit & Beck, 2012).

The randomization of the participants after collection of baseline data is recommended since this minimizes the possibility for the assignment to influence the outcomes. Nevertheless, randomisation does not guarantee that the groups are equal (Polit & Beck, 2012). Another way of preventing recruitment bias implemented in this study was that the participants were informed about which groups they would be assigned to after baseline data were collected. The estimated sample size of 32 in each group was met and so there was no threat to external validity.

8.3.3 Implementation of the intervention

It is emphasized that clinical trials should be designed to target the group which will receive the most benefit (Polit & Beck, 2012). The Sonas programme has been widely used in Ireland for more than 20 years and was developed for people with dementia. A strength of the Sonas programme is that it is standardized and can therefore be easily replicated, due to well-documented manuals, which strengthen the external validity. The Sonas group and the reading group were equivalent concerning number of participants in the group and frequency and duration of interventions.

Even though the Sonas programme is standardized and the SLP's were given three days' training on how to conduct the Sonas programme, that does not exclude the possibility that the SLP's delivering the programme might conduct the sessions slightly differently and thereby could influence the outcome. This could be a threat to internal validity, which is explained as "extraneous events which might influence the outcome" (Taylor & Asmundson, 2008, p. 24). Another threat to internal validity could be the other activities which were offered in the nursing home. One way of minimizing this threat could have been to keep a log of other activities the residents attended, which was not performed.

The novelty effect is considered as a threat to construct validity. This means that the effect is caused by an increased interest because something is new (Polit & Beck, 2012, p. 301), in this case the Sonas programme. This might explain the improvement in communication found after 12 weeks among those with severe dementia, which ceased after 24 weeks. However, the novelty effect might be felt by the participants in the reading group as well.

A threat to construct validity could be that the participants knew they were part of a study and therefore expected changes, called the Hawthorne effect (Polit & Beck, 2012). However, the possibility of this is rather small since the participants average cognitive level revealed severe dementia. Even though the person probably would be aware of participating in a new programme, it is unlikely that they would reason around the effect. It is more likely that the implementation of the programme could have had an effect on the staff, bringing more "life" into the units.

8.3.4 Method of collecting data and outcome measures

An important question in relation to construct validity is whether the measurements used are appropriate and seen in relation to the aims of the study. The MMSE and the HCS, which were used in the study, have both been psychometrically tested. Even though the MMSE has been found to have satisfactory reliability and validity (Tombaugh & McIntyre, 1992), a challenge occurs when the person being interviewed has difficulties expressing themselves verbally. The outcome score will then be zero, which indicates severe cognitive decline. With this in mind, the interpretation of the outcome should be done with caution. McCormack (2004) further emphasizes that even though assessments are used, we should be careful not to adopt the reductionist model where a judgement about the person's competence is based on a single assessment.

The HCS, which is based on observations carried out by staff, was psychometrically tested as part of this thesis (Strøm, Engedal, Benth, et al., 2016). The advantage of the HCS is that it is proxy-rated and does not require that the participants can express themselves verbally. This was important based on the inclusion criteria where only persons with moderate and severe dementia were included. Nevertheless, the use of proxy requires that the assessor has a knowledge about the person, which makes it difficult to use blinding (Polit & Beck, 2012). Although the nurses who carried out the assessments were either involved with the interventions or explicitly informed about the allocation of participants to groups, it was impossible to keep them blinded except for the collection of baseline data. This could cause a threat to internal validity since the assessors might expect changes, at the same time it is emphasized that it is not realistic to use blinding when carrying out psychosocial interventions (Boutron et al., 2008).

The nurses who carried out the assessments underwent two hours of training in how to do the assessments in order to optimize a common understanding as much as possible. Nevertheless, this would not prevent them from observing the participants differently. Even though limiting the number of nurses carrying out the assessments to two to three within each nursing home, two nurses in one nursing home could have been asked to assess the same resident without conferring with each other. This would have ensured inter-rater reliability, which was not done as part of the psychometric evaluation of the HCS. The project leader collected data after baseline, 12 weeks and 24 weeks, respectively to prevent the assessors from being influenced by the previous assessments carried out.

8.3.5 Drop-out and withdrawal

Attrition could be a threat to internal validity if not random (Taylor & Asmundson, 2008). Nevertheless, leaving out participants who drop out can make it difficult to compare the remaining groups since they might differ from the other 105 participants (Polit & Beck, 2012). The total drop-out was 12.5%, which was lower than the expected 30%. Ten of the drop-outs were due to death, one to illness, two were transferred to another nursing home and two did not want to continue in the Sonas group. Their MMSE score was 14 and 13, respectively, indicating moderate dementia and the reason for leaving the group was that they did not like the Sonas programme. That those who decided to leave the Sonas group had moderate dementia is consistent with Cohen-Mansfield, Marx, et al. (2009) who found a correlation between cognitive function and refusal rate; the higher the cognitive level the higher the refusal rate.

Even though by using a mixed model analysis there is no need to impute data to replace missing values in the data set, the small percentage of missing values should not affect the estimates of effect size or power either (higher than 20%) (Polit & Beck, 2012). Therefore, we assume that the attrition is random and not likely to be a threat to internal validity.

8.3.6 Choice of data analysis

When conducting a study, the question of appropriate use of statistics, called statistical conclusion validity, will arise (Shadish et al., 2002). In sub-study 2, which was a psychometric evaluation of the HCS, one of the limitations, as already mentioned was the lack of inter-rater reliability. The fact that this is the first psychometric evaluation of the HCS, including the inter-rater reliability test would have strengthened its use in further studies. Based on the previous discussion of the component structure of the HCS, a forced two-factor analysis could have been performed.

The overall aim in sub-study 3 was to measure the effect of the Sonas programme on communication in nursing home residents with moderate to severe dementia. A linear mixed model analysis was chosen, which allows for random effects for time. Another strength of a linear mixed model is that there is no need for any 'ad hoc' imputation of missing values (Chakraborty & Gu, 2009). Even though this did not become a problem in the present thesis, the risk was considered relatively high keeping in mind the group involved.

When measuring effect the question would be to find out "how probable it is that observed results are due to chance". However, there is an increased risk of accepting an effect which is not present (Type I error) or rejecting an effect which is present (Type II error) (Polit & Beck, 2012, p. 588). To minimize the risk of type I error the alpha level was set to .05, which means that it is with 95% certainty that the effect is due to the intervention.

The power calculation performed on the primary outcome measure (HCS) showed a need for at least 24 in each group, which increased to 32 due to the high risk of attrition. However, by ensuring a high power, the risk of a type II error was considered minimal. Despite this, a question of under-power occurred when measuring the intervention effect stratifying the participants by moderate and severe dementia. However, an almost equal sample size in each group and a linear mixed model approach lowered the risk of under-power considerably.

9 Conclusion

The overall conclusion of this doctoral thesis is that even though there is a growing number of interventions developed to improve the life of people living with dementia, several of them lack a theoretical foundation or have methodological limitations. While the majority of the studies use different aspects of BPSD as outcome, communication was only used as the outcome measure in one of the studies. A few instruments developed to assess communication ability in people with dementia have been found. However, even though the HCS has been used in several studies, this instrument had not been psychometrically evaluated. The psychometric evaluation of the HCS revealed the instrument to be a reliable and valid instrument for assessing communication ability in persons with dementia.

The Sonas programme did not reveal an overall significant effect on communication, however, an intervention effect between the Sonas group and the reading and control groups, respectively was found. Furthermore, the significant improvement in the Sonas group, where the reading group showed an almost unchanged communication ability and the control group a decrease, indicates that the Sonas programme can improve the communication ability in persons with dementia. In addition, the significant effect found regarding some of the communication aspects, as well as an improvement in communication ability among those with severe dementia, demonstrated that the Sonas programme seems to be most suitable for people with severe dementia. The present study has also overcome some of the methodological weaknesses found in previous research on the Sonas programme.

9.1 Relevance and implication for clinical practice and future research

The importance of being engaged with meaningful activities for people living in nursing homes is emphasized. For people with dementia who have difficulties interpreting what they see, hear, feel, smell and taste, the need for stimuli will increase. This thesis has highlighted the use of sensory stimulation in order to improve the communication ability among people living with dementia.

Since maintaining communication can support the person's identity and improve their well-being, it is essential for practitioners to have knowledge and become more aware of the use of sensory stimulation and how it can influence the person's communication ability.

However, it is important that the interventions are built on a theoretical foundation since the understanding of how the mechanism behind the intervention works is essential to know before recommending these approaches as part of the daily care. The relatively solid

theoretical foundation of the Sonas programme strengthens the possibility of implementing this multi-sensory stimulation programme in different settings across countries.

Even though the present study did not demonstrate an overall effect of the Sonas programme on communication, an intervention effect and a significant effect was reported on some aspects of communication and for those with severe dementia. These findings support the appropriateness of the programme for improving the communication ability in persons with severe dementia, particularly on some aspects of communication. A better understanding of the different aspects of communication could also provide the practitioners with a more nuanced picture of the person's capacity and make it easier to find the person's resources rather than focusing on their limitations.

