

**Zelfmanagement voor ouderen met een
auditief-visuele beperking: een effectieve
aanpak?**

Lieve Roets-Merken

COLOFON

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For reasons of consistency within this thesis, some terms have been standardized throughout the text. As a consequence, the text may differ from the articles that have been published.

Cover design: Sinds1961, based on an aquarelle of mrs. Andrea Ruijters who, together with her husband Henk Ruijters, was one of the pioniers in developing services for deafblind adults in the Netherlands.

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Zelfmanagement voor ouderen met een auditief-visuele beperking: een effectieve aanpak?

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CHAPTER 1

GENERAL INTRODUCTION



This thesis focuses on improving and supporting the social participation of older adults who acquire a dual sensory impairment (DSI) at an advanced age. DSI is associated with a number of serious risks such as depressive feelings and social isolation. Usual care for sensory impaired older adults includes medical treatment, technical device provision and psychosocial rehabilitation interventions. Despite all efforts made, the extent to which usual care addresses DSI is limited so that this group's problems and needs in daily life are often not fully recognized, and its impact on social participation is underestimated.

DSI acquired at an advanced age predominately affects people aged 80 and above. The prevalence among this age group ranges from 12% - 32% [1-4]. Given the increasing numbers of older adults and their predicted longevity, there is a great need to investigate what can be done to better support the social participation of DSI older adults. This led us to develop a nurse-supported self-management program, which was developed and tested in long-term care (LTC) situations.

Background

1. Problems associated with dual sensory impairment acquired at advanced age

DSI acquired at an advanced age is associated with serious risks. It has been linked to an augmented risk of depressive feelings [5, 6] and mortality [7-9]. It is also associated with the risk of decreased functional independence [10-12], decreased communication interactions [13], and decreased social participation [14-16]. Among older adults aged 85 and older, an association was found between DSI and cognitive decline [17]. As a consequence, DSI increases the risk of dependency on both informal and professional care.

2. A nurse-supported self-management intervention for DSI older adults

In this thesis, we present a comprehensive study on the development, relevance, feasibility and the effectiveness of a self-management intervention on the social participation of DSI older adults. Given that DSI endangers the social participation of the older adults, the provision of self-management support may help them cope with their changing physical, mental and social challenges, and to function with fulfilment and a feeling of wellbeing, despite their DSI [18].

The effectiveness study has been embedded into a series of studies providing

the underpinning of the intervention and the adequate selection of older adults with DSI in LTC. Because little was known about psychosocial interventions for DSI older adults and to help us select an appropriate intervention, we first conducted a literature search assessing the effectiveness of psychosocial interventions for sensory impaired older adults. To enable the selection of older adults with DSI among LTC residents, we translated the Severe Dual Sensory Loss (SDSL) screening tool, and validated it for the Dutch population. We then developed a nurse-supported Self-Management Program for DSI older adults (SMP-DSI) and an SMP-DSI training program for licensed practical nurses in order to help the nurses support the DSI older adults to improve social participation. We tested this intervention in a cluster randomized controlled trial (cRCT) in LTC facilities.

In order to provide a comprehensive evaluation of the effectiveness and the underlying factors, we performed two qualitative studies in parallel with the cRCT. To gain insights in the relevance and feasibility of the SMP-DSI, we first analyzed the process of nurses' perceptions when implementing the SMP-DSI, and second, to gain greater insights in the factors that hinder the DSI older adults in daily life, we performed a qualitative analysis of the problems identified by the DSI older adults.

In this thesis, we present the results of these different studies.

3. Defining dual sensory impairment

The term *dual sensory impairment* (DSI) refers to the presence of both a hearing and a visual impairment; it is relatively new and has yet to be more precisely defined and conceptualized. Depending on the context, the term is interchangeably used with others like *concurrent hearing and visual impairment* and *deafblindness*.

The term *concurrent hearing and visual impairment* was commonly used in large population-based studies published before 2006 [19, 20]. This neutral description suited the aim of these studies, i.e. to search for prevalence, comorbidities, and the possible impact of the co-occurrence of a hearing and a visual impairment. Consequently, hearing and visual impairments were defined separately using gold standard criteria for each sensory impairment [21, 22], or using self-evaluations of older adults measured by Likert-scales [23]. In 2007, clinical specialists in either hearing impairment or visual impairment attempted to bridge the gap between the two sensory impairments and introduced the new



term *dual sensory impairment* [24, 25].

In contrast to the population-based studies, education and rehabilitation specialists working with individuals with a combined hearing and visual impairment, most commonly use the term *deafblindness*. This term refers to those persons who are deaf and blind, as well as to those who have residual hearing and/or vision. In this way, they aim to emphasize the great impact of the co-occurrence of both sensory impairments on an individual's functioning, although early on, this term was mainly used for children. The term deafblind was first introduced in the 1960s, after a pandemic rubella infection caused multiple birth defects among numerous babies around the world, including cataracts, and other eye problems, mental retardation, deafness, and other problems, leading to dramatic barriers in the development of those children. This congenital rubella syndrome was the trigger for the development of new education programs set up to improve the communication and interrelationship of deafblind children [26, 27]. It then became apparent that deafblindness not only affected childhood development, but also hindered the individual in adult life. The term deafblind was extended to a broader population, including young persons with Usher syndrome who were born hearing impaired but faced a progressive visual impairment, as well as a large group of elderly people experiencing age-related vision and hearing loss [28]. Nowadays, some patient groups and professionals in education and rehabilitation disciplines use the term deafblindness as an umbrella term for congenital as well as for acquired dual sensory impairment [29]. This explains why the Dutch term *ouderdomsdoofblindheid* (= age-related deafblindness) is in vogue among Dutch sensory-specific services targeting DSI older adults.

In this thesis, we have chosen to use the term *dual sensory impairment* and not the term deafblindness, for two reasons. First, although clinical practice suggests that the co-occurrence of both sensory impairments has a major impact on the quality of lives of the older adults, it is still unclear what this impact is and how DSI acquired at an advanced age relates to DSI acquired at a younger age. Second, we observed the unfamiliarity with and even resistance among older adults and LTC professionals against the term deafblind. Older adults explained that, as they still experienced residual hearing and/or visual loss, they did not feel deaf and blind. In formal contacts and publications related to this study, we used the Dutch term *ouderen met een auditief-visuele beperking* (*older adults with a hearing and visual impairment*). In contacts with the older adults and

in the training sessions with the nurses, we used the more informal term *older adults with hearing and visual problems* (*In Dutch: ouderen met problemen in horen en zien*).

4. Epidemiology

The prevalence of DSI between the different age groups is heterogeneous, but it is obvious that it predominately affects the oldest group of older persons. Table 1 presents a selection of prevalence studies published from 2004 onwards. The prevalence among people aged 65 or younger is very low, ranging from 0% to 1% [1, 2]. In contrast, the prevalence among those aged 80 and over ranges between 12% and 32% [1-4], the percentages tend to be higher among care-dependent older adults [3, 4, 30]. Separate figures on the prevalence among those aged 65 - 80 are scarce [2]. The low prevalence of 1% found by Schneck and colleagues among people aged 75 and 76 seems to confirm that DSI increases enormously from the age of 80.

One Australian study examined the incidence of DSI among older adults [1]. They showed that in community dwelling older adults aged 80 and over without DSI, 25% acquired DSI within five years, ending up with 100% dual sensory impairment among centenarians.

5. Usual care

5.1. Usual care offered by sensory-specific services

When DSI older adults seek help for their deteriorating hearing or vision, they first turn to healthcare providers specialized in either hearing or visual impairment for services like medical treatment and technical device provision. Unfortunately, the extent to which these services can address DSI, which includes advanced age-related hearing problems like presbycusis, and age-related visual problems like macular degeneration, is often limited.

Dutch visual rehabilitation centers offer services to DSI adults aiming to strengthen 'the other sense' by teaching them how to increase the use of hearing devices and communicative abilities. Two studies were performed to evaluate parts of these services. Vreeken [32] showed that a screening and training protocol for DSI older adults had a modest beneficial effect on handling hearing aids. Schneider [33] showed that a screening protocol facilitated access to appropriate technologies and rehabilitation, which may improve hearing aid retention and benefit.



Table 1. Prevalence of dual sensory impairment among populations aged 55 year and over

Reference	Country	Period data collection	Data sources	Population data collection	Population size	Criteria HL/VA	Age group	Prevalence of DSI per age group
Brennan 2005	USA	1984	Longitudinal Study on Aging	GP	5151	SR/sr	>70	21%
Chou 2004	China	1996	National Household Review	GP	2003	SR/sr	>60	6.5%
Haanes 2014	Norway	2011	Home care agencies	Clients home care	93	>25dB/ v.a. 20/40dpt	>80	28%
Jee 2005	Australia	2003	Geriatric Assessment Center	Residential care	188	>25dB/ v.a. 20/40dpt	>65	22.5%
Schneck 2012	USA	1998-2000	Longitudinal Study on Vision and Function	GP	464	40dB/ v.a. 20/70dpt	<65 75-76 >85	0% 1% 12%
Schneider 2012	Australia	1997-1999	Blue Mountain Hearing Study	GP	2015	>25dB/ v.a. 20/40dpt	<60 >80	0% 28%
Vaal 2007	Netherlands	1997-2005	Different epidemiologic studies	GP	> 20000	SR/sr	>55	0.5%-16.7%
Yamada 2014	7 EU countries & Israel	2009-2011	Nursing homes	Nursing home	4156	RAI	Average 83.4	32%

GP = general public data; HL = hearing loss; VA = visual acuity; dB = decibel; dpt = diopter; SR = self-report hearing loss; sr = self-report visual loss; RAI = Resident Assessment Instrument [31]

In some West-European countries, for example in the Netherlands, UK and Scandinavian countries, community living older adults with DSI have access to services designed for deafblind adults who acquired DSI at an earlier stage in life. These services offer ongoing support from social workers and interpreters and address communication, information access, and mobility problems in daily life. Until now, we were unable to find any studies that report on the effectiveness of these services.

5.2. Usual care offered by mainstream aged care

Apart from the sensory-specific-services mentioned above, the majority of older adults with DSI receive standard care services for the aged. However, both in mainstream LTC as well as in expertise centers for long-term care for older adults, DSI is not viewed as a special issue that needs attention. Although LTC environments are known to aggravate several adverse conditions for sensory impaired older adults [34, 35], and cognitive abilities of DSI older adults may be underestimated if sensory problems are not considered [36], the incidence of DSI is often overlooked and is poorly documented [37, 38]. A contributing factor for this ignorance might be that sensory impairments are mainly considered as medical conditions of the individual person that ought to be solved by medical or rehabilitation specialists. An example of this is the fact that enabling local hearing care professionals and local opticians to meet residents every month at the LTC facility for technical aid checks and delivery, is considered 'best practice' [39]. In general, it can be said that there is little or no focus on psychosocial or behavioral measures to support DSI older clients in LTC.

6. A dynamic concept of health

The study is built upon a dynamic view on health and human capacities. Nowadays, the idea that people with a chronic illness can feel healthy despite their problems and limitations is widely shared, and has been confirmed by research [40, 41]. The shared awareness that impairment and perceived health are indirectly related led to changes in defining the concept of health. In 2010, the Health Council of the Netherlands redefined health as a dynamic and functional concept, referring to the person's capacity to maintain and restore integrity, equilibrium, and sense of wellbeing, and accentuating the *ability to adapt and to self-manage* [42]. Subsequently, Huber described social health as 'a dynamic balance between



opportunities and limitations, shifting through life and affected by external conditions such as social challenges, aiming to function with fulfilment and a feeling of wellbeing despite limitations, including aspects of ability to adapt and to self-manage' [18]. The theoretical background in this thesis is in line with the concepts proposed by Huber and the Health Council of the Netherlands.

7. Social participation

In anticipation of the development of a psychosocial intervention for DSI older adults, a focus group of DSI older adults and professionals from the Kalorama Center for the Deafblind, advised that social participation be assigned as a primary outcome of a psychosocial intervention aiming to enhance the social health of DSI older adults. They adopted the definition by Broese van Groenou [43]: social participation are those activities undertaken in and outside the home that allow individuals to meet others, contribute to society, and stay involved in society. The advantage of this definition is that it emphasizes practical activities enabling a person to survive physically, as well as activities enabling a social role in a persons' living environment [44]. And that is exactly what is endangered by DSI: being able to live an autonomous life in contact and in alignment with others.

Aim of this thesis

The aim of this thesis was to develop and to investigate the relevance, feasibility and effectiveness of a self-management program for DSI older adults in LTC on social participation.

Research questions

In this thesis, we address three main research questions. To ensure clarity and structure, research question 1 is divided into three sub-questions, and research question 2 has two sub-questions:

1. How should a self-management intervention aiming to support the social participation of DSI older adults, look like?
 - 1a. What is known about the effectiveness of psychosocial interventions in improving emotional and functional status, self-efficacy and social participation in hearing or visual impaired older adults?
 - 1b. How can DSI older adults be identified in an LTC population? Is the Severe Dual Sensory Loss (SDSL) screening tool a valid tool to help nurses and care assistants identify hearing, visual and dual sensory impairment in older adults?
 - 1c. Based on results of the systematic review conducted to answer question 1a, which components are relevant for inclusion in a Self-Management Program for Dual Sensory Impaired older adults (SMP-DSI) and what should the SMP-DSI program look like? What should the related SMP-DSI training program of nurses look like?
2. What is the relevance and the feasibility of the SMP-DSI?
 - 2a. Which insights can be gained from nurses' perceptions when implementing the SMP-DSI, and from the factors that contributed to changes in their perceptions?
 - 2b. Which problems did the DSI older adults identify to be addressed with the SMP-DSI?
3. Is the nurse-supported SMP-DSI effective in improving social participation of dual sensory impaired older adults in LTC?



Outline of the thesis

In **Chapter 2**, we answer research question 1a. We present the results of a systematic review and meta-analysis set up to detect the effectiveness of psychosocial interventions intended to improve emotional and functional status, self-efficacy, and social participation of older adults with an age-related hearing, visual or dual sensory impairment. We describe which psychosocial interventions are available, what is known about their effectiveness, and which characteristics distinguish effective psychosocial interventions from ineffective ones.

In **Chapter 3**, we answer research question 1c. We present the results of our validity study on the SDSL screening tool. We discuss the psychometric properties of this screening tool that aims to help nurses to detect DSI through observations of the behavior of the older adults. In addition, we discuss the prevalence of DSI in the study population.

In **Chapter 4**, we answer research question 1b and the overall research question 1 by presenting the study protocol of the cluster randomized controlled trial investigating the effectiveness of the SMP-DSI among DSI older adults in LTC.

In **Chapter 5**, we answer research question 2a. We present the findings on the relevance and feasibility of the SMP-DSI as perceived by the nurses and describe the longitudinal process of nurses' perceptions when implementing the SMP-DSI, and the factors that contributed to changes in their perceptions.

In **Chapter 6**, we answer research question 2b. We present the findings of our qualitative content analysis of the problems identified by the DSI older adults to be addressed with the SMP-DSI. We describe the factors that hinder the DSI older adults in daily life, and discuss the environmental support that aligns with their needs.

In **Chapter 7**, we answer research question 3. We present the results of our effectiveness study on the SMP-DSI in improving social participation of DSI older adults in LTC.

In **Chapter 8**, we discuss the main findings of the studies reported in this thesis. We reflect on the results of these studies, and place them in a broader scientific, methodological, and societal context. To conclude, we discuss the implications and give recommendations for future policy, education and research.

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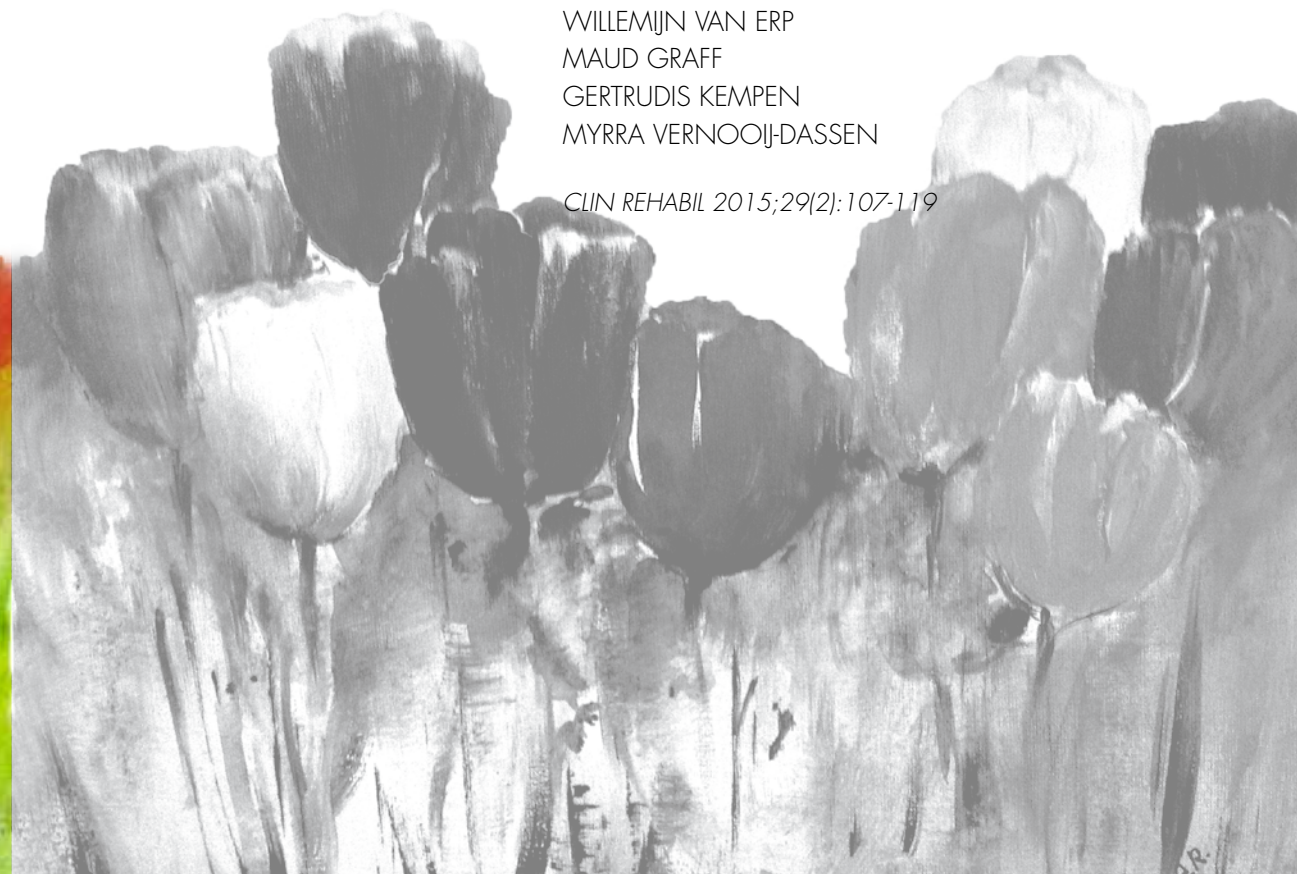


CHAPTER 2

EFFECTIVENESS OF REHABILITATION
INTERVENTIONS IN IMPROVING
EMOTIONAL AND FUNCTIONAL STATUS IN
HEARING OR VISUALLY IMPAIRED OLDER
ADULTS: A SYSTEMATIC REVIEW WITH
META-ANALYSES

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CLIN REHABIL 2015;29(2):107-119



Abstract

Objective: To assess the effectiveness of non-equipment based rehabilitation interventions for older adults with an age-related hearing or visual impairment.

Data sources: We searched PubMed, EMBASE, PsychInfo, CINAHL, and the Cochrane Central Register of Controlled Trials.

Review methods: Two authors independently assessed trial eligibility, extracted data and assessed methodological quality. Controlled studies with more than 80% of participants aged ≥ 55 years and with rehabilitation interventions either separately or in combination with technical device provision were included. Meta-analyses were undertaken for the primary outcomes: emotional status, functional status, self-efficacy and social participation. All studies were categorized into 3 subgroups of intervention approaches (cognitive restructuring, education, and problem solving), and subgroup analysis was performed.

Results: Fourteen studies were identified: six on hearing impairment and eight on visual impairment, involving 1622 sensory impaired participants (mean age 70). Methodological quality of the studies was modest. Eight studies offered data for meta-analysis. No significant effects in favor of interventions on either emotional or functional status, self-efficacy, or social participation were found. In the subgroup analysis, only the problem solving approach showed a positive effect on emotional status.

Conclusions: This review found no effects of non-equipment based rehabilitation interventions on emotional and functional status, self-efficacy, and social participation. However, subgroup analysis showed problem solving as a potential effective approach for positively affecting emotional status.

Introduction

Hearing and vision impairments are common chronic conditions among older people, and their prevalence is increasing as the population ages. The percentages of hearing, visual and dual sensory impairment in the group aged 70-79 were 51%, 9% and 5%, and in the group aged 80 and older, 78%, 31% and 25% respectively [1]. Sensory impairment in older adults is associated with a decrease in daily life activity and social participation [2], loss of quality of life [3, 4], and depressive feelings [5-7]. It also has a negative impact on autonomy through an increased reliance on community or family [8, 9]. Older adults who suffer from a dual sensory impairment experience significant difficulties in functioning due to restrictions in communication, information and mobility [10, 11].

The usual care regimes for older adults with a hearing or visual impairment focus on medical treatment, technical aids and rehabilitation interventions. In general, these rehabilitation interventions aim at providing individuals with the tools needed to cope with their condition, and to maintain their daily life activities and social participation [12, 13]. There are many interventions for the hearing impaired, ranging from speech training, communication strategies to social counselling [14]. For the visually impaired these vary from mobility training, independent living support, to rehabilitation counselling [15]. Usually these are offered by multidisciplinary teams of audiological or low vision rehabilitation services, immediately after or combined with technical device provision [16, 17]. Systematic reviews on the effectiveness of non-equipment based rehabilitation interventions for sensory impaired older adults are scarce and none of the reviews found included meta-analyses [18-21].

The aim of this review is to assess the effectiveness of non-equipment based rehabilitation interventions for older adults with an age-related hearing or visual impairment on their emotional and functional status, self-efficacy and social participation.

Methods

Randomized controlled trials and controlled trials examining the effectiveness of interventions for hearing and/or visually impaired older adults were included.

Inclusion criteria were: (1) more than 80% of the participants aged 55 or over,



(2) participants with an objectively measured hearing and/or a visual impairment, (3) interventions related to rehabilitation, health education, problem solving, disability management, chronic care, independent living, activities of daily living, orientation and mobility, communication, and counselling, and (4) outcome domains related to emotional status, functional status, self-efficacy or social participation.

Exclusion criteria were: (1) studies with a sample size smaller than 30 participants, (2) studies targeting pre-lingual deaf persons, (3) studies focusing on pharmacological interventions, and (4) studies exclusively focusing on technical devices and equipment.

We searched PubMed (including Medline), EMBASE, PsychInfo, CINAHL databases and the Cochrane Central Register of Controlled Trials, without any limits, up to 5 May 2014. The databases were searched using a combination of keywords, medical subject headings (MeSH), and free text synonyms for hearing impairment, visual impairment, aged, psychosocial intervention, rehabilitation and controlled trial (Appendix 1 of Chapter 2). We also searched the references from the retrieved studies.

Two review authors (LR, SZ) independently assessed the retrieved titles and abstracts. They obtained the full copy of all relevant or potentially relevant studies and assessed whether the studies met the inclusion and exclusion criteria for this review. Multiple reports of a single study, and follow-up studies of the same sample were identified. Both authors were not masked to any trial details when making their assessments. Disagreements about whether a trial should be included were resolved by discussion and consensus. The review authors attempted to contact the authors of the studies through an open-ended request to obtain missing information or for clarification whenever necessary. Data from studies in languages not known to the review authors (other languages than English, German, French, Dutch) were extracted with help from appropriate translators, wherever possible.

All eligible trials were analyzed on study characteristics including participation selection, intervention and outcome measures. Three review authors (LR, ID, MVD) clustered the outcome measurements into categories. Two authors (LR, WvE) independently assessed the trials for bias according to the Cochrane methods [22]. Each source of potential bias was assessed with respect to the following quality elements: randomization, sequence generation, baseline comparability (selection

bias); blinding of participants or providers, or both (performance bias); blinding of outcome assessors (detection bias); reporting of attrition rate (attrition bias).

We used Review Manager 5.2 to conduct a meta-analysis of the data following the Cochrane methods. Only studies providing summary statistics (n , mean scores and standard deviations), or with data that could be converted into these summary statistics, were used for meta-analysis. If mean scores were provided and standard deviations were not and could not be obtained from the authors of the study, standard deviations were pooled from identical outcomes of the other included trials, or were imputed from other publications, as suggested by Higgins and colleagues [23].

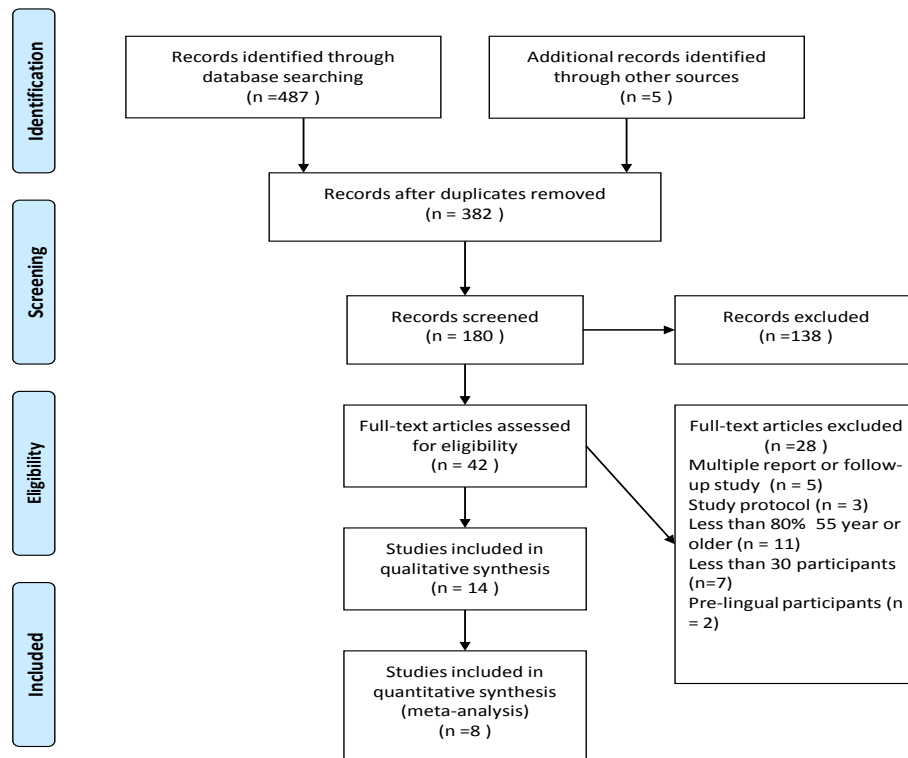
Since there is a great variety of non-equipment based rehabilitation interventions, heterogeneity might affect the study effects. We performed tests for heterogeneity using a standard χ^2 statistic and an I^2 statistic, and studies were considered heterogeneous if $P \leq 0.05$. In general, this meant an $I^2 > 50\%$. If heterogeneity was high, a random effect model was used in which case the confidence intervals are wider than those of a fixed effect model.

Results

A total of 14 studies met the inclusion criteria (Figure 1). Six studies were on interventions for hearing impaired persons [24-29], and eight were on interventions for visually impaired persons [30-37]. No interventions were found for older adults with a dual sensory impairment. Table 1 presents an overview of the study characteristics. The number of participants in the trials varied from 30 to 231, with a total of 1622. Mean age ranged from 69 to 83. All studies set a criterion level for hearing or visual impairment, the minimum 30 dB, maximum levels for visual acuity varied from 0.40 to 0.10 diopter. The main cause of hearing impairment was presbycusis, and the main cause of visual impairment was age-related macular degeneration. Table 1 also shows that most studies recruited patients from medical or rehabilitation centers. The exclusion criteria most frequently mentioned were cognitive or neurological problems [24-26, 28, 30, 31, 33, 35-37] and dual sensory impairment: two of the six hearing studies excluded for visual disorders [24, 26], and five of the eight visual studies excluded for communication problems or hearing impairment [30, 32-35]. Most control groups of the included studies solely received technical device provision.



Figure 1. Flow diagram of search for relevant controlled trials



training with psycho-education [24, 26-29], except one study which added counselling [25]. Of the visual studies, one study applied cognitive restructuring [34], four studies applied an educational approach such as functional training [27, 32] or a combination of functional training, psycho-education and counselling [31, 35], and three studies applied a problem solving approach [30, 33, 37].



We identified three types of intervention approaches applied among the 14 studies: cognitive restructuring, education and problem-solving interventions. The cognitive restructuring intervention was restricted to an informational presentation on emotional and functional adjustments, aiming to instill adaptive beliefs. Among the educational approach, we identified three main methods: (1) functional training, for example communication training for hearing impaired persons or occupational training for visually impaired persons, (2) psycho-education, including education about the nature of the sensory impairment, strategy development, assertiveness, stress management, and personal adjustment, and (3) counselling, focusing on emotional support and/or on facilitating grief or bereavement in relation to the sensory impairment. Finally, the problem solving approach showed an emphasis on participants' empowerment and ownership for problem identification, resource seeking, planning, action and evaluation.

All hearing studies applied an educational approach, and combined functional

Table 1. Characteristics of the included trials

Reference	Methods	Participants	Intervention	Intervention Characteristics	Post test and Follow-up	Outcomes and categories
Studies involving hearing impaired participants						
Abrams et al. (1992)	Controlled trial	Country: USA; Number 31 Age range 55-82 Gender M100% Drop out 2 SI hearing, diagnose > 30dB Recruitment: Med.Cen.	E1: HA + counselling + AR program E2: HA + counselling	E1: counselling, information and skills 1-.30hrs x 3wks group treatment Professional: no info Setting: no information	Post test	Self-perception of hearing-handicap (HHIE)
Abrams et al. (2002)	RCT	Country: USA; Number 105 Age E1 73.0 sd 7.6, E2 74.5 sd 6.9 Gender F 38% Drop out: no information SI hearing, diagnose > 30dB Recruitment: Med.Cen.	E1: HA +AR C1: HA	E1: information and communication strategies; 2hrs x 4wks group treatment Professional: no information Setting: no information	Post test	Quality of life (SF-36)
Beynon et al. (1997)	RCT	Country: UK Number 47 Age E1 68.7 range 47-80 Gender E1 F13 M8, E2 F14,M12 Drop out 6 SI hearing, diagnose mild to moderate hearing loss Recruitment: audiological department of hospital, first time HA-users	E1: HA+AR E2: HA	E1: communication course: explanation, instruction, relaxation; 4wks group treatment, 5-7 people Professional: hearing therapist; Setting: no information	Post test	Reduction of hearing handicap (QDS)
Chisolm et al. (2004)	RCT	Country: USA Number: 106 Age E1 74.5,sd 5.0, C1 72.3, sd 6.6 Gender F 38%;Drop out 10 SI hearing, diagnose >30dB Recruitment: audiological center, first time HA-users	E1: HA and AR program, C1: HA	E1: communication strategies /environment; 4 x 2hrs weekly group sessions professional: no information; setting: audiological center	Post test; 6 months; 1 year	Communication (CPHI)

(Continued)

Table 1. (Continued)

Reference	Methods	Participants	Intervention	Intervention Characteristics	Post test and Follow-up	Outcomes and categories
Hickson et al. (2007)	RCT	Country: Australia Number 178; Age 73.87 range 53-94, sd 8.29 Gender: F 58% Drop out: no information SI hearing, diagnose: >25 dB Recruitment: older adult organizations and community, with and without HA	E1: ACE program, E2: social program	E1: communication strategies, problem solving; 5 x 2hrs weekly interactive group sessions; Professional: no information; Setting: community location	Post test; 6 months	Quality of life (SF-36) Psychological well-being (Ryff) Communication (QDS) Communication (SAC) Participation (HHQ)
Kramer et al. (2005)	RCT	Country: Netherlands Number: 48 Age E1 69,sd 7.7; C1 71,sd 8.5 Gender: F 66% Drop out 10 SI hearing, mean >53dB Recruitment: audiological center, first time HA-users	E1: HA + self administered home education program; C1: HA	E1: communication strategies in everyday life situations; 5 video training sessions of Professional: not involved Setting: at home	Post test; 6 months	Disability (HDI-a) Communication (SAC-a)
Studies involving visually impaired participants						
Brody et al. (2002)	RCT	Country: USA Setting: community dwelling Number: 231 Age 80.89, sd 6.12 Gender F 67% Drop out:21 SI vision, diagnose AMD, VA <20/60,20/100 Recruitment: ophthalmologists, media, older adult centers, health fairs	E1: self-management program, C1/C2: audio taped health lectures/ waiting list	E1: 6 X 2hrs group sessions of self-management program, 8 to 10 participants/group; Professional: public health and behavioural medicine specialist; Setting: eye center	Post test	Mood (POMS) Everyday functioning (NEI-VFQ) Self-efficacy (AMD-SEQ) Outlook on life (LOT-R)

(Continued)



Table 1. (Continued)

Reference	Methods	Participants	Intervention	Intervention Characteristics	Post test and Follow-up	Outcomes and categories
Dahlin et al. (2002)	RCT	Country: Sweden Setting: no information Number 187 Median age 79 Gender no information Drop out: 66 SI vision, diagnose AMD, distance VA >0.1diopter Recruitment: low vision clinic	E1: health education program focused on daily occupations, C1: individual program as usual	E1: 8 weekly group sessions of 2hrs each; Professional: occupational therapists Setting: low vision clinics	Post test	Perceived security (QPS)
de Boer et al. (2006)	Controlled trial	Country: the Netherlands Setting: visual rehabilitation centers Number 215 Mean age 78 Gender E1 F 64% E2 F 65% Drop out: 81 (27.4%) SI vision, diagnose: low vision referral Recruitment: visual rehabilitation center	E1: conventional multidisciplinary low-vision approach C1: conventional optometric low-vision approach	E1: advice and instruction low vision devices + adl-training + counselling; frequency of contact depending on needs of participants; Professionals: optometric specialist, occupational specialist, social worker or psychologist Setting: visual rehabilitation center	Post test	Low Vision related quality of Life (VMC1; LVQOL)
Girdler et al. (2010)	RCT	Country: Australia Setting: community dwelling Number 77 Median age 79, age range 65-97 Gender E1 F 72%, C1 F 58% Drop out 10 SI vision, diagnose ARVL Recruitment: vision rehabilitation service	E1: usual care + self-management group intervention, C1: usual care	E1: learning + practice activities + homework assignments; 8 X 3hrs group sessions; 6 to 10 participants/group; Professional: occupational therapist or social worker; Setting: visual rehabilitation center	Post test; 3 months	Mood (GDS) Quality of Life (SF-36) Adaptation to visual loss (AVLS) Self-efficacy (GSES; AMD-SEQ) Participation (ACS)

(Continued)

Table 1. Continued)

Reference	Methods	Participants	Intervention	Intervention Characteristics	Post test and Follow-up	Outcomes and categories
Goldstein et al. (2007)	RCT	Country: USA Setting: community Number: 154 Age median 77.5, age range 39-92 Gender F64% Drop out: no information SI vision, diagnose low vision Recruitment: eye research institute	E1: patient education video, C1: no intervention	E1: image-enhanced educational and motivational video Professionals: not involved; Setting: home environment	Post-test; 3 months	Knowledge, self-efficacy and attitudes (Goldstein-questionnaire)
McCabe et al. (2000)	RCT	Country: USA Setting: community dwelling Number 97 Median age 76, age range 19-91 Gender E1 F 41%, C1: F 48% Drop out 12 SI vision, diagnose VA <20/100 Recruitment: vision rehabilitation service	E1: VR program with SO, C1: VR without SO	E1: visual rehabilitation program (optometry/occupational/social work services); Professionals: optometrist, occupational specialist, social worker Setting: vision rehabilitation service	Post-test	Functional ability (FAQ)
Pankow et al. (2004)	Controlled trial	Country: USA Setting: home-dwelling Number: 30 Age 65-90 Gender: no information Drop out: no information SI vision, diagnose VA <20/50 Recruitment: rehabilitation services	E1: individual goal setting and treatment, C1: waiting list	E1: according individual goals: reading, orientation & mobility, daily occupations; Professional disciplines according goals: mobility-trainer, occupational therapist, rehabilitation specialist	Post-test	Functional independence (FIMBA) Psychological reaction to vision loss (NASZ)

(Continued)



Table 1. (Continued)

Reference	Methods	Participants	Intervention	Intervention Characteristics	Post test and Follow-up	Outcomes and categories
Rovner et al. (2013)	RCT	Country: USA Setting: home-dwelling Number: 214 Mean age 82.7 Gender: E1 F 82%, C1 F 71% Drop out: 23 SI vision, diagnose AMD, VA between 20/70 and 20/400 Recruitment: retina practices	E1: problem solving therapy, C1: supportive therapy	E1: individual problem solving skill training for vision-dependent tasks (problem clarifying, goal setting, generating alternatives, choosing, implementing and evaluating); C1: individual empathetic support sessions; Duration E1 and C1: no information; Professional discipline: social scientists trained by clinical psychologist	Post test; 6 months	Targeted vision function (TVF) Everyday functioning (NEI-VFQ)

ACS = Activity Card Sort; AMD = age-related macular degeneration; AMD-SEQ = Age-related Macular Degeneration-Self-Efficacy Questionnaire; AR = audiological rehabilitation; ARVL = age-related visual loss; AVLS = Adaptation to Visual Loss; CPHI = Communication Profile for the Hearing Impaired; dB = decibel; FAQ = Functional Assessment Questionnaire; FIMBA = Functional Independence Measure for Blind Adults; FVPT = Functional Vision Performance Test; GDS = Geriatric Depression Scale; GSES = Generalized Self-Efficacy Scale; GQ = Goldstein Questionnaire geared to video-approach; HA = hearing aid; HHDA = Hearing Handicap Disability Inventory-adaptation; HHIE = Hearing Handicap Inventory for the Elderly; HHQ = Hearing Handicap Questionnaire; LVQOL = Low Vision Quality of Life Questionnaire; Med. Cen. = medical center; NASZ = Nottingham Adjustment Scale 2; NEI-VFQ = National Eye Institute Visual Function Questionnaire; POMS = Profile of Mood States; QDS = Quantified Denver Scale of Communicative Function; QPS = Questionnaire Perceived Security; Ryff = Ryff Psychological Well-Being Scale; SAC = Self-Assessment of Communication; SF-36 = Short-Form36 health-related quality of life measure; SI = sensory impairment; SO = significant other; VA = visual acuity; VMC1 = Vision Quality of Life Core Measure; VR = visual rehabilitation



The interventions under study aimed at 23 different self-report outcome measures and one observer-rated outcome measure. We clustered the outcome measurements into four categories: emotional status, functional status, self-efficacy and participation, as presented in Appendix 2 of Chapter 2. Six studies measured the primary outcome with a generic instrument aiming at e.g. quality of life or mood; the other eight studies used an impairment specific instrument.

