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THE ART OF PERSONALISING PSYCHOSOCIAL INTERVENTIONS FOR PEOPLE WITH DEMENTIA

Development, evaluation and implementation

IRIS HENDRIKS



**THE ART OF PERSONALISING
PSYCHOSOCIAL INTERVENTIONS
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VRIJE UNIVERSITEIT

**THE ART OF PERSONALISING PSYCHOSOCIAL INTERVENTIONS
FOR PEOPLE WITH DEMENTIA**

Development, evaluation and implementation

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CHAPTER 1

INTRODUCTION



DEMENTIA

Dementia is a syndrome, a combination of symptoms characterised by cognitive deterioration in memory, thinking, speech, planning and functioning in daily activities. It results from brain diseases or injuries and is usually progressive (World Health Organization, n.d.a). The most common types of dementia are Alzheimer's disease, vascular dementia, frontotemporal dementia and dementia with Lewy Bodies.

Dementia is one of the leading causes of death worldwide. Currently the number of people with dementia is estimated around 50 million and this is expected to almost triple by 2050. The majority of people with dementia lives in the community. Dementia increasingly has the attention of policy makers, doctors, health care professionals, social workers and researchers around the world (World Health Organization, n.d.b).

It is obvious that medical support for people with dementia, when focused primarily at diagnostics and (psycho)pharmacological treatment, covers only part of their need for support (Van der Roest et al., 2009). The problems people with dementia encounter and have to deal with as a consequence of their disease are often more functional and (psycho)social. Because of their disabilities in daily functioning, people with dementia often experience feelings of insecurity and anxiety (Riley et al., 2014). While, on the other hand, just like any other human being, people with dementia are also looking for pleasure and enjoyment and want to continue doing the things they used to do and be useful to others (Miranda-Castillo et al., 2013; Wolverson et al., 2016).

SUPPORTING PEOPLE WITH DEMENTIA AND THEIR FAMILIES TO MAINTAIN QUALITY OF LIFE

As there is currently no cure for dementia it is essential to support people living with dementia by helping them to cope with the consequences and maintain their quality of life. Quality of life can be defined as 'the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' (World Health Organization, n.d.c).

Besides the person with dementia, his or her family caregivers should also be supported. Caring for a loved one with dementia is burdensome and often causes distress in caregivers. About half of the caregivers provide daily or continuous care to the person with dementia, almost half feels burdened by their care task and about one seventh feels overburdened. Furthermore, more than a third has less contact with family and friends since they care for the person with dementia (Nivel, 2020). In other words, dementia does not only impact the psychosocial wellbeing of the person living with it, it also influences the wellbeing of their family and loved ones. Luckily family caregivers do also experience positive aspects of caregiving such as a sense of personal growth and accomplishment and purpose in life (Doris et al., 2018).

PSYCHOSOCIAL INTERVENTIONS

To help maintain their quality of life many psychosocial interventions for people with dementia and their (in)formal caregivers have been developed and studied over the past 30 years (Parker et al., 2008). Psychosocial interventions in dementia care are non-pharmacological interventions ‘that involve interactions between people to improve psychological or social functioning’ (Moniz-Cook et al., 2011). These interventions help to manage the negative emotions and behaviours disruptions that may develop as a consequence of, for example, inadequate coping, unmet needs or miscommunication with the social environment. For all types and stages of dementia and different care settings, psychosocial interventions are available. Psychosocial interventions exist in many types and forms, and can be used for a short period or permanently, for an individual or for groups. Examples are reminiscence, cognitive stimulation therapy, music and movement therapy, occupational therapy, nature and visual art interventions. Psychosocial interventions often aim to respond to people’s social needs. Indeed, these are among the most important needs for people with dementia: to have company and engage in social interactions (Cohen-Mansfield et al., 2015; Van der Roest et al., 2009). Many psychosocial interventions have been shown to positively impact activities of daily living skills and cognition, mood and quality of life (Carrion et al., 2013; Dröes et al., 2011; Graff et al., 2006; Spector et al., 2003; Oyebode & Parveen, 2019).

NATURE-BASED AND ART-BASED INTERVENTIONS

In this thesis the focus lies on two specific psychosocial interventions: nature-based and art interventions. Nature-based activities and art or museum activities

both support active citizenship and social inclusion (De Bruin et al., 2019; Lea & Synnes, 2021; Marsh et al., 2018). The outdoor environment offers the opportunity for informal encounters with neighbours, friends and other people that contribute to the social inclusion of people with dementia (Duggan et al., 2008). Furthermore, Lea and Synnes (2021) found that art programmes may ‘offer people with dementia a way to stay connected both to themselves and to the wider community through active participation in a cultural discourse’. Art programmes in which people with dementia visit a museum may contribute to the social inclusion of people with dementia and the sense of belonging of the individual as museums are also frequently visited by ‘healthy’ people. Moreover, the presence of people with dementia in such public space spaces may help to overcome the stigma of dementia in our society (Schneider, 2018).

Nature-based and art interventions also have in common that they appeal to the need for social contact and promote social interaction (Evans et al., 2019; Ward et al., 2020). Both can also contribute to the sense of autonomy, self-worth and identity of people with dementia (Cook, 2020; Mmako et al., 2020; Navarro et al., 2015, Neth, 2019). For instance, therapeutically designed gardens provide an outdoor place people can have access to without guidance. This can provide residents of nursing homes with feelings of control and autonomy (Reynolds et al., 2018).

Social inclusion, social interaction, autonomy and identity are closely linked to the concept of personhood which is crucial in the delivery of person-centred care (Kitwood, 1997).