In this study, the data was collected using a standardised assessment tool (HCS). However, further research is needed to investigate the immediate effect during and after the Sonas sessions, which could be done by using the outcome of the TCT or by observation, e.g. by means of using video tape recording. Qualitative interviews with the SLP's on how to run the Sonas programme would be beneficial in order to revise the manual used for Sonas training. Additionally, interviews with the DON might give valuable information on the challenges of running the Sonas programme and the evaluation of standardized approaches to stimulate the persons with dementia.

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The Holden Communication Scale (HCS)

The Holden communication scale (HCS) has been developed by Una Holden and includes 12 items. The score range from 0-48 and the higher score the more difficulties. Choose only **ONE** answer. The HCS was psychometric tested in 2016 (Strøm, Engedal, Saltyte Benth, & Grov, 2016).

Holden		Score
Conversation		
1. Response	0. Initiates conversation deeply involved with anyone	
	1. Good for those familiar to person	
	2. Fair response to those close by; no initiation of conversation	
	3. Rather confused; poor comprehension	
	4. Rarely or never converse	
2. Interest in past events	0. Long, full account of past events	
	1. Fairly good description	
	2. Short description; a little confused	
	3. Confused or disinterested	
	4. No response	
3. Pleasure	0. Shows real pleasure in situation /achievement	
	1. Smiles and shows interest	
	2. Variable response; slight smile; vague	
	3. Rarely shows even a smile	
	4. No response or just weeps	
4. Humour	0. Creates situation or tells funny story on own initiative	
	1. Enjoys comic situations or stories	
	2. Needs an explanation and encouragement to respond	
	3. Vague smile; simply copies others	
	4. No response or negativistic	
Awareness and knowledge		
5. Names	0. Knows most people's names on ward	
	1. Knows a few names	
	2. Needs a constant reminder	
	3. Knows own name only	
	4. Forgotten even own name	
6. General orientation	0. Knows day, month, weather and whereabouts	
	1. Can forget one or two items	
	2. Usually gets two right but tries	
	3. Vague; may guess one	
	4. Very confused	
7. General knowledge	0. Good on current events; generally able	
	1. Outstanding events only; fair on general knowledge	

	2.No current knowledge; poor general information	
	3.Confused about many things; gets anxious and upset	
	4.Confused about everything; does not respond	
8.Ability to join in games etc.	0.Joins in games and activities with ease	
	1.Requieres careful instructions but joins in	
	2.Can only join in simple activities	
	3.Becomes anxious and upset	
	4.Cannot or will not join in	
Communication		
9.Speech	0.No known difficulty	
	1.Slight hesitation or odd wording	
	2.Very few words; mainly automatic phrases	
	3.Inappropriate words; odd words; nodding	
	4.Little or no verbalisation	
10.Attempts at communication	0.Communicates with ease	
	1.Tries hard to speak clearly	
	2.Tries to draw; gesticulates needs etc.	
	3.Euphoric laughter; weeping; aggressive	
	4.No attempt	
11.Interest and response to objects	0.Responds with interest and comment	
	1.Despite difficulties shows interest	
	2Shows some interest, but rather vague	
	3.Weeps; rejects objects; shows aggression	
	4.No response; no comprehension	
12.Success in communication	0.Clearly understood	
	1.Uses gestures and sounds effectively	
	2.Understanding restricted to a few people	
	3.Becomes frustrated and angry	
	4.Makes no attempt	
Total score		
Sign		
Date		

References

Strøm, B. S., Engedal, K., Saltyte Benth, J., & Grov, E. K. (2016). Psychometric evaluation of the Holden Communication Scale (HCS) for persons with dementia. *BMJ Open*, 6(12), e013447. doi:10.1136/bmjopen-2016-013447



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To whom it may concern

With regards to the study *The effect of multi-sensory stimulation on quality of life, depression, anxiety, agitation and communication in nursing home residents with moderate to advanced dementia.*

We hereby confirm that the Regional Committee for Medical and Health Research Ethics, section South-East C, Norway, has approved the project *The effect of multi-sensory stimulation on quality of life, depression, anxiety, agitation and communication in nursing home residents with moderate to advanced dementia* (Norwegian title: *Effekten av multisensorisk stimuleringsprogram på livskvalitet for personer med moderat til langtkommen demen*)..

The project was approved on the 25th of February 2014.

The ethics committee system consists of seven independent regional committees, with authority to either approve or disapprove medical research studies conducted within Norway, or by Norwegian institutions, in accordance with ACT 2008-06-20 no. 44: Act on medical and health research (the Health Research Act).

Please do not hesitate to contact the Regional Committee for Medical and Health Research Ethics, section South-East C (REK Sør-Øst C) if further information is required.

Yours sincerely,

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Professor of Medicine,
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Paper I

Strøm, B., Ytrehus, S., & Grov, E. (2016). Sensory stimulation for persons with dementia: A review of the literature. *Journal of Clinical Nursing*, 25(13-14), 1805-1834. DOI: 10.1111/jocn.13169

Paper I: Not in the file in Brage because of copyright restrictions.

BMJ Open Psychometric evaluation of the Holden Communication Scale (HCS) for persons with dementia

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To cite: Strøm BS, Engedal K, Šaltytė Benth J, *et al.* Psychometric evaluation of the Holden Communication Scale (HCS) for persons with dementia. *BMJ Open* 2016;**6**: e013447. doi:10.1136/bmjopen-2016-013447

► Prepublication history for this paper is available online. To view these files please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2016-013447>).

Received 13 July 2016
Revised 26 September 2016
Accepted 3 November 2016

ABSTRACT

Objective: To investigate the psychometric properties of the Holden Communication Scale (HCS) and the association between scores on HCS and cognitive function among persons with dementia.

Method: Internal consistency was assessed by the Cronbach's α coefficient and inter-item correlations. Test-retest was carried out to test the instrument's stability. An exploratory factor analysis with the principal components extraction method and oblimin rotation was performed to evaluate construct validity. Pearson's correlation coefficients were calculated to explore associations between the scores on the HCS and cognitive function.

Results: A total of 128 persons with moderate-to-severe cognitive impairment (mean Mini-Mental State Examination (MMSE) score 8.9 (SD 7.0)) participated. The mean age was 85.2 (SD 7.2) and 101 of the participants were women. The Cronbach's α of the HCS was 0.94 and test-retest reliability was $r=0.71$. The corrected item-total correlation ranged from 0.63 to 0.79 and factor analysis showed a 1-factor structure of the HCS, which explained 63% of the variance. However, a forced 3-factor structure explained 76% of the variance. The correlation between cognitive function as measured by the MMSE and ability to communicate as measured with HCS was found to be moderate for those with an MMSE score of 0–10 (-0.61) and low for persons with an MMSE score of 11–20 (-0.06).

Conclusions: The HCS is a reliable and valid scale for assessing communication ability in persons with moderate and severe cognitive impairment, and might have a 1-factor or 3-factor structure.

INTRODUCTION

Speech and language impairments among persons with dementia are well known and lead to difficulties in communication.¹ The impairments are suggested to be due to language (extralinguistic) rather than speech (linguistic) deficits. However, this will depend on the cause of dementia. Persons with Alzheimer's dementia have, first of all, language deficits which are expressed by difficulties finding words, recalling names and

Strengths and limitations of this study

- Psychometric properties performed in a structured way.
- Relatively few participants.
- The inter-rater reliability of the HCS was not studied.

difficulties putting ideas into words,² whereas persons with vascular dementia often have speech deficits such as slurred speech or difficulties with spoken and written language.¹

There is a close relationship between cognitive deficits and language impairments² and as the dementia progresses, the communication ability will gradually decline.³ However, the need for belonging and companionship is a basic human need and does not change with increasing cognitive decline.^{3 4} This need for belonging is fundamental to carry out person-centred care,⁵ and we therefore have to learn how to communicate with people with dementia with moderate and severe cognitive impairment who have a communication deficit.

Valuable research has documented that behaviour and psychological symptoms in dementia (BPSD) could be an expression of communication.^{6 7} However, limited attention has been given to how to examine the ability to communicate⁸ and the association between the different aspects of communication and cognitive function in persons with severe dementia.

Reviews conducted by Strøm *et al*⁸ and Egan *et al*⁹ reported that several tools have been developed to assess different aspects of communication for persons with dementia. Most of those studies are focusing on the person's expression in terms of agitation and aggression rather than the ability to communicate. To the best of our knowledge, only two dementia-specific communication tools focusing on communication ability have been developed, the Threadgold Communication



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Tool (TCT)¹⁰ and the Holden Communication Scale (HCS).¹¹ A psychometric evaluation of the TCT revealed that this is a reliable and valid instrument, suitable for measuring communication among persons with dementia.¹² The HCS, which has been used in several studies, has never been validated. The overall aim of this study is therefore to investigate the psychometric properties of the English version of the HCS in a sample of persons with moderate-to-severe cognitive impairment living in nursing homes in Ireland. In addition, we wanted to evaluate the original three subgroups of the instrument, referred to by Holden and Woods.¹¹ We further wanted to investigate the association between the ability to communicate and cognitive function, as measured by the HCS and Mini-Mental State Examination (MMSE), respectively.