The methodological quality of the studies was generally modest (Table 2). The primary risks of bias were incompleteness of reports on allocation concealment

Table 2. Methodological quality

Study	Selection bias		Performance bias	Detection bias	Attrition bias
	Random sequence generation	Allocation concealment	Blinding participants and providers	Blinding outcome assessors	Reporting drop out
Abrams 1992	C	C	B	B	B
Abrams 2002	A	B	B	B	B
Beynon 1997	C	C	B	B	C
Brody 2002	A	A	B	B	A
Chisolm 2004	A	B	A	B	A
Dahlin 2002	A	B	B	B	C
De Boer 2006	C	C	C	B	A
Girdler 2009	A	B	C	B	A
Goldstein 2007	A	B	C	B	A
Hickson 2007	A	B	A	A	B
Kramer 2005	A	B	A	B	C
Mc Cabe 2000	C	B	C	C	A
Pankow 2004	C	C	C	C	B
Rovner 2013	A	A	C	A	A

A= adequate; B=unclear; C=inadequate

and on blinding of the outcome assessors. The high risk of performance bias is common in studies including non-equipment based rehabilitation interventions, as it is difficult or impossible to blind the intervention providers.

Seven studies measured emotional status. Of these, the data from six studies were suitable for meta-analysis. The combined results from these six trials [24, 28-30, 33, 36] showed no overall significant benefit of interventions on emotional status (SMD - 0.12; 95% CI - 0.34 to 0.10) (Figure 2).

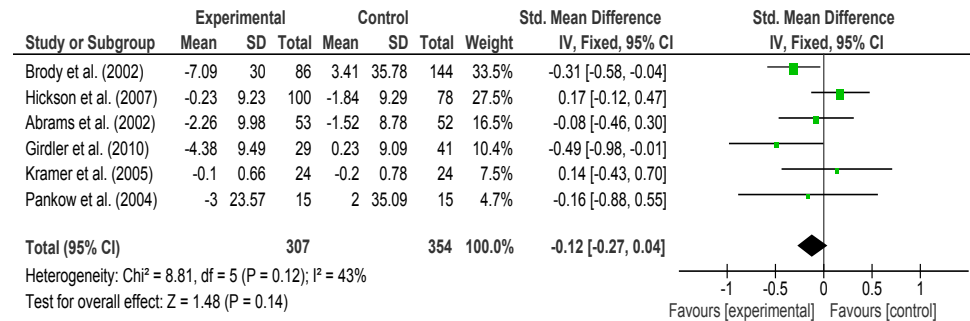


Figure 2. Forest plot of comparison: emotional status

Six studies measured functional status and all six were suitable for meta-analysis. The combined results from the included trials [26, 28-30, 36, 37] showed no significant benefit from the intervention on functional status (SMD - 0.09; 95% CI - 0.23 to 0.05) (Figure 3).

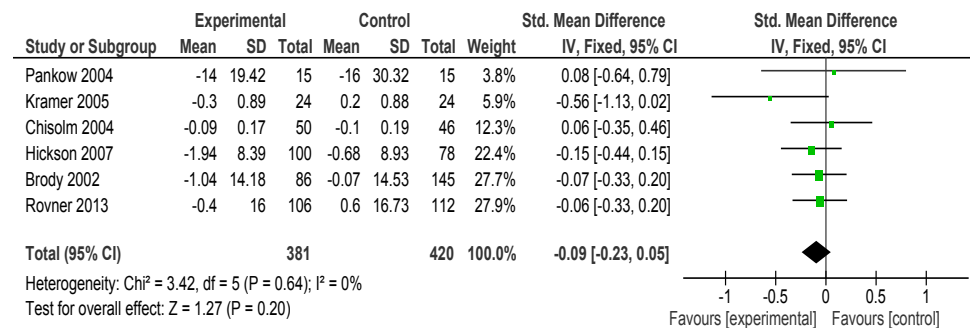


Figure 3. Forest plot of comparison: functional status

Four studies measured self-efficacy, of which two were suitable for meta-analysis. The combined results from the included trials [30, 33] showed no significant benefit from the intervention on self-efficacy (SMD - 12.15; 95% CI - 28.06 to 3.76) (Figure 4).

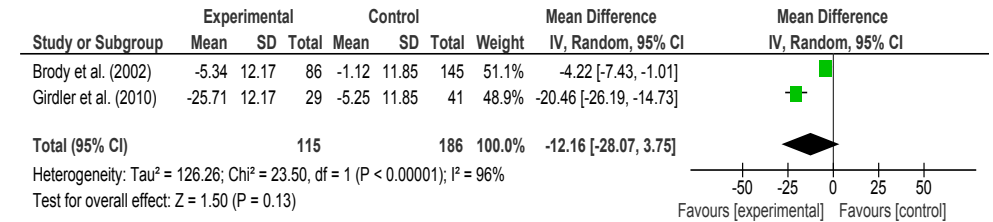


Figure 4. Forest plot of comparison: self-efficacy

Three studies measured social participation as outcome, of which two reported results suitable for meta-analysis. The combined results from the included trials [28,33] showed no significant benefit from the interventions on social participation (SMD - 4.17; 95% CI - 12.07 to 3.72) (Figure 5).

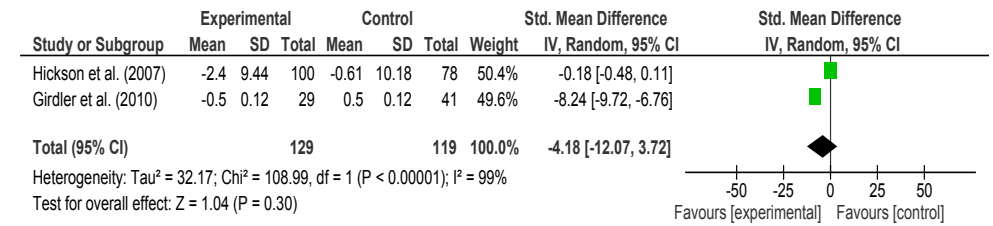


Figure 5. Forest plot of comparison: social participation

Comparison of the three different types of intervention approaches showed an advantage on emotional status for those studies using a problem solving approach. Brody and colleagues [30] showed a significant positive effect (MD - 10.50; 95% CI - 19.12 to - 1.88) and Girdler and colleagues [33] showed a significant positive effect (MD - 4.61; 95% CI - 9.17 to - 0.05), both on emotional status. Rovner and colleagues found a significant effect on emotional status when subscales of the multidimensional scale were combined (F(4,192)=2.46; P=0.05) [37]. No significant effects were found in individual studies using an educational or cognitive restructuring approach.



Discussion

The meta-analyses on the effectiveness of the included interventions for the sensory impaired older adults showed no effects on emotional or functional status, self-efficacy, or social participation. This is a critical result in view of their needs for high quality professional support [38]. However, analysis by intervention approach showed that the studies using a problem solving program had modest beneficial effect on the emotional status of the participants.

Focusing on the main differences between the problem solving and the educational approach might help to explain our findings. We found differences (1) between the procedures to identify participant's problems, (2) between the procedures for searching and utilizing resources, and (3) in the emphasis on participant's autonomy [39, 40]. In problem solving approaches, older adults define their problems themselves; in contrast, in educational approaches, providers/experts start from problems generally associated with sensory impairment. Furthermore, in problem solving, older adults search for resources and solutions that fit them and their personal circumstances; in education, providers offer their solutions. Finally, in problem solving, the older adults control their own behaviour throughout the whole process; in education, they have to adjust their behaviour to the expectations of the provider. These differences can be expected to result in essentially different effects. Cimarolli and colleagues showed that (unidirectional) educational interventions could threaten the individual adaptation process and mastery of the environment [41]. They recommend adapting the interventions to the actual needs of the older adults [42], as in problem solving approaches. Our findings support this recommendation.

Another explanation for the lack of beneficial effects of the educational approaches may be found in a possible adverse effect of functional training. Interventions such as mobility training and communication strategy training can confront the older adults with the risks and hurdles of learning complicated new skills and strategies. Familiar activities such as crossing the road or participating in a group conversation can suddenly feel difficult and threatening, requiring increased attention and assertiveness. All this may trigger resistance or fear. De Boer and colleagues [31] found a decline in outcomes on emotional status in the intervention group participating in mobility training in comparison with the control group without the training. This is consistent with Boerner and colleagues,

who reported that mobility training could encourage the older person to move away from emotional coping. Our results add to these findings [43].

There are several limitations to this review. No studies were found on problem solving interventions for hearing impaired and dual sensory older adults, therefore we are not able to generalize our findings to these two target groups. The number of available RCTs and controlled trials was small, and the methodological quality of the included studies modest. Moreover, despite our intensive efforts, we were not able to obtain additional data from two of the authors, so we had to impute data from comparable studies to perform the meta-analysis. The included studies are heterogeneous with respect to type of impairment, the intervention and the outcome measures used. Yet, as we aimed to assess the effectiveness of rehabilitation interventions in general and not of one specific intervention type, it was possible to combine heterogeneous interventions into meta-analysis [44]. Two meta-analyses, one on the outcome self-efficacy, and one on participation compared two studies only. We are aware of the possible risks, but decided to combine this minimum of two studies in a meta-analysis following suggestions made by Borenstein and colleagues [44]. They suggest that a statistical summary with known, but perhaps poor, properties may be superior to an *ad hoc* summary with unknown properties. Being one of the first reviews and meta-analyses in this area of research, our review has proved useful in discovering commonalities among the interventions, their goals and theoretical backgrounds.

This review found no overall effects of non-equipment based rehabilitation interventions for sensory impaired older adults on their emotional and functional status, self-efficacy and social participation. However, the problem solving approach appears to be effective in alleviating the emotional burden. This suggests that the intervention approach should be chosen cautiously when older adults are involved. Further research is needed in order to identify effective approaches in interventions for older adults with sensory impairments.

Clinical messages

There is no evidence that non-equipment based rehabilitation interventions improve quality of life or daily functioning of sensory impaired older adults. Problem solving approaches seem to be favored above cognitive restructuring and educational interventions, including those using functional training.



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Chapter 2 - Appendix 1

Search Combination PubMed 5 May 2014

((“Aged”[Mesh] OR “Frail Elderly”[Mesh] OR “Aged, 80 and over”[Mesh] OR “Middle Aged”[Mesh]) OR “older people”[Text Word] OR “elderly”[All Fields] OR “seniors”[All Fields]) AND ((“Visually Impaired Persons”[Mesh] OR (visually[All Fields] AND impaired[All Fields]) OR (“vision, low”[MeSH Terms] OR (“vision”[All Fields] AND “low”[All Fields]) OR “low vision”[All Fields] OR (“visual”[All Fields] AND “loss”[All Fields]) OR “visual loss”[All Fields]) OR (“visual”[All Fields] AND “impairment”[All Fields]) OR “visual impairment”[All Fields]) OR (visual[All Fields] AND impairments[All Fields]) OR (“visually impaired persons”[MeSH Terms] OR (“visually”[All Fields] AND “impaired”[All Fields] AND “persons”[All Fields]) OR “visually impaired persons”[All Fields] OR (“blind”[All Fields] AND “person”[All Fields]) OR “blind person”[All Fields])) OR (“Hearing Loss”[Mesh] OR (“hearing loss”[MeSH Terms] OR (“hearing”[All Fields] AND “loss”[All Fields]) OR “hearing loss”[All Fields] OR (“hearing”[All Fields] AND “impairment”[All Fields]) OR “hearing impairment”[All Fields]) OR (“hearing impaired persons”[MeSH Terms] OR (“hearing”[All Fields] AND “impaired”[All Fields] AND “persons”[All Fields]) OR “hearing impaired persons”[All Fields]) OR ((“hearing loss”[MeSH Terms] OR (“hearing”[All Fields] AND “loss”[All Fields]) OR “hearing loss”[All Fields] OR (“hearing”[All Fields] AND “impairment”[All Fields]) OR “hearing impaired”[All Fields]) OR hearing impaired/deaf[All Fields] OR hearing impaired/developmentally[All Fields] OR hearing impairment[All Fields] OR (“hearing loss”[MeSH Terms] OR (“hearing”[All Fields] AND “loss”[All Fields]) OR “hearing loss”[All Fields] OR (“hearing”[All Fields] AND “impairment”[All Fields]) OR “hearing impairment”[All Fields]) OR hearing impairment/deafness[All Fields] OR hearing impairment/dementia[All Fields] OR hearing impairment/disability[All Fields] OR hearing impairment/handicap[All Fields] OR hearing impairments[All Fields]) OR (“deafness”[MeSH Terms] OR “deafness”[All Fields]) OR (“hearing impaired persons”[MeSH Terms] OR (“hearing”[All Fields] AND “impaired”[All Fields] AND “persons”[All Fields]) OR “hearing impaired persons”[All Fields] OR “deaf”[All Fields]) OR (“hearing loss”[MeSH Terms] OR (“hearing”[All Fields] AND “loss”[All Fields]) OR “hearing loss”[All Fields] OR (“hard”[All Fields] AND “hearing”[All Fields]) OR “hard of hearing”[All Fields]) OR (“hearing disorders”[MeSH Terms] OR (“hearing”[All Fields] AND “disorders”[All Fields]) OR “hearing disorders”[All Fields]) OR (“presbycusis”[MeSH Terms] OR “presbycusis”[All Fields])) OR (“Deaf-Blind Disorders”[Mesh] OR deafblind[All Fields] OR (dual[All Fields] AND sensory[All Fields] AND loss[All Fields]) OR (dual[All Fields] AND sensory[All Fields] AND impairment[All Fields]) OR (dual[All Fields] AND sensory[All Fields] AND impairments[All Fields]) OR (dual[All Fields] AND sensory[All Fields] AND impaired[All Fields])) AND (“Self Care”[Mesh] OR “Rehabilitation”[Mesh] OR “Rehabilitation of Speech and Language Disorders”[Mesh] OR “Rehabilitation of Hearing Impaired”[Mesh] OR “Rehabilitation, Vocational”[Mesh] OR “Activities of Daily Living”[Mesh] OR “psychosocial interventions”[All Fields] OR “psychosocial intervention”[All Fields] OR “self-management”[All Fields] OR “selfmanagement”[All Fields]) AND (“Clinical Trials as Topic”[Mesh] OR (“clinical trial”[Publication Type] OR “clinical trials as topic”[MeSH Terms] OR “clinical trial”[All Fields]) OR (controlled[All Fields] AND (“clinical trials as topic”[MeSH Terms] OR (“clinical”[All Fields] AND “trials”[All Fields] AND “topic”[All Fields]) OR “clinical trials as topic”[All Fields] OR “trial”[All Fields])))



Chapter 2 - Appendix 2

Clustering of outcome scales

EMOTIONAL STATUS

Mood

Geriatric Depression Scale (GDS)

Profile of Mood States (POMS)

Outlook of life

Life Optimism Test-Revised (LOT-R)

Impairment adaptation

Adaptation to Visual Loss (AVLS)

Nottingham Adjustment Scale 2 (NAS2)

Wellbeing

Ryff Psychological Well-Being Scale (Ryff)

Health-related quality of life

Short-Form36 health-related quality of life measure (SF-36)

Impairment-related quality of life

Vision Quality of Life Core Measure (VMC1)

Low Vision Quality of Life Questionnaire (LVQOL)

FUNCTIONAL STATUS

Communication strategies

Communication Profile for the Hearing Impaired (CPHI)

Hearing Handicap Disability Inventory-adaptation (HHDIa)

Self-Assessment of Communication (SACa)

Everyday functioning

National Eye Institute Visual Function Questionnaire (NEI-VFQ)

Functional independence

Functional Assessment Questionnaire (FAQ)

Functional Independence Measure for Blind Adults (FIMBA)

Functional Vision Performance Test (FVPT)

SELF-EFFICACY

Generic self-efficacy

Generalized Self-Efficacy Scale (GSES)

Vision-related self-efficacy

Age-related Macular Degeneration-Self-Efficacy Questionnaire (AMD-SEQ)

Goldstein-questionnaire

Perceived security

Questionnaire Perceived Security (QPS)

PARTICIPATION

Reduction of hearing handicap

Quantified Denver Scale of Communicative Function (QDS)

Hearing Handicap Inventory for the Elderly (HHIE)

Hearing Handicap Questionnaire (HHQ)

Activity levels on household activities, social activities and leisure activities Activity Card Sort (ACS)



CHAPTER 3

SCREENING FOR HEARING, VISUAL AND
DUAL SENSORY IMPAIRMENT IN OLDER
ADULTS USING BEHAVIOURAL
CUES: A VALIDATION STUDY

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Abstract

Objective: This study investigated the psychometric properties of the Severe Dual Sensory Loss screening tool, a tool designed to help nurses and care assistants to identify hearing, visual and dual sensory impairment in older adults.

Design: Construct validity of the Severe Dual Sensory Loss screening tool was evaluated using Cronbach's alpha and factor analysis. Interrater reliability was calculated using Kappa statistics. To evaluate the predictive validity, sensitivity and specificity were calculated by comparison with the criterion standard assessment for hearing and vision. The criterion used for hearing impairment was a hearing loss of ≥ 40 decibel measured by pure-tone audiometry, and the criterion for visual impairment was a visual acuity of ≤ 0.3 diopter or a visual field of $\leq 0.3^\circ$. Feasibility was evaluated by the time needed to fill in the screening tool and the clarity of the instruction and items. Prevalence of dual sensory impairment was calculated.

Results: A total of 56 older adults receiving aged care and 12 of their nurses and care assistants participated in the study. Cronbach's alpha was 0.81 for the hearing subscale and 0.84 for the visual subscale. Factor analysis showed two constructs for hearing and two for vision. Kappa was 0.71 for the hearing subscale and 0.74 for the visual subscale. The predictive validity showed a sensitivity of 0.71 and a specificity of 0.72 for the hearing subscale; and a sensitivity of 0.69 and a specificity of 0.78 for the visual subscale. The optimum cut-off point for each subscale was score 1. The nurses and care assistants reported that the Severe Dual Sensory Loss screening tool was easy to use. The prevalence of hearing and vision impairment was 55% and 29%, respectively, and that of dual sensory impairment was 20%.

Conclusions: The Severe Dual Sensory Loss screening tool was compared with the criterion standards for hearing and visual impairment and was found a valid and reliable tool, enabling nurses and care assistants to identify hearing, visual and dual sensory impairment among older adults.

Background

Sensory impairment is widespread among older adults; however the consequences for daily life are often overlooked. The percentage of hearing and visual impairment in the group aged 80 and older was found to be 78% and 31% respectively; 25% of them suffered a dual sensory impairment (DSI), i.e. the combination of a hearing and a visual impairment. The highest percentages were found among older adults living in residential care settings [1]. Although age-related sensory impairment is often viewed as a normal ageing process, the consequences are far-reaching, as hearing, visual and dual sensory impairment are associated with functional decline [2], loss in social participation [3], loss of quality of life [4, 5], depressive feelings [6-9], and cognitive decline [10]; Lin and colleagues showed that older adults with hearing loss demonstrated a 30% to 40% accelerated rate of cognitive decline. In daily life, hearing impairment disrupts communication, visual impairment impedes orientation and mobility, and dual sensory impairment is connected with problems of communication and mobility as well as problems in accessing information [11].

Usual care aims at medical treatment and the use of technical aids. Although technical devices and equipment are important, sensory impaired older adults need additional measures and special support from professional and informal caregivers [12-14]. In case of dual sensory impairment, specific communication, interpreting and mobility support and environmental alterations are required [15, 16]. Nursing staff can play a key role in supporting the sensory impaired older adult by maximizing communication [17-19] and functional opportunities in a way that promotes autonomy [20-22].

In healthcare settings, there is limited awareness of sensory impairments and their effects [23, 24]. Despite the substantial evidence of the negative associations between sensory impairment, depression and cognitive decline, and despite the findings that change in sensory impairment could predict change in cognitive impairment [25], the influence of sensory impairment is often disregarded when diagnosing or addressing depressive behaviour or cognitive decline [26].

There is need for a tool which can identify hearing and visual impairment, and, once identified, they can be addressed relatively easily, especially by nurses and care assistants during their daily contacts.

A range of screening tools have been developed to help identify the perception



of the sensory impaired individual, such as the widely used Hearing Handicap Inventory Scale for the Elderly (HHIE) [27] and the 25-Item National Eye Institute Visual Function Questionnaire (NEI-VFQ) [28]. However, these are self-report screening tools and therefore are not applicable as observational tools for care staff. We only found one instrument developed to support nurses and care assistants when observing behaviour related to sensory impairment: the Severe Dual Sensory Loss in Old Age screening tool (SDSL screening tool). This tool, developed by Lyng and Svingen, is a nurse-rated checklist with a subscale of six questions on hearing-related behaviour, and a subscale of six questions on visual-related behaviour [29]. The items focus on participation and daily activities and were selected by Lyng and Svingen as being behavioural consequences and adaptations to the age-related decline of the auditory and visual system and its neurological processes. For example, they assumed that a decline in visual contrast perception causes difficulties in recognizing other persons, and a decline in aural discrimination frustrates participation in group conversations. The tool was developed as the first step in a protocol to detect and address dual sensory impairment among 719 Norwegian older adults receiving long-term care. Sixty five individuals were screened as dual sensory impaired; thirty three of them participated in the second step, i.e. an auditory and visual assessment and an interview on problems and needs. Although Lyng and Svingen did not estimate the validity and reliability of the SDSL screening tool separately, it has been used widely and translated for use in several European countries and by different authors. Until now, no validation studies have been published.

The aim of this study is to assess the reliability, validity and feasibility of the SDSL screening tool.

Methods

Translation of the SDSL screening tool

The original Norwegian authors produced both a Norwegian and an English version of their SDSL screening tool. With their permission, the English version was translated into Dutch by the researchers (authors LR and SZ) and back-translated into English by an independent native English speaker who was blinded to the original questionnaire [30]. Both English-language versions were subsequently compared and problem items were revised by a committee consisting of the

researchers (authors LR, SZ, and GK) and two speech language specialists. The English version of the SDSL screening tool is included in Appendix 2 of the Supplementary Data.

Recruitment of participating older adults, nurses and care assistants

Older adults were recruited from three different types of aged care at the Kalorama Foundation in the eastern part of the Netherlands, i.e. residential care, a social day center, and a day center with rehabilitation services. Inclusion criteria were an age of 65 years and older and written informed consent from the participant, if possible, or from his/her legal guardian. The exclusion criterion was the risk of overburdening the older adult in participating the hearing and visual measurements as evaluated by nursing staff working at the aged care setting.

Inclusion criterion for the nurses and care assistants was regular contact (at least twice a week) with the participating older adult.

Procedure

The nurses and care assistants received a written version of the SDSL screening tool, including a short written instruction. For each participating older adult, the tool was administered by two different staff members independent of each other. Nurses and care assistants recorded the time spent administering each SDSL screening tool, and were asked to give their opinion on the clarity of the instruction and of the items.

After completing the SDSL screening, pure-tone audiometry (PTA) was tested in each older adult by a speech language specialist, and visual acuity, visual field, and contrast sensitivity was tested by a low-vision specialist. The criterion standard used for hearing impairment through bilateral PTA was determined as the pure-tone average of audiometric thresholds at 1000, 2000, and 4000 Hz (Fletcher-high) in the better ear. The older adults were classified as having normal hearing or a hearing impairment, defining a moderate to severe hearing impairment as $PTA \geq 40$ dB [31]. The criterion standard for visual impairment was determined as a score of the best-corrected visual acuity of < 0.3 diopter or a visual field of $< 30^\circ$, according to the low vision criteria formulated by the Dutch Ophthalmological Society [32].



Analysis

To evaluate the construct validity of the SDSL screening tool, we measured the internal consistency of the hearing and visual subscales using Cronbach's alpha; values greater than 0.70 indicate adequate internal consistency [33]. In addition, we used exploratory factor analysis to gain an impression of the factor structure and internal cohesion of the 2 subscales. Initially, factors with Eigen values >1 were extracted and orthogonally rotated to achieve simple structure (Varimax). To avoid insufficient correlation with other items, only items with factor loadings ≥ 0.4 were considered relevant [34]. The highest factor loading of a particular item determined the factor to which the item should be assigned. For each factor, the variance explained was given. Interrater reliability was calculated using Kappa statistics, values between 0.61 and 0.80 indicate substantial agreement [35].

To evaluate the predictive validity we compared the results of the SDSL screening tool (hearing and visual subscales separately) with the criterion standards for hearing and vision. We calculated sensitivity, specificity and receiver operating characteristics (ROC) with 95% CI [36]. Sensitivity represents the proportion of the older adults screened as sensory impaired by the SDSL screening tool among those identified as sensory impaired by the criterion standard measurement (True Positives = TP). Specificity represents the proportion of the older adults screened as not having a sensory impairment among those identified as not sensory impaired by the criterion standard measurement (True Negatives = TN). Sensitivity and specificity were calculated for each score of each subscale, allowing for the selection of which score (cut-off point) can be used to discriminate between sensory impaired and not sensory impaired. The choice of the cut-off point is an arbitrary decision, as there is an interchange between sensitivity and specificity: sensitivity can be increased only at the expense of specificity, and vice versa. In this study, we chose the optimum cut-off point as the score with maximum sensitivity combined with maximum specificity. To visualize the relationship between sensitivity and specificity we used the area underneath the ROC (AUC). Sensitivity is plotted on the left vertical axis against the specificity on the bottom horizontal axis. An AUC of 1.00 indicates a perfect predictive screening tool relative to the criterion standard, whereas a random guess would have an AUC of 0.5. The greater the area under the curve, the more accurate the screening tool, with the optimal accuracy represented by upper left scores.

All analyses were conducted using SPSS version 19.

Results

Participants

A total of 83 older adults who met the age criterion were invited to participate in the study. Written consent was obtained from 60 individuals, no consent was obtained by legal guardians. Four older adults had missing data because they were hospitalized (n = 2) or had moved to a nursing home elsewhere (n = 2). Among the remaining 56 older adults, 22 lived in a residential setting, 34 lived at home, of whom 20 visited a social day center and 14 visited a day center with rehabilitation services. Age ranged from 65 to 96 years with a mean age of 82.8 years (S.D. = 6.1). Furthermore, 70% of the participants were female. In total 12 staff members participated in the study: 1 registered nurse, 2 licensed practical nurses and 3 care assistants of the residential setting, and 3 licensed practical nurses and 3 care assistants of the day centers. They needed between 1 to 3 minutes to complete the 12 items of the tool. They reported that the written instruction was clear and needed no additional explanation, and that answering the questions of the SDSL screening tool was easy in most of the cases (95%); however, two staff members reported problems for three of their clients with cognitive impairment in answering items 1 and 3 of the visual subscale (see Supplementary Data - Appendix 2). For both residential setting and day centers the average contact time of the staff member with the older adult was 4 h a week. Contacts in the day centers were more often group encounters, and in the residential setting the contacts were mainly individual, daily care contacts. Three of the six staff members of the residential setting preferred to complete the screening tool without an extra observation of the older adult, while four of the six staff members of the day centers waited with completion until they had the opportunity for an additional observation of the older adults.

Reliability and validity

SDSL hearing subscale

Construct validity: Cronbach's alpha was 0.81, indicating a strong internal consistency (Table 1). Factor analysis identified two domains, *social environment* and *individual environment*, which explained 38% and 33% of the variance respectively (total variance explained, 71%) (Table 2).

Interrater reliability measured by Kappa statistics was 0.71 (95% CI = 0.56-



0.86), indicating a substantial interrater agreement (Table 1).

Predictive validity: Fig. 1 presents the ROC of the SDSL hearing subscale against the criterion standard showing an AUC of 0.73 (95% CI = 0.60-0.86) (Table 1), which is considered as satisfactory. The optimal accuracy is starred with an asterisk. To examine the predictive value of each score (1-6) of the subscale, we compared the sensitivity and specificity of each score. Table 3 shows that score 1 was the optimum cut-off point to differentiate between hearing impaired and not hearing impaired, with a moderate to good sensitivity of 0.71 (95% CI = 0.52-0.85) and moderate to good specificity of 0.72 (95% CI = 0.50-0.87).

Table 1. Cronbach’s alpha, Kappa and Area under the receiver operating characteristic curve (AUC) for the SDSL screening tool

	Number of items	Cronbach’s alpha	Kappa	95% Confidence interval Kappa		Area under curve (AUC)	95% Confidence interval AUC	
				Lower	Upper		Lower	Upper
Hearing Subscale	6	0.81	0.71	0.56	0.86	0.73	0.60	0.86
Vision Subscale	6	0.84	0.74	0.55	0.92	0.79	0.64	0.94

SDSL visual subscale

Construct validity: Cronbach’s alpha was 0.84, indicating a strong internal consistency (Table 1). Factor analysis identified two domains, daily living activities and reading, which explained 61% and 23% of the variance, respectively (total variance explained, 83%) (Table 2).

Interrater reliability: Kappa statistics was 0.74 (95% CI = 0.55-0.92), indicating a substantial interrater agreement (Table 1).

Predictive validity: Fig. 1 presents the ROC of the SDSL visual subscale against the criterion standard for visual impairment, showing an AUC of 0.79 (95% CI = 0.64-0.94) (Table 1), which is considered as satisfactory.

Table 2. Results of factor structure of the hearing and visual subscale of the SDSL screening tool^(*)

	Factor 1	Factor 2
Hearing subscale	Social environment	Individual environment
H3. Speech recognition in noisy environment	0.89	
H4. Speech recognition in group conversation	0.79	
H6. Complains about reduced hearing	0.72	
H1. Doorbell		0.92
H5. Speech recognition from television, radio		0.81
H2. Speech recognition in quiet environment	0.55	0.56
Vision subscale	Daily activities	Reading
V3. Locating objects	0.97	
V4. Using watch	0.91	
V5. Independency outdoor/unfamiliar places	0.91	
V1. Recognition of familiar persons	0.87	
V6. Complains about worsening vision		0.94
V2. Reading newspaper, watching television	0.54	0.62

^(*) only factor loadings >0.40 are listed

Figure 1. Receiver operating characteristic (ROC) curves for the SDSL screening tool comparing with criterion measurements of hearing and vision as reference standard

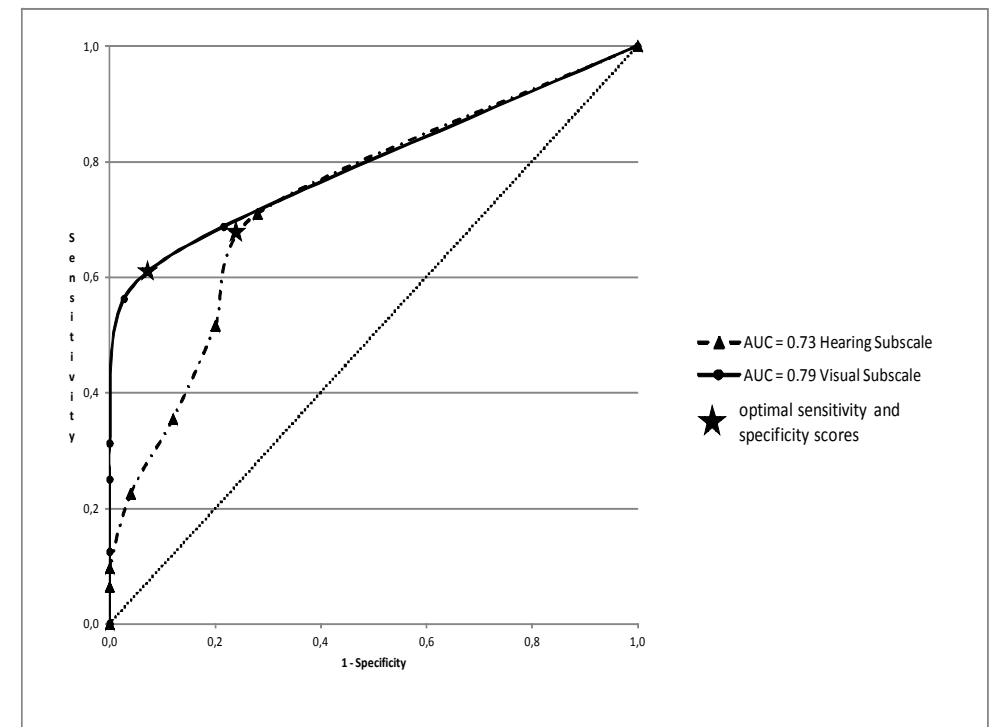


Table 3, including the sensitivity and specificity of each score, shows that score 1 was the optimum cut-off point to differentiate between visually impaired and not visually impaired, with a sensitivity of 0.69 (95% CI = 0.41-0.88) and a specificity of 0.78 (95% CI = 0.61-0.89).