PERSON-CENTRED CARE

Psychosocial interventions are most effective when tailored to the person with their individual needs, wishes and abilities and to their caregivers (Fazio et al., 2018; Lawrence et al., 2012; Vernooij-Dassen & Moniz-Cook, 2014). In other words, when the care is person-centred. In the last decade the term personalised care is also frequently being used.

Currently, several approaches to person-centred care exist. Already in the 1990s Kitwood (1997) stated that the person with dementia should be treated as a person, and that their psychological needs should be the focus of care. Kitwood’s work can be seen as the theoretical basis of person-centred care. Brooker and Latham (2016) have built further on this concept by developing the VIPS model in which

the four key elements of person-centred care are explained: 'Valuing people with dementia and those who care for them (V); treating people as Individuals (I); looking at the world from the Perspective of the person with dementia (P); and a positive Social environment in which the person living with dementia can experience relative wellbeing (S)'. Edvardsson et al. (2010) studied how person-centred care is perceived by people with dementia, their family members and staff in residential aged care. They found that the core category of person-centred care was 'promoting a continuation of self and normality'. The study participants described that dementia 'eroded the conceptions of self-hood and the 'normal' life people with dementia and their family had'. Other categories that were found were: knowing the person, welcoming family, providing meaningful activities, being in a personalised environment and experiencing flexibility and continuity. Nowadays, person-centred care is often linked to the concept of Positive Health (Huber et al., 2011). Positive Health does not focus on the illness, but on the people experiencing the illness, on their resilience and on what makes their lives meaningful. Although the above concepts vary in their operationalisations, they have one thing in common: the experiences and needs of the person with dementia are central.

Providing person-centred care has been shown to be associated with higher quality of care. The study of Lood et al. (2019) showed that relatives' experiences of a more person-centred climate were associated with higher ratings of the quality of care. Cohen-Mansfield et al. (2007) demonstrated that the use of a systematic individualised intervention decreased agitation and increased pleasure and interest of people with dementia living in a nursing home.

Since Kitwood published his book 'Dementia reconsidered; the person comes first' in 1997 the attitudes towards dementia have gradually changed. In the last two decades the focus in dementia care has shifted from the disease itself, to the person living with the disease. Person-centred care is internationally known as a best-practice model to improve dementia care (Edvardsson et al., 2008; Mitchell & Agnelli, 2015) and recommended in practice guidelines (NICE, 2018; Verenso, 2018; Vilans, 2020). Policy makers increasingly highlight the importance of supporting people with dementia and encourage research into person-centred interventions that promote their quality of life (Raad voor Volksgezondheid en Samenleving, 2020).

Even though person-centred care is generally recommended worldwide, it is not yet implemented in all countries, cultures and care settings. Poor quality dementia care still exists. And even though attitudes are changing, people with dementia still experience stigma (Lion et al., 2019). To truly value people with dementia as persons, not as their disease, a fundamental change in the perception of people with dementia is needed (Gerritsen et al., 2018). A systematic approach in the development, evaluation and implementation of person-centred psychosocial interventions could contribute to this.

DEVELOPMENT OF PERSON-CENTRED PSYCHOSOCIAL INTERVENTIONS

When developing (person-centred) psychosocial interventions it is advantageous to make use of a thorough developmental strategy. Pilot studies are important to ensure acceptability and feasibility of the intervention and to make sure the instructions for the person who guides the intervention are clear (Brown et al., 2015). The intervention is more likely to be effective when in the development process - in addition to relevant previous studies - also the views, needs and wishes of the future users (people with dementia and (in)formal caregivers) are taken into account. To make sure the intervention is optimally tailored to the needs and wishes of the target group, field experts should also be consulted (Yates et al., 2015). However, still little is known about effective methods to personalise psychosocial interventions to individual people with dementia. Therefore, more research into the personalised provision of psychosocial interventions is needed.

EVALUATION OF PERSON-CENTRED PSYCHOSOCIAL INTERVENTIONS

Many innovative person-centred interventions have been developed over the years and implemented in care practice. Not all of the often applied interventions are evidence based. Scientific studies are needed to know whether a newly developed intervention is effective in practice, to understand the working mechanisms, and how people benefit from them. More research should be done to strengthen the evidence base of person-centred psychosocial interventions (Lawrence et al., 2012).

The selection of methods to evaluate an intervention is very important. Measures that are specifically tailored for dementia populations should be used, as generic

measures 'may not fully capture the unique and important aspects of people with dementia's experiences' (Ready & Ott, 2003). In the selection of measurements, people are used to taking into account the intervention goals, contexts and target groups. However, in the light of person-centred care it would also be logical to use instruments that take into account the personal preferences and needs of the individual person. In case of quality of life it would, of course, be especially interesting to know whether an intervention made a difference in the quality of life domains the person finds important. This is supported by the study of Dröes et al. (2006). They asked people with dementia what aspects are important for their quality of life and compared these aspects to those mentioned by caregivers and in literature. They found differences in the perspectives on quality of life among the persons with dementia, their caregivers and theoretical models. When evaluating the effect of an intervention on quality of life it is not only important to choose the most fitting instrument but also to personalise the assessment. Unfortunately, only few quality of life instruments exist that take into account personal needs and wishes, and none of them are specifically developed for people with dementia.