METHOD

Sample and procedure

A convenience sample of 128 persons over 65 years living in seven nursing homes in Ireland was recruited. The mean age of the residents was 85.2 (SD 7.2) and 101 (79%) were women. The recruitment process took place between January and March 2014. Persons with dementia, defined by an MMSE score of 0–20, were included in the study. Persons in the palliative phase and not expected to live longer than 6 months, and those with major depression or severe pain, were excluded. Data were collected prior to randomisation.

Measures

Nurses collected the demographic data from medical and nursing home records. Cognitive function and communication ability were assessed by means of the MMSE and the HCS at baseline of the RCT (n=128) and HCS was also assessed at 1-week follow-up (n=88 to measure test-retest reliability) by one and the same nurse in each of the seven nursing homes.

Nurses who knew the residents well over a long period of time received 2 hours training about how to carry out the assessments.

Mini-Mental State Examination

MMSE is an instrument used to assess cognitive performance which can be used as a surrogate for the Clinical Dementia Rating (CDR) for the staging of dementia.¹³ The scale comprises 20 questions that cover orientation, memory, attention and calculation, recall and language. Each question is scored, and the summing up leaves a possibility of 30 points, with a higher score indicating a better cognitive performance.¹⁴

The HCS

The HCS is a proxy-based instrument initially developed to assess reality orientation approaches and reminiscence programmes. The Scale includes 12 items assessing conversation, awareness and knowledge, and communication. Each item contains five response

options, ranging from 0 to 4, with a maximum score of 48. A higher score indicates more difficulties with communication.¹¹

Statistical analysis

Data were analysed using the SPSS V.22.0. The distribution of data was assessed graphically by inspecting the histograms and no obvious deviations from normality were found. Inter-item Pearson correlations were calculated to explore if all items of the HCS measure the same underlying characteristics. The Cronbach's α coefficient and corrected item-total correlations were used to analyse internal consistency reliability. The criterion function for acceptable reliability was set to $\alpha \geq 0.7$.¹⁵

Test-retest reliability was assessed by calculating Pearson's correlation coefficient. The criterion for acceptance was set to at least 0.7. Bias was assessed by paired samples Student's t-test and 95% limits of agreement were calculated. Even though no a priori width for limits of agreement was specified, these might be useful in assessing the spread in the difference between test and retest measurements.

An exploratory factor analyses (FA) with a principal components extraction method was performed, including all 12 items of the HCS with the aim to explore the component structure and construct validity. Bartlett's test of sphericity (significance better than 0.05) and the Kaiser-Meyer-Olkin (KMO) (higher than 0.60) test were carried out prior to FA. Oblimin rotation was applied to allow for correlated factors. First, the number of components was defined by inspection of the scree plot and the Kaiser criterion (eigenvalue ≥ 1). Next, since the original version of the HCS divides the scale into three subgroups, an FA with three components was carried out. The concurrent validity was examined by calculating Pearson correlation coefficients between the HCS and MMSE, stratified into those with an MMSE score of 0–10 (severely impaired, n=67) and those with a score of 11–20 (moderately impaired, n=61). We did not measure the inter-rater reliability since the same nurse in each of the seven nursing homes scored the HCS on both occasions.

Informed consent was obtained from the next of kin since the persons with dementia were unable to sign the informed consent.

RESULTS

At baseline, the mean MMSE score was 8.9 (SD 7.0) and the mean HCS score was 22.3 (SD 12.0) among the 128 participants.

Internal consistency

The Cronbach's α for the total HCS score was 0.94. The inter-item correlations were all positive and above 0.37, with the majority of the correlation coefficients between 0.50 and 0.70. The highest correlations were between: *success in communication and attempts to communicate* (0.79), *speech and attempts to communicate* (0.76), *success in*

Table 1 Correlation matrix for the 12 items in Holden Communication Scale (HCS) (n=128)

	1	2	3	4	5	6	7	8	9	10	11	12
1. Response	1											
2. Interest in past events	0.64	1										
3. Pleasure	0.68	0.63	1									
4. Humour	0.70	0.70	0.71	1								
5. Names	0.50	0.60	0.37	0.54	1							
6. General orientation	0.46	0.58	0.44	0.52	0.64	1						
7. General knowledge	0.54	0.59	0.56	0.57	0.54	0.60	1					
8. Ability to join in games, etc	0.60	0.54	0.61	0.62	0.44	0.50	0.54	1				
9. Speech	0.70	0.61	0.51	0.62	0.56	0.43	0.58	0.59	1			
10. Attempts at communication	0.66	0.61	0.50	0.65	0.54	0.48	0.55	0.50	0.76	1		
11. Interest and response to objects	0.63	0.64	0.67	0.65	0.48	0.51	0.62	0.60	0.61	0.63	1	
12. Success in communication	0.70	0.61	0.54	0.59	0.55	0.46	0.56	0.55	0.73	0.79	0.69	1

communication and speech (0.73), humour and pleasure (0.71) and speech and response (0.70). The correlation between pleasure and remembering names (0.37) and remembering names and the ability to join in games (0.44) was low (table 1).

All corrected item-total correlations ranged from 0.63 to 0.79 (table 2).

Test-retest reliability

The total score on HCS between baseline and 1-week (table 3) did not differ significantly (22.6 (SD 12.5) and 22.2 (SD 12.1)), $p=0.35$ for paired samples Student's

t-test. Assessing the individual items, a small bias was only revealed in *ability to join in games, etc.* ($p=0.04$). The 95% limits of agreement interval, which would contain the differences between test and retest ~95% of the time, were rather narrow for all items as well as total HCS score (table 3). This clearly indicates reliable measurements.

Factor analysis

Bartlett's test of sphericity was statistically significant ($p<0.001$), and the KMO measure was 0.94, both implying satisfactory values. The FA using a criterion of eigenvalue ≥ 1 and inspection of the scree plot revealed a one-component structure accounting for 63% of the variance. A three-factor analysis was performed to assess the original three subgroups structure of the HCS.¹¹ The three factors explained 76% of the variance. Factor 1 had a Cronbach's α of 0.89 and accounted for 62.1% of the variance, while factor 2 had a Cronbach's α of 0.81 and factor 3 a Cronbach's α of 0.91, accounting for 7.3% and 6.6% of the variance, respectively. Most of the loadings on three factors were strong, and most of the items loaded substantially on only one factor. However, an inspection of the scree plot revealed a clear break after the first component (table 4).

Relationship between the ability to communicate and cognition function

The HCS correlated as expected with the MMSE, suggesting that lower levels of cognitive functioning were related to increased communication difficulties (-0.67). However, when dividing between moderate and severe cognitive decline, strong correlation was only found between severe cognitive decline and HCS (-0.61) and not between moderate cognitive decline and HCS (-0.06). Among those with severe cognitive impairment, the strongest correlation was found between cognitive dysfunction and *speech* (-0.59), whereas among those with moderate cognitive impairment *interest in past events* (-0.30) was found to be strongest.

Table 2 Item performance for the Holden Communication Scale (HCS) (n=128)

Items	Mean	SD	Corrected item-total correlation	Cronbach's α if item deleted
Conversation				
1. Response	1.7	1.4	0.79	0.94
2. Interest in past events	2.2	1.2	0.78	0.94
3. Pleasure	1.5	1.0	0.71	0.94
4. Humour	1.9	1.2	0.79	0.94
Awareness and knowledge				
5. Names	2.1	1.2	0.66	0.94
6. General orientation	2.8	1.2	0.63	0.94
7. General knowledge	2.6	1.1	0.72	0.94
8. Ability to join in games, etc	2.1	1.3	0.69	0.94
Communication				
9. Speech	1.4	1.5	0.78	0.94
10. Attempts at communication	1.2	1.5	0.78	0.94
11. Interest and response to objects	1.6	1.3	0.78	0.94
12. Success in communication	1.4	1.4	0.79	0.94

Table 3 Test-retest reliability measures for the Holden Communication Scale (HCS) (n=88)

Scale	Baseline Test mean (SD)	1 week Retest mean (SD)	Bias and 95% limits of agreement	p Value
Conversation				
1. Response	1.68 (1.37)	1.65 (1.29)	0.03 (−0.11; 0.17)	0.63
2. Interest in past events	2.18 (1.16)	2.17 (1.17)	0.01 (−0.07; 0.09)	0.78
3. Pleasure	1.42 (0.99)	1.41 (0.94)	0.01 (−0.13; 0.15)	0.87
4. Humour	1.86 (1.21)	1.80 (1.19)	0.07 (−0.06; 0.19)	0.27
Awareness and knowledge				
5. Names	2.20 (1.22)	2.18 (1.17)	0.02 (−0.08; 0.13)	0.67
6. General orientation	2.74 (1.28)	2.78 (1.28)	0.05 (−0.12; 0.03)	0.25
7. General knowledge	2.60 (1.05)	2.59 (1.04)	0.01 (−0.09; 0.12)	0.83
8. Ability to join in games, etc	2.10 (1.37)	1.92 (1.24)	0.18 (0.01; 0.35)	0.04
Communication				
9. Speech	1.50 (1.52)	1.49 (1.53)	0.01 (−0.09; 0.12)	0.83
10. Attempts at communication	1.27 (1.48)	1.26 (1.44)	0.01 (−0.08; 0.11)	0.81
11. Interest and response to objects	1.51 (1.32)	1.47 (1.30)	0.05 (−0.08; 0.17)	0.47
12. Success in communication	1.50 (1.46)	1.44 (1.43)	0.06 (−0.04; 0.15)	0.23
Total score	22.6 (12.5)	22.1 (12.1)	0.38 (−0.42; 1.17)	0.35