Table 3. Cut-off scores and validity of the SDSL screening tool comparing with criterion measurements of hearing and vision as reference standard

	Number of subjects				Predictive Validity	
	True Positive	False Positive	False Negative	True Negative	Sensitivity	Specificity
Hearing Subscale						
Cut-off score						
1	22	7	9	18	0.71	0.72
2	16	5	15	20	0.52	0.80
3	11	3	20	22	0.35	0.88
4	7	1	24	24	0.23	0.96
5	3	0	28	25	0.10	1
6	2	0	29	25	0.06	1
Visual Subscale						
Cut-off score						
1	11	7	5	31	0.69	0.78
2	9	1	7	38	0.56	0.97
3	5	1	11	38	0.31	0.97
4	5	0	11	40	0.31	1
5	4	0	12	40	0.25	1
6	2	0	14	40	0.12	1

Prevalence of dual sensory impairment

Of the 56 participants, 11 (20%) had a measured dual sensory impairment (Table 4). Furthermore, 31 participants (55%) had a hearing impairment and 16 participants (29%) had a visual impairment. Dual sensory impairment was found in 27% of those receiving residential care and in 15% of the home-dwelling older adults.

Table 4. Prevalence of dual sensory impairment among older adults in care facilities ($n=56$).

Screening Tool	Dual Sensory Impairment		No Sensory Impairment		Single Hearing Impairment		Single Visual Impairment	
	N	%	N	%	N	%	N	%
Criterion standard	11	20	20	35	20	35	5	9
SDSL screening tool	15	27	22	39	14	25	5	9

Discussion

We found that the SDSL screening tool is a valid, reliable, and easy-to-administer tool to identify sensory impairment among older adults. Moderate to good sensitivity and specificity were found for the hearing and visual subscales. The internal consistency of the items was strong and the interrater reliability of the tool was substantial. Factor analysis identified two domains in the hearing subscale (social environment and individual environment) and two domains in the vision subscale (daily living activities and reading).

The psychometric results of the SDSL screening tool were comparable with those from self-report questionnaires for single sensory functions when used in community screening. The HHIE-S showed sensitivities and specificities ranging from 0.36 to 1.00 and from 0.60 to 0.92, respectively, and the NEI-VFQ-25 showed a sensitivity of 69% and specificity of 82% [37, 38]. In contrast to our study, Owen and colleagues only used visual acuity as criterion standard for visual impairment, and left out visual field measurement. Although visual acuity appears to be an important determinant for visual performance, visual field is of eminent importance when older adults are concerned [39]. Another contrast includes the distinct character of the items of the HHIE-S and NEI-VFQ versus the SDSL screening tool. Both the HHIE-S and NEI-VFQ require older adults themselves to assess the social and emotional difficulties that were provoked by their hearing or visual impairment. In contrast, the items of the SDSL screening tool focus on specific and visible behaviour that can be observed by a professional. The latter may facilitate the use of the SDSL screening tool among older adults with cognitive impairment. The Deafblind Index of the Resident Assessment Instrument for Home Care (RAI-HC) which is currently being used in multiple regions in Canada and the US, was calculated for home care clients, but psychometric comparison of the index with objectively measured data was not provided [40]. The Deafblind Index was initially developed to assess the needs and abilities of deafblind younger adults whose educational or professional development was threatened by their dual sensory impairment [41]. In contrast with the SDSL screening tool, the Deafblind Index requires trained assessors, and is a far more extensive instrument as it includes domains of importance after diagnosis of dual sensory impairment. This study found high factor loadings ranging from 0.79 to 0.89 on items on speech recognition in noisy and social environments, which corresponds with



research showing that, even at an early stage or mild degree of audiometric hearing impairment, a noisy environment stresses the central auditory processing of understanding spoken language by older adults [42]. The high factor loadings in the visual subscale, ranging between 0.87 and 0.97, on items focusing on an independent lifestyle correspond with the findings that visual impairment highly impacts the instrumental activities of daily living [43].

Our second finding was the high prevalence of 20% of dual sensory impairment in this sample; this was higher in residential care, when compared with community dwelling older adults. The findings correspond with the objectively measurements of Jee and colleagues who found 22% of dual sensory impairment among aged care clients [44]. In comparison, Swenor and colleagues measured a prevalence of 11.7% of dual sensory impairment among noninstitutionalized US citizens aged 80+ [45] and Smith and co-workers found >20% among patients of 85 years and over at auditory and visual medical centers [46].

This study has several limitations. First, owing to the small sample size, we were unable to differentiate the results between older adults with and without cognitive problems. Second, although we invited 83 older adults, only 67% (N = 56) could be included in the analysis. Attrition bias may have affected our results.

Given (1) the high occurrence and the special needs of older adults with dual sensory impairment, (2) the strong negative associations between sensory impairment and two other prominent issues in aged care, namely cognitive decline and depressive feelings, and (3) the potential that the consequences of the sensory impairment can be mitigated, it is important that professional caregivers recognize behaviour indicative of sensory impairment. Research in the area of sensory impairment is in its infancy, especially in the area of dual sensory impairment. An implication of this study is that the SDSL screening tool allows nurses and care assistants to have a key role in regular screening of the population in aged care, and in referring older adults to objective auditory and visual assessment, medical care or technical provision services. Moreover, the tool facilitates identification and awareness of the sensory impaired behaviour, which offers the nurses and care assistants a basis for better aligning their behaviour to the communication and functional needs of the sensory impaired, frail older adults in aged care.

Conclusions

In healthcare, the impact of hearing and visual impairment is underestimated and the mutual negative influence on cognitive functioning and depressive behaviour neglected. Older adults need social and environmental support in addition to medical treatment and technical device use. Nurses and care assistants have a key role in recognizing behaviours and in maximizing communication and functional opportunities. The SDSL screening tool is developed for use by nurses and care assistants to identify sensory impaired related behaviours among older adults. In the present study the SDSL screening tool was validated against criterion measurements pure-tone screening audiogram and low vision screening. The results show that the SDSL-Dutch version is a reliable, valid, easy-to-administer and inexpensive tool for nurses and care assistants when identifying sensory impairment in older adults. We propose to incorporate the SDSL screening tool in routine screening, either as a separate tool or as a distinctive addition to existing observational diagnostic tools for depression or cognitive impairment.



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CHAPTER 4

EFFECTIVENESS OF A SELF-MANAGEMENT
PROGRAM FOR DUAL SENSORY IMPAIRED
OLDER ADULTS IN LONG-TERM CARE
SETTINGS: STUDY PROTOCOL FOR A
CLUSTER RANDOMIZED CONTROLLED TRIAL

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Abstract

Background: Five to 25 percent of residents in long-term care settings have a combined hearing and visual sensory impairment. Usual care is generally restricted to single sensory impairment, neglecting the consequences of dual sensory impairment on social participation and autonomy. The aim of this study is to evaluate the effectiveness of a self-management program for older adults who acquired dual sensory impairment at old age.

Methods/Design: In a cluster randomized, single-blind controlled trial, with long-term care settings as the unit of randomization, the effectiveness of a self-management program will be compared to usual care. A minimum of 14 and maximum of 20 settings will be randomized to either the intervention cluster or the control cluster, aiming to include a total of 132 older adults with dual sensory impairment. Each older adult will be linked to a licensed practical nurse working at the setting. During a five to six month intervention period, nurses at the intervention clusters will be trained in a self-management program to support and empower older adults to use self-management strategies. In two separate diaries, nurses keep track of the interviews with the older adults and their reflections on their own learning process. Nurses of the control clusters offer care as usual. At older adult level, the primary outcome is the social participation of the older adults measured using the Hearing Handicap Questionnaire and the Activity Card Sort, and secondary outcomes are mood, autonomy and quality of life. At nurse level, the outcome is job satisfaction. Effectiveness will be evaluated using linear mixed model analysis.

Discussion: The results of this study will provide evidence for the effectiveness of the Self-Management Program for older adults with dual sensory impairment living in long-term care settings. The findings are expected to contribute to the knowledge on the program's potential to enhance social participation and autonomy of the older adults, as well as increasing the job satisfaction of the licensed practical nurses. Furthermore, an extensive process evaluation will take place which will offer insight in the quality and feasibility of the sampling and intervention process. If it is shown to be effective and feasible, this Self-Management Program could be widely disseminated.

Background

As people age, the increasing chance of acquiring a combined hearing and visual impairment adds to the risk of dependency on informal and professional care. In the Dutch population of people aged 80 and over, 5 to 25 percent have a dual sensory impairment (DSI) acquired at old age; the highest percentages were found among older adults living in residential care settings [1].

People with DSI experience barriers in communication, mobility, and information access [2,3], and DSI older adults are at higher risk of depressive feelings [4,5], functional decline [6,7], and social isolation [8]. The consequences of DSI are believed to go beyond those difficulties experienced by older adults suffering from single sensory loss [9], endangering their social participation and autonomy [10,11].

Usual care for older adults with DSI aims to reduce the effects of single sensory impairment, for example by providing technical devices, in some cases supplemented by communication strategies for hearing-impaired older adults, or by training in reading and daily living skills of visually impaired older adults. In some West European countries (for example the Netherlands, UK and Scandinavian countries), home-dwelling older adults with DSI have access to services designed for deafblind adults who acquired dual sensory impairment at an earlier stage in life. These services offer support from social workers and interpreters to address the participation restrictions. In contrast, DSI older adults living in residential care settings are often deprived of special support. Healthcare settings are found to be environments where there is limited awareness of the hearing and visual impairment of the patients, leading to a lack of supportive measures in the social and physical environment [12,13]. Hearing or visual impairment is often seen as an individual problem that can be solved by the individual, through medical treatment and technical devices. Sometimes, loneliness and depression are recognized as separate problems, but not as a consequence of a DSI.

Based on what we know from the limited number of available trials, self-management strategies can be expected to be beneficial for sensory impaired older adults [14], with a potentially higher impact among older adults with depressive feelings [15]. As DSI is associated with participation restrictions, this trial includes social participation as a primary outcome at older adult level.

This trial aims to evaluate the effectiveness of a self-management intervention for



DSI older adults living in long-term care settings. We chose cluster randomization in order to avoid contamination resulting from the effects of possible exchange of information by nurses within the age care setting. We hypothesize that the intervention group will have a more favorable development in social participation, and in nurses' job satisfaction than the control group. In addition, we hypothesize that older adults suffering from depressive feelings will benefit more from the intervention, and that intervention outcomes at both the level of the older adults and of the nurses will be associated with the adherence of the nurses to the program.

Methods/Design

Study design

The study is designed as a cluster randomized, single-blind controlled trial (Figure 1). A cluster is defined as an long-term care setting with an assigned team of nursing staff. A professional caregiver from the setting who has daily care contact with the participating older adult will be linked to that older adult; we decided to choose licensed practical nurses as they provide the majority of the daily care in long-term care settings in the Netherlands. The older adults in the intervention cluster are offered the Self-Management Program for Dual Sensory Impaired Older adults (SMP-DSI) supported by their own nurse. The older adults in the control cluster are offered usual care. An independent statistician will randomize the settings in blocks using a computer generated random sequence. Data on self-reported outcome measures will be collected at baseline (T0) and four to six weeks after the intervention is finished (T1).

Study sample

The study sample will consist of age care settings where DSI older adults live. The inclusion criteria for the long-term care settings are (1) care organizations offering residential care to older adults, (2) with nursing teams assigned to one setting or location. The inclusion criteria for the care professionals are (1) provision of regular direct daily care (at least twice a week) to the participating older adult, (2) qualified as a licensed practical nurse, that is, a three-year basic nursing vocational training at secondary level, and (3) consent given to participate.

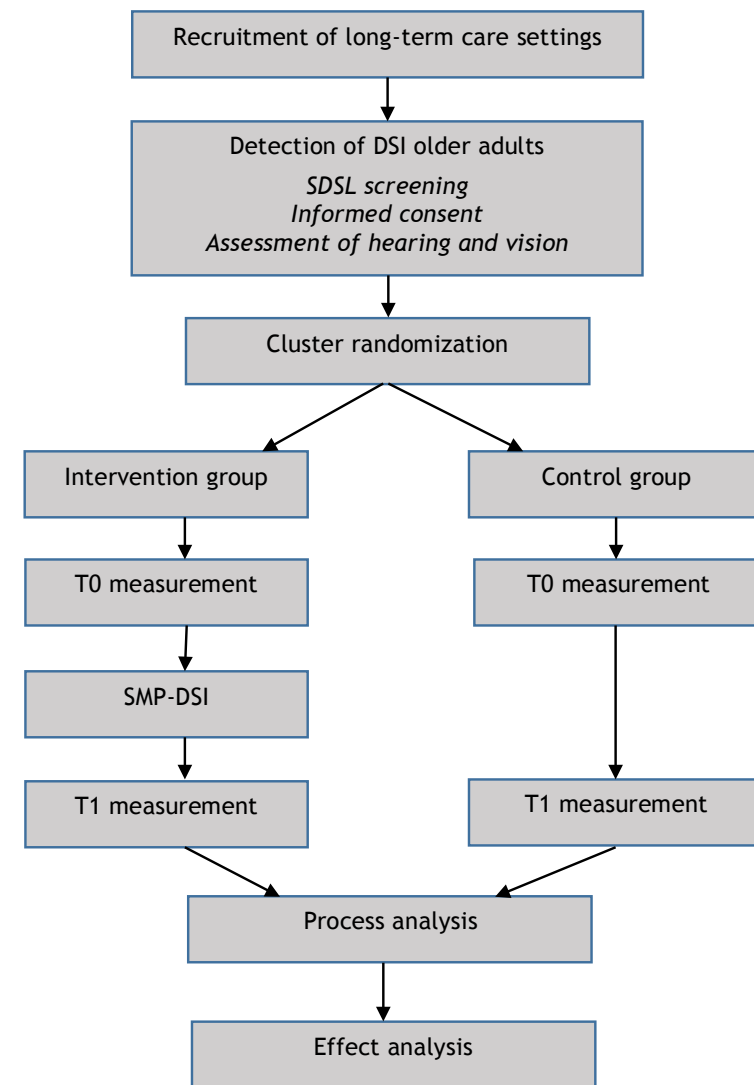


Figure 1. Study design

The inclusion criteria for the older adults are (1) aged 55 or over, (2) a hearing loss of PTA ≥ 40 dB [16], (3) a visual loss, with a best-corrected visual acuity of < 0.3 diopter or with a visual field of $< 30^\circ$ [17], and (4) informed consent given by the older adults. Exclusion criteria for the older adults are prelingual deafness, a dual sensory loss acquired before the age of 50, and inability to complete interviews due to cognitive problems.



Assessment of cognitive functioning in older adults with dual sensory impairment

To assess cognitive functioning, we will use the DSM IV criteria for capacities in executive functioning: planning, organizing, sequencing and abstracting [18]. These criteria have been selected for their relevance when performing self-management strategies. The list with instructions shows how the DSM IV criteria will be used. We have added these instructions to create valid communication conditions in order to be able to observe cognitive functioning, considering the communication barriers associated with dual sensory impairment. The procedure to assess for cognitive eligibility for participation in the trial is described in Appendix 1 of the Supplementary Data.

Procedures

We will start recruitment of the long-term care settings by sending an invitational email and an information brochure to the board and the scientific committees of long-term care organizations, followed by a personal visit to those organizations interested in participating. Nurses at the participating settings will screen older adults using the Severe Dual Sensory Loss screening tool (SDSL), a questionnaire validated for the Dutch population for DSI [19]. If the SDSL detects DSI-related behaviour in a older adult, this older adult will be invited to participate in the research project, starting with a hearing and vision assessment. Research assistants will observe the cognitive functioning of the older adult. Hearing and visual loss will be assessed by a speech therapist and optician. After inclusion of the older adults, licensed practical nurses will be asked to join the program. Each older adult will be paired with a nurse; one nurse can be linked to a maximum of two participating older adults.

Cluster randomization occurs after inclusion of older adults in the trial. Settings where no older adult participates are therefore not included in the randomization.

Blinding

The study will be single-blinded, which means that older adults, nurses and trainers will be aware of the allocation arm but will be blinded to the results of any previous assessments. The outcome assessors will be blinded to allocation of the long-term care setting of the older adults and the nurses.

Intervention

The Self-Management Program for Dual Sensory Impaired older adults (SMP-DSI)

In this study, the self-management program aims to empower and enable older adults to develop confidence and motivation in the use of their own skills, using resources to participate in a good, safe and emotionally satisfying life in the context of their dual sensory impairment. The SMP-DSI focuses on three self-management tasks to help DSI older adults regain autonomy in their daily lives: (1) to take care of the medical and rehabilitation aspects of the disease (medical management); (2) to carry out normal activities to sustain social participation (role management); and (3) to manage emotional changes as a consequence of being chronically ill (emotional management) [20]. The program has been developed based on the concepts of Bandura's self-efficacy theory [21], D'Zurilla's problem solving theory [22] and Bakker's constructive behavioural analysis [23]. The structure of the SMP-DSI is a modification of the core self-management skills described by Lorig and Holman combined with the practice-based experiences of social workers and their DSI clients at the Kalorama Foundation [24]. The five steps and related actions of the older adult and possible support of the nurses within the program are depicted in Table 1. Due to the communication problems inherent to DSI, the SMP-DSI has been developed using one-to-one interviews. The intervention is delivered at the older adult's residence during daily care contacts, spread over a period of five to six months, starting at the beginning of the nurses' training program.



Table 1. Key Features of the self-management program for older adults with dual sensory impairment

Steps	Older adult actions	Nurse support	Key questions	Ideal support	Pitfalls
1 Problem identification	Mentions problem Decides to take action		You mentioned that you have a problem with...Would you like to do something about it?	Name the problem using the older adult's own words. If the older adult doesn't want to take action, do not interfere	Ask for an explanation, take on the problem, insistence
2 Collecting alternatives	Collects a minimum of 3 alternatives: either by themselves, or by asking others for help		What could you do about this? Are there other options?	Stimulate older adult to answer. In cases where the older adult doesn't come up with enough alternatives, provide information. Leave the choice to the older adult	Impose solutions, make judgements, provide advice
3 Choice and planning	Select an alternative that the older adult will act on Plan actions		How do you think you will manage this?	If the older adult has difficulties planning, then apply the key question 2 procedure	Takeover the choice/ planning; provide coercive advice
4 Execution	Executes action			Lets the older adult execute the action	Executes action for older adult
5 Reflection	Reflects on own action, mentions what went well		What was the result? What are you happy about: about what you could do on your own? What would you do differently the next time?	Ask What, When, How questions	Ask for an explanation

SMP-DSI training program for the licensed practical nurses

Nurses in the intervention group will be trained to support the older adults using the SMP-DSI program. The training program consists of nine meetings over a five to six month period, totaling about 18 hours, divided into three rounds; each round consists of a three-hour training session, a 1-hour coaching on the job session, and a one and a half hour supervision session. An interval of two to three weeks is planned between each meeting to give the older adult-nurse pairs the opportunity to practice the SMP-DSI in daily care situations.

1. *Training.* The training sessions provide nurses with the background and theory of the SMP-DSI, and focus on the conversational and supporting interview methods needed to assist older adult clients in their process of self-management. Each training session involves clearly defined goals and home assignments.

2. *Coaching on the job.* Individual coaching sessions are held to address nurses' individual experiences regarding the application of the SMP-DSI in practice. Nurses reflect on the process and results of their professional performance.

3. *Supervision.* Participating nurses from different intervention clusters share their experiences using the SMP-DSI and discuss any issues.

Training and supervision sessions are group meetings attended by nurses from one or more settings and led by a trainer. The on-the-job coaching is conducted in individual sessions between the nurse and trainer. Nurses keep two semi-structured diaries: a diary on the interviews with their older adult, and a diary with their own learning experiences and consecutive learning goals. Five qualified nurses with long experience of supporting dual sensory impaired older adults will be coached to deliver the SMP-DSI training program to the participating nurses.

Control condition

Older adults in the control group will receive care as usual, mostly using personal technical devices.

Outcome measures

At older adult level, the primary outcome measure is social participation, as measured by the Hearing Handicap Questionnaire (HHQ) [25,26] and the Activity Card Sort (ACS) [27-29] (see Table 2). The HHQ is a 12-item questionnaire that identifies participation restrictions related to hearing impairment. The ACS has



been validated in a number of samples of older adults, and adapted for use by visually impaired older adults. It consists of labelled photographs of older people participating in a range of activities. Completion requires clients to sort the photographs into categories to reflect their current participation. A standardized description of the images of the validated Dutch ACS is read to those participants unable to see the magnified photographs. Secondary outcome measures for the older adults are mood (Center for Epidemiology Studies Depression Scale (CES-D)) [30], autonomy (Patient Autonomy Questionnaire (PAQ)) [31], perceived control (Pearlin Mastery Scale (PMS)) [32], quality of life (Short-Form 36 Health Survey (SF-36)) [33], and personality-2 factors, extraversion and neuroticism (Neuroticism-Extraversion-Openness Inventory (NEO-FFI)) [34].

At nurse level, the outcome measure is job satisfaction, as measured by the Maastricht Job Satisfaction Scale for Healthcare (MJSS-HC) [35], a questionnaire validated for the Dutch population.

In addition, at older adult level we will collect at baseline sociodemographic, personality and communication characteristics. The following variables will be recorded: age, marital status, highest completed education, profession (before retirement), preferred communication modality (speech, written language, tactile language such as hands on or tactile alphabet system), use of hearing or visual devices. Data on functional status will be collected by administering the basic activities of daily living relevant for the target group [36] and the instrumental activities of daily living (ACS-subtest Instrumental activities of daily living (IADL)) score. At nurse level, we will collect data about the educational and professional background of the nurses. At the level of the age care settings, we will collect data on demographic and administrative characteristics.

Two research assistants will collect the data from both older adults and nurses at baseline, and at five to six weeks after the end of the intervention. The research assistants will be blinded for group allocation, and each participant will be followed up by the same assessor. All data from the older adults will be obtained during one-to-one interviews at the older adult home environment; data from nurses will be obtained using a written questionnaire. Nurses who meet the participation requirements of 80% will receive a participation certificate from Radboud University Nijmegen and the Kalorama Foundation.

Table 2. Data sources for measurements and application of variables

Variable	Instrument	Application of variable
Older adults		
Social participation	Activity Card Sort (ACS) [26-28]	Primary Outcome
Social Participation	Hearing Handicap Questionnaire (HHQ) [1, 2]	Primary Outcome
Mood	Center for Epidemiology Studies Depression Scale (CES-D) [3]	Secondary Outcome
Autonomy	Patient Autonomy Questionnaire (PAQ) [4]	Secondary Outcome
Perceived control	Pearlin Mastery Scale (PMS) [11]	Secondary Outcome
Quality of life	Short Form 36 Health Survey (SF-36) [23]	Secondary Outcome
Personality-2 factors: Extraversion & Neuroticism	Neuroticism-Extraversion-Openness Inventory (NEO-FFI) [24]	Control Variables
Demographic and communication variables		Control Variables
Nurses		
Job Satisfaction	Maastricht Job Satisfaction Scale for Healthcare (MJSS-HC) [26]	Secondary Outcome
Demographic variables	Self-developed questionnaire	Control Variables
Long-term care settings		
Demographic and administrative variables	Self-developed inventory and public sources	Control Variables

Two research assistants will collect the data from both older adults and nurses at baseline, and at five to six weeks after the end of the intervention. The research assistants will be blinded for group allocation, and each participant will be followed up by the same assessor. All data from the older adults will be obtained during one-to-one interviews at the older adult home environment; data from nurses will be obtained using a written questionnaire.

Sample size and power calculations

For practical reasons, we expect to be able to include 14 to 20 long-term care settings, with a maximum of 132 DSI older adults and their nurses. Improvement in either one of the two social participation scales (one scale for hearing-related social participation, and one general scale for social participation), is considered a success; study success is defined as a statistically significant difference on either



HHQ or ACS. The enrolment of 14 to 20 settings will enable us to detect an effect size of 0.7 or larger with 80% power on either HHQ or ACS (or equivalently stated, a precision (half-width of the 95% confidence interval for the estimate) of 0.36 standard deviation (SD)), based on the following reasoning: (1) Randomization is at the level of the long-term care setting to avoid contamination that may arise should control group nurses come into contact with DSI older adult nurses in the intervention group. (2) Uncorrected for clustering, a sample size of 32 per group is needed for the mentioned effect size and power (or equivalently, the stated precision). (3) Given a prevalence of 20% and accounting for low participation rates as found in most studies of very aged and medically compromised older adults, and an average size of a setting (100 to 200 older adults), we expect to recruit five to ten DSI older adults per setting. Typically, a nurse at each setting will coach one to two older adults, so that five nurses from one setting will be involved. Thus, older adults are nested within nurses within long-term care settings. To account for this clustering (assuming an intra-nurse correlation between older adults of at most 0.3 and an intra- setting correlation between nurses of at most 0.10), the sample size has to be increased by a factor between 1.12 (if each setting has five nurses each with one older adult) and 1.54 (if each setting has five nurses each with two older adults) [37]. In order to allow for an expected 25% dropout, the sample size per group needs to be between 48 and 66, which comes down to between 20 and 14 settings in total. For simplicity of recruitment, we aim to include 132 older adults.

Statistical methods

Descriptive statistics (mean standard deviation or median and interquartile range) will be used to describe the baseline characteristics of the long-term care setting and of the older adults. We will use a linear mixed model to analyze the outcomes and to account for clustering of older adults within nurses within the settings and for repeated measurements. The influence of relevant/prognostic characteristics of long-term care setting/older adults on the outcomes will also be investigated by including these as covariates. The analysis will be based on all the resulting data using the intention-to-treat principle. Moreover, a per protocol analysis and a regression analysis with the adherence to intervention protocol (see below) will be performed to assess the influence of compliance. For all tests, significance will be tested using two-sided tests with an alpha level of .05.

Process evaluation

In order to assess the internal and external validity of the study, we will evaluate process data on sampling quality (recruitment, randomization and reach) and on intervention quality (relevance, feasibility, adherence and treatment delivery). The data will be performed alongside the SMP-DSI study, and the process evaluation will be executed prior to the effect analysis. Quantitative and qualitative data will be collected from the research database, the intervention diaries and the coaching diaries of the nurses, the semi-standardized records of the trainers, the assessors, the research assistants and the researcher.

To evaluate sampling quality, recruitment and randomization will be defined by description of the recruitment and randomization procedure for the long-term care settings; the informed consent and allocation procedure of the older adults; and by description of the barriers and facilitators to the recruiting of the long-term care settings, nurses and older adults. Reach will be determined by the proportion of the older adults participating in the SMP-DSI and the number of nurses involved in the intervention. To evaluate the intervention quality, we will analyze adherence and treatment delivery using data on the frequency and extent to which the SMP-DSI was performed by each pair of older adult and nurse, and data on attendance of nurses in the training program. We will also describe the reasons for refusal before the start or during the intervention by long-term care setting, nurse and older adult. Relevance and feasibility will be defined by the nurses' diaries and learning goals, the trainers' training and coaching evaluations, and opinions of the older adults, nurses and trainers about the program. Incentives and barriers toward treatment delivery at the level of long-term care settings, nurses and older adults will be classified using the Grol and Wensing framework [38].

Informed consent and ethical approval

In accordance with the Dutch Medical Research Involving Human Subjects Act (WMO), this study has been approved by the Committee on Research involving Human Subjects of the Arnhem-Nijmegen region, ABR 26192.091.08. All participating older adults will be requested to sign a consent form prior to data collection.



Discussion

In this paper we describe the study design for a Self-Management Program for older adults with a Dual Sensory Impairment (SMP-DSI) living in long-term care settings, with the aim of improving social participation and autonomy in older adults and job satisfaction in nurses.

This study adds to usual care by expanding the role of the professional caregivers who offer daily care to older adults whose autonomy is threatened. For reasons of feasibility, we only included licensed practical nurses as they are the professional caregivers who offer the majority of the daily care in long-term care settings in the Netherlands, but the SMP-DSI could also be used by healthcare assistants or nurse assistants. In the Netherlands, licensed practical nurses and nurse assistants are specially trained in the provision of somatic care and in responding to challenging behaviour, but little attention is given to methods aiming at improving older adults' autonomy and self-management. A strength of this study is that the consecutive coaching sessions offer the professional caregivers solid opportunities to get acquainted with the intervention. However, the long training period increases the risk of drop-out among the aged and vulnerable older adults.

Some specific issues on assessment and outcome measures need to be discussed. First, the assessment of hearing and visual impairment necessary to identify eligible older adults may contribute to the awareness among older adults and nurses of the presence of a DSI, and may influence usual care, resulting in a decrease of the potential effect. Second, we assess cognitive functioning using the DSM IV criteria in relation to the performances needed when executing self-management strategies. Third, we had to tackle a methodological difficulty concerning the selection of outcome measures. As no validated outcome measures on social participation were available for the dual sensory impaired older adult population, we selected two outcome measures: one validated for hearing impaired older adults, and one validated in a number of samples of older adults, and adapted for visually impaired older adults. In addition, we included several secondary outcome measures that each captures one or more aspects related to the consequences of a dual sensory impairment, such as mood, autonomy and functional decline (measured by a comprehensive quality of life scale). Moreover, as depressive feelings may impact the results, mood will be considered as an effect modifier for the analysis.

Finally, as recruitment for trials in residential settings and logistic planning is often a challenge, in the research team we will include special members who have access to an extensive network of care providers for older adults, and we will organize the training sessions in the region of the intervention clusters, adopting flexible schedules for the long-term care settings. If the SMP-DSI proves effective in the long-term care setting, wider implementation will be recommended in order to improve the social participation and autonomy of the older adults.



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CHAPTER 5

EVALUATION OF NURSES' CHANGING PERCEPTIONS WHEN TRAINED TO IMPLEMENT A SELF-MANAGEMENT PROGRAM FOR DUAL SENSORY IMPAIRED OLDER ADULTS IN LONG-TERM CARE: A QUALITATIVE STUDY

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Abstract

Objectives: To gain insights into the process of nurses' changing perceptions when trained to implement a self-management program for dual sensory impaired older adults in long-term care, and into the factors that contributed to these changes in their perceptions.

Design: Qualitative study alongside a cluster randomized controlled trial.

Setting: 17 long-term care homes spread across the Netherlands.

Participants: 34 licensed practical nurses supporting 54 dual sensory impaired older adults.

Intervention: A 5-month training program designed to enable nurses to support the self-management of dual sensory impaired older adults in long-term care.

Primary outcomes: Nurses' perceptions on relevance and feasibility of the self-management program collected from nurses' semi-structured coaching diaries over the 5-month training and intervention period, as well as from trainers' reports.

Results: Nurses' initial negative perceptions on relevance and feasibility of the intervention changed to positive as nurses better understood the concept of autonomy. Through interactions with older adults and by self-evaluations of the effect of their behaviour, nurses discovered that their usual care conflicted with client-autonomy. From that moment, nurses felt encouraged to adapt their behaviour to the older adults' autonomy needs. However, nurses' initial unfamiliarity with conversation techniques required a longer exploration period than planned. Once client-autonomy was understood, nurses recommended expanding the intervention as a generic approach to all their clients, whether dual sensory impaired or not.

Conclusions: Longitudinal data collection enabled exploration of nurses' changes in perceptions when moving towards self-management support. The training program stimulated nurses to go beyond 'protocol thinking', discovering client-autonomy and exploring the need for their own behavioural adaptations. Educational programs for practical nurses should offer more longitudinal coaching of autonomy supportive conversational skills. Intervention programming should acknowledge that change is a process rather than an event, and should include self-evaluations of professional behaviours over a period of time.

Background

The prevalence of an age-related combination of hearing and visual impairment is increasing rapidly among older adults in long-term care (LTC): from 12% in 2007 to 32% in 2014 [1, 2]. Dual sensory impairment (DSI) endangers independent functioning [3] and social participation [4]; however, the occurrence and impact of sensory impairment are often underestimated in LTC [5, 6].

A number of self-management interventions have been developed to improve independent functioning and social participation and to empower older individuals to address their actual personal needs, (re)using self-management strategies gained in earlier life. Although the evidence for their efficacy in older adults is mixed, self-management has been found to be an effective intervention for older adults with visual impairment [7-9]. DSI older adults, therefore, may also benefit from self-management interventions. However, there is strong evidence that service care providers' perceptions are critical to the success of self-management interventions, and that their focus is often on controlling patient behaviour rather than on collaborative client-provider partnership and client-autonomy [10-13]. There is a need for a deeper understanding of the challenges and demanding learning processes associated with the implementation of nurse-supported self-management interventions.

Between 2011 and 2014, we designed and implemented a training program for nurses to support the self-management of DSI older adults and an intervention program, the Self-Management Program for Dual Sensory Impaired older adults (SMP-DSI). The SMP-DSI was used in a cluster randomized controlled trial (cRCT) among nurses and DSI older adults in 30 LTC homes spread across the Netherlands. Nurses (n=34) of the intervention group (n=17 LTC homes) participated in a group training and were individually coached to introduce the SMP-DSI to the DSI older adults (n=54) they were linked with. Details of the methods of the cRCT are described elsewhere [14]. We performed a qualitative study alongside the cRCT. Since the SMP-DSI involves dialogues between nurses and older adults and appeals to nurses' novel interaction skills and attitudes, we monitored, trained and coached the nurses and asked them to keep diaries on the progress of the self-management intervention over a period of five months. In addition, we asked the trainers to report on the individual coaching sessions.

The aim of this qualitative study was to gain insights into the longitudinal changes



in nurses' perceptions on relevance and feasibility when trained to implement the self-management intervention among dual sensory impaired older adults in LTC, and into the factors that contributed to their changes in perceptions.

