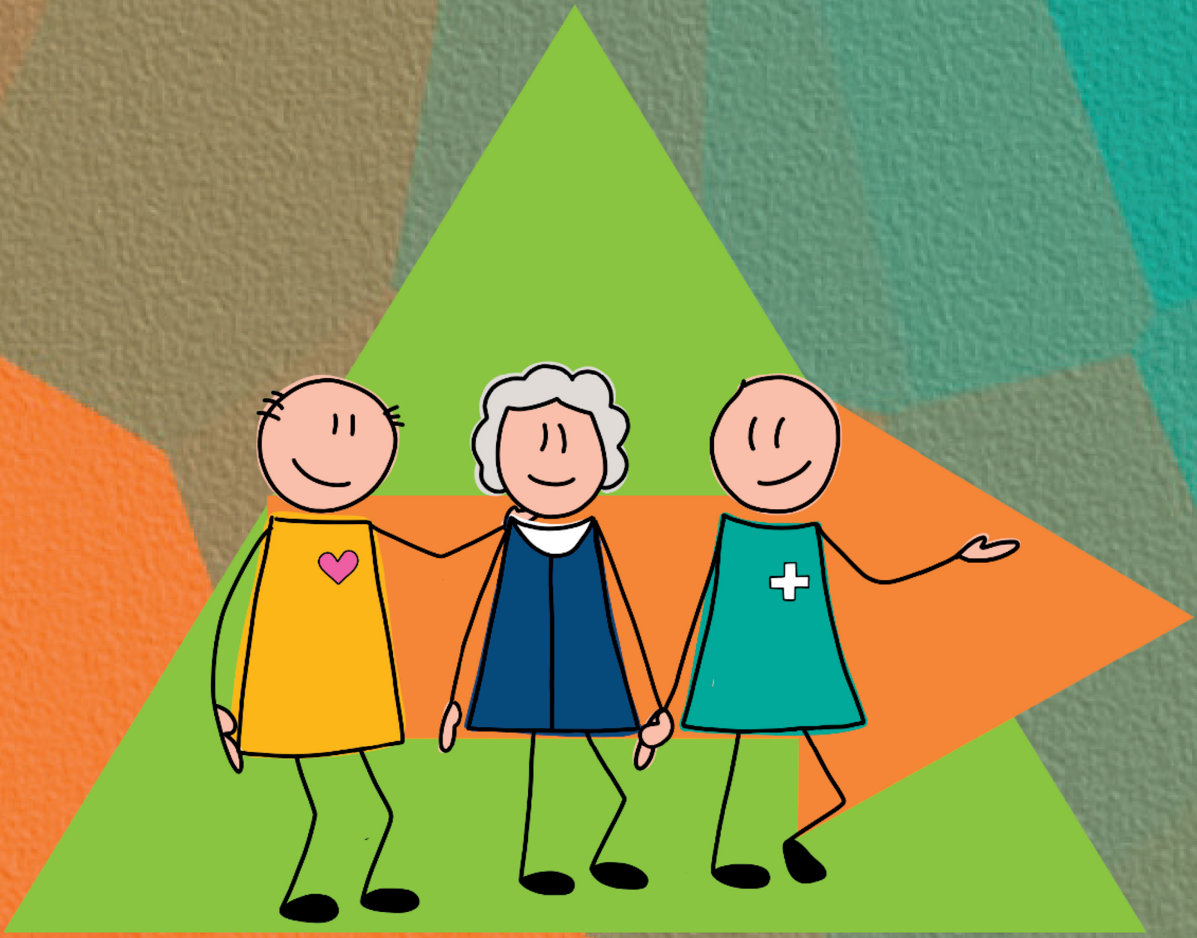
Apathy in persons living in nursing homes: *moving forward*

Consequences, identification and management



Hanneke Nijsten

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Colofon

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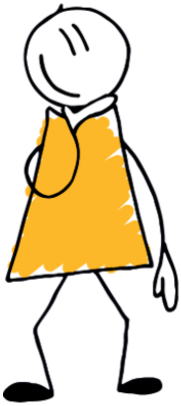
CONTENTS

‘Apathy is that… erm… people increasingly… erm… do less in their daily lives and take less action to go and do something.’ (Family caregiver, 04)

“And apathy in terms of, like, not being able to get things started, it’s not always that the person is okay with it or doesn’t feel like it or doesn’t want to, but that’s just a part of it: they simply can’t do it.” (Professional caregiver, 01)

“Not feeling like it, but also not being able to feel like it. It’s not only wanting to but, in part, also a matter of ability…that they just don’t, do not, have the energy to get started.” (Professional caregiver, 09)



1

General introduction

GENERAL INTRODUCTION

Apathy: background and definition

The word *apathy* originates from the Greek *apatheia*, from *a-* («without, not») and *pathos* («emotion») [1]. In Greek, the term *apatheia* was used in Stoicism. This philosophy was based upon the idea that one is only responsible for one's own representations and judgments and not for all things exterior. *Apatheia* was then used to indicate a (desirable) state of indifference towards events and things that were beyond one's control and referred to a state of mind in which one was free from emotional disturbances.

The meaning of the modern English word apathy is quite different from that of *apatheia* and nowadays has a negative connotation. Over time, the concept of apathy has undergone several changes in meaning and definition, although a state of indifference or inertia has remained [2-5]. In general, apathy is considered to comprise three core dimensions – behavioral, cognitive and emotional – that each contribute to reduced goal-directed behavior [3]. In people with neuro-cognitive disorders, apathy is best defined as diminished initiative, diminished interest, or diminished emotional expression/responsiveness [6]. Diminished initiative refers to the behavior dimension of apathy where a quantitative reduction of self-initiated goal-directed behavior is most present. This regards decreased initiative in starting or maintaining behavior or reduced levels of general activity and social interaction. Diminished interest reflects the cognitive dimension of apathy, referring to a decrease in ideas, curiosity, interest in activities or an increased difficulty in making choices. Finally, diminished emotional expression/responsiveness refers to the emotional or affective dimension of apathy, characterized by less spontaneous emotions, a blunting or flattening affect in response to positive or negative events. To diagnose apathy in persons with neurocognitive disorders, at least one symptom in at least two of the three dimensions needs to be present and persistent or frequently recurrent over at least four weeks. The symptom(s) also need to represent a change from the patient's usual behavior, cause(s) significant functional impairment and it/they must not be exclusively explained by other etiologies [3, 6].

Specific fronto-subcortical systems in the brain – i.e., frontal-cortex - basal ganglia circuits – are involved in apathy and related to different subtypes or dimensions of apathy [7-10]. These subtypes depend on the brain region affected, where each region relates to the disruption of specific goal-directed behavior. Brain damage and neurodegeneration in these brain systems are found in people with a wide variety of neurological and neurodegenerative diseases and neuro-cognitive disorders. Therefore, apathy is common in persons with Alzheimer's disease [11], (young onset) dementia [12, 13], acquired brain damage [14], stroke [14-16], amyotrophic lateral sclerosis [17], multiple sclerosis [18], Parkinson's disease [19], Korsakoff syndrome [20], and Huntington's disease [21]. Apathy is found to be a profound predictor for the conversion of mild cognitive impairment to all types of dementia [22]. In these conditions, apathy is known to be common, persistent and has been associated with functional impairment, cognitive decline and reduced qualitative participation in social contact or activities [23-27]. Apathy is also known to be negatively related to activities of daily living, caregiver burden and earlier admission to a nursing home (NH) [14, 28-30]. Although apathy, depression and cognitive decline often co-occur, they are nowadays regarded as separate entities, meaning that apathy is regarded as an independent construct [31-34].

Apathy in nursing home care

In the Netherlands, it is common that persons with (very) frail somatic conditions and those with (advanced) dementia who live in NHs reside in specialized care units, namely somatic care (SC) or dementia special care (DSC) units. The majority of persons living in Dutch NHs have at least one of the previously described conditions. Often, the type of NH unit in which a person resides is primarily determined by the severity of the cognitive impairment and the coexistence of neuropsychiatric symptoms (NPS). NPS is an umbrella term for a variety of symptoms including apathy and other symptoms like anxiety, depression, aggression, agitation, disinhibition, delusions and hallucinations [35]. In dementia research, these NPS are also referred to as the behavioral and psychological symptoms in dementia (BPSD). However, in this thesis we prefer the term NPS as we consider apathy in both persons living in NHs with dementia as well as those without dementia. In NHs, apathy is persistent and common in different NH resident groups, affecting approximately 50% of persons in NHs living in SC and DSC units [11, 35].

Nevertheless, despite its profound negative effects – and in contrast to other NPS – we know from clinical experiences and previous research that apathy in people living in NHs is seldomly diagnosed nor specifically treated by the multidisciplinary team involved in the care for people living in NHs [36, 37]. Research on the treatment of apathy has primarily focused on pharmacological interventions. Low-quality evidence has been found of pharmacological treatment reducing apathy in people with dementia, for example with methylphenidate [38-40]. For Parkinson's Disease, only methylphenidate, rotigotine and rivastigmine have shown some promise in the treatment of apathy [36]. Regarding dementia with Lewy bodies and fronto temporal dementia, studies with rivastigmine and agomelatine, respectively, have suggested benefits. For apathy in vascular dementia and Huntington's disease, no drugs have demonstrated benefits [36]. Adverse effects (e.g., gastrointestinal disturbances) and medical contraindications (e.g., cardiovascular) limit the clinical use of drugs with positive results [39]. Overall, to date there is no pharmacological treatment that has proven to be very effective [38, 39, 41]. Psycho-social interventions are first-choice treatment in reducing apathy in people with dementia [42] as they are quite safe and well accepted. Previous research has suggested that persons with apathy might benefit from individualized interventions that consider residents' preferences, physical abilities and environmental factors [43]. Some studies on psycho-social interventions seem promising [37, 44, 45], like those using guided activities [46], multisensory therapy, music therapy or art therapy [37, 47-49]. However, these interventions have not yet been implemented in the daily practice of clinicians in NHs or they are not applicable as the qualified professional staff that they rely on are not (sufficiently) available in nursing homes (for example, music therapy needs to be given by a certified musical therapist).

Apathy as multifaceted phenomenon

Massimo et al. [50] described a conceptual model (see figure 1) to find new angles in understanding the concept of apathy and how interactions between the person with apathy and dementia caregivers and the environment contribute to it, along with neural and neurobiological mechanisms. The conceptual model described patient factors (like the type of dementia, dementia severity, presence of other BPSD, genetics, acute medical problems, unmet needs), caregiver factors (stress/burden/depression, lack of education about dementia/misinterpretation of apathy as volitional behavior, communication issues, mismatch of expectations and dementia severity) and environmental factors (over- or under-stimulation, lack of activities and structure, lack of established routines, lack of rewards, safety issues) [23, 50, 51]. Some of the factors in the conceptual model had a significant evidence base, while others were hypothesized and require scientific evidence. For this thesis, inspired by Massimo et al.'s model, we looked at apathy as a multifaceted phenomenon associated with factors regarding the person with apathy, the family caregivers and professional caregivers, and the environment. Despite growing research on apathy, important knowledge gaps remain. For example, to improve the understanding of factors regarding persons with apathy, it is important to understand the impact of apathy from their perspective. Additionally, it is necessary to explore whether and how apathy has an impact on the mortality of those living in SC and DSC units and if this influence differs between these resident groups. Furthermore, NPS are associated with reduced quality of life (QoL), although this has not yet been investigated extensively for apathy nor for persons with apathy living in different NH units. Additionally, it is important to gain insights into whether and how cognition and depression moderate the relationship between apathy and mortality, and the relationship between apathy and QoL.

Apathy not only directly affects the persons themselves but also the people taking care of them. For instance, apathy is known to be a burden for caregivers at home and the lack of emotional response associated with apathy interferes with the connection and meaningful interaction between spouses including one person with apathy [52-54]. By contrast, professional caregivers seldomly regard apathy as challenging [55-58]. However, it remains unclear whether and how factors regarding the family caregivers and professional caregivers like knowledge, expectations and individual experiences are related to the perceived impact of apathy. Furthermore, insight is needed into how experiences and (unmet) needs of family caregivers and professional caregivers influence the identification and management of apathy in persons living in NHs.

AIMS AND OUTLINE OF THIS THESIS

This thesis addresses the consequences, identification and management of apathy in persons living in NHs. It aims to provide insights into the impact of apathy from different perspectives to increase knowledge of important aspects regarding the person with apathy, the family and professional caregivers and the environment, and to contribute to improved apathy care in NHs.

Part I of this thesis describes a quantitative approach to increase the knowledge of the consequences of apathy for persons with apathy living in SC and DSC units. The prognostic value of apathy on mortality was studied for both resident groups, while we also explored whether and how depression and cognition influence the relationship between apathy and mortality. Additionally, we explored how apathy relates to the QoL of persons with apathy, their family caregivers and professional caregivers. Data were used from previous research on the effects of a structured multidisciplinary approach for the treatment of depression in NH residents [46].

Part II of this thesis describes a qualitative approach focused on apathy in persons living in DSC units, as previous research has indicated that a psycho-social intervention could positively influence apathy in persons with dementia [46]. In this second part of this thesis, we addressed apathy by looking at factors regarding the persons with apathy and dementia, as well as factors regarding the family caregivers and professional caregivers. We aimed to unravel how the different stakeholders experience the identification of apathy in persons with dementia in NHs and what challenges they encounter while doing so. Further, we explored whether and how family caregivers and professional caregivers respond to apathy and why. The qualitative studies provided insights into the experiences, needs and wishes of family caregivers and professional caregivers regarding the identification and management of apathy in NHs. This provides input for a tailor-made intervention aiming to empower family caregivers and professional caregivers in identifying and managing apathy in NHs. We developed a specific intervention for apathy based on theoretical frameworks and in co-creation with family and professional caregivers, before subsequently testing and evaluating its feasibility and implementation process in different NHs [59].

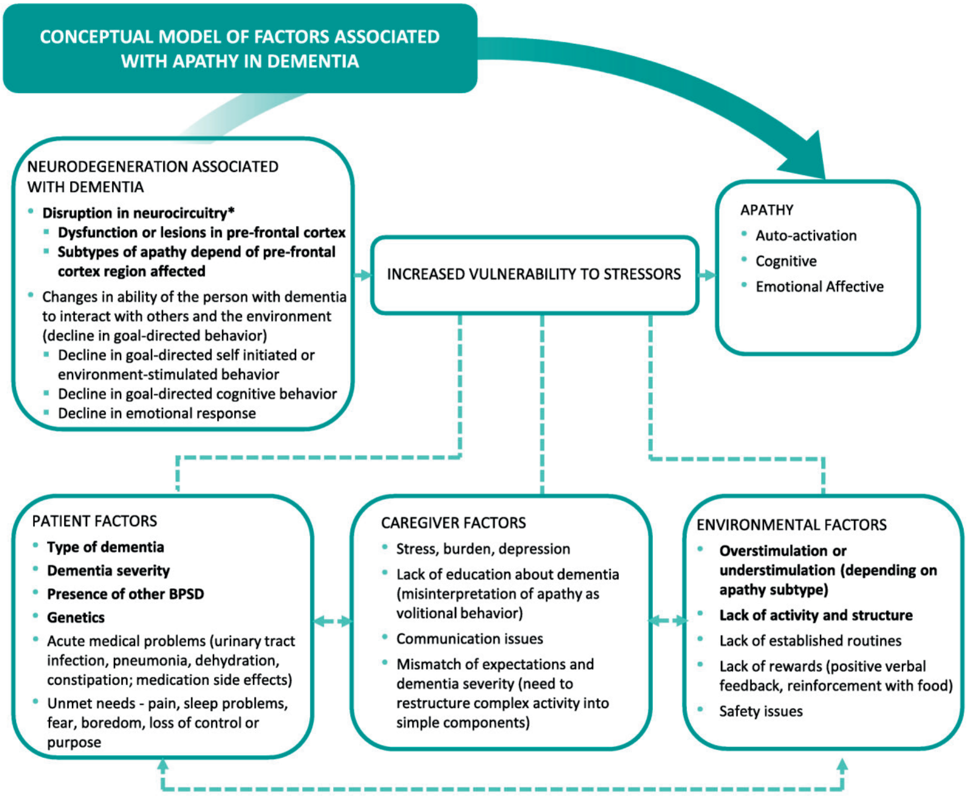
In **chapter 2**, we present a quantitative study exploring the relationship between apathy and mortality in NH residents of SC and DSC units and whether and how cognition and depression moderate these relationships.

Next, the quantitative study in **chapter 3** explores the association between apathy and health-related QoL and whether cognition and depression moderate this. For this purpose, we explored the perspectives of different stakeholders, namely the perspective of the persons with apathy, and proxy perspectives of professional caregivers.

Subsequently, **chapter 4** describes a qualitative study focusing on the experiences of family caregivers and professional caregivers in identifying and managing apathy when they visit or care for a person with dementia.

Next, **chapter 5** contains the qualitative study on the development and feasibility of an intervention to identify and manage apathy for family caregivers and professional caregivers: the Shared Action for Breaking through Apathy (SABA) program.

Finally, the general discussion in **chapter 6** provides a summary of the main findings, and a critical review of their results and methodology. In addition, implications for clinical practice, education, policy and future research are presented.



*Factors with a significant evidence base are bolded; non-bolded factors are hypothesized

Figure 1. Printed with permission of the author [50].

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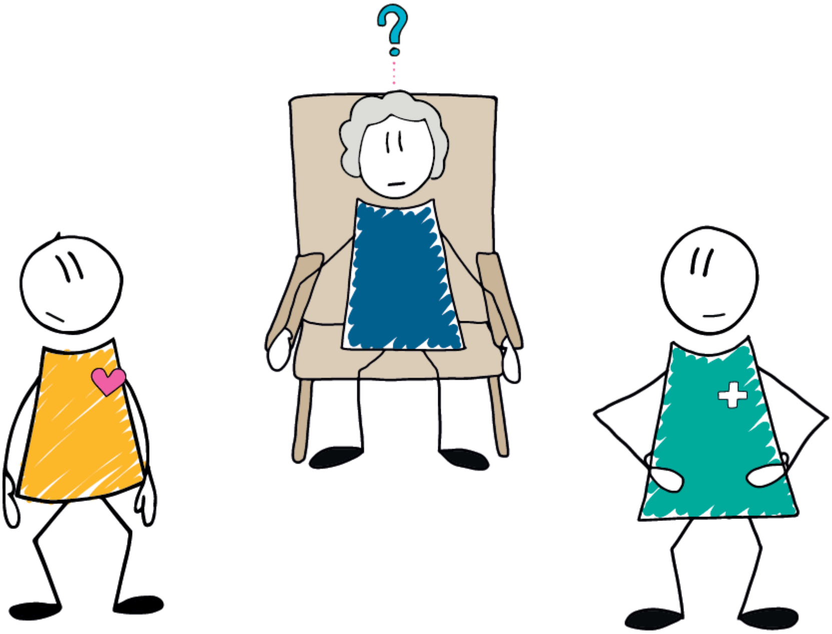
“At a given moment our mum sat on a chair and just stayed seated.” (Family caregiver, 01)

“Yes, I think there is a danger that you might think ‘it won’t work out, so I won’t pay any attention to it anymore.’ That you think, ‘yes, hopeless, I’ll move on.’ Kind of sad, of course. Then you basically say, ‘I won’t put any time into it,’ even though that gentleman or lady really needs it.” (Professional caregiver, 08)



2

Apathy: risk factor for mortality in nursing home patients

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Abstract

Objectives: determine the prognostic value of apathy for mortality in patients of somatic (SC) and dementia special care (DSC) nursing home (NH) units.

Design: longitudinal design, secondary analyses of a two-year cluster-randomized trial with six measurements approximately 4 months in between.

Settings: SC and DSC-units of Dutch NHs

Participants: NH patients of seventeen SC-units (n=342) and sixteen DCS-units (n=371).

Measurements: Data were available for 713 NH patients, 266 of whom died during the study. Apathy was assessed using the 10-item Apathy Evaluation Scale (AES-10) and applied as categorical variable using known cut-off scores as well as dimensional variable. Additionally, depressive symptoms were assessed using the Cornell Scale for Depression in Dementia.

Results: Mixed effects cox models conducted with the coxme package in R revealed a higher risk of mortality if apathy was present (Hazard Ratio [HR]=1.77; 95% confidence interval (CI)=1.35 to 2.31, $p<0.001$). The results remained significant (HR=1.64; 95% CI=1.23 to 2.19, $p<0.001$) when controlled for depressive symptoms. DSC-units and SC-units did not differ ($p>0.05$) in the effect of apathy on mortality. Male gender (HR=1.67; 95% CI=1.23 to 2.27, $p<0.001$), and higher age in years (HR=1.06; 95% CI=1.04 to 1.08, $p<0.001$) were also predictors of mortality. Regarding apathy as a dimensional construct, one standard deviation increase of AES-10 scores was associated with a 62% increase of mortality risk (HR=1.62, 95% CI=1.40 to 1.88, $p<0.001$).

Conclusions: Apathy is associated with increased mortality in patients of both SC and DSC-units, even when controlling for depressive symptoms. These data suggest that screening and treatment strategies for apathy should be developed for this patient polulation.

INTRODUCTION

Apathy is common in nursing home (NH) patients with dementia and is repeatedly found to be the most prevalent neuropsychiatric symptom[1-3]. Apathy is defined by diminished or lack of motivational, goal-directed behavior, and a lack of cognition and emotional affect. Apathy leads to reduced interest and participation in the main activities of daily living, diminished initiative, early withdrawal from initiated activities, indifference, and flattening of affect [4, 5]. Over the last two decades, more scientific knowledge has become available about specific fronto-subcortical systems in the brain that seem to be highly involved in apathy [6, 7]. Disruptions in these systems have been found in patients with frontal lobe damage resulting from, for instance, (early-onset) dementia, traumatic brain injury, stroke, or multiple sclerosis [8-10]. Fronto-subcortical circuits also play an important role in neurological disorders involving the basal ganglia such as Parkinson's disease and Huntington's disease [9, 11, 12]. The neurodegenerative diseases and acquired brain injuries mentioned here are highly prevalent in patients receiving long-term somatic care (SC), and the widespread clinical manifestation of apathy in SC units of NHs is thought to be related. However, in contrast to the abundance of research into apathy in patients within dementia special care (DSC), research into apathy in SC patients without dementia is rare.

Furthermore, although apathy is common in NH patients and has been found to be associated with adverse outcomes including poor treatment response, more rapid cognitive decline, increased reliance on caregivers, and earlier institutionalization {10, 13-17] it is rarely considered a problem by professional staff in that setting [18, 19].

Interestingly, only a few studies have investigated the prognostic value of apathy for mortality, and the findings are inconsistent. Hölttä et al. [20] found that apathy had a negative effect on survival rates in acute geriatric wards and NHs, and predicted mortality after controlling for age, gender, delirium, and dementia (HR = 1.89, 95% CI 1.24 to 2.89; P = 0.003). On the other hand, in their study of elderly people living in the community or in NHs, Okura et al. [21] found that agitation, depression, and delusion - but not apathy - were of independent prognostic value for mortality. Peters et al. [22] found that earlier death was associated with psychosis, affective symptoms, and agitation/aggression, but not with apathy. However, these studies have used the concept of apathy as categorical construct with apathy being either present or not. This simple dichotomization of apathetic behavior does not reflect the nosological complexity of apathy, which could also be considered a dimensional concept varying from slightly diminished interest to total absence of initiative, goal-directed behavior, emptiness of thoughts, and emotional blunting [23]. Apathy has traditionally been considered a symptom of depression. Loss of interest or pleasure is a principal symptom used to diagnose depression, even when depressed mood is not present [24, 25]. While various studies support the concept that apathy can be discriminated from depression [5, 26, 27] a combination of different and overlapping risk factors necessitates taking depression into account when studying apathy.

Since apathy is very common in NH patients and may lead to a poor prognosis, clear insight into its risk for mortality is needed and NH staff need to understand this risk.

As apathy has rarely been studied in patients without dementia living in SC units, and the question of whether apathy should best be considered as a dimensional or a categorical variable has not yet received much attention, the aims of the current study are: (1) exploring the relationship between apathy and mortality in NH patients and to investigate whether there is a difference in the prognostic value of apathy for mortality in patients of SC units and in patients of DSC units, and (2) exploring the relationship between apathy and mortality for apathy both as a categorical and dimensional variable.

METHODS

Design, Participants and Ethics

Data is derived from the Act in Case of Depression (AiD) study, a Dutch stepped-wedge cluster-randomized trial with five groups and six time points (T0–T5) with approximately 4 months between measurements thus providing longitudinal data. [28]. A stepped-wedge design is a crossover design with repeated measurements and with randomization of time points for crossing over from the control condition to the intervention condition. This enables comparison between and within clusters. All clusters were in the control condition at baseline (T0). A randomly selected group of clusters implemented the intervention shortly after T0. Other groups crossed over after T1, T2, T3, and T4, respectively. At T5, all clusters were in the intervention condition. In the intervention condition, a program containing depression assessment procedures and multidisciplinary treatment (activating strategies, psychotherapy, and medication) was introduced. The duration of the intervention at T5 varied from 4 months (group five) to 20 months (group one). Details of the design and methods of the original study and its findings have been reported elsewhere [1].

Data were collected from May 2009 to April 2011 on 16 DSC units and 17 SC units within organizations of the Nijmegen University Nursing Home Network (UKON), a collaboration between 15 care organizations and the Department of Primary and Community Care of the Radboud University Medical Centre, Nijmegen. The Medical Ethics Committee (CMO Arnhem-Nijmegen) rated the AiD study.

Procedure

At the start of the parent study all patients residing on participating units at that time were approached for participation. Written informed consent was obtained from each patient or a relative/representative when a patient could not provide informed consent.

Only subjects with informed consent were included in the study. Individual participants were assessed at each measurement point, providing longitudinal data up to 6 measurements per participant if the participant started at T0 and continued the study through T5. During the study period, newly admitted patients were included and their baseline assessment was performed at the next measurement point. Apathy and depressive symptoms were assessed by interviewing the nursing staff. Cognition was assessed in those participants who could be tested [29]. For the current analyses, participants were excluded if only a baseline measurement was available without further assessments. If a participant died, moved, or withdrew informed consent between two measurements, the already performed measurements were included in the analyses (see flow chart, Figure 1). No data were available on whether patients were in a palliative state. Therefore, to exclude the influence of a possible palliative state and increase validity we excluded a measurement if a patient died within 10 days after the measurement.

Measurements

Sociodemographic Characteristics and Mortality

For all patients, data was available on age, gender, date of institutionalization as well as type of care unit for the 20-month duration of the study. Date of death was obtained from the medical file.

Apathy: Abbreviated Apathy Evaluation Scale (AES-10)

Apathy was determined using the 10-item Apathy Evaluation Scale (AES-10) [4, 30]. The 10 items of the observation scale all give an example of apathetic behavior. The response categories vary from 1 (not at all characteristic) to 4 (very characteristic), resulting in a total sum score ranging from 10 to 40. To conceptualize apathy, we used both a continuous measure (AES-10 total score, more apathetic behavior is indicated by a higher total AES score) and a categorical entity (apathy is present or not). A cut-off score of > 21 was used in patients of SC units and of > 29 in patients of DSC units based on the validation study of Leontjevas et al. [31] which showed cut-off points for distinguishing those with apathy from those without apathy.

Depressive Symptoms: Cornell Scale for Depression in Dementia (CSDD)

The CSDD consists of 19 items, each rated as 0 (absent), 1 (mild), and 2 (severe). A higher total-sum score indicates more severe depressive symptoms. The scale was validated in patients with dementia [32], as well as in NH patients with and without dementia [33].

Cognitive Functioning: Mini-Mental State Examination (MMSE)

The standardized MMSE [34] was administered, for those patients testable, in a structured interview with the patient for assessing global cognitive functioning. The MMSE is a 30-point screening that examines functions including registration, recall, language, ability to follow simple commands, and orientation. The scores range from 0 to 30, and a score of ≥ 24 is considered as normal cognition and < 24 is considered impaired cognition.

Other Variables

Other factors known to be related to mortality such as functional status, neuropathology, type of dementia, cognition, and comorbidity were accounted for using the proxy variable 'type of unit'. The patient characteristics on SC and DSC units differ considerably on those factors: overall in SC units caregiving is centered more on symptoms due to physical frailty, and in DSC units caregiving is centered on cognitive and behavioral symptoms due to dementia [35, 36].

Statistical Analysis

Longitudinal data represent up to 5 repeated measurements of survival predictors. Survival/death was registered within the period between the measurements or, for the 5th measurement, before the end of the study. If data for apathy or depression scores were missing in a patient in between other measurements that were available, the mean score of the data available on the nearest time point before and after the missing time point was imputed (CDSS observations n=132, AES n=73). When two successive measurements were missing, the data were adjusted by calculating the expected value in between two available measurements.

Descriptive statistics were generated for the total sample and for patients of SC units and DSC units separately. Patients of SC and DSC units were compared on gender, age, apathy (as a categorical or dimensional construct (AES-10)), CSDD, and MMSE. To analyze differences between patients in SC and DSC, paired *t*-tests for dimensional variables and X^2-tests for categorical variables were performed. By calculating cluster means, all numbers were adjusted for clustering.

The coxme package in the R statistical environment was used for building multi-level mixed effects cox models [37] for patients clustered in NH units, and measurements clustered within patients. At the patient level, we used days between available time-point measurements and, if relevant, between the last measurement and date of death. All models were adjusted for age and gender. We built models with apathy as a categorical and dimensional predictor (standarized score), respectively. We then adjusted the models for CSDD (standarized score). To explore the difference between DSC and SC units, we built additional models with the type of unit and its interaction with apathy. We did not adjust the models for the status intervention/control because being in the intervention condition or control condition did not improve the fit of models predicting mortality (e.g. X^2 [1]=0.740, p>0.05 for comparing models with AES-score adjusted and not adjusted for the intervention condition).

A Kaplan-Meier plot was generated to visualize survival probabilities for patients with and without apathy in SC-units and DSC-units.

RESULTS

The present study includes data of 713 patients, 266 of whom died during the study (see flowchart, Figure 1). As Table 1 shows, most of the patients were female (n=484, 68%), both in SC's (n=220 [64%]) and DSC's (n=264 [71%]). Patients in SC-units were significantly younger (77.8 [SD 13.1]) than patients in DSC-units (83.1 [SD 6.9]). At baseline, if regarded as categorical construct, half of all patients showed apathy (n=366, [51%]). Mean AES-10-scores were lower in patients of SC units (SC 23.2 [SD 8.5]) than in patients of DSC units (29.1 [SD 7.6]). Patients in SC units had higher levels of cognitive function by MMSE than patients in DSC-units (SC, 19.9 [SD 7.3]; DSC, 8.5 [SD 7.6]).

Apathy as a Categorical Construct

Mixed effects cox models revealed a higher risk of mortality in the total sample if apathy (categorical) was present (HR = 1.77, 95% CI = 1.35 to 1.81; p < 0.001) (Table 2). Although apathy seemed more strongly related to mortality in SC patients (HR = 2.24, 95% CI = 1.44 to 3.47, p < 0.001) than in DSC patients (HR = 1.53, 95% CI = 1.09 to 2.15, p = 0.014), the difference between unit types in risk of mortality was not significant (p=0.18; Figure 2).

Table 1. Patient characteristics at their first measurement, N=713

	Somatic	**Dementia**	**P**	**Total**
	N = 342	N = 371		N = 713
Gender (female) [n, (%)]	342 (64)	371 (71)	0.051	713 (68)
Age(years) [SD]	77.8 (13.1)	83.1(6.9)	<0.001	80.6 (10.7)
Apathy (categorical)* [n, (%)]	182 (48)	184 (52)	0.334	366 (51)
Apathy (dimensional) (AES10) [mean, (SD) /n]	23.2 (8.5)	29.1 (7.6)	0.004	26.2 (8.6) /709
Cognition (MMSE) [mean, (SD) /n]	19.9 (7.3)	8.5 (7.6)	0.044	14.2 (7.6) /545
Depressive symptoms (CSDD) [mean, (SD) /n]	9.5 (7.6)	9.6 (6.9)	0.020	9.6 (7.3) /697

*Apathy (categorical): AES10 cut-off scores of >29 in dementia patients and >21 in somatic care patients [33].

Apathy (dimensional): standardized score on the AES10. Cognition: score on the MMSE. Depressive symptoms: standardized score on the CSDD. All numbers are adjusted for clustering.

Dementia: patients of Dementia Special Care units (DSC); Somatic: patients of Somatic Care Units (SC).

P: significance for the difference between patients DSC and SC. T-test, P<0.05; P<0.001.