Table 4 Three component structure of the Holden Communication Scale (HCS)

Holden	Component 1	Component 2	Component 3
3. Pleasure	0.970	0.051	0.041
8. Ability to join in games, etc	0.689	0.135	0.056
4. Humour	0.615	0.155	0.212
11. Interest and response to objects	0.553	0.095	0.307
2. Interest in past events	0.407	0.378	0.206
6. General orientation	0.156	0.907	0.152
5. Names	0.190	0.792	0.307
7. General knowledge	0.354	0.503	0.085
10. Attempts at communication	0.022	0.059	0.896
12. Success in communication	0.076	0.005	0.858
9. Speech	0.064	0.029	0.841
1. Response	0.479	0.056	0.521
Explained variance	62.1%	7.3%	6.6%
Cronbach's α	0.89	0.81	0.91

Bold formatting highlights the three components.

The correlation between cognitive dysfunction and humour was strongest for those with severe cognitive impairment (−0.56), whereas those with moderate cognitive impairment exhibited a low correlation (−0.06). There was little difference in the ability to express pleasure in persons with severe cognitive impairment and those with moderate cognitive impairment, −0.31 and −0.18, respectively (table 5).

DISCUSSION

To the best of our knowledge, this is the first study to investigate the psychometric properties of the English version of the HCS for persons with moderate-to-severe cognitive impairment living in Irish nursing homes.

Internal consistency

The Cronbach's α for the total HCS was 0.94, indicating a satisfactory internal consistency. However, a high

Cronbach's α coefficient might indicate the need to assess if there are some items measuring the same construct.

The strong correlation between *attempts at communication* and *success in communication* (0.79) was not expected since the attempts to communicate do not necessarily follow the success in communication. Further, the strong correlation between speech and attempts at communication (0.76) and success in communication (0.73) was not expected either, since the speech ability depends on motor functioning, while communication is connected to language.¹ On the other side, the strong correlation between *speech* and *response* (0.70) was as expected. A person who is able to respond would certainly be expected to be able to express in terms of speech.

Although *pleasure* and *humour* are closely connected, we would not expect them to have such strong correlation (0.71). The experience of pleasure is subjective and considered one of the core dimensions of emotion.

Table 5 Pearson's correlations between HCS items and cognitive function (MMSE) (n=128)

Holden/MMSE	MMSE	MMSE
	score	score
	0–10	11–20
	(n=67)	(n=61)
Conversation		
1. Response	–0.55	–0.10
2. Interest in past events	–0.49	–0.30
3. Pleasure	–0.31	–0.18
4. Humour	–0.56	–0.06
Awareness and knowledge		
5. Names	–0.30	–0.04
6. General orientation	–0.16	–0.22
7. General knowledge	–0.42	–0.10
8. Ability to join in games, etc	–0.46	–0.07
Communication		
9. Speech	–0.59	–0.13
10. Attempts at communication	–0.52	–0.09
11. Interest and response to objects	–0.47	–0.13
12. Success in communication	–0.52	–0.03
Total Holden	–0.61	–0.06

HCS, Holden Communication Scale; MMSE, Mini-Mental State Examination.

The experience is a positive feeling or sensation correlated with external circumstances such as having a good meal, performing exercises, enjoying art, literature and dancing,¹⁶ sharing music,¹⁷ showing real pleasure in situations or smiling.¹¹ Humour, on the other hand, is a complex phenomenon with no clear definition and has often been considered synonymous with 'joke', 'laughter' and 'wit'. However, it is important to distinguish these concepts from humour even if they are related since they do not contain the same conceptual phenomena. Humour can be described as a subjective, emotional response that comes from the recognition and expression of incongruity of a comic, absurd, or impulsive situation or remark, and enhances feelings of togetherness and closeness.¹⁸ This could be such as enjoying comic situations or telling funny stories on one's own initiative¹¹ or be used as a tool in creating relationship and communication.¹⁹

As expected, the *ability to remember names* and *express pleasure* revealed low correlation (0.37). The ability to remember names is associated with semantic memory,³ which has to do with long-term memory, while the ability to express pleasure is based on an experience and does not depend on memory. Further, the ability to join in games and remember names (0.44) was weakly correlated. This was not as expected since the ability to join in games would depend on a certain function of cognition, which again is connected with memory (table 1).

Some of the items, like humour and pleasure, were difficult to differentiate since a smile can be an indication for both humour as well as pleasure. Another challenge with the HCS is that some of the scoring values refer to expression as well as experience, such as in item

12: success in communication (clearly understood (0), uses gestures and sounds effectively (1), understanding restricted to a few people (2), becomes frustrated and angry (3) and makes no attempt (4)). Success in communication refers to the degree to which the person is clearly understood or not. However, value number 1 addresses if the person is using non-verbal communication, while value number 3 refers to the person's reaction. Such inconsistent naming of scoring values makes it difficult to get a clear opinion of what is assessed and thus could lead to misleading results.

The inter-item correlations were all positive and above 0.37, indicating that all items measure the same underlying aspect of communication and correlate with the total score (table 1).

Test-retest reliability

The test-retest analysis revealed no significant difference in the total score of HCS at baseline and after 1-week (paired sample Student's t-test; $p=0.35$). However, by inspecting each single item, a significant bias ($p=0.04$) was found for one item, *the ability to join in games, etc.* Despite the significantly different score for this item, the result indicates a good test-retest reliability for the HCS. We can therefore conclude that the nurses carried out the assessments in a consistent way (table 3).

Validity

The FA resulted in a one-component structure, explaining 63% of the variance and this was expected since the corrected item-total correlation was between 0.63 and 0.79 (table 2). However, Holden and Woods¹¹ who constructed the scale considered HCS to consist of three subscales: *conversation*, *awareness and knowledge*, and *communication*. On the basis of this suggestion, we forced a three-factor analysis. The three-factor solution explained a total of 76% of the variance, all loading above 0.4, with a sufficient Cronbach's α for each factor (table 4). In the original HCS, items 1–4 made up one subgroup (conversation), items 5–8 subgroup two (awareness and knowledge), and items 9–12 subgroup three (communication). As illustrated in table 4, the three-factor solution resulted in an almost equal distribution of items among the three subgroups, however, with a different structure than the original HCS. In the present study, item 1 was connected to factor 3, whereas items 8 and 11 were connected to factor 1.

Although item 1 loaded almost the same on factors 1 and 3 (loadings 0.48 and 0.52, respectively), after looking more closely we suggest that the response in this setting might be understood as being involved in conversation. Item number 1 could be connected to items 9, 10 and 12, all of which have to do with verbal communication. The same language pattern is proposed for item 11 (interest and response to objects), which is connected to non-verbal communication and therefore subscale 1. However, item 2 (interest in past events), which loaded almost the same on factors 1 and 2 (loadings



0.40 and 38, respectively), is clearly connected to aspects of communication that require memory. It would therefore be preferable to move this item to factor 2.

Although a one-component structure was revealed, the forced three-factor analysis indicates that a three-factor solution is stronger than the one-component structure.²⁰ On this basis, we therefore suggest that the scale be divided into three subscales: subscale 1, non-verbal communication; subscale 2, knowledge/understanding; and subscale 3, verbal communication. This would also be obvious when considering the face validity.

The correlation between cognitive function and the ability to communicate

This study demonstrated a moderate negative correlation between cognitive function, as measured with the MMSE, and the ability to communicate (−0.67), suggesting that lower levels of cognitive functioning were related to increased communication difficulties. This test gives evidence of good clinical validity of the HCS. Although a strong correlation was found among those with severe cognitive impairment (−0.61), a low negative correlation was found among those with moderate cognitive impairment (−0.06). On the basis of these findings, we might question the validity of using the HCS among those at the moderate stage of dementia.

The strong correlation between cognitive dysfunction and the item *speech* among those with severe cognitive impairment (−0.59) was considerably lower for those with moderate cognitive impairment (−0.13), and is consistent with previous research reporting the speech ability to decline as part of the dementia process.²¹

The correlation between cognitive function and the item *humour* was strongest among those with severe cognitive impairment (−0.56) and low among those with moderate cognitive impairment (−0.06). This finding is supported by previous research where an altered sense of humour in persons with dementia is reported²² and that appropriateness of humour depends on cognitive function.²³ However, little difference in the ability to express pleasure was reported between the groups, −0.31 and −0.18, respectively. Cohen-Mansfield *et al*²⁴ gives support to this finding: persons with severe dementia are still capable of showing pleasure.