Methods

Design

The longitudinal process data for this qualitative study were taken from nurses' coaching diaries and trainers' reports collected during a 5-month training program of the intervention group which was participating in a cRCT which compared the effectiveness of the SMP-DSI to usual care [14]. This qualitative study used the content comparison approach to analyze nurses' perceptions on the relevance and feasibility of the SMP-DSI. Nurses were asked to keep diaries on the progress of the intervention, including satisfaction and dissatisfaction with their actions when performing the SMP-DSI. Other process data, on sampling quality (recruitment, reach, retention) and intervention quality (treatment delivery, adherence), are reported and discussed in a separate publication (in preparation) in combination with the effect outcome.

Participants

The participants in this study were 34 licensed practical nurses who worked at 1 of the 17 LTC homes assigned to the intervention group of the cRCT. They were asked to support a total of 54 DSI older adults; each nurse was linked to one or two DSI older adults. Inclusion criteria for nurses were (1) at least twice-weekly direct daily care contact with the participating older adult, and (2) qualified as a licensed practical nurse, that is, a 3-year basic nursing vocational training at secondary level. In the Netherlands, licensed practical nurses in LTC participate in a nursing team of registered nurses, practical nurses and nurse assistants, representing a diversity of functions and skills. Licensed practical nurses provide the majority of the daily care in LTC, and work under supervision of a unit manager, who is often a registered nurse. Licensed practical nurses play a key role in the yearly update of the care plan, documenting the individual needs and care preferences of the older adult. Nurses were approached for participation by their local manager.

Inclusion criteria for older adults were (1) a moderate-to-severe hearing

impairment of ≥ 40 decibel (pure-tone audiometry) and a moderate-to-severe visual impairment with a best-corrected visual acuity of < 0.3 diopter or with a visual field of $< 30^\circ$, measured using the criterion standards for hearing and visual impairment [15, 16] and (2) informed consent. Exclusion criteria were (1) prelingual deafness, (2) a DSI acquired before the age of 50 and (3) inability to complete interviews due to severe cognitive problems. To assess cognitive functioning, we developed a semi structured interview based on the Diagnostic and Statistical Manual of Mental Disorders IV (DSM IV) criteria for capacities in executive functioning: planning, organizing, sequencing and abstracting [17]. The procedures for assessing DSI and cognitive problems are described in the study protocol [14].

The intervention and training program

The SMP-DSI was developed as a five-step interview including problem identification (step 1), collecting alternatives (step 2), choice and planning (step 3), execution (step 4) and reflection (step 5). The SMP-DSI was based on D'Zurilla and Goldfried's [18] problem solving therapy, Holman and Lorig's [19] core self-management skills and Bakker's [20] constructive behavioural analysis, aiming to support the individual to develop feasible solutions and inviting reflection on recent successful behaviour. The theoretical background and overview of the SMP-DSI are described in the study protocol [14]. Nurses in the intervention group were trained to introduce the SMP-DSI approach when they observed that the DSI older adult had a problem or request. Table 1 (first column) reflects the key questions of the SMP-DSI. Nurses received nine training sessions that were spread over a period of 5 months, parallel to the intervention period and divided into three consecutive rounds, totaling 16.5 hours. Each round consisted of three successive sessions: (1) a 3-hour group training session, (2) 1 hour of individual coaching and (3) 1.5 hours of group supervision, with a 2-3 weeks interval between each session. Nurses were asked to practice the SMP-DSI at least once during the 2-3 weeks interval with the older adult(s) they were linked with, and to fill in an intervention and coaching diary. The group training sessions focused on the knowledge and skills required by the nurses to use the SMP-DSI. In the individual coaching sessions, the trainer invited the nurse to reflect on and evaluate her own behaviour during the interactions with the older adult when offering the SMP-DSI. In group supervision sessions, nurses shared their successes



and goals. The training program and the nurses' home assignments are described in Appendix 3 of the Supplementary Data in this thesis.

Table 1. Key questions of the SMP-DSI, coaching diary and individual coaching session

Key Questions SMP-DSI	Questions Coaching Diary	Questions Individual Coaching
<i>Nurse asks the older adult</i>	<i>Nurse fills in question 1 after practice with the older adult, and questions 2 and 3 at the end of the individual coaching session.</i>	<i>Trainer invites nurse to reflect, 'Looking back on your interview, what are you happy about?' and asks questions 1, 2 and 3, and fills in question 4 during the individual coaching session.</i>
Step 1. <i>Problem Identification</i> Would you like to do something about it?	1. Looking back on your interview with the older adult: What are you happy about, about what you did yourself? What barriers did you encounter? What would you do differently next time?	1. What did you observe in the older adult? 2. How did you align your behaviour? 3. What was the effect of your behaviour/reaction on the older adult? Did it suit the older adult? How do you evaluate your action?
Step 2. <i>Collecting Alternatives</i> What could you do about it? Are there other options?	2. Summary of the feedback you received.	
Step 3. <i>Choice and Planning</i> How do you think you will manage this?	3. What are your main learning goals for the next period?	4. When the nurse reflected on her actions: 4a. What facilitators did she mention? What was she happy about? 4b. Which barriers did she mention/what problems did she encounter?
Step 4. <i>.Execution</i>		
Step 5. <i>Reflection</i> What was the result? What are you happy about: about what you could do on your own? What would you do differently next time?		

Five social workers, employees of a rehabilitation center for DSI adults and specialized in supporting DSI older adults, were trained to coach the nurses. Four of the trainers started their career as a licensed practical nurse, and none had professional coaching experience prior to this trial. In preparation for their training tasks, they attended a training program of three group sessions of 1.5 hours at the rehabilitation center, with the aim of becoming familiar with the nurse-supported SMP-DSI and with the training program and the individual coaching approach for the nurses. During the 5-month training and intervention period, the trainers participated in three group supervision sessions of 1.5 hours each, led by a professional coach of licensed practical nurses. Special emphasis was given to the individual coaching approach for nurses. Trainers were asked to start each individual coaching session with a question similar to the first question

of the coaching diary: 'When looking back on your interview with the older adult, what are you happy about, about what you did yourself?' and to invite the nurses to reflect on their interactions with the older adult using three questions: (1) What did you observe in the older adult? (2) How did you align your behaviour? (3) What was the effect of your behaviour on the older adult? The third question could be completed by asking the nurse what she would do differently (identical to step 5 of the SMP-DSI—see table 1) and what alternative actions she could think of (identical to step 2 of the SMP-DSI). Table 1 (columns 2 and 3) lists the key questions of the coaching diary and of the individual coaching session.

Ten training groups at 10 different locations started with an average size of 4 nurses per group (range 1-7). Each training group was organized in the neighborhood of the LTC homes of the participating nurses. Two trainers were allotted to each training group: one gave the three group training sessions, and the other conducted the individual coaching and supervision sessions.

Longitudinal data collection

Longitudinal data from the nurses' semi structured coaching diaries were collected over the 5-month intervention and training period, and from the verbatim quotes of nurses collected by the trainer during the individual coaching sessions. The coaching diaries were developed and used as a coaching tool: nurses were asked to reflect on their behaviour and to write these reflections down in their coaching diary immediately after their interview with the older adult. At the end of each training session, nurses were asked to add their learning goals, then the diaries were copied and the copy was handed over to the trainer. In addition, the most recent diary was used at the start of the individual coaching, focusing on the first question. During and at the end of the individual coaching session, nurses were able to complete or change their notes. Trainers were asked to report nurses' verbatim quotes when they expressed either satisfaction or dissatisfaction during the individual coaching sessions. After each session, the trainers posted the coaching diaries and their own reports to the researcher.

Process outcomes and data analyses

Nurses' perceptions on relevance and feasibility of the intervention were the process outcomes analyzed in this study. Prior to the analyses, an administrative assistant transcribed each handwritten coaching diary in a digital MSWord



document and linked it with the corresponding verbatim quotes reported by the trainers. Each document was anonymized and provided with a code referring to the nurse. These documents were independently coded by authors LMR-M and MKD, applying the constant comparison approach based on the grounded theory and using ATLAS-ti V.7.0.92 software [21]. First, the data were given conceptual labels (=codes) which were closely related to the text fragments; these codes were compared and discussed between the two authors until they reached consensus. They then grouped the codes referring to the same phenomenon into categories, and the categories into themes. To check their interpretations, they sent the results of the qualitative analysis to the trainers and asked for written comments.

Findings

Nurses' perceptions on the relevance of the intervention

Table 2 shows nurses' perceptions on relevance of the intervention, and the evolution of these perceptions (last column in table 2). The first three columns represent the themes, categories and codes that emerged. The last column represents the distribution of nurses' perceptions spread over the nine sessions when data were collected, offering an impression of the changes in the perceptions in the course of the 5-month intervention and training period. After performing content analysis on the data of the coaching diaries and verbatim quotes of the nurses, two themes, that is, *barriers* and *facilitators*, emerged.

The two categories that emerged in the theme *barriers* were (1) *conflictive to usual care and to professional autonomy* and later on (2) *usual care was conflictive to client-autonomy*. At the start, the nurses' initial perceptions were distinctly negative. They were convinced that any support to enhance autonomy of the older adults was superfluous, and that the intervention would endanger the nurses' actual responsibilities and autonomy. They believed in their competence to recognize the needs of the older adult, and emphasized that the key element of their job was to act and care for the older adult, and that there was no need to consult or interact with them. In contrast, they advised not to bother the older adult with questions.

Nurse 4: We prevent the older adults from having problems, we protect them, that's our job, that's why I became a nurse.

Nurse 14: Autonomy is already warranted as we ask each older adult once or twice a year what he wants, and note it down in the individual care plan.

The first barrier category *conflictive to usual care and to professional autonomy* altered when nurses started practicing the SMP-DSI, and was gradually supplanted by a second barrier category *usual care was conflictive to client-autonomy*. During the individual coaching sessions, when answering the three key questions, nurses became aware that they were used to providing care favoring their own autonomy rather than that of their clients, and of their habit of steering and decision making and imposing solutions without consulting the older adult. They discovered that it was not usual for them or their colleagues to approach older adults with an open mind to their needs. In addition to these discoveries, nurses were willing to look critically at their own behaviours, and an ongoing number of learning goals aimed at changing their habits appeared. However, despite these intentions, nurses reported that it was difficult to change their behaviour. The second barrier category emerged from nurses' numerous reports of their own and their colleagues 'automatism' of taking over, which hindered the performance of the SMP-DSI, and thereby blurring their perceptions on what the intervention could offer.

Nurse 20: I had put forward my ideas, but had forgotten to ask my client for his view on a solution.

Nurse 28: I have been struggling with myself; I became aware that I usually focus on the problem and its solution, rather than on the needs of the older adult.

Nurse 2: It feels odd to see that the older person makes other choices than I would have made.

Nurse 12: When the older lady wanted to execute the plan we discussed the day before (taking her jacket with her to the dining room), my colleague wouldn't let her do so.

A first facilitator category *interaction with the older adult* emerged soon after nurses had started practicing the intervention, and was consolidated in the course of the intervention period. Nurses observed relief and enthusiasm in the



Table 2. Longitudinal content analysis of the perceptions of the nurses on relevance of the SMP-DSI

Themes	Categories	Codes	Course of perceptions Sessions of data collection																			
			1	2	3	4	5	6	7	8	9											
Barriers	Conflictive to usual care and to professional autonomy	Belief that nurses' task is to prevent older adults from having problems	X																			
		Belief in own competence to recognize wishes of older adults	X																			
		Belief that autonomy of older adults is already warranted by care plan	X																			
		Aim to avoid bothering the older adult	X																			
		Belief that key element of nursing is hands-on caring, not talking or interacting	X																			
		Awareness of automatism of taking over	X			X	X	X	X	X												
		Tendency to solve problems without consulting the older adult				X	X	X	X	X												
		Belief that usual care does not match wishes of older adults				X	X	X	X	X												
		Discovery of having an open mind towards wishes and needs of older adult is not obvious				X	X	X	X	X												
		Awareness of automatism of imposing solutions on older adults				X	X	X	X	X												
Facilitators	Interaction with older adult	Belief that wishes and aims of older adults are not key in usual care								X	X	X	X	X	X	X	X	X	X	X		
		Suits older adults								X	X	X	X	X	X	X	X	X	X	X	X	
		Satisfaction of older adult								X	X	X	X	X	X	X	X	X	X	X	X	
		Motivates older adult								X	X	X	X	X	X	X	X	X	X	X	X	
		Helps to reveal the individual behind the older adult								X	X	X	X	X	X	X	X	X	X	X	X	
		Increases autonomy of older adult								X	X	X	X	X	X	X	X	X	X	X	X	
		Demands a different way of thinking								X	X	X	X	X	X	X	X	X	X	X	X	
		Encourages getting rid of 'taking over' care								X	X	X	X	X	X	X	X	X	X	X	X	
		Distinguishes between autonomy and independency								X	X	X	X	X	X	X	X	X	X	X	X	X
		Encourages getting rid of thinking in terms of problems and solutions								X	X	X	X	X	X	X	X	X	X	X	X	X
Improvement of care	Innovative learning	Encourages behavioural change																				
		Encourages shared decision making																				
		Useful in conflictive situations																				
		Increases the understanding of the impairments of the older adult								X	X	X	X	X	X	X	X	X	X	X	X	
		Meets needs in daily care and practice								X	X	X	X	X	X	X	X	X	X	X	X	
		Beneficial for older adult								X	X	X	X	X	X	X	X	X	X	X	X	
		Program is broadly applicable								X	X	X	X	X	X	X	X	X	X	X	X	
		Contributes to personalized care								X	X	X	X	X	X	X	X	X	X	X	X	
		Increases respect for autonomy of older adult								X	X	X	X	X	X	X	X	X	X	X	X	
		Improves relation with older adult								X	X	X	X	X	X	X	X	X	X	X	X	
User program will disseminate program	Meaningful approach	Should be included in education program for nurses																				
		User program will disseminate program																				
		Increases the understanding of the impairments of the older adult								X	X	X	X	X	X	X	X	X	X	X	X	
		Meets needs in daily care and practice								X	X	X	X	X	X	X	X	X	X	X	X	
		Beneficial for older adult								X	X	X	X	X	X	X	X	X	X	X	X	
		Program is broadly applicable								X	X	X	X	X	X	X	X	X	X	X	X	
		Contributes to personalized care								X	X	X	X	X	X	X	X	X	X	X	X	
		Increases respect for autonomy of older adult								X	X	X	X	X	X	X	X	X	X	X	X	
		Improves relation with older adult								X	X	X	X	X	X	X	X	X	X	X	X	
		Meaningful approach								X	X	X	X	X	X	X	X	X	X	X	X	



older adults when they invited the older adults to search for and think about alternative solutions jointly.

Nurse 41: He enjoyed it when I asked 'Would you allow me to think along with you?'

Nurse 48: Mrs. X completely revived during our conversation; it gave me energy.

A second facilitator category emerged in the further course of the intervention period: *innovative learning*. From the start, nurses appreciated this different way of thinking. Gradually, they got a better understanding of what autonomy meant, and how they could support the older adults to take a sense of control of their lives. They reported being able to see now how autonomy contrasted with independency, self-care and care, and felt encouraged by their experiences of getting better insights into what shared decision making involved. A third facilitator category *improvement of care* emerged when nurses reported that the intervention met the needs of the older adults, and that their positive perceptions increased in the second half of the intervention period. Eventually, an unintended but widely spread opinion was reported: nurses perceived the SMP-DSI as a relevant instrument for all of their patients, whether they had sensory impairments or not.

Nurse 28: Interacting, talking and listening to each other, looking at the person, that's what autonomy support is.

Nurse 14: I saw another person, he revived. Although we did not find a solution, I saw he was happy and in control. Nurse 27: I'm going to use these steps with other residents, it helps older adults to maintain their self-esteem.

Nurse 47: The steps allow you to intensify the contact with the older adults. I also use the steps with other clients; they grow when they feel that they are empowered to take as much control of their lives as they can.

In two different homes, the first barrier category *conflictive to usual care and to professional autonomy* was stronger and lasted longer. In individual coaching sessions, three of the six nurses explained that their residents did not have any problems, as the nurses solved every possible problem for them. Interviewing older

adults about their problems and alternative solutions would demonstrate that older adults had unresolved issues, and that could be interpreted by the management as proof of shortcomings of the nursing staff.

Nurse 46: If a resident wants something, then it has to happen right away, otherwise we get an official reprimand.

Nurse 52: I feel a lot of resistance towards this approach, our clients are already greatly spoiled. The principle here in the house is: your wish is our command.

Nurses' perceptions of the feasibility of the intervention

Table 3 shows nurses' perceptions on feasibility of the intervention, and the evolution of these perceptions (last column in table 3) in the course of the intervention period. Two themes emerged, that is, *barriers* and *facilitators*. Among the theme barriers, three categories emerged: (1) the intervention was perceived as *not suited for older adults*, (2) the *conversation techniques were unfamiliar* to the nurses and (3) the nurses reported being worried about a *challenging work environment*. These three barrier categories reflected nurses' beliefs that older adults were too passive and institutionalized to take part in the intervention, that having conversations with older adults was too demanding and time-consuming, and that a huge workload, lack of planning facilities and conflicts in their team and organization hindered interaction with the older adults.

Nurse 20: Let them rest, older adults don't think or feel so deeply.

Nurse 11: Having conversations, what a daft idea! That means endless empathic listening, and tiresome searching for the question behind the question.

Nurse 32: It's difficult to concentrate on a new approach when my team is quarreling about daily routines.

Moreover, when first introducing the intervention, nurses observed reservation and anxiety in the older adults; three older adults even panicked. Nurses succeeded in reassuring the older adults by rephrasing their first question, asking them to focus on wishes or on something they would like to change, instead of asking them to identify a problem.



Nurse 22 quotes an older adult: Why do you spend so much time on me? I remember earlier that the nurses also asked Mr. Jansen a lot of questions, and after a while he was transferred to the ward with demented people.

Nurse 47 quotes an older adult: If I complain about something, your colleagues immediately react negatively.

The second barrier category *unfamiliar with conversation techniques* emerged at the start, but the content altered during the intervention period. Nurses started with a widely reported opinion that having a conversation was identical to long-lasting empathic listening and intuitive in-depth questioning. However, in parallel with the increasing awareness of the relevance of the intervention, nurses continued to struggle with, and succeeded in making steady progress with getting acquainted with the semi structured conversational style. When practicing, nurses discovered strengths and pitfalls which eventually led to their conclusion that more practice and coaching was needed.

Nurse 43: I forget to take every step; next time I'll take the list of questions with me.

In the course of the intervention period, reports on the third barrier category *challenging work environment* faded away. Gradually, facilitators came into view. The facilitator category *supportiveness of the program and the coaching* emerged in nurses' perceptions of the simple and transparent structure of the SMP-DSI. At the end of the intervention period, nurses recommended sharing their experiences with other nurses, as a factor for creating better options to integrate the intervention in usual care.

Nurse 41: The hold that the program gives me on the conversation makes me feel free.

Nurse 23: We discussed the approach at a team meeting, they should know that it suits the view of our home.

Nurse 6: A yearly update would be helpful, for us all, as steering and taking over has become such a second nature to us nurses.

Nurse 47: Why didn't they teach us this before?

Discussion

This study resulted in new insights into the longitudinal changes in nurses' perceptions towards relevance and feasibility when implementing a self-management intervention for dual sensory impaired (DSI) older adults in LTC, and into the factors that contributed to their changes in perceptions. A key finding of this study is that the longitudinal evolution of nurses' perceptions stresses the need to support nurses over a period of months to facilitate and consolidate their move towards autonomy support in dialogues with the older adults. It was only during the performance of the intervention, in interaction with the older adults and in consecutive self-evaluations, that nurses started to sense what autonomy implied and what it could do for older adults.

The initial negative perceptions of the nurses on relevance changed into positive ones as they better understood the concept of autonomy for their clients. This changed from a concept focusing on choices based on the nurses' solutions, towards a concept which stimulated the sense of control of older adults by offering support and discussing alternative solutions. The initial negative perceptions on feasibility altered when the nurses discovered the strengths of conversational techniques, but eventually nurses expressed their need for a longer learning period. An important factor contributing to the changes was the longitudinal combination of nurses' interactions with the older adults and self-evaluations, enabling nurses to recognize the conflictive effect of usual care on client-autonomy and helping them explore behavioural alterations to adapt to the autonomy needs of the older adults. Eventually, the nurses noted that the intervention was relevant for all of their clients, whether they were dual sensory impaired or not.

The findings on nurses' initial negative perceptions are similar to those reported in previous studies on client-autonomy, characterized by nurses' persistence on their expert caring role, feeling responsible for preventing any problems and/or discomfort in their older adults [22]. A novel finding in our study was that of the changes in nurses' perceptions. Previous research shows a contrast between the findings of nurses' positive assumptions to act in line with the choices of the older adult versus the findings of having limited involvement of older adults in decision making [23, 24]. However, to the best of our knowledge, there are no other studies that have investigated the change of nurses' perceptions when being trained and implementing an autonomy supportive of self-management intervention.



Table 3. Longitudinal content analysis of the perceptions of the nurses on feasibility of the SMP-DSI

Themes	Categories	Codes	Course of perceptions Sessions of data collection																	
			1	2	3	4	5	6	7	8	9									
Barriers	Intervention not suited for older adults	Belief older adults are no longer used to think for themselves; are too old and tired	X																	
		Belief that older adults are passive and institutionalized	X																	
		Belief that older adults are not familiar with having conversations	X																	
		Belief autonomy support is not suited to older adults	X																	
		Older adults play down their problems		X																
	Unfamiliar with conversation techniques	Older adults feel threatened by attention of nurse		X	X	X														
		Older adults fear being seen as a troublemaker		X	X	X														
		Assumption that interviewing older adults involves endless empathic listening	X	X																
		Expectation that interviewing involves in-depth questioning	X	X																
		Intervention that requires specific communication skills		X	X															
Challenging work environment	Supporting older adult	Forget to use SMP-DSI steps when interviewing		X	X	X														
		Creating opportunities for older adult to deliberate requires time and mental space		X	X	X														
		Supporting older adult in thinking and deliberating requires specific skills		X	X	X														
		Structuring a <i>professional</i> conversation requires specific communicative skills					X													
		New knowledge and skills need more practice					X													
	Challenging work environment	Not feeling confident about using program without support of coach																		
		Huge workload	X																	
		Lack of planning facilities	X	X																
		Conflicts in care organization																		
		Conflicts in team, between colleagues																		

Table 3. (Continued)

Facilitators	Supportiveness of SMP-DSI and training program	SMP-DSI structure provides grip		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
		Coaching increases insights into own functioning			X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
		SMP-DSI steps and structure motivate				X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
		Importance of coaching				X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
		Individual coaching facilitates implementation				X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Comfort of program	Program facilitates managing the conversation	Pleasant approach, gives energy; makes job more enjoyable																		
		Time investment is not too bad																		



Exploring the evolution in nurses' perceptions allowed us to identify three challenging areas when expanding client-autonomy in LTC: (1) the care plan, (2) nurses' interactions and conversation techniques, and (3) the role of licensed practical nurses.

First, our findings suggest that care plans might obstruct the autonomy of frail older adults. Initially, nurses expressed that client-autonomy was secured by the care plan as they asked 'each older adult once or twice a year what he wants'. These perceptions reflect a consumer-driven perception of client-autonomy and care planning. O'Dwyer [25] showed that residential care is often portrayed as consumer-driven, with a hotel-like service and residents as discerning consumers, and suggested that this type of care may suit assertive and independent younger older adults, but may be questioned when frail and care-dependent older adults are involved. As a consequence of nurses' perceptions that client-autonomy was warranted, they perceived alignment and dialogue with the older adult in daily care as being superfluous. Illustrating this lack of alignment were the feelings of unsafety at the start of the intervention among both stakeholders: older adults covered up their problems in reaction to the unexpected and unfamiliar attention of the nurses for their problems; and nurses held on to their to-do list derived from the yearly care plan. However, nurses' reports of the positive reactions of the DSI older adults in the course of this trial, and the increased number and variety of problems and wishes DSI older adults mentioned [26] (described in a separate study in preparation) when compared with the problems mentioned in routine care plans, stress the need for ongoing alignment in daily care. Our findings suggest that, without alignment, nurses risk remaining unaware of the changing challenges in the older adult, and thereby are unable to support the older adults to adapt and self-manage their social health, that is, to function with fulfilment and a feeling of well-being despite chronic disabilities [27, 28].

Second, the training in interaction and communication techniques used in this study contributed to nurses' awareness and contentment with using an interview structure, that is, a tool that provides structure when discussing with older adults. The nurses in this study demonstrated that they were fully conversant with empathetic listening; however, they had not been trained in professional conversational skills like interviewing. Initially, they associated empathy negatively with endless listening and pretending to be interested, and their initial

interaction and dialogues with the older adults were found to be scarce. Their unfamiliarity resulted in feelings of helplessness, which might have contributed to the steering behaviours noted in this study, as well as in several other studies [29, 30], and demonstrated the need for introducing generic autonomy supportive conversational skills among nurses.

Finally, the role of the licensed practical nurse as a member of the nursing team is a current subject of discussion in LTC [31, 32]. In the Netherlands, there is a tendency to exclude practical nurses from consulting older adults, with the argument that their education level might be too low or too practical for the learning process needed. However, nurses' changing perceptions as demonstrated in this study illustrates their abilities and motivation to move forward in autonomy and self-management support. This finding should be taken into consideration when developing policies for an optimal functional diversity of nursing staff in LTC, especially regarding the role of the practical nurses.

Strengths and limitations

A strength of this study was that nurses' perceptions were collected longitudinally, from the start to the end of the intervention period. An important limitation of the study was that only one or two nurses in a team participated in the training program, so the exchange of experiences between colleagues in a team was restricted. A second limitation was that nurses did not voluntarily present themselves for participation in the trial. After inclusion of the older adults, we asked the manager to link the older adult with an eligible nurse who was familiar with the participating older adult. This was done for practical reasons, in spite of research findings that voluntariness of the health professional contributes to the success of the intervention [33]. Since the number of eligible licensed practical nurses per team was limited, the risk that the manager's choice would induce a selection bias was limited. Another limitation involved the data collection. Since the coaching diaries were developed and used as coaching tools, and were collected by the trainers, they might have induced a more positive reporting. There is a risk that the nurses wanted to please their trainers, and that the trainers might have wanted their coaching work to result in positive outcomes. However, the quality of the data may also have benefited from the use of coaching data, revealing a variety of barriers and facilitators experienced by the nurses under real 'field' situations. Finally, we did not interview the older adults on their



perceptions of barriers and facilitators of the intervention. We avoided this for ethical reasons, as questioning could be interpreted as a check on the nurse's performance, and could compromise older adults' loyalty to their nurse.

Practical implications

This study is one of only a few that explores the changing perceptions of nurses when supporting client-autonomy in LTC. For care planning, our findings suggest that policymakers in LTC should consider broadening their views on care plans, and daily alignments in daily care should be encouraged. With regard to psychosocial intervention programming, our findings indicate that generic autonomy supportive conversational techniques should be introduced to practical nurses as a first step in facilitating autonomy and self-management of older adults. Evidence-based conversation techniques such as narrative interviewing and shared decision making may contribute to bridge the gap in nurses' competences. Furthermore, education programs should take into account that nurses have to undergo a lengthy learning process of ongoing practice and sustained support, including interactions and self-evaluations. Eventually, increasing the range of skills and capacities of practical nurses can facilitate the development of an optimal autonomy-supportive function diversity of nursing staff in LTC.

Scientific implications

Longitudinal detection of the barriers and facilitators enabled us to follow the factors affecting nurses' perceptual change processes throughout the trial. We recommend that implementation research should more explicitly acknowledge that change is a process rather than an event, and that future process evaluations should therefore include self-evaluations of professional behaviours over a period of time. The insights gained by longitudinal process evaluation may accelerate the scope for improved implementation of psychosocial interventions in healthcare practice.

Conclusions

Longitudinal data collection enabled an exploration of nurses' changes in perceptions towards self-management and autonomy of their clients. The findings stress the need for ongoing support of nurses to facilitate and consolidate their move towards autonomy support in a dialogue with the older adults. Training programs for nurses should focus on these topics of autonomy support by including narrative communication techniques and shared decision making techniques. Future research needs to review the effectiveness of the changes in attitudes and behaviours in LTC on client-autonomy and nurses' job satisfaction, and should include a longitudinal process evaluation.



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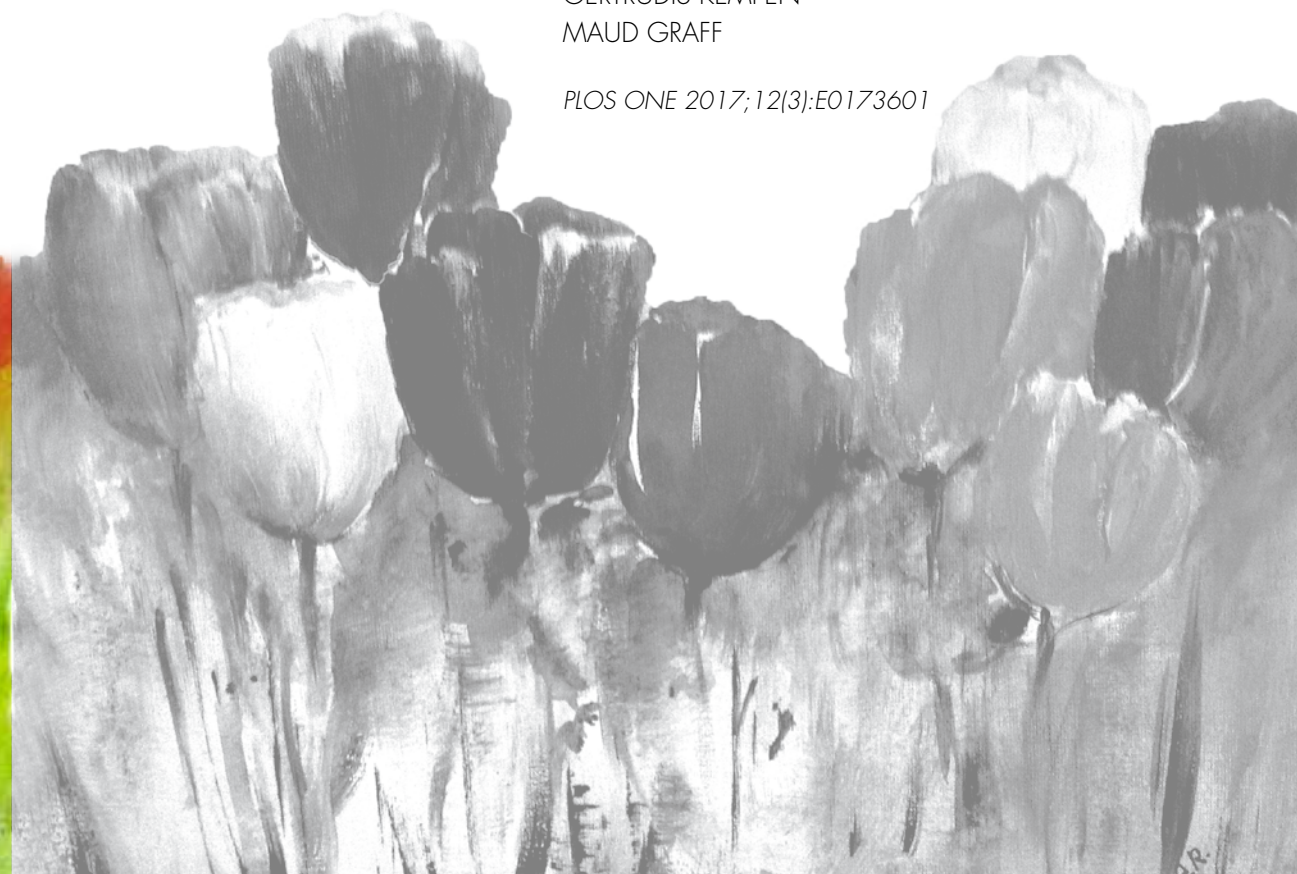


CHAPTER 6

PROBLEMS IDENTIFIED BY DUAL SENSORY
IMPAIRED OLDER ADULTS IN LONG-TERM
CARE WHEN USING A SELF-MANAGEMENT
PROGRAM: A QUALITATIVE STUDY

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Abstract

Objective: To gain insights into the problems of dual sensory impaired older adults in long-term care. Insights into these problems are essential for developing adequate policies which address the needs of the increasing population of dual sensory impaired older adults in long-term care.

Methods: A qualitative study was conducted in parallel with a cluster randomized controlled trial. Dual sensory impaired older adults in the intervention group (n = 47, age range 82-98) were invited by a familiar nurse to identify the problems they wanted to address. Data were taken from the semi-structured intervention diaries in which nurses noted the older adults' verbal responses during a five-month intervention period in 17 long-term care homes across the Netherlands. The data were analyzed using descriptive statistics and qualitative content analysis based on the Grounded Theory.

Findings: The 47 dual sensory impaired older adults identified a total of 122 problems. Qualitative content analysis showed that the older adults encountered participation problems and problems controlling what happens in their personal environment. Three categories of participation problems emerged: (1) existential concerns of not belonging or not being able to connect with other people, (2) lack of access to communication, information and mobility, and (3) the desire to be actively involved in care delivery. Two categories of control-in-personal-space problems emerged: (1) lack of control of their own physical belongings, and (2) lack of control regarding the behaviour of nurses providing daily care in their personal environment.

Conclusions: The invasive problems identified indicate that dual sensory impaired older adults experience great existential pressures on their lives. Long-term care providers need to develop and implement policies that identify and address these problems, and be aware of adverse consequences of usual care, in order to improve dual sensory impaired residents' autonomy and quality of life.

Introduction

The prevalence of dual sensory impairment (DSI) among older adults in long-term care (LTC) facilities has increased rapidly from 12% in 2005 to 33.9% in 2016 and is expected to continue to grow strongly [1, 2]. DSI has been linked to an augmented risk of depressive feelings, cognitive decline and mortality, and to decreased functional independence, and limited communication and interaction [3-7]. Research showed that DSI residents in LTC who were involved in activities did not have a higher mortality than a comparable group of non-DSI residents, while residents with DSI who were not involved in activities had a 51% higher mortality [8].

Since the new millennium, the LTC-population in the Netherlands has greatly altered; from being a relatively independent 70+ population, it has become an 85+ population suffering from a complex of age-related diseases, highly dependent on professional care [9]. Consequently, it is not clear if the current LTC-policies towards sensory impairment are still adequate for the current population. For the pre-millennium LTC population, a sensory impairment was primarily an individual problem that could be addressed at an individual level by medical treatment, device provision, and possibly a psychosocial rehabilitation program. After having completed this 'cure and care' program, LTC residents with their (often single) sensory impairment, were expected to be able to cope independently and to self-manage daily activities adequately. Therefore, sensory impairment was given low priority in LTC. Until now, expertise centers for aged care and hearing or visual rehabilitation recommend an annual screening of both hearing and vision as best practice, with, if necessary, a referral to relevant medical specialists or device providers, supplemented with nurse attention for correct use of the devices [10, 11].