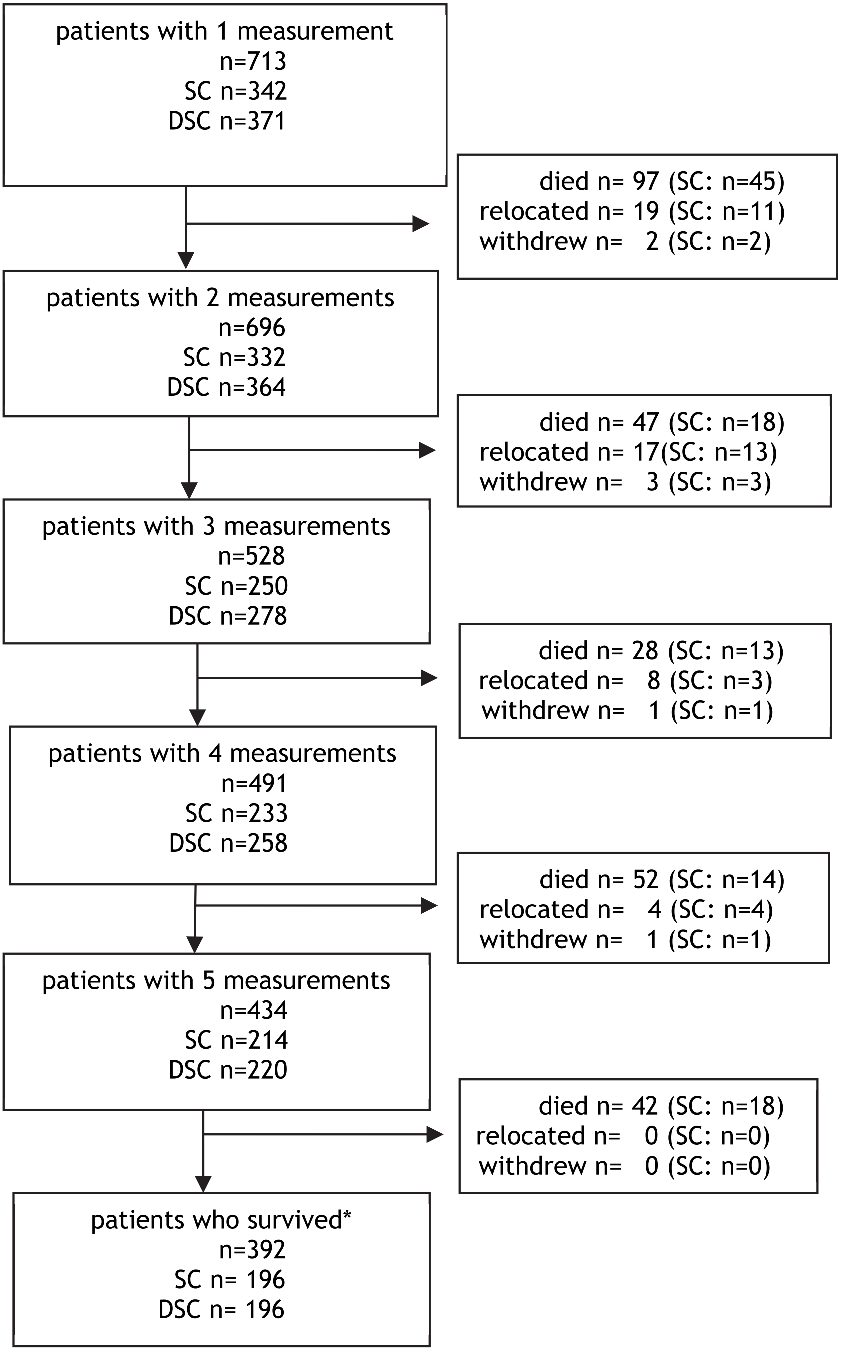

Figure 1. Flow chart measurements of patients.

*patients who were alive at the end of the study

Adjusting for depressive symptoms (CSDD), the results remained significant in the total sample (Table 2 model 2; HR = 1.64, 95% CI = 1.23 to 2.19, $p < 0.001$). Also, although the point estimations of the Hazard ratio decreased slightly after the correction for the CSDD, the results remained significant in both unit types and the 95% CI before and after the correction overlapped.

Apathy as a Dimensional Construct

Using a continuous measure of apathy, we found that one SD increase of AES-10 scores was associated with a 62% increased mortality risk (HR = 1.62, 95% CI = 1.40 to 1.88, $p < 0.001$). Although apathy as a dimensional construct seemed more strongly related to mortality in somatic patients (HR = 1.79, 95% CI = 1.44 to 2.23, $p < 0.001$) than it did to mortality in DSC patients (HR = 1.55, 95% CI = 1.25 to 1.91, $p < 0.001$), the difference between SC units and DSC units was not significant (p = 0.34).

After correction for depressive symptoms, the point estimations of the Hazard ratio in SC and DSC units seemed to decrease slightly, but the prognostic value for apathy as a dimensional construct remained significant (HR = 1.56, 95% CI = 1.33 to 1.83), and the 95% CI before and after the correction overlapped.

Of the covariates, male gender (HR = 1.67; 95% CI = 1.23 to 2.27, $p < 0.001$), and older age (HR = 1.06, 95% CI = 1.04 to 1.08, $p < 0.001$) were significant predictors of mortality in all mixed models (numbers above presented for model 1, apathy as a categorical construct).

Of the covariates, male gender (HR=1.67; 95% CI=1.23 to 2.27, $p<0.001$), and older age (HR=1.06, 95% CI=1.04 to 1.08, $p<0.001$) were significant predictors of mortality in all mixed models (numbers represent model 1, apathy as a categorical construct).

Sensitivity analyses in a subsample of patients with available MMSE-scores showed that adjusting for MMSE decreases the point estimation of the effect of apathy (Supplementary Appendix S1). For example, HR decreased from 1.63 (95 % CI=1.39 to 1.91, $p<0.001$) to 1.48 (95% CI=1.23 to 1.78, $p<0.001$) in a model with AES-10 as predictor after correcting for MMSE. However, it could be concluded that the unique effect of apathy remains after the correction for MMSE because the 95% confidence intervals of the HR's overlap for models before and after correcting for MMSE, and most models showed significant coefficients for apathy (except for apathy as a dichotomous variable in DSC units).

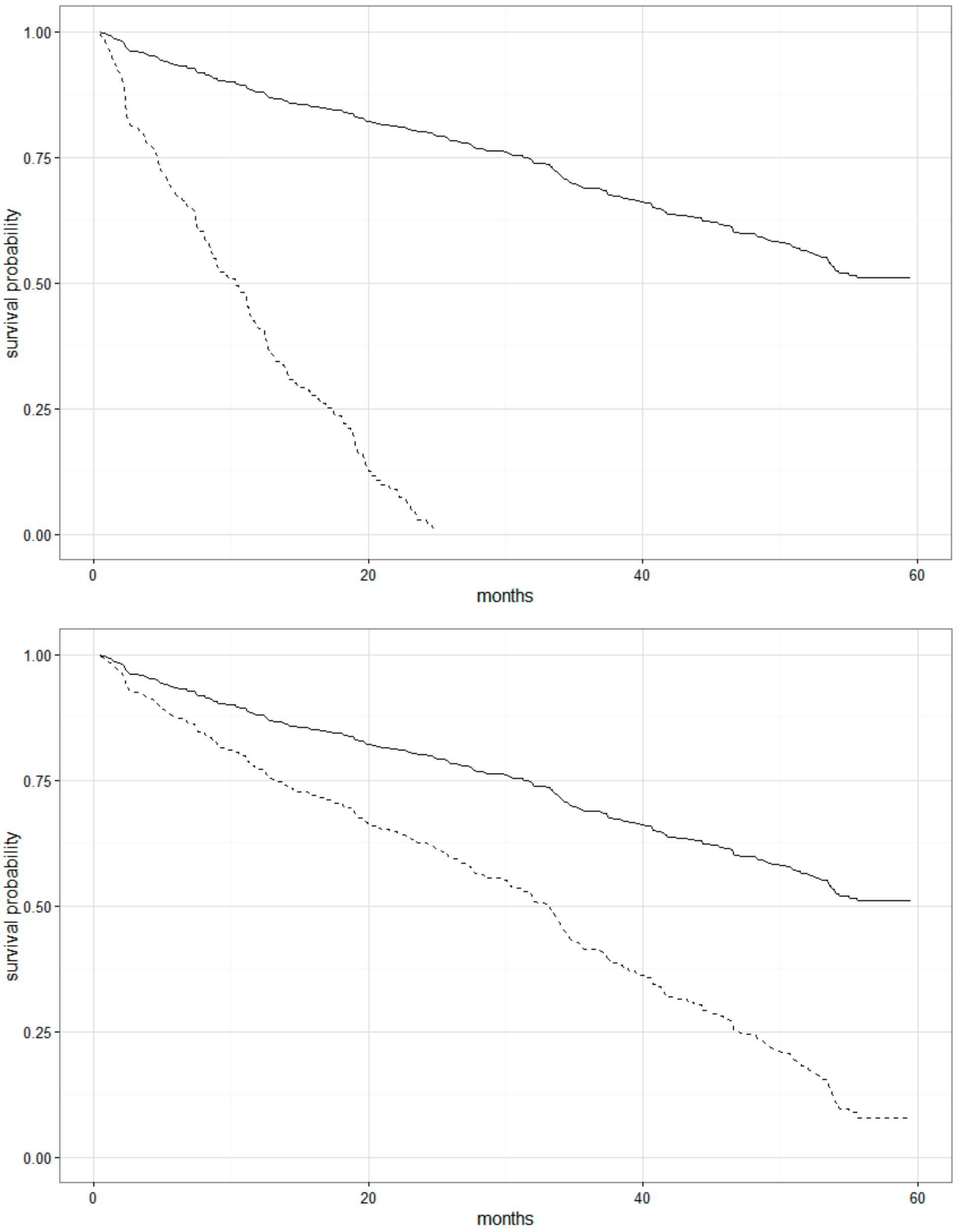

Figure 2. Survival probability in months for patients of SC (top) and DSC (bottom), for patients with apathy (dotted line) and patients without apathy (black line), apathy as categorical construct.

Table 2. Presence of Apathy and Risk of Dying in Somatic Care and Dementia Special Care

	Somatic (SC)		**Dementia** (DSC)		**Total**		**SC versus DSC**
	HR [95% CI]	p	HR [95% CI]	P	HR [95% CI]	p	p
Apathy (categorical)							
Model 1	2.24 (1.44 to 3.47)	<0.001	1.53 (1.09 to 2.15)	0.014	1.77 (1.35 to 2.31)	<0.001	0.18
Model 2	2.08 (1.29 to 3.33)	<0.05	1.44 (1.01 to 2.06)	<0.05	1.64 (1.23 to 2.19)	<0.001	0.22
Apathy (dimensional)							
Model 1	1.79 (1.44 to 2.23)	<0.001	1.55 (1.25 to 1.91)	<0.001	1.62 (1.40 to 1.88)	<0.001	0.34
Model 2	1.73 (1.37 to 2.19)	<0.001	1.48 (1.18 to 1.84)	<0.001	1.56 (1.33 to 1.83)	<0.001	0.32

Model 1, not corrected for the effect of CSDD; Model 2, adjusted for the effect of CSDD. All models corrected for age and gender.

Apathy (categorical): cut-off scores of > 29 in dementia patients and > 21 in somatic care patients; Apathy (dimensional): AES-10 sum scores

Hazard Ratios (HR) using coxme package in R with depression symptoms as the dependent variable

SC = somatic care; DSC = dementia special care, P-values in Mixed Effects Cox Models (coxme package in R)

DISCUSSION

In this study, apathy was found to be associated with highly increased mortality in SC patients and in DSC patients in Dutch NHs when the construct was conceptualized both as a categorical and as a dimensional variable. Apathy significantly increased the risk of dying in the total sample. When regarded as categorical construct, apathy was present in half of the NH patients, implying that it is a very common neuropsychiatric phenomenon in patients of both SC units and DSC units. Although apathy seemed to be more strongly related to mortality in somatic patients than in patients of DSC units, we did not find a significant difference between the unit types regarding the mortality risk. Also, when the analyses accounted for co-occurring depressive symptoms, there remained a strong and significant relationship between apathy and mortality. This result differs from the findings of Okura et al. [21] and Peters et al. [22] who found that assessing each individually symptom of the Neuro Psychiatric Inventory (NPI) depression, psychosis, and aggression/agitation, but not apathy, were associated with greater risk of death. Different instruments for assessing apathy and differences in patients and neuropsychiatric symptoms that were examined, might explain the difference with our results. Regarding apathy - both categorical and as a dimensional construct - , in this study we found that even a small increase of one standard deviation in apathy reflects a greater risk of dying. This is in line with a study by Vilalta-Franch et al. [17], who found that in Alzheimer's disease, apathy as a syndrome predicts increased mortality. Apathy may thus point to poor prognosis in patients residing in NHs. Moreover, when the analyses accounted for co-occurring depressive symptoms, apathy still appeared to be a significant predictor of mortality, thereby highlighting the independent association between apathy and mortality. This underlines that apathy and depression are not the same. These findings are consistent with previous research that found that apathy independently predicts mortality [17, 20]. It also underpins the need for consensus on assessment, diagnostic, and treatment guidelines as stated by Mulin [38] and Starkstein & Leentjes [39] so that apathy can be adequately detected and treated.

The current study has several strengths and limitations. To our knowledge, it is the first to examine the association between apathy and mortality in a large sample with multiple measurements of patients of SC units and DSC units, thus providing insight into similarity and differences between those patient groups. Additionally, apathy and depression are mostly assessed in research as categorical constructs using the NPI [40], where in this study we used other valid questionnaires to specifically assess apathetic behavior (AES-10) and depressive symptoms (CSDD).

Several factors are individually associated with mortality in frail elderly people and NH patients, including comorbidity, physical functioning, neuropathology, cognitive decline, psychotropic drug prescription and type of dementia [20, 21, 41]. A potential limitation of this study is that we did not correct for each possible confounders. We used a proxy measure (the type of care-unit) to account for these variables. Within a smaller subset of patients with MMSE-data available, we found that the prognostic value of apathy as dimensional construct on mortality remained significant when accounted for cognition. Although previous studies show that apathy is associated with severity of cognitive decline and cognitive impairment [5, 17], the results in this study point to the prognostic value of apathy in mortality being more strongly present in SC units than it is in DSC units. That this difference was not significant, may indicate that some of the characteristics common to patients in SC units [8,9,11] and DSC units [10,42] involved impairments in the fronto-subcortical brain circuits where executive cognitive functioning is mediated and simple ideas, movements, and actions are transitioned into complex goal-directed behaviors. Yet, the impact of cognitive deficits on the findings might have been underrated as the adjustment for MMSE-scores regarded a subsample that may not have included those participants who were most severely impaired and at higher risk for mortality. Also, functional disability and anti-psychotic drug use are known to be related to mortality [3,17] these are not accounted for separately in this study because these were not assessed in the parent study [1]. Functional impairment, however, has been found to be more strongly related to apathy than to cognitive deficits [5, 45] but little is known on about the underlying potential mechanism, suggesting further research is requiered into the influence of functional impairment on the relationship of apathy with mortality. Known side-effects of psychotropic drugs include extrapyramidal symptoms and drowsiness/sedation and, like cognitive decline and delirium, they may enhance frailty and apathy, while increasing the risk of developing pneumonia and malnutrition, which are also associated with mortality in nursing homes [3, 17, 20, 46, 47].

Another limitation may be that the analyses were constrained by the design of the parent study, an intervention study, and the effect of the intervention on the relationship between apathy and mortality could not be fully assessed. Although we did explore the possible effect of being in the intervention condition and no significant effect was found, it might have been better to use data from patients in the same condition. However, because patients waited to cross over to the intervention condition in the within-between subject design of the parent study, this would have caused a survival bias in favor of the intervention condition.

Our results underpin that apathy is a common neuropsychiatric phenomenon with a serious adverse outcome in NH patients and that it has important implications for patients and their families, and for NH staff. Despite increased interest in the treatment of apathy, results of intervention studies are inconsistent and no treatment has yet been established. Recent research has targeted medical treatment[43], deep brain stimulation of the subthalamic nucleus [44], and psychosocial treatment (cognitive rehabilitation, psychotherapy, activity, and occupational therapy) [45-47].

To increase awareness and identification and because apathy is still rarely identified as a problem in NHs [18, 19], further research is needed. Effective screening and treatment strategies should be developed and analyzed for their effects on reducing apathy in patients and improving quality of life (QoL). Surprisingly, little is known about the relationship between apathy and QoL. Few studies have been conducted and their results have been inconsistent [5, 48, 49]. Although in this study the prognostic value of apathy for mortality was not influenced by patients receiving multidisciplinary treatment (activity strategies, psychotherapy, and medication), this treatment was found to reduce apathy in patients with dementia, which was mainly attributable to activating strategies [45]. These promising findings can direct further investigations that focus on the relationship between apathy and QoL and adjusting environmental factors in NHs through enhancing patient engagement in activation programs. In the meantime, daily practice should be focused on improving QoL and advanced care planning when apathy is present in a NH patient.

CONCLUSIONS

Apathy is present in half of the patients of both SC units and DSC units and is associated with highly increased risk for mortality, also when accounting for depressive symptoms. Considered as both a categorical and dimensional construct, apathy reflects poor prognosis in patients residing in NHs. When regarded as a dimensional variable, even a small increase of apathy reflects a greater risk of dying. No effective treatment for apathy has yet been established. Further research is needed on effective screening and treatment for apathy and enhancing professional caregivers' awareness of apathy as a poor prognostic sign. The presence of apathy in NHs should become a point of particular concern in daily care and should initiate establising goals of care to improve quality of life and advanced care planning in the context of decreased life expectancy.

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Additional File: Appendix 1. Presence of Apathy and Risk of Dying in Somatic Care and Dementia Special Care in a Subsample with MMSE-scores available (N=545)

	Somatic (SC)		**Dementia (DSC)**		**Total**		**SC versus DSC**
	HR [95% CI]	p	HR [95% CI]	p	HR [95% CI]	p	p
Apathy (categorical)							
Model 1	2.59 (1.57 to 4.29)	<0.001	1.46 (1.01 to 2.10)	<0.05	1.80 (1.34 to 2.42)	<0.001	0.07
Model 2	2.62 (1.53 to 4.48)	<0.05	1.44 (1.01 to 2.06)	0.05	1.73 (1.27 to 2.36)	<0.001	0.22
Model 3	2.03 (1.21 to 3.40)	0.01	1.14 (0.78 to 1.67)	0.50	1.46 (1.07 to 2.00)	0.02	0.07
Model 4	2.00 (1.15 to 3.47)	0.01	1.06 (0.72 to 1.57)	0.77	1.39 (1.00 to 1.92)	0.05	0.06
Apathy (dimensional)							
Model 1	1.79 (1.40 to 2.28)	<0.001	1.55 (1.24 to 1.94)	<0.001	1.63 (1.39 to 1.91)	<0.001	0.39
Model 2	1.79 (1.38 to 2.31)	<0.001	1.49 (1.18 to 1.88)	<0.001	1.59 (1.34 to 1.89)	<0.001	0.29
Model 3	1.63 (1.26 to 2.10)	<0.001	1.37 (1.08 to 1.74)	0.01	1.48 (1.23 to 1.78)	<0.001	0.30
Model 4	1.58 (1.21 to 2.08)	<0.001	1.28 (1.00 to 1.64)	0.05	1.41 (1.16 to 1.72)	<0.001	0.22

Model 1, not corrected for the effect of CSDD and MMSE; Model 2, adjusted for the effect of CSDD; Model 3, adjusted for the effect of MMSE; Model 4, adjusted for the effect of CSDD and MMSE. All models corrected for age and gender.
Apathy (categorical): cut-off scores of > 29 in dementia patients and > 21 in somatic care patients; Apathy (dimensional): AES-10 sum scores.
Hazard Ratios (HR) using coxme package in R with depression symptoms and cognition as the dependent variable.
SC = somatic care; DSC = dementia special care, P-values in Mixed Effects Cox Models (coxme package in R).

Apathy as Categorical Construct

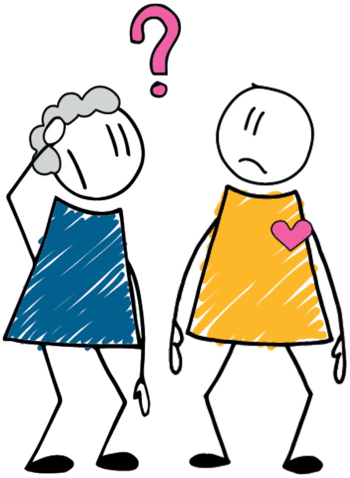
In a subsample of patients with known MMSE scores mortality rate was higher when not corrected for depressive symptoms in the total sample (Model 1: HR=1.80, 95% CI=1.34 to 2.42, p<0.001), for the SC patients (HR=2.59, 95% CI=1.57 to 4.29, P<0.001) and for the DSC patients (HR1.46, 95% CI= 1.01 to 2.10, p<0.05). The results are statistically significant after correction for depressive symptoms in the total subsample (Model 2: HR=1.73, 95% CI=1.27 to 2.36, p<0.001) and the different unit type4s (SC: HR=2.62, 95% CI=1.53 to 4.48, p<0.05; DSC: HR=1.44, 95% CI=1.01 to 2.06, p=0.05). After correction for cognition (MMSE) the point estimations of Hazard ratio decreased in the total subsample (Model 3: HR=1.46, 95% CI=1.07 to 2.00), p=0.02) suggesting that a better cognition does affect the relationship between apathy and mortality in a positive direction. In none of the models for this subsample the difference between unit types in risk of mortality was significant.

Apathy as Dimensional Construct

For apathy as dimensional construct there was increased risk of mortality when apathy was present in the total subsample (Model 1: HR=1.63, 95% CI=1.39 to 1.91, P<0.001) and this effect remained significant when corrected for depressive symptoms (Model 2: HR=1.59, 95% CI=1.34 to 1.91). When corrected for cognition the HR decreased, and the effect remained significant (p<0.001) in the total subsample (HR=1.48 95% CI=1.23 to 1.78) and in SC sample (HR=1.63 95% CI=1.26 to 2.10). When corrected for depressive symptoms and cognition the result remained significant for apathy as dimensional construct in the total subsample (Model 4: HR=1.41 95% CI=1.16 to 1.72, p<0.001) as well as the SC (HR= 1.58, 95% CI=1.21 to 2.08, P<0.001) and the DCS (HR= 1.28 95% CI= 1.00 to 1.64, p=0.05). The difference between unit types in risk of mortality was not significant in any of the models.

“I walk to the hallway and sit again. I used to knit a lot, well, they don’t see me doing that anymore.” (Person with apathy, 03)

“Yes, burden is a big term, I do think it bothers them, but they can’t really express themselves. I can’t imagine otherwise than it must bother you if you don’t initiate anything. That – to me – seems very disturbing, but I think they can’t express that.” (Professional caregiver, 05)



3

Apathy and health-related quality of life in nursing home residents

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Abstract

Purpose: To explore the association between apathy and health-related quality of life (HRQoL) from resident and proxy perspectives and whether cognition and depression moderate this relationship.

Methods: Secondary analyses with baseline data from a cluster randomized trial into the effects of a care program for depression in Nursing Homes (NHs). For HRQoL, the Visual Analogue Scale (VAS) and the Dutch version of the European Quality of Life (EQ-5D) were administered to 521 NH residents, and to professional caregivers reporting from the perspective of the NH resident (Resident-Proxy) and from their own perspective (Proxy-Proxy). Utility scores (U) were calculated for the three perspectives. Apathy, depression and cognition were measured using the 10-item Apathy Evaluation Scale (AES-10), the Cornell Scale for Depression in Dementia and the standardized Mini-Mental State Examination, respectively.

Results: Mixed models adjusted for clustering within NH units revealed that apathy was negatively associated with HRQoL both from the Resident-Proxy perspective (EQ-5D VAS: estimated effect, -0.31, *P* <0.001; EQ-5D Utility: -0.30, *P* <0.001) and from the Proxy-Proxy perspective (VAS: -0.29, *P*<0.001; U: -0.03, *P*<0.001), but not from the Resident-Resident perspective (VAS: -0.05, *P*=0.423; Utility: -0.08, *P* =0.161). Controlling for depression and cognition and their interaction terms with apathy did not change the results.

Conclusion: Apathy is negatively associated with NH-resident HRQoL as reported by proxies. Depression and cognitive functioning do not moderate this association. NH residents do not self-report a relationship between apathy and HRQoL. More research is needed to understand caregiver and NH resident attitudes and underlying assumptions regarding apathy and HRQoL.

INTRODUCTION

Apathy is a very prevalent neuropsychiatric symptom (NPS) in people with neurological or neurodegenerative diseases such as dementia, stroke and Parkinson's disease [1-5]. The core features of apathy are reduced interest or reduced participation in activities of daily living, early withdrawal from activities, diminished initiative, flattening of affect, and indifference [6-8]. Apathy is associated with adverse outcomes such as increased dependence on and burden in caregivers, earlier institutionalization, more rapid cognitive decline, and increased mortality [5, 9-13].

Predictably, apathy is very common in Nursing Home (NH) residents. Selbaek et al. [5] found that in dementia NH residents, the weighted mean prevalence of apathy was 36% (range 17–82). Although apathy has been shown to be associated with several adverse outcomes in NH residents, the relationship between Apathy and QoL is still unclear [14-16]. Mjorud [17] found a negative relationship between proxy-rated apathy and self-reported QoL in NH residents with severe dementia. Gerritsen [18] found that cognition played a moderating role in the relationship between proxy-rated apathy and self-reported QoL: apathy was negatively related with general QoL in NH residents with a high level of cognitive functioning, and positively related with QoL in those with a lower level of cognitive functioning. Accordingly, Yeager [19] found that increased apathy based on proxy-rating was associated with worse self-reported QoL, but only for those community-dwelling people with Alzheimer dementia with better cognitive functioning.

The relationship between apathy, cognition and depression is complex. Fronto-subcortical circuits are involved in apathy, and different anatomical and neural networks relate to different dimensions of apathy such as reduced goal-directed cognitive activity, i.e., cognitive apathy; diminished spontaneous or reactive emotional expression, i.e., emotional apathy; or impaired goal-directed behavior, i.e., auto-activating or behavioral apathy [20-22]. Therefore, cognition needs to be accounted for when exploring the relationship between QoL and apathy [2, 17, 23, 24]. But so does depression, especially given its the overlapping features with (emotional) apathy that may (partially) explain the relationship between apathy and QoL [7, 25, 26], and the negative association that exists between depression and QoL in NH residents with dementia [14-16].

QoL is a multidimensional concept. Two approaches are commonly used to measure QoL, the first of which is more general and considers life as a whole. Frameworks that are based on a broad approach are for instance Lawton's framework and social production functions (SPF) theory [27]. Especially for people with dementia, several measurement instruments based on a broad approach exist, such as the Qualidem [28] and the QOL-AD [29]. The second approach looks specifically at health-related QoL (HRQoL) and those dimensions of life affected by disease or treatment [27, 30]. Inconclusive results in previous studies about the relation between QoL and apathy might be due to different conceptual approaches. Results may also differ depending on whose perspective is being considered: QoL measurements can be based either on proxy reports or on self-report. In proxy-based measurement, the informal or professional caregiver estimates the resident's QoL. In self-report measurement, the patient is asked to report his/her own QoL. The self-report measurement is commonly considered the gold standard, but self-reports are not always possible or reliable, as, for instance, in patients with severe dementia [31].

This study was conducted using a health-related QoL approach and its aim was (1) to explore the relationship between apathy and HRQoL using self-reports and proxy-reports in NH residents and (2) to explore the possible influence of depression and cognition on the relationship between apathy and HRQoL from a resident perspective and a proxy perspective.

METHODS

Participants and Design

In this study, residents' baseline data from a large multicenter study into the effect of a multidisciplinary care program for depression management in NHs were used [32, 33]. Within the stepped-wedge cluster randomized trial of the parent study, randomly selected clustered groups cross-over to the intervention condition at several time points (T1-T4). All clusters were in the control condition at T0, and at T5 all clusters were in the intervention condition. Within the Nijmegen University Network of NHs, 16 Dementia Special Care (DSC) units (specializing in dementia care), and 17 Somatic Care (SC) units (providing special care for somatic and physically frail NH residents with or without cognitive complaints) provided data from May 2009 to April 2011. At the start of the parent study all patients residing on participating units at that time were approached for participation. Written informed consent was obtained from each patient or a relative/representative when a resident could not provide informed consent. Only residents with informed consent were included in the study. The study was approved by the Medical Ethics Committee of the region Arnhem-Nijmegen (http://www.ccmo.nl/nl/erkende-metc-s/cmo-regio-arnhem-nijmegen). Furthermore, the study is undertaken in accordance with the declaration of Helsinki (https://www.wma.net//declaration-of-helsinki) and the applicable Dutch legislation, and in agreement with the Code of Conduct for Health Research (version 2005; https://www.federa.org/federa-english). Details and findings of the parent study have been published elsewhere [32, 33].

Measurements

Sociodemographic characteristics

Data regarding sex, age, date of institutionalization and type of care unit (DSC or SC) were available for all NH residents at their first measurement in the parent study.

Apathy

Apathy was assessed using the 10-item Apathy Evaluation Scale (AES-10) [34]. Item scores of this validated observational scale vary from ‘not at all characteristic’ (1) to ‘very characteristic’ (4); a higher sum score therefore reflects more apathetic symptoms (range 10–40) [35].

Health-related Quality of Life

The Dutch version of the European Quality of Life five dimensions questionnaire (EQ-5D) was used to measure HRQoL [36]. In the first section of the EQ-5D, an indication of the NH resident’s health state is given ranging from no problems (1), some problems (2) to severe problems (3) based on five domains. These domains are mobility, self-care, usual activity, pain/discomfort and anxiety/depression, and they can be used to calculate utility scores. Utility scores are used to express an individual’s preferred health status. A utility score of (1) refers to a preferred perfect state and a utility score of (0) represents death. The second section of the EQ-5D consists of a vertical visual analogue scale (VAS). Scores on the VAS vary from worst imaginable health (0) to perfect health (100). Information on HRQoL is provided from three different perspectives: the NH resident’s own rating is the resident-resident (RR) perspective (How do you rate your general health status today?), the resident-proxy (RP) perspective represents professional caregivers who estimated QoL from the point of view of the NH resident (How do you think the resident rates his/her general health-status today?), and the proxy-proxy (PP) perspective refers to the caregiver’s own estimate of the NH resident’s QoL (How do you rate the resident’s general health-status today?).

Depressive symptoms

The Cornell Scale for Depression in Dementia (CSDD) [37], which has been validated in NH residents with and without dementia, was used to assess depressive symptoms [38, 39]. Item response categories vary from absent (0), mild (1), or severe (2), with more severe depressive symptoms being represented by a higher sum score.

Cognitive functioning

For those NH residents who were testable, global cognitive functioning was assessed by administering the standardized Mini-Mental State Examination (MMSE) [40]. Scores range from 0 to 30 with lower scores representing greater cognitive impairment.

Procedure

Only those NH residents with provided written informed consent were included in the parent study. Self-reported QoL (EQ-5D-RR) and the MMSE were assessed by trained interviewers (master students psychology and psychologists employed by the research team) in NH resident interviews if the NH resident was capable of being interviewed.

Proxy-reported QoL (EQ-5D-RP/PP), AES-10 and CSDD were assessed through structured interviews by the same trained interviewers with the nursing staff. Data in this study represent only a NH resident's first/baseline measurement, collected between May 2009 and April 2011. Only NH residents with available scores on AES, CSDD and MMSE and at least a VAS or utility score from one of the perspectives on EQ-5D (RR, RP, PP) were included. Information on age and day of institutionalization was obtained from the NH resident's medical file.

Statistical Analysis

All statistical analyses were conducted using SPSS software version 24 (Chicago, IL). For all included NH residents, descriptive statistics were generated for age, sex, AES-10, CSDD, MMSE, and for the EQ-5D (VAS & Utility) from the RR, RP and PP perspectives. In this study, the Dutch tariff was used to calculate utility scores for the EQ-5D [41] and, because missing scores of the individual EQ-5D domains are expected not to be random, missing scores were not imputed [42]. For a maximum of two missing items on AES-10 the lowest score (1) was imputed. For the CSDD, a missing score was registered as (0) with a maximum of 4 missing individual CSDD items [39]. If a NH resident could not be tested for reasons of cognitive impairment, the MMSE score was registered as (0).