The strength of this study is the presentation of the psychometric properties performed in a structured way. However, a weakness is that it is based on relatively few participants, as well as the fact that the participants had moderate-to-severe cognitive decline and were mainly women. Another weakness is the fact that the same nurse was completing both the MMSE and the HCS, which could influence the ratings. Another weakness is related to the fact that we did not study the inter-rater reliability of the HCS. However, since the same nurse did the assessments on both occasions, we consider this bias to be small. Transferring the results from this study to all stages of dementia might therefore be a challenge.

CONCLUSION

The psychometric evaluation reveals HCS to be a reliable and valid instrument, suitable for assessing communication in persons with dementia. The analyses demonstrate high internal consistency and test-retest reliability. Further, there is a moderate correlation between communication ability and cognitive function among persons with severe cognitive decline, whereas this correlation is low among those with moderate cognitive decline.

A one-structure solution was found, where all items loaded satisfactorily. However, a forced three-factor analysis revealed a different distribution of the items, compared with the original subgrouping by Holden and Woods, with a higher explained variance.

The findings of the study may help clinicians to detect the ability to communicate in persons with dementia. Focusing on ability rather than limitations presents an important clinical perspective in the communication with persons having dementia.

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Acknowledgements The authors would like to thank Sister Morag Collins SJC for her detailed proof reading.

Contributors BSS, KE and E-KG contributed to the design of the study, accountability and approval of the published version. BSS was involved in drafting of the work. KE, E-KG and JSB revised the work.

Competing interests None declared.

Patient consent Obtained.

Ethics approval The study was approved by the Regional committees for medical and health research ethics of Norway (REC) under registration number IRB 0000 1870. No ethical approval was needed in Ireland, except from the board of management in each nursing home.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement The data will be available at NSD after the study has been completed.

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Psychometric evaluation of the Holden Communication Scale (HCS) for persons with dementia

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BMJ Open 2016 6:
doi: 10.1136/bmjopen-2016-013447

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Original Research Article

Effect of the Sonas Programme on Communication in People with Dementia: A Randomized Controlled Trial

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Keywords

Communication · Dementia · Elderly · The Sonas programme

Abstract

Background: Strategies to improve communication in people with dementia are warranted. We examined the effect of the Sonas programme on communication ability in persons with moderate to severe dementia. **Methods:** A 24-week 3-armed (Sonas, reading, and control group) randomized controlled trial including 120 nursing home residents with dementia was conducted; 105 completed the follow-up assessments. The main outcome was change in communication abilities measured by the Holden Communication Scale (HCS). **Results:** We found no overall significant effect of the Sonas programme with regard to communication ability as measured by the HCS. However, an effect between the Sonas group and the reading group and between the Sonas group and the control group from T0 to T1 and T2 was found, as well as a significant improvement in communication in the Sonas group. Among people with severe dementia, the Sonas group scored significantly better on the HCS compared to the reading group after 12 weeks, but not after 24 weeks. **Conclusion:** This study failed to document an overall effect of the Sonas programme on communication; however, the findings indicate that the Sonas programme has a significant effect on communication among those with severe dementia.

© 2017 The Author(s)
Published by S. Karger AG, Basel

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Introduction

Approximately 47 million people worldwide are estimated to live with dementia and the incidence per year is estimated to be 9.9 million cases [1].

Dementia presents a wide range of symptoms, such as cognitive impairment and behavioural and motoric changes. Communication difficulties are among the earliest symptoms of dementia [2], especially verbal communication difficulties, which are seen as a significant problem among those with severe dementia [3, 4]. However, the urge to communicate and the need to be part of the society will remain, regardless of the degree of dementia [5]. The lack of verbal communication can make people with dementia appear unreachable and lead to fewer attempts by carers to communicate with the person [6], and even result in “social death” [7].

People with dementia at a severe stage are less able to be active and therefore tend to be isolated and bored. The use of psychosocial interventions in dementia care is highly recommended since antipsychotic treatment may have serious side effects in the management of behavioural and psychological symptoms of dementia [8, 9]. Psychosocial interventions are also referred to as a way of promoting person-centred care for individuals with dementia [10].

Lubinski [11] emphasizes the importance of cognitive stimulation through the senses for those with dementia. This is supported by Vozzella [12] who claims that as the person regresses, the need for stimulation increases. Bakshi [13] found that individuals with moderate to severe dementia were given less antipsychotic medication after having received stimulation. However, despite the evidence that communication difficulties are problematic for persons with dementia, a review conducted by Strøm et al. [14] of available sensory stimulation strategies identified only one quantitative study that measured the effect on communication. This study, conducted by Hutson et al. [15], found no effect of the Sonas programme on communication.

The majority of available sensory stimulation interventions include stimulation of only 1 of the senses, such as music, light therapy, acupressure/reflexology, massage/aromatherapy and doll therapy/pet therapy/toy therapy [14]. However, the Sonas programme, which is a multi-sensory stimulation programme developed by Sr. Mary Threadgold in 1990, involves cognitive, sensory, and social stimulation, including all 5 senses: touch, smell, taste, hearing, and sight. The programme is a therapeutic activity for people who have significant communication impairment, primarily as a result of dementia. The aims of the Sonas programme are: (1) to activate whatever potential for communication has been retained by an older person with communication impairment, (2) to encourage the creation of an environment which will facilitate communication, and (3) to have activation of the potential for communication recognized and accepted as an essential part of care planning for older people. However, research investigating the effectiveness of the Sonas programme is limited with only few studies published, one of which assessing the effect on communication as a secondary outcome measure.

Of the relevant studies on this topic, the first was an observation study carried out by Brown [16] who reported some positive changes in well-being, self-confidence, self-esteem, and trust as well as improved alertness, happiness, quality of life (QoL), and relaxation after attending the Sonas sessions. No benefit was found on agitation and aggression. However, this study has several limitations, with an unknown number of participants and undisclosed length of the intervention period as well as outcome measures, and no control group. Parrish et al. [17] used Dementia Care Mapping to observe 51 participants with dementia in day hospitals and care wards in institutions attending Sonas sessions. Although no benefit was reported on reduced agitation or aggression, a significant number of participants showed a

positive change in well-being after attending the Sonas sessions as well as being more animated and initiating conversation and singing.

The first randomized controlled trial (RCT) measuring the effect of the Sonas programme was conducted in 2003 by Jackson et al. [18]. All 75 participants were randomly selected to either attend a weekly Sonas session for 8 weeks or be part of the control group where the participants received standard care. No significant differences were found between the groups in relation to aggression, agitation, depression or cognitive impairment. A recent pilot RCT [15] included 36 residents with moderate to severe dementia, of whom 20 participated in Sonas sessions twice weekly over a period of 7 weeks; no statistically significant differences in depression, anxiety, communication, and QoL were reported. However, there was some improvement for both groups in relation to depression and anxiety, where the control group demonstrated greater improvement than the Sonas group. Further, the Sonas group demonstrated an improvement in communication ability and QoL, as well as a greater reduction in behavioural and mood disturbance than the control group.

The need for high-quality research investigating psychosocial interventions for older people with dementia has been emphasized [19]. In addition, only few studies have investigated the effectiveness of techniques to improve communication for people with dementia, which is of importance as communication is essential for social life of people regardless of cognitive function [20]. With just few published studies examining the effect of the Sonas programme, some showing methodological limitations, short duration and small sample sizes, the overall aim of this study was to examine the effect of the Sonas programme on communication ability for people with moderate to severe dementia living in a nursing home. The secondary aim was to explore if any effect could be related to cognitive function and different aspects of communication.

Method

The study is reported according to the CONSORT statement 2010 [21] and the extended version of the CONSORT statement for non-pharmacological treatment [22].

Study Design

The study is an RCT where the participants were assigned to 1 of the 3 groups for 24 weeks: (1) the Sonas programme, (2) the reading group, and (3) standard care. The reading group was set up in order to rule out the possibility that an effect of attending the Sonas sessions could be caused by the attention given by staff leading the group, rather than the actual Sonas programme. The study took place from April to October 2014. Data collection was carried out at baseline (T0) before randomization, and after 12 weeks (T1) and 24 weeks (T2), respectively.

Setting

In all 168 nursing homes in Dublin, Ireland, and the 5 surrounding counties, all registered with the independent authority, i.e., "Health Information and Quality Authority" (HIQA), were considered eligible. The goal of HIQA is to perform continuous improvement in Ireland's health and social care services [23]. Only long-term facilities with at least 40 beds and which had not used the Sonas programme earlier were initially chosen to take part in the study. Of the 168 nursing homes, 47 have less than 40 beds, 18 are hospitals, and 78 had already used the Sonas programme according to the last inspection report carried out by HIQA. The remaining 25 nursing homes received an e-mail about the trial. The first author surveyed the 25 nursing homes to determine whether there were adequate numbers of potential partici-

- The programme consists of the following elements:
- Signature tune and greeting song
 - Exercises to music
 - Smell
 - A "sing-along" which includes three familiar songs
 - Relaxation music/massage (the senses of taste and touch are stimulated)
 - Music with percussion instruments
 - Joining in proverbs
 - Listening to poetry
 - Contribution
 - Second "sing-along"
 - Closing song and signature tune

Fig. 1. The Sonas programme.

pants with dementia. Eight nursing homes agreed to participate; however, 1 withdrew. Two more counties were included and 1 of the 9 eligible nursing homes in these counties accepted to participate. Another nursing home withdrew and 1 did not have enough participants for 2 groups, which left us with 6 nursing homes for this RCT (Fig. 1).