IMPLEMENTATION OF PERSON-CENTRED PSYCHOSOCIAL INTERVENTIONS

When an intervention is proven to be successful in one situation, it does not necessarily mean the intervention is successful in another context and outside a research context. Indeed, an intervention used in dementia care often does not show the results as expected from earlier research. Vernooij-Dassen and Moniz-Cook (2014) state that the lack of impact of trials in dementia care can not only be explained by genuine ineffectiveness, but also by a so-called implementation error. Implementation refers to 'a set of planned, intentional activities that aim to put into practice evidence-informed policies and practices in real-world services' (European Implementation Collaborative, n.d.). Without good implementation even the most effective interventions as shown by research, may not work in practice. A good implementation is associated with a better chance that interventions will achieve more prominent results and benefits for participants (Khanassov et al., 2014). The success of the intervention depends on, and should be adapted to, the local circumstances. Implementation of care interventions that have been proven to be effective has been shown to not always be easy (Meiland et al., 2004). Dementia care may benefit from implementation research in which the implementation of (new) interventions is studied, a stakeholder analysis is done and the barriers and

facilitators to implementation at a micro, meso and macro level are described and taken into account. Despite the recent attention to the development and evaluation of person-centred psychosocial interventions for people with dementia, relatively little research has been done into the implementation of these interventions (Boersma et al., 2015; Van Mierlo et al., 2016; Van Rijn et al., 2019).

CONTENT OF THIS THESIS

The aim of the research presented in this thesis was to contribute to the further development, evaluation and implementation of person-centred psychosocial interventions.

The research focussed on the following research questions:

1. How can a psychosocial nature intervention for people with dementia be designed in a person-centred way?
2. How is an art intervention, developed and positively evaluated abroad, appreciated and experienced by people with dementia and caregivers in the Netherlands and how can it be implemented in an adaptive way nationwide?
3. How to determine the quality of life of people with dementia, as outcome of a psychosocial intervention, in a person-centred way?

This thesis comprises five chapters, describing three studies: Chapter 2 reports on a study into the development of a person-centred nature intervention for people with dementia. In this study people with dementia were involved in developing a tool for designing nature activities to the person's personal wishes, needs and experiences. The tool and activities were tried out regarding acceptability and experience of the intervention in a pilot study. Additionally, the organisational feasibility was investigated. Chapters 3, 4 and 5 describe the studies into the evaluation and nationwide implementation of the Unforgettable museum programme in the Netherlands. Unforgettable is a positively evaluated interactive museum programme for people with dementia and their caregivers developed by the Museum of Modern Art (MoMA) in New York. Chapter 3 reports on the results of the study into the experience with and appreciation of the programme by participants (people with dementia and their caregivers) in the Netherlands. This study also investigated whether the user experience and appreciation were associated with their background characteristics. The research described in chapter 4 investigated whether all types of art are equally suitable for use in the interactive museum programme. It

investigated whether responsiveness of the persons with dementia during museum programs depends on the type of art work shown and/or characteristics of the person with dementia, such as severity of dementia or specific cognitive impairments. In chapter 5 the nationwide adaptive implementation of the museum programme was evaluated and the impact of this implementation on the attitudes towards dementia of the museum staff was studied. Chapter 6 reports on a study into the use of an individualised quality of life measurement. This study was carried out within the framework of the European MEETINGDEM project into the adaptive implementation of the Dutch Meeting Centres model for people with dementia and their family caregivers in three countries (Italy, Poland and the UK). The study investigated whether the personalised versions of two dementia specific quality of life scales, i.e. the Dementia Quality of Life instrument (DQoL) and the Quality of Life Alzheimers Disease scale (QoL-AD) were more valid to detect variations in quality of life than their standard versions for people with mild to moderate dementia. Also, the relationship between the personalised quality of life measures and severity of dementia was studied. Finally, differences between countries regarding the personalised overall quality of life and differences in the by participants indicated importance of individual quality of life domains were explored.

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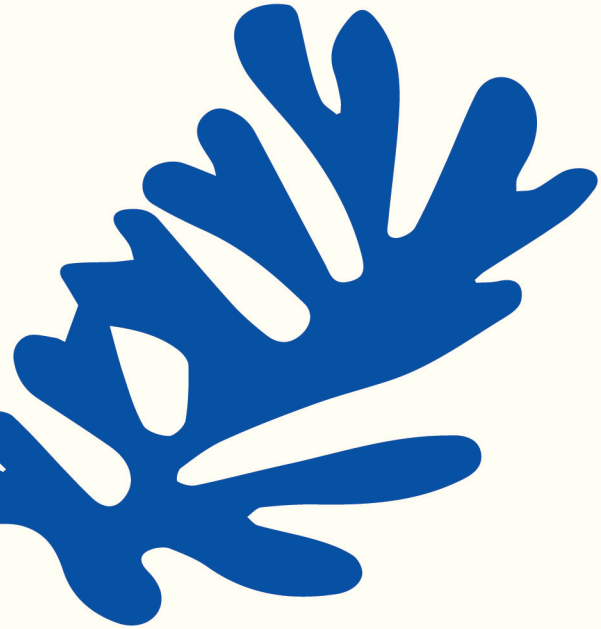
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CHAPTER 2

NATURE AND DEMENTIA: DEVELOPMENT OF A PERSON-CENTRED APPROACH

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ABSTRACT

Background: The aim of this study is to develop and try out an approach for personalised nature activities for people with dementia.

Method: A qualitative descriptive study using focus group interviews with people with dementia was conducted. Based on the results of the focus groups and the relevant literature the approach was developed. In a qualitative descriptive pilot study with a one-group design we tried out the approach regarding acceptability and experience of the intervention among people with dementia, and satisfaction with the approach among health care professionals. Additionally, we investigated the organisational feasibility.