Mixed models that accounted for clustering within NH units were built to explore the association between apathy (AES-10 standardized score as predictor variable) and HRQoL (VAS and Utility from three perspectives: RR RP and PP). Based on literature [14, 43], the models were controlled for age, sex, standardized MMSE and standardized CSDD. Additionally, we explored whether the relationship was moderated by cognition and depression. For this, we built two models with the interaction terms apathy x cognition and apathy x depression. Likelihood ratio tests were used to compare a model with the interaction term to a model without the interaction term.

RESULTS

Resident characteristics and mental status

The present study included data from 521 NH residents, half of whom resided in DSC units (n = 259, 50%). As shown in Table 1, most NH residents were women (n = 433, 66%) and the mean age was 80.2 years (SD = 10.7). The mean apathy score on AES-10 was 25.5 (SD = 8.6). The mean EQ-5D VAS score of Resident-Resident perspective (RR) was 64.8 (SD = 21.7) and the mean EQ-5D utility score was M = 0.6 (SD = 0.3). In the Resident-Proxy (RP) perspective, the mean VAS score was 64.7 (SD = 17.1) and the mean utility score was 0.5 (SD = 0.3). In the Proxy-Proxy (PP) perspective, the mean VAS and utility scores were 63.1 (SD = 14.7) and 0.45 (SD = 0.26) respectively.

Table 1. Characteristics of Nursing Home Residents, Mental Status and Health-Related Quality of Life from Different Perspectives

		N (%)	Min/max score	mean	SD
Characteristics					
Age, years			31 -102	80.1	10.7
Residents (female %)		521 (344/ 66)			
Dementia Special Care unit		259 (50)			
Mental Status					
Apathy[*]	AES-10	521	10.0 - 40.0	25.5	8.6
Depressive symptoms[†]	CSDD	521	0.0 - 40.0	9.3	7.3
Cognitive functioning[‡]	MMSE	521	0.0 - 30.0	14.3	9.3
Quality of Life	EQ-5D[‖]	265			
Resident's own rating (RR)[§]	VAS[¶]	360		64.8	21.7
	Utility[¶¶]	421		0.6	0.3
Resident-Proxy-perspective (RP)[**]	VAS	497		64.7	17.3
	Utility	486		0.5	0.3
Proxy- proxy perspective (PP)[††]	VAS	520		63.1	14.7
	Utility	520		0.5	0.3

[*]Apathy: standardized scores on AES-10); [†]Depressive symptoms: standardized score on the CSDD; [‡]Cognition: score on the MMSE. Quality of Life: Dutch version of the European Quality of Life (EQ-5D[‖]): VAS[¶]: score on Visual Analogue Scale; Utility[¶¶]: preferred health status calculated using Dutch Tariff
[§]RR: resident-resident perspective, resident's own rating; [**]RP: proxy- resident perspective, proxy rating by imagining the resident perspective; [††]PP: proxy-proxy perspective, proxy's own rating

Relationship between apathy and QoL (EQ-5D) from different perspectives

Mixed models showed no statistically significant association between apathy and HRQoL from the RR perspective, nor when corrected for cognition and depression (RR EQ-5D VAS: Estimated effect -0.05, 95% CI -0.18 to 0.08, *P* = 0.423; RR EQ-5D Utility: -0.08, 95% CI -0.20 to 0.03, *P* = 0.161 (see Table 2). From the RP and PP perspectives, there was a negative association of apathy with QoL ([RP EQ-5D VAS: Estimated effect -0.31, 95% CI -0.48 to -0.15, *P* <0.001; RP EQ-5D Utility: -0.30, 95% CI -0.46 to -0.14, *P* <0.001]; [PP EQ-5D VAS: -0.29, 95% CI -0.44 to -0.14, *P* <0.001; PP EQ-5D Utility: -0.30, 95% CI -0.45 to -0.14, *P* <0.001]), also after correction for depression and cognition. As shown in Table 2, the fit of the models was not improved by adding interaction terms. Results indicate that better cognitive functioning (higher score on MMSE) was related to lower HRQoL utility scores from the Resident-Resident perspective (RR EQ-5D-Utility: estimated effect -0.25, 95% CI -0.39 to -0.10, *P* <0.001) (Table 2).

Table 2. Apathy as Predictor of Health-Related Quality of Life from Resident and Proxy Perspective

		Resident-Resident§ perspective QoL			Resident-Proxy** perspective QoL			Proxy-Proxy†† perspective QoL		
		VAS n=360; Utility n=421			VAS n=497; Utility n=486			VAS n=520 Utility n=520		
		Estimated effect (95 %CI)	df	*p*	Estimated effect (95 %CI)	df	*p*	Estimated effect (95 %CI)	df	*p*
Quality of Life (EQ-5D VAS)[¶]										
Model 1	Apathy	-0.05 (-0.18 to 0.08)	353.60	0.423	-0.31 (-0.48 to -0.15)	230.56	<0.001	-0.29 (-0.44 to -0.14)	232.24	<0.001
	Depression	-0.04 (-0.14 to 0.07)	353.99	0.503	-0.02 (-0.14 to 0.10)	223.31	0.746	0.00 (-0.11 to 0.12)	231.98	0.971
	Cognition	-0.15 (-0.31 to 0.01)	290.10	0.070	-0.19 (-0.44 to 0.07)	228.29	0.146	-0.11 (-0.34 to 0.12)	205.59	0.358
Model 2	Apathy x Depression	-0.04 (-0.14 to 0.06)	344.04	0.434	0.00 (-0.09 to 0.09)	477.50	0.968	0.00 (-0.12 to 0.11)	226.85	0.948
Model 3	Apathy x Cognition	0.10 (-0.04 to 0.24)	351.13	0.180	0.03 (-0.06 to 0.13)	478.91	0.494	0.00 (-0.21 to 0.21)	231.80	0.987
Quality of Life (EQ-5D Utility)[¶¶]										
Model 1	Apathy	-0.08 (-0.20 to 0.03)	414.49	0.161	-0.30 (-0.46 to -0.14)	228.73	<0.001	-0.30 (-0.45 to -0.14)	232.08	<0.001
	Depression	-0.09 (-0.18 to 0.01)	414.80	0.094	-0.05 (-0.17 to 0.06)	224.72	0.358	-0.08 (-0.19 to 0.04)	227.85	0.197
	Cognition	-0.25 (-0.39 to -0.10)	363.76	0.001	-0.24 (-0.47 to 0.00)	218.65	0.053	-0.04 (-0.28 to 0.19)	228.04	0.720
Model 2	Apathy x Depression	-0.04 (-0.13 to 0.06)	402.99	0.444	0.03 (-0.08 to 0.15)	219.24	0.565	0.03 (-0.08 to 0.14)	222.84	0.625
Model 3	Apathy x Cognition	0.03 (-0.10 to 0.15)	406.35	0.683	0.02 (-0.19 to 0.23)	227.27	0.847	0.02 (-0.19 to 0.23)	227.27	0.847

[*] Apathy: standardized scores on AES-10; [†]Depressive symptoms: standardized score on the CSDD; [‡]Cognition: score on the MMSE. [¶]VAS: score on Visual Analogue Scale of EQ-5D for health-related Quality of Life; [¶¶]Utility: preferred health status calculated using Dutch Tariff on EQ-5D.

[§] RR: resident-resident perspective, resident's own rating; [**]RP: proxy-resident perspective, proxy's rating by estimating the resident's perspective; [††]PP: proxy-proxy perspective, proxy's own rating.

[||] Model 1: Mixed models for RR, RP and PP perspective (VAS and Utility) with correction for depression and cognition. The main effects are reported for the models without the interaction terms because the models with the interaction terms did not improve the model fit. [§§]Model 2: Mixed models for RR, RP and PP perspective (VAS and Utility) with interaction term Apathy x Depression; [‡‡]Model 3: Mixed models for RR, RP and PP perspective (VAS and Utility) with interaction term Apathy x Cognition. The estimated effects for the interaction terms are reported for the models 2 + 3 with those interaction terms. All models corrected for clustering, age, sex, standardized MMSE, standardized Cornell

DISCUSSION

To our knowledge, this study is one of the first to explore the association between apathy and HRQoL from the NH resident's own perspective and from two proxy perspectives using a large sample of NH residents of DSC units and SC units, the most common types of units for elderly residents in the Netherlands. We found that apathy was negatively associated with HRQoL in NH residents when estimated using proxy-based reports provided by professional caregivers; the same association was not found when HRQoL was estimated from the NH resident's own self-reported perspective. When accounting for cognitive functioning and depressive symptoms, a significant negative relationship remained between apathy and HRQoL from the proxy perspective, and no moderating effect of either depression or cognition was found.

Our finding that apathy in NH residents is associated with lower proxy-based HRQoL is in line with results from recent studies of Hongisto [44] and Appelhof [15], who also found that apathy was associated with lower general proxy-based QoL in NH residents with dementia. Our findings are in line with findings of studies in other parts of the Netherlands and previous findings on neuropsychiatric symptoms and QoL in NHs [16, 43, 45]. Also, a recent study into possible differences in QoL and Quality of care (QoC) in Europe [46] shows that, despite great variation in QoL and QoC scores among European countries and settings, there are no overall differences regarding QoL for persons with dementia living at home and those living in nursing homes. Selbaek et al. [5] found that the weighted mean prevalence of apathy was 36% (range 17–82) in NH residents with dementia. In previous research of our research group based on the same dataset [13] we confirmed that the apathy scores of our sample fall within this range; regarding apathy as a categorical construct we found the prevalence of apathy to be 50% in NH's. Therefore, we believe our sample to be representative for Dutch NH's and NH's in general.

In this study, we found no significant association between apathy and self-reported HRQoL. This is in line with previous findings that NPS in general in dementia do not influence self-reported QoL [44]. Memory problems (due to hippocampus degeneration) and problems in self-awareness and executive functioning (due to decreased functioning of fronto-subcortical circuits) might influence a person's judgement on his/her own QoL. One can speculate that as their ability to reflect retrospectively may be impaired, NH residents with severe cognitive problems might judge QoL only in light of the emotional status and thoughts of the person in the present moment, which, in the context, is often a positive interaction with an interviewer. This might account for the differences we found in the association between apathy and QoL from the resident perspective and the proxy perspective. Self-report can be regarded as the most important perspective when assessing perceived QoL, also when it would 'only' refer to a specific moment as described above. However, a response reflecting a longer period in time will often be important. When a NH resident loses the ability to clearly report about his/her experience due to decline of cognition, awareness and communication abilities, reliance on proxy judgment by informal and formal caregivers increases. Our study shows the implications of this reliance, as we found different results based on different perspectives. Therefore, we recommend to use different perspectives, of which we have shown in earlier research [31] that the proxy-resident perspective is more similar to the resident-resident perspective than the proxy-proxy perspective is, indicating that nursing staff may be able to put themselves in the residents' shoes to some extent.

Besides, we found that for the resident perspective, better cognition was associated with lower HRQoL. This is in line with previous findings of Gerritsen [18] and Yeager [19] that the relationship between proxy-rated apathy and general self-reported QoL is influenced by cognition, which may suggest that NH residents with better cognition have insight into their deficits, which perhaps results in experiencing lower QoL.

Although previous research shows that apathy is not reported as a very disturbing neuropsychiatric symptom by professional caregivers [47, 48], our results suggest that professional caregivers may nevertheless consider apathy to negatively influence HRQoL. A possible explanation might be that caregivers compare and reflect on presumed differences between previous and current health status in light of a NH resident's decreased independence, social disengagement and other (behavioral) changes due to apathy. In contrast to the current status, the status before apathy as measured with the AES-10 (with questions regarding–among others–like taking initiative, interest in new things, motivation, engaging life with intenseness), might therefore be considered the preferred health status. Although the disability paradox [49] could be an explanation for a tendency in proxies to underestimate the NH residents' QoL as compared to the NH residents' own perceptions of their QoL, in a recent study, Leontjevas [31] found that professional caregivers did not tend to report systematically poorer HRQoL in NH residents but instead attenuated scores toward the middle.

The current study has strengths and limitations. The large representative sample of NH residents in DSC and SC units is one of the strengths of this study. Also, HRQoL was considered from the resident perspective as well as from two proxy perspectives. Our findings are based on a specific apathy scale (AES-10) validated in both NH residents with and without dementia, in contrast to a single-item apathy subscale of NPI often used in other studies. A potential limitation of this study is that its results were based on a relatively narrow QoL approach: the health-related dimensions of EQ-5D and its VAS regarding the subjective evaluation of one's health status. The EQ5D was selected for the parent study because it was regarded as the only instrument available to explore HRQoL from three perspectives in the long-stay nursing home population with and without cognitive impairments. However other possible aspects, such as environmental aspects and social interaction, have not been accounted for in this study [50, 51] and their relationship with apathy need further exploration in future research. Yet, differences in proxy based ratings versus self-reported measurements have been seen in other instruments with a broader conceptualization of QoL [14, 52].

Also, although we controlled for depression and cognition and investigated whether they moderated the relationship between apathy and HRQoL, we did not account for dementia subtype, medication use and other NPS, such as agitation or psychosis [16, 17], because these were not registered or fully accounted for in the parent study. Besides we could not account for possible environmental differences due to unit type or characteristics of persons living in SC units and DSC units and it might have been better to use data from residents in the same condition. However, impairments in fronto-subcortical brain circuits that are involved in apathy are known to be present in residents living in DSC-units[2] as well as in residents of SC units[4, 53]. Additionally, within DSC there are people with different levels of dementia and cognitive impairment due to neurological diseases like Parkinson's disease or strokes, and within SC units there are residents with and without cognitive impairments. Therefore, we investigated the effect of cognition as a dimensional variable, rather than using SC and DSC as categorical variable for cognitive functioning or medical conditions.

Also, we only used data from those NH residents who were testable for the resident perspective. If an MMSE was missing for reasons of cognitive impairment, we assigned a minimal MMSE-score of (0) to those NH residents, but missing HRQoL-scores were not imputed. Several other causes were related to missing residents' own rating scores such as absence, sickness, temporary admission to hospital or lack of cooperation during a measurement. This led to a smaller subsample of patients with available self-reports. It is a challenge to estimate QoL in NH residents with advanced dementia who are not able to communicate their perspective [54]. Therefore, for those NH residents unable to rate HRQoL due to incomprehension, the association between apathy and self-reported QoL is still unclear. However, from the proxy perspective, cognition did not moderate the association, so there is little reason to assume it would be moderated in the resident perspective.

The findings from the proxy perspective provide further confirmation that apathy is a relevant target of care. Yet, although research indicates that therapeutic activities reduce apathy in NH residents with dementia [55-57], apathy is often not treated. Most interventions in NHs are directed towards disruptive behavioral symptoms. Apathy causes the least distress in nursing staff [48] and is regarded as the least difficult symptom to manage [47], which might explain why apathy is rarely identified as a problem that needs specific treatment. To our knowledge this has, however, never been truly investigated. Therefore, further insight is necessary into the attitudes, beliefs and behavior of multidisciplinary NH professionals regarding apathy and its treatment.

CONCLUSION

Results indicate that apathy is negatively associated with HRQoL of NH residents as reported by professional caregivers (proxies) and that this association is not influenced by depression or cognitive functioning of the NH residents. Reducing apathy appears important in order to optimize HRQoL in NH residents. Given a non-significant association between apathy and HRQoL in self-reports, and given that caregivers, on the other hand, usually do not consider apathy a goal of treatment, further research is necessary to explore attitudes and beliefs among NH residents and caregivers towards apathy and its consequences.

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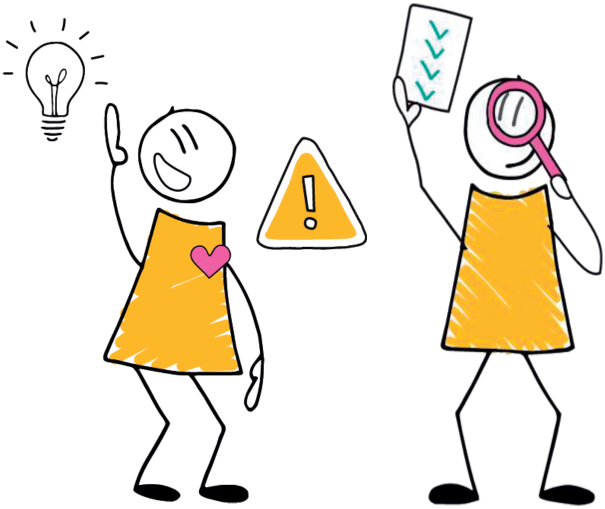
“I used to do needlework like this, knitting the most beautiful sweaters, and crocheting, and now I don’t do anything.” (Person with apathy, 01)

“I don’t think you can totally take it [apathy] away, because someone with severe dementia can’t be “on” all of the time, they cannot. I think when now and then, there are those moments of contact, pleasant activities and once in a while you see somebody is enjoying themselves, then I think you have come a long way.” (Professional caregiver, 05)



4

Identifying and managing apathy in people with dementia living in nursing homes: a qualitative study

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Background : Although apathy is common in people with dementia and has profound negative effects, it is rarely diagnosed nor specifically treated in nursing homes. The aim of this study is to explore experiences in identifying and managing apathy from the perspectives of people with dementia and apathy (PwA), family caregivers (FCs) and professional caregivers (PCs).

Methods: Descriptive qualitative study with purposive sampling, comprising eleven semi-structured in-depth interviews with PwA, FCs or PCs and focus groups with twelve PCs in Dutch nursing homes. Seventeen additional in-depth interviews with caregivers were held, after signals of increasing apathy during the first Covid-19 lockdown. Using an inductive approach, data was analysed thematically to explore the experiences in identifying and managing apathy from the perspective of different stakeholders.

Results: Three themes were identified: 1) the challenge to appraise signals, 2) the perceived impact on well-being, 3) applied strategies to manage apathy. Although participants described apathy in line with diagnostic criteria, they were unfamiliar with the term apathy and had difficulties in appraising signals of apathy. Also, the perceived impact of apathy varied per stakeholder. PwA had difficulties reflecting on their internal state. FCs and PCs experienced apathy as challenging when it reduced the well-being of PwA or when they themselves experienced ambiguity, frustration, insecurity, disappointment or turning away. Dealing with apathy required applying specific strategies that included stimulating meaningful contact, adjusting one's expectations, and appreciating little successes.

Conclusions: When addressing apathy in nursing homes, it is important to consider that a) all stakeholders experience that appraising signals of apathy is challenging; b) apathy negatively influences the well-being of people with dementia and especially their FCs and PCs; and c) FCs and PCs can successfully, albeit temporarily, manage apathy by using specific strategies.

BACKGROUND

Apathy comprises cognitive, affective and behavioral symptoms and is described as diminished interest, emotional expression/responsiveness or initiative, which causes significant functional impairment and reduced qualitative participation in daily living, social contact or activities [1, 2]. While apathy, depression and cognitive decline often co-occur, they are regarded as separate entities [3, 4]. Reduced interest, initiative and decreased motivation are overlapping symptoms in apathy and depression that sometimes makes the differentiation between them difficult. However, apathy and depression are considered distinct clinical syndromes. Sadness and feelings of helplessness, hopelessness and worthlessness are typical for depression and not for apathy [1, 5]. In addition to the neural and neurobiological mechanisms (e.g., frontal-striatal circuits) associated with neurocognitive disorders, other factors can contribute to apathy. These include individual factors like neuropsychiatric symptoms (NPS), caregiver factors like stress and burden, communication issues, unrealistic expectations or a lack of knowledge and environmental factors such as the presence of activities and structure, and over- or under-stimulation [6-8].

Apathy is common in people with neurological and neurodegenerative diseases, affecting approximately 50% of nursing home (NH) residents with and without dementia [9-11]. In people with dementia, apathy is the most common neuropsychiatric symptom and its prevalence is similar throughout different dementia stages (54% in mild, 59% in moderate and 43% in severe dementia) or subtypes (60% in Alzheimer Disease, 60% in Vascular Dementia) [9, 12]. Furthermore, apathy is known to be persistent and associated with functional and cognitive decline, and apathy is a risk factor for increased mortality [10, 13-15]. Nevertheless, despite its profound negative effects, and in contrast to other NPS, apathy in people living in NHs is seldomly explicitly diagnosed nor specifically treated.

Despite growing scientific interest, the impact of apathy on well-being for people with dementia in NHs and their family caregivers (FCs) and professional caregivers (PCs) remains unclear. In people with dementia living at home, apathy has been associated with an increased reliance and burden on caregivers, as well as earlier admission to a NH [16-18]. Previous research has found that from the proxy perspective apathy is negatively associated with health-related quality of life in young as well as late onset dementia [19, 20]. Furthermore, the literature on the effect of apathy on self-reported quality of life in people with dementia living in NHs is inconsistent [19, 21]. Some studies suggest reflecting on apathy can be very difficult for people with dementia due to lack of insight and awareness, resulting in apathy having no effect on self-reported quality of life [19, 21], while other studies suggest that apathy can be seen as a coping strategy of persons with dementia to protect themselves from confrontation with failure, and disappointment [22, 23]. Moreover, although FCs from community-dwelling people with dementia struggle to cope with apathy of their loved-ones [24], in NHs apathy is seldom reported as a problem by persons with dementia themselves or PCs. Behavior like agitation, aggression or depression interfere with work routines and demand attention and therefore are likely to trigger action from PCs. In contrast, apathy is characterized by diminished or absent behavior and emotion, that does not trigger action easily and is therefore seldom reported as a problem by PCs [25-28].

There is currently no distinct pharmacological or psycho-social treatment for apathy [29, 30]. Some psycho-social interventions are promising when provided multidisciplinary [30] like adapted physical activity[31], therapeutic activities [32, 33] and music therapy [34]. Psycho-social interventions are the first choice when managing apathy [35, 36]. Indeed, although apathy is very prevalent in NHs [11], has distinct negative outcomes and is commonly part of the assessment of neuropsychiatric symptoms in dementia, diagnosing and targeting apathy by specific treatment is uncommon in daily nursing home practice [30, 37, 38]. In this study, we therefore explore the experiences of persons with apathy (PwA), their FCs and PCs in identifying and managing apathy in NHs.

METHODS

Study Design

In the Shared Action for Breaking through Apathy project (SABA), an intervention to identify and manage apathy in NHs was co-created together with PwA, FCs, and PCs. In this paper, we report on the first step towards creating the intervention. To study people's subjective attitudes, opinions, beliefs and reflections we used a generic qualitative research design with an inductive and descriptive approach [39]. Founded on main principles in qualitative research, the generic qualitative design uses methods adopted from established qualitative approaches, such as data triangulation and the constant comparative method [40, 41]. Based on purpose sampling, we held face-to-face semi-structured interviews with PwA, their FC(s) and different PCs to get broad insight into participants' experiences. The FCs (all legal representatives) of PwA were approached after multidisciplinary screening indicated that their loved one had apathy. They were provided with written and verbal information by the local psychologist and asked for permission to participate. Thereafter, an interview with the PwA and their FC(s) was scheduled by the researcher (HN). The PwA was interviewed in the own apartment with their FCs present. Before the interview the PwA and their FCs were informed on the study and were able to ask questions.

PCs were approached by the local coordinator of each participating organization to participate. They were given verbal and written information on the study. Thereafter, they were approached for an interview with researcher HN. Subsequently, in the iterative process, we held focus groups with PCs, to further explore the topics addressed in the interviews and explore multidisciplinary viewpoints. Before each interview and focus group discussion, verbal information was given and participants were able to ask questions. During restrictive measures (visitor ban) in NHs due to the Covid-19 pandemic, apathy seemed to be more profound in people with dementia [42]. As this may have broadened or deepened their experiences with apathy, we held additional interviews with a FC and with PCs who had specifically mentioned effects on apathy in an online survey on behavioral changes during lock-down [43]. The PCs had volunteered to be approached for an interview. They were given written information. Moreover, verbal information was provided before the interview and they were able to ask questions on forehand through mail and at the start of the interview. This study was described using the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [44] (see Additional File 1).

Setting and participants

Two Dutch care organizations of the University Knowledge Network for Older Adult Care Nijmegen participated in this project. Residents classified as having Alzheimer's dementia, vascular dementia and dementia not otherwise specified were included and screened for apathy.

A physician and/or psychologist evaluated all residents in the participating dementia special care units and selected which of them showed apathy symptoms. Those selected were screened with the shortened Apathy Evaluation Scale (AES-10) [45] by a nurse and psychologist familiar with the resident. The ten items of this validated observational scale vary from 1 (not at all characteristic) to 4 (very characteristic), whereby a higher sum score reflects more apathy symptoms (range 10-40). If the AES-10 score indicated apathy (>21)[45], the physician and psychologist ruled out those with apathy due to untreated depressive disorder, acute illness or medication, or apathy representing a resident's character rather than a symptom. As our previous research showed that apathy can best be considered as a dimensional construct [10] the AES-10 was used to assess the severity of apathy, rather than the often used subscale of the Neuropsychiatry Inventory that assesses apathy categorical and has moderate validity [46, 47]. Additionally, the physician registered the type of dementia based on the medical file and the severity of dementia using the validated Global Deterioration Scale (GDS) [48]. The GDS describes seven stages of cognitive decline in primary degenerative dementia from mild cognitive impairment (stage 1) to severe dementia (stage 7). Of the residents who met the inclusion criteria, a nurse and psychologist familiar to the resident estimated which of them would be able to participate in an interview and communicate about their experiences.

A purposive sampling process was used to recruit a representative sample of PCs involved in daily care. They were invited for an individual interview and/or focus group.

The sample comprised of nurse assistants, nurses, specialized nurses, psychologists, physicians, and activity coordinators (at least one per participating organization) with variation in age, sex, cultural background and educational level.

Data collection

Those PwA and their FC were then approached for participation by the same nurse or psychologist. PwA and their family member were interviewed together by the interviewer (HN) in the resident's own room at the unit of residence in September 2019.

Between September and December 2019, PCs were interviewed separately by the same interviewer (HN) on site. Moreover, focus groups with PCs were held at location and moderated by two moderators (AB+HN; HN+AP). All interviews and focus groups were audio recorded with permission of the participants. To increase the trustworthiness of results, ideally the findings should be confirmed with participants [49]. However, none of the interviewees wanted a written member check, but a verbal summary and member check was performed at the end of each interview.

The guides for the interviews and focus groups were compiled by the research team (HN, AP, DG; see Additional File 3). The topics discussed were the experiences of the interviewees in recognizing and dealing with apathy and whether and how apathy was burdensome to them. Open responses were encouraged in all interviews and focus groups. Input from the interviews was used in two multidisciplinary focus groups with PCs to further explore and discuss possible different viewpoints for generating a wider range of ideas and perspectives. The data collection proceeded until constant comparison analysis revealed that information saturation was achieved, which was defined as no new codes generated from the interviews or focus groups.

The additional interviews were held between June and September 2020 with a FC and PCs. The initial topic guide was adapted for these interviews to explore experiences in recognizing and dealing with apathy in the specific context of the lock-down in which apathy appeared to become more prevalent [43] (see additional file 3). Due to ongoing restrictions, these interviews (HN, AP) were held using digital connection (Zoom, MS Teams) and audio-recorded.

The research team was a multidisciplinary team consisting of members with a medical (MS, RK, AP) or psychological background (HN, RL, DG) all of whom have experience in older adult care and qualitative research.

Data analysis

Data were analyzed concurrently with the data collection. After transcribing the interviews and focus groups verbatim, the data were anonymized and analyzed using Atlas.ti (version 8.4.20) using inductive thematic analysis [41, 50]. Two researchers (HN, AP) independently derived codes from the data and discussed them until they reached consensus. The codes were then, independently by each researcher, grouped into higher-order categories based on meaning or content. To enhance the process of achieving consensus and analytic rigor, the researchers (HN, AP) engaged in a reiterant process of discussing areas of agreement and disagreements. The final themes were discussed with the research team (DG, MS, RK, RL) to reach consensus on the themes that characterize the different stakeholders' experiences in identifying and managing apathy.

Ethical considerations

The study was conducted according to the guidelines of the declaration of Helsinki and approved by The Medical Ethics Review Committee (CMO Arnhem-Nijmegen) region (File number 2019-5539) and the local ethical committees of the participating organizations. All participants were informed and gave written informed consent before participation. For the additional interviews during the COVID-19 pandemic, informed consent was given verbally by the participants and audio recorded. During the recruitment of participants for the study in this paper, it became clear the PwA were unable to give informed consent due to cognitive and communication issues. With permission of CMO Arnhem-Nijmegen (file number 2019-5539), we than adjusted the inclusion procedure for PwA in the second step of SABA (outside the scope of this paper). In this step (the development and feasibility of an intervention) informed consent was provided by the legal representatives of PwA. Further details on this step are presented elsewhere [51].

RESULTS

Participants' characteristics

After screening all 117 residents of participating units, 34 residents were suspected of apathy and therefore evaluated multidisciplinary. Of the nine residents with an apathy-indicating AES score, six were able to communicate about their apathy. They were invited with their FCs to participate in an interview. Two of them gave informed consent. Reasons for not participating were no interest (N=2), deceased (N=1) and unknown (N=1). The two residents with dementia who were able to communicate about their apathy and willing to participate were interviewed together with one or two FC(s). The residents had moderately severe dementia according to the GDS (stage 5 and 6, respectively) and AES scores of 29 and 30, respectively. Six PCs were interviewed individually (two of each specific profession) and two focus groups were held with five and seven PCs, respectively. The PCs were nurse assistants, nurses, specialized nurses, psychologists, physicians, and activity coordinators (at least one per participating organization) with variation in age, sex, cultural background and educational level. One FC and sixteen PCs participated in the additional interviews (see Table 1 for participants' details). The interviews lasted between 39 and 67 minutes and the focus group discussions lasted 90 minutes.

Table 1. Demographic characteristics of people with dementia and apathy, family caregivers and professional caregivers

	Participated in interview	**Participated in focus group**	**Participated in additional interview**	**Age range**	**Sex**	**Educational level**
	n {% of interviewees}	*n* {% of focus group participants}	*n* {% of interviewees}		*n* {% female}	{n}
People with apathy	2 {18.2}	-	-	84-93	2 {100.0}	Low {2}
Family caregivers	3 {27.3}	-	1 {5.9} [1**]	60-64	2 {66.7}	Middle {1} High {2}
Professional caregivers						
Care / nurse assistant	-	3 {25.0}	-	30-57	3 {100.0}	Low {1} Middle {2}
Nurse {in training}	2 {18.2}	2 {16.7} [1*]	5 {29.4} [1*; 1**]	33-65	7{77.6}	Middle {8} High {1}
Specialist nurse {in training}	-	3 {25.0}	-	20-47	2 {66.7}	High{2}
Activity coordinator	-	-	3 {17.6}	27-37	3 {100.0}	Middle {3}
Psychologist	2 {18.2}	2 {16.7}	6 {35.2} [1**]	24-63	9 {77.8}	High {9}
Physician	2 {18.2}	2 {16.7} {1*}	2 {11.8} [1***]	32-54	3 {100.0}	High {3}
Total	11 {100}	12 {100}	17 {100}			

[*n**] = participated in one interview and a focus group; [*n***] = participated in two interviews; [*n****] =participated in two interviews and a focus group

Qualitative findings

Themes and subthemes

Based on the views of PwA, FCs and PCs, we identified three central themes regarding apathy in NHs that help to understand how the identification and management of apathy is experienced (1) the challenge to appraise signals, (2) the perceived impact on well-being, and (3) applied strategies to manage apathy. Below, each theme is discussed and illustrated with meaningful quotes from the interviews and focus groups. See Table 2 for an overview of themes and subthemes and Additional File 2 for additional quotes.

Table 2. Overview of themes and subthemes

Themes	Subthemes
The challenge to appraise signals	Perceiving loss of emotions and behavior The importance of knowing the context Apathy as part of dementia
The perceived impact on well-being	Perceived impact of apathy on well-being of a PwA Perceived impact of apathy on the well-being of FCs and PCs
Applied strategies to manage apathy	Stimulating meaningful contact Adjusting expectations Appreciating little successes

PwA = person with apathy and dementia; FC = family caregiver; PC = professional caregiver;

Theme: "The challenge to appraise signals"

One of the themes that was identified from the analysis was the challenge of appraising signals of apathy adequately and as being relevant. This theme included perceiving a loss of emotions and behavior, the importance of knowing the context and apathy as an undeniable part of dementia.

Perceiving loss of emotions and behavior. Stakeholders mostly described apathy as a decrease or absence of emotions, behavior or engagement. This absence of signals makes it difficult for them to see which emotions, behavior or engagement are relevant because it requires seeing what's not or no longer there. PwA described a '*loss of initiative*', '*indifference*' or stated '*I don't feel like it*', but they were unfamiliar with the term 'apathy' when asked specifically. Some PCs mentioned being familiar with the term apathy, whereas others were not. Several FCs and PCs described apathy as a decrease in emotional reaction, a lack of initiating behavior or social engagement as well as a person's body language '*just sitting*'.