Participants

The participants were recruited between January and March 2014 and the Director of Nursing in each nursing home identified potential male and female residents. A total of 147 persons were considered eligible for the study. Informed consent was obtained from the next-of-kin since the persons with dementia were unable to sign the informed consent. Persons were considered suitable for participation when they were >65 years of age, were diagnosed with dementia, had moderate to severe cognitive functioning as classified by pre-trial Mini-Mental State Examination (MMSE) scores of 0–20, spoke English and were living in the nursing home. Persons at a palliative stage, those with major depression, current or partial remission, severe pain, or those having been exposed to previous Sonas sessions were not included. Three of the nursing homes had enough eligible participants for 3 groups of 8, while the other 3 only had enough eligible participants for 2 groups. This left us with 120 participants, while 27 were left out of the study.

Randomization Process

Due to ethical considerations, it was decided beforehand that each nursing home would have 1 Sonas group in order to give them the possibility to attend a new programme. The Director of Nursing at each site and this article's first author placed the name of the participants in a container and study participants were then drawn: 24 participants from 3 nursing homes and 16 from the other 3 nursing homes. After baseline data had been collected, the randomization was carried out by the same persons.

The participants were randomly assigned to either the Sonas group ($n = 48$), the reading group ($n = 32$) or the control group ($n = 40$), by drawing lots. For the nursing homes with 24 eligible participants, the participants were randomly allocated to 1 of the 3 groups. For the nursing homes with 16 eligible participants, 8 were first randomly allocated to the Sonas group, whereas the remaining 8 participants were randomly allocated to either a reading or control group, by drawing lots.

Intervention

The Sonas programme was carried out twice a week in groups of 8 residents over a period of 24 weeks. Each session lasted 45 min and was led by a person trained in the Sonas programme (Sonas licensed practitioner) and an assistant. The programme consists of 13

Table 1. Characteristics of participants at baseline

Characteristics	Total (n = 120)	Sonas group (n = 48)	Reading group (n = 32)	Control group (n = 40)
Gender				
Women	93 (77.5)	40 (83.3)	25 (78.1)	28 (70)
Men	27 (22.5)	8 (16.7)	7 (21.9)	12 (30)
Marital status				
Single	36 (30)	12 (25.0)	11 (34.4)	13 (32.5)
Married	22 (18.3)	8 (16.7)	6 (18.8)	8 (20.0)
Widowed	61 (50.8)	27 (56.3)	15 (46.9)	19 (47.5)
Divorced	1 (0.8)	1 (2.1)	0 (0)	0 (0)
Degree of cognitive function				
Severe (MMSE score 0–10)	63 (52.5)	29 (60.4)	15 (46.9)	19 (47.5)
Moderate (MMSE score 11–20)	57 (47.5)	19 (39.6)	17 (53.1)	21 (52.5)
Age, years	84.8±7.0	86.1±6.6	84.9±7.2	83.3±7.1
MMSE score	9.0±7.1	7.7±6.7	10.0±7.2	9.7±7.5
HCS score	22.0±11.9	24.7±12.1	18.2±12.0	21.9±10.9

Values are mean ± standard deviation or n (%). MMSE, Mini-Mental State Examination; HCS, Holden Communication Scale.

elements and follows the same structure each time, believing that repetition is a way of helping the individual to remember [24]. The participants are seated in a semi-circle and the session begins with a welcome song where each one is individually greeted by name (Fig. 1). The reading group received 45 min of reading from a newspaper twice a week for 24 weeks. The participants of the control group did not participate either in the Sonas sessions or the reading groups, but continued with their daily routines, for example, attending the activity programme set up by the nursing home. The staff (Sonas licensed practitioners and care assistants) involved in the study, either received (1) a 3 days' training consisting of training and support in the Sonas programme or (2) preparation to lead the reading group by this article's first author. The other staff did not receive any extra training.

Main Outcome and Assessments

The main outcome measure was the Holden Communication Scale (HCS) which measures communication ability. The HCS includes 12 items assessing conversation, awareness, humour, and responsiveness. The score range was from 0 to 48, and a higher score denotes more difficulties with communication [25]. The HCS has been evaluated to be a reliable and valid instrument to measure communication ability in persons with dementia [26].

The degree of cognitive functioning was assessed by the MMSE. The questionnaire comprises 20 questions that cover orientation, memory, reading, calculation, recall, and language. Each question is scored, and the sum score can vary between 0 and 30. A higher score denotes better cognition [27]. The MMSE has been found to have a satisfactory reliability and construct validity [28]. Residents' characteristics were obtained from their records at baseline (Table 1).

Participants were assessed at baseline (T0), after 12 weeks (T1), and after 24 weeks (T2) by nurses who had received training in the use of the instruments and were not involved in either the Sonas sessions or reading groups. They were blinded at baseline data collection, but this was not possible at follow-ups.

Data Analysis

Power Calculation

We aimed at comparing the HCS score between the Sonas and the reading group as the primary analysis, and assumed Cohen's $d = 0.80$ as our effect size. With the significance level of 5% and power of 80%, we estimated a minimum sample size of 24 in each group. A drop-out rate of 30% was assumed. The sample size required was therefore adjusted to 32 persons per group.

Analysis

Each participant's characteristics at baseline were summarized as frequencies and percentages for the categorical variables and as means and standard deviations for the continuous variables. The normality of continuous variables was assessed by inspecting histograms.

None of the participants changed the group they originally had been assigned to; hence, there was no need for an intention-to-treat approach.

Differences in HCS total scores between the intervention group, the reading group, and the control group were assessed by estimating a linear mixed model with fixed effects for the time component up to second-order and group variable. Interaction between the two was included as well. A significant interaction term would imply differences between the groups in development of the HCS score through the follow-up period. Random effects for participants nested within nursing homes were included in the model. Such a model correctly accounts for intra-participant correlations due to repeated measurements for each participant as well as cluster effect within each nursing home. The linear mixed model handles unbalanced data by including all available information, also from drop-outs. An exploratory analysis was performed by estimating the same model for each component of the HCS.

A similar model as above was estimated in order to assess changes among those with moderate and with severe cognitive decline. For this purpose, an extra fixed effect for cognitive decline level was included together with the interaction between the level and time and the level and the group with moderate and severe cognitive decline. Such an analysis was performed in order to explore which of these 2 groups benefits most from the Sonas programme compared with the reading and control group.

The statistical analyses were conducted using SPSS version 22 and SAS version 9.4. Results with p values below 0.05 were considered statistically significant.

Ethical Considerations

The study was approved by the Regional Ethics Committee of Norway (REK) under the registration number IRB 0000 1870. No ethical approval was needed in Ireland, except from the board of management in each nursing home.

Results

Participant Characteristics

The mean age of the participants was 84.8 ± 7.0 years (range 67–100) and the majority were women (77.5%). The mean MMSE score was 9.0 ± 7.1 . A moderate degree of communication difficulties was seen, with a mean HCS score of 22.0 ± 11.9 (Table 1).

Drop-Outs and Attendance

Of the 120 assessed at baseline, a total of 105 residents completed the study. In the Sonas group, 3 dropped out (2.5%; 2 left the group and 1 withdrew because of serious illness),