Results: From the focus groups eight key aspects of experiencing nature were identified as being important for quality of life (e.g. relaxation, freedom), as well as six categories of preferred activities (e.g. active, passive and social activities). Based on these themes and categories, an approach was developed to design nature activities according to the personal wishes, needs and experiences of people with dementia. During the intervention, participants in the pilot study showed high levels of positive behaviours and low levels of negative behaviours. As regards organisational feasibility, eight themes for successful implementation of nature activities were identified.

Conclusion: This exploratory study contributes to the knowledge regarding the development and implementation of person-centred nature activities for people with dementia. The implementation of the activities could be improved by training professionals in person-centred care. The effect of the person-centred nature activities approach should be investigated.

INTRODUCTION

Nature can play a vital role in human well-being (Kaplan, 1995; Maller et al., 2005). For people with dementia, the natural environment can provide several therapeutic benefits: it may stimulate them through light (Connell et al., 2007) and sensory experiences, as nature is an abundant source of multi-sensory stimulation (Gibson et al., 2007). It can provide pleasant and meaningful activities (Kane, 2001) and restore or maintain a sense of self (Cohen-Mansfield et al., 2000). Although the evidence base in dementia care is still quite small, the review of Gonzalez and Kirkevold (2013) on sensory gardens and horticultural activities is very insightful. They included sixteen studies with participants with dementia visiting a day centre or living in a nursing home or care home. Based on the results of the studies reviewed they concluded that these types of non-pharmacological interventions may reduce agitation, increase the engagement in activities and improve sleep and wellbeing of people with dementia. One of the included studies (Lee & Kim 2008) showed that the cognition of people with dementia significantly improved after indoor gardening. In a recent study into the clinical use of sensory gardens and outdoor environments (Gonzalez & Kirkevold, 2015), leaders and staff of Norwegian nursing homes reported that the sensory gardens positively influenced agitation, restlessness, pacing, balance and mobility of people with dementia, and also improved their sleep. Other reviews on the use of nature interventions for people with dementia, show positive results on the quality of life and again also effect on behaviour and mood problems, especially on agitation and mood/affect (Whear et al., 2014; Olsson et al., 2013). In general, nature seems to contribute positively to the health of people with dementia (Maller et al., 2005; Milligan et al., 2004).

Several controlled trials in day care, residential care and nursing homes showed that personalised care is more effective than usual care offered in these settings (Chenoweth et al., 2009; Dröes et al., 2004; Finnema et al., 2005). Also, meeting the personal needs and wishes of persons with dementia is thought to be important in managing behaviour and emotional dysregulation according to the need-driven dementia-compromised behaviour model (Algase et al., 1996, Kovach et al., 2005). Personalised nature activities are an attractive addition to the traditional activities in dementia care and give an extra opportunity to fulfil individual needs.

Nature and outdoor spaces may thus be important for persons with dementia and improve their wellbeing. However, nature is often not easily available for people with

dementia living in a nursing home, or it is underused for different reasons (Chalfont, 2007), such as a non-supportive organisational policy or the lack of provision of activities that are meaningful to persons with dementia (Connell et al., 2007; Grant & Wineman, 2007). Moreover, there is still a lack of knowledge on how to use nature in a person-centred way for the target group (Gonzalez & Kirkevold, 2013).

Utilisation of nature and outdoor activities and their effectiveness may be improved by developing a series of personalisable activities, which can then be shaped for individual persons based on their preferences, wishes and abilities and on the 'nature experience' they specifically find important for their wellbeing and quality of life. Dröes et al. (2006) interviewed people with dementia about what they find important for their quality of life. This revealed several domains of importance, such as: health, mood and enjoyment of activities.

Although the previously mentioned reviews provide important insights into the possible impact of nature and being outdoors on the wellbeing of people with dementia, not much is known about how to translate these insights into personalised activities that are optimally attuned to people's preferences, wishes, abilities and nature experience. Furthermore, little is known about the possible barriers to implementing nature activities in a personalised way. The aim of this study was therefore to develop an approach, including examples of personalisable nature activities and a decision tool to design personalised nature activities for people with dementia, and to try this out among people with behaviour and mood disruptions. The study had the following research questions:

- 1) Which aspects of being in nature or outdoor spaces do people with dementia find important for their quality of life?
- 2) What types of activities in nature do people with dementia prefer?
- 3) What tool can be developed to support the execution of nature activities among people with dementia living in the community and in long-term care settings in a person-centred way?
- 4) A. Do people with dementia who experience behaviour and mood dysregulation appreciate personalised nature activities?
B. Are personalised nature activities feasible according to professionals in care practice?

METHODS

The local Medical Ethics Review Committee stated that the study was not subject to the Medical Research Involving Human Subjects Act. Nursing home management boards gave permission for the study, which was conducted in accordance with the Declaration of Helsinki (1964). An informed consent procedure was followed to make sure that people with dementia (and a representative family caregiver) confirmed they were willing to participate in this study.

Research Question 1 and 2

Design

A qualitative descriptive study using focus group methodology was conducted. An international literature review on nature activities for people with dementia with a special focus on preferred activities and nature experiences was executed beforehand to provide input for the composition of a discussion guide that was applied in the focus group study.

Participants and setting

Focus group interviews were conducted in different health care settings in different regions of the Netherlands to maximise the diversity of views of people with dementia in different stages of dementia and contexts. Six focus group interviews were conducted in total: two at meeting centres for people with dementia and their informal caregivers, two at day care centres and two in long-term care institutions. The centres were recruited via the national meeting centre-network and via the long-term care organisations of an academic network. Inclusion criteria were: having a dementia diagnosis, no aphasia, interest in nature and having provided informed consent. There were no specific exclusion criteria. People were invited to participate by the coordinators of the different care centres. All participants received a small gift after the focus group interview to thank them for their participation.