> *'At a given moment our mum sat on a chair and just stayed seated.' (FC,001)*

> *'I did nothing, I didn't do anything anymore.' (PwA,001)*

> *'Sometimes they [people with apathy] are slightly aware of the environment, they are very turned inward, sometimes I see them looking around but not really interacting. You don't see them engage in an activity. They just sit there. They are people about whom I always think: if it got dark, they would just remain in the dark because they wouldn't take the initiative to get up and switch on the light.' (PC,004)*

When asked, people with dementia mentioned that they did not know why they did not initiate action or dropped out from activities, and one woman with apathy mentioned that she "*just didn't think about it*".

According to FCs and PCs, PwA frequently dropped out from activities offered to them or prematurely withdrew from social interaction. They mainly ascribed this to the inability to express and fulfil one's actual needs as a result of apathy, rather than being unwilling to interact or engage.

> *'I used to do needlework like this, knitting the most beautiful sweaters, and crocheting, and now I don't do anything.' (PwA,002)*

> *'And apathy in terms of, like, not being able to get things started, it's not always that the person is okay with it or doesn't feel like it or doesn't want to, but that's just a part of it: they simply can't do it.' (PC,001)*

The importance of knowing the context. Apathy was described by all stakeholders as being recognizable by a change compared with the way in which a person with dementia was before. PCs mentioned the importance of knowing the personal life history and personality of a PwA in order to compare character traits from the past to observed current behavior. Moreover, they expressed using observation and conversation to check apathy symptoms after ruling out other probable causes for the observed behavior, such as depression or side effects of medication.

> *'It's often when things change that it's [apathy] more noticeable and then you will discuss it. Yes, it's only really noticeable if the change is significant.' (PC,007)*

PCs mentioned that a sudden change and reduction in environmental stimuli due to the COVID-19 lockdown made apathy more apparent and visible for them, and that this was mostly reversed when the lockdown ended and activities and social contact were re-established. A PC described that people were more in their own world and less easy to stimulate because normal activities and social contact had disappeared "*as if the daily wheel of rhythm' stopped and had to be restarted*" *(PC,004).*

> *'What struck me most is that you really can see that when a lot is omitted, if- due to lockdown – there are no family, no volunteers, no activities and a lot of things have to be done by protocol, then you see that apathetic behavior increases a lot. Yes, you just notice that, also in people you wouldn't expect.' (PC,002)*

Apathy as an undeniable part of dementia. Both caregiver groups mentioned that they see dementia as a probable and natural cause of apathy, making it difficult to distinguish or recognize apathy as a separate entity that needs attention. However, at the same time they realize that apathy should be addressed if it negatively affects the person with dementia or those around them. PwA did not mention this subtheme.

> *'But in cases of people with severe dementia, don't they act because they no longer can, or because they're hindered by their apathy, and is there any difference between these? [….] Or do we still call that apathy and just no longer think that's something bad?' (PC,003)*

Theme: "The perceived impact on well-being"

The second theme that emerged from the interviews regarded the perceived impact of apathy on well-being. PwA only referred to their own well-being, while FCs and PCs reflected on the well-being of the PwA as appraised from their proxy perspective, as well as their own well-being.

Perceived impact of apathy on the well-being of the person with dementia. The persons with dementia described the impact of apathy on well-being as a loss of interest and feeling indifferent towards activities. They agreed when FCs or the interviewer mentioned examples, but did not mention examples or express a burden themselves.

> *'If we talk about it like this, about apathy, does it bother you like it is now? (Interviewer) Sometimes it does, sometimes it doesn't. It probably depends on, how shall I say, it depends on how I'm feeling'. (PwA,002) And what influences that? (Interviewer)I don't know. If I lay down or sit a lot…Yes, then I also nod off.' (PwA,002)*

FCs and PCs mentioned that it was difficult for them to evaluate the well-being of a person with dementia and apathy as they often did not express emotions or burden.

> *'It looks like residents don't suffer from apathy because they lack the insight into what's the matter with them, so they can't express themselves like: 'Well I'm here all day long not doing anything at all'. They can't really say. So, it more or less depends on the observations that we or I do.' (PC,002)*

> *'I think it differs whether you see somebody with apathy who at the same time looks miserable or makes an unhappy impression, or if somebody is without initiative but at the same time looks relaxed' (PC,006)*

On the other hand, caregivers emphasized that they imagine it must be disturbing to have apathy and not be able to take initiative or express oneself. FCs and PCs felt that people with apathy must experience apathy as lack of meaning in life.

> *'Yes, burden is a big term, I do think it bothers them, but they can't really express themselves. I can't imagine otherwise than it must bother you if you don't initiate anything. That – to me – seems very disturbing, but I think they can't express that.' (PC,005)*

> *'Well, if there's no meaning in life at all, and people just shut down from everything and everybody, then there's nothing left at all. And every human being deserves to feel that they are allowed to be there until the very end.' (PC,002)*

Both caregiver groups stated that apathy became more challenging and triggered them to react when they estimated that apathy reduced the well-being of the person with dementia or led to further deterioration. Especially when a sad mood was noted in combination with apathy, this was considered burdensome for the person with dementia.

> *'Well, you must have the impression that there is some kind of, yes, some kind of suffering by someone, by the resident, by the caregiver or by the family. So somewhere there has to be some kind of, kind of burden, yes, before any real action is taken.' (PC,007)*

> *'I worry because I think that it [apathy] is just something very negative for a resident. Those people who suffer from apathy, they don't experience enough stimuli because they don't seek it themselves. So, what you get is that someone only deteriorates further. So, you feel like: I need to activate someone. That's very much the feeling I get from someone, like, go, go and do something!' (PC,001)*

Impact of apathy on the well-being of the FCs and PCs. Both caregiver groups described that visiting and interacting with or taking care of a person with dementia and apathy can be challenging and can lead to frustration, disappointment, insecurity or turning away.

> *'Well, you can keep asking, there is no reaction. If I sit [with her] for an hour and I ask different things, then no, you won't get a response, so you really do not know: "am I doing this right, half right or am I not doing it right at all?"' (FC,003)*

> *'I think it is difficult because, well, sometimes you want something [in contact] and if there is nothing, it is a kind of frustration you have to manage and be patient, and sometimes it just won't work.' (PC,007)*

FCs felt that apathy might not be very challenging for PCs as the PwA would not demand a lot of attention. PCs mentioned apathy to be some kind of challenging behavior, albeit not a very burdensome one.

> *'Our mom is very quiet, so maybe she'll be more easily ignored for certain things, because the others require a lot more attention.' (FC,002)*

> *'I think it's some kind of challenging behavior, but it's not a behavior that causes a challenge for us.' (PC,005)*

FCs and PCs emphasized that it was very rewarding for them when they were able to overcome apathy in a person with dementia. When they establish some kind of reaction, even if short-lived, this positively reflected on their own feelings.

> *'Yes, how nice it is when you see somebody with apathy smile for whatever reason, because of something you said or just a reaction or becoming happy, even if it only lasts for a short while. That, I find beautiful.' (PC,008)*

Theme: "Applied strategies to manage apathy"

The third theme referred to the skills and capabilities of FCs and PCs to apply strategies to manage apathy. FCs and PCs used different skills and capabilities to manage apathy in a person with dementia that were sometimes used consciously and sometimes more unconsciously.

Stimulating meaningful contact. FCs and PCs described that they stimulated the person with dementia into some kind of action or response to overcome the lack of meaningful interaction they experienced as a result of the person's apathy. This was described as the motivation to keep trying to stimulate the person with dementia into some kind of action or positive response.

> *Because these things [person-centered activities], if it works, that's what secretly you're always looking for: that you can give somebody a good time and make them feel good.' (PC,006)*

FCs and PCs emphasized the importance of person-centered activities that refer to former and familiar routines, interests or hobbies. By supporting communication in a non-verbal manner, meaningful contact was realized more easily, especially with people with more advanced dementia.

> *Well, it depends on the [dementia] stage of a person. We had a resident with quite advanced dementia, but when he heard his name and saw his wife in a video call, then he really revived. I saw a twinkle in his eyes and I noticed the recognition was there. And that family was very good in communicating in a non-verbal way: waving, blowing kisses, blinking, showing the dog. One could see the man really perk up. That was very nice.' (PC,002)*

FCs and PCs talked about how people with apathy were stimulated to engage in activities by simply taking them to an activity or starting a specific activity rather than asking if they wanted to participate. The interviewed people with apathy agreed with this statement. This strategy was based on experiences that people with apathy enjoyed an activity once they started participating. Moreover, PCs mentioned examples in which they started the activity '*like starting the engine*' and once having started, the PwA could continue by him-/herself for a short while.

> *'So, when it [an activity] is unfamiliar, it's hard to participate? (Interviewer) 'Yes, I'm just not in the mood for it. But if somebody asked: 'Would you put a needle into this for me [for sowing]?" I would do so.' (PwA,002)*

> *'There are people of whom you know that – once you get them involved in an activity – they really enjoy it, but they can't take the initiative themselves somehow. It's a pity when it [inviting to participate in an activity] does not work, because I know, afterwards they would have enjoyed it, they would have had such a pleasant afternoon, or hour. So yeah, you really want it to work.' (PC,006)*

Adjusting expectations. Another strategy in dealing with apathy mentioned by FCs and PCs was adapting their own expectations to be more realistic and, the capability to change their own behaviour when taking care of or visiting a person with dementia and apathy.

> *'But then I realized it's the way it is. She no longer is able to, willing to [participate]. She won't do it herself, so I need to change myself.' (FC,001)*

> *'You'll always aim high, yet when you are dealing with someone with apathy, you shouldn't aim too high, start low.' (PC,009)*

The importance of keeping a balance between stimulating and letting the PwA be was emphasized by both caregiver groups. This also meant that a caregiver sometimes needed to accept apathy in a person with dementia temporarily. One PwA described that simply sitting with other people without actually participating in conversation was pleasant enough for her.

> *'If I know I have done everything, tried everything, then automatically I come to realize: 'It is what it is'. This does not mean that I accept it [apathy] or won't put effort into it, but I can leave it be for a while and then start over again later on.' (PC,002)*

Appreciating little successes.

FCs and PCs mentioned that a decrease in apathy is often short-lived and ends when the external stimulation stops. However, they stated that when they were aware of and appreciated little successes (of meaningful interaction) this was rewarding for them. It motivated them to try different strategies and activities to interrupt apathy in a person with dementia. This was described as '*the effort that makes it worthwhile*'.

> *'I know she doesn't want to do anything. So, what we'll always do if we're here, we go drink a cup of coffee downstairs or take a little walk. That is about all that is needed. We – my brothers and me – once took her to the zoo. We thought we would do her a favor, so we took her around but she wasn't even looking at the animals. Instead, she said "Can we please go home?" (FC,001)*

> *'The moment we achieve something very small and I feel good about it and the resident does too, then this reflects on the resident. In contrast, if you achieve something small and you yourself don't feel it is good enough, that also has an effect on the resident.' (PC,009)*

By sharing information and learning from each other, FCs and PCs stated that they were able to expand successful experiences in interrupting apathy.

> *'At a certain moment, we discovered that a resident spontaneously started knitting once we gave her knitting needles. So we took a picture and sent that to her family. They responded surprised: "Does our mom still know how to knit? Yes, your mother can still knit!" It's those little things we learned to enjoy more.' (PC,002)*

DISCUSSION

To the best of our knowledge, this study is the first to explore experiences of PwA. FCs and PCs regarding identifying and managing apathy in NHs. We found three themes that relate to the experiences of the stakeholders: (1) the challenge to appraise signals, (2) the perceived impact on well-being, (3) and applied strategies to manage apathy.

Regarding the first theme, our study confirms that all stakeholders relate to the description of the different domains of apathy by Miller et al. [52]. Nevertheless, we found that FCs as well as PCs have difficulties in identifying and appraising signals of apathy adequately in people with dementia. Different aspects seem to relate to this. For a start, although, PwA do recognize change within themselves, they cannot reflect on the consequences of apathy, nor express it actively. At the same time, FCs and PCs find it difficult to detect diminished or absent emotions and behavior. However, if FCs and PCs for example know the character, life history and social preferences of the PwA, this helps them to recognize changes in the resident's behavior. This is important because caregivers do tend to realize the relevance of signals of apathy and (re)act upon them when they believe these signals represent a significant change [53, 54] or when they estimate apathy has a negative impact on the well-being of the PwA. So, the resident context is important when interpreting signals of apathy. Nevertheless, FCs and PCs may be uncertain when and to what extent the treatment of apathy is relevant. In line with recent literature, this is especially true in light off the needs and compelling behavior of other residents with dementia that also require attention [22, 55] or when they see apathy as a natural phenomenon of (advanced) dementia [53, 56].

The second theme we found concerns the perceived impact of apathy on well-being. FCs and PCs think apathy has a negative effect on the well-being of a person with dementia when it reflects a decline or loss of abilities compared to the person's previously more independent, socially engaged or active behavior. In contrast to the study of Baber et al. [23], the PwA in our study did not express that apathy influenced their well-being. This matches known literature and underlines that apathy is usually reported as more impactful from the proxy perspective than from the perspective of the PwA [19, 57, 58]. Additionally, in line with other research comparing the burden of NPS [54], our study shows that PC do not express apathy as burdensome [26, 27, 54]. Nonetheless, both caregiver groups in our study describe that they experience frustration, disappointment, insecurity or withdrawal due to the lack of engagement with the PwA. This confirms previous findings that apathy negatively influences QoL of FCs and PCs especially when they experience incompetence, insufficient skills and capabilities or negative feelings when supporting the persons with apathy [24, 55, 59, 60]. In FCs of home-dwelling people with apathy, avoiding or reducing deception or other negative feelings was even found to be a subconscious motivator to avoid the PwA [24]. For the

FCs and PCs in our study, these negative feelings may make visiting or caring for a PwA difficult, as dealing with apathy requires effort and perseverance.

The third theme of our study shows that several caregivers have the skills and capabilities to apply specific strategies to manage apathy in a person with dementia. They do this by stimulating meaningful contact, adjusting expectation and appreciating little successes. However, for most FCs and PCs it is difficult to make or maintain a meaningful connection with the PwA when visiting or taking care, an experience that is shared with many FCs of people with dementia [61, 62]. Additionally, our study shows that FCs and PCs experience doubt as they want to offer the PwA a choice of whether or not to participate in activities or interaction, while they know from experience that PwA are unable to overcome apathy without external stimulation. This struggle is also experienced by spouses of community-dwelling people with apathy and dementia [24]. Our findings emphasize, in line with previous research, the importance of remaining engaged in meaningful activities and being involved in social interaction as important sources for the well-being of PwA [23, 63].

This study shows that PwA and dementia in NHs have difficulties in expressing their actual needs, starting goal directed behavior and remaining involved in social interaction, which emphasizes their dependence on others for support and external stimulation to interrupt apathy. Systematic follow-up research on the long-term effects of treatment for apathy is lacking [64] but clinical experience suggests that although apathy can be momentarily interrupted, resolving it permanently may not be possible in daily care for people with dementia in NHs as the effect on apathy seems to wane unless activities or stimulation are continued. The absence of visitors and reduction of activities due to the restrictive measures during the COVID-19 pandemic (first wave), for example, led to an increase in apathy in nursing home residents [42]. Our findings suggest that in some residents with dementia apathy became more apparent as it was no longer interrupted by the external factors or reinforcing social interactions. Previous research showed that apathy can be interrupted when sufficient small-scale, individualized and person-centered activities are provided, social stimuli are well dosed and balanced and environmental factors are taken into account [8, 15, 43, 65]. Nevertheless, by focusing on what is possible in dealing with apathy instead of what is no longer possible, and by empowering FCs and PCs, people with dementia can be supported in maintaining their engagement in activities and social contact. Our findings indicate that educating FCs and PCs could increase the awareness and identification of apathy in NHs. Moreover, it seems important that FCs and PCs are supported to develop skills and capabilities to apply successful strategies to manage apathy in a person with dementia. The results of our study can thus direct the future development of psycho-social interventions for apathy.

Strengths and limitations

One key strength of this study is the broad exploration of experiences with apathy and how FCs and PCs deal with it. Including participants from different professional backgrounds reduces the influence of preliminary education and can be helpful to determine how an intervention can best match training courses of different PCs as suggested in recent literature [66]. Another strength is the way in which this qualitative study was conducted, with data triangulation applied through the combination of interviews and focus groups which provided in broad and deep experiences from the participants. Experiences regarding apathy were explored within as well as between interviews and focus groups until saturation was achieved. Moreover, we used the deplorable yet unique situation of the restrictive measures in NHs due to COVID-19 to deepen the understanding of caregivers' experiences with apathy.

However, some limitations must be mentioned. Unfortunately, we could only include a few PwA and FCs. For PwA, our criterion 'to be able to communicate and reflect on their experiences with apathy' limited inclusion. Due to issues with distance, mobility, health and COVID-19-restrictions, FCs were unable to participate in a focus group. This reduced representativeness of the results from the perspective of the PwA and their FCs and generalizations must be made with caution. Another potential limitation of this study is that the prevalence of apathy in participating NHs appeared lower than we expected based on previous studies. The PCs in this study reported difficulties in identifying apathy using the AES-10 in people with severe dementia. This may have played a role, and is in line with previous research highlighting the challenges in accurate apathy assessment in people with dementia in long-term care [58].

CONCLUSIONS AND IMPLICATIONS

Based on the perspectives of PwA, FCs and PCs, we can conclude that all stakeholders are familiar with apathy as formulated in the diagnostic criteria for apathy in dementia, although oftentimes they do not know the term 'apathy'. Appraising signals of apathy in people with dementia is challenging and this complicates the identification of apathy as significant NPS. However, it is important that apathy in people with dementia living in NHs is considered a relevant problem that needs attending to. FCs and PCs estimate that apathy negatively influences the well-being of the person with dementia, while PwA themselves only report a change to the person they were before. Moreover, apathy in a person with dementia has a negative impact on the well-being of both caregiver groups, as they experience negative feelings while dealing with apathy. The current study adds to the growing body of literature on apathy and how this relates to well-being, especially in FCs and PCs. FCs and PCs that have the skills and capabilities to apply specific strategies to manage apathy successfully can positively influence their own well-being when taking care or visiting a PwA. Our study shows that apathy - although briefly - can be interrupted successfully and repeatedly, when FCs and PCs apply strategies like stimulating meaningful contact, adjusting expectations and appreciating little successes. When interrupting apathy it is important that caregivers keep balance between under-stimulating (thereby maintaining apathy) and over-stimulating PwA, who -like all people- sometimes need moments to just do nothing. Future research is needed to support identification and appraisal of signals of apathy in people with dementia in long-term care and explore how FCs and PCs can be supported to positively interact and perform activities with a PwA. The results of this study provide a basis for developing a psycho-social intervention for FCs and PCs to identify and manage apathy in people with dementia in NHs.

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Additional file 1. Consolidated Criteria for Reporting Qualitative Research (COREQ): 32-item list

	Topic	Description	This study	Section
	Domain 1: research team and reflexivity			
	Personal characteristics			
1.	Interviewer/ facilitator	Which author/s conducted the interview or focus group?	Interviews HN; AP Focus group Discussions HN, AP, AB	5
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	HN: PhD student; MS Professor, MD, PhD; AP MD, PhD; RK, Professor, MD PhD; RL, PhD; Associate Professor DG Professor, PhD; AB: PhD (moderator at 1 focus group)	Author check-list
3.	Occupation	What was their occupation at the time of the study?	HN: licenced clinical neuropsychologist + PhD student MS: MD, postdoc researcher AP: postdoc researcher RK: professor, postdoc researcher DG: professor, postdoc researcher AB: postdoc researcher	
4.	Gender	Was the researcher male or female?	HN,AP, DG are female, MS, RK, RL are male	
5.	Experience and training	What experience or training did the researcher have?	HN: Psychology, experienced and licensed clinical neuropsychologist, Followed additional Course 'Training performing qualitative research with interviews and focus groups' before the study AP: Medicine, Elderly Care Physician (not practicing). Experienced post doc researcher in qualitative research. Research team: The researchers have diverse backgrounds; medical (RK, MS, AP) and psychological (DG, RL, HN) and are all specialized in elder care. All have a rich research experience in qualitative as well as quantitative research and clinical experience in nursing homes.	Author check-list
	Relationship with participants			
6	Relationship established	Was a relationship established prior to study commencement?	HN+ AP did not know the people with apathy or their family caregivers. HN knew one professional caregiver before interviewing from the past as (former) college. In the last 5 years she did not collaborate with this participant. AP did not know any of the participants before the study.	

Additional file 1. Consolidated Criteria for Reporting Qualitative Research (COREQ): 32-item list (*continued*)

	Topic	Description	This study	Section
7	Participant knowledge of the interviewer	What did the participant know about the researcher? *E.g. personal goals, reasons for doing the research*	Informed Consent Statement At the start of the interviews participants were informed of the rationale of the research and were informed of HN being a PhD candidate.	methods
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? *E.g. bias, assumptions, research and interests in the research topic*	It was written in the invitational letter and orally stated that the researchers had no conflict of interest with the outcome of SABA. The research team is particularly concerned about the low identification rate of apathy in nursing homes whilst apathy is very common and has severe outcomes	
	Domain 2: study design			
	Theoretical framework			
9	Methodological orientation and theory	What methodological orientation was stated to underpin the study? *E.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Generic Qualitative Research Approach (Kahle, 2014), using descriptive approach and inductive thematic analysis during the iterative process of data analysis	methods
	Participant selection			
10	Sampling	How were participants selected? *E.g. purposive, convenience, consecutive, snowball*	Purposive sampling • By conducting purposive sampling, a sample of people with apathy and dementia, family caregivers and professional caregivers with different professions (nurses, psychologists, physicians, activities coordinator) with variation in age, sex, cultural background and educational level was obtained. Professions represent a cross-section of processionals in Dutch NHs involved in daily care for PwA	methods
11	Method of approach	How were participants approached? *E.g. face-to-face, telephone, mail, email*	Face-to-face and/or by telephone and/or e-mail • Of the residents and their family caregivers who met the inclusion criteria, those who were able to participate in an interview and communicate about apathy were approached face-to-face and/or by telephone and/or e-mail for participation by a familiar nurse or psychologist. • The professional caregivers were approached face-to-face and/or by telephone and/or e-mail by the local coordinator at the participating organization. • The participants of the additional interviews after the first COVID-19 lockdown were approached by e-mail. They specifically gave permission to be approached for other research projects after they had voluntarily participated in a study on the impact of COVID-19 lockdown measurements on behavioral problems in Dutch nursing homes • All interviews and focus groups were conducted in Dutch. Translation of the quotes was done by a registered translation office and checked by an native speaker	methods

Additional file 1. Consolidated Criteria for Reporting Qualitative Research (COREQ): 32-item list (*continued*)

	Topic	Description	This study	Section
12	Sample size	How many participants were in the study?	40 (of whom 7 participated more than ones, see question 18) • 11 in-depth interviews (2 people with apathy and dementia, 3 family caregivers, 6 professional caregivers) • 12 professional caregivers in 2 focus group discussions (N=5 and N=6) • 17 additional in-depth interviews after COVID-19 lockdown (1 family caregiver and 16 professional caregivers)	See table 1 for detailed information
13	Non-participation	How many people refused to participate or dropped out? Reasons?	4 people with apathy and their caregivers refused to participate, • Reasons for not participating were no interest(N=2), deceased (N=1) unknown(N=1) • 2 PwA and 3 FC consented to be interviewed, none dropped out None of the approached professional caregivers declined	
	Setting			
14	Setting of data collection	Where was the data collected? *E.g. home, clinic, workplace*	At location in the participating nursing home units + online • People with dementia and apathy and their family were interviewed together by the interviewer (HN) in their own room at the unit of residence. • The separate interviews and focus groups with professional caregivers took place at the participating nursing home. This was the workplace of the professional caregiver • Due to ongoing restrictions, the additional interviews after the first COVID-19 lockdown were held by HN and AP using digital connection (ZOOM, MSTeams)	methods
15	Presence of non-participants	Was anyone else present besides the participants and researchers?	No • The people with apathy and dementia were interviewed simultaneously with their family caregiver (including the legal representative) who also participated in the study. • Besides researchers and participants no one else was present at the focus group discussions	
16	Description of sample	What are the important characteristics of the sample? *E.g. demographic data, date*	See table 1 for details of demographic characteristics	See results and table 1
	Data collection			
17	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	An interview topic guide was used. The interview guide was not pilot tested • A semi-structured in-depth interview guide was used, and at the end of the interview it was checked whether or not all topics were discussed and/ or if there were specific additional topics that needed addressing according to the participant. • Interviewees did not want to do have a written member check, but there was a verbal summary and member check performed at the end of each interview.	See additional file 1. Topic guide for details

Additional file 1. Consolidated Criteria for Reporting Qualitative Research (COREQ): 32-item list (*continued*)

	Topic	Description	This study	Section
18	Repeat interviews	Were repeat interviews carried out? If yes, how many?	Yes • 23 participants were interviewed once. • 10 professional caregivers participated in one of two focus group discussion • Three professional caregivers participated in an interview and one focus group. • Three professional caregivers participated in first and second interview (post covid). • One family caregiver participated in both interviews and one focus group	See Table 1 for participants' details
19	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Yes: Audio recordings were used to collect the data • All interviews were audio-taped (by HN) • Thereafter these recordings were transcribed verbatim (all by a research assistant) using the same instructions. • A selection of the transcripts were checked against the tape recordings (HN, AP)	methods
20	Field notes	Were field notes made during and/or after the interview or focus group?	Yes • During the interview the topic guide was used as a prompt. Afterward each interview fieldnotes and a summary were written. • A topic guide was used during focus groups discussions . Afterwards fieldnotes and a summary was written	additional file 1 Topic guide for details
21	Duration	What was the duration of the interviews or focus group?	• Interviews lasted between 53-107 minutes • Both focus group discussions lasted 120 minutes including a 20 minute break • The additional online interviews (post COVID-19 lockdown) lasted between 39-104 minutes	
22	Data saturation	Was data saturation discussed?	Yes • Findings and data saturation was discussed with the research group regularly (DG, HN, AP, RK, MS, RL) . Data saturation was reached when no more new ideas emerged • Input from interviews was used in focus groups discussions to further explore, broaden and deepen the understanding of experiences of PCs	methods
23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No: • At the end of the interview a verbal summary was given and checked and it was offered to receive a transcript for comment and/or correction. None of the participants required a written transcript	methods
	Domain 3: analysis and findings			

Additional file 1. Consolidated Criteria for Reporting Qualitative Research (COREQ): 32-item list (*continued*)

	Topic	Description	This study	Section
	Data analysis			
24	Number of data coders	How many data coders coded the data?	Two • Researchers (HN, AP) separately coded the data	
25	Description of the coding tree	Did authors provide a description of the coding tree?	Yes • See additional file 2 for an overview of themes, subthemes and codes	Results + additional file 2
26	Derivation of themes	Were themes identified in advance or derived from the data?	Three themes were derived from the data. An overview of themes, categories and codes is provided in the article text and additional quotes are provided in additional file 2	results
27	Software	What software, if applicable, was used to manage the data?	Analysis was done with Atlas.ti 8.4.20 (Atlas.ti Scientific Software Development, Berlin, Germany)	methods
28	Participant checking	Did participants provide feedback on the findings?	Yes • At the end of each interview the participants a summary was given by the interviewer. Additionally al participants were asked if they would like to receive a transcript of the interview to provide feedback, which none of them wanted. • Feedback on the findings was given by the research team and the adversary expert team comprising two professional caregivers and one family caregiver	methods
	Reporting			
29	Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? *E.g. participant number*	Yes, see results section and Additional File 2	results
30	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes. • In the results section quotations are used to illustrate the consistency	results, discussion and Additional File 2
31	Clarity of major themes	Were major themes clearly presented in the findings?	Yes	results, discussion and Additional File 2
32	Clarity of minor themes	Is there a description of diverse cases of discussion of minor themes?	Yes • Whitin the selected data, diverse cases are described and minor themes discussed	results and discussion

Developed from: Allison Tong, Peter Sainsbury, Jonathan Craig, Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, International Journal for Quality in Health Care, Volume 19, Issue 6, December 2007, Pages 349–357, https://doi.org/10.1093/intqhc/mzm042

Additional File 2. Overview of themes, subthemes and additional illustrative quotes

Themes (heading) and subthemes	Illustrative quotes
The challenge to appraise signals	
Perceiving loss of emotions and behaviour	*‘I’ve heard the term [apathy]. Actually, very briefly, being absent. (FC,003) And what do you mean by that? (Interviewer) Being a little nonchalant. Indifferent. (FC,003)* *‘Often these are the people who do not stand out and who are no burden to other people.’ (PC,001)* *‘How do I notice apathy? What I myself notice is that I’ll recognize apathy by the family’s remarks. Because they know the person better and then they make comments like “She is so withdrawn, or she takes so little action, she sits in the armchair most of the time”.’ (PC,003)* *‘Once somebody [with apathy] is doing something, then he/she can stay occupied.’ (PC,011)*
The importance of knowing the context	*‘I walk to the hallway and sit again. I used to knit a lot, well, they don’t see me doing that anymore. (PwA,002)* *‘I think it [apathy]is far more noticeable now[during lockdown] in a lot of resedents, just because what countered it before fell away. Take that lady for example, who was visited by her husband every day, we saw her sitting listless, while she usually sits with her husband and they sometimes participate in activities.’ (PC,004)*
Apathy as part of dementia	*‘I also think the more people progress in their dementia, the more the question raises whether they are still aware of the things happening around them or are they more in their own world? But in my opinion that doesn’t necessarily mean those people have apathy.’ (PC,006)* *‘I think there are different kinds [of apathy]. Those that occur suddenly. And indeed, with depression someone becomes more apathetic or with advanced dementia someone [with apathy] turns more and more into his own world and becomes more closed off from the environment.’ (PC,007)*
Perceiced impact on wellbeing	
Perceived impact of apathy on well-being of a PwA	*‘Well sometimes you plod, you walk to the living room and then, I guess, they [staff] ask if you need something, but you won’t ask it for yourself. (FC,001) No, not by myself. (PwA,001).’* *‘And if you find that it is difficult to start on your own? (I) I don’t experience that. (PwA,001) You don’t find it hard that you aren’t able to start the day, don’t have lots of interest in things? (I) No, I always try, always did, by the way.’ (PwA,001)*

Additional File 2. Overview of themes, subthemes and additional illustrative quotes (*continued*)

Themes (heading) and subthemes	Illustrative quotes
	'If someone really doesn't initiate anything at all and if that's a problem, when we see that a resident suffers from it, then we'll discuss it.' (PC,015) *'Well, if you don't initiate anything at all, when you have no contact with others, when your world is so empty…What do you have? Then, you just sit there and that's it. That, to me, really seems terrible.' (PC,005)*
Perceived impact of apathy on the well-being of the FC and PC	*'At first this [decline in activities] was annoying for me, I thought "Mother come on!" But then I realised it's not that she doesn't want to, she just isn't able anymore.' (FC,003)* *I think for professional caregivers and family apathy oftentimes is challenging because you'll put effort in it, and get nothing in return. Then, it becomes a [viscous] circle in which someone [with apathy] decreases, because you think "It doesn't matter if I put energy in, the person won't respond anyway, so I don't need to anymore. And then the behaviour gets worse and worse. (PC, 016)*
Applied strategies to manage apathy	
Stimulating meaningful contact	*'Not outside the unit, but inside the unit, you can achieve beautiful moments. When you can break through the apathy of [someone] who never wants anything, who always says: "leave me be" or "it's not necessary", and then one afternoon Spotify is on and you find yourself having the time of your life. And then you can say [to the PwA] "we really enjoyed ourselves, didn't we?" (PC, 006)* *'I saw a resident with a stone-like expression and this person – of course – said he didn't want to go anywere, doesn't feel up to anything, doesn't want to eat, wants to go to bed, and one morning I sat with him, just making small talk and then suddenly I see a smile on his face and then it's all different. And that stays for half an hour until I leave and then its just the way it was before, before I sat down with him.' (PC,010)*
Adjusting expectations	*'I don't think you can totally take it [apathy] away, because someone with severe dementia can't be "on" all of the time, they cannot. I think when now and then, there are those moments of contact, pleasant activities and once in a while you see somebody is enjoying themselves, then I think you have come a long way.' (PC,005)* *'I think sometimes we just expect too much in terms of interaction. That just being present is enough. Just sit with somebody, perhaps reading but you are there. Or you read the paper and once in a while you say something like "Oh look what it reads here...this and that.. it's something right?" And then you move on. You are present and you feel the connection.' (PC,012)*

Additional File 2. Overview of themes, subthemes and additional illustrative quotes (*continued*)

Themes (heading) and subthemes	Illustrative quotes
<u>Appreciating little successes</u>	*We often think activities should be huge, or we must do a lot, but sometimes there is enough there already, like the smell of food can give a positive stimulus (PC,009)* *'And how can you gauge if something you do helps in case of apathy [in a person with dementia]? (I). By the little success you achieve, the little things. When you see somebody [with apathy] brighten up, sit up, still go to an activity and afterwards being cheerful and making small talk.' (PC,006)*

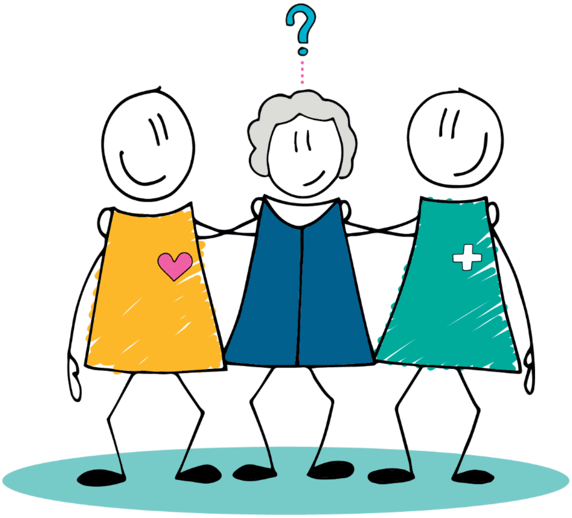
Themes (**bold**), subthemes (<u>underlined</u>) and additional illustrative quotes (*italic*)
PwA = person with apathy and dementia; FC = family caregiver; PC = professional caregiver; I = intervie

“That I think, yes, with people who are, so to speak, ‘vacuous’, you have to try to strike the right chord, that is custom work that is different for everyone. And when you get the right tools, well, that’s what the PAP-A form does, then I hope [for] those moments of happiness, the smile or, erm, the eye contact or whatever was also mentioned in the [animation] video. Then, at that moment, even if it’s just for an instance, you can break through apathy.”