However, findings from research and practice question the effectiveness and substantiation of the current LTC policies towards the needs of the increasing number of DSI residents with aggravated mental, sensory, and physical conditions. First, a lack of adequate hearing and visual screening has been reported. LTC facilities often overlook and poorly document the incidence of a hearing and/or visual impairment [12, 13]. Furthermore, more often than in the pre-millennium LTC population, the current frail elderly population suffer from an advanced hearing or visual disease such as age-related macular degeneration, diabetic



retinopathy or presbycusis. These diseases cannot always be sufficiently addressed by medical treatment and/or compensated by device provision. In addition, the psychosocial rehabilitation programs that are offered either in combination with or subsequent to hearing aid or low vision device provision, are found to have limited effect for older adults [14]. Finally, whereas a single sensory impairment can be more or less compensated by using the other sense, individuals with a DSI cannot rely on any compensation and therefore need new coping measures and support.

Until now, little is known about the problems and needs which the DSI older adults encounter in LTC in their daily lives. Consequently, little is known about the support and solutions LTC facilities could create to alleviate these problems and improve their quality of life. The aim of this qualitative study is to gain insights into the problems identified by DSI older adults in LTC.

Methods

Study design and ethical approval

This qualitative study was conducted in parallel with a cRCT that assessed the effectiveness of a self-management program for dual sensory impaired older adults (the SMP-DSI program) on social participation, and was performed between August 2011 and April 2014. Details of the cRCT methods are available in the study protocol [15]. The study design and protocol of the RCT and connected qualitative studies was approved by the Dutch Committee on Research involving Human Subjects region Arnhem-Nijmegen, ABR 26192.091.08. This qualitative study focused on older adults problems and needs by analyzing the quotes of the older adults' verbal responses as noted by the nurses in their' semi-structured intervention diaries, and collected during a five-month SMP-DSI intervention period in 17 long-term care homes across the Netherlands. The data were analyzed using descriptive statistics and qualitative content analysis based on the Grounded Theory. Trial registration: Clinical Trials NCT01217502.

Study participants

In total, 47 DSI older adults participated in the qualitative study. They were residents of one of the 17 LTC homes allocated to the cRCT intervention group. The inclusion criteria for the residents were (1) aged 55 or over, (2) a hearing

impairment of PTA ≥ 40 dB (best ear) and a visual impairment with a best-corrected visual acuity of < 0.3 diopter or with a visual field of $< 30^\circ$, measured using the criterion standards for hearing and visual impairment [16, 17] and (3) written informed consent. Exclusion criteria were (1) prelingual deafness, (2) a DSI acquired before the age of 50, and (3) inability to complete interviews due to cognitive problems, as assessed using the DSM IV criteria for capacities in executive functioning [14, 18]. Each eligible older adult was linked to a licensed practical nurse. Prior to the start of the intervention, the DSI older adults were interviewed following the guidelines of the study protocol and interview guide. We collected demographics and characteristics on native language, preferred communication modality, and care dependency when performing daily activities. Care dependency was measured using the Katz-ADL index (bathing, dressing, toileting, transferring and feeding), with scores ranging from 0 to 5 with a higher score indicating more dependency [19].

After inclusion of the eligible DSI older adults, the manager invited nurses familiar with the dual sensory impaired older adult to participate in the study. The nurses ($n = 34$) who verbally accepted the invitation were linked to one or two DSI older adults. Inclusion criteria for nurses were (1) at least twice-weekly direct daily care contact with the participating older adult, and (2) qualified as a licensed practical nurse, that is, a three-year basic nursing vocational training at secondary level.

In accordance with the consent procedure of the Dutch Committee on Research involving Human Subjects region Arnhem-Nijmegen, the written consent given by the older adults for participation in the hearing and visual measurement, and if eligible, for participation in the trial, were documented in the research database and archived in the research file. The names and contact information of the nurses who were invited by their manager and who verbally consented to participate were documented in the research database.

Data collection

In individual sessions, the nurses invited their DSI older adults to identify problems, wishes or things they wanted to alter or address. This invitation was the first step of the Self-Management Program for Dual Sensory Impaired older adults (SMP-DSI). In accordance with the design of the problem solving therapy and self-management programs, nurses did not ask the older adults to restrict



their problems to the LTC environment nor to DSI-related issues [20-22].

Nurses were asked to introduce the SMP-DSI to the DSI older adult at least every three weeks over the five-month intervention period and to literally quote the older adults' verbal responses in a semi-structured intervention diary during or immediately after the interview with the DSI older adult. Every two months, research assistants collected the nurses' intervention diaries and posted them to the research team.

Data analysis

Prior to the analyses, an administrative assistant transcribed each handwritten intervention diary in a digital MSWord document. Each document was anonymized and given a code referring to the older adult and the nurse. To analyze the data qualitative content analysis was performed using the constant comparison approach based on the Grounded Theory [23]. Two authors, each with a different background, LRM (psychologist) and MD (general practitioner) independently analyzed the data through a process of inductive comparison and reasoning, starting from the collected data and not from preexisting theories. After reading and re-reading the transcriptions, the two authors developed the emergent themes following a series of coding steps. Firstly (open coding), initial coding was generated by coding chunks of the transcripts which were given conceptual labels (= codes) closely related to the participants' words to isolate the basic units of meaning. Both authors compared and discussed these codes until they reached consensus. Next (axial coding), they identified relations between the initial codes and grouped those codes referring to the same phenomenon into categories. Here again, the two authors discussed these categories until consensus was reached. Finally (selective coding), the categories were organized into themes, and discussed until consensus was reached. The results of this inductive analysis were not sent to the DSI older adults or to the nurses; they were sent to the trainers who were then asked to provide written feedback. ATLAS-ti version 7.0.92 software was used during this process of analysis [24].

Findings

Demographics

Forty-seven older adults participated in the intervention. Their ages ranged from 82-98 years, with a mean (SD) age of 90.8 years (SD = 4.4). Thirty-four (72.3%) of them were women, and 43 (91.4%) were widowed or lived without partner. They were moderately to severely dependent on support when performing daily activities; the Katz-ADL index was 3.7 (SD = 1.1). All were native Dutch speakers and their preferred communication modality was speech, none of the participants used tactile communication. Pure-tone audiometry showed that 34 (72.3%) older adults had a moderate hearing loss ranging between 40-60 decibels (average threshold of the frequencies between 1000, 2000 and 4000 Hertz of the best ear), 9 (19.1%) persons had a severe hearing loss ranging between 61-80 decibels, and 4 (8.5%) showed a profound hearing loss ≥ 81 decibels. Measurements of visual acuity, visual field and self-reported visual problems gave 14 (29.7%) participants with a moderate visual impairment (visual acuity ≥ 0.5 -0.3 diopter with additional reading and/or visual field problems and self-reported visual problems), 12 (25.5%) a low vision (visual acuity 0.3-0.05 diopter) and 21 (44.6%) a profound low vision (visual acuity ≤ 0.05 diopter). A total of 258 intervention diaries were collected, showing 122 different problems identified by the DSI older adults. Table 1 presents the results of the qualitative content analysis based on those 122 problems. Two themes of problems emerged from the constant comparison approach: the participation problems and control-in-personal-space (CIPS) problems. Seventy-eight (64%) of the 122 problems belonged to the participation theme and 44 (36%) to the control-in-personal-space theme. Although nurses did not ask to restrict the problems and wishes to the LTC environment, all 122 problems were related to the daily life and care in LTC; not one referred to the family or private social life of the older adults.



Table 1. Problems Identified by the Older Adults using the SMP-DSI

Themes	Categories	Codes
Participation	Existential concerns	Feelings of not belonging; solitude; not being able to connect with others; shame; fear to behave foolishly; emptiness; aimless days; fear of being forgotten
	Lack of access	Not being able to understand what others are saying; not being able to recognize others when passing them in the corridor; not being able to get information about what happens in the surroundings; not being able to orientate in and around the setting
	Care delivery	Negotiation on the planning and organization of care; adjustment of appointments; dissatisfaction with behaviour of care staff; dissatisfaction with changes introduced by the management
Control-in-personal-space	Lack of control on physical belongings	Not being able to control medication intake; no overview of the placement of furniture in own apartment; not being able to retrieve personal belongings from cupboard or wardrobe; not being able to use technical devices properly; not being able to identify drinking cups, dinner sets or cutlery
	Lack of control on the support of the nurses	Uncertainty what nurses do with medications; uncertainty what nurses do with personal belongings of the older adult

Participation problems

The theme participation reflects three categories: (1) the existential concerns of DSI older adults not to be able to belong to, to connect with other people or to behave appropriately (n = 23 problems), (2) the lack of access to communication, information and moving around freely (n = 29), and (3), the desire to be actively involved in care delivery (n = 26). Examples of participation problems identified by the DSI older adults and noted by the nurses in the intervention diaries are:

Category existential concern

P 38: I can't go to the day care; I feel stupid, I don't recognize anyone: they might say things to me that I can't understand.

P 47: You and your colleagues have forgotten me for two days, I was ill in bed, you probably thought I was asleep, I didn't hear or see you.

Category lack of access

P 3: I can't read the home's newsletter.

P 12: I find it really difficult to communicate with my neighbor.

P 6: I can't find my way to the bench outside.

Category care delivery

P 33: The doctor is always too late for the appointment; usually they come at lunchtime. Then it takes a lot of energy to get to my room, but I don't dare tell her.

P 67: I'm not happy with the care plan drawn up for me.

Control-in-personal-space problems

The theme control-in-personal-space reflects the lack of control of DSI older adults regarding (1) their own physical belongings (n = 26), and (2) on nurses' support when handling these belongings and medications during daily care (n = 18). Examples of CIPS problems identified by the DSI older adults and noted by the nurses in the intervention diaries are:

Category lack of control on physical belongings

P 56: I'd like to better position the furniture in my room.

P 19: I can't feel the difference between the front and back of my sweater.

Category lack of control on the support of the nurses

P 37: The nurse said something, her name or something like that, put something in my fridge, and quickly went away, I'm not sure who she was and what she did.

P 41: The nurse said that the medicine is the same, but I don't really believe her, I can feel that they are a different shape.



Discussion

In this study, qualitative content analysis based on the Grounded Theory identified participation and control-in-personal-space (CIPS) as main problem themes amongst dual sensory impaired (DSI) older adults in long-term care (LTC). Among the participation problems, existential problems like the fear of not being able to connect with others emerged, as well as problems about access to communication, information and moving around freely, and in care delivery. Among the CIPS problems, lack of control over physical belongings and nurse support when manipulating these belongings emerged as issues. All categories of problems were related to daily life and care in the LTC setting. The findings suggest that the DSI older adults feel threatened in their existence as a social human being; they feel unable to reach out to others, to be aware of what is happening in their environment, or to discuss and negotiate about the care they receive. In addition, they feel hindered in using their physical belongings properly, and in controlling the professionals' support and handling of their belongings.

Our findings are in line with the limited number of studies that have identified either social isolation, decreased functional independence, or problematic communicative interactions as important risks of DSI at an advanced age [5, 7, 25]. However, the qualitative content analysis performed in this study helped produce a more coherent and overarching picture of the problems of DSI in this group. Our findings suggest that DSI is not associated with a single problem, but that a complex of invasive problems threatens the social, mental and physical health of the DSI older adult.

Although the DSI older adults participating in this study differ greatly from deafblind persons who acquired a DSI at an early stage of life, our findings are most consistent with those found in the literature on deafblindness. The term deafblind is primarily reserved for children and younger adults whose development is greatly affected by the early onset of the DSI. The DSI older participants in our study acquired DSI at an advanced age, having led a 'normal' life, and therefore being accustomed to participating in a hearing and sighted community and using spoken language. Despite these differences, our finding of participation problems among the DSI older adults is in line with the literature on these deafblind younger adults, who describe participation problems as the main and overarching risk of deafblindness [26-28]. There is a strong similarity between the category lack of

access that we found among the older adults, and the three classic domains that are usually aimed at in deafblind rehabilitation, i.e. (1) problems in communication, (2) acquisition of information, and (3), spatial orientation and moving around freely. However, there are some differences. The DSI older adults in our study added existential concerns like fear of not being able to connect, or the fear of behaving inappropriately, to the list of DSI-related problems. In addition, whereas deafblind youngsters attempt to acquire independency through self-help skills, the older adults in this study did not primarily show a desire to regain these skills, but to be able to control their own activities and those of care providers when handling their belongings or medication. In conclusion, whereas the deafblind literature and education concentrate on the development of communication and self-help skills of the younger adults [29], the findings in this study highlight the need to concentrate on and address the existential pressure, including feelings of fear and shame, and on the lack of control that DSI older adults experience.

At first sight, the participation problems found in this study seem in line with the feelings of social isolation found among the frail older adults in LTC [30]. Problems such as loneliness and aimless days may occur among both DSI and non-sensory impaired older adults, but some participation problems identified in this study show a connection with their DSI, so there is a need for an LTC to be cautious when addressing these participation problems. Whereas hearing and sighted older adults can benefit from an LTC environment that offers stimulating group activities to support participation [31], our study shows that DSI older adults may encounter serious barriers when meeting other people, which increases the risk of heightening their feelings of not belonging.

A key lesson that can be learned from our findings on problems such as lack of access and lack of control is that the DSI older adults primarily need interaction and alignment with their environment. Although they are well aware of the existence of the environment, without interaction, information, and alignment, the DSI older adults are unable to function as a social being nor as a person undertaking daily activities. Interactions during daily care, receiving information, having conversations about daily care and on daily LTC circumstances, might enable the DSI older adults to connect and live their lives as human beings, in connection with others. This form of support requires person-centered communication attitudes and LTC professionals' skills, especially of the nurses who provide daily care.



Strengths and limitations

This study contributes to the limited body of qualitative data regarding the problems of DSI older adults in LTC. As the problems were collected at an individual level between older adult and a familiar nurse, our study provides in-depth insights into the personal and actual problems, which could not have been achieved via previous population-based data collection using inventories or observation scales. However, the involvement of a familiar nurse may have introduced bias due to DSI older adults' feelings of dependency of the nurse for their care; they may therefore have had difficulties expressing care-related problems. In a separate study, describing nurses' changing perceptions in the course of the intervention period, nurses observed an initial reluctance among the DSI older adults to share their problems [32]. However, they also observed that this reluctance disappeared when nurses invited the DSI older adults to jointly search for and think about alternative solutions. The findings in this study support nurses' observations that the older adults overcame their initial reluctance and felt free to express care-related problems, as the categories care delivery (theme participation) and lack of control on the support of the nurses (theme CIPS) only reflect problems related to the behaviours of professional care workers. Nevertheless, our finding that all of the problems identified by the older adults focused solely on LTC situations and that none of the older adults shared problems related to their family or private life, may suggest that the older adults did not completely feel free. This may be explained by their unfamiliarity with the role of the nurses as a partner in discussing problems, and by their attempts to uphold their socially valued identity as a family member [33]. Another limitation in this study was that the interviewing approach of the SMP-DSI did not allow the inclusion of DSI older adults with severe cognitive problems, whereas recent research shows that an increasing number of DSI older adults in LTC suffer from severe cognitive impairment [2, 6]. Although our findings cannot be generalized to a population with severe cognitive problems and DSI, this first qualitative insight into the problems collected among DSI older adults who were able to articulate their problems, might contribute to the knowledge on those DSI older adults who are not able to clearly express their problems and needs. Further work is required to develop tools that enable observation and identification of the problems of the latter target group.

In conclusion, this study is one of the first to offer insights into the problems

perceived by DSI older adults in LTC. These problems show great similarities with the problems experienced by deafblind individuals towards access in communication, information and mobility, but with the addition of existential concerns and lack of control for the DSI older adults. The findings highlight the importance of identifying the problems among this fast-growing group of DSI older adults in LTC and urges LTC facilities and carers to reconsider what they offer as usual care. To address the participation and CIPS problems of DSI older adults, LTC professionals and researchers need to develop and test programs providing autonomy based and person-centered participation support such as, for example, the SMP-DSI program.



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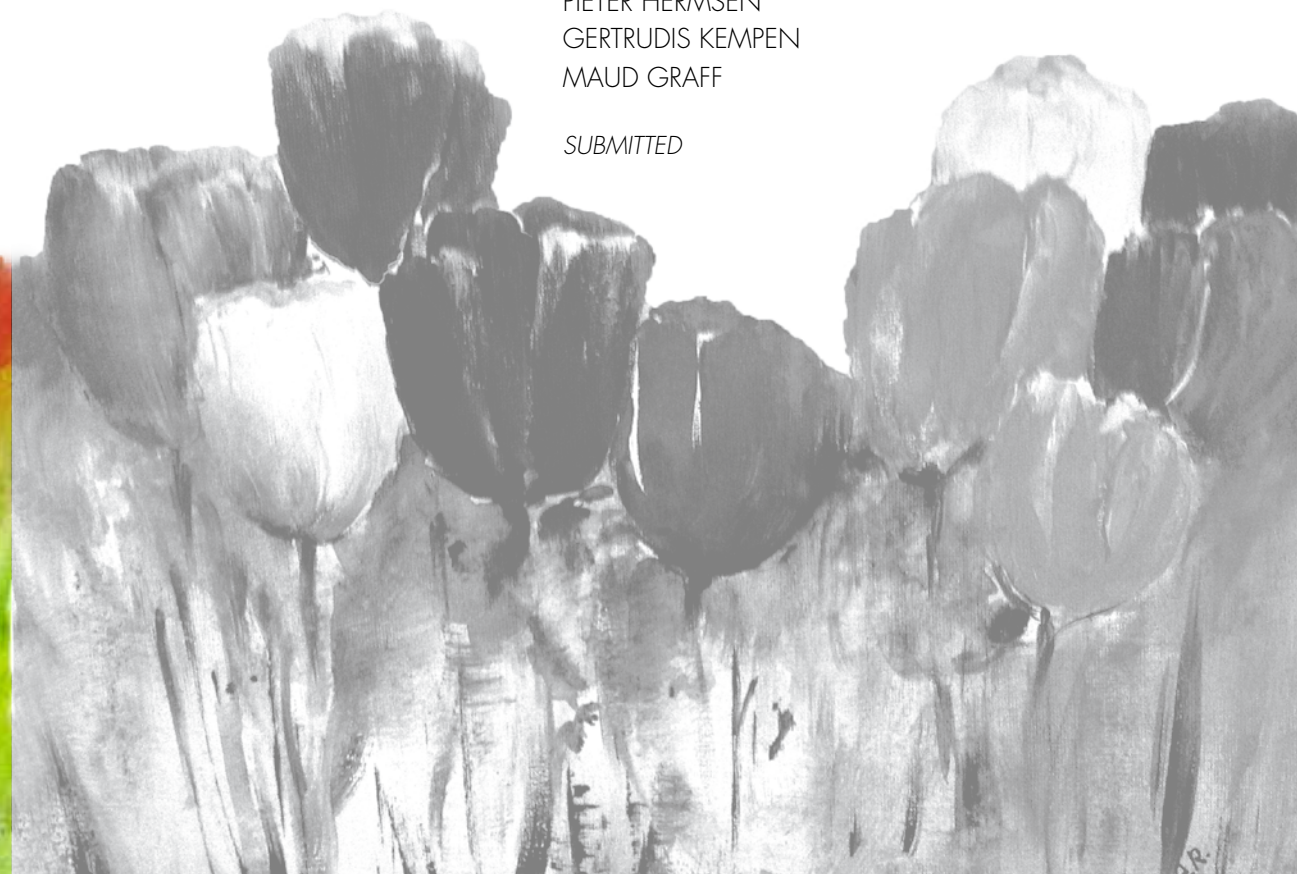


CHAPTER 7

EFFECTIVENESS OF A NURSE-SUPPORTED
SELF-MANAGEMENT PROGRAM FOR DUAL
SENSORY IMPAIRED OLDER ADULTS IN LONG-
TERM CARE: A CLUSTER RANDOMIZED
CONTROLLED TRIAL

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ABSTRACT

Objective: To evaluate the effectiveness of a nurse-supported self-management program to improve social participation of dual sensory impaired older adults in long-term care homes.

Design: Cluster randomized controlled trial.

Setting: Thirty long-term care homes across the Netherlands.

Participants: Long-term care homes were randomized into intervention clusters (n=17) and control clusters (n=13), involving 89 dual sensory impaired older adults and 56 licensed practical nurses.

Intervention: Nurse-supported self-management program.

Measurements: Effectiveness was evaluated by the primary outcome social participation using a participation scale adapted for visually impaired older adults distinguishing four domains: instrumental activities of daily living, social-cultural activities, high-physical-demand and low-physical-demand leisure activities. A questionnaire assessing hearing-related participation problems was added as supportive outcome. Secondary outcomes were autonomy, control, mood and quality of life, and nurses' job satisfaction. For effectiveness analyses, linear mixed models were used. Sampling and intervention quality were analyzed using descriptive statistics.

Results: Self-management did not affect all four domains of social participation, however the domain 'instrumental activities of daily living' had a significant effect in favor of the intervention group ($p=0.04$; 95% CI 0.12 - 8.5). Sampling and intervention quality was adequate.

Conclusions: A nurse-supported self-management program was effective in empowering the dual sensory impaired older adults to address the domain 'instrumental activities of daily living', but no differences were found in addressing the other three participation domains. Self-management showed to be beneficial for managing practical problems, but not for those problems requiring behavioural adaptations of other persons.

Trial registration: Clinical Trials NCT01217502.

BACKGROUND

We are currently seeing a rapid growth in the prevalence of dual sensory impairment (DSI) in long-term care (LTC) populations in Europe; from 12% in 2007 to 32% in 2016 [1, 2]. The co-occurrence of an age-related hearing and visual impairment predominantly affects people aged 80 and above [3, 4]. DSI is highly associated with social participation problems [5, 6]. Barriers in communication and access to information reduce the ability of those with DSI to participate and align with others. It makes it difficult for them to interact, to make choices and to undertake activities. Consequently, DSI is a threat for the social health of older adults [7], and it increases the risk that they withdraw within themselves and become dependent on others [8]. Usual care focuses on either hearing or visual impairment, and mostly comprises medical treatment, technical device provision, and psychosocial rehabilitation interventions. Unfortunately, the extent to which usual care succeeds in addressing sensory impairment in old age is limited [9]. The literature shows however, that in LTC, the occurrence and impact of hearing and visual impairment are often overlooked [10, 11]. Moreover, living in LTC causes a variety of conditions that negatively affect the participation of hearing and visual impaired persons, such as the multiplicity of people, noise, confusing social encounters, and logistics [12, 13].

Despite the increasing prevalence of DSI, psychosocial interventions to support DSI older adults are still scarce. Two studies aiming to improve hearing aid or sensory-specific service use among DSI older adults showed a modest beneficial effect on handling hearing aids, and on facilitating access to the appropriate hearing technologies and rehabilitation services respectively [14, 15]. However, there is a lack of intervention studies aiming to improve DSI older adults' social participation and alignment with others in daily life. Research showed that self-management interventions had beneficial effects on social participation among patients with chronic illnesses [16]. A systematic review of controlled intervention studies showed beneficial effects of self-management interventions for older people with visual impairment [9]. The review also showed that self-management interventions using a problem solving approach had a modest beneficial effect on quality of life of the visually impaired older adults [17, 18], whereas educational approaches showed no effect [19, 20]. In self-management interventions using a problem solving approach, older adults are encouraged to discuss strategies for the problems that bother them



most, and to explore solutions that fit them and their personal circumstances [21]. In contrast, in self-management interventions using an educational approach, experts teach individuals to recognize the negative symptoms of their disease and to choose from a package of alternative solutions [22].

In the Netherlands, LTC homes offer a sheltered care and living environment to older adults who suffer from physical and/or cognitive conditions and who are in need of professional care and on-site surveillance at frequent intervals throughout the day. Usual LTC care as defined by the government covers four domains: physical wellbeing, mental wellbeing, a safe living environment, and participation. The latter aims at providing attractive opportunities to participate in personal hobbies and interests, and to enable a social life with other residents and the social network [23]. In the once or twice-a-year care plan meeting, the person's individual wishes and needs are noted for each domain. Licensed practical nurses, under supervision of registered nurses, provide the majority of assistance with activities of daily living and on-site surveillance. Their frequent daily encounters with DSI older adults place the licensed practical nurses in an outstanding position to provide psychosocial support. However, they are taught very little about how best to provide this type of support when at school or at work [24]. This in turn can lead to less pleasure in their work and a higher rate of job loss [25].

There is a need to investigate how DSI older adults can be supported to address their barriers in social participation and alignment with others in daily life. To respond to this need, we developed the nurse-supported Self-Management Program for Dual Sensory Impaired Older Adults (SMP-DSI). In addition, we developed an SMP-DSI training program for licensed practical nurses, aiming to train and coach the nurses to support the DSI older adults using the SMP-DSI. Thereafter, we set up a cluster randomized controlled trial (cRCT) to compare the effectiveness of the SMP-DSI versus usual care in LTC. Due to the multiple and competitive demands placed on LTC nurses, psychosocial interventions such as self-management performed in routine care settings are sensitive to implementation errors which can impact the intervention quality [26]. Therefore, in parallel with this cRCT, we conducted a process evaluation evaluating the sample and intervention quality of the trial. Finally, as the training program may influence the job satisfaction of the participating nurses, we added job satisfaction as an outcome for the nurses.

We hypothesized that the SMP-DSI would positively affect social participation of the DSI older adults.

METHODS

Study Design

The study was designed as a cluster randomized, single-blind controlled trial, comparing the effectiveness of the SMP-DSI program to usual care. Thirty LTC homes (clusters) spread across the Netherlands participated in the cRCT. DSI older adults living in the LTC homes were linked to a familiar licensed practical nurse. Nurses in the intervention group were trained to support the self-management of the DSI older adults using the SMP-DSI. To avoid possible contamination arising from control group nurses coming into contact with DSI older adults or nurses of the intervention group, randomization took place at the level of LTC homes. The primary outcome was social participation, and the Activity Card Sort (ACS) [27] was chosen as the most important primary outcome to measure this, so the study was powered for this endpoint. The remaining endpoints were considered as supportive outcomes. Further details of the methods of the cRCT are described in the study protocol [28]. The study was approved by the Dutch Committee on Research involving Human Subjects region Arnhem-Nijmegen, ABR 26192.091.08. Written informed consent was obtained from all older participants. Nurses invited for participation in the cRCT gave verbal consent.

Recruitment

Participating DSI older adults and nurses were recruited among LTC homes spread across the Netherlands. The older adults were assessed for eligibility prior to randomization of the homes. Inclusion criteria for the DSI older adults were (1) aged 55 or over, (2) a hearing impairment measured by pure tone audiometry of ≥ 40 decibels (best ear, mean of frequencies 1000, 2000 and 4000Hertz), and a visual impairment with a best-corrected visual acuity ≤ 0.3 diopter or, if additional visual problems were present, a visual acuity of ≤ 0.5 diopter, following the criterion standards for hearing and visual impairment [29, 30] and (3) written informed consent. Exclusion criteria were (1) prelingual deafness, (2) a DSI acquired before the age of 50, and (3) inability to complete interviews due to cognitive problems. Appendix 1 of the Supplementary data gives details of the assessment procedure used to detect eligible older adults among the LTC residents.

Inclusion criteria for nurses were (1) at least twice-weekly direct daily care contact with the participating older adult, and (2) qualified as a licensed practical nurse, that is, a three-year basic nursing vocational training at secondary level. Nurses were



invited for participation by their manager, and gave verbal consent. Each nurse was linked with one or two DSI older participants.

Randomization and Masking

Due to planning issues in the LTC homes and the availability of the trainers, the LTC homes were recruited in consecutive blocks. An independent statistician randomized the LTC homes in blocks using a computer-generated random sequence. The aim was to randomize a minimum of 14 and maximum of 20 homes, expecting to include a total of 132 DSI older adults. The control group received care as usual, the intervention group received the SMP-DSI, and the nurses linked to the DSI older adults of the intervention group were trained to implement the SMP-DSI. The study was single blinded. Research assistants involved in the pre- and follow-up interviews were blinded to the allocation of the LTC homes. Older adults, nurses and trainers of the intervention group were aware of the allocation, but were blinded to the result of any previous assessments.

Self-Management Program and SMP-DSI training Program

The SMP-DSI was developed as a five-step interview including Problem Identification (step 1), Collecting Alternatives (step 2), Choice and Planning (step 3), Execution (step 4) and Reflection (step 5). Table 1 reflects the key features of the SMP-DSI, including the nurses' supportive questions.

The SMP-DSI was based on D'Zurilla and Goldfried's problem solving therapy [21], Lorig and Holman's core self-management skills [22], and Bakkers' constructional behaviour therapy [31]. The aim was to empower the older adults to develop feasible solutions and to cope with possible social or physical constraints, using familiar strategies and by reflecting on recent successful behaviour. In conformance with the problem solving approach, the older adults were not asked to restrict problems to DSI-related problems only, nor to justify choices, even if it was a choice not to take further action.

The licensed practical nurses were asked to introduce the SMP-DSI to the DSI older adults in daily encounters when they observed that the older adult had a problem or request. However, at the start of the training program, nurses stated that they were unaware of possible problems or needs among the DSI older adults. Therefore, nurses were encouraged to use open questions, for example by asking the DSI older adult if there were things he/she would like to change.

Table 1. Key questions of the SMP-DSI and nurses' supportive questions

Steps	Actions older adult	Nurse support
		Key questions
1 Problem identification	Mentions problem Decides to take action	<i>You mentioned that you have a problem with...Would you like to do something about it?</i>
2 Collecting alternatives	Collects a minimum of 3 alternatives: either by themselves, or by asking others for help	<i>What could you do about this?</i> <i>Are there other options?</i>
3 Choice and planning	Select an alternative that the older adult will act on Plan actions	<i>How do you think you will manage this?</i>
4 Execution	Executes action	
5 Reflection	Reflects on own action, mentions what went well	<i>What was the result?</i> <i>What are you happy about: about what you could do on your own? What would you do differently the next time?</i>
		Ideal support
		Name the problem using the older person own words. If the older adult doesn't want to take action, do not interfere
		Stimulate older person to answer.
		In cases where the older person doesn't come up with enough alternatives, provide information. Leave the choice to the him/her
		If the older person has difficulties planning, then apply the key question 2 procedure
		Let the older person execute the action
		Ask What, When, How questions
		Ask for an explanation
		Pitfalls
		Ask for an explanation, take on the problem, insistence
		Impose solutions, make judgements, provide advice
		Takeover the choice/ planning; provide coercive advice
		Execute action for older person



As the performance of the SMP-DSI required the licensed practical nurses to adopt new skills, a training program was developed and implemented based on Grol's implementation model for psychosocial interventions [32]. Nurses received a total 16.5 hours training spread over nine sessions in five months, consisting of 3 successive rounds of (1) a 3-hour group training session, (2) a 1-hour individual coaching session on the job, and (3) a 1.5-hour group supervision session. The training sessions were offered in parallel to the intervention period, allowing the nurses to improve and deepen their insights and skills in using the SMP-DSI. Nurses were asked to practice using the SMP-DSI at least once during the 2- to 3-week interval between each training session. As the performance of the SMP-DSI was dependent on the initiative of the nurses in daily care situations, they were asked to keep track of their SMP-DSI interviews by using two separate semi-structured diaries. In the intervention diary, nurses literally quoted the older adults' verbal responses, either immediately or during the SMP-DSI interview; in the coaching diary, nurses reflected on and evaluated their own behaviour. Both diaries were used as coaching tools and handed over to the trainer at the end of each individual coaching session. Moreover, they gave the research team an overview of the performance of the intervention. Appendix 3 of the Supplementary data provides an overview of the SMP-DSI training program and trainers' roles.

In total, three hours of the group training sessions were dedicated to offering nurses insights into the problems and needs associated with DSI and deafblindness. Based on both the literature and practical experience, the problems and solutions towards communication, information access, daily activities and mobility were described and discussed. These discussions included the need for technical and rehabilitation resources, and psychosocial supportive measures for DSI older adults, such as one-to-one conversations, elimination of background noise, and the use of shapes, contrast and lighting [6].

Nurses who met the training attendance criterion (a minimum of seven of the nine training sessions) and who completed the diaries criterion (a minimum of seven intervention diaries per nurse per older adult), received a certificate.

Data Collection

The primary outcome measure for older adults was social participation, measured by the Activity Card Sort (ACS) [27]. The ACS identifies a person's activity pattern in social participation and its four domains; instrumental activities of daily living

(IADL), social-cultural activities, high-physical-demand leisure activities, and low-physical-demand leisure activities. The ACS has been adapted for use in visually impaired older adults and has been validated in a number of samples of older adults [33-35]. The weighted scores of each of the four domains range from 0 to 100%, higher scores are indicative of higher levels of participation. As the ACS did not explicitly cover social participation problems as a result of hearing impairment, we chose the Hearing Handicap Questionnaire (HHQ) as an addition to the primary outcome [36]. The HHQ is a 12-item questionnaire that identifies participation restrictions related to hearing impairment. Total scores range from 12 to 60, with lower scores being indicative of higher levels of participation. Secondary outcomes were autonomy, mood, perceived control, and quality of life, measured using the Patient Autonomy Questionnaire (PAQ) [37], the Centre for Epidemiology Studies Depression Scale (CES-D) [38], the Pearlin Mastery Scale (PMS) [39] and the Rand Short-Form 36 Health Survey (RAND-36), respectively [40]. At nurse level, the outcome measure was job satisfaction, measured by the Maastricht Job Satisfaction Scale for Healthcare (MJSSH) [41]. Research assistants collected the data for baseline in month 1 and for post-test in month 10. The intervention period started in month 3 and ended in month 7, leaving three months between the end of the intervention period and the post-test. Initially, post-test was planned within the month after the end of the intervention period (month 8) [28], however the nurses needed more time to get familiar with the intervention. As a longer implementation period might add to the success of psychosocial interventions [42], we moved the post-test to month 10 in the intervention and control group.

For process analysis, we used Leontjevas' framework [43]. We evaluated sampling quality (recruitment and reach) and intervention quality (treatment delivery, adherence, relevance and feasibility). Sampling quality was evaluated using qualitative data collected from the research data base. Intervention quality was evaluated using quantitative and qualitative collected from the research data base and from the intervention and coaching diaries. Treatment delivery was evaluated using quantitative data retrieved from the intervention diaries: (1) the number of diaries reflecting the number of sessions between the DSI older adults and their nurse, (2) the number of problems addressed, (3) the number of problems discussed by each pair, and (4) the extent to which these problems were addressed using the SMP-DSI-steps. We evaluated adherence using quantitative



data retrieved from the research data base: (1) the extent to which the nurses met the attendance criteria and (2) the extent to which the nurses met the diaries criteria. Relevance and feasibility as perceived by the nurses were evaluated using qualitative and quantitative data from the coaching diaries. Our findings on relevance and feasibility have been reported in a separate qualitative study [44]. In addition, we analyzed the collection of problems addressed with the SMP-DSI in this cRCT; these were reported in a second separate qualitative study [45].

The intervention and coaching diaries were handed over by the nurses to the trainer at the end of each individual training session; the trainer then posted the diaries to the research team.

Data Analysis.