Measurements and procedure

In the focus groups questions were asked regarding nature experiences and activities, for example: 'What would you like to do in nature?', 'What do you experience when being in nature?', 'Do you think you go outside enough? If not, why?'. The focus group interviews lasted approximately one hour and were tape recorded. Skilled moderators with experience in communicating with people with dementia facilitated

the discussions. One moderator had previous experience in moderating focus groups of people with dementia. The other moderator was theoretically and practically trained by the experienced moderator before conducting focus groups herself. All focus group participants were supported in a person-centred way. The moderators took into account the severity of dementia when asking the questions. In case of more severe dementia more closed questions were asked (e.g. 'Do you like to walk in the park?', 'Would you like to grow a vegetable garden?'). In all but one focus group, a health care professional who knew the participants well joined the focus group. In one focus group the professional was absent because of illness. In this focus group the moderator was joined by a research assistant (a Master student in cultural anthropology) who was trained in conducting focus groups and observation studies.

Data analysis

All tape-recorded focus group interviews were completely transcribed verbatim. Using ATLAS.ti, content analysis of the transcriptions was carried out by two independent researchers to identify themes from the data on which nature experiences and activities people with dementia found important for their quality of life. These themes were categorised into quality of life domains as described by Dröes et al. (2006) and examples of activities were provided for each category.

Research question 3

Design

We used the results of the focus groups and the literature review, to develop a first version of the approach, consisting of a decision tool and example activities that could be personalised by means of the decision tool.

Participants and setting

The developed decision tool and example activities were presented for feedback to five persons with dementia (three people from a meeting centre and two people from a day care centre), and to nine professionals in the field of dementia care or nature interventions (one activity coordinator, one social worker, two psychologists, one coordinator of a meeting centre, one coordinator of a day care centre, two staff members of a care institution, and one director of a nature foundation).

Measurements and procedure

The draft version of the approach, consisting of a decision tool and three example nature activities, was presented for feedback to persons with dementia and professionals in the field of dementia care or nature interventions. Of the decision tool, two graphical formats were presented (one with a checklist with only words and one with a combination of pictures and words). To inform them on the applicability of the approach in practice, the personalisation possibilities were explained.

The people with dementia were asked for feedback in a semi-structured interview in which a professional or a researcher actually used the decision tool together with the person with dementia. After answering the personal interest questions in the decision tool, the researcher presented the relevant example activities and the persons with dementia were asked if they would like to participate in one or more of these activities, and how the activity could be improved in their opinion. The professionals received the two graphical formats of the decision tool and the instruction of the three example nature activities. They were asked in a structured interview about the relevance of the approach ('How do the personalised nature activities relate to usual and nature activities that are already offered?' and 'Do the personalised nature activities match the needs of the persons with dementia?') and the feasibility of the approach (e.g. 'Is the instruction of the tool clear?', 'Do you foresee barriers in executing the personalised nature activities?').

Research question 4

Design

The approach was tried out in a qualitative descriptive pilot study with a one-group design among people with dementia regarding the acceptability, experience of, and satisfaction with the intervention. Additionally, the organisational feasibility was investigated (see Appendix A).

Participants and setting

Persons with dementia were recruited for the pilot-study through the meeting centre, the day care facility and the long-term care units that also participated in the focus group study. Participants were included if they had a dementia diagnosis and provided informed consent. A purposive sampling strategy was used, with a specific focus on recruiting persons with dementia who were known to have one or more behaviour or mood problems (based on the NPI, see measurements and

procedure). One activity coordinator, one staff member, two care coordinators and four volunteers guided the activities.

Measurements and procedure

Before the intervention, data were collected on background characteristics of the participants: age, gender, diagnosis, severity of dementia (Global Deterioration Scale, Reisberg et al., 1982), living situation/care setting and behaviour problems present in the last month (Neuropsychiatric Inventory (NPI-Q), Kaufer et al., 1998).

To assess the acceptability of the designed person-centred nature activities by people with dementia, systematic observations of their mood and (positive and negative) behaviour were conducted during the activity by the researchers using the 5-item Observed Emotion Rating Scale (OERS, Lawton et al., 1996) and the Interact instrument as used by Van Dijk et al. (Baker & Dowling 1995; Van Dijk et al., 2012). However, we used the six 'relating to person' items twice, i.e. relating to the professional/volunteer guiding the activity and relating to the other participants. Both instruments are frequently used in (Dutch) dementia care research and have been shown to have good psychometric properties (Van Weert et al., 2005). Results of the Interact are commonly reported per item; no total score is calculated (Van Dijk et al., 2012; Van Weert et al., 2005)

After the activity, semi-structured interviews were conducted with people with dementia, which focused on their experience of and satisfaction with the activity, and with health care professionals about the organisational feasibility of the approach.

Intervention in pilot study

Before offering the nature activities, a health care professional used the decision tool (see Figure 1) to determine, in a conversation with the person with dementia the persons' experiences, needs and wishes concerning nature. Based on the outcomes of the decision tool, participants were assigned to one of the three designed example activities (i.e. nature walk, gardening, and sensory activation in nature) that fitted their preferences best. All activities were adapted to the individual's needs, wishes and preferred experiences, as determined by the professional caregiver using the decision tool. The activities were offered in a group context.

The nature walk was guided by a health care professional or volunteer who used cards with small assignments, for example regarding memories, sensory stimulation, feeling useful and rest/relaxation, to connect optimally to the person with dementia.