(Family caregiver, 06)

“The moment we achieve something very small and I feel good about it and the resident does too, then this reflects on the resident. In contrast, if you achieve something small and you yourself don’t feel it is good enough, that also has an effect on the resident.”

(Professional caregiver, 09



5

The development and feasibility evaluation of a program to identify and manage apathy in people with dementia: the SABA program

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Abstract

Objectives: To develop and evaluate feasibility of a program for family and professional caregivers to identify and manage apathy in people with dementia: the Shared Action for Breaking through Apathy program (SABA).

Methods: A theory- and practice-based intervention was developed and tested among ten persons with apathy and dementia in two Dutch nursing homes from 2019 to 2021. Feasibility was evaluated with interviews with family caregivers (n=7) and professional caregivers (n=4) and two multidisciplinary focus groups with professional caregivers (n=5 and n=6).

Results: SABA was found feasible for identifying and managing apathy. Caregivers mentioned increased knowledge and awareness regarding recognizing apathy and its impact on their relationship with the person with apathy. They experienced increased skills to manage apathy, a greater focus on small-scale activities and increased appreciation of small moments of success. The content, form and accessibility of the program's materials were considered facilitating by all stakeholders, as was the compatibility of the procedures with the usual way of working. The expertise and involvement of stakeholders, staff stability and the support of an ambassador and/or manager were facilitating, while insufficient collaboration was a barrier. Organizational and external aspects like not prioritizing apathy, staff discontinuity, and the Covid-19 pandemic were perceived as barriers. A stimulating physical environment with small-scale living rooms, and access to supplies for activities were considered facilitating.

Conclusions: SABA empowers family and professional caregivers to succesfully identify and manage apathy. For implementation, it is important to take into account the facilitators and barriers resulting from our study.

INTRODUCTION

Apathy is common in people with dementia living in nursing homes [1-3] and related to adverse outcomes on functional independence, cognitive functioning, quality of life and mortality [4-6]. Nevertheless, apathy is rarely diagnosed nor specifically treated in nursing homes (NHs). Previous research and interventions have focussed on challeging behavior in general, and agitation and depression in particular [7]. This leaves those with apathy at risk of being overlooked. Although, to date no medical treatment has proven effective [8, 9], psychosocial interventions targeting apathy have recently received growing attention and can have a positive clinical impact in reducing apathy in people with dementia [10-12]. However, research shows that family and professional caregivers experience difficulties in identifying apathy in people with dementia and can experience challenges in managing apathy [13, 14]. Nonetheless, they may feel more successful in managing apathy when they adjust their expectations, appreciate small successes and strive for meaningful contact [14]. Moreover, empowering family and professional caregivers in managing apathy may improve the well-being of those involved. Indeed, integrating positive sources of interest and pleasant interactions into a practice-based intervention could help to support persons with apathy and their caregivers [15, 16].

Therefore, in this study we developed and piloted a theory- and practice-based intervention to empower family and professional caregivers in identifying and managing apathy in people with dementia in NHs: the Shared Action for Breaking through Apathy program (SABA).

METHODS AND MATERIAL

Design*:*

The British Medical Research Council's (MRC) framework on complex interventions [17] directed the development and feasibility evaluation of the SABA program. The MRC framework includes four phases: (I) development of the intervention, (II) small-scale assessment of the feasibility and acceptability of the intervention, (III) large-scale evaluation of fidelity, quality of the implementation, mechanism of change and context, and (IV) implementation. This paper describes phases I and II.

In *MRC phase I,* we used intervention mapping (IM) [18], which comprises six different steps: (1) conducting a needs assessment to identify potential improvements, (2) defining the behaviors, determinants and beliefs to be targeted by the intervention, (3) selecting behavior change techniques and ways to integrate them into the program, (4) designing a coherent and executable program, (5) specifying an implementation plan, and (6) generating an evaluation plan to conduct the intervention and a process evaluation to measure the program's effectiveness.

MRC phase II was guided by the approach described by Bowen et al. [19], which defines feasibility in terms of the constructs of demand, acceptability, implementation, practicality, integration and limited efficacy. *Demand* is the extent to which the program is likely to be used, *acceptability* refers to the suitability in daily practice, *implementation* refers to the degree of delivery, *practicality* refers to the extent to which the program is carried out as intended, *integration* refers to the extent to which the program can be integrated in existing systems, and *limited efficacy* addresses the promise that the program shows in terms of being effective.

Setting and Participants

Two Dutch NHs of the University Knowledge network for Older adult care Nijmegen (UKON) participated between June 2019 and October 2021. Family caregivers (relatives and/or legal representatives) and professional caregivers (nurses, activity coordinators, psychologists and physicians) were participants in our study. Persons with apathy participated in the study as they were offered the SABA-program. They did not participate in interviews or focus group discussions.

Materials and Procedures

MRC phase I: Intervention development

Phase I lasted from June 2019 to August 2021, during which each of the two participating organizations formed a multidisciplinary working group that regularly met and was chaired by the researchers (HN and AP). All participants were familiar with at least one of the persons with apathy included as a professional or family caregiver. The working group meetings were held in steps 1, 4 and 5 (see below) to reflect on the wishes and needs of caregivers and select, discuss the content and finetune potential intervention materials and procedures.

In step 1 of IM, we conducted a needs assessment to establish potential improvements, as described in an other paper [14]. Three central themes were identified that need to be addressed for enhancing the identification and management of apathy.

Next, in step 2, we determined the behavioral elements to be targeted for family and professional caregivers to identify and manage apathy.

In step 3, the selection of behavior change techniques was guided by the themes of the needs assessment in step 1, the known literature [20, 21] and the professional expertise of the project team.

The design of the program – specified in step 4 – was supervised by the project team, comprising a family representative, the local coordinating psychologists, and the authors.

Finally, in step 5, we composed a feasibility study.

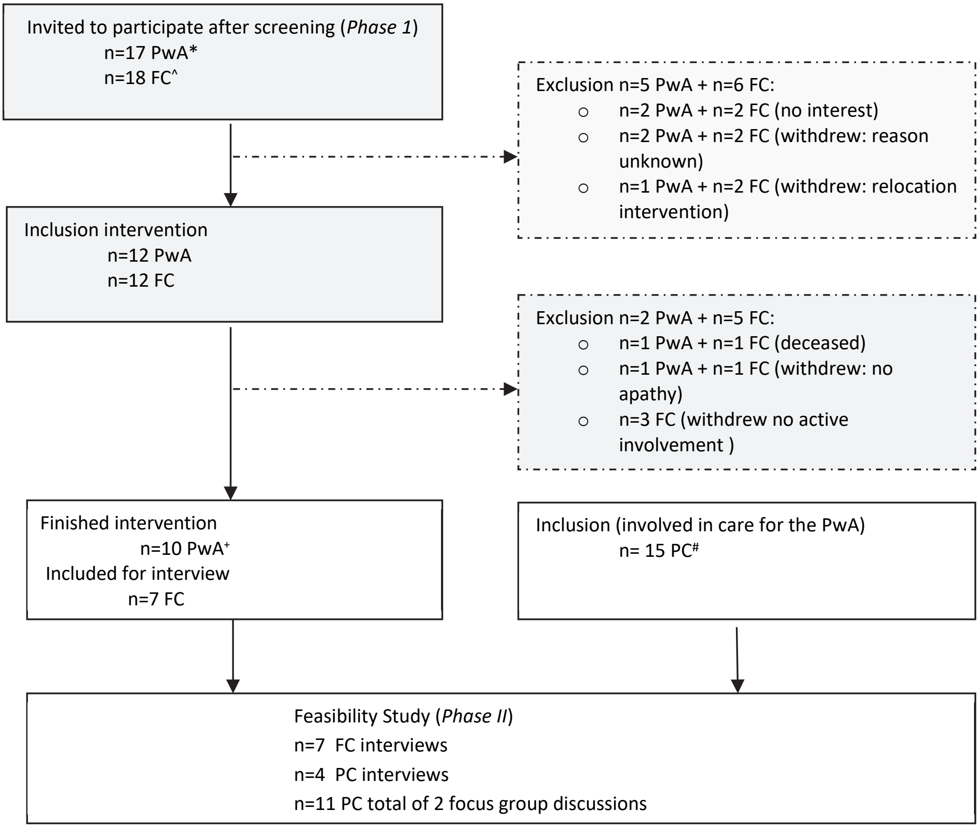


Figure 1. Flowchart recruitment participants feasibility study

*PwA = Person with apathy ^ FC = Family caregiver (all legal representatives) #PC = Professional caregivers. Light grey: recruitment of participants in phase I of SABA-program (beyond the scope of this paper); White: recruitment of participants phase II feasibility study (scope of this paper). +Received intervention, did not participate in interview or focus group discussion in phase II.

MRC phase II: Feasibility evaluation

Phase II started with testing of the SABA program in March 2020, but had to be stopped after two weeks due to the outbreak of the COVID-19 pandemic. Subsequently, it was restarted and tested between October 2020 and August 2021, with pauses in between due to outbreaks of COVID-19 on participating units and associated restrictive measures. The SABA program was tested by the stakeholders of each person with apathy involved for two months. After the completion of the intervention, we evaluated its feasibility between June and September 2021. Afterwards, we developed an *implementation guide* based upon the feasibility evaluation in MRC phase II. This *implementation guide* was also presented to an implementation expert of the UKON and the Netherlands Organization for Health Research and Development (ZonMw) for feedback.

Data collection phase II: Feasibility evaluation

For persons with apathy, family caregivers and professional caregivers, data were collected on age, sex, educational level. For the persons with apathy the type of dementia was retrieved from personal files. Family caregivers were asked to describe their relationship with the persons with apathy.

Qualitative data were collected for the elements of the feasibility framework. We used the fieldnotes of all local multidisciplinary working group meetings. We held face-to-face or online individual interviews with family and professional caregivers (by choice), whereby these interviews were performed by a research student (FM). Moreover, we held one multidisciplinary focus group per organization, which took place at the local nursing home and was moderated by the first and second author (HN, AP). An interview guide was used (See appendix I) and all interviews and focus group discussions were tape-recorded, anonymized and transcribed verbatim by a research student (FM).

Additional quantitative data: Upon inclusion, the severity of dementia was assessed by professional caregivers, using the validated Global Deterioration Scale (GDS) [22], which describes seven stages of dementia.

Before and after the intervention, professional caregivers provided a medication overview to exclude side effects as a cause of apathy. Moreover, to add to the qualitative data on limited efficacy, additional quantitative data were collected. Both caregiver groups assessed the severity of apathy using the Abbreviated Apathy Evaluation Scale (AES-10) [23], a ten-item validated observation scale to measure apathy in NHs. They also filled in the Revised Index for Social Engagement for Long-term Care (RISE) [24], which comprises six questions regarding social engagement.

Family caregivers also filled in questions 20 to 22 of the TOPICS-MDS, which concern the perceived quality of life of the person with apathy and the health-related quality of life of family caregivers [25].

Data analysis phase II: Feasibility evaluation

The qualitative data were analyzed using Atlas.ti (version 8.4.22). We used deductive thematic analysis [26], guided by the elements of Bowen et al.'s [19] approach to categorize relevant data. When applicable, the codes within an element were categorized into experiences regarding the procedures, materials and collaboration between family and professional caregivers. For the deductive analysis, three researchers (HN, AP, FM) independently derived codes from the data and discussed them in pairs (HN, FM; AP, FM; HN, AP) until consensus was reached. Additionally, we used an inductive approach to classify facilitators and barriers for Bowen et al.'s *implementation* element. For this inductive analysis, two researchers (HN, AP) separately assigned codes within the element *implementation* and discussed them until consensus was reached. Subsequently, codes were grouped by the researchers independently into higher-order categories based on meaning or content and thereafter discussed with the research team (DG, MS, RK, RL) to reach consensus. The consolidated criteria for reporting qualitative research (COREQ) were followed [27] (see Appendix II).

To describe the quantitative data, descriptive statistics were applied, using SPSS version 27 (IBM Corp. 2020).

Ethical Considerations

The study was conducted in accordance with the applicable Dutch legislation, and in agreement with the Code of Conduct for Health Research and the declaration of Helsinki. The Medical Ethics Review Committee of the Arnhem-Nijmegen region reviewed this study (File nr 2019-5539) and the local ethics committees of the participating organizations gave their approval.

In phase I, step 1 (beyond the scope of this paper) persons with apathy were provided with verbal and written information and were able to ask questions, as were their FCs and PCs. However, it came became clear the persons with apathy were unable to give informed consent due to cognitive and communication issues. With permission of The Medical Ethics Review Committee of the Arnhem-Nijmegen region (2019-5539), we than adjusted the inclusion procedure for persons with apathy and asked for informed consent of their legal representative.

All participants received written and face-to-face information, were able to ask questions and were asked to provide written consent before participation. Participants were free to participate in *MRC phase I, II* or both.

RESULTS

Participants' characteristics

Ten persons with apathy and dementia were included in the intervention (see Figure 1). The recruitment procedure is described in detail elswhere [14]. In the feasibility study, seven family and four professional caregivers participated in an interview, each lasting between 43 and 105 minutes. Eleven professional caregivers participated in a focus group discussion that lasted 90 minutes (see Table 1 for participant characteristics).

Table 1. Demographic characteristics of participants feasibility study

Participant	*n*	Age Mean (range)	Sex *n* female (%)	Educational level (*n*)
Persons with dementia and apathy *	10	82.9 (67-94)	8 (80)	Low (4) Middle (3) Missing (3)
Family caregiver	7	56.6 (38-69)	5 (71.4)	Middle (2) High (4) Missing (1)
Professional caregiver	15	32.7 (22-63)	15 (100)	Middle (8) High (7)
Care / nurse assistant	1			
Nurse / in training	5			
Specialist nurse / in training	1			
Activity coordinator	1			
Psychologist	4			
Physician	1			
Manager	1			
Other	1			
Total caregivers	22			

* received the intervention, did not participate in an interview or focus group discussions

Phase I: intervention development

As step 1 of IM, we performed a needs assessment with stakeholders in a previous study [14]. Three themes were identified that need to be addressed to enhance the identification and management of apathy: A) relevance of signals: appraising signals of apathy in people with dementia is difficult for caregivers; B) the impact on well-being: the perceived impact of apathy varies per stakeholder; and C) skills and capabilities: dealing with apathy requires adjusting one's expectations, appreciating little successes, and striving for meaningful contact.

For step 2, the project team defined six behavior aspects in both caregiver groups that needed to be addressed by the intervention: 1) attitude (recognizing the negative consequences of apathy), 2) knowledge (knowing what apathy is and how to identify apathy in people with dementia), 3) experience (reflect on how apathy impacts one's own feelings as a caregiver), 4) outcome expectations (expecting that specifically targeting apathy will increase the well-being of persons with apathy and their caregivers), 5) skills (demonstrating the ability to act on and manage apathy) and 6) self-efficacy (believing and expressing confidence in the ability to manage apathy).

Next, in step 3, we selected different behavior change techniques to address the targets of step 2: participatory problem-solving, belief selection, active learning, tailoring, raising consciousness and using visual material [28]. These formed the basis for the development of materials (see Figure 2: SABA toolbox for details) and procedures of SABA (see Figure 3 for a graphical representation).

The *Information Leaflet, Animation, 'What's apathy? Educational Module*' and the *Apathy Guide* were designed to overcome a lack of knowledge and support identifying apathy by family and professional caregivers, and were in line with the diagnostic criteria for apathy in people with dementia [29]. These targeted theme A of the needs assessment and the behavioral change targets concerning attitude (1) and knowledge (2).

Guided by theme B of the needs assessment and the behavioral change targets of (3) experience and (4) outcome expectations, the *Animation* and the *Manual for Group Discussion* were developed.

Finally, resulting from theme C and the behavioral change targets of skills (5) and self-efficacy (6), we developed practical materials to support caregivers in managing apathy: the *Pleasant Activities Plan-Apathy (PAP-A),* the *Activity Sheet* and the *'Active Time' Educational Module*.

For the design of the program in step 4 of IM, the local working groups gave direction to the form and content of the different materials and procedures of SABA. They monitored the suitability of materials and procedures for caregivers with different professions or educational backgrounds. The project team ensured that the tasks and roles within SABA were clear and appropriate for all stakeholders.

Finally, as step 5 of IM, we composed the feasibility study. Therefore, we integrated the practice-based experiences of the project team and local working groups to make the implementation of SABA suitable for each organization and participating unit. Due to discontinuity of important ambassadors within one organization, the local working group decided to reassign the intervention to another unit and location within the same organization.

Materials

The *‘Information Leaflet’* contains easily understandable and general information about apathy to inform family and professional caregivers.

The ‘*Animation’* supports family and professional caregivers in recognizing signals of apathy and increases awareness in challenging experiences while managing apathy.

The ‘*‘What’s Apathy? Educational Module’* was developed to enhance knowledge of apathy and to inform both caregivers groups in a meeting.

The ‘*Discussion Guide’* is a practical recommendation in line with the diagnostic criteria for apathy in people with dementia, that supports professional caregivers in identifying and diagnosing apathy.

The ‘*Instruction Manual for Guided Group Discussion*’ enables psychologists to have an informative and supportive group meeting with professional caregivers about a PwA.

The *‘Pleasant Activities Plan -Apathy*’ (‘PAP-A’) supports the execution of pleasant activities that meet the needs, possibilities and interests of a PwA.

The ‘*Activity Sheet*’ is a list of practical, low-cost and suitable activities in case of apathy, including specific activities for people with severe dementia and male residents.

The ‘*‘Active Time’ Educational Module’* contains easily understandable and general information and supports caregivers or volunteers in making meaningful contact and execute activities.

Procedures

The *Family Meeting* is a meeting between the coordination nurse, family caregiver(s)/legal representative(s) (and activity coordinator) to discuss signals and diagnosis of apathy, to introduce SABA and provide input on personal interest, preferred activities and successful strategies to interact with the PwA for the PAP-A.

The *Guided Group Discussion* is a meeting for professional caregivers (nurses, nurse assistants, activity coordinators) to support identifying and managing apathy in a specific PwA. This meeting is guided by a psychologist familiar to them and the PwA.

The *Multidisciplinary Meeting* is a meeting between the nurse(s), elderly care physician and psychologist familiar to the PwA to discuss and diagnose apathy and make specific arrangements on the execution of SABA.

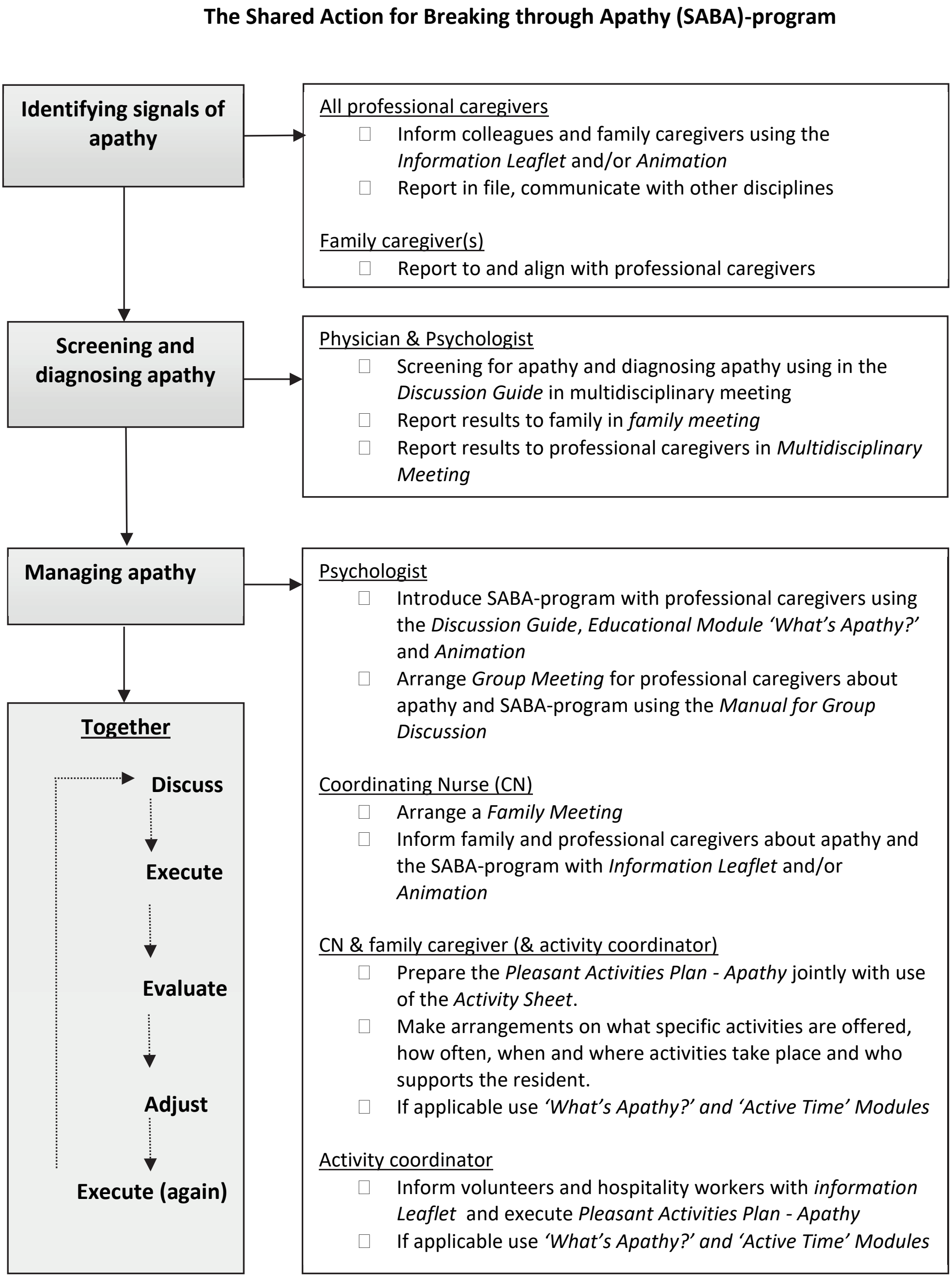
Support for implementation

The ‘*Implementation Guide’* is a guideline containing facilitators to support the implementation of SABA and suggestions to tackle the know barriers.

The ‘*Overview of Implementation Strategies’* consists of a list of implementation strategies and practical tips that can be used to support the implementation of SABA.

The *Presentation ‘Organize Wisely’* is a ready-to-use PowerPoint presentation to inform a project team, management and/or teams on SABA and the steps and strategies to implement it.

Figure 2. The SABA toolbox: materials and procedures of the SABA-program



The Shared Action for Breaking through Apathy (SABA)-program

All professional caregivers

- ☐ Inform colleagues and family caregivers using the *Information Leaflet* and/or *Animation*
- ☐ Report in file, communicate with other disciplines

Family caregiver(s)

- ☐ Report to and align with professional caregivers

Physician & Psychologist

- ☐ Screening for apathy and diagnosing apathy using in the *Discussion Guide* in multidisciplinary meeting
- ☐ Report results to family in *family meeting*
- ☐ Report results to professional caregivers in *Multidisciplinary Meeting*

Psychologist

- ☐ Introduce SABA-program with professional caregivers using the *Discussion Guide*, *Educational Module 'What's Apathy?'* and *Animation*
- ☐ Arrange *Group Meeting* for professional caregivers about apathy and SABA-program using the *Manual for Group Discussion*

Coordinating Nurse (CN)

- ☐ Arrange a *Family Meeting*
- ☐ Inform family and professional caregivers about apathy and the SABA-program with *Information Leaflet* and/or *Animation*

CN & family caregiver (& activity coordinator)

- ☐ Prepare the *Pleasant Activities Plan - Apathy* jointly with use of the *Activity Sheet*.
- ☐ Make arrangements on what specific activities are offered, how often, when and where activities take place and who supports the resident.
- ☐ If applicable use *'What's Apathy?' and 'Active Time' Modules*

Activity coordinator

- ☐ Inform volunteers and hospitality workers with *information Leaflet* and execute *Pleasant Activities Plan - Apathy*
- ☐ If applicable use *'What's Apathy?' and 'Active Time' Modules*

Figure 3: graphical representation of the SABA-program
Bold: activity of SABA; Underlined: participant; *Italic*: procedures and materials of SABA

Phase II: assesment of feasibility

Qualitative results regarding Bowen et al.'s elements

All stakeholders reflected on the procedures and materials of SABA as well as their collaboration, if applicable.

Demand:

Both caregiver groups mentioned that a specific intervention targeting apathy in persons with apathy was likely to be used. They had been looking forward to collaborating and expressed their hope that SABA would provide extra attention and activities for persons with apathy.

> *'Yes, but what I am afraid of is that- I believe that, erm, you can still achieve things-something with him. But he is, of course… yes, look, if someone is apathic and just sits there in that chair, then, at those moments, I guess he doesn't ask for much attention, and then he is… yes, he's somewhat overlooked, and then, I guess, the attention goes to someone else. Erm, and that is sorry.' (Family caregiver 01)*

Acceptability:

When asked about their experiences, both caregiver groups were satisfied with the procedure of organizing a *family meeting* at the start of the intervention. Professional caregivers also mentioned that the *group meeting* guided by the psychologist was helpful for better recognizing apathy and understanding its effect on their interaction with the person with dementia.

> *'Yes, I recall that '[family] meeting. It was a nice meeting in which a lot of questions were asked, concerning my mother personally.' (Family caregiver 02)*

Both caregiver groups were highly satisfied with most of the intervention materials developed. They thought that the materials were promising, had great potential and benefits and therefore should be made available for all family and professional caregivers. They also suggested that the materials could be useful for people with dementia in general and people in NHs with apathy but without dementia.

> *'Erm, I think it is explained very clearly, also with those, like, animation figures. And also, that you become aware that like, gosh, actually you can still do something.' (Family caregiver 01)*

Regarding their collaboration in executing SABA, both caregiver groups appreciated their interaction during the *family meeting* at the start of SABA. However, family caregivers would have preferred to be involved and informed spontaneously more often during the execution of SABA. Nonetheless, when family caregivers specifically asked for additional information, this was provided by professional caregivers. Professional caregivers were satisfied about the collaboration with family caregivers, although their involvement was diverse and some family caregivers and legal representatives of an administration office were not in close contact with the persons with apathy.

> *'Yes, these family caregivers are not very involved. So, I think that makes it [executing SABA] more difficult. I think, if you have family that is very involved, it is easier to have a conversation like "Gosh, we want to plan things [activities] in a structured manner" so, like, someone expects we are going to do that, do you want to participate? And for these two ladies that isn't the case, so that makes it quite difficult.' (Professional caregiver 01)*

Implementation:
We identified three themes in the qualitative analysis regarding barriers and facilitators to implementation: (1) intervention aspects, (2) the expertise and involvement of stakeholders and (3) organizational and external aspects.

<u>Theme 1 'intervention aspects'</u> included aspects of the design and content of materials as well as the procedures and collaboration between caregivers. The face-to-face *family meeting* in which information on SABA and preferences of the person with apathy were exchanged, was regarded as facilitating, as were the small-scale activities that could be integrated in care routines, matched preferences and daily routines of the persons with apathy and skills of the caregiver.

> *'Yes, that you're given suggestions, ideas of what you could do. I see plants here [on activity sheet] so next time I'll bring a watering can!' (Family caregiver 03)*

Both caregiver groups mentioned that the attractiveness, clarity and practicality of the SABA materials were supportive for implementation.

> *'Well, that notebook with activities that I've written down, because it's very nice to see what suits the client… that you don't have to find out for yourself and, erm, some [caregivers] think too complicated, while it [activity] can be very small'. (Professional caregiver 02)*

However, barriers were also mentioned, namely the lack of regular consultation between family and professional caregivers during SABA as the *family meeting* was executed at the start of the intervention, family meetings by telephone and family caregivers missing a copy of the *PAP-A*.

> *'Maybe they [professional caregivers] could have planned another moment of contact in between. "Guys we did this, we are going to do that, or we're still planning to…" having a moment of reflection somewhere.' (Family caregiver 04)*

Theme 2 'the expertise and involvement of stakeholders' concerned the expertise of both caregiver groups, as well as their involvement in executing SABA and prioritizing attention for apathy. Both caregiver groups mentioned that having sufficient expertise was important and necessary to manage apathy. They stated that a low educational level or lack of experience in dementia care of caregivers and volunteers could have hindered the execution of SABA. However, they considered the *'Active Time' Educational Module* to be supportive in enhancing knowledge and facilitative for the execution of the *PAP-A*.

> *'Yes, colleagues mentioned that even when it said so [on the PAP-A] like "have a chat", the actual question was "how?" and "What should I talk about with this client?" I must say that it wasn't so clear to me in advance that this would be a difficult step, so, yes, in hindsight, I think… erm…' (Professional caregiver 03)*

Both caregiver groups mentioned the level of involvement as important for the implementation of SABA. According to both caregiver groups, multidisciplinary collaboration, the involvement of all team members and the support of an 'ambassador' were facilitating aspects. By contrast, less involvement of the psychologist and physician, other team members or family caregivers was mentioned as a possible barrier.

> *'No. No… but that is because the psychologist has helped us here and has pointed us in the right direction. Look, if you must do that all by yourself, then it can be quite a puzzle, and you think "yes, and now what?" But because we have been supported well, erm… yes I think that changes things quite a lot.' (Professional caregiver 01)*

Regular evaluation with team members and encouraging each other motivated professional caregivers in implementing SABA. They also mentioned that integrating small-scale activities in regular care routines was facilitating. At the same time, both caregiver groups expressed worries about the long-term sustainability of SABA and feared that prioritizing attention for apathy might be difficult in case of staff shortages, high workload or the presence of residents with challenging behavior in a unit. Family and professional caregivers considered it a barrier if agreements were unclear regarding who, when or how SABA would be executed.

> *'Yes, I just keep finding it [SABA] very useful, but I notice when there are three or four new clients with challenging behavior, then this [SABA] really gets the worst of it, erm, at least that's what I experienced.' (Professional caregiver 04)*

Theme 3 'organizational and external aspects' included a physical environment with different possibilities – like access to a garden or kitchen – which was considered facilitating. Other facilitating aspects of the environment were a small number of residents living in a unit, a small-scale living room and an appealing atmosphere in the living room. Furthermore, good accessibility to SABA materials and supplies for activities was considered to be facilitating. By contrast, a large-scale unit, a large living room and limited access to materials or supplies for activities were considered barriers.