Older adults' outcomes were analyzed using a linear mixed model accounting for clustering of older adults within LTC homes (random effect for home) and repeated measurements (random effect for an older adult within a home). As a consequence, the estimated effect was corrected for baseline value of the outcome of interest. As more than half of the nurses only had one older adult, the data did not provide sufficient information to estimate variation of older adults within nurse i.e. models including nurse as level, so no estimates could be made for 'within older adult within nurse within home' due to computational non-convergence. Therefore, the intermediate level of nurse was omitted from the analyses. Nurses' outcomes were similarly analyzed (random effect for home and for nurses within home). The ACS was chosen as the most important primary outcome endpoint, and the study was powered for this endpoint. The HHQ and the secondary endpoints were considered as supportive outcomes. As previous research has shown that the effectiveness of a self-management intervention among visually impaired older adults was significantly greater for subjects suffering from depressive feelings than for subjects without depressive feelings [46], effect-modification was planned for the outcome mood, measured using the CES-D scale.

We used descriptive statistics to evaluate sampling and intervention quality.

RESULTS

Recruitment and reach

Between April 2011 and June 2014, 67 LTC homes spread across all regions of the Netherlands were approached for participation. Consent for participation was received from 31 LTC homes (46%), however in one home, no eligible older adults were found. The 30 remaining homes (clusters) were successively randomized, spread over seven blocks ($n_1=8$ LTC homes; $n_2=7$; $n_3=2$; $n_4=5$; $n_5=4$; $n_6=2$; $n_7=2$); 17 to the intervention arm (54 older adults) and 13 to the control arm (35 older adults). The average size of the homes was 78 beds (minimum 32, maximum 124). Figure 1 presents the CONSORT Flow Diagram, including the enrolment of eligible older adults prior to the randomization of the LTC homes.

At the 31 selected homes, 2313 residents were screened using the Severe Dual Sensory Loss (SDSL) screening tool [47]. Figure 1 shows that 727 (31%) were screened as possibly having DSI, of whom 525 (72%) were excluded either due to severe cognitive problems ($n=352$; 67%), or because LTC professionals judged that they were too frail to be interviewed ($n=173$; 33%). The average number of older participants per home was three (minimum 1, maximum 9). Seven of the eligible 54 older adults dropped out after randomization but before the start of the intervention, as did four of the 35 older adults of the control group. This resulted in 16 homes where the intervention started, including 47 older adults linked with 34 nurses, and 13 homes in the control group, including 31 older adults linked with 22 nurses.

Treatment delivery and adherence

A total of 258 intervention diaries were collected, addressing 122 different problems, showing that the overall extent of program performance was fair. Over the five-month intervention period, each pair of nurse and older adult discussed two to three problems and spent two to four sessions addressing a single problem. Of the 122 problems, 57 (46.7%) were fully addressed using all five steps of the SMP-DSI, and 65 (53.2%) were interrupted after step 2 or 3.

Twenty-seven (80%) of the 34 nurses who started the training program met the criteria on attendance and the diaries assignments, and received a certificate. Seven nurses (20%) did not receive a certificate as they were unable to meet



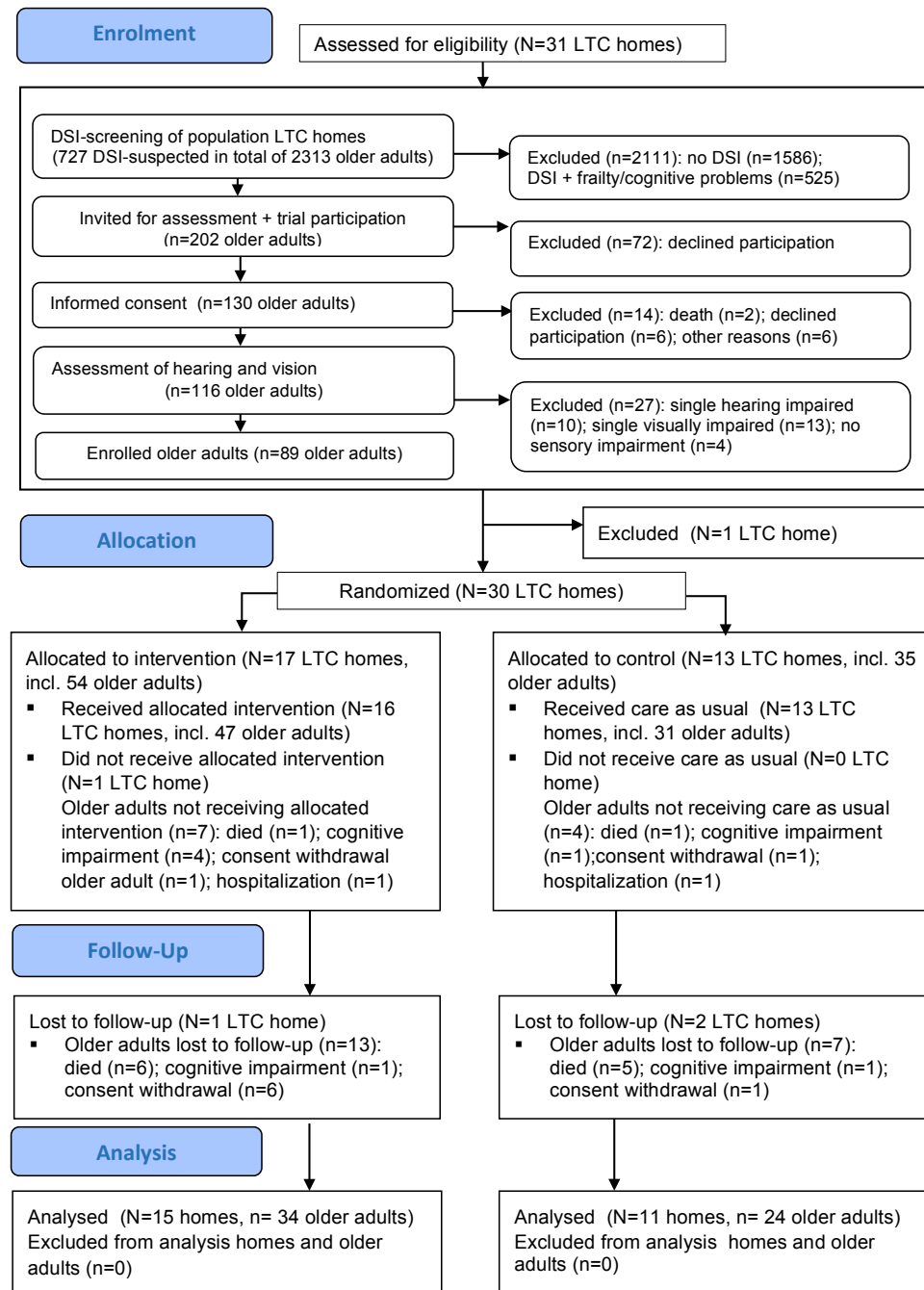


Figure 1. CONSORT flow diagram enrolment

the criteria due to staffing problems (5 nurses), death (1 nurse) or unknown reason (1 nurse). In the case of those nurses who did not meet the criteria, two colleague-nurses who were already involved in the intervention took over, two other nurses were lost for follow-up, and the other 3 nurses remained involved in the intervention.

Baseline comparison

Table 2 presents the baseline characteristics of the intervention and control group. Control for potential confounders showed no relevant change in the intervention estimate, i.e. the differences in baseline characteristics did not confound the intervention effect.

Effect outcomes

Table 3 presents the effect outcome results, showing no statistical significant differences in social participation between the intervention and control group as measured by ACS-total (0.3; 95% CI -3.4 - 3.9) and by HHQ (-1.3; 95% CI -5.7; 3.0). The ACS-domain IADL had an effect in favor of the intervention group. Measured from baseline to follow-up, the IADL in the control group had an estimated decline of 6.7 points ($p \leq 0.001$; 95% CI -9.9 - -3.5), while the intervention group, showed a 4.3-point lower decline than the control group ($p=0.04$; 95% CI 0.12 - 8.5).

Secondary outcome measurement on autonomy (PAQ), perceived control (PMS) and mood (CES-D) showed no significant differences between the intervention and control groups. Analysis of effect-modification showed no significant differences between the DSI impaired older adults suffering from depressive feelings and the older adults without depressive feelings. The nurses' outcomes showed no significant changes over time regarding job satisfaction (MJSSH).



Table 2. Baseline Characteristics of Older Adults and Nurses in Intervention Group and Control Group (N = 89 Older Adults, 56 Nurses)

Older adults factors	Intervention N = 54	Control N = 35	Total N = 89
Socio demographic characteristics			
Mean (SD) age, years	90 (4.8)	89.3 (4.9)	89 (4.9)
Women N (%)	38 (70.3%)	28 (80%)	66 (74.1%)
Widowed/living without partner N (%)	50 (92.5%)	29 (82.8%)	70 (88.7%)
Native language N (% Dutch)	54 (100%)	35 (100%)	89 (100%)
Communication modality (% speech, hearing)	54 (100%)	35 (100%)	89 (100%)
Hearing and Vision			
Average threshold (SD) in decibels (dB) of the frequencies between 1000, 2000 and 4000 Hertz of best ear	60 (18.2)	52 (6.9)	57 (15.2)
- Moderate hearing loss 40-60 dB N (%)	39 (72.2%)	32 (91.4%)	71 (79.7%)
- Severe hearing loss 61-80 dB N (%)	8 (14.8%)	3 (8.5%)	11 (12.3%)
- Profound hearing loss ≥81 dB N (%)	7 (12.9%)	0 (0%)	7 (7.8%)
Hearing aid ownership N (%)	39 (72.2%)	24 (68.5%)	63 (70.7%)
Diopter (SD, visual acuity (Snellen), best eye	0.24 (0.22)	0.18 (0.19)	0.22 (0.21)
- VA ≤0.5 - 0.3 diopter (dpt) & additional visual problems N (%)	14 (25.9%)	3 (8.5%)	17 (19.1%)
- Severe VA ≤0.3 - 0.05 dpt N (%)	16 (29.6%)	10 (28.5%)	26 (29.2%)
- Blindness <0.05 dpt N (%)	24 (44.4%)	22 (62.8%)	46 (51.6%)
Low vision aid ownership N (%)	20 (36.3%)	6 (17.1%)	26 (29.2%)
Health and health related functioning			
Physical health (RAND-36), mean (SD)	173 (58)	176 (75)	
Mental health (RAND-36), mean (SD)	275 (79)	272 (89)	
ADL (Katz), mean (SD)	3.8 (1.5)	3.8 (1.4)	3.8 (1.4)
Depression (CES-D), mean (SD)	17.3 (9.9)	16.0 (8.9)	16.8 (9.5)
Extraversion (NEO-FFI), mean (SD)	38.5 (4.4)	39.1 (3.7)	38.8 (4.1)
Neuroticism (NEO-FFI), mean (SD)	31.5 (6.2)	32.5 (6.3)	31.9 (6.2)
Nurses factors			
	N = 34	N = 22	N = 56
Women (%)	30 (93.7%)	22 (100%)	52 (96.2%)
Education (% licensed practical nurse)	31 (96.8%)	22 (100%)	53 (98.1%)
Mean (SD) years of nursing experience	15.1 (9.9)	11.1 (7.4)	13.5 (9.1)

Table 3. Means (SD) and Estimates from the Repeated Measurements Model for Primary and Secondary Outcomes (N = 89)

Primary outcomes	Means (SD)		Estimates from the Repeated Measurements Model*		Effect **
	Baseline (SD)	Unadjusted mean difference baseline - 9 months (SD)	Baseline I + C group	Change at 9 months in control group	
ACS-overall			25.5 (22.6;28.5)	-2.7 (-5.7;0.1)	0.3 (-3.4;3.9)
I-group	26.1 (11.7)	-2.9 (2.5)			
C-group	25.4 (11.4)	-1.6 (2.8)			
ACS-IADL			23.4 (19.9;26.9)	-6.7 (-9.9;-3.5)	4.3 (0.12;8.5)
I-group	23.7 (12)	-2.7 (2.8)			
C-group	23.1 (13.9)	-4.9 (3.3)			
ACS-leisure LPh			37.7 (33.6;41.7)	-2.1 (-6.8;2.5)	0.7 (-5.3;6.6)
I-group	38.8 (18.3)	-4.3 (3.9)			
C-group	36.5 (16.4)	-0.8 (4.1)			
ACS-leisure HPh			10.6 (7.3;14.0)	-4.4 (-10.8;1.9)	-3.6 (-11.1;3.9)
I-group	10.5 (14.9)	-7.8 (2.7)			
C-group	12.3 (18.6)	-4.9 (4.3)			
ACS-social-cultural			24.6 (20.4;28.8)	2.1 (-3.0;7.2)	-3.6 (-10.1;2.8)
I-group	24.8 (15.1)	-0.9 (3.3)			
C-group	24.6 (14.9)	2 (4)			
HHQ***			28.3 (25.3;31.4)	-0.9 (-4.3;2.5)	-1.3 (-5.7;3.0)
I-group	26.4 (11.1)	-1.6 (2.4)			
C-group	30.8 (13.1)	-3.8 (3.5)			



Table 3. (Continued)

	Means (SD)		Estimates from the Repeated Measurements Model*	
Secondary outcomes				
PAQ***				
I-group	8 (4.8)	-1.1 (1)	9.4 (8.2;10.7)	-0.7 (-2.3;0.9)
C-group	10.8 (4.1)	-1.4 (1.1)		
PMS***				
I-group	13.3 (5)	-0.1 (1.1)	13.9 (12.6;15.2)	-0.4 (-2.4;1.6)
C-group	14.5 (4.1)	-1.2 (1.2)		
CES-D***				
I-group	17.3 (9.9)	0.1 (2.2)	17.6 (14.8;20.4)	0.8 (-2.4;3.9)
C-group	16 (8.9)	0.6 (2.8)		
RAND-36 Physical				
I-group	173 (58)	-2.3 (12.9)	171 (154;188)	-18 (-42;6)
C-group	176 (74.5)	-12.8 (18.6)		
RAND-36 Mental				
I-group	275 (79)	9.5 (18)	269 (245;292)	12 (-20;44)
C-group	272 (89)	18.8 (22.4)		
MJSSH-nurses				
I-group	78.2 (7.2)	0.9 (1.6)	79.6 (77.4;81.7)	1.0 (-0.8;2.7)
C-group	81 (7)	1.1 (1.7)		

* The linear mixed model accounts for the randomization, the clustering within homes, the repeated measurements within clients and estimates the systematic effect of time and intervention.
 **Effect = difference between intervention and control group in change from baseline
 ***Lower scores indicate a better rating
 I-group = intervention group; C-group = control group; ACS-overall = Activity Card Sort overall participation; IADL = Instrumental Activities of Daily Living; ACS-leisure LPh = low-physical-demand leisure activities; ACS-leisure HPh = high-physical-demand leisure activities; HHQ = Hearing Handicap Questionnaire; PAQ = Patient Autonomy Questionnaire; CES-D = Mood by the Centre for Epidemiology Studies Depression Scale; PMS = Pearlin Mastery Scale; RAND-36 = Rand Short-Form 36 Health Survey; MJSSH = Maastricht Job Satisfaction Scale for Healthcare

DISCUSSION

This study evaluated the effectiveness of a Self-Management Program for Dual Sensory Impairment older adults (SMP-DSI) in long-term care (LTC). We found no positive effect in social participation as measured by the ACS-total, nor in three domains of the ACS; social-cultural, high-physical-demand and low-physical-demand leisure activities. However, we found a beneficial effect on the ACS-domain ‘instrumental activities of daily life’ (IADL) as the decline significantly slowed down. In contrast to previous research among visually impaired older adults, no differences in effectiveness were found between the older adults suffering from depressive feelings and the older adults without depressive feelings.

Evaluation of the sampling and intervention quality showed that the trial was carried out adequately. The consent rate of LTC homes (46%) is acceptable, and in line with other studies [48]. The consent rate of DSI older adults (64%) is satisfactory and is comparable with the 62% obtained by Leontjevas [49], but should be interpreted with caution, as recruitment and reach figures have seldom been fully described in psychosocial intervention studies on LTC residents. Overall, treatment delivery was fair. When compared with the findings of the parallel study analyzing the problems addressed with the SMP-DSI [45], we observed differences in treatment delivery: problems in controlling personal space were addressed to a greater extent than were the problems requiring behavioural involvement of others. Of the problems in controlling personal space, 27 of the 44 (61.3%) were fully addressed using all five SMP-DSI steps. Of the problems requiring behavioural involvement with others, only 30 of the 78 problems (38.4%) were fully addressed.

A comparable contrast in the effectiveness of addressing IADL versus social leisure and cultural activities has been reported in earlier studies of older adults with disabilities [50]. The large and positive effect on the ACS IADL domain (more than 60% reduction of the decline) and the higher rate of treatment delivery for problems in controlling in personal space (61.3%) suggest that the older adults were able to self-manage concrete daily living problems such as budgeting or medication management with the support of their nurse. Two factors may have contributed to this positive result. First, the self-management intervention was offered in the everyday environment of the older adult, the problems were identified by the older adults themselves, and solutions were explored within that same everyday environment. This is line with research findings showing



that ‘real-world’ interventions stimulate cognitive, social, and physical activity among older adults [51]. Secondly, the problems were concrete and assignable, which may have endorsed the feeling of mutual partnership between nurse and older adult to engage in and explore possible practical and concrete solutions together. This aligns with research findings showing that the creation of trust and partnership between the healthcare worker and patient is an important factor in the success of self-management interventions [52].

However, the interventions had no effect on the ACS domains leisure and social-cultural activities. This lack of effectiveness on these domains and the low rate of treatment delivery of the participation problems requiring behavioural involvement of other persons (38.4%), seem to align with research findings that the social network of older adults steadily decreases due to age-related life events [53]. However, by identifying their participation problems and searching for alternative solutions (steps 1 and 2 of the SMP-DSI respectively), the DSI older adults showed that they were eager to alter those problems. Treatment delivery showed that they tended to ‘give up’ when choices and plans had to be made requiring interactive routes. A factor that might have provoked this reluctance is that they felt no partnership with the LTC professional caretakers who were targeted. Mudge et al. showed that healthcare professionals felt tense and unfamiliar when forming a partnership with patients, and dedicating time to practice reciprocity in communication style [54]. At the start of the intervention period, we observed a similar lack of partnership between the DSI older adults and their nurse [44]. The feelings of partnership only developed after nurses and older adults started a dialogue based on the SMP-DSI-steps.

This study faced several challenges regarding recruitment due to the rapidly increasing incidence of advanced stages of cognitive problems and frailty among DSI older adults in Dutch LTC homes. The study suffered from a large exclusion rate, as 72% of older adults were unable to participate due to cognitive problems or frailty. This had been partially anticipated, as earlier studies noted an increased risk of co-morbidities in DSI older adults [55, 56]. However, the increased prevalence of DSI in LTC and the large exclusion rate may be partly explained by the rapidly changing LTC home population resulting from recent policy changes introduced by the Dutch government. After the start of our trial, the admission to LTC homes became restricted to only those older adults who needed intensive care or 24-hour surveillance due to their advanced stage of

cognitive impairment. As recruitment per cluster was lower than planned, we recruited more clusters than planned. However, the statistical power of the study may therefore have been smaller than originally planned.

Another limitation was that nurses did not voluntarily present for participation. After inclusion of the older adults, the manager invited nurses who were familiar with the participating older person to join the trial. This was mainly due to practical reasons, although the degree of health professionals’ voluntary participation has been shown to contribute to the success of an intervention [57]. Since the number of eligible nurses per team was limited, the risk that the managers’ invitation would create a bias is limited. However, nurses’ changing perceptions in the course of the intervention, starting from fairly negative to positive perceptions (as reported in our parallel study), might have negatively affected the results [44].

As this is one of the first intervention studies on DSI among care-dependent older adults, lessons can be learned for practice and research for frail older adults in LTC as well as for community living DSI older adults. First, the interactive and problem solving characteristics of the SMP-DSI provide nurses with a structure for a dialogue aiming at psychosocial support in daily encounters. Nurses’ changing perceptions when trained to introduce the SMP-DSI stress the need to introduce such a structure to practical nurses. Eventually, nurses recommended expanding the SMP-DSI as a generic approach for all their clients, whether DSI or not [44]. Second, as there are no evidence-based interventions aiming at alignment between the DSI older adults who live at home and their social and professional network, implementing the SMP-DSI could help healthcare professionals and researchers identify the problems and further explore the value of the SMP-DSI.

In summary, this study demonstrates that the nurse-supported SMP-DSI was not successful in addressing problems related to social-cultural and leisure activities in DSI older adults, but it does show beneficial effects in addressing IADL problems. By combining the results of the effect study with the qualitative process findings, we explored barriers and solutions, and show that the participation of DSI older adults can benefit from enhanced dialogues and partnership with their LTC professionals.

Ethical approval

The study design and protocol has been approved by the Dutch Committee on



Research involving Human Subjects region Arnhem-Nijmegen, ABR 26192.091.08. Informed consent was completed by all participants before starting the assessments and interventions.

Data sharing statement: The dataset and statistical code are available from the Data Archiving and Networking Service (DANS). <https://easy.dans.knaw.nl/ui/datasets/id/easy-dataset:65449>.

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CHAPTER 8

GENERAL DISCUSSION



Introduction

The focus of this thesis is on improving and supporting the social participation of older adults who acquired a dual sensory impairment (DSI) at an advanced age. DSI is known to be associated with serious risks for people's social participation. Despite all the therapeutic regimes, including medical treatment, technical device provision and psychosocial rehabilitation interventions, DSI older adults face a variety of problems in social participation in daily life; the latter issues are often only partially addressed. Thus, in order to improve and support DSI older adults with social participation related issues, we developed a novel program for self-management: the self-management program for dual sensory impaired older adults (SMP-DSI).

The overall aim of our thesis was to evaluate the relevance, feasibility and effectiveness of the SMP-DSI on social participation. First, we investigated what an ideal self-management intervention for DSI older adults should look like (**Research question 1**). We started our study with a systematic search of the literature, investigating the effectiveness of psychosocial interventions for sensory impaired older adults (**Sub-question 1a**) (Chapter 2). As there was a need for a systematic procedure to detect the DSI target group for the intervention, we adapted and validated the Severe Dual Sensory Loss (SDSL) screening tool for the Dutch population of older adults (**Sub-question 1b**) (Chapter 3). Thereafter, based on the results of our systematic review, we developed the nurse-supported SMP-DSI and the SMP-DSI training program for licensed practical nurses (**Sub-question 1c**) (Appendix 3 - Supplementary data). Consecutively, we designed a cluster randomized controlled trial (cRCT) (Chapter 4).

We tested the relevance, feasibility and effectiveness of the SMP-DSI in a cRCT in 30 long-term care (LTC) homes spread across the Netherlands. We performed three related studies: we investigated the relevance and feasibility of the SMP-DSI (**Research question 2a**), the problems addressed by the SMP-DSI (**Research question 2b**), and the effectiveness of the SMP-DSI (**Research question 3**). To detect the relevance and feasibility of the SMP-DSI, we performed a longitudinal process evaluation in parallel with the cRCT, and analyzed nurses' changing perceptions when implementing the SMP-DSI (Chapter 5). As the cRCT gave us unique insights in the problems of DSI older adults, we analyzed the problems identified by the DSI older adults to be addressed with the SMP-DSI (Chapter 6).

Finally, we investigated the effectiveness of the SMP-DSI (Chapter 7).

In this chapter, we have summarized the main findings and relate them to a broader theoretical and methodological context. We end this chapter with recommendations for future policy, education, practice and research.

Research questions

In this thesis, we address three main research questions. To ensure clarity and structure, research question 1 is divided into three sub-questions, and research question 2 has two sub-questions:

1. How should a self-management intervention aiming to support the social participation of DSI older adults, look like?
 - 1a. What is known about the effectiveness of psychosocial interventions in improving emotional and functional status, self-efficacy and social participation in hearing or visual impaired older adults?
 - 1b. How can DSI older adults be identified in an LTC population? Is the Severe Dual Sensory Loss (SDSL) screening tool a valid tool to help nurses and care assistants identify hearing, visual and dual sensory impairment in older adults?
 - 1c. Based on results of the systematic review conducted to answer question 1a, which components are relevant for inclusion in a Self-Management Program for Dual Sensory Impaired older adults (SMP-DSI) and what should the SMP-DSI program look like? What should the related SMP-DSI training program of nurses look like?
2. What is the relevance and the feasibility of the SMP-DSI?
 - 2a. Which insights can be gained from nurses' perceptions when implementing the SMP-DSI, and from the factors that contributed to changes in their perceptions?
 - 2b. Which problems did the DSI older adults identify to be addressed with the SMP-DSI?
3. Is the nurse-supported SMP-DSI effective in improving social participation of dual sensory impaired older adults in LTC?



Main research findings

Our main finding is that the nurse-supported SMP-DSI was an effective aid to address instrumental-activities-in-daily-life (IADL) problems facilitating social participation in DSI older adults. We were unable to demonstrate beneficial effects regarding the social participation domains social-cultural activities, high-physical-demand and low-physical-demand leisure activities. The hypothesis that the intervention group would have a more favorable development in overall social participation was therefore not confirmed.

However, the SMP-DSI was found to be a relevant tool which helped licensed practical nurses to move towards greater autonomy support when in dialogue with the DSI older adults. The feasibility of the SMP-DSI was fair, as nurses required a longer exploration period than anticipated.

In the systematic review, we found no effects of psychosocial interventions on the emotional and functional status, self-efficacy and social participation of sensory impaired older adults. However, subgroup analysis identified problem-solving as a potential effective approach for positively affecting emotional status. The SMP-DSI was thus developed in line with these findings, adopting a generic and problem-solving self-management approach. Accordingly, we developed an SMP-DSI training program for nurses.

As there was a need for a systematic procedure to detect the appropriate research group, we adapted and validated the existing SDSL screening tool for the Dutch population. The SDSL screening tool was found to be a valid and reliable tool, enabling nurses and care assistants to identify hearing, visual and dual sensory impaired related behaviors among older adults, and allowing us to systematically identify eligible DSI older adults.

Our longitudinal process evaluation, performed in parallel with the cRCT, showed that nurses' initial perceptions on relevance and feasibility of the SMP-DSI were negative, but changed to positive as they better understood the meaning of client-autonomy. Through interactions with the DSI older adults and by self-evaluations of the effect of their behavior, nurses discovered that their usual care conflicted with client-autonomy. Eventually, nurses recommended expanding the intervention as a generic approach to all their clients, whether DSI or not.

Among the problems collected by the DSI older adults to be addressed with the SMP-DSI, we identified three categories of participation problems and two

categories of control-in-personal-space problems. The three categories of participation problems were: (1) existential concerns of not belonging, (2) lack of access to communication, information, and mobility, and (3) the desire to be actively involved in care delivery. The two categories of control-in-personal-space (CIPS) problems were: (1) lack of control of their own physical belongings, and (2) lack of control regarding the behavior of nurses providing daily care in their personal environment. These findings indicate that DSI older adults experience great existential pressures on their lives and long for access and control in their daily care environment.

Theoretical considerations

We started this study with a number of assumptions regarding self-management and social participation. On reflection, our research confirmed some of these assumptions, but others were swept away and needed to be revised. In this section, we reflect on our choices towards the type of self-management and the primary outcome social participation. We also look at the role of the older adult-nurse partnership when implementing psychosocial support in LTC.

1. Characteristics of a self-management approach for DSI older adults

1.1. A generic approach fits DSI

In this study, we used a generic - and not a sensory-specific - self-management approach. Sensory-specific knowledge and skills were interwoven in nurses' SMP-DSI training program, but were not a principal characteristic of the training. The findings in this study endorse our choice for a generic approach.

Among the five categories that emerged from the problems identified by the DSI older adults, four referred to barriers in access and control, suggesting a strong association with sensory impairment. Therefore, at first sight, these sensory-related barriers suggested a need for a sensory-specific support. However, all problems were embedded in daily life in LTC, and the DSI older adults searched for alternative solutions in their daily living environment. We were unable to identify any requests for sensory-specific medical or rehabilitative treatment, nor for sensory-specific skills or techniques. For example, a reading problem was not addressed by searching for a technical reading device, but by searching for



possibilities in the LTC environment to receive printed information in large, bold letters. These findings endorse the choice for a generic approach. Moreover, the finding that nurses were successful in supporting IADL- problems although they received only a short introduction with respect to sensory-specific problems and solutions, also supports the preference for a generic self-management approach.

1.2. A uniform package of solutions does not fit DSI

In this study, we used a problem-solving version of self-management support. We did this, despite the large volume of research on successful self-management programs using an educational approach. Our findings suggest that a problem-solving approach aligns better with the consequences of DSI.

Educational self-management approaches are widely used and have proved to be effective when supporting patients with physical diseases such as diabetes or musculoskeletal disorders [1, 2]. These educational self-management programs ‘educate’ the patients to become experts in recognizing the negative symptoms of their diseases, and support them when deciding which alternative actions can be taken should these negative symptoms occur in daily life. It was tempting to develop a training program which would ‘educate’ persons with DSI, helping them to become experts in the field of DSI. However, the results of our systematic review had already warned us against educational programs, some parts would even have an adverse effect for sensory impaired older adults. Later on, our cRCT showed that DSI is associated with problems embedded in the environment, requiring interaction and alignment with others. In parallel to those suffering from physical diseases who learn to recognize physical negative symptoms in an educational approach, DSI persons would have to learn to recognize negative symptoms embedded in the environment. But that is exactly what the problematic for DSI older adults showed to be: they lack access and control, they have to guess what is happening in their surroundings, and what other persons are saying, doing or expecting. The findings suggest that the heterogeneous and momentary characteristics of the social environment hinder the ability to learn to address these problems and risks with an in advance compounded, clear package of alternative solutions. Therefore, a problem-solving approach, including a supportive partnership between the DSI older adults and their healthcare professional, might align better to address these consequences of DSI in daily life in LTC.

1.3. The SMP-DSI in the context of opportunities and limitations

The responses of the DSI older adults showed their eagerness to work on social health, reflecting their relief and enthusiasm to search for and think about alternative solutions jointly with the nurses.

The major strength of the SMP-DSI was in its first two steps, *Identification* and *Alternative Solutions*. For the DSI older adults, it opened-up opportunities to be actively involved and appreciated in a mutual, supportive partnership when collecting alternative solutions to address their needs. For the nurses, it offered direction and gave them a tool to free themselves from their usual imposing behavior, and to explore the opportunities for supporting and interacting with the older adults. These findings emphasize the importance of the nurses’ role: the awareness that their interactions influenced the balance between DSI older adults’ opportunities and limitations.

Another value of the SMP-DSI proved to be in solving concrete problems in controlling personal space together. However, a limitation occurred when solutions and plans needed the involvement of others, needing behavioral changes of those with a lack of partnership. Future research should explore the partnership and alignment between DSI older adults and their LTC healthcare professionals, and explore how all LTC disciplines can contribute to the self-management process of the older adults.

2. Social participation, a different content

When reflecting on the cRCT, we noted that the concept of social participation had a different content for the DSI older adults than we expected. The focus of the DSI older adults in our study was mainly on their professional care network and their existence in a professional care environment, and not on social exchanges and leisure activities with other residents, nor on contacts with their social network.

When choosing social participation as a primary outcome, we assumed that the DSI older adults would long for contacts with others, especially with the other older adults living in the LTC environment, and with family members or other persons of their familiar social network. These initial assumptions were in line with the results of research conducted in care homes, interpreting social participation as



a desire to interact and have positive relationships with others residents [3, 4].

The DSI older adults in our cRCT did state the need for social participation, but in a different way than we expected. With regards to our first assumption - longing for contacts with other older adults living in the LTC - they showed their fear of being excluded or of being judged as behaving peculiarly. In relation to their peers, their responses were not about the need for an active search on how to establish contacts and social exchanges, but rather to avoid negative valuations by their peers. These findings are in line with the findings of Goll and colleagues, that loneliness among non-sensory impaired community-living older adults was linked to fears of social rejection [5]. The findings suggest that the usual expectations in LTC that social participation should be facilitated by bringing older adults together, doing things together, should be redirected, at least when DSI older adults are involved.

Our second assumption, that DSI elderly would long for contacts with members of their family or network, was also placed in a different perspective: not a single problem identified by the DSI older adults referred to situations related to family members or other social contacts. This might be partly due to an initial reluctance to and being unfamiliar with discussing problems with the nurses; discussing family related problems with their nurse may have been a bridge too far. Similar findings among non-sensory impaired older adults were described by Donkers and colleagues, suggesting that older adults did not want to lose valued aspects of their identity [6]. Our data do not give insights into whether sharing private problems should be encouraged in LTC. However, the DSI older adults made one thing clear: they showed that they had the awareness and strength to distinguish and move between two social roles, i.e. their role as a care receiver in LTC, and their role as a family member. This was a surprising performance of older adults, as they were initially considered by their familiar nurses as being too frail to be consulted. When working in close conjunction with family members, LTC professionals should be aware of the DSI older adults' preferences for specific roles.

On reflection, the interpretation of social participation should be reconsidered when DSI older adults are involved. If social participation is chosen as primary outcome, the content should be in line with the desire of the DSI older adults as shown in this study, i.e. their aim for greater access, control and alignment with the care environment, and protection from fears of not belonging or being judged as behaving peculiarly.

3. Partnership, a missing link in LTC

Although client-centeredness and demand-led care are common concepts in the literature and practice in LTC, our study showed that an important link was missing in the client-centered care for frail, care-dependent older adults, i.e. the active, ongoing partnership in daily care between older adults and their familiar nurses.

Self-management interventions such as the SMP-DSI demand an interactive collaboration between the older adult and healthcare professional [7]. The creation of trust and partnership between the elderly with a long-term condition and their healthcare worker is an important factor in the success of self-management interventions [8, 9]. Our longitudinal process analysis showed a lack of partnership between the nurses and the DSI older adults. Ongoing, daily interaction and conversations between nurses and DSI older adults failed, and nurses were unaware of the problems and wishes of the older adults. What was notable was that the nurses initially believed their care was client-centered because they delivered care as recorded in the care plan. In their opinion, there was no need to interact with the older adults, as they thought they knew the choices and preferences of the older adults well enough from the care plan.

The nurses' initial responses suggest that LTC has a consumer-driven application of the care plan, i.e. a list of choices and preferences collected in an annual interview which is then transferred to a to-do list. This format may explain the lack of partnership and alignment that we report on. Schoot [10] and O' Dwyer [11] suggested that a consumer-driven care plan might suit autonomously functioning older adults, but might not do justice to frail older adults who need to be supported when expressing their problems and making choices. Both authors did not provide examples of the kind of support that should be offered to this specific group. For example, should the support offered detect every single need encountered by the older adult in daily life, in order to collect these problems in an overall care plan 'basket' and then transfer them in a detailed to-do-list? Or, should it support the older adults in identifying their problems in daily life and attempt to address these problems in partnership with their nurses during daily encounters? Our SMP-DSI matches this last version of support, showing results that are in line with the ultimate goal of care planning and client-centeredness: the nurses became accustomed to aligning the care provided to the frail older adults' daily needs, thereby involving and supporting the older adults in daily care.



Methodological Considerations

In this section, we reflect on the methods chosen for this study and on the generalizability of its findings. We successively discuss the study's strengths and its limitations with regard to recruitment and design.