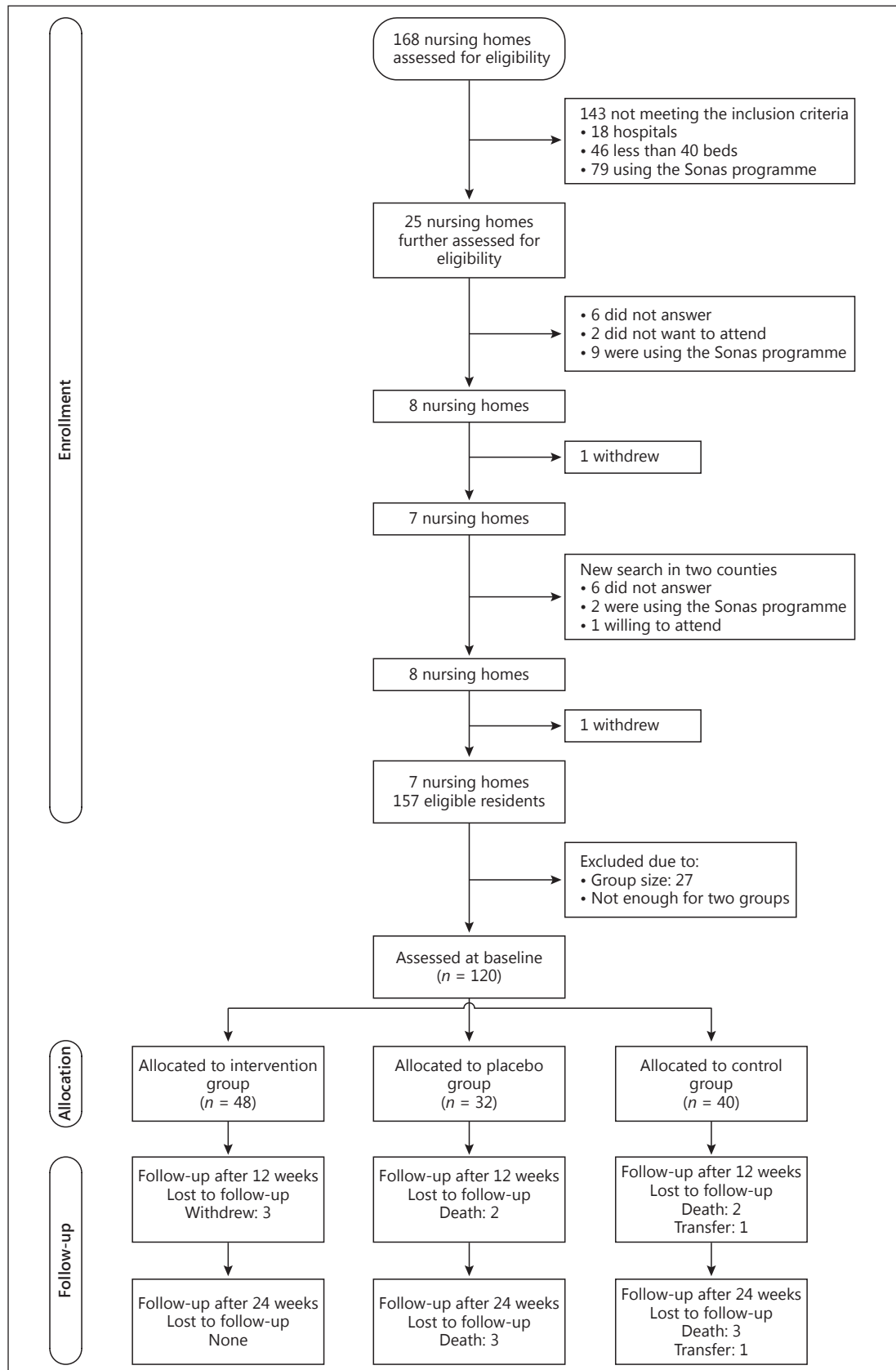


Fig. 2. CONSORT flow diagram.

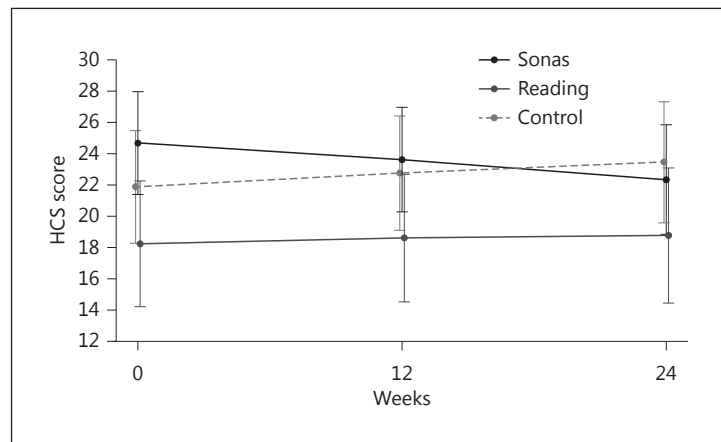


Fig. 3. Mean HCS score at baseline, 3 months and 6 months.

there were 5 drop-outs in the reading group (4.1%; 5 died) and 7 in the control group (5.8%; 5 died and 2 were transferred to another nursing home), i.e., a total drop-out rate of 12.4% (Fig. 2).

The participants were reported to attend the Sonas programme at an average of 39.8 ± 11.8 sessions (range 1–48). In the reading group, the average attendance rate was 42.1 ± 6.9 (range 1–48).

Effect of Intervention

The linear mixed model analysis through 3 time periods (T0, T1, and T2) did not show an overall communication effect of the Sonas programme. However, we found a significant difference in the level of change in communication ability through the whole study period between the Sonas and the reading group ($p = 0.019$) and between the Sonas and the control group ($p = 0.001$). As illustrated in Figure 3, the mean HCS score in the Sonas group decreased from 24.7 at T0 to 23.6 at T1 ($p = 0.014$) and 24.7 at T0 to 22.3 at T2 ($p = 0.002$), indicating a significant improvement in communication abilities. In contrast, the control group had an increase in HCS mean score from 21.9 at T0 to 23.5 at T2. An almost unchanged mean score of HCS was reported for the reading group (18.2 at T0 to 18.8 at T2). The number of sessions attended did not affect the outcome of the HCS.

An overall effect was demonstrated regarding *interest in past events, humour and having general knowledge*, whereas no significant differences were found in aspects which would be expected to require a higher level of cognitive function such as: *remembering names, speech, having success in communication and showing interest in and response to objects*. For further details, see Table 2.

When stratifying on MMSE (moderate and severe; cut-off of 10 points), a significant difference was found between the Sonas group and the reading group among those with an MMSE score of 0–10 at T0 ($p = 0.011$) and at T1 ($p = 0.044$), while among those with an MMSE score of 11–20, there was a significant difference between the Sonas and the reading group at baseline ($p = 0.026$). No difference was found between the Sonas and the control group. There was a significant reduction in mean HCS score from T0 to T1 ($p = 0.015$ in the group with an MMSE score of 11–20 and $p = 0.017$ in the group with an MMSE score of 0–10) and from T0 to T2 ($p = 0.009$ in the group with an MMSE score of 11–20 and $p = 0.008$ in the group with an MMSE score of 0–10) in the Sonas group. No significant changes were found in the other 2 groups (Table 3).

Table 2. HCS subtype means and standard deviations

	Sonas group (n = 48)	Reading group (n = 32)	Control group (n = 40)	Sonas vs. reading, p value	Sonas vs. control, p value
Response					
Baseline	1.8 (1.4)	1.5 (1.3)	1.7 (1.4)	0.678	0.032
12 weeks	1.7 (1.3)	1.4 (1.2)	1.8 (1.4)		
24 weeks	1.7 (1.3)	1.4 (1.3)	1.8 (1.5)		
Interest in past events					
Baseline	2.4 (1.1)	1.8 (1.2)	2.1 (1.1)	0.026	0.010
12 weeks	2.3 (1.2)	1.8 (1.1)	2.0 (1.1)		
24 weeks	2.2 (1.2)	1.9 (1.2)	3.0 (1.1)		
Pleasure					
Baseline	1.5 (0.9)	1.2 (1.0)	1.5 (1.0)	0.035	0.232
12 weeks	1.5 (1.0)	1.2 (1.1)	1.5 (0.9)		
24 weeks	1.3 (0.8)	1.2 (0.9)	1.2 (0.9)		
Humour					
Baseline	2.0 (1.2)	1.4 (1.1)	1.8 (1.3)	0.018	0.013
12 weeks	2.0 (1.2)	1.3 (1.1)	1.8 (1.2)		
24 weeks	1.9 (1.2)	1.6 (1.2)	1.8 (1.2)		
Remembering names					
Baseline	2.4 (1.3)	1.8 (1.1)	1.9 (1.2)	0.486	0.413
12 weeks	2.4 (1.1)	2.0 (1.4)	1.9 (1.0)		
24 weeks	2.3 (1.1)	1.8 (1.2)	1.9 (1.0)		
General orientation					
Baseline	3.0 (1.2)	2.3 (1.3)	2.9 (1.1)	0.047	0.131
12 weeks	2.1 (1.0)	2.6 (1.7)	3.0 (1.0)		
24 weeks	3.1 (1.0)	2.7 (1.2)	3.0 (1.0)		
General knowledge					
Baseline	2.8 (1.0)	2.2 (1.0)	2.6 (1.1)	0.019	0.022
12 weeks	2.8 (0.9)	2.2 (1.0)	2.6 (1.1)		
24 weeks	2.6 (1.0)	2.3 (1.1)	2.6 (1.0)		
Ability to join in games					
Baseline	2.1 (1.3)	2.0 (1.6)	2.2 (1.3)	0.893	0.015
12 weeks	2.0 (1.2)	1.8 (1.2)	1.5 (1.4)		
24 weeks	2.0 (1.3)	1.6 (1.2)	2.3 (1.3)		
Speech					
Baseline	1.7 (1.5)	1.1 (1.6)	1.1 (1.4)	0.319	0.063
12 weeks	1.6 (1.4)	0.9 (1.4)	1.2 (1.5)		
24 weeks	1.6 (1.3)	0.9 (1.4)	1.0 (1.4)		
Attempts at communication					
Baseline	1.5 (1.5)	0.8 (1.3)	1.2 (1.4)	0.024	0.086
12 weeks	1.4 (1.5)	0.8 (1.3)	1.0 (1.3)		
24 weeks	1.4 (1.4)	0.9 (1.4)	1.0 (1.4)		
Interest and response to objects					
Baseline	1.7 (1.3)	1.1 (1.2)	1.7 (1.1)	0.075	0.079
12 weeks	1.5 (1.2)	1.1 (1.1)	1.7 (1.2)		
24 weeks	1.7 (1.4)	1.1 (1.2)	1.4 (1.1)		
Success in communication					
Baseline	1.7 (1.4)	1.0 (1.1)	1.1 (1.4)	0.641	0.252
12 weeks	1.8 (1.5)	0.8 (1.3)	0.9 (1.3)		
24 weeks	1.6 (1.5)	0.8 (1.3)	0.8 (1.2)		

Figures are means with standard deviations in parentheses. Figures in bold indicate a significant effect.