> *'Hospitality workers don't have access to the personal file of the resident. They need a daily chart with clear instructions what to do with whom today.' (Professional caregiver 05)*

The COVID-19 measures were mentioned as a major barrier in the execution of the SABA program as such measures threatened the continuity of the intervention phase and affected meetings, communication and collaboration between caregivers. Other barriers were the high workload and turnover of the professional caregivers involved. By contrast, professional caregivers who were especially assigned to support hospitality and activities in the living room facilitated executing SABA.

Practicality

When asked about the extent to which SABA was carried out as intended, all but one family caregiver mentioned having had a *family meeting* with the psychologist and coordinating nurse (CN) at the start. According to caregivers, this meeting focused on an explanation of the intervention, sharing information on the resident's former life, character, interests and possibilities for activities. Two out of eleven *family meetings* took place online or by telephone due to COVID-19 measures. Additionally, professional caregivers stated that guided *group meetings* took place to discuss the apathy of the person with dementia, inform team members about SABA, formulate goals for activities and motivate colleagues.

Participants were asked if they followed procedures and had seen or used the different materials during the intervention. Regarding the *Information Leaflet* or *Apathy Guide,* family and professional caregivers did not recall having seen them at all, or they could not recall the content. All professional caregivers mentioned having seen the *Animation*. Three family caregivers mentioned having seen the *Animation*, while the others were interviewed before the completion of the *Animation*. The *PAP-A* was mostly filled in by or with support of the psychologist using input from a *family meeting* and/or *group meeting*. Two family and two professional caregivers recalled having seen the *Activity Sheet* and used it to fill in the *PAP-A*. According to professional caregivers, the reporting and documentation possibilities in the electronical files of the persons with apathy were not used optimally, neither was the use of the *Apathy Guide* in *Multidisciplinary Meetings*.

Integration

When asked about their experiences regarding the extent to which SABA can be integrated in daily care, both caregiver groups stated that SABA could easily be integrated in existing working processes and routines. They mentioned that the procedures and materials of SABA were supportive for working in a methodical way, which was considered important for the quality of care.

> *'Yes, and I also think the things you provide don't necessarily need to take a lot of time. If I put on his headphones and play music, yes, that takes less than a minute, so to speak. But he benefits from it. Only, you need to put some effort into it, to figure out, like, what works.' (Family caregiver 01)*

Limited evaluation of efficacy

Qualitative results. In terms of Bowen et al.'s 'limited efficacy', the different stakeholders found SABA to be promising. According to all family and professional caregivers, persons with apathy responded positively to the intervention.

> *'I notice that, the resident turns towards those people [caregivers] that try to break through it [apathy], thus executing the plan. There develops more of a bond. They link them to an activity or doing something together. And then it becomes more easy.' (Professional caregiver 02)*

Family caregivers mentioned that SABA was promising for them as it empowered them to have a more conscious and deliberate approach towards apathy in a person with dementia.

> *'Erm , I try to involve her in things more. And to tell more and… erm… For example, we sometimes take the birthday calendar down and talk about it. "Look who is almost having a birthday, shall we send her a birthday card? Here, write your name on it." Before she always said: "You write it", but now I try to let her do it herself, and then she got a card back from this gentleman who used to do a lot of things for her in the past. And, ah, that is so happy and so glad and everything.' (Family caregiver 05)*

Additionally, all professional caregivers mentioned SABA as promising in terms of its contribution to increasing the awareness and knowledge of apathy and their empowerment in how to manage apathy. They described having come to realize that small-scale activities and efforts matter for persons with apathy, whereas before SABA they thought that managing apathy required considerable effort and/or organizing major activities.

> *'Erm.. I think in some situations I just thought that the person with apathy just wasn't in the mood and was fine with not doing anything substantial. And that so you might soon underestimate that this is in fact apathy rather than unwillingness.' (Professional caregiver 02)*

<u>Quantitative data</u>. Unfortunately, for all but one resident some or all of the questionnaire data were missing. Therefore, we cannot report adequately on these data. Reasons for missing data varied, including one or more items or questionnaires being missing, family caregivers or legal representatives not completing the questionnaires because they were not actively involved, or the date of completion before and after the intervention overlapped (see Appendix III for details).

DISCUSSION

To the authors' best knowledge, this is the first study to develop and evaluate a specific program to identify and manage apathy in people with dementia in co-creation with stakeholders. According to family and professional caregivers, SABA was feasible to help them to identify and manage apathy in people with dementia living in NHs. Family and professional caregivers emphasized that the form, quality and content of the materials and procedures developed met their needs and empowered them in maintaining meaningful contact with the persons with apathy. Previous research has shown the importance of the self-efficacy and empowerment of family and healthcare professionals [16, 30, 31] and the SABA program provided procedures and materials to help to overcome a lack of knowledge, enhance consciousness, manage expectations and support the skills of caregivers.

Despite family and professional caregivers' willingness to be involved, the collaboration between them was suboptimal. This study provides the insight that some family caregivers desired more feedback and active participation during the intervention, while other family caregivers or legal representatives were not closely involved in daily care, thus making it difficult to provide input. This is in line with previous research highlighting the impact and complexity of involvement of family caregivers while executing and implementing care programs [32]. It also underlines that professional caregivers need to involve family caregivers, while being sensitive to their individual preferences in communication and collaboration [33-35]. However, this demands competencies that should receive more attention than is currently the case in their professional training [36].

Strengths and weaknesses

A key strength of our study is the methodological combination of several research frameworks with practice-based experiences for the development and feasibility evaluation of SABA. Simultaneously, experiences from clinical practice provided input to enhance practice-based evidence. Another strength is the explicit involvement of important stakeholders, which is regarded as an essential – but difficult-to-apply – element within intervention research [17]. Building on a thorough needs assessment, stakeholders participated in the steps and phases of the development and testing of the materials, procedures and collaboration in executing the intervention. As a result, the final version of SABA is accessible, practical, applicable and integrable into standard working procedures and routines, with materials and procedures that match the needs of family as well as professional caregivers. The rich qualitative data of this study revealed that caregivers were very positive about the content, diversity and presentation of the materials and procedures developed. SABA thus shows potential in successfully identifying and managing apathy in NHs.

However, one limitation of this study is that the intervention was tested and evaluated on a small scale, and thus the results should be interpreted with caution. In addition, traditional research methods with questionnaires, may only capture the effect of an intervention when admitted shortly before, during and after an intervention, before an effect on apathy wanes off. Additionally, in future, measurements that can track behavior in real time (e.g. observations) might be preferable to capture the effect of an intervention on apathy. Although qualitative data indicated possible effectiveness for all stakeholders, the incomplete quantitative data constrained a thorough evaluation of the limited efficacy, and more research is needed to determine this aspect of feasibility. Nevertheless, we believe that the participants in this study are a small but representative sample of both family and professional caregivers in Dutch NHs nowadays, with similar variation in age, educational level and relationship to the person with apathy and caregivers mostly being female.

Furthermore, intervention research in long-term care facilities is known to be complex [32-34, 37], as underlined by our study. Despite the study design enabling us to adapt to and integrate the complex context of long-term care facilities as much as possible, not all factors could be addressed. For example, the lack of continuity in executing the intervention might have influenced the results of this study. First, the COVID-19 pandemic caused an important hitch in the execution of the intervention as it started, stopped and restarted again six months later, thus requiring additional effort to prioritize the study in light of daily actuality within an organization. Second, in the meantime there was staff turnover and a relocation of an intervention unit, which might have influenced the motivation of stakeholders to contribute to executing the intervention and data collection.

Future directives and practical implications

Persons with apathy are dependent on others to overcome apathy, whereby this effect wanes over time [12, 30]. Therefore, continued effort and attention by family and professional caregivers regarding identifying and managing apathy is important. To support this, the procedures of SABA are made compatible with the usual way of working. We advise structural screening and multidisciplinary evaluation of apathy to become part of the usual care in NHs, in addition to the evaluation and management of more pronounced challenging behavior**.** Moreover, the materials can support small-scale and practical activities that meet the preferences and possibilities of the persons with apathy as well as the family and professional caregivers. SABA thereby enables caregivers to provide person-centered care, which is known to be important for the well-being of people with dementia [33, 38, 39].

Implementing interventions in NHs is known to be difficult [32], as underlined by the barriers presented in our results. Therefore, we advise using the *implementation guide* to support the implementation of SABA in Dutch NHs to account for possible facilitators and barriers resulting from our study. Besides, SABA is made freely accessible to support further dissemination. Moreover, to enhance the collaboration between family and professional caregivers, we recommend careful communication about mutual expectations and interim evaluations during the execution of SABA, taking into account the needs and possibilities of both caregiver groups. Furthermore, our study suggests that the physical environment, interior and availability of supplies for activities can facilitate the management of apathy for caregivers. Healthcare organizations could support this with a vision and policy in NHs where its residents and their caregivers live, recreate and work with pleasure.

The findings in this study indicate that SABA might be generalizable for use in other groups of NH residents. The elements to enhance the knowledge and skills of stakeholders in performing activities might be useful for people with dementia in general. Other elements were suggested to be useful for other resident groups in NHs, like those with young onset dementia [40] or without dementia but with apathy as important feature, like people with Parkinson's disease or Korsakov's Syndrome [41, 42]. The sense of competence is a strong and consistent predictor of caregiver burden [43], and apathy is known to be especially challenging for caregivers of persons with apathy living at home [13]. As our study indicates that SABA can empower family caregivers in identifying and managing apathy, future research could investigate whether and how the SABA program can positively influence the well-being of Persons with apathy and their caregivers living at home to reduce caregiver burden and thereby delay or prevent admission to an NH.

Moreover, to increase awareness and take action in addressing apathy in NHs, it is necessary to educate nurses, activity coordinators, psychologists and physicians. Therefore, it is useful to investigate how SABA could be integrated into the educational curricula of these professionals.

Finally, future research should target investigating the effects of SABA by means of a large-scale randomized trial to evaluate the fidelity and quality of the intervention, the mechanisms of change and context, as suggested as a next step in the MRC framework [17].

CONCLUSION

SABA is a promising intervention to identify and manage apathy in persons with dementia and can thereby positively influence the well-being of different stakeholders. Apathy in people with dementia calls for action and SABA provides practical procedures and materials to support family and professional caregivers in increasing their awareness and skills when caring for persons with apathy. The effects of SABA on well-being could be investigated in future research. For implementing SABA, it is important to consider the facilitators and barriers revealed in our study.

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Appendix I: Topic lists feasibility of the SABA program

Family /professional caregiver (interviews or focus group discussions)

Recognizing apathy:

- Could you describe if your opinion about apathy, has changed? If applicable, please explain.
- Has anything changed in recognizing apathy in [name of the person with dementia]. If applicable, please explain

Managing apathy:

- Has anything changed in the way you manage apathy when you're visiting or taking care of [name of the person with dementia]? If so, please explain.

Feasibility: Demand:

- To what extend is it relevant to develop an intervention to *identify* apathy in persons with dementia?
  Can you explain why this is (not) important to you?
- To what extend is it relevant to develop an intervention to *manage* apathy in persons with dementia?
  Can you explain why this is (not) important to you?
- What were your expectation of the SABA-program before start?
  - What did you hope for?
  - Did the SABA-program meet your expectations? Please explain.
- Materials:
  - To what extend are you in need of information in general about apathy?
  - To what extend are you in need of suggestions on how to identify apathy?
  - To what extend are you in need of suggestions on how to manage apathy?
  - To what extend are you in need of illustrations or visual material about apathy or to support identification and management?
  - To what extend are you in need of a guide for diagnosing apathy?
  - For psychologists: To what extend are you in need of a guide or manual to support the nursing staff?
  - To what extend are you in need of practical support on managing apathy in a person with dementia?
  - To what extend are you in need of examples of activities that can be done with a person with apathy and dementia?
- Procedures
  - To what extend is it necessary to have meetings between family caregivers and/or professional caregivers? Who should at least intend at this meeting?
  - For professional caregivers: Which procedures or working routines would support identifying and managing apathy?

- Collaboration
  - Should family and professional caregivers collaborate in the SABA-program? If applicable, please explain.
  - Should professional caregivers collaborate in the SABA-program? If applicable, please explain.

Feasibility: Acceptability:

- How did you experience the provided information about apathy?
- How did you experience the provided suggestions on how to identify apathy?
- How did you experience the provided suggestions on how to manage apathy?
- How were your experiences regarding receiving the '*Information leaflet'*?
- What do you think about the lay-out, form and content? Was it useful for you? Did you miss something? Would you recommend the use of it to others?
- How were your experiences regarding watching the '*Animation'* about apathy?
  - What do you think about the lay-out, form and content? Was it useful for you? Did you miss something? Would you recommend the use of it to others?
- How were your experiences regarding the use of the '*Apathy Discussion Guide'*
  - What do you think about the lay-out, form and content? Was it useful for you? Did you miss something? Would you recommend the use of it to others?
- How were your experiences regarding the use of practical support on managing apathy in a person with dementia?
- How were your experiences regarding the *educational module 'What's Apathy?'*
  - What do you think about the lay-out, form and content. Was it useful for you? Did you mis something? Would you recommend the use of it to others?
- How were your experiences regarding the use of the *Pleasant Activity Program-Apathy*'
  - What do you think about the lay-out, form and content. Was it useful for you? Did you mis something? Would you recommend the use of it to others?
- How were your experiences regarding the use of the '*Activity Sheet*'?
- What do you think about the lay-out, form and content. Was it useful for you? Was it useful in combination with the PAP-A? Did you mis something? Would you recommend the use of it to others?

For psychologists

How did you experience the guiding the *group meeting* apathy?

How were your experiences regarding the use of the '*Manual for Guided Group Discussion*' about apathy? What do you think about the lay-out, form and content. Was it useful for you? Did you mis something? Would you recommend the use of it to others?

Feasibility: Implementation:

- Materials

    - In your opinion, what materials of the SABA-program could be implemented?
        - What were your experiences? If any, what material(s) was (were) helpful and could be implemented?
        - What should be altered to improve the content and/or use of the *'Information Leaflet'*?
        - What should be altered to improve the content and/or use of the *'Animation'*
        - What should be altered to improve the content and/or use of the *'Apathy Discussion Guide'*
        - <u>For psychologists</u> What should be altered to improve the content and/or use of the *'Instruction Manual for Guided Group Discussion'*
        - What should be altered to improve the content and/or use of the *'Pleasant Activity Program-Apathy'*?
        - What should be altered to improve the content and/or use of the *'Activity Sheet'*?
        - What should be altered to improve the content and/or use of *the educational module 'What is Apathy?'*?
        - What should be altered to improve the content and/or use of *the educational module 'Active Time'*?
- Procedures
    - In your opinion, what procedures of the SABA-program could be implemented?
        - What were your experiences? If any, what was helpful and could be implemented?
        - How can the procedures of the SABA program be implemented? What could improve the *family meeting*?
        - <u>For professional caregivers</u>: What could improve the collaboration in the *group meeting*? How could the collaboration in the *multidisciplinary evaluation* be improved?
        - <u>For psychologists</u> How could the content and process of the *'Guided Group Discussion'* be improved?
- Collaboration
    - In your opinion, how was the collaboration between family and professional caregivers?
        - How did you shape this collaboration? What did your experience? What went well? What was not helpful?
        - <u>For family caregivers</u>: Did professional caregivers inform you about the (execution of the) SABA-program on their own?
        - <u>For professional caregivers</u>: Did family caregivers inform you about the (execution of the) SABA-program on their own?
        - What should be altered to improve the collaboration between family and professional caregivers?
    - In your opinion, how was the collaboration between professional caregivers?
        - How did you shape this collaboration? What was your experience? What went well? What was not helpful?

    - What should be adjusted to improve the collaboration between professional caregivers? How could challenges be addressed in your opinion?
  - How did you experience the task and role you had in executing the SABA-program?

Feasibility: Practicality:

- Materials
  - Were you shown SABA-materials? If so: what materials did you see? Who showed them to you? Where and when were these materials shown?
- Procedures
  - Did you have a family meeting at start of the SABA intervention? If so: What did it involve? Where or how did this take place (online /live) ? Who were attending? How did you experience this meeting?
  - For professional caregivers: Did you have a team-meeting at the start of SABA-program? If not: please explain reason. If so: What did it involve? How was this organized (online/live) and who were attending? What was the role of the different participants. How did you experience this meeting?
- Collaboration
  - Can you illustrate how your collaboration was with the family/professional caregivers during the SABA-program?
  - What or who supported you- as a family/professional caregiver- in managing apathy?

Feasibility: Integration:

- SABA-program
  - In your opinion, to what extend is the SABA-program (in total) practical and applicable in daily use?
    - For professional caregivers Can it be integrated in the usual way of working in the organization / at the unit? Please explain. Does it fit your working routine or process? Does it fit the clientele you're working with? Please explain.
  - Did you experience sufficient knowledge, support and guidance to get started with the SABA-program? If not: what was missing?
  - To what extend was the SABA-program a topic in your team?
- Materials
  - In your opinion, to what extend are the SABA materials practical and applicable in daily use?
    - For professional caregivers: Can the materials be integrated in the usual way of working in the organization / at the ward? Do they fit your working routine or process? Does it match with the clientele you're working with? Please explain.
- Procedures
  - In your opinion, to what extend are the SABA procedures practically and applicable in daily use?

    - For professional caregivers: Can the procedures be integrated in the usual way of working in the organization / at the unit? Please explain. Do they fit your working routine or process? Does it match with the clientele you're working with? Please explain.
- Collaboration
  - In your opinion, how was the collaboration between family and professional caregivers?
    - What were your experiences? What was helpful and what was not?
    - What should be altered to improve this collaboration?

Feasibility: Limited Efficacy:

- To what extend do you think the SABA-program has an effect on apathy in the person with dementia?
  - Can you explain if and how the person with apathy is changed by the SABA-program, compared to the time before?
  - Can you illustrate if you notice any difference in the person with apathy when apathy is interrupted? What difference do you notice? How did you notice this? Who noticed a difference?
- How do you – as a family/ professional caregiver- experience identifying apathy after the SABA-program?
  - Can you explain if the way you identify apathy is changed by the SABA-program, compared to the time before? Please explain.
  - What would be necessary to better identify apathy in people with dementia?
- How do you – as a family/ professional caregiver- experience managing apathy after the SABA-program?
  - Has something changed in the way you manage apathy, compared to the way before the SABA-program? Can you explain in what way?
  - If nothing has changed, can you explain why this is the case in your opinion?
  - If applicable, how does apathy influence your contact a person with dementia after the SABA-program?
- Can you explain if there is a difference in the way family/professional caregivers manage apathy?
  - If applicable, what and how do you notice this?

Appendix II. Consolidated criteria for reporting qualitative research (COREQ) for the feasibility study

Topic	Guide questions / description	In this study	Section
Domain 1: research team and reflexivity			
Personal characteristics			
1. Interviewer facilitator	Which author/s conducted the interview or focus group?	FM: Interviews, HN, AP: Focus Group Discussions,	
2. Credentials	What were the researcher's credentials?	HN: Msc, PhD candidate; AP: PhD; post doc researcher MS: Professor, MD, PhD; RK: Professor, MD, PhD; RL: PhD; assistant professor, postdoc researcher DG: Professor, PhD; FM: Msc	Author checklist
3. Occupation	What was their occupation at the time of the study?	HN: licensed clinical neuropsychologist + PhD candidate AP: Postdoc researcher MS: Professor, RK: Professor, RL: Assistant professor, postdoc researcher DG: Professor, FM: Research assistant	Author checklist
4. Gender	Was the researcher male or female?	HN; AP; FM: DG female MS; RK; RL: male	

Appendix II. Consolidated criteria for reporting qualitative research (COREQ) for the feasibility study (*continued*)

Topic	Guide questions / description	In this study	Section
5. Experience and training	What experience or training did the researcher have?	HN: experienced licensed clinical neuropsychologist, additionally, followed a training performing qualitative research with interviews and focus group discussions AP: Medicine, Elderly Care Physician (not practicing) Research team: the researchers have diverse backgrounds; medical (RK, MS, AP) and psychological (DG, RL, HN) and are all specialized in and experienced in care for older people and qualitative research. FM: research student. Msc Communication, Health and life sciences, socialization in Health and Society	Author checklist
	Reflexivity and positionality	The researchers are all familiar with the clinical work in nursing homes for people with dementia, including those with apathy and their caregivers. Their expierences could have influenced their perception of apathy and made them curious about how apathy is expierienced and handled by the different stakeholders. HN and AP kept a detailed audit trail that contained their own reflections and methodlogical choices of al practical steps. This was discussed regularly between HN and AP (weekly). After each local working group, field notes were made and HN and AP discussed and reflected on the main issues and divergent input of participants. Additionally, HN and AP discussed the audit trail topics, reflections and issues in their regular meetings with the project supervisor DG (1 x 3-4 weeks) and with the project team members (RL, MS, RK + local coordinator+ representative of FCs) (1x 2-3 months). During the data analyses proces, HN and AP crosschecked and re-adjusted the codes to neutral and non-suggestive codes. Also they crosschecked codes from each other and discussed the meaning and content of a tekst fragment when needed.	
Relationship with participants			
6. Relationship established	Was a relationship established prior to study commencement?	AP and FM did not know the people with apathy (PwA), their family caregivers (FC) or the professional caregivers (PC) prior to the study. HN did not know the people with apathy (PwA)and their family caregivers (FC) or most professional caregivers. She knew two professional caregivers of one focus group discussion from the past (>4 years) as (former) colleague. In the recent past she did not collaborate with those participants.	

Appendix II. Consolidated criteria for reporting qualitative research (COREQ) for the feasibility study (*continued*)

Topic	Guide questions / description	In this study	Section
7. Participant knowledge of the interviewer	What did the participant know about the researcher?	At the start of the interviews participants were informed of the rationale of the research. Researchers also introduced themselves.	Methods
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator?	It was written in the invitational letter and orally stated that the researchers had no conflict of interest with the outcome of SABA	
Domain 2: study design			
Theoretical framework			
9. Methodological orientation and theory	What methodological orientation was stated to underpin the study?	Deductive thematic analysis using the elements of Bowen's approach to categorize relevant data. To classify facilitators and barriers for Bowens's element *implementation* we used inductive thematic analysis based on principles of grounded theory.	Methods
Participant selection			
10. Sampling	How were participants selected?	By conducting convenience sampling, a sample of PwA and FC were selected at the unit of implementation. By conducting purposive sampling, a representable mix of PC with different professions was selected (nurses, psychologists, physicians, activities coordinators) with variation in age, sex, cultural background and educational level.	See Figure 1 flowchart + Methods
11. Method of approach	How were participants approached?	Before start of the intervention the legal representatives /FC of PwA who met the inclusion criteria, were approached face-to-face and/or by telephone and/or e-mail for participation by a familiar nurse or psychologist. The PC were approached face-to-face and/or by telephone and/or e-mail by the local coordinator at the participating organization.	Methods
12. Sample size	How many participants were in the study?	N=10 PwA and dementia (received intervention, but were not interviewed), N=7 FC were interviewed, N=15 PC participated (interviews N=4 + two focus groups with N=5 and N=6 PC)	See Table 1

Appendix II. Consolidated criteria for reporting qualitative research (COREQ) for the feasibility study (*continued*)

Topic	Guide questions / description	In this study	Section
13. Non-participation	How many people refused to participate or dropped out? Reasons?	In total 18 PwA and their FC were invited to participate of whom 12 consented to be interviewed. Reasons for not participating were: no interest (n=2 PwA+ n=2 FC), ; deceased (n=1 PwA+ 1=1FC); relocation of the intervention unit (n=1 PwA and n=2 FC). Additionally, after multidisciplinary screening n=1 PwA + n=1 FC dropped out (deceased), n=1 PwA + n=1 FC were excluded (no apathy), n=3 FC withdrew (all were legal representatives from a legal office who were not closely involved in daily care of the PwA)	See flow-chart
Setting			
14. Setting of data collection	Where was the data collected?	Five family caregivers were interviewed by the interviewer (FM) at the organization were the PwA resided and two online using digital connection (MS-Teams). The multidisciplinary focus group discussions took place at the local nursing home and both were moderated by the first and second author (HN, AP)The separate interviews and focus groups with professional caregivers took place at the participating organization.	Methods
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Besides researchers and participant(s) no one else was present at the interviews or focus group discussions	
16. Description of sample	What are the important characteristics of the sample?	See Table 1 for participants characteristics	Results
Data collection			
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	A semi-structured interview guide was used (see Appendix I), and at the end of the interview it was checked whether or not all topics were discussed and/ or if there were specific additional topics that needed addressing according to the participant. The interview guide was not pilot tested.	Appendix I

Appendix II. Consolidated criteria for reporting qualitative research (COREQ) for the feasibility study (*continued*)

Topic	Guide questions / description	In this study	Section
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No All FC were interviewed once. The PC participated only in an interview or in one of two focus group discussion.	
19. Audio/ visual recording	Did the research use audio or visual recording to collect the data?	All interviews were audio-taped and transcribed (by research student FM) using the same instructions. A selection of the transcripts was checked against the tape recordings by HN and AP.	Methods
20. Field notes	Were field notes made during and/or after the interview or focus group?	During the interviews and focus group discussions a topic guide was used as a prompt. Afterwards fieldnotes and a summary were written.	
21. Duration	What was the duration of the interviews or focus group?	The duration of the interviews was between 43 and 105 minutes. The focus group discussions lasted 110 minutes minutes including a 20 minute break.	Methods
22. Data saturation	Was data saturation discussed?	Findings and data saturation were discussed with the research group regularly(DG, HN, AP, RK, MS, RL) and project team comprising of the research group and two professional caregivers and one family caregiver.	Methods
23. Transcripts returned	Were transcripts returned to participants for comment and/ or correction?	At the end of the interview a verbal summary was given and checked and it was offered to receive a transcript for comment and/or correction. None of the participants required a written transcript	Methods
Domain 3: analysis and findings			
Data analysis			
24. Number of data coders	How many data coders coded the data?	For the deductive analyses, three researchers (HN, AP, FM) independently derived codes from the data and discussed them in pairs (HN, FM; AP, FM; HN, AP) until consensus was reached	Methods

Appendix II. Consolidated criteria for reporting qualitative research (COREQ) for the feasibility study (*continued*)

Topic	Guide questions / description	In this study	Section
25. Description of the coding tree	Did authors provide a description of the coding tree?	No, but codes, categories and themes are decribed in the in the paper	Results
26. Derivation of themes	Were themes identified in advance or derived from the data?	Themes were identified in advance regarding the elements of Bowen's approach using thematic analysis. Themes were derived from data afterwards to classify facilitators and barriers for Bowens's element implementation. A description of themes and quates is provided in the article text	Methods
27. Software	What software, if applicable, was used to manage the data?	Analysis was done with Atlas.ti 8.4.22 (Atlas.ti Scientific Software Development, Berlin, Germany) and IBM SPPS version 27 (IBM SPSS Statistics for Windows, version 27.0, Armonk, NY: IBM Corp.)	Methods
28. Participant checking	Did participants provide feedback on the findings?	At the end of each interview a summary was given by the interviewer. Additionally al participants were asked if they would like to receive a transcript of the interview to provide feedback, which none of them required.	Methods
Reporting			
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? *E.g. participant number*	Yes, see results section	Results
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes, see results section, discussion section and Figures 1 & 2, Table 1 and appendices I-III	Results Discussion Appendices
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes, see results section, discussion section	Results Discussion

Appendix II. Consolidated criteria for reporting qualitative research (COREQ) for the feasibility study (*continued*)

Topic	Guide questions / description	In this study	Section
32. Clarity of minor themes	Is there a description of diverse cases of discussion of minor themes?	Yes, see results section and discussion session	Results Discussion

Developed from: Allison Tong, Peter Sainsbury, Jonathan Craig, Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, International Journal for Quality in Health Care, Volume 19, Issue 6, December 2007, Pages 349–357, https://doi.org/10.1093/intqhc/mzm042

[1] Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. Nursing & health sciences, 15(3), 398–405. https://doi.org/10.1111/nhs.12048

Appendix III: Table 2. Overview quantitative data at inclusion, start and finish intervention

INCLUSION					START INTERVENTION								FINISH INTERVENTTION							
Professional caregiver					**Professional caregiver**				**Family caregiver**				**Professional caregiver**				**Family caregiver**			
Code	Sexe, age	DIA *origin	AES-10	GDS stage	Code	MED	AES-10	RISE total	Code	AES-10	RISE total	TOPICS 20-22	Code	MED	AES -10	RISE total	Code	AES -10	RISE total	TOPICS 20-22
PwA 1	F, 84	2	30	6	PC 01	x"	27	4	FC01	40	2	-	PC 01	-	29	4	-	-	-	-
PwA02	F, 94	7	29	6	PC 02	x	32	5	FC02	4**	4	x	PC 02	x	32	-	FC02	40	3	- -
PwA 3	M, 86	7	40	7	PC 02	x	40	0	FC03^^	-	-	-	PC 02	x	40	-	-	-	-	-
PwA 4	M, 81	7	30	5	§															
PwA 5	F, 85	3	39	6	PC 01	x	39	4	FC04	35	5	x	PC 01	x	30	5	FC04	35	-	x
PwA 6	F, 67	9	40	7	PC 02	x	40	3	LR01^	-	-	-	PC 02	x	40	0	-	-	-	-
PwA07	F, 84	3	34	5	PC 03	-	29	1	FC05	29	-	x	-	x	-	-	-	-	-	-
PwA 8	F, 85	2	38	6	PC 03	-	38	-	LR02^	24	6	-	-	x	-	-	-	-	-	-

Appendix III: Table 2. Overview quantitative data at inclusion, start and finish intervention (*continued*)

INCLUSION					START INTERVENTION								FINISH INTERVENTTION							
Professional caregiver					**Professional caregiver**				**Family caregiver**				**Professional caregiver**				**Family caregiver**			
Code	Sexe, age	DIA *origin	AES-10	GDS stage	Code	MED	AES-10	RISE total	Code	AES-10	RISE total	TOPICS 20-22	Code	MED	AES -10	RISE total	Code	AES -10	RISE total	TOPICS 20-22
PwA 9	F, 86	1	38	6	-	x	6^{**}	1	FC06	-	0	x	-	x	22	2	FC6	36	0	x
PwA 10	M, 75	1	24	6	-	x	3	3	FC07	$39^{\#}$	$0^{\#}$	-	-	x	5^{**}	1	FC7	39	0	-
PwA 11	F, 89	7	23	5	PC 04	-	33	0	FC08$^{\wedge\wedge}$	-	-	-	-	x	15	6	FC8	-	-	-
PwA 12	F, 82	3	39	6	-	x	-	-	FC09	35	3	x	§							

Code = Participants code, PwA= Person with apathy, PC=Professional Caregiver, FC=Family caregiver, $^{\wedge}$LC=Legal representative from an Administration office, doesn't know PwA personally

$^{"}$x=complete; $^{-}$ =missing; §Withdrawn: no apathy diagnosis / deceased; $^{\#}$ date of completion at start and finish overlap; $^{\wedge\wedge}$ Family caregiver not actively involved

DIA = Diagnosis, *origin: 1= Alzheimer's Disease, 2=Vascular Dementia, 3=mixed Dementia, 4=Dementia not otherwise described, 9=other Required Brain Damage

MED=Medication

The AES-10 response categories vary from 1 (not at all characteristic) to 4 (very characteristic), resulting in a total sum score ranging from 10 to 40 with a higher score representing more apathy. **= low score due to 7-9 items not applicable

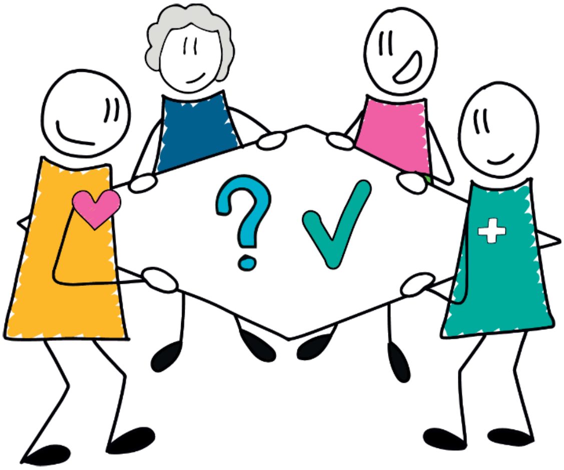
The RISE consists of six questions regarding social engagement, rated as either absent (0) or present (1) leading to a total sum score ranging from 0 to 6 with lower scores indicating less social engagement

The GDS describes seven stages of cognitive decline in primary degenerative dementia. from mild cognitive impairment (stage 1) to severe dementia (stage 7)

“The feedback that there should indeed be collaboration with the family and the care provided there. Erm, yes and that’s pretty much it. It’s something you have to do together. You can’t put it all on the family, you can’t put it all on healthcare professionals, that won’t work.”