Strengths

A major strength was the combination of a multi-centered cRCT with longitudinal process evaluations. The controlled conditions inherent of a cRCT combined with the longitudinal process evaluation, evaluating the sample quality (recruitment, reach, treatment delivery and adherence) and intervention quality (relevance, feasibility) attributed to the validity and generalizability of the findings. This study was one of the first interventions studies ever undertaken to target DSI in LTC. The longitudinal process evaluation of nurses' changing perceptions is unique, and adds to the range of methods available to researchers for evaluating the feasibility and accessibility of psychosocial interventions in healthcare.

Limitations

Recruitment. The recruitment of eligible DSI older adults was negatively affected by the rapidly changing admission regulations in LTC introduced by the Dutch government during the study period. As initial recruitment of DSI individuals was lower than anticipated, we aimed at sufficient power by recruiting more clusters.

Dyads. We believe that the linkage of a single DSI older adult to one nurse reduced the empowerment-effect of the SMP-DSI. First, the 1-to-1 linkage limited treatment delivery, as the pairs of older adults and nurses were only able to perform the intervention when that particular nurse was present. Second, colleague-nurses were not involved in the intervention and continued with their usual nursing care behavior, with the risk of frustrating the awakening feelings of autonomy and empowerment in the older adults. In some cases, the colleague-nurses hindered and even prevented the execution of the agreements made between the DSI older adult and the trained intervention nurse.

On reflection, the intervention would have benefited from an LTC environment where all members of the nursing team were familiar with the basic principles of autonomy support and professional conversation techniques such as those used in the SMP-DSI.

Implications for policy, education, and practice

A key lesson learned is that addressing problems associated with DSI requires a cultural change in LTC towards client-autonomy and social health. Our findings show that it is not sensory-specific know-how that LTC should put on top of its priority list, but that LTC should give first priority to a substantial change in its expertise and practice related to client-centeredness and psychosocial support for all of their clients. This should not only be communicated with the nurses, but also with policy makers, educators, curriculum developers and psychologists.

However, in the current LTC climate, which is suffering from serious challenges due to the increasing complexity of LTC residents needs, it is not obvious that, in the near future, LTC will place DSI high on its list of priorities. Although DSI has a major impact on the daily lives of older adults in LTC, we show that the DSI-problems are often hidden in usual care. A high degree of client-centeredness and partnership is required in order to be open to problems and needs that are - in the eyes of the average healthcare worker - invisible, not life-threatening, and that do not provoke aggressive or otherwise challenging behaviors.

With this in mind, we reflect on three domains which we consider as being most relevant for the development of support of DSI older adults.

1. Competences in partnership and alignment

1.1. Involvement of the DSI older adults

Policy makers and professionals in LTC need to be critical about too rapidly excluding older adults' opinion and involvement. In contrast to nurses' initial perceptions, the DSI older adults in this study showed that they enjoyed being involved in and consulted about their daily care and life. Moreover, the current concept of client-autonomy should be redirected: we need to move away from the idea that client-autonomy is warranted by a once-a-year collection of preferences and choices, to a concept whereby the older adults are consulted in their daily encounters, and are treated as equal partners when searching for possible solutions and approaches.

1.2. Partnership and alignment with all LTC clients, whether DSI or not

LTC should go towards offering partnership and alignment for all frail, care-dependent older adults, whether they have DSI or not. A client-autonomy support



such as the one used in the first two steps in the SMP-DSI offered to every frail older adult, will increase nurses' professional competences in improving client-autonomy, and will increase the probability that the approach will also be used for DSI older adults.

1.3. Reflection on successful professional behaviors

The care plan for DSI older adults should be enlarged with a communication and interaction plan. The primary aim should be that potential successful behaviors are etched in the memory of each nurse. Therefore, it should not only list the problems of the older adult, but it should primarily list the solutions and nurse-behaviors that worked well in the recent past when interacting with the DSI older adult. In line with the Kwaliteitskader Verantwoorde Zorg 2017 (Quality framework for responsible care) [12] that calls upon LTC-organizations to develop methods to reflect and learn from experiences and results of their actions, and in line with the reflective coaching method developed for our SMP-DSI training program, nurses should learn to reflect on their behavior and on the effect of their behavior on the older adults.

2. Nurses' role and education

The underlying causes of the barriers for licensed practical nurses when offering the SMP-DSI may be tied up in policy and educational measures. LTC should develop coherency in its expertise in client-centered care and psychosocial support. Moreover, LTC should define the role of licensed practical nurses towards client-centeredness and psychosocial support.

Our findings show that the work of licensed practical nurses reflects several negative conditions encountered in their daily practice. Based on these findings, we suggest three domains that might make it easier for nurses to offer client-centered and psychosocial support:

2.1. Nurses' role

Nurses described that it was their task to prevent the older adults from having problems. As they claimed to 'know' the problems and needs of the older adults based on the care plan, they concluded that any interactions with the older adults would be superfluous, and even conflictive to their professional autonomy. They indicated that hands-on-nursing was a key element of their nursing tasks, not

talking or interacting with the older adults. Their descriptions evoked a restricted interpretation of their job.

These findings show that nurses, and probably their managers, have an ambivalent, inconsistent view on client-centeredness and client-autonomy. There is a need for a clear policy towards LTC's responsibility for the autonomy and the social health of their clients, and a clear statement on nurses' role in it. Our findings demonstrate that the role of licensed practical nurses is essential in supporting the DSI older adult, as the problems of the DSI older adults are embedded in daily care and life and the older adults long for alignment with their nurses.

2.2. Nurses' education

Our analysis shows that nurses lack an overview and that they are unfamiliar with basic skills in psychosocial support and professional conversation techniques. In addition to their unawareness, their initial perceptions also show that they carry a large 'ballast' of ideas and skills taught to them. Examples of this are their views on how to show empathy (standing there, endless listening, just giving clients some attention) and on how to 'interrogate' the older adults (searching for the question behind the question, asking in-depth questions).

These findings reveal that there is a lack of a theoretical know-how and cohesion in their educational programs and in LTC policy on psychosocial support. Educational curriculums should be developed that support nurses in mastering basic and straightforward psychosocial supportive skills which enhance the feelings of partnership between nurses and DSI older adults, such as: (1) giving information and discussing alternatives without imposing a choice; (2) being able to observe explicit and implicit needs in the older adult; (3) exploring to align their behavior to the needs of the older adults, and evaluating their behavior [13].

2.3. Nurses' position among actual developments towards psychosocial interventions in LTC

In the last decade, a variety of psychosocial interventions have been developed in LTC, often initiated and financed by the Dutch government [14]. It illustrates the eagerness and needs present in LTC to improve psychosocial support. However, the flourishing number of new interventions risks sending mixed messages to



nurses; they are then faced with the need to master different programs, each addressing a separate problem, each with a different theoretical construct and different approach. Our findings suggest an alternative approach: start by helping nurses to gain basic psychosocial skills such as those described above in section 2.1 and 2.2 on nurses' role and education, rather than offering them different programs. In our study, we noted that the delay in nurses' mastery of the SMP-DSI was due to their unawareness of psychosocial supportive skills, especially their unfamiliarity with autonomy support, dyadic conversations, and aligning their behavior to the older adults' responses. These basic skills should be grounded in a coherent theoretical or practical framework which guides the nurses, educators, curriculum developers and psychologists to align the kind of psychosocial support with the actual needs of the older adults.

3. Role of DSI-specific services

There is a need to break through the impasse in LTC of overlooking and underestimating DSI and its consequences. It is important that DSI-specific services should become aware that transferring their usual rehabilitation know-how to the LTC is simply not enough to overcome the impasse. DSI-specific services should apply methods like the SMP-DSI, which facilitate the DSI older adults and their social and professional network to communicate with each other, sharing and discussing DSI-related problems and possible solutions.

The findings in this study demonstrate that in the case of DSI, it is necessary to get to the heart of LTC, i.e. to the individual daily interaction between nurse and DSI older adult. Only LTC professionals in daily care can have access to that micro level. Sensory-specific rehabilitation services cannot go as deep, as they are not an active member in daily care. Consequently, the question remains regarding what DSI-specific services can do to support LTC. Currently, these services place an emphasis on providing information and exploring what it is like to have a combination of poor hearing and poor vision, and on communicative and visual rehabilitation principles. However, our findings stress the need to support LTC nurses to change their one-way 'from - to' interaction to a mutual dialogical interaction, using reflective coaching tools. Lessons can be learned from our qualitative study on nurses' perceptions, our SMP-DSI training program, and from the extensively described and tested dialogical, sustained-interaction approach developed to support congenitally deafblind persons [15].

4. Role of LTC facilities towards DSI

The initiative to introduce support for their clients with DSI lies in the hands of LTC. However, there are many barriers to placing DSI high on the list of priorities. When reflecting on the issues which made up the priorities in LTC in the last decade, we note that in most of cases, change was formulated in quality frameworks initiated by the Ministry of Public Health, and its effectuation was monitored by the public health inspectorate. Examples of priorities, in random order, are: dealing with decubitus, depressive symptoms, use of physical restraints, use of psychotropic drugs, and physical and hygienic safety.

It is difficult to visualize a similar path for DSI as a major difference is that these issues seem to align better with the usual LTC expertise approach, i.e. from diagnosis to action; the diagnosis shows what needs to be done. In comparison, DSI requires a dyadic, sustained interaction, and the professionals' behavior is part of the ongoing 'diagnosis', i.e. they have to observe their own behavior while interacting with the DSI older adult, and align this behavior in response to the older adults. A better approach may be to raise the level of the interaction and alignment for all frail, care-dependent LTC clients, and put this on the agenda of the policy makers. It should help LTC to sharpen their focus on social health, and acknowledge the essential role of the practical nurses in supporting frail older adults to live up to their own potential and tip the balance towards opportunities and away from limitations.

Another approach may be to empower the DSI older adults and their social network, and stimulate the community to put DSI on the agenda. The DSI-specific services should collaborate with both DSI-patient associations and senior citizen associations. Together they can develop methods and materials which facilitate DSI older adults to discuss the specific and daily impact of DSI with their social and professional network. The result of sharing and discussing problems may better support the community living DSI older adults, and prepare them and their social network for follow-up conversations with the LTC professionals.



Implications for future research on DSI

The study is one of the first interventions studies in the field of DSI concerning older adults, and there are many issues yet to be explored. Our findings highlight the need to continue research regarding:

1. Recognizing and addressing the impact of DSI in the behavior of DSI older adults with severe cognitive problems

The SDSL screening tool presented in this thesis helps nurses to identify DSI among older adults. However, to face the challenges connected with the increasing population of DSI older adults with severe cognitive problems, there is a need for more extensive tools and guidelines which facilitate nurses to better recognize the consequences of the DSI in the behaviors of those cognitively-impaired older adults with whom verbal alignment is not possible, and that guide the nurses through the process of addressing these consequences. The problem themes and categories found in this study, based on data from DSI older adults themselves, provide an excellent source for developing new tools and guidelines.

2. Tools to empower community living DSI older adults

Due to practical considerations in home care organizations, we were unable to include community living DSI older adults in our study. The SMP-DSI should be adapted and tested in a community living environment, with relevant social network members and professional caretakers as partners of the DSI older adults

3. The development of a primary outcome scale for DSI older adults

Our findings show the need to develop and validate an outcome scale that better matches the DSI target group, and that is closer to the intervention than the scales used in this study. When measuring the effectiveness of a self-management intervention, key questions of the outcome scale should include whether the DSI older adults feel involved and consulted in daily care, and whether they feel that possible solutions are being discussed with them, in an atmosphere of mutual partnership.

General conclusion

In this study, we demonstrate that the nurse-supported SMP-DSI was successful in addressing instrumental-activities-in-daily-life problems for DSI older adults, however it did not show beneficial effects in addressing problems related to social-cultural activities and leisure activities. The hypothesis that the intervention group would have a more favorable development in overall social participation was therefore not confirmed.

The study adds to the improved detection and support of DSI older adults in LTC, as well as giving deeper insights in DSI-related problems. The study shows that DSI older adults experience great existential pressures on their lives, and that they reach out for greater access to and control in their daily care environment. These access and control characteristics and the eagerness of the DSI older adults to discuss and align their problems and needs with the nurses, emphasize the importance of the role of the LTC professionals in supporting the DSI older adults to better manage their lives and cope with their impairments.

A major strength of this study is its combination of a multi-centered cRCT with longitudinal process evaluations. This allowed us to monitor nurses' changing perceptions when performing the SMP-DSI and when reflecting on their behavior over a lengthy period. Nurses showed to be unaware of the problems and impact of DSI on the older adults life in LTC. Their perceptions revealed that they lacked professional, sustained interactions and alignments with the older adults in LTC. Nurses' initial negative perceptions towards the relevance and feasibility of the SMP-DSI only became positive after they better started to grasp the meaning of client-autonomy when in dialogue with the older adults.

The discrepancy found between the interactive needs of the DSI older adults versus LTC's lack of alignment in daily care, demonstrates the need for a cultural change in LTC. Policy-makers need to be critical about too rapidly excluding older adults' opinions and involvement. Care planning should be broadened with alignments in daily care. In nurses' education, priority should be given to ensuring a substantial change regarding their expertise and practice in client-autonomy and psychosocial support. Implementation programming should include ongoing practice and sustained coaching, combining nurses' interactions with the DSI older adults with self-reflections on the effect of their professional behavior.



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S U M M A R Y



In this thesis, we report on our research in which we set out to investigate ways of improving and supporting the social participation of dual sensory impaired (DSI) older adults. DSI older adults have both a hearing and visual impairment acquired at an advanced age. Despite all the efforts of therapeutic regimes, including medical treatment, technical device provision and psychosocial rehabilitation interventions, they face a number of serious risks such as depressive feelings and social isolation. In daily life, the problems and needs related to DSI are often not fully recognized, and its impact on social participation is underestimated.

Although the prevalence and negative associations have been well studied, there is still a great need for effective psychosocial intervention programs for DSI older adults. For these reasons, we set out to develop and investigate the relevance, feasibility and effectiveness of a self-management program for DSI older adults on social participation.

We first investigated what an ideal intervention for this group should look like. Therefore, we performed a systematic search of the literature, investigating the effectiveness of psychosocial interventions for sensory impaired older adults. As there was a need for a systematic procedure to detect the DSI target group for the intervention among the long-term care (LTC) population, we adapted and validated a screening tool. Then, we developed the nurse-supported self-management program for DSI older adults (SMP-DSI) and a related SMP-DSI training program for licensed practical nurses. We tested the SMP-DSI in a cluster randomized controlled trial (cRCT) in 30 LTC homes. To detect the relevance and feasibility of the SMP-DSI, we performed a longitudinal process evaluation in parallel with the cRCT. As the cRCT gave us unique insights in the problems of DSI older adults, we analyzed the problems identified by the DSI older adults to be addressed with the SMP-DSI. Finally, we investigated the effectiveness of the SMP-DSI and performed a process evaluation in parallel, analyzing sample and intervention quality.

Chapter 1, the general introduction, provides background information on DSI including the problems associated with DSI, epidemiologic data, definitions, usual care, the theoretical basic of the study, and the choice for a primary outcome. Chapter 1 ends with the research questions and an outline of this thesis.

Assessing the effectiveness of psychosocial interventions for sensory impaired older adults

In **Chapter 2 (research question 1a)**, we report the results of our systematic review assessing the effectiveness of psychosocial interventions for older adults with an age-related hearing and/or visual impairment. We found no controlled studies on psychosocial interventions for DSI older adults. However, we were able to include 14 intervention studies aiming at single sensory impaired older adults: six studies on hearing impairment and eight on visual impairment, involving 1622 sensory impaired participants (mean age 70). All included studies were controlled studies with more than 80% of participants aged ≥ 55 years and with rehabilitation interventions either separately or in combination with technical device provision. The interventions aimed at (1) *functional training*, such as communication training for hearing impaired persons or occupational training for visually impaired persons, and/or (2) *psycho-education*, including knowledge about the nature of the sensory impairment, strategy development, assertiveness, stress management, and personal adjustment, and/or (3) *counselling*, including emotional, grief or bereavement support in relation to the sensory impairment. All studies were categorized into 3 subgroups of intervention approaches, *cognitive restructuring, education, and problem solving*, and subgroup analysis was performed.

The main finding was that the systematic review and meta-analysis showed no effects on emotional and functional status, nor on self-efficacy and social participation. However, when subgroup analysis compared the effectiveness of the educational approach with the problem solving approach, problem solving was found to be a potential effective approach for affecting emotional status.

The findings suggest that the intervention approach should be chosen cautiously when older adults are involved, as it is likely that differences in approach will result in essentially different effects.

A screening tool to detect hearing, visual and dual sensory impairment

In **Chapter 3 (research question 1b)**, we report on our study among older adults and their nurses and care assistants to assess the accuracy of the SDSL screening tool to detect DSI among the LTC population. The SDSL screening tool, developed by Svengen and Lyng, includes 6 items addressing hearing and 6 items addressing vision. The items aim at participation and daily activities as being behavioural

consequences and adaptations to the age-related decline of the auditory and visual system and its neurological processes. A total of 56 older adults receiving long-term care and 12 of their nurses participated in the study. For each older adult, the tool was completed by two different nurses independent of each other. After completion, pure-tone audiometry, visual acuity, visual field and contrast sensitivity were tested and compared with the SDSL scores.

Our investigation of the psychometric properties of the SDSL showed a strong internal consistency (construct validity) for both subscales: Cronbach's alpha was 0.81 and 0.84 respectively. Factor analysis showed two constructs for hearing (social versus individual environment) and two for vision (daily living and reading), explaining 71% and 84% of the variance respectively. We calculated the interrater reliability and found a substantial agreement between nurses' scoring: Kappa was 0.71 for the hearing and 0.74 for the visual subscale. We calculated the predictive validity by comparison with the criterion standard assessment for hearing and vision, which showed to be satisfactory: the ROC-AUC for the hearing subscale was 0.73, and for the vision subscale 0.79. The optimum cut-off point to differentiate between hearing impaired versus not hearing impaired, and between visually impaired and not visually impaired, was score 1 for both subscales, with a moderate to good sensitivity (0.71 for hearing, 0.69 for vision), and a moderate to good specificity (0.69 for hearing, 0.78 for vision). Feasibility was evaluated by the time needed to fill in the screening tool and the clarity of the instruction and items. The nurses and care assistants reported that the SDSL screening tool was easy to use. The prevalence of hearing and vision impairment was 55% and 29%, respectively, and that of dual sensory impairment was 20%.

Considering the psychometric results, the SDSL screening tool was found to be a valid, reliable and feasible tool that can be used on a regular basis in long-term care to detect the hearing, visual or dual sensory impairment among older adults.

The development of the SMP-DSI and the training program for licensed practical nurses, and of the cluster randomized controlled trial

In **Chapter 4 (research question 1 and sub-question 1a)**, we describe the study protocol defined after the nurse-supported SMP-DSI and the related SMP-DSI training program for nurses were developed.

We developed the SMP-DSI and the training program in line with the findings of the systematic review. Therefore, we took fundamental elements from three

different problem solving intervention models, i.e. d'Zurilla's problem solving therapy, Lorig's self-management intervention for persons with chronic diseases, and Bakker's constructional behaviour analysis. The SMP-DSI resulted in a five-steps program, urging the DSI older adult to systematically identify his problems (Step1), generate alternative solutions for each problem (Step 2), select the best solution, develop a plan (Step 3), execute the plan (Step 4), and evaluate whether the problem was solved and what went well (Step 5). Nurses' role was to help the DSI older adult to develop feasible solutions and review available resources to support the process of generating solutions. The SMP-DSI training program focused on the conversational and supporting interview methods needed to assist older clients in their process of self-management. Sensory-specific knowledge and skills were interwoven in nurses' SMP-DSI training program. A key feature in the training were the individual reflective coaching sessions, inviting nurses to reflect on the process and results of their professional behaviour when performing the SMP-DSI. The nine sessions of the training program were planned alongside the intervention period. An interval of two to three weeks was planned between each training session to give the older adult-nurse pairs the opportunity to practice the SMP-DSI in daily care situations. Nurses were asked to keep track of the SMP-DSI performance with the older adults in an intervention diary, and of their reflections on their professional behaviours and learning process in a coaching diary. Appendix 3 of the Supplementary data at the end of this thesis describes the key features of the SMP-DSI and the SMP-DSI training program.

At different stages in the development process of the SMP-DSI and the training program, the concepts were tested, commented on and refined by clients of the Kalorama LTC setting, their licensed practical nurses, and by social workers of the Kalorama Center for the Deafblind. A cRCT with long-term care settings as the unit of randomization was developed, and its design is described in the study protocol.

The relevance and feasibility of the SMP-DSI

In **Chapter 5 (research question 2a)**, we report on the findings of a qualitative study performed alongside the cRCT, aiming to evaluate the relevance and feasibility of the SMP-DSI.

The participants in this study were 34 licensed practical nurses who worked at one of the 17 LTC homes assigned to the intervention group of the cRCT,

supporting 54 DSI older adults. Nurses were trained and asked to practice the SMP-DSI with the older adult(s) they were linked with, and to fill in a coaching diary over the 5-month training and intervention period. In individual coaching sessions, nurses were invited to reflect on and evaluate their own behaviour when offering the SMP-DSI. Data of nurses' perceptions were collected from nurses' coaching diaries, as well as from trainers' reports. These longitudinal data were analyzed using the content comparison approach based on the Grounded Theory.

The five-month data collection enabled exploration of nurses' changes in perceptions in the course of the intervention period. Nurses' initial negative perceptions on relevance and feasibility of the intervention changed to positive as nurses better understood the concept of client-autonomy. Through interactions with the DSI older adults and by self-evaluations of the effect of their behaviour, nurses discovered that their usual care conflicted with client-autonomy and felt encouraged to adapt their behaviour to the older adults' autonomy needs. The SMP-DSI and its related training program offered nurses direction and gave them a tool to free themselves from their usual imposing behaviour, and to explore the opportunities for supporting and interacting with the older adults. However, nurses' initial unfamiliarity with conversation techniques required a longer exploration period than planned. Eventually, nurses recommended expanding the intervention as a generic approach to all their clients, whether dual sensory impaired or not.

In conclusion, educational programs for licensed practical nurses should offer longitudinal coaching of autonomy supportive conversational skills. Intervention programming should acknowledge that change is a process rather than an event, and should include self-evaluations of professional behaviours over a period of time.

Problems identified by the DSI older adults

In **Chapter 6** (research question 2b), we report the findings of our second qualitative study. As the cRCT gave us unique insights in the problems of DSI older adults, we analyzed the problems identified by the DSI older adults to be addressed with the SMP-DSI.

DSI older adults in the intervention group of the cRCT (n = 47, age range 82-98) were invited by a familiar nurse to identify the problems they wanted to address with the SMP-DSI. Data were taken from the semi-structured intervention diaries in which nurses noted the older adults' verbal responses during a five-month intervention period in 17 long-term care homes across the Netherlands. We analyzed the data using descriptive statistics and qualitative content analysis based on the Grounded Theory.

The 47 dual sensory impaired older adults identified a total of 122 problems. We found that the older adults encountered participation problems and problems controlling what happens in their personal environment. Three categories of participation problems emerged: (1) existential concerns of not belonging or not being able to connect with other people, (2) lack of access to communication, information and mobility, and (3) the desire to be actively involved in care delivery. Two categories of control-in-personal-space problems emerged: (1) lack of control of their own physical belongings, and (2) lack of control regarding the behaviour of nurses providing daily care in their personal environment.

Our findings suggest that DSI is not associated with a single problem, but that a complex of invasive problems threatens the social health of the DSI older adult. The problems found show great similarities with the problems experienced by persons who became deafblind at an early stage in life, towards access in communication, information and mobility, but added with the existential concerns and lack of control for the DSI older adults. When compared with hearing and sighted older adults who can benefit from group activities in LTC, the findings show that DSI older adults encounter serious barriers when meeting other people, which increases the risk of heightening their feelings of not belonging.

A key lesson to be learned from our findings, is that DSI older adults primarily search for access and control, and reach for interaction and alignment with their environment, especially with the professionals who offer them LTC care.

Effectiveness of the SMP-DSI

In **Chapter 7** (research question 3), we report the results of the cRCT testing the effectiveness of the SMP-DSI program to improve social participation of DSI older adults in 30 LTC homes across the Netherlands.

The LTC homes were randomized into intervention clusters (n=17) and control clusters (n=13), involving 89 dual sensory impaired older adults and 56 licensed practical nurses. DSI older adults living in the LTC homes were linked to a familiar licensed practical nurse. Nurses in the intervention group were trained to support the self-management of the DSI older adults they were linked with, using the SMP-DSI. To avoid possible contamination arising from control group nurses coming into contact with DSI older adults or nurses of the intervention group, randomization took place at the level of LTC homes. The primary outcome was social participation, and the Activity Card Sort distinguishing four domains: instrumental activities of daily living, social-cultural activities, high-physical-demand and low-physical-demand leisure activities, and a participation scale for hearing impaired persons, was chosen as the most important primary outcome to measure this. For effectiveness analyses, linear mixed models were used. Sampling and intervention quality were analyzed using descriptive statistics.

The SMP-DSI did not affect all four domains of social participation, however the domain 'instrumental activities of daily living' had a significant effect in favor of the intervention group ($p=0.04$; 95% CI 0.12 - 8.5). Sampling and intervention quality was adequate. Of the problems in controlling in personal space, 61% were fully addressed with the SMP-DSI, as were 38% of the participation problems, suggesting that the SMP-DSI is beneficial for managing practical problems, but not for those problems requiring behavioural alignment with other persons.

General discussion

In **Chapter 8**, the general discussion, we discuss the most important findings and conclusions in relation to the theoretical and methodological issues, and introduce a series of recommendations for policy, education, practice and future research.

This study demonstrated that the nurse-supported SMP-DSI was successful in addressing instrumental-activities-in-daily-life problems for DSI older adults, however it did not show beneficial effects in addressing problems related to social-cultural activities and leisure activities.

The study adds to the improved detection and support of DSI older adults in LTC, as well as giving deeper insights in DSI-related problems. The study shows that DSI older adults experience great existential pressures on their lives, and that they reach out for greater access to and control in their daily care environment. These access and control characteristics and the eagerness of the DSI older adults to discuss and align their problems and needs with the nurses, emphasize the importance of the role of the LTC professionals in supporting the DSI older adults to better manage their lives and cope with their impairments.

A major strength of this study is its combination of a multi-centered cRCT with longitudinal process evaluations. This allowed us to monitor nurses' changing perceptions when performing the SMP-DSI and when reflecting on their behaviour over a lengthy period. Nurses showed to be unaware of the problems and impact of DSI on the older adults life in LTC. Their perceptions revealed that they lacked professional, sustained interactions and alignments with the older adults in LTC. Nurses' initial negative perceptions towards the relevance and feasibility of the SMP-DSI only became positive after they better started to grasp the meaning of client-autonomy when in dialogue with the older adults.

The discrepancy found between the interactive needs of the DSI older adults versus LTC's lack of alignment in daily care, demonstrates the need for a cultural change in LTC. Policy-makers need to be critical about too rapidly excluding older adults' opinions and involvement. Care planning should be broadened with alignments in daily care. In nurses' education, priority should be given to ensuring a substantial change regarding their expertise and practice in client-autonomy and psychosocial support. Implementation programming should include ongoing practice and sustained coaching, combining nurses' interactions with the DSI older adults with self-reflections on the effect of their professional behaviour.

SAMENVATTING



In dit proefschrift behandelen we de ontwikkeling en evaluatie van een interventieprogramma bedoeld om ouderen met een auditief-visuele beperking te ondersteunen in hun sociale participatie.

Vooraf mensen ouder dan tachtig jaar krijgen op latere leeftijd te maken met zowel slechthoortendheid als slechthorendheid. In de huidige gezondheidszorg is het gebruikelijk dat deze ouderen beroep doen op medische behandeling, technische hulpmiddelen en in sommige situaties ook op het aanleren van revalidatievaardigheden. Deze zorgverlening richt zich meestal op een van de twee zintuiglijke beperkingen waarbij men er vanuit gaat dat de oudere na behandeling op eigen kracht weer verder kan. Echter, wanneer er sprake is van een gecombineerde zintuiglijke beperking loopt de oudere persoon een verhoogd risico op depressieve gevoelens en sociaal isolement. Bovendien worden de problemen en gevolgen van de auditief-visuele beperking in het dagelijks leven vaak niet onderkend, en de impact op sociale participatie wordt over het hoofd gezien.

Er is behoefte aan inzicht in hoe deze ouderen in het dagelijks leven effectief ondersteund kunnen worden. Eerder onderzoek toonde aan dat de prevalentie van auditief-visuele beperkingen onder ouderen hoog is: bij de zorgafhankelijke ouderen van 80 jaar en ouder varieert de prevalentie tussen 12% en 32%. Ook zijn de problemen die mogelijk geassocieerd zijn aan auditief-visuele beperkingen bij ouderen in kaart gebracht. Maar ons onderzoek is een van de eerste die de vervolgstap neemt, en een antwoord wil geven op de vraag welke ondersteuning effectief kan zijn voor deze ouderen.

Dit proefschrift beschrijft de ontwikkeling van een interventieprogramma en onderzoekt de relevantie, gebruiksgemak en effectiviteit van dat programma op de sociale participatie van de ouderen.

Om een interventieprogramma te kunnen ontwikkelen verkenden we eerst de literatuur, we zochten hoe een ideale interventie voor ouderen met een auditief-visuele beperking eruit zou moeten zien. Daarna zochten we naar een snelle en gemakkelijke manier om binnen de huidige ouderenpopulatie de ouderen met een auditief-visuele beperking te detecteren. Vervolgens ontwikkelden we het Zelfmanagementprogramma voor Ouderen met een Auditief-Visuele Beperking, in dit proefschrift aangeduid met de afkorting SMP-DSI (Self-management Program for Dual Sensory Impaired older adults). Om de verzorgenden te helpen zich het

programma eigen te maken en aan de ouderen aan te bieden, ontwikkelden we ook een SMP-DSI trainingsprogramma.

Middels een cluster-gerandomiseerd gecontroleerd onderzoek (cRCT) testten we het SMP-DSI in 30 verzorgingshuizen verspreid over Nederland. We evalueerden de effectiviteit van het SMP-DSI op de sociale participatie van de ouderen met een auditief-visuele beperking. Daarnaast evalueerden we ook de relevantie en het gebruiksgemak van het SMP-DSI. Tenslotte, aangezien de cRCT ons een unieke inkijk gaf in de dagelijkse problemen en behoeften van ouderen met een auditief-visuele beperking, analyseerden we deze problemen en behoeften en brachten ze inzichtelijk in kaart.

Algemene inleiding

Hoofdstuk 1 geeft achtergrondinformatie over de auditief-visuele beperking en beschrijft de problemen die geassocieerd worden met deze beperking, de epidemiologische data, definities en gebruikelijke zorg. Ook geeft het informatie over de theoretische achtergrond van de studie en de keuze voor de primaire uitkomstmaat. Hoofdstuk 1 eindigt met de onderzoeksvragen en de indeling van dit proefschrift.

Een systematisch review van de effectiviteit van psychosociale interventies voor ouderen met een zintuiglijke beperking

Hoofdstuk 2 (onderzoeksvraag 1a) beschrijft de resultaten van ons systematisch review en meta-analyses.

Onze zoektocht in de wetenschappelijke literatuur toonde aan dat er tot nog toe geen psychosociale interventiestudies zijn gericht op ouderen met een *gecombineerde* auditief-visuele beperking. Wel vonden we veertien gecontroleerde interventiestudies gericht op ouderen met een *enkelvoudige* zintuiglijke beperking: zes studies gericht op slechthorende ouderen, acht studies op slechthorende ouderen.

Onze meta-analyses vonden geen statistisch positief effect van de verschillende interventies, niet op emotionele status of functionele status, niet op self-efficacy noch op sociale participatie.

Echter, subanalyse liet een positief effect zien, afhankelijk van de methodiek die gebruikt werd tijdens de interventie. Educatieve methodieken die kennis willen overbrengen en vaardigheden instrueren bleken niet effectief te zijn bij

de ouderen. Daarentegen, methodieken die beroep doen op probleemoplossing en zelfmanagement bleken potentieel wel effectief.

Gezien de enorme professionele en financiële inspanningen van de revalidatiezorg om de groeiende groep ouderen met een (enkelvoudige) zintuiglijke beperking te ondersteunen, is dit een belangrijke bevinding.

Een screeningsinstrument om slechthorendheid, slechtziendheid en/of een auditief-visuele beperking te detecteren

Hoofdstuk 3 (onderzoeksvraag 1b) beschrijft de ontwikkeling van een screeningsinstrument. Dit instrument helpt zorgprofessionals om zowel slechthorendheid, slechtziendheid en de combinatie van beide, te detecteren bij hun cliënten.

We valideerden de Severe Dual Sensory Loss screeningslijst (SDSL) van Svingen en Lyng voor de Nederlandse populatie. Twaalf zorgprofessionals (helpenden, verzorgenden, verpleegkundigen) vulden de lijst in over 56 ouderen die beroep deden op dagbehandeling en/of wonen van het verzorgingshuis 't Höfke van de stichting Kalorama. Voor iedere oudere werd de lijst ingevuld door twee zorgverleners onafhankelijk van elkaar. Daarna lieten de ouderen zich testen op horen en zien.

De psychometrische eigenschappen van de SDSL screeningslijst werden berekend door de resultaten van de auditieve meting (toonaudiogram) en de visuele metingen (visuele acuity, gezichtsveld en contrastgevoeligheid) te vergelijken met de SDSL-resultaten. Uit deze berekeningen blijkt dat de SDSL-screeningslijst beschikt over een sterke interne samenhang (construct validiteit): een Cronbach alpha van 0.81 voor de auditieve items, en 0.84 voor de visuele items. De factorstructuur vertoont twee constructen voor de auditieve subschaal (sociale omgeving en persoonlijke omgeving), en twee voor de visuele schaal (dagelijks levensverrichtingen en lezen). De overeenkomst tussen de scores van beide zorgverleners (interrater betrouwbaarheid) is substantieel: een Kappa van 0.71 voor de auditieve subschaal, en 0.74 voor de visuele subschaal. De voorspellende waarde (predictieve validiteit) blijkt voldoende: de ROC-AUC voor de auditieve subschaal is 0.73 en voor de visuele subschaal 0.79. Het optimale afkappunt voor beide subschalen is score 1. De sensitiviteit is gemiddeld tot goed voor beide subschalen: 0.69 voor de auditieve subschaal, en 0.78 voor de visuele subschaal. Verder beoordelen de zorgprofessionals de lijst als gebruiksvriendelijk.

De prevalentie van slechthorendheid, slechtziendheid en auditief-visuele beperking onder de deelnemers was respectievelijk 55%, 29% en 20%.

De ontwikkeling van het SMP-DSI, het trainingsprogramma en studieprotocol
Hoofdstuk 4 (onderzoeksvraag 1 en 1a) beschrijft de ontwikkeling van het SMP-DSI, het SMP-DSI trainingsprogramma voor verzorgenden en de vaststelling van het studieprotocol.