The gardening sessions could each focus on different central themes, e.g.: flowers, herbs, fruit trees and vegetable garden, including sowing, fertilising and watering, harvesting and cooking with home-grown vegetables.

The sensory activation activity uses nature attributes belonging to a theme (for example farm, forest, beach) that could be matched to the person's history. People are invited to sit in a calm place outside and the health care professional or volunteer guiding the activity, let him or her see, feel and smell the attributes and stimulates the person to talk about his history by asking questions.

The pilot study was executed during the Spring of 2015.

Data analysis

All collected data were entered in an anonymous database. Using SPSS, descriptive analyses (mean, sd) were conducted on the quantitative data (background characteristics, GDS, NPI, OERS, and Interact). Based on this analysis descriptions were made of the participants' background characteristics and behaviour problems before the activity, as well as their mood and (positive and negative) behaviour during the activity. Qualitative data from the interviews on acceptability, satisfaction and feasibility were thematically analysed and summarised.

RESULTS

Research question 1 and 2

A total sample of 34 participants took part in the focus groups, full demographic information is shown in Table 1.

Table 1. Group characteristics of the participants for each focus group

	Group 1 MC*	Group 2 MC	Group 3 NH	Group 4 DC	Group 5 DC	Group 6 NH	Total
Number in group	5	6	6	6	7	4	34
Gender (n)							
Female	4	3	6	4	5	3	25
Male	1	3	0	2	2	1	9
Age (mean, SD)	81.96 (3.48)	73.2 (7.84)	86.96 (4.44)	83.53 (9.33)	78.41 (6.75)	84.97 (5.52)	81.22 (7.76)
Type of dementia (n)							
Alzheimer's	3	5	6	0	3	2	19
Vascular	0	0	0	1	1	1	3
FTD	0	1	0	0	1	0	2
Other	2	0	0	5	2	1	10

*MC = Meeting Centre, DC = Day Care Centre, NH = Nursing home

Research question 1

Concerning the question what kind of experiences people with dementia find important for their wellbeing and quality of life when being in nature, eight key themes emerged: pleasure, relaxation, feeling fit, enjoying the beauty of nature, feeling free, the social aspect of nature, feeling useful and memories.

'Well, sometimes nature calms me, when I am very sad and I walk and see the sunset.'

(Meeting Centre (MC))

'I enjoy the fresh air, the freedom.'(Nursing Home (NH))

'Also the skies. The colours of the skies. It is so beautiful.' (Day Care Centre (DC))

Research question 2

Concerning the question what nature activities people with dementia prefer, participants mentioned active activities like walking, cycling, swimming, and exercising; passive activities like sitting outside, watching and talking about nature; social activities like drinking coffee outside with family and watching children play; activities involving animals; activities with flowers and plants, like gardening; and inside nature activities, like watching a film about nature or handicraft with flowers.

'I often go for a walk. With the walker. My grandchildren want to sit on it.'(DC)

'If the weather is good, we often sit outside, drinking coffee.'(DC)

'We used to pick blueberries, my mother made jam of them and we would secretly eat of it!'(DC)

Some participants were fine with the amount of time spent in nature. Others indicated they would like to be outside more often. They mentioned that it is often not possible to go outside because someone needs to accompany them because of mobility problems. Some people felt they were not able to go outside anymore because they were getting 'old'. Some said they did not go outside that often because of the weather being too hot or too cold. When asked about their wishes concerning nature activities, walking was often named as an activity they would like to do. Also gardening and activities with animals were mentioned. Some participants indicated preferring doing activities they can choose themselves.

'When possible, I am outside. But being outside more would even be better.' (NH)

'I enjoy being in the garden. I also like to take care of flowers. But it's all gone now, so what can you do?'(NH)

'If it were possible, I would go with somebody else. Otherwise I have to go alone, and that is less appealing of course.' (NH)

Research Question 3

Development of approach

Based on the results of the focus groups, we designed a decision tool in two graphical formats and three example activities. We chose these three specific activities for the following reasons: walking was the activity that was mentioned most often in the focus groups as an activity the participants would like to do; gardening was also mentioned in the focus group as an activity people would like to do, but which they felt they were no longer able to do. The sensory stimulation activity was added because in the focus groups many participants said they enjoyed the beauty of nature, and because we also wanted to offer an activity that could be applied to people who had more advanced dementia, or who had limited mobility. These activities were designed to be useable outdoors as well as indoors and in different stages of dementia.

Staff and user feedback on person-centred approach

First, the draft version of the decision tool (representing relevant experiences, categorised in quality-of-life domains, and activities) was presented for feedback to

nine professional caregivers. Two graphical formats were presented: one with pictures and words (decision tree, see figure 1) and one in checklist format. The majority of the nine professionals preferred the format with pictures over the checklist format, especially because of its appealing design. The decision tool was considered highly (n=5) or reasonably feasible (n=1). It was mentioned it could make care staff more aware of possible nature activities. However, some professionals indicated the accompanying questions may be too difficult for people with dementia to answer, especially for those in advanced stages of dementia. They proposed that in these situations, family members could be asked to answer the questions. Some suggestions were made to include additional activities in both formats of the decision tool. In addition, professionals suggested that the instruction should clarify that the decision tree should not be applied too strictly, but should be used as a guide to talk about nature and to get to know a person's needs, preferences and experiences with nature. The idea of developing an app, to be used on a tablet, with more pictures to make the decision tree even more visual and easier to use in practice, was generally considered a good idea.