(Family caregiver, 05)

Well, I think dealing with apathy, being there, is very important, but also, yes, just showing that you are there for that person and only touch them even, or you give them a little support, like ‘it’s alright,’ or, like, familiar touches. [...] Then you give them a hand or an arm and then you’re inviting people to come into contact with you.” (Professional caregiver, 013)



6

General discussion

GENERAL DISCUSSION

This thesis comprises a research project using quantitative and qualitative methods to gather knowledge and improve the care for persons with apathy in nursing homes (NHs) in the Netherlands. This general discussion first provides a summary of the main findings, and reflection and elaboration against the background of recent literature. Next, several conceptual and methodological considerations are addressed. Finally, this chapter provides implications and recommendations for practice, education, policy and future research.

Summary of the main findings

The first part of this thesis describes two quantitative studies on the consequences of apathy for people living in dementia special care (DSC) and somatic care (SC) units within Dutch NHs, as well as their family caregivers and professional caregivers. Secondary analyses were performed on data from a cluster randomized trial exploring the effects of a care program for depression in NHs [1].

In **chapter 2**, we use a longitudinal design to investigate the relationship between apathy and mortality for NH residents living in DSC units (*n=371*) and SC units (*n=342*). To identify and measure apathy, we used the Neuro Psychiatric Inventory (NPI) [2] and the shortened Apathy Evaluation Scale (AES-10) [3]. The NPI can detect whether apathy is present, while the AES-10 provides information on the severity of apathy (varying from absent to severe apathy). We found a significantly higher risk of mortality over a four-month period if apathy was present. These results remained significant when controlling for depressive symptoms. The effect of apathy on mortality did not differ between DSC and SC units. Male gender and age were also predictors of mortality. An increase of one standard deviation on the AES-10 scores was associated with a 62% increase in mortality risk.

Chapter 3 describes a cross-sectional study on the relationship between apathy and health-related quality of life (HRQoL) in persons with dementia and apathy. We explored whether depression and cognition moderated this relationship. Therefore, using the trial's baseline data of residents living in DSC units (*n=259*) and SC units (*n=262*), we explored the perspective of residents as well as professional caregivers who reported from the perspective of the NH resident (resident-proxy) and their own perspective (proxy-proxy). Based on self-reports, no relationship was found between apathy and HRQoL. However, apathy was negatively associated with NH residents' HRQoL as reported by proxies from both perspectives. Depression and cognition did not moderate this association.

The second part of this thesis focuses on apathy in persons with dementia living in DSC units, their family caregivers and professional caregivers. Previous research has indicated that apathy in people with dementia could be positively affected [4]. Moreover,

in the care for persons with dementia, those with apathy seem to be overlooked easily compared to residents with other challenging or externalizing behaviors like agitation, restlessness or depression. The studies in part II of this thesis used qualitative research based upon the experiences of the participants, which they shared in semi-structured in-depth interviews and focus group discussions as part of action research [5, 6].

In **chapter 4**, we explore the experiences of persons with apathy and dementia, family caregivers and professional caregivers in terms of identifying and managing apathy. Hence, we held individual interviews with persons with apathy (*n=2*), family caregivers (*n=3*) and professional caregivers (n=6) and two focus groups with professional caregivers (*n=5* and *n=7*). Additionally, we held interviews with a family caregiver (n=1) and professional caregivers (*n=16*) after signals of increasing apathy during the first Covid-19 lockdown. Three important themes were identified regarding apathy in people with dementia: 1) the challenge to appraise signals of apathy, 2) the perceived impact on well-being, and 3) strategies applied to manage apathy. Although participants described apathy in line with diagnostic criteria, they were unfamiliar with the term apathy itself and found it difficult to appraise signals of apathy. We found that the perceived impact of apathy varied among the stakeholders. Persons with apathy had difficulties reflecting on their internal state and experiences of apathy, while family and professional caregivers experienced apathy as challenging when it reduced the well-being of persons with dementia or they personally experienced ambiguity, frustration, insecurity, disappointment or avoiding when interacting with the person with apathy. Successfully dealing with apathy required family and professional caregivers to apply specific strategies. Caregivers see (moments of) apathy as a natural part or state of (advanced) dementia. They believed and experienced that the effect of their efforts to overcome apathy waned over time, and that apathy could only be briefly resolved, which is in line with our clinical experience. In this thesis, we therefore consider apathy as a neuro psychiatric symptom (NPS) that can be successfully interrupted temporarily, rather than a phenomenon that can be cured or stopped permanently.

In **chapter 5**, we report on the development and feasibility of an intervention to identify and manage apathy by family caregivers and professional caregivers jointly, called the Shared Action for Breaking through Apathy program (SABA) (Samen in Actie Bij Apathie, in Dutch). Guided by the Medical Research Council framework [7], the intervention mapping method [8] and applying the results from chapter 4, we developed SABA together with family and professional caregivers. An overview of the procedures and materials of SABA can be found in chapter 5 and at www.ukonnetwerk.nl/tools/saba (in Dutch). A pilot implementation of SABA was offered to ten persons with apathy and dementia. We evaluated the potential effectiveness of SABA by means of a feasibility study using interviews with family caregivers (*n=7*) and professional caregivers (*n=4*) and two focus groups with professional caregivers (*n=5*, and *n=6*). According to family caregivers and professional caregivers, SABA was feasible for supporting the identification and management of apathy in persons with dementia in NHs. Both caregiver groups mentioned increased knowledge and awareness regarding recognizing apathy and its impact on their relationship with the person with apathy. They also experienced increased skills to manage apathy, more focus on small-scale activities and more appreciation of small moments of success. However, for the implementation of SABA, it was important to consider the facilitators and barriers found. All stakeholders considered the form, content and accessibility of the intervention aspects (materials and procedures) as facilitating. Likewise, the expertise and involvement of stakeholders, multidisciplinary collaboration, staff stability and the support of an ambassador and/or manager were also perceived as being facilitating, while insufficient collaboration was percieved as a barrier to implementation. Organizational and external factors like not prioritizing apathy, staff discontinuity, and the Covid-19-pandemic were perceived as barriers to implementing and sustaining SABA. A stimulating physical environment with small-scale living rooms and access to supplies for activities were considered as facilitating. Family and professional caregivers stated that SABA enabled them to successfully identify and manage apathy.

Reflections on the findings

Overall, the results of our studies illustrate that apathy is a complex phenomenon that should be regarded within a broader context of all those involved, their interactions and the NH environment. In this section, the findings will be considered and connected to existing literature in an attempt to place the results of our studies regarding the consequences of apathy as well as the characteristics regarding the person with apathy, the family and professional caregivers as well as the environment in perspective, and move forward in improving the identification and management of apathy in people living in NHs.

Factors regarding the person with apathy

Some researchers have suggested that apathy can be seen as a coping strategy of community-dwelling people with mild-moderate dementia to protect themselves from confrontation with failure and disappointment [9, 10]. We could not confirm this, but instead we found that persons with apathy and dementia in NHs experienced apathy as a negative change compared with how they were before. This might be explained by differences in participant characteristics. For the participants in our study, communicating about and reflecting on the feelings of apathy experienced was difficult due to cognitive and communication problems related to their moderate-severe dementia. This is in line with previous findings of apathy being associated with reduced awareness into one's cognitive and functional limitations and progress of dementia over time [11-13]. A lack of insight has also been found in other persons with cognitive impairments and apathy, like those with young onset Alzheimer's disease, fronto-temporal dementia, Korsakoff's syndrome or Huntington's disease [14-17]. The lack of insight of persons with cognitive impairment combined with the core features of apathy may trap them in a vicious circle, whereby their reduced initiative, interest and emotional reaction originating from apathy is incorrectly interpreted by caregivers as conscious and desirable behavior, which then leaves persons with apathy at risk of being overlooked and undertreated. For persons living in NHs, apathy complicates their ability to self-manage or play an active role in fulfilling their personal needs independently [18, 19].

Our research adds to the growing evidence that apathy is an independent NPS despite the overlap with depression and cognition [20, 21]. In most research, apathy is considered a dichotomous or categorical construct that is either present or not. However, our research provides insight that it might be more suitable to regard apathy as a dimensional construct, since an increase in apathy leads to an increased mortality risk. This is important because recently more insight has been gained that people with higher levels of NPS like apathy have greater treatment benefits than those with lower levels of NPS [22, 23]. Therefore, proper screening and measurement of apathy and other NPS can help to determine which residents are most at risk and might benefit most from psycho-social interventions such as SABA.

This thesis underlines both clinical experiences as previous research that apathy in people with dementia is an NPS that can be successfully interrupted temporarily rather than a phenomenon that can be cured or stopped permanently [24]. Even though the effects may wane over time, short-term meaningful interaction and activities matter for persons with apathy and might help them to regain their sense of usefulness, feel empowered and enhance well-being [25]. Indeed, we found that persons with apathy can socially interact with others and engage in meaningful activities when they are provided with the appropriate external support and stimulation. At an individual level, the results of chapter 5 suggest that persons with apathy benefited from the structural offering of activities by using the Pleasant Activity Plan – Apathy (PAP-A) of SABA [26]. In line with the concept of social health, in the care for persons with apathy in NHs, the focus should be on their potential and abilities to support their engagement and well-being [27]. Persons with cognitive impairments can learn new information and skills and be trained to perform daily activities using the principles of errorless learning [28]. It requires further exploration whether implicit learning and the principles of errorless learning can be useful for persons with apathy to independently perform parts of SABA, like activities and chores from the PAP-A.

Factors regarding the caregiver

Family and professional caregivers face several challenges with identifying and managing apathy in persons living in NHs. First, in contrast to rating actively present symptoms such as restlessness or agitation, rating apathy requires a complex evaluation concerning whether the resident generally shows signs of diminished behavior or lowered responsiveness. Furthermore, family and professional caregivers must evaluate whether this represents a behavioral change or the resident's character or premorbid state. A lack of knowledge of apathy and its negative consequences as well as the difficulty in appraising signals of apathy in people with (advanced) dementia hinders the proper identification of apathy as an important NPS.

Second, caregivers need to overcome the discrepancy between respecting the autonomy of persons with apathy while simultaneously continuing to stimulate them in their best interests, despite the lack of initiative, interest and emotional response. This suggests that family caregivers and professional caregivers are crucial and need to play an active role to empower people with apathy, support their well-being and help them in fulfilling their needs. Important research has been conducted on empowerment and relationship-centered care, which emphasizes reciprocity in interactions and relationships between people with dementia, family caregivers and professional caregivers [29, 30]. Further exploration is needed to explore whether and how the concept of relationship-centered care can support identifying and managing apathy in NHs.

Third, managing apathy and maintaining meaningful contact requires the effort and endurance of caregivers when they visit or take care of persons with apathy and dementia. Family and professional caregivers not only need to assist persons with apathy in social interactions, activities, and engagement in daily life, but they also need to deal with their own feelings of ambiguity, frustration, insecurity, disappointment or avoidance when interacting with the person with apathy. We found that caregiver factors like their experienced competence, quality of life and capabilities to apply specific strategies are important to manage apathy. Accordingly, we contribute prudent empirical evidence to the caregiver factors [that were hypothesized] in the conceptual model of Massimo (stress or burden or depression, lack of education about dementia, misinterpretation of apathy as volitional behavior, communication issues and mismatch of expectations).

We found that it is important for family caregivers and professional caregivers to feel useful and empowered in the management of apathy, and optimal collaboration stimulates both in more active involvement or stimulated learning from each other. However, our feasibility study showed that the collaboration between family caregivers and professional caregivers is challenging. This is in line with previous findings suggesting that specific attention to mutual exchange and reciprocity between family and staff is important [31, 32]. Additionally, our findings underline the findings of research into interprofessional collaboration, which has shown that features like mutual acquaintanceship, communication, task characteristics, the role of individuals, and team identity are important for successful collaboration [33, 34].

Factors regarding the environment and context

The second part of this thesis took place in a timeframe when the world was overwhelmed by the Covid-19 pandemic. This not only pushed healthcare to its limits, but it also deeply interfered with research all over the world. In our case, the Covid-19 measures of the Dutch government forced us to postpone our feasibility study of the SABA intervention. Simultaneously, one of these measures – the visitor ban in NHs – unintentionally provided the opportunity to deepen our understanding of the role of the physical and social environment on apathy. Due to the abrupt isolation from social interaction and activities, and the loss of structure and routines, apathy in persons in NHs suddenly became more obvious to family and professional caregivers. This underlines some of the environmental factors (under-stimulation, lack of activity and structure) of Massimo's conceptual model and previous findings suggesting that the social and physical environment might have an important impact on reducing apathy [35].

More specifically, we found that factors of the physical environment such as units with smaller numbers of residents, a vivid ambiance and access to a garden or supplies for activities provided opportunities to manage or prevent apathy, as has been previously suggested [36, 37]. Our findings further indicate that organizational factors like a high workload, staff turnover and restrictive measures on a unit during a disease outbreak need to be considered when addressing apathy. The participating care organizations from the studies in part II differed in their way of management and organization policy. In line with previous findings [38], we found that the implementation of an intervention in long-term care facilities is challenging, especially within organizations that use principles of self-organization.

Methodological considerations

Some methodological considerations of our mixed-methods approach should be mentioned. First, the results of the quantitative studies are based on secondary analyses, which were therefore constrained by the outcome measures and data of the parent study, which was not designed nor powered for our studies [1, 39]. As a result, we could not include variables such as functional status or dementia subtype, which can be related to apathy [40, 41]. Moreover, we could not control for the use of psychotropic drugs, which can also be related to apathy [42-47]. Furthermore, the measurement of QoL in people with dementia and cognitive disorders is complicated. Our results on QoL in chapter 3 were based upon health-related QoL concerning a subjective judgment of the residents' health status. However, this is a limited definition of QoL and we can only interpret the findings of chapter 3 as such.

Second, some possible limitations regarding the trustworthiness of our qualitative studies must be mentioned. For instance, despite several efforts, limited input was gathered from persons with apathy themselves. Several factors may explain this. To start with, the lack of awareness and routine assessment of apathy as important NPS might have played a role [48]. It might explain why we had difficulties recruiting persons with apathy for our studies in part II, despite estimations made beforehand about high prevalence rates of apathy based on literature and our own research presented in chapter 2. Furthermore, persons with apathy living in DSC units nowadays have moderate or severe dementia [49], which might influence their ability to reflect and participate in interviews due to communication issues, cognitive impairments or a frail physical condition. Indeed, the limited research into experiences from the perspective of the person with apathy involves those persons with dementia living at home [9, 10]. The participants in our studies represented a heterogeneous group and we did not account for dementia subtypes or other underlying neurological, neurodegenerative conditions or physical functioning. In addition, recent research has indicated sex differences for several NPS, with apathy being more severe among men [50]. As in our sample 80% of the participants were female, the distribution of gender was unequal in our studies, which limits generalizability. Although our study shows potential positive effects on persons with apathy and their caregivers, the effects of our intervention only considered a two-month period when SABA was applied, and this might have been different with a longer period of implementing SABA. Moreover, because qualitative research is interpretative, it is sensitive to the bias of the researchers [5, 6] and it cannot be ruled out that a different composition of the research team might have led to different or additional information. Finally, our qualitative data in chapters 4 and 5 are based upon a small sample of organizations in the Southern part of the Netherlands. Although we strived for a representative and inclusive mix of participants with different cultural and educational backgrounds, the participant mix might have been different in another region or country or with different participating organizations [51].

Third, the possible suboptimal measurement of apathy reflects a limitation. The identification of apathy is complicated by the unfamiliarity of family caregivers and professional caregivers with apathy as NPS. Besides, they experienced difficulties in appraising the signals of apathy as relevant, which has also recently been found in a study of Burgon et al. [9]. Another limitation could lie in the measurement instruments applied in our studies. To identify and measure apathy, we used the NPI [2] and the AES-10 [3]. The AES-10 is considered a reliable and valid questionnaire [52, 53], and thus we chose to use it in our feasibility study. However, we experienced that the clinical use of the AES-10 was difficult as several items were found not to be applicable for persons with apathy and severe dementia [54]. This might have influenced the evaluation of the effect of SABA. Rather than being continuous and gradual, apathy and other NPS can fluctuate from day to day and within a day, and co-depend on the complex interaction of resident, caregiver, social and environmental factors [9, 55, 56]. Furthermore, although different domains have been distinguished in apathy [57, 58], we did not explore different apathy domains in our studies. The clinical relevance of differentiating between apathy domains in people with dementia has yet to be explored, although differentiating apathy in domains might help to explain which activities work in which domain of apathy and why this is the case [59].

This thesis has shown the importance and additional value of a co-creative approach and practical study designs that involve family caregivers and professional caregivers, which is known to be complex in long-term care [38]. Action research addresses real-world problems in a participatory, collaborative, and cyclical manner through the simultaneous process of taking action and conducting research and makes it possible to respond to the complexity and changeability of reality within NHs [51]. The action research design enabled us to specifically develop and design the SABA materials with accessible language and clear pictures to support the understanding irrespective of the language proficiency of the caregiver. Furthermore, as a result of their active involvement, the procedures and content of the materials fit the needs of family caregivers and professional caregivers**.**

Implications and recommendations for the future

Practice

This thesis provides important clinical implications for the care for NH residents with apathy. First, we have gained more insight into the negative consequences of apathy for persons living in SC and DSC units, as well as for family caregivers and professional caregivers. Therefore, structural screening and multidisciplinary evaluation of apathy should become part of the usual way of working in NHs. The elderly care physician, (health care) psychologist and nurse of the DSC unit's multidisciplinary team should initiate and carry out this apathy screening and evaluation, in addition to the evaluation and management of more pronounced NPS. Furthermore, given its negative outcomes, family and professional caregivers should regard apathy as an NPS that is worth treating. In the Netherlands, there is currently no separate guideline for apathy in persons living in NH. The available Dutch Guideline for behavioral problems in persons with dementia [60] contains a paragraph on apathy that is general and broadly defined. It directs professional caregivers to execute – among other things – a careful multidisciplinary evaluation and fit intervention(s) accordingly to differentiate the burden for different stakeholders and provide psycho-education and management of expectations. Professional caregivers usually give general advice to family caregivers regarding apathy, like explaining that the person with apathy has trouble initiating activities, while they often enjoy activities once they are participating [61]. By using SABA, professional caregivers might feel supported to translate the broad general directives of the professional guideline [60] into concrete advice and specific action plans to target apathy.

Regarding the treatment of apathy, it seems appropriate to enrich the NH environment in which persons with apathy live by providing an attractive physical and social environment that stimulates them to engage with others and their surroundings [62, 63]. Moreover, new interventions like those using virtual reality are evolving and might be suitable for targeting apathy [64, 65].

The Dutch National Health Care Institute [66] advises that interventions are preferably integrated into electronic medical files of patients. SABA is designed to be compatible with the usual way of working and the procedures can be integrated into multidisciplinary care routines within an organization. Besides, the varied materials are available in a digital format that can be imported in electronic medical files. It needs further exploration whether and how the multidisciplinary identification and management of apathy can be supported digitally within electronic files. Transferring academic knowledge to clinical practice is challenging and the implementation of interventions is known be difficult [38]. To optimize the implementation of interventions in clinical practice, implementation should be part of the regular working routines and policies in NHs. This thesis provides additional knowledge on barriers and facilitators to implementing the materials and methods of the SABA intervention. This knowledge was merged in materials that can support successful implementation in Dutch NHs. In addition, SABA might stimulate and incorporate the use of available social technology and digital devices that support everyday life (such as wearables and software apps for persons with dementia) for persons with dementia and support person-centered care and social interaction in living rooms at NH units [67-69].

Education

In the education of physicians, psychologists, nurses and activity coordinators, apathy in people with dementia is hardly a topic. Educational programs should incorporate apathy in curricula for the key professionals involved in the care for persons with apathy to tackle the lack of knowledge, identification and management of apathy. Furthermore, these educational programs should integrate psycho-social interventions such as SABA to support the recommended guidelines on non-pharmacological management of apathy in NHs. Within SABA, an educational module ("What's apathy?") is available, aiming to enhance awareness and knowledge of family caregivers and professional caregivers. A first study [70] shows promise in the effect of this module on the attitude and knowledge of professional caregivers towards apathy in people with dementia. Further research could provide insights into which elements of SABA meet the needs of those involved in the care for persons with apathy as well as whether and how this might vary for different professionals, thus helping to adjust education accordingly.

Furthermore, we recommend unlocking knowledge about apathy and how to identify and manage it to a broad public. This dissemination of knowledge could be accomplished in collaboration with the national patient association (Dutch Alzheimer Association/Alzheimer NL), academic networks for aging and long-term care similar to the University Knowledge Network for Older Adult Care Nijmegen (UKON) and the National Centre of Expertise for Long-term Care in the Netherlands (Vilans).

Additionally, the collaboration between family caregivers and professional caregivers is important for the management of apathy. Therefore, family caregivers and professional caregivers should be educated and specific attention should be devoted to pitfalls and successes in their collaboration and communication. In this way, they can complement and learn from each other and jointly provide optimal care for persons with apathy.

Policy

The Dutch National Health Care Institute has installed a Databank of Approved Interventions (Databank Erkende Interventies) [71]. The first policy recommendation is to present SABA for the approval trajectory in this databank given its quality and feasibility.

Policy makers and NH management could have an important role in facilitating alterations and improvements in the living environment in NHs that stimulate and activate those with apathy [72-74]. They should be aware that apathy can be influenced by the layout of the units in NHs, the offering of activities, the daily structure in a living environments and the care policy of an organization [75]. Policy makers and NH management can therefore contribute substantially to the improvement of care for persons with apathy in NHs.

Given that frail older people stay at home for longer nowadays – despite old age, cognitive or physical problems, or NPS like apathy – and managing apathy is challenging ***f***or family caregivers of community-dwelling persons with dementia [76], family caregivers must be adequately supported. In the Netherlands, community-dwelling persons with dementia and their family caregivers are supported by professional caregivers such as home care nurses, case managers, general practitioners, and memory clinic physicians. However, they report a lack of knowledge and confidence in managing NPS including apathy in persons with dementia [48, 77-79]. Therefore, policy makers need to acknowledge apathy as a relevant NPS in people with dementia living at home, and family caregivers and professional caregivers need to be equipped adequately to timely identify and manage apathy [80, 81].

In the near future, the costs of dementia will increase, as will the strain on informal caregivers and the primary and community care in general [82]. In the social context and due to demographic developments such as population aging, the number of potential family caregivers will decline, while the demand for care will continue to grow. Apathy is related to functional and cognitive decline, caregiver burden and a higher risk of nursing home admission [83, 84]. A recent systematic review has shown that the severity of dementia and functional dependence are strongly associated with a increased amount of given monthly and the costs to society, which persist over time [85]. More specifically, a recent study suggests that apathy is a significant factor that increases care costs for persons with mild to moderate Alzheimer's dementia and that these costs further increase when apathy is more severe. Therefore, the effective treatment of apathy is important as it might reduce overall costs in persons with Alzheimer's dementia [86], which make up the majority of persons with dementia. Thus, when proven effective, SABA might perhaps be able to reduce healthcare costs as this thesis shows that SABA is a feasible intervention for the identification and management of apathy in persons with dementia in NHs. Moreover, SABA focuses on small, basic and low-cost activities that can be provided easily using available supplies for or activities. Besides, all SABA materials, procedures and the guide for implementation are freely available to support their use and implementation and thereby increase the impact on persons with apathy and their caregivers.

In the last decade, the participation of patients in research, education and policy has increased and patient participation nowadays is an important condition to have funding and research protocols accepted by medical ethics committees [87]. However, participation is challenging for people with cognitive and mental impairments. It can only be successful if they or their representatives are able and empowered to fulfill these tasks [88, 89]. Our study has shown that persons with apathy living in DSC units could not actively participate due to cognitive and communication issues. Some legal representatives also faced issues that hindered them from participating in our research, such as problems with mobility, own health issues, hesitation about visiting the nursing home due to Covid-19 and/or a lack of time or engagement. This underlines the finding that – despite best intentions – the prevalence of patient engagement in patient-oriented interventional research is often very poor [90] and more insight is needed to determine the best practice for meaningful engagement of stakeholders involved in apathy in research, education and policy. A promising development is the installation of advisory boards of patients and/or representatives at research institutes or patient associations that can be consulted at different stages of research [91].

Research in NHs could further benefit from an increase in research awareness in daily practice, action research designs, digitalized data collection and practical support for the data collection and coordination at the location. For example, the paperwork required for our research felt like an administrative burden for stakeholders, which hindered the practical implementation of SABA and this might have demotivated them or negatively affected their experiences with the intervention. Moreover, the different rules, guidelines, and protocols for researchers (like privacy rules, research protocols and guidelines, policy within organizations) complicate the collaboration between informal and formal caregivers and make research in long-term care complex and possibly demotivating. Moreover, these rules also create tension between the wish and need for the involvement of informal caregivers like family caregivers and volunteers on the one hand and restrictions that prevent them to have equal and simultaneous access to information on the other, hindering the integration of informal and formal care [34]. Policy makers, care organizations and research institutions should collaborate in finding pragmatic agreements to tackle these issues.

Future research

The first recommendation for future research is to execute the next step of the MRC framework: a large-scale evaluation of the effectiveness of SABA among different stakeholders [7]. A multi-center study with a larger study sample that also takes into account multiple aspects of the physical environment and organizations might be most suitable to evaluate the effect of our intervention. Therefore, it is advised to conduct a pragmatic clinical trial with a stepped-wedge design that that considers effects in 'real-life' conditions in NHs, minimizes the research load and allows all participants to benefit from the intervention. In addition, a longitudinal qualitative study that aims to understand experiences or behaviors over time might also be appropriate to study our intervention [92-94].

The second recommendation is to explore whether and how it is possible to generalize SABA. Given some similarities that we found between resident characteristics in SC and DSC units, SABA might be fit to identify and manage apathy of residents living in SC units. Future research should also explore in depth the lived experiences persons with apathy in NHs without dementia. Further, to support other NH resident groups with apathy, it should be studied whether SABA is or can be made suitable for those living with Korsakoff's syndrome, Huntington's disease, Parkinson's disease or young onset dementia. Finally, given the burden of apathy on family caregivers at home, the increased risk of institutionalization, the sociodemographic developments in the (near) future and the healthcare costs of apathy, it is worth studying the value and effectiveness of SABA for persons with apathy living at home and their family caregivers and professional caregivers.

Traditional research methods applying questionnaires like the NPI and AES before and after the intervention might not be suitable to capture all effects of an intervention on apathy and other NPS [95]**.** Perhaps multiple case studies and practice-based research methods that monitor individual manifestations of apathy in real time (e.g., by using observations, experience sampling methods, environmental sensing approaches, time-series-gathering or apps that objectively and passively measure altered social behavior [96, 97]) might be more suitable to provide relevant data for the evaluation of interventions such as SABA within the context of persons with dementia, and their family and professional caregivers [98].

Future research should be conducted on translating and testing alternative existing measurements to improve the measurement of apathy and the effects of interventions on apathy. Regarding the identification of apathy, professionals can use the Dementia Apathy Interview and Rating scale (DAIR) to determine how the development of apathy in persons with Alzheimer's dementia relates to their personality before the manifestation of the disease [52, 99]. Furthermore, Jao et al. [100, 101] have developed the Person-Environment Apathy Rating scale (PEAR), an alternative measure that considers the impact of environmental stimulation on apathy. Radakovic et al. [102, 103] have developed a multidimensional apathy measure called the Dimensional Apathy Scale (DAS) and a brief DAS (b-DAS). The (b-)DAS comprises three subscales – executive, emotional, and initiation – that were developed to better profile apathy subtypes in people with neurodegenerative and neurological diseases. Unfortunately, the PEAR, DAIR, DAS and b-DAS are not yet available in Dutch, although translating these assessment instruments into Dutch and validating them for use in the Netherlands has already been recommended [54]. Furthermore, different domains have been distinguished in apathy [57, 104], although the clinical relevance of differentiating between apathy domains in people with dementia is yet to be explored. This might be important as differentiating apathy into domains might help to explain which activities work in which domain of apathy and why this is the case [59]. To differentiate between different domains of apathy, the Apathy Motivation Index (AMI) has been developed [104, 105] and recently translated into Dutch and validated for those with Korsakoff's syndrome [17]. The validity and use of the AMI and the AMI-caregiver version among persons with apathy and dementia needs to be studied in future research.

As described before, in the care for people living in NHs, collaboration between informal and formal caregivers is becoming increasingly common [106, 107]. On the one hand, this does justice to the experience and expertise of informal caregivers, while on the other hand it is necessary due to changing circumstances in NHs, with staff shortages being the main threat to the continuity of care [108]. Collaboration between family caregivers and professional caregivers is also a crucial element for the successful implementation of interventions [109] and should be taken into account in intervention research in NHs. The Interprofessional Collaboration Scale [110] – which has recently been developed to measure the collaboration within teams of professional caregivers – might be a good starting point for measuring collaboration in future research [51, 111-113].

Innovations in elderly and long-term care practice can be stimulated by the involvement of older persons, family caregivers and nurses and other healthcare professionals in the needs analysis and designing phases [74, 114]. Nowadays, collaboration between research institutes with different disciplines, patient organizations and care organizations is evolving, combining their strengths and accelerating the development of new knowledge, innovations and best practices [115-117]. These promising developments might provide opportunities to address apathy in future research within the broad context of those involved, their interactions and the NHs environment.

CONCLUSIONS

This thesis provides the insight that apathy in NH care needs to be regarded in the context of the different perspectives and social relationships of those involved. The results of our studies show why apathy matters and display important implications for care and support of persons with apathy living in NHs as well as their family and professional caregivers. Apathy should be considered as a health issue as well as a separate and important neuropsychiatric symptom in the context of neurobiological changes and cognitive impairment. Alongside, apathy has consequences for the wellbeing of those involved. Apathy has consequences for the persons living in a nursing home to participate in a meaningful way and remain independent and socially engaged as much as possible. Besides, apathy in persons with dementia living in NHs has to be seen in the context of the environment in which they reside. They need social support from their family and professional caregivers to interrupt apathy and contribute to a stimulating supportive living environment. The SABA program seems to be a promising practical intervention for family and professional caregivers to concurrently identify and manage apathy successfully in persons with dementia living in NHs.

Now the time has come to act and move forward, because each moment of interrupting apathy matters!

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7

Samenvatting (summary in Dutch)

Datamanagement

Dankwoord (acknowledgement in Dutch)

Portfolio (in Dutch)

Curriculum Vitae (in Dutch)

SAMENVATTING

Inleiding en doel van het proefschrift

In **hoofdstuk 1** van dit proefschrift geven we achtergrondinformatie over apathie en gaan we in op wat er bekend is over apathie bij mensen die in verpleeghuizen wonen. In de loop van de tijd is de betekenis en definitie van apathie veranderd. Tegenwoordig gaan we er vanuit dat apathie bestaat uit drie kerndimensies - gedragsmatig, cognitief en emotioneel - die elk bijdragen aan verminderd doelgericht gedrag. Bij mensen met neurocognitieve stoornissen kan apathie het best worden gedefinieerd als verminderd initiatief, verminderde interesse of verminderde emotionele expressie/reactie. Specifieke fronto-subcorticale systemen in de hersenen zijn betrokken bij apathie en zijn gerelateerd aan verschillende subtypes of dimensies van apathie. Beschadigingen en neurodegeneratie in deze hersensystemen worden aangetroffen bij mensen die in een verpleeghuis wonen met een breed scala aan neurologische en neurodegeneratieve ziekten en neurocognitieve stoornissen. Het is bekend dat apathie bij deze aandoeningen vaak voorkomt en aanhoudt en negatieve gevolgen heeft. Voor dit proefschrift keken we naar apathie als een veelzijdig fenomeen, beïnvloed door factoren met betrekking tot de persoon met apathie, factoren met betrekking tot de mantelzorgers en professionele zorgverleners, en factoren met betrekking tot de omgeving. Apathie heeft niet alleen gevolgen voor de personen met apathie zelf, maar ook voor de mensen die voor hen zorgen. We wilden weten of en hoe factoren met betrekking tot de mantelzorgers en professionele zorgverleners, zoals kennis, verwachtingen en individuele ervaringen, verband houden met de door hen ervaren impact van apathie. Verder wilden we weten hoe ervaringen en (onvervulde) behoeften van mantelzorgers en professionele zorgverleners van invloed zijn op het identificeren en hanteren van apathie bij mensen die in verpleeghuizen wonen.