Table 3. Ratings of the ability to communicate across time by groups stratified on the level of cognition (MMSE)

Time	Sonas group	Reading group	Control group	Sonas vs. reading, <i>p</i> value	Sonas vs. control, <i>p</i> value
MMSE score 11–20					
Baseline	23.9 (20.6; 27.3)	18.0 (14.0; 22.0)	20.4 (16.8; 24.1)	0.026	0.380
12 weeks	22.7 (19.3; 26.1)	18.1 (14.0; 22.2)	20.9 (17.1; 24.6)	0.092	0.325
24 weeks	21.5 (17.9; 25.1)	18.3 (13.9; 22.8)	21.4 (17.4; 25.4)	0.267	0.301
MMSE score 0–10					
Baseline	25.2 (22.0; 28.5)	18.6 (14.5; 22.6)	23.3 (19.7; 27.0)	0.011	0.081
12 weeks	24.1 (20.8; 27.4)	18.8 (14.8; 22.8)	23.9 (20.3; 27.5)	0.044	0.061
24 weeks	23.0 (19.5; 26.5)	19.1 (14.8; 23.3)	24.6 (20.7; 28.4)	0.156	0.057
MMSE score 11–20					
0 vs. 12 weeks	0.015	0.867	0.411		
0 vs. 24 weeks	0.009	0.792	0.319		
12 vs. 24 weeks	0.015	0.867	0.411		
MMSE score 0–10					
0 vs. 12 weeks	0.017	0.698	0.283		
0 vs. 24 weeks	0.008	0.608	0.194		
12 vs. 24 weeks	0.017	0.698	0.283		

Figures are means with 95% CI in parentheses. Figures in bold indicate a significant effect.

Discussion

No overall significant effect of the Sonas programme was found. However, there was an intervention effect between the Sonas group and the reading group and between the Sonas group and the control group from T0 to T1 and T2, as well as a significant improvement in communication in the Sonas group. The reading group demonstrated almost unchanged communication ability, while the control group showed a decrease in communication ability. When exploring the subscores of the HCS, a significant improvement in communication ability was found in some of the subscores. Further, a significant effect between the Sonas and the reading group was found for participants with severe dementia after 3 months, but this effect ceased after 6 months. These findings will be discussed in the following.

Effect of the Sonas Programme on Communication

The lack of an overall significant effect on communication ability in our study is consistent with a previous study [15] and could have different explanations. First of all, there is the challenge of measuring effect in people who are expected to have an increase in cognitive decline as part of the dementia progress, which also affects their communication ability [3]. Another aspect is the importance of tailoring the intervention to the resident's background and preferences [29], choosing music according to the person's cultural context [30] as well as likes and dislikes [31]. Even though our study was carried out in the culture it was developed for, using Irish poetry and music, it was not based on individual preferences, which might also explain the lack of effect. However, the interaction effect found indicates that attending the Sonas sessions could improve communication ability more than by attending the reading group or being part of the control group. It is possible that this could be explained by the multi-sensory approach of the Sonas programme, or by the fact that receiving attention by being part of a reading group is not sufficient to improve

communication ability. The significant improvement in communication ability in the Sonas group and an almost unchanged mean score on the HCS in the reading group during the 24 weeks could support these findings.

The Impact on Aspects of Communication

The overall effect on *interest in past events, humour and having general knowledge*, and lack of effect in *remembering names, speech, interest in and response to objects and success in communication* could be explained by the fact that sensory stimulation does not have an effect on aspects of communication which require the ability to give a verbal response. Based on this, including persons with severe dementia, who are rarely able to express themselves verbally, demonstrate a challenge and could affect the results. However, we did not expect the Sonas programme to have an effect on *general knowledge* since the ability to communicate verbally decreased as part of the dementia process [3]. It was also interesting to see a significant effect on *humour*, which has been described to be altered in persons with dementia [32] and that the ability to understand humour depends on cognitive function [33]. However, the outcome would depend on the staff's interpretation of humour, where they might see smiling as an expression of humour although this has been described as pleasure [25]. It is therefore interesting to observe the significant improvement in *pleasure* in the Sonas group after 24 weeks, while the reading group remained stable and the control group decreased. An explanation for this could be that pleasure, which is a positive feeling or sensation [34], could be an expression of well-being, which has been reported to be preserved in people with severe dementia [35]. Optimizing well-being is, as described by Threadgold [24], one of the purposes performing the Sonas programme.

Effect on Communication When Stratified on Cognitive Function

The significant difference in communication ability between the Sonas group compared with the reading group after 12 weeks, when stratified on cognitive function, could have several explanations. First of all implementing something new to a group of people who have difficulties attending other activities offered in the nursing home could explain the effect. At the same time, there is the probability of a greater improvement in this group than for those with moderate dementia since they might be more involved in other activities.

Additionally, lack of communication improvement might be explained by the ceiling effect due to lack of reserve capacity and the fact that dementia is progressing.

Although no previous study of the Sonas programme has measured the effect by stratifying on cognitive function, the findings from our study are consistent with a previous study [36] where they measured the effect of robot-assisted activity on quality of life, reporting a significant effect among people with severe dementia.

The ceased significant effect for the Sonas group with severe cognitive decline, seen after 24 weeks, could be due to progression in dementia or due to the fact that the participants have become bored by attending the same programme twice a week. However, it is important to note that this group was the only group which showed a significant increase in communication ability during the whole study period whereas the other 2 groups showed a decrease.

As well as giving an indication of what aspects of communication are retained in persons with severe dementia, these findings demonstrate that the Sonas programme has a potential to improve communication ability in persons with dementia, emphasizing the importance of individually tailored interventions where the persons cognitive level is taken into account.

Strengths and Limitations

To our knowledge, this is the first RCT of the Sonas programme carried out in Ireland. To overcome some challenges in previous research, we included a reading group in order to rule

out a possible effect of social contact by attending the Sonas group. Further, we included a larger sample based on a power calculation. The study was also conducted over a longer period of time compared to a previous study with the same main outcome [15], with a low drop-out rate and high attendance rate over 24 weeks. Another strength was that we focused on communication outcome, which is the overall aim of the Sonas programme. Even though we used a psychometrically tested instrument to assess communication, the HCS is assessing communication deficit and such a negative approach is not in line with the philosophy of the Sonas programme, where the importance is to focus on communication abilities. Further, the subscores in the HCS focus mainly on verbal communication and aspects of communication which require verbal response from the participants that might give a lower outcome on the total score for persons with severe dementia. In order to overcome some of these challenges, we explored the subscores as well as stratified the total score on cognitive function.

Even though all nursing homes were registered with HIQA and therefore had a certain standard, there will always be differences. A limitation is that we did not have control over the participant's daily routine, other activities or stimuli or the use of psychotropic medication, which can affect the outcome. All 6 centres offered some activities, ranging from a singing group once a week to daily activity programme. We assume that the qualification of staff differed among the nursing homes as well as the involvement from the managers. Although all Sonas licensed practitioners had undergone a 3-day formal training, there is no guarantee that the Sonas sessions were conducted in the same way. They can, for example, have different involvement and suitability, or even the way they were prepared for the sessions. Further, the room where the sessions were carried out, the time of the day and if they were interrupted during the sessions would all influence the result.

Although the assessors were blinded at baseline, this was not possible at the 12 and 24 weeks' assessment. However, in order to minimize the risk of contamination, this article's first author collected data after each assessment in order to prevent the assessors from seeing what they scored the previous time. Another limitation was that we were not able to get the same number of groups in all 6 nursing homes, which made the randomization process more difficult. Another consequence of using 6 different nursing homes is the use of 12 different assessors. However, in order to overcome some of the challenges, they underwent a 2-h training about how to carry out the assessment beforehand.

An attention placebo control group with just human presence and no other stimuli might have given other results. However, we found offering human presence without any form of additional stimuli to be unethical and therefore a reading group was chosen as an attention placebo control group.

As the intervention was implemented for people with moderate to severe dementia, the result indicates that this group could benefit from the programme. However, it is not possible to generalize the findings.

Conclusion

To our knowledge, this is the largest clinical trial examining the effect of the Sonas programme, and the first performed in Ireland. Even though this study failed to document an overall effect of the Sonas programme on communication, the findings indicate that the Sonas programme has a significant effect on those with severe dementia, as well as some aspects of communication.

Further studies are needed to look at the immediate effect during and after sessions, which could be done by the use of Dementia Care Mapping, where the different aspects of communication could be further explored.

Acknowledgement

We extend our sincere thanks to the participants and the Sonas licensed practitioners in each nursing home. We would also like to thank Sister Morag Collins SJC for her detailed proof reading.

Disclosure Statement

The authors declare that they have no conflicts of interest.

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