Secondly, the professionals were asked for their opinion on the content and feasibility of the developed example nature activities. Overall, in all settings, the content of the activities was rated positively and thought to match the needs of people with dementia. The nature walk and the gardening activity were preferred most, while the sensory activation was preferred by only two professionals (working in a nursing home and working for a nature foundation). Two professionals working in a Meeting Centre and in a day care centre, indicated this activity was 'not suitable for our people, but more suitable for people with severe dementia'. Concerning the nature walk, four professionals thought the cards with assignments would provide a useful basis for the activity and would stimulate staff awareness that walking in the park can be more than just exercise. One professional suggested adding more cards with assignments to optimise the personalisation of the activity. However, another professional indicated the assignment cards were too difficult to be used by staff in practice. Regarding the gardening activity, suggestions were made for more assignments during the activity. Regarding sensory stimulation, one professional suggested putting the nature attributes in a box to make the activity applicable indoors also.

Concerning the expected feasibility of the activities, most professionals thought the staff working in day facilities and care institutions would be motivated to execute these nature activities. However, some professionals, from different backgrounds, believed

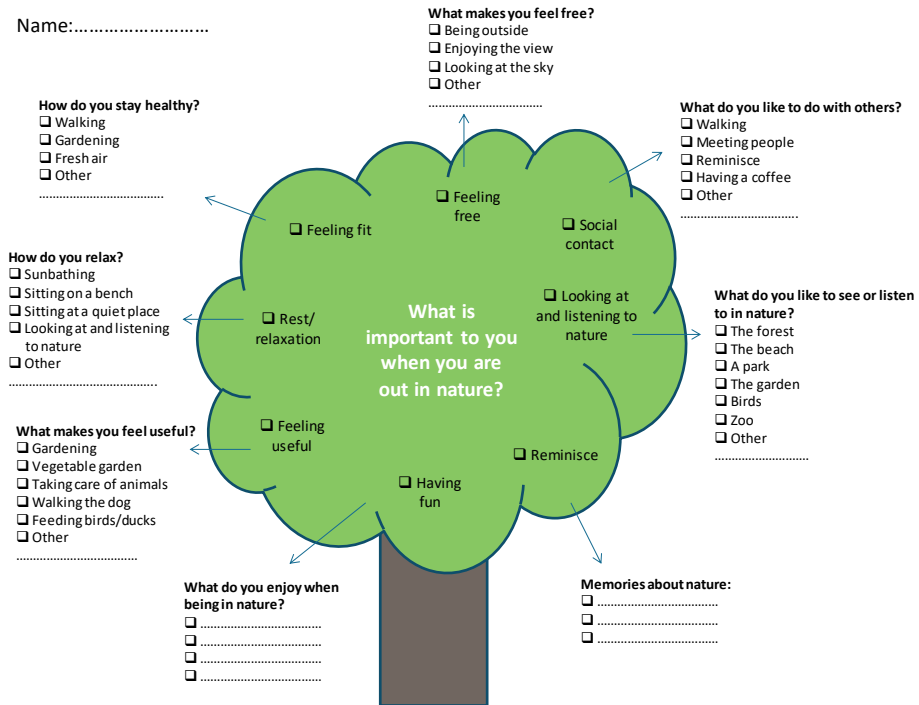
that the staff did not have enough expertise and experience to guide personalised nature activities. Concerning the instruction of the activities, two professionals thought the written instruction was not sufficient. Additional training for people who assist in executing nature activities was suggested. Three professionals noted the importance of emphasising in the instruction of the activities that the assignments should be executed in a spontaneous way. One professional was concerned too many actions are needed for the implementation of the person-centred approach: first administrating the questions of the decision tool, secondly recording the answers in the care dossier, and lastly staff having to read the instruction material before providing the nature activity. Other barriers to implementing personalised nature activities mentioned were: no (suitable) outdoor space, not enough doors to the garden so people cannot go outside by themselves, not enough personnel to guide people individually, and personnel lacking time to guide the activity. Two professionals were concerned about how to finance nature activities. Suggested solutions for this problem were: ask rotary clubs for support, make use of volunteers and family members. Expected facilitators to implement nature activities were: motivating and training personnel to assist in executing nature activities, utilising volunteers and family members, and asking people from nature associations to help with the activities.

Thirdly, one of the two formats of the decision tool and the nature activities were presented to people with dementia. Based on their answers to the questions on the decision tool, the participating people with dementia were asked if they would like to do the nature walk and/or the gardening activity. The sensory activation activity appeared not to match these participants' preferences. People reacted enthusiastically to the proposed activities. It should be noted that for some people with dementia it appeared to be quite difficult to answer the open-ended questions of the decision tree, the closed questions were easier.

Adaptations based on feedback

In line with the recommendations of the professionals and the experiences using the decision tool together with people with dementia, the instructions of the decision tree and the nature walk were adapted. Also, more assignment cards were added for the nature walk and gardening activity. Concerning the sensory stimulation activity, the recommended boxes were included in the activity. Because of the preference for the decision tree, we decided to use this format of the person-centred approach in the pilot study (see figure 1).

Figure 1. Decision tree



Research Question 4

In total 13 participants took part in the nature walk or gardening activity, full demographic information is shown in Table 2.