Belangrijkste resultaten

Het eerste deel van dit proefschrift beschrijft twee kwantitatieve onderzoeken naar de gevolgen van apathie voor mensen die wonen in Nederlandse verpleeghuizen (VPH) op psychogeriatrische (PG) of somatische (SOM) afdelingen, en hun mantelzorgers en professionele zorgverleners. Hiervoor zijn secundaire analyses uitgevoerd op data van een eerdere grote cluster gerandomiseerde studie Doen bij Depressie (DbD) naar de effecten van een zorgprogramma voor depressie in verpleeghuizen.

In **hoofdstuk 2** hebben we een longitudinaal design gebruikt om de relatie tussen apathie en overlijden te onderzoeken bij mensen die woonden in verpleeghuizen in PG (*n=371*) of in SOM afdelingen (*n=342*). Om apathie te identificeren en te meten, gebruikten we de Neuro Psychiatrisch vragenlijst (NPI) en de verkorte Apathie Evaluatie Schaal (AES-10). De NPI kan detecteren of apathie aanwezig is of niet, terwijl de AES-10 informatie geeft over de ernst van apathie (variërend van afwezige tot ernstige apathie).

We vonden een significant hoger risico op overlijden over een periode van vier maanden als apathie aanwezig was. Deze resultaten bleven significant wanneer we in de analyses rekening hielden met depressieve symptomen. Het effect van apathie op de kans op overlijden verschilde niet tussen psychogeriatrische en somatische afdelingen. Andere voorspellers van overlijden waren een mannelijk geslacht en leeftijd. Een toename van één standaarddeviatie op de AES-10-scores was geassocieerd met een toename van 62% van het overlijdensrisico.

Hoofdstuk 3 beschrijft een cross-sectionele studie naar de relatie tussen apathie en gezondheid-gerelateerde kwaliteit van leven bij mensen met apathie in het verpleeghuis. We onderzochten of depressie en cognitie deze relatie modereerden. Met behulp van de baseline gegevens uit DbD van mensen die op PG (*n=259*) of SOM-afdelingen (*n=262*) woonden, hebben we verschillende perspectieven onderzocht: het perspectief van de persoon met apathie, en dat van professionele zorgverleners die rapporteerden vanuit het perspectief van de betreffende persoon met apathie (Resident-Proxy) en vanuit hun eigen perspectief (Proxy-Proxy). Op basis van zelfrapportages van personen met apathie leek er geen relatie te bestaan tussen apathie en ervaren kwaliteit van leven. Apathie was echter negatief geassocieerd met de kwaliteit van leven van mensen die in het verpleeghuis wonen, zoals gerapporteerd door mantelzorgers en professionele zorgverleners vanuit beide proxy-perspectieven. Depressie en cognitie matigden deze associatie niet.

Het tweede deel van dit proefschrift richt zich op apathie bij mensen met dementie die op PG afdelingen wonen, hun mantelzorgers en professionele mantelzorgers. Uit eerder onderzoek (DbD) bleek dat apathie bij mensen met dementie positief kon worden beïnvloed door een activiteitenprogramma. In de praktijk leken mensen met apathie in het verpleeghuis gemakkelijk over het hoofd te worden gezien, in vergelijking met mensen met dementie met externaliserend of ander uitdagend gedrag zoals agitatie, rusteloosheid of depressie. De studies in deel II van dit proefschrift beschrijven kwalitatieve onderzoeken op basis van de ervaringen van de deelnemers die ze vertelden in semigestructureerde diepte-interviews en focusgroep discussies, als onderdeel van actieonderzoek.

In **hoofdstuk 4** onderzochten we de ervaringen van mensen met apathie en dementie, mantelzorgers en professionele zorgverleners met betrekking tot het herkennen en omgaan met apathie. Daarvoor hielden we individuele interviews met personen met dementie en apathie (*n=2),* mantelzorgers (*n=3*) en professionele mantelzorgers (*n=6*) en twee focusgroepen met professionele mantelzorgers *(n=5* en *n=7*). Daarnaast hielden we interviews met een mantelzorger (*n=1*) en professionele mantelzorgers (*n=16*), na signalen van toenemende apathie tijdens de eerste Covid-19 lockdown. We identificeerden drie belangrijke thema's met betrekking tot apathie bij mensen met dementie: 1) de uitdaging om signalen van apathie te beoordelen, 2) de waargenomen impact op het welbevinden, 3) toegepaste strategieën om met apathie om te gaan. Hoewel deelnemers apathie beschreven in overeenstemming met diagnostische criteria, waren ze niet bekend met de term 'apathie' en vonden ze het moeilijk om signalen van apathie te beoordelen. We ontdekten dat de ervaren impact van apathie per stakeholder verschilde. Mensen met apathie en dementie vonden het moeilijk om te communiceren en reflecteren op de gevoelens die ze hadden bij apathie. Dit kwam door problemen met communicatie en cognitie passend bij hun matige of gevorderde dementie. Mantelzorgers en professionele zorgverleners vonden apathie lastig wanneer apathie het welbevinden van de persoon met dementie verminderde of wanneer ze zelf gevoelens van ambiguïteit, frustratie, onzekerheid, teleurstelling of vermijding merkten in de interactie met de persoon met apathie. Om succesvol met apathie om te gaan, was het belangrijk dat familie en professionele zorgverleners specifieke strategieën konden toepassen, zoals het bijstellen van verwachtingen, het waarderen van kleine successen en het streven naar betekenisvol contact. Stakeholders zagen (momenten van) apathie als natuurlijk onderdeel of staat van (vergevorderde) dementie. Ze geloofden en merkten dat het effect van hun pogingen om apathie te doorbreken in de loop van de tijd afnam en dat apathie slechts kortstondig kon worden onderbroken.

In **hoofdstuk 5** beschrijven we de ontwikkeling en haalbaarheid van een interventie genaamd Samen in Actie Bij Apathie (SABA), waarmee mantelzorgers en professionele zorgverleners gezamenlijk apathie kunnen identificeren en hanteren. Geleid door het Medical Research Council framework, de intervention mapping methode, en het toepassen van de resultaten uit hoofdstuk 4, ontwikkelden we SABA samen met familie en professionele zorgverleners. Een overzicht van de procedures en materialen van SABA is te vinden op www.ukonnetwerk.nl/tools/saba en in het schema op blz. 152. Tien mensen met apathie en dementie kregen SABA aangeboden in een pilot. De potentiële effectiviteit van SABA werd geëvalueerd, door middel van een haalbaarheidsstudie aan de hand van interviews met mantelzorgers *(n=7)* en professionele zorgverleners (*n=4*) en twee focusgroepen met professionele zorgverleners (*n=5 en* n=*6*). Volgens mantelzorgers en professionele zorgverleners was SABA geschikt voor het ondersteunen van de identificatie en het hanteren van apathie bij mensen met dementie in het verpleeghuis. Beide groepen zorgverleners noemden verhoogde kennis en bewustzijn met betrekking tot het identificeren van apathie en de impact ervan op hun relatie met de persoon met apathie. Ze merkten ook meer vaardigheden om met apathie om te gaan, meer focus op kleinschalige activiteiten en meer waardering voor kleine momenten van succes. Voor de implementatie van SABA bleek het belangrijk om rekening te houden met de een aantal bevorderende en belemmerende factoren. De vorm, inhoud en toegankelijkheid van de onderdelen van de interventie (materialen en procedures) werden als faciliterend ervaren. Ook expertise en betrokkenheid van stakeholders, multidisciplinaire samenwerking, stabiliteit van het team en ondersteuning van een kartrekker en/of manager werden als bevorderend ervaren, terwijl onvoldoende samenwerking als belemmerend werd ervaren. Organisatorische en externe aspecten zoals het niet prioriteren van apathie, onvoldoende continuïteit van medewerkers en de Covid-19-pandemie, werden gezien als belemmeringen om SABA te implementeren en te ondersteunen. Een stimulerende fysieke omgeving met kleinschalige huiskamers en toegang tot benodigdheden voor activiteiten waren bevorderend. Familie en professionele zorgverleners verklaarden dat SABA hen in staat stelde om apathie met succes te identificeren en onderbreken.

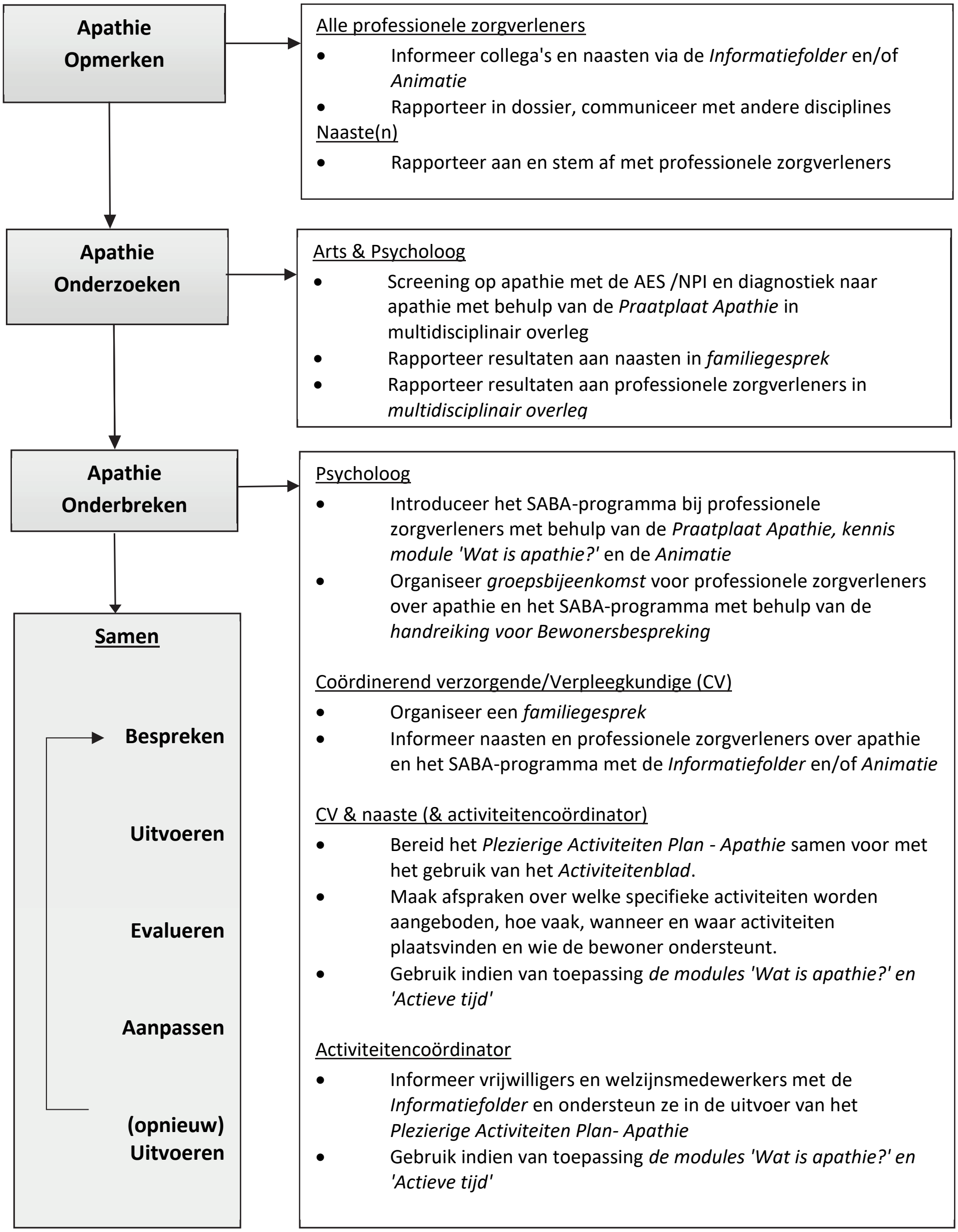
Tenslotte plaatsen we in **Hoofdstuk 6** de belangrijkste bevindingen in dit proefschrift in perspectief. We kijken naar factoren die samenhangen met de persoon met apathie, factoren die betrekking hebben op de mantelzorgers en professionele zorgverleners en factoren die samenhangen met de omgeving of de context. Ook wordt ingegaan op methodologische aspecten, implicaties voor de dagelijkse praktijk, onderwijs, beleid en toekomstig onderzoek en geven we hiervoor aanbevelingen.

CONCLUSIE

Dit proefschrift geeft het inzicht dat apathie bij mensen in het verpleeghuis moet worden beschouwd als een gezondheidsprobleem én binnen de context van persoonlijke en sociale perspectieven en relaties van betrokkenen. De resultaten van onze onderzoeken laten zien waarom apathie belangrijk is en hebben belangrijke implicaties voor de zorg en ondersteuning van mensen met apathie die in verpleeghuizen wonen en hun mantelzorgers en professionele zorgverleners. Apathie moet niet alleen worden gezien als een afzonderlijk en belangrijk neuropsychiatrisch symptoom in de context van neurobiologische veranderingen en cognitieve stoornissen. Het moet ook gezien worden in de context van de gevolgen voor de mensen met apathie om op een zinvolle manier deel te nemen aan het dagelijks leven en zoveel mogelijk onafhankelijk en sociaal betrokken te blijven. Bovendien moet apathie bij mensen met dementie in het verpleeghuis worden beschouwd in samenhang met de omgeving waarin ze leven. Ze hebben daarbij steun nodig van hun mantelzorgers en professionele zorgverleners om apathie te onderbreken en een stimulerende leefomgeving vorm te geven. Het SABA-programma lijkt een veelbelovende praktische interventie voor mantelzorgers en professionele zorgverleners om gezamenlijk apathie te identificeren en hanteren bij mensen met dementie in het verpleeghuis en kan daarmee het welbevinden van de verschillende betrokkenen positief beïnvloeden.

Nu is het tijd om in actie te komen en een stap vooruit te zetten, want elk moment waarin apathie wordt onderbroken telt!

De interventie Samen in Actie bij Apathie(SABA)



Apathie Opmerken

<u>Alle professionele zorgverleners</u>

- Informeer collega's en naasten via de *Informatiefolder* en/of *Animatie*
- Rapporteer in dossier, communiceer met andere disciplines

<u>Naaste(n)</u>

- Rapporteer aan en stem af met professionele zorgverleners

Apathie Onderzoeken

<u>Arts & Psycholoog</u>

- Screening op apathie met de AES /NPI en diagnostiek naar apathie met behulp van de *Praatplaat Apathie* in multidisciplinair overleg
- Rapporteer resultaten aan naasten in *familiegesprek*
- Rapporteer resultaten aan professionele zorgverleners in *multidisciplinair overleg*

Apathie Onderbreken

<u>Psycholoog</u>

- Introduceer het SABA-programma bij professionele zorgverleners met behulp van de *Praatplaat Apathie, kennis module 'Wat is apathie?'* en de *Animatie*
- Organiseer *groepsbijeenkomst* voor professionele zorgverleners over apathie en het SABA-programma met behulp van de *handreiking voor Bewonersbespreking*

<u>Coördinerend verzorgende/Verpleegkundige (CV)</u>

- Organiseer een *familiegesprek*
- Informeer naasten en professionele zorgverleners over apathie en het SABA-programma met de *Informatiefolder* en/of *Animatie*

<u>CV & naaste (& activiteitencoördinator)</u>

- Bereid het *Plezierige Activiteiten Plan - Apathie* samen voor met het gebruik van het *Activiteitenblad*.
- Maak afspraken over welke specifieke activiteiten worden aangeboden, hoe vaak, wanneer en waar activiteiten plaatsvinden en wie de bewoner ondersteunt.
- Gebruik indien van toepassing *de modules 'Wat is apathie?' en 'Actieve tijd'*

<u>Activiteitencoördinator</u>

- Informeer vrijwilligers en welzijnsmedewerkers met de *Informatiefolder* en ondersteun ze in de uitvoer van het *Plezierige Activiteiten Plan- Apathie*
- Gebruik indien van toepassing *de modules 'Wat is apathie?' en 'Actieve tijd'*

Vetgedrukt: activiteit van SABA; <u>Onderstreept</u>: deelnemer; *Cursief*: werkwijze en materialen van SABA

Materiaal

De *'Informatiefolder'* bevat begrijpelijke en algemene informatie over apathie om mantelzorgers en professionele zorgverleners te informeren.

De '*Animatie*' ondersteunt mantelzorgers en professionele zorgverleners bij het herkennen van signalen van apathie en maakt hen bewust van hun eigen ervaringen wanneer ze omgaan met een persoon met apathie.

De kennis module *'Wat is Apathie?'* is ontwikkeld om de kennis over apathie te vergroten en mantelzorgers of professionele zorgverleners in een bijeenkomst te informeren.

De '*Praatplaat Apathie*' is een praktische hulpmiddel dat professionele zorgverleners ondersteunt bij het opmerken, onderzoeken en onderbreken van apathie. De officiële diagnostische criteria voor apathie bij dementie zijn hierin verwerkt.

De *'Handreiking Begeleide Bewonersbespreking* helpt psychologen bij het begeleiden van een informatieve en ondersteunende groepsbijeenkomst met professionele zorgverleners over apathie bij een persoon met dementie.

Het *Plezierige Activiteiten Plan-Apathie'* ('PAP-A') ondersteunt de uitvoering van plezierige activiteiten die aansluiten bij de behoeften, mogelijkheden en interesses van een persoon met apathie en dementie.

Het *'Activiteitenblad*' is een lijst van praktische, goedkope en geschikte activiteiten om apathie te onderbreken, waaronder specifieke activiteiten voor mensen met gevorderde dementie en mannelijke bewoners.

De kennis module '*Actieve Tijd' bevat* begrijpelijke en algemene informatie en ondersteunt mantelzorgers of vrijwilligers bij het maken van zinvol contact en het uitvoeren van activiteiten.

Werkwijze

Het *familiegesprek* is een bijeenkomst tussen de coördinerend verzorgende/verpleegkundige, mantelzorger(s)/wettelijke vertegenwoordiger(s) (en activiteitencoördinator) te bespreken dat een persoon met dementie signalen van apathie heeft, uitleg te geven over SABA en informatie uit te wisselen over de persoonlijke interesses, voorkeursactiviteiten en succesvolle manieren van contact maken, passend bij de persoon met apathie en dementie..

De *begeleide Bewonersbespreking* is een bijeenkomst voor professionele zorgverleners (verzorgenden, verpleegkundigen, helpenden, activiteitencoördinatoren) die ondersteunt bij het herkennen en omgaan met apathie bij een specifieke persoon met dementie. Deze bijeenkomst wordt begeleid door een psycholoog die bekend is bij hen en de persoon met apathie en dementie.

De *Multidisciplinair Overleg* is een bijeenkomst tussen de verzorgende/verpleegkundige, specialist ouderengeneeskunde en (gezondheidszorg)psycholoog die de persoon met dementie kennen, om te bespreken en te onderzoeken of iemand apathie heeft en specifieke afspraken te maken over de uitvoering van SABA.

Ondersteuning bij implementatie

De '*Handreiking Implementatie*' is een stappenplan om de implementatie van SABA in het verpleeghuis te bevorderen, inclusief tips om bekende belemmerende factoren aan te pakken.

Het 'Overzicht implementatiestrategieën' bestaat uit een lijst met implementatiestrategieën en praktische tips die gebruikt kunnen worden om de implementatie en uitvoer van SABA te ondersteunen.

De *presentatie 'Organisatie Wijs'* is een kant-en-klare PowerPoint presentatie om een projectteam, management en/of multidisciplinair team te informeren over SABA en de stappen en strategieën om SABA te implementeren.

Info over SABA:

DATAMANAGEMENT

Ethics and privacy

This thesis is based on quantitative and qualitative data of persons living in nursing homes, family caregivers and professional caregivers. The study was conducted in accordance with Dutch law and the Declaration of Helsinki [1]. The studies described in chapter 2 and 3 were based on secondary analyses of data from a previous study. The Medical Ethics Review committee on Research Involving Human Subjects Region Arnhem Nijmegen (METC Oost Nederland) approved conducting the study and declared that it was not burdensome for the participants (file number 2008-205). The METC Oost Nederland has declared that the study described in chapter 4 and 5 is not subject to the Medical Research Involving Human Subjects Act (WMO). The local Medical Ethics Review committee of Radboud university medical center (CMO-Radboud) declared that it is not burdensome for the participants (file number NL 2019-5539). The local Research Committees of the participating organizations approved the study. Informed consent was obtained from all research participants. Participants were informed about the use and re-use of data in the information letter and could opt-in for the use of their anonymized data in scientific research depositories on the informed consent form. The privacy of all participants was warranted by the use of encryption and unique individual subject codes. These codes were stored separately from the study data. Technical and organizational measures were followed to safeguard the availability, integrity and confidentiality of the data (these measures include the use of pseudonymization, access authorization and secure data storage).

Data collection and storage

Data storage was guided by the Findable, Accessible, Interoperable and Reusable (FAIR) principles [2]. Data for chapter 4 and 5 were collected through interviews and focus group discussions that were tape-recorded, pseudonymized and transcribed verbatim in Microsoft Word. Transcripts were entered into Atlas.ti (version 8.4.22) for data analysis. Paper data from these studies were entered into Case Report Forms (eCRF) using CASTOR EDC. From Castor EDC data were exported to SPSS (SPSS Inc., Chicago, Illinois, USA). Pseudonymized data were stored on the department server and in Castor EDC and are only accessible by project members working at the Radboudumc. Paper (hardcopy) data and informed consent forms are stored in the locked archive of the Department of Primary and Community Care of the Radboud university medical center.

Availability of data

All digital data is stored at the H-station of the Department of Primary and Community Care. The data is only accessible to employees responsible for archiving and for the project manager of the SABA project upon request. The datasets from chapter 4 and 5 will be partially available after publication of this thesis from the Radboudumc Data Archiving and Networked Services DANS-EASY (DANS) data repository at https://doi.org/10.17026/dans-2bv-vbvx. Topic guides, lists of codes and themes, a selective quantitative datafile and the published articles will be uploaded. In order to ensure participants' privacy, full qualitative and quantitative datasets will only be available from the researchers upon reasonable request. The study described in chapter 4 and 5 included some questions from The Older Persons and Informal Caregivers Survey - Minimum Data Set (TOPICS-MDS). This data is shared with the TOPICS-MDS data manager. The anonymized data will be archived for 15 years after termination of the study. After expiry of this period, Prof. dr. D. Gerritsen will decide if the data can be destroyed or has to be stored for a longer period of time. In the latter case, the period of storage will be determined. The Radboudumc is responsible for the backup of the records and files.

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Als eerste wil ik alle mensen met apathie en hun naasten bedanken die mee hebben gedaan aan dit onderzoek. Dat geldt ook voor de medewerkers van de deelnemende organisaties die hebben bijgedragen aan het onderzoek. Enorm bedankt voor jullie medewerking, zonder jullie deelname en inzet was dit onderzoek niet mogelijk geweest. Lilian en Maartje, vanaf het eerste moment waren jullie enthousiast en hebben jullie positief kritisch meegedacht en het uitvoeren van het onderzoek in de praktijk ondersteund.

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PORTFOLIO (in Dutch)

Congressen en symposia

- International Neuropsychological Society, Annual Meeting, 7 Juli 2016, London; posterpresentatie
- Centrale Rino Groep, slotconferentie Wetenschappelijk onderzoek, 22 september 2017, Utrecht; posterpresentatie + pitch
- Archipel kennisconferentie, 14 januari 2018, Eindhoven; presentatie
- Universitair Kennisnetwerk Ouderenzorg Nijmegen, symposium, 28 september 2021, Den Bosch; workshop
- Onderwijs & Onderzoekdag, Eerste Lijns Geneeskunde, 4 juli 2019, Nijmegen; presentatie
- Kick-off Doelgroepennetwerk Korsakov Kenniscentrum, 8 juni 2022, Den Bosch; presentatie
- Universitair Kennisnetwerk Ouderenzorg Nijmegen, Expertteam psychologen, 21 juni 2022; online presentatie
- Samenwerkende Academische Netwerken Ouderenzorg, Wetenschapsdag, 22 september 2022, Leiden; presentatie
- Universitair Kennisnetwerk Ouderenzorg Nijmegen, netwerkmiddag implementatie, 29 september 2022; workshop
- De Zorgboog, 4 oktober 2022, Helmond; workshop
- Archipel, Archipel Deeldagen, 16 + 18 oktober 2022, Eindhoven; workshop
- Vincent van Gogh instituut, Referaat cyclus, 17 november 2022, Venray; referaat
- Stichting Verpleeghuizen Regio Zeeland, 6 december 2022; online presentatie
- Universitair Netwerk Ouderenzorg-UMCG, themagroep probleemgedrag, 13 december 2022; online presentatie
- Universitair Kennisnetwerk Ouderenzorg Nijmegen, 4 april 2023 lustrum symposium, Den Bosch; stand kennisfestival
- Centrale Rino Groep, Seminar Neuropsychotherapie: diagnostiek en behandeling van agitatie en apathie, 14 april 2023, Utrecht; workshop
- Psycho Geriatrische Dienst, psychologische expertise Ouderenzorg, 7 juni 2023, Bussum; workshop
- De Zorggroep Noord- en Midden-Limburg, 28 september 2023; online presentatie
- Alzheimer Europe 33th, 15 t/m 18 oktober 2023, Helsinki; 2 x posterpresentatie

Supervisie van stagiaires / studenten

- Supervisie onderzoek student (2021)
- Supervisie onderzoek student (2022)

Cursussen

- Radboud Institute for Health Sciences Introduction course, 31 oktober + 1 november 2019, Nijmegen
- Qualitative Research Methods in Health Care (introduction), 21 + 22 januari 2020, Nijmegen
- Kwalitatieve analyse, 12 + 13 maart 2020, Rotterdam
- e-BROK course for Radboudumc (for researchers working with human subjects), 5 maart 2021, online
- Writing Scientific Articles, 4 mei t/m 21 september 2021, online
- Statistiek voor promovendi, 2 november t/m 14 december 2021, online
- ELG -bijeenkomst Scientific integrity, online 2021
- Scientific Integrity Course, 12 + 26 november 2021, online

Interviews

- Alzheimer NL, oktober 2020
- Vilans, Kenniscentrum Langdurige zorg, april 2022
- Archipel Relatiemagazine, juni 2022
- Radboud Alzheimer Centrum, nieuwbrief juni 2022
- Netwerk 100, nieuwsbrief juli 2022
- Tijdschrift voor Verzorgenden, januari 2024

Overige publicaties buiten dit proefschrift

- Veenhuizen, R., Nijsten, H., van Roosmalen, P., Lammertsen, K., Stor, T., de Jager, L., de Man, J., van der Doelen, R., Landa, K., Grond, V., Heffels, J., Groenewoud, R., Rovers, L., Bakker, C., Leiwakabessy, S., van der Wedden, D., van Blitterswijk, J., & van den Bosch, D. (2018). Huntington's Disease Outpatient Clinic for Functional Diagnosis and Treatment: Coming to Consensus: How Long Term Care Facility Procedures Complement Specialist Diagnosis and Treatment. *Journal of Huntington's disease*, *7*(2), 189–191. https://doi.org/10.3233/JHD-180298
- Oosterloo, M., Craufurd, D., Nijsten, H., & van Duijn, E. (2019). Obsessive-Compulsive and Perseverative Behaviors in Huntington's Disease. *Journal of Huntington's disease*, *8*(1), 1–7. https://doi.org/10.3233/JHD-180335
- Gerritsen, D., Nijsten, H., de Bonth, H., Koxk, M. Psycholoog in de ouderenzorg: 10 adviezen bij de coronacrisis 2020-2021 Uitwerking van 6 tips met diverse bijdragen online. *Universitair Kennisnetwerk Ouderenzorg Nijmegen*, Psychologen (ukon-netwerk.nl)
- Knippenberg, I., Leontjevas, R., Nijsten, J., Bakker, C., Koopmans, R., & Gerritsen, D. (2021). 400 - Environmental stimuli in nursing homes during the COVID-19 pandemic: Lessons learned to improve the management of challenging behavior. *International Psychogeriatrics, 33*(S1), 27-28. doi:10.1017/S1041610221001599

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- Nijsten, J.M.H., & Herben-Dekker., M. (2023). Huntington's Disease. In R.Kessels (Ed.) *Clinical Neuropsychology* (revised edition), (pp 501-514). Amsterdam, The Netherlands: Boom.
- Debby Gerritsen, D., Noordam, H., Nijsten, H., & Donkers, H. (2023). Sociotherapeutic Living environments in nursing homes. In R. Charras (Ed). *Dementia Environment*: *addressing inclusive design from homes to cities,* (chapter 13). (under review)

CURRICULUM VITAE (in Dutch)

Hanneke Nijsten werd geboren op 25 maart 1972 in Heel en Panheel en groeide samen met haar broer op in Midden-Limburg. Ze behaalde in 1989 haar Atheneum-B diploma aan St. Ursula in Horn.

Na een korte tijd fotografie op de Kunstacademie in Den Haag, besloot ze psychologie te gaan studeren in Nijmegen, afstudeerrichting gerontologie. Haar klinische stage en afstudeeronderzoek bij de afdeling Geriatrie van het Radboud UMC waren de eerste ervaringen in het klinisch werk en onderzoek voor ouderen. Na haar afstuderen in 1996, werkte ze in verschillende verpleeghuizen in Nederland op afdelingen voor mensen met cognitieve stoornissen of somatische aandoeningen.

Na het behalen van de registratie tot gezondheidszorgpsycholoog in 2001, ging Hanneke bij Archipel in Eindhoven werken. De laatste 15 jaar werkte Hanneke op locaties Landrijt en Dommelhoef, de expertise centra van Archipel voor gespecialiseerd verpleeghuiszorg voor volwassenen en ouderen met een bijzondere zorgvraag. Ze heeft hier o.a. gewerkt met mensen met dementie op jonge leeftijd, mensen met het syndroom van Korsakov en mensen met niet aangeboren hersenletsel. Vanaf 2012 heeft ze zich gespecialiseerd in de zorg voor mensen met de ziekte van Huntington. Hanneke is programmaleider van het zorgprogramma Huntington en werkzaam binnen het Regionale Expertise Centrum Huntington van Archipel.

Van 2014-2018 heeft Hanneke de postdoctorale opleiding tot Specialist Klinisch Neuropsychologie gevolgd. Onderdeel van deze opleiding was het uitvoeren van wetenschappelijke onderzoek. Hoewel in eerste instantie wat huiverig en roestig, bleek Hanneke het wetenschappelijk onderzoek boeiend te vinden. Ze was nieuwsgierig naar het onderwerp apathie bij mensen met in het verpleeghuis. Door de verbinding van Archipel met het UKON was een samenwerking voor onderzoek snel gerealiseerd. Na twee onderzoeken over de gevolgen van apathie, werd in 2018 subsidie toegekend door ZonMW om een interventie te ontwikkelen voor het opmerken, onderzoeken en onderbreken apathie bij mensen met dementie in het verpleeghuis: het project Samen in Actie Bij Apathie (SABA). Dit proefschrift is het resultaat van deze onderzoeken. Sinds 2019 heeft Hanneke van Archipel de mogelijkheid gekregen om haar promotieonderzoek te doen naast haar klinische werkzaamheden als klinisch neuropsycholoog.

Toekomstplannen betreffen het bevorderen van bewustzijn en kennis over apathie. Onder andere door het door ontwikkelen van SABA voor mensen met dementie in de thuissituatie (in samenwerking met en gefinancierd door Alzheimer NL) en het geschikt te maken van SABA voor toepassing in het onderwijs voor zorgmedewerkers (Verspreidings- en Implementatie Impuls toegekend door ZonMW). Ook het geschikt maken van SABA voor bijzondere doelgroepen behoort tot de toekomstplannen. Als voorzitter van de onderzoek- en wetenschapscommissie en onderzoeker wil ze bijdragen aan het verstevigen van de verbinding tussen praktijk en onderzoek. Zowel voor de langdurende zorg binnen en buiten het verpleeghuis als voor de zorg voor mensen met een bijzondere complexe zorgvraag. Als praktijkopleider van de post-universitaire opleidingen tot gezondheidszorgpsycholoog en klinisch neuropsycholoog wil ze zich blijven inzetten voor generalistische en specialistische psychologie opleidingen binnen de ouderenzorg en de sector Verpleeg- en Verzorgingshuizen en Thuiszorg.

Hanneke woont met haar man Mike, hun tweeling zoons Merijn (2004) en Timo (2004) en dochter Kira (2009) in Geldrop. Ook woont hier een beestenboel en groeit er van alles in de kas en moestuin.

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