Op basis van de bevindingen uit ons systematisch review kozen we voor een zelfmanagementmethodiek die gebruikt maakt van probleemoplossende technieken. Daarvoor ontleenden we fundamentele elementen uit drie verschillende probleemoplossende interventiemodellen:

- d’Zurilla’s probleemoplossende therapie
- Lorig’s zelfmanagement voor personen met een chronische ziekte
- Bakker’s constructieve gedragsanalyse

Het SMP-DSI bestaat uit een vijfstappenprogramma waarbij de verzorgende de oudere persoon uitnodigt om:

1. een probleem of wens te benoemen
2. samen alternatieven te verzamelen hoe dat probleem opgelost of die wens gerealiseerd zou kunnen worden
3. een van de alternatieven te kiezen en samen een plan te maken hoe dat alternatief te verwezenlijken
4. uit te voeren
5. terug te kijken op het resultaat en op waar men tevreden over was.

Vervolgens ontwikkelden we een SMP-DSI trainingsprogramma voor verzorgenden, bedoeld om verzorgenden te trainen en te coachen in de gesprekstechnieken en psychosociale vaardigheden passend bij de zelfmanagementmethodiek. Het trainingsprogramma bestaat uit negen groeps- en individuele sessies die parallel aan de interventieperiode wordt gegeven. Een tussenperiode van twee tot drie weken tussen iedere trainingssessie geeft de verzorgende de kans om het SMP-DSI in dagelijkse zorgsituaties te oefenen.

In een interventiedagboek noteert de verzorgende de respons van de oudere persoon tijdens de gesprekken waarbij het SMP-DSI wordt toegepast. In het coachingsdagboek reflecteert de verzorgende op haar eigen gedrag en leerproces.

Het hoofddaccent van het SMP-DSI trainingsprogramma voor verzorgenden ligt op

de gespreksvaardigheden en interactie van de verzorgende met de oudere persoon, maar ook specifieke kennis en vaardigheden op het gebied van horen en zien zit in de training verweven. Tijdens het ontwikkelproces van het SMP-DSI en van het trainingsprogramma zijn verschillende conceptversies getest, becommentarieerd en bijgesteld door cliënten en verzorgenden van het verzorgingshuis 't Höfke Kalorama, en door doofblindenbegeleiders van het Centrum voor Doofblinden van Kalorama.

Daarna werd het studieprotocol vastgesteld. Het onderzoek naar de effectiviteit van het SMP-DSI maakt gebruik van een cluster-gerandomiseerde en gecontroleerde opzet, met verzorgingshuizen als clusters. Alle bewoners van de deelnemende verzorgingshuizen worden vooraf gescreend op auditief-visuele beperkingen. Na toestemming vindt een gehoor- en gezichtsmeting plaats bij de kandidaat-deelnemers. Dan vindt blokrandomisering plaats en wordt iedere deelnemende oudere aan een vertrouwde verzorgende gekoppeld. De verzorgenden van de verzorgingshuizen van de interventiegroep krijgen de SMP-DSI training en passen het SMP-DSI toe bij de oudere persoon. De controlegroep ontvangt de gebruikelijke zorg. De primaire uitkomstmaat is sociale participatie, de secundaire uitkomstmaten zijn stemming, autonomie en kwaliteit van leven. De uitkomstmaat voor verzorgenden is arbeidstevredenheid. Er wordt een lineaire mixed model analyse gebruikt om de effecten te evalueren. Daarnaast worden kwantitatieve en kwalitatieve procesanalyses uitgevoerd om de mate van implementatie en belemmerende en bevorderende factoren voor het toepassen van het SMP-DSI te onderzoeken.

De relevantie en gebruiksgemak van het SMP-DSI

Hoofdstuk 5 (onderzoeksvraag 2a) beschrijft relevantie en het gebruiksgemak van het SMP-DSI.

Deze kwalitatieve studie werd parallel aan de cRCT uitgevoerd. Data werden ontleend aan de coachingsdagboeken van 34 verzorgenden uit de interventiegroep en aan de rapportages van de coaches. We voerden een kwalitatieve inhoudsanalyse uit, gebaseerd op de Grounded Theory. Aangezien we kwalitatieve data over een periode van vijf maanden (interventie- en trainingsperiode) hadden verzameld, konden we de longitudinale veranderingen in de percepties bij de verzorgenden volgen en analyseren.

Relevantie van het SMP-DSI

Aanvankelijk vonden de verzorgenden het SMP-DSI niet relevant. Ze vonden dat hun gebruikelijke zorg tegemoet kwam aan alle wensen en problemen van de ouderen. Aangezien zij hun werk uitvoerden conform de afspraken in het zorgleefplan, vonden zij dat de autonomie van de ouderen gegarandeerd werd. Gesprek voeren met de ouderen werd ervaren als overbodig en zelfs ongewenst, want tijdrovend en te belastend voor de ouderen zelf. Echter, nadat de verzorgenden daadwerkelijk startten met samen met de oudere persoon oefenen met het SMP-DSI kandelde deze perceptie. De aanvankelijk aarzelende, maar daarna enthousiaste respons van de ouderen zelf was daarbij essentieel. Het begrip autonomie kreeg een andere inhoud voor de verzorgenden, en ze ontdekten dat hun gebruikelijke zorg de autonomie van de oudere personen belemmerde. Vanaf dan beoordeelden de verzorgenden het SMP-DSI als zeer relevant.

Gebruiksgemak van het SMP-DSI

De data gaven ook inzicht in de percepties van de verzorgenden omtrent het gebruiksgemak van het SMP-DSI. Aanvankelijk waren de verzorgenden vol zelfvertrouwen wat betreft hun vaardigheden in gespreksvoering met de ouderen. Gaandeweg ontdekten ze dat ze behoefte hadden aan andere professionele gespreks- en ondersteuningsvaardigheden dan ze tot nog toe kenden. Het SMP-DSI en de trainingsperiode van vijf maanden gaf hen houvast om zich los te maken van hun gebruikelijke attitude en gedrag. Na afloop van de interventie- en trainingsperiode adviseerden verzorgenden om het SMP-DSI uit te breiden naar al hun cliënten, ook naar cliënten zonder een auditief-visuele beperking.

Problemen die de ouderen benoemden om met het SMP-DSI aan te pakken

Hoofdstuk 6 (onderzoeksvraag 2b) beschrijft de problemen die de ouderen identificeerden en wilden aanpakken met het SMP-DSI.

Voor deze kwalitatieve studie gebruikten we de data uit de interventiedagboeken waarin de verzorgenden de mondelinge respons van de ouderen noteerden bij de toepassing van het SMP-DSI. De interventiedagboeken van 47 oudere deelnemers (in leeftijd variërend van 82 tot 98 jaar) uit de interventiegroep van de cRCT werden verzameld en geanalyseerd.

In totaal werden 122 verschillende problemen en wensen geïnventariseerd. Kwalitatieve inhoudsanalyse toonde aan dat de problemen van deze ouderen met

een auditief-visuele beperking zich concentreren rond twee thema's:

1. *Participatie*
2. *Controle*

Binnen het thema *Participatie* konden we drie categorieën onderscheiden:

1. *Existentiële bezorgdheid*: de ouderen zijn bezorgd om er niet bij te horen en voelen zich niet verbonden met anderen (andere ouderen en zorgprofessionals). Ze zijn bang om vergeten te worden.
2. *Gebrek aan toegang*: de ouderen vinden het moeilijk om anderen te verstaan, communicatie met zorgprofessionals is lastig, ze krijgen moeilijk informatie ter beschikking, en kunnen zich moeilijk vrij bewegen in de omgeving.
3. *Afstemming van de zorgverlening*: de ouderen willen betere kansen om actief met hun zorgprofessionals te overleggen over de zorg die ze ontvangen.

Binnen het thema *Controle* vonden we twee categorieën:

1. *Gebrek aan controle over hun eigen fysieke bezittingen*: ouderen willen weten waar welke eigendommen te vinden zijn, en willen aanpassingen aan kunnen brengen zodat ze voorwerpen en materialen beter kunnen gebruiken.
2. *Gebrek aan controle over het gedrag van zorgprofessionals*: ouderen willen meer informatie en invloed op wat verzorgenden en andere professionals in hun persoonlijke omgeving precies uitvoeren.

Een aantal van de gevonden categorieën vertonen grote gelijkenis met de problemen van mensen die in een vroeg stadium van hun leven doofblind werden. Ook zij ervaren problemen in toegang tot communicatie, informatie en mobiliteit. De ouderen in deze studie voegen daar een drietal categorieën aan toe: zij uiten hun existentiële angst om er niet bij te horen, en zij uiten hun wens om meer overleg met zorgprofessionals en meer controle op zaken die in hun persoonlijke omgeving gebeuren.

De bevindingen laten bovendien zien dat de problemen die deze ouderen ervaren sterk samenhangen met het gedrag van de personen in de omgeving, en vooral van de regie-mogelijkheden die de omgeving deze ouderen biedt. Deze studie toont aan dat een omgeving die interactie en afstemming biedt een essentiële voorwaarde is om ouderen met een auditief-visuele beperking te kunnen ondersteunen.

Effectiviteit van het SMP-DSI

Hoofdstuk 7 (onderzoeksvraag 3) beschrijft de resultaten van het clustergerandomiseerd gecontroleerd onderzoek naar de effectiviteit van het SMP-DSI op de sociale participatie van ouderen met een auditief-visuele beperking.

Aan dit onderzoek namen 30 verzorgingshuizen deel, via blokrandomisering verdeeld in 17 interventieclusters en 13 controleclusters. In totaal namen 89 bewoners met een auditief-visuele beperking en 56 verzorgenden uit de 30 verzorgingshuizen deel aan dit interventieonderzoek. Iedere verzorgende werd aan een of twee ouderen gekoppeld. De verzorgenden van de interventiegroep werden getraind en gecoacht in het aanbieden van het SMP-DSI. De resultaten lieten geen statistisch significant effect zien op de mate van sociale participatie (primaire uitkomstmaat gemeten met de Activity Card Sort). Wel werd een statistisch positief effect van de SMP-DSI interventie gevonden op het uitvoeren van instrumentale activiteiten van het dagelijks leven (IADL) ($p = 0,04$; 95% CI 0,12 - 8,5). Andere sociale participatie-domeinen zoals sociaal-culturele en recreatieve activiteiten gaven geen statistisch significant effect te zien. Deze resultaten tonen aan dat de ouderen met de hulp van de verzorgenden in staat zijn om praktische problemen op te lossen, maar niet die problemen waarbij de betrokkenheid van anderen nodig is om ze samen op te lossen. Mogelijk speelt bij dit laatste de behoefte een rol dat die ander zijn gedrag en communicatie aanpast aan de oudere met een auditief-visuele beperking, iets dat deze laatste mogelijk niet kan of durft te vragen aan die ander ondanks de ondersteuning van de verzorgende.

Algemene discussie

Hoofdstuk 8 geeft een overzicht van de belangrijkste bevindingen en conclusies in dit proefschrift, bediscussieert de theoretische en methodologische beperkingen en formuleert een aantal aanbevelingen voor beleid, onderwijs, praktijk en verder onderzoek.

Dit proefschrift laat zien dat het zelfmanagementprogramma voor ouderen met een auditief-visuele beperking succesvol problemen op het gebied van instrumentele activiteiten in het dagelijks leven kan aanpakken, maar dat het geen aantoonbare verbetering geeft op het gebied van sociaal-culturele en vrijetijdsactiviteiten.

Concluderend kan gesteld worden dat ouderen met een auditief-visuele

beperving behoefte hebben aan afstemming en interactie met hun omgeving en zorgprofessionals. In tegenstelling tot de verwachtingen van de verzorgenden bleken de ouderen graag betrokken te willen worden bij wat er in hun omgeving gebeurt en op welke wijze zij zorg ontvangen. De combinatie van een clustergerandomiseerd gecontroleerde studie met een longitudinale procesevaluatie maakte het mogelijk om de veranderingen bij de verzorgenden te volgen bij hun toepassing van het zelfmanagementprogramma. Dit leerde ons dat de gebruikelijke zorg zich vaak niet bewust is van de behoefte van de ouderen aan interactie en afstemming, noch van de problemen en de impact van de auditief-visuele beperking op het leven van de ouderen. Maar het leerde ons ook dat interactieve praktijkoefeningen gekoppeld aan individuele, reflecterende coachingssessies de verzorgenden helpt om hun gedrag te veranderen, en af te stemmen op de autonomie- en controlewensen van de ouderen.

Om ouderen met een auditief-visuele beperking te ondersteunen is een aanpak nodig die zowel generiek als probleemoplossend is. Dit staat in contrast tot de gebruikelijke zintuigspecifieke en educatieve interventies. Echter, zulk een generieke en probleemoplossende aanpak vereist dat de dagelijkse professionele omgeving in staat is om de ouderen te raadplegen in een sfeer van positief partnerschap.

Onze bevindingen pleiten voor een culturele verandering in de ouderenzorg, en voor een hernieuwde visie op de rol van de verzorgende. Zorgaanbieders die social health hoog in hun vaandel hebben staan en de veerkracht van de ouderen willen ondersteunen, dienen er oog voor te krijgen dat verzorgenden een essentiële rol moeten en kunnen hebben in de psychosociale ondersteuning van de ouderen. Opleidingen dienen in hun curriculum prioriteit te geven aan transparante, vraag- en doelgerichte psychosociale gespreksvoering, en aan implementatiemethodieken die praktijk en reflectie op het effect van het eigen handelen combineren, en dat over een langere periode.

DANKWOORD



‘Ga toch fietsen!’. Dit was het welgemeend advies van mijn schoonzus Josée toen ze hoorde van mijn onderzoeksplannen. Nee, mijn omgeving reageerde nou niet bepaald enthousiast: heb je bijna een leeftijd bereikt waarop je kan gaan ‘free-wheelen’, ga je je als fin-de-carrière-promovendus vastleggen. Maar Gust, mijn robuuste steun en toeverlaat in het leven, reageerde op het onderzoeksvoorstel van Kalorama met: ‘Lieve, dit is precies iets voor jou, moet je doen!’.

Een onderzoekstraject als dit vergt samenwerking en overleg met talloze anderen, met tal van doofblinde mensen, ouderenzorgmedewerkers, doofblindenbegeleiders, managers, bestuurders, onderzoekers, behandelaren, patiëntengroepen en beroepsnetwerken. Zonder al deze mensen had dit onderzoek simpelweg niet kunnen plaatsvinden.

Mijn aanvankelijk vaag omljnd idee van wat wetenschappelijk onderzoek was, werd door Myrra op scherp gesteld. Myrra, jij nam het op je om mij tot wetenschappelijk onderzoeker om te turnen. Of je dat gelukt is? Wij weten het antwoord, maar laten we de lezer van dit proefschrift dat verder zelf ontdekken. In ieder geval Myrra: dank voor je deskundige leiding en vasthoudendheid. Je liet me een breed scala van onderzoeksmethodieken verkennen, en daar heb ik van genoten.

Samen met Myrra was er het team Ruud, Sytse, Maud en Pieter. Ik zeg bewust ‘team’, want de sfeer bij bijeenkomsten van de (co)promotoren was altijd collegiaal. Dit onderzoek heeft veel baat gehad bij het eigen profiel en specialisme van ieder teamlid afzonderlijk. Chapeau! Ik heb een enorm respect gekregen voor jullie deskundigheid en inzet. Eén kritische vraag: wanneer nemen jullie een keer vrij? Het lijkt wel of jullie altijd aan het werk zijn. Ik kon altijd rekenen op jullie efficiënte tandem: wanneer ik mijn concepten aan jullie doorstuurde was het bijna altijd Ruud die binnen een of twee dagen als eerste reageerde. De reactie van Sytse kwam meestal op donderdagavond laat of op vrijdag. Dan ging ik alvast aan de slag met jullie opmerkingen, en een weekje later kwamen de voorstellen van Maud, vaak met suggesties op net die punten waar ik mee worstelde. Dank voor jullie ondersteuning!

Pieter, het Hora Est protocol liet niet toe om jouw naam toe te voegen in de rij van (co)promotoren. Maar daar hoort je naam wel thuis: jij was het die mij op dit onderzoekspad loodste. Daarna volgde en ondersteunde je ons waar je maar kon. Je optimisme en integer vakmanschap heeft veel voor me betekend. Bovendien gaf je ook nog eens praktische ondersteuning: dankzij jouw naam en faam gingen de deuren van zorgaanbieders en -bestuurders vlot voor ons open. Citaat van een van hen: ‘Als Pieter Hermsen hier achter staat, dan is het goed, dan doen wij mee.’.

Ook dank aan de bestuurders van Kalorama die het lef hadden dit onderzoek te starten. Hetty Stieger stond destijds aan de wieg, Fieke van Deutekom geeft er nu een vervolg aan. En natuurlijk dank aan leden van de Raad van Toezicht van Kalorama. Ik ben hen vooral erkentelijk voor hun vasthoudende visie dat het werk van verzorgenden uiterst waardevol is en een wetenschappelijke basis verdient. Dank ook aan de Joannes de Deo Stichting en het Moeder Catharinafonds voor het financieel faciliteren van dit onderzoek.

En nu kom ik op glad ijs, want wie mag ik zeker niet vergeten? Er zijn zovele Kalorama-collega’s die een bijdrage hebben geleverd aan dit onderzoek, zichtbaar en onzichtbaar, in een rol als coach, docent, onderzoeksassistent, planner, procesbegeleider, data-invoerder, opleidingsfunctionaris, administratief medewerker, personeelswerker, of gewoon als collegiaal meedenker, adviseur of ‘mogelijkmaker’. Dus Cherry, Lizan, Tessa, Merel, Ria, Liesbeth, Jan vB, Jan P, Han, Irma, Marian, Annita, Thea, Antoinette, Ans, Jolanda, Karin, Margje, Wim, Annelies, Vanessa, Ellen, Wilma, Saskia, Bert, Anita, Maria, Hans, verzorgenden van ’t Höfke, ambulante begeleiders en doofblindenbegeleiders, en tijdelijke collega’s Marleentje, Katja en Marjolein, en nog zovele anderen: hartelijk dank!

Genoten heb ik ook van de contacten en uitwisseling met collega-onderzoekers, journalclubleden en medewerkers van het Radboudumc. Vooral dank aan Steven, een baken van rust en helderheid die mij geduldig over alle kwantitatieve paden loodste. IQ Healthcare voelde als een warm bad, altijd bereid om mee te denken en mij mee te laten kijken in hun onderzoekskeuken. En steeds was er Alice die me vrolijk en vriendelijk de weg wees.

Bijzonder dank ook aan Roger, zonder hem zou dit onderzoek veel minder leuk zijn geweest. Uit zijn reacties op mijn teksten sprak zo'n aanstekelijk joie-de-vivre dat ik daar op mijn beurt ook weer vrolijk van werd.

Een warm dankjewel aan de vele doofblinde mensen, aan de ouderen die dit onderzoek mee hebben voorbereid en proactief meedachten, aan de ouderen in de diverse verzorgingshuizen die als deelnemer dit onderzoek mogelijk gemaakt hebben, en aan de verzorgenden die bereid waren hun denk- en werkwijze met ons te delen.

Tenslotte, aan mijn familie, vrienden, sportmaatjes en alle anderen voor wie ik soms weinig tijd had: bereid je voor! Ik heb een aardig snelle 'biologische' fiets, ik werk eerst nog even aan mijn fysieke conditie, en dan kom ik zeker bij jullie langs- en aanfietsen!

CURRICULUM VITAE



Vrij snel na de afronding van mijn studie psychologie in Antwerpen stapte ik de wereld van dove en doofblinde kinderen binnen. Deze wereld waar communicatie en interactie centraal staan, bleek mijn habitat. De kern van het vak leerde ik in het Instituut voor Doven te Sint-Michielsgestel (nu Koninklijke Kentalis). In 1987 startte ik bij het Centrum voor Doofblinden Kalorama in Beek-Ubbergen.

Education permanente was vanzelfsprekend. Diverse vervolgoopleidingen en specialisaties volgden, onder meer in Leuven (leer- en ontwikkelingspsychologie), Tilburg (buitengewoon onderwijs - gehoorstoornissen), Utrecht (neuropsychologie; constructionele gedragstherapie).

Opleidingen zijn nodig en nuttig. Echter, wat iemand tot een professional maakt en elan geeft aan het vak, zijn de coaches, de collega's om je heen, en je cliënten. Ik had het geluk - puur toeval - om achtereenvolgens samen te kunnen werken met enkele uiterst talentrijke, vernieuwende collega's, mensen die hun inzichten en enthousiasme deelden en uitdroegen. In Sint-Michielsgestel leerde dr. Antoine van Uden mij zijn gespreksmethode, dr. Jan van Dijk leerde me de kern van diagnostic teaching, en van andere Rafael-medewerkers pikte ik de pioniers- en ontwikkelmentaliteit op. In Kalorama leerde ik via drs. Paul Andreoli het werk van dr. Beata Bakker kennen, en de invloed van de omgeving op het gedrag van de cliënt.

Naast hun grote expertise en pioniersmentaliteit, deelden deze mensen één belangrijke eigenschap: ze zochten naar kansen voor hun cliënt. Hun boodschap was niet te blijven stilstaan bij de problemen die doofblindheid zeker met zich meebrengt, maar te zoeken naar de beste kansen die de omgeving het doofblinde kind of volwassene kan bieden. Van Uden leerde me om systematisch naar de sterke kanten van meervoudig gehandicapte kinderen te zoeken. Voor ieder leerprofiel dat we vonden wilde hij wel 'een witte villa' kopen waar kinderen met een identiek leerprofiel samen konden leren. Van Dijk liet op een onnavolgbare wijze zien hoe je totaal in zichzelf gekeerde doofblinde kindjes kon uitlokken om de wereld te exploreren. Voor de omstaanders leek zo'n diagnostische sessie een happening. Maar na zo'n happening had van Dijk alle mogelijkheden verkend en wist hij precies welke aanpak bij dit specifieke kindje kans van slagen had.

Kalorama bleek een eldorado om met deze kennis en expertise verder te werken, bij volwassen doofblinde mensen dit keer. En dat in een tijd dat protocollen en vinkjes nog niet tot de dagelijkse plicht van een behandelaar behoorde. Het gedachtengoed van dr. Beata Bakker werd de uitvalbasis om diverse interactieve, psychosociale methodieken te ontwikkelen. Het ging er niet om hoe de cliënt zich gedraagt, maar om de interactie van de cliënt met zijn omgeving, en vooral, om het creëren van kansen voor de cliënt om te werken aan zijn gevoel van welbevinden. Interdisciplinair werken, met een ervaren team collega's, geadviseerd en waar nodig bijgestuurd door doofblinde cliënten, leverde pareltjes van expertise-ontwikkeling en werkplezier op, en vooral: van cliënten die hun leven weer konden oppakken.

Organisatorische factoren maakten een einde aan deze ontwikkeling. Een late switch naar wetenschappelijk onderzoek in dit unieke werkveld bleek een mooie optie. Een nieuw avontuur lokte, met nieuwe denk- en werkwijzen. Maar toch, de inhoud van dit proefschrift is in de lijn van het gedachtengoed dat ik meekreeg uit mijn tijd als behandelaar. Immers, ook zorgafhankelijke ouderen - met of zonder een auditief-visuele beperking - hebben baat bij een interactieve omgeving die kansen creëert.

SUPPLEMENTARY DATA



Supplementary Data - Appendix 1

Procedure to assess for eligibility for participation in the cluster randomized controlled trial

To detect eligible older adults among the long-term care residents, three consecutive assessments were performed: two assessments to detect dual sensory impairment, and one assessment to detect severe problems in cognitive functioning.

- First, the residents of the LTC homes were assessed for dual sensory impairment (DSI) using the Severe Dual Sensory Loss screening tool (SDSL).
- Of those who were suspected of having DSI and who had given written consent was assessed:
 - hearing impairment: pure-tone audiometry was screened by a speech language specialist
 - visual impairment: distance and near visual acuity, visual field, and contrast sensitivity were screened by an optician.
 Both audiometry and vision screening were performed at the LTC setting, in a quiet, uniformly brightly illuminated room of at least 5 meters long.
- Assessment of cognitive functioning. An interview protocol based on DSM IV criteria was used to exclude older adults unable to complete interviews due to an advanced stage of cognitive problems [1]. To assess cognitive functioning, we used the DSM IV criteria for capacities in executive functioning: planning, organizing, sequencing and abstracting. These criteria have been selected for their relevance when performing self-management strategies. The interview protocol shows how the DSM IV criteria are used. To this protocol, we have added instructions how to create valid communication conditions in order to be able to observe cognitive functioning, considering the communication barriers associated with dual sensory impairment.

Interview protocol for the assessment of cognitive functioning [2]

Step 1. Create valid communication conditions

a. Adapt your output to the auditory and visual needs of the DSI person
Adapt your articulation, face orientation, rhythm and tempo of your speech, and adapt conditions such as lighting, distance, height, and exclude glare and environment noise. If provided, ask the older adult to use his/her familiar (hearing) devices.

b. If the person does not understand your speech, switch to writing
Adapt size, color and contrast of your writing, adapt paper and pencil type.

c. Structure your information

Divide your information into clear parts, avoid sentences with multiple clauses, and pause between each sentence to give the older person time to absorb and comprehend the information

Step 2. Observe cognitive functioning

a. Find proof that the person comprehends your introduction

Is he aware who you are?

Does he comprehend that you want to provide information about a research project?

Does he concentrate on you or your information?

Is he trying to understand and comprehend?

Or does he repeatedly ask who you are, and what you want? Does he persist in talking about his/her own issues or in continuing with own activities?

b. Induce the older adult in cognitive planning and reasoning

Ask the persons' help or preference in planning your next visit; invite him to choose between two or three alternatives (planning)

Invite the person to talk about his experiences with his hearing and vision, and the adaptations he has already established (abstracting, organizing)

Invite the person to tell you what a normal day looks like (sequencing, organizing)

Invite the person to tell you what a weekend day looks like (abstracting, sequencing)

Observe the contribution of the older adult during this conversation: are his reactions adequate answers to your questions? Are his answers coherent?

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Supplementary Data - Appendix 2
SDSL screening tool

Instruction: The screen should be administered by a professional nurse familiar with the older person. Put a mark on all of the statements in the screen, which coincide with observed problems.

Subscale 1: Hearing functioning

- H1. He/she does not hear you when you knock on the door or ring the doorbell.
- H2. You have to speak very loudly, clearly and/or slowly for him/her to be able to understand what you are saying (although it is quiet around you).
- H3. He/she has problems understanding what you are saying when there is noise in the room (e.g. sound from a radio, vacuum cleaner, traffic, etc.).
- H4. He/she has problems following a conversation when there are several people present.
- H5. He/she has problems understanding what is being said on television, on the radio or other amplified source (e.g. sits very close to the source of the sound or/and turns the volume very high).
- H6. He/she has complained about reduced hearing.

Subscale 2: Visual functioning

- V1. You are not recognized when you visit unexpectedly
- V2. He/she has problems reading the newspaper and watching television (e.g. sits very close to the screen).
- V3. He/she needs help to find objects that have been mislaid.
- V4. He/she has problems knowing what the time is because he/she cannot see the clock face or watch.
- V5. He/she needs a companion or is afraid when moving about out of doors and/or indoors in unfamiliar places (except when this is due to difficulties in walking or other physical impairment).
- V6. He/she complains about worsening vision.

Sum-score subscale Hearing	
Sum-score subscale Vision	
Total score	

Scores per item are 0 (no) or 1 (yes). For each subscale, the sum-score ranges from 0 to 6. Cut-off score for each subscale is score 1.

Supplementary Data - Appendix 3

The development of the nurse-supported SMP-DSI and of the SMP-DSI training program for nurses

In this Appendix, we consecutively (1) describe the fundamentals upon which we built the SMP-DSI, (2) we present the key features of the SMP-DSI, and (3) we present an overview of the training program for nurses that was developed in accordance with the SMP-DSI program and was refined in different stages in collaboration with the residents and their licensed practical nurses of the Kalorama LTC home and with social workers of the Kalorama Center for the Deafblind.

1. The fundamentals of the SMP-DSI

The systematic review identified problem solving as a potential effective approach for positively affecting emotional status. Therefore, we took fundamental elements from three different behaviouristic intervention models and combined them with practical experiences with the functioning-oriented rehabilitation model developed at the Kalorama Center for the Deafblind.

First, we used concepts from the problem solving therapy; developed to enhance mental and physical health by teaching patients psychosocial skills [1]. In this model, patients undergoing psychotherapy were urged to systematically identify their problems, generate alternative solutions for each problem, select the best solution, develop and conduct a plan, and evaluate whether this resolved the problem. The therapist helped the person to develop feasible solutions and reviewed available rehabilitative services and devices to support the process of generating solutions [2, 3].

Secondly, we used the concepts of the self-management intervention for persons with chronic diseases as described and tested by Lorig and colleagues [4, 5]. This concept extended the problem solving therapy to become a model for people with chronic conditions, reflecting the view that self-managing a chronic illness is a lifetime task, and only the person can be responsible for his or her day-to-day care over the length of the illness. In this model, identification of clients' perceived problems was set as a prerequisite to start a self-management intervention. Five basic self-management tasks were identified and taught to people with chronic diseases: problem solving, decision making, resource

utilization, forming of a patient/healthcare provider partnership, and taking action.

Thirdly, we used concepts of the functioning-oriented rehabilitation model developed at the Kalorama Center for the Deafblind. Similar to Lorig's self-management model, this rehabilitation model also uses concepts of an intervention previously introduced and tested in psychotherapy and based on behaviouristic thoughts, i.e. constructional behaviour analysis of Bakker [6, 7]. In this analysis method, the interaction between individual and environment is viewed as the main strength to enhance personal wellbeing, and the person is invited to reflect on recent successful behaviour. By looking outwards and exploring aspects in the environment, the client is stimulated to detect leads that work for him/her, i.e. that contribute to individual satisfactory functioning. This model has been extended at the Kalorama Center for the Deafblind for use in daily living, to recover or strengthen the personal wellbeing of the deafblind clients. After introducing this functioning-oriented rehabilitation model, we saw a spectacular decrease in depressive feelings, anxiety, and problem behaviour among the heterogeneous population of residential and community living deafblind clients of Kalorama [8-10].

2. The SMP-DSI and its key features

The SMP-DSI was developed as a five-step interview including problem identification (step 1), collecting alternatives (step 2), choice and planning (step 3), execution (step 4) and reflection (step 5). Table 1 (first column) reflects the key features of the SMP-DSI.

Table 1. Key features of the SMP-DSI

<i>Program Steps</i>	<i>Actions Older Adults</i>	<i>Supportive Key Questions of Nurse</i>
1.Problem Identification	Mentions problem Decides to take action	You mentioned that you have a problem with ... Would you like to do something about it?
2.Collecting Alternatives	Collects a minimum of three alternatives: either by themselves, or by asking others for help	What could you do about this? Are there other options?
3.Choice and Planning	Selects an alternative that he/she will act on Plans action	How do you think you will manage this?
4.Execution	Executes action	
5.Reflection	Reflects on own action, mentions what went well	What was the result? What are you happy about: What you could do on your own? What would you do differently the next time?

3. An overview of the training program

The training program was developed as a longitudinal training and coaching program based on Bakker’s constructive behavioural analysis, aiming to support the individual to develop feasible solutions and inviting reflection on recent successful behaviour. Interwoven in each group training, nurses were made aware of DSI-specific issues.

Nurses received nine training sessions that were spread over a period of 5 months, parallel to the intervention period and divided into three consecutive rounds, totaling 16.5 hours. Each round consisted of three successive sessions: (1) a 3-hour group training session, (2) 1 hour of individual coaching and (3) 1.5 hours of group supervision, with a 2-3 weeks interval between each session. Nurses were asked to practice the SMP-DSI at least once during the 2-3 weeks interval with the older adult(s) they were linked with, and to fill in an intervention and coaching diary. The group training sessions focused on the knowledge and skills required by the nurses to use the SMP-DSI. In the individual coaching sessions, the trainer invited the nurse to reflect on and evaluate her own behaviour during the interactions with the older adult when offering the SMP-DSI. In group supervision sessions, nurses shared their successes and goals. Table 2 gives an overview of the content of training program.

Training of the trainers. During the 5-month training and intervention period, the trainers participated in three group supervision sessions of 1.5 hours each, led by a professional coach of licensed practical nurses. Special emphasis was given to the individual coaching approach for nurses. Trainers were asked to start each individual coaching session with a question similar to the first question of the coaching diary: ‘When looking back on your interview with the older adult, what are you happy about, about what you did yourself?’ and to invite the nurses to reflect on their interactions with the older adult using three questions: (1) What did you observe in the older adult? (2) How did you align your behaviour? (3) What was the effect of your behaviour on the older adult? The third question could be completed by asking the nurse what she would do differently (identical to step 5 of the SMP-DSI—see table 1) and what alternative actions she could think of (identical to step 2 of the SMP-DSI).

Table 2. Overview of the SMP-DSI training program

Round 1	
<i>Session 1 Group training</i>	
Activity 1	Introduction - *Identification of problems and needs related to DSI
Activity 2	Training overview and responsibilities
Activity 3	Identification of self-management in personal life
Activity 4	Introduction of the 5 steps structure of the SMP-DSI
Activity 5	*Experiencing/simulating being dual sensory impaired
Activity 6	*Exercising how to adjust to the communicative needs of DSI older adults
Activity 7	Exercising step 1 Problem Identification and step 2 Alternatives
Activity 8	Home assignments (<i>communication adjustment</i> ; SMP-DSI)
Activity 9	Identifying personal learning goals
<i>Session 2 Individual coaching</i>	
Activity 1	Feedback- training overview and responsibilities
Activity 2	Feedback -home assignments (<i>communication adjustment</i> ; SMP-DSI)
Activity 3	Identifying personal learning goals
<i>Session 3 Group supervision</i>	
Activity 1	Exchange of experiences
Activity 2	Identifying personal learning goals
Round 2	
<i>Session 4 Group training</i>	
Activity 1	Feedback/ SMP-DSI
Activity 2	Practicing step 3, support in making an action plan
Activity 3	SMP-DSI in complex situations
Activity 4	*Practicing how to open up information for DSI older clients
Activity 5	Practicing step 3 Plan and step 5 Evaluation
Activity 6	Home assignments (SMP-DSI)
Activity 7	Identifying personal learning goals
<i>Session 5 Individual coaching</i>	
Activity 1	Feedback - home assignments
Activity 2	Identifying personal learning goals
<i>Session 6 Group supervision</i>	
Activity 1	Exchange of experiences
Activity 2	Identifying personal learning goals
Round 3	
<i>Session 7 Group training</i>	
Activity 1	Feedback/SMP-DSI steps/shared decision making
Activity 2	Self-management- key issues

Activity 3	Traps when using SMP-DSI
Activity 4	*Experiencing ADL and IADL needs of DSI older adults
Activity 5	*Environmental alterations to meet DSI-needs
Activity 6	Practicing the SMP-DSI in challenging situations
Activity 7	Identifying personal learning goals
<i>Session 8 Individual coaching</i>	
Activity 1	Feedback - home assignment
Activity 2	Identifying personal learning goals
<i>Session 9 Group supervision</i>	
Activity 1	Exchange of experiences
Activity 2	Closing

*Specific dual sensory impaired related training
 ADL = activities of daily living; IADL = instrumental activities of daily living

References Appendix 3

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