Observations during activity

Scores on the Interact showed that participants overall displayed high levels of ‘positive’ behaviours during the activities (such as happy/content, alert/active, enthusiasm, spontaneous talk, relate well with professional/volunteer, co-operate with others, focus on activity, doing things on one’s own initiative, enjoying oneself) (mostly >3), and low levels of ‘negative’ behaviours (such as tearful/sad, fearful/anxious, confused, bored, aggressive, negativistic, reluctance, repetitious mannerism, wandering) (all < 1) during the activities (see Appendix B). Negative behaviours were absent in five participants (not in table). Four of the thirteen participants showed lower levels of positive behaviour (most scores < 3) and higher levels of negative behaviours compared to the rest of the group (not in table). Overall, the highest scores were found for relating to professional/volunteer and relating

Table 2. Background characteristics of the people with dementia participating in the pilot study

	Meeting Centre		Day Care*	Nursing home**	Total
	Gardening	Nature walk	Gardening	Nature walk	
Number in group (n)	3	2	4	4	13
Gender (n)					
Female	2	-	2	3	7
Male	1	2	2	1	6
Age (mean, SD)	78.71 (4.29)	72.23 (5.22)	72.87 (2.61)	85.78 (4.62)	78.09 (6.85)
Type of dementia (n)					
Alzheimer's	3	1	-	1	5
Vascular	-	1	-	-	1
Lewy Body	-	-	2	-	2
FTD	-	-	1	-	1
Not specified	-	-	1	3	4
Severity dementia (n)					
Very mild cognitive decline	-	-	1	-	1
Mild cognitive decline	-	-	1	-	2
Moderate cognitive decline	1	-	2	1	4
Moderately severe cognitive decline	2	2	-	-	4
Severe cognitive decline	-	-	-	2	2
Neuropsychiatric symptoms (n)					
Delusions	-	-	1	1	2
Hallucinations	-	-	1	-	1
Agitation	2	-	1	2	5
Depression	3	2	3	3	11
Anxiety	2	-	-	3	5
Euphoria	-	-	1	-	1
Apathy	2	2	2	1	7
Disinhibition	-	-	2	2	4
Irritability	3	1	1	3	8
Aberrant motor behaviour	-	1	1	1	3
Sleeping disturbances	-	-	2	3	5
Eating disturbances	3	-	1	2	6

Three participants also participated in the focus groups.

*People in the Day Care group only participated in the gardening activity

**People in the Nursing Home group only participated in the nature walk

to environment, the most variation in scores was found for speech and relating to other participants.

Results on the OERS showed that none of the participants displayed anger, fear or sadness during any of the activities. Expression of pleasure as measured by the OERS (laughing, singing, kissing etc.) was infrequent, with two participants showing pleasure for more than 5 minutes, three participants showing pleasure for 1 to 5 minutes, four participants for 16-59 seconds and four participants less than 16 seconds. Alertness was most commonly observed. Twelve participants were alert for longer than 5 minutes and one for 1 to 5 minutes.

Evaluation of the experience of, and satisfaction with, the activity

All participants enjoyed the activity and almost all of them would like to do the activity again. Some said the activity brought back memories, and some participants mentioned they enjoyed being with others during the activity (see Table 3).

Evaluation of facilitators, barriers and recommendations

From the interviews with four professionals, three volunteers and twelve people with dementia after the activities, eight themes for the successful implementation of the nature activities were identified: preparation, guidance, location, weather, material, duration, group conditions and cultural aspects of the organisation.

As shown in Tables 4a and 4b, good preparation is crucial to successfully implement the nature activities. One of the professionals guiding the gardening activity noted the importance of making a plan beforehand. The lack of preparation resulted in less attention for the participants and interfered with the activity. To personalise the nature activities it is important to know the needs, wishes, abilities and experiences with nature of the participants. In one of the gardening sessions and in one of the nature walk sessions, the filled out decision trees were not seen by all persons guiding the activity. Moreover, the instruction was not read adequately, resulting in a less person-centred and less stimulating setting. Because of the importance of one-on-one support during the personalised nature activities, one of the professionals mentioned using volunteers as very helpful.

In some of the care settings the professionals and volunteers were not used to individualised working. One professional (DC) noted that the staff at her care

institution did not think they needed to change the way they work. Therefore, professionals and volunteers need information and training to become familiar with the personalised way of working and to keep them motivated.

We did not find large differences in facilitating and obstructing factors for implementation between the different care settings (meeting centre, day care centre and nursing home ward).

Table 3. Experience and satisfaction of participants

		Experience	Appreciation		
			Did you enjoy	Would you do it again	Grade for appreciation
Gardening					
Group 1 (MC*) (n=3)	1	Gave a little satisfaction.	A little	No	8
	2	Seeing the start of spring, lifts my spirit.	Yes	Yes	7
	3	Brings back memories.	Yes	Yes	8
Group 2 (DC*) (n=4)	4	Brings back memories.	Yes	No	5
	5	I didn't feel good, but that is related to not having my driving license.	Yes	Yes	5
	6	Nice to put your hands in the sand. To be together with others.	Yes	Yes	8
	7	I felt useful and it is nice to do it together.	Yes	Yes	8
Nature walk					
Group 1 (MC*) (n=2)	8	Nice to be with people you know, to chat.	Yes	Yes	7.5-8
	9	Good feeling to be outside.	Yes	Yes	5
Group 2 (NH*) (n=4)	10	-	-	-	-
	11	Brings back memories	Yes	Yes	7
	12	It is nice to be outside	Yes	Yes	5
	13	Feeling happy, being outside, looking at nature	Yes	Yes	8

*MC = Meeting Centre; DC = Day Care Centre; NH = Nursing home

Table 4a. Evaluation of facilitators, barriers and recommendations for personalised nature activities - gardening

Gardening	
Facilitators	Barriers
<p>Guidance by professional:</p> <ul style="list-style-type: none"> Enthusiasm (D*) <i>'She is very enthusiastic, she thinks I am a true gardener.'</i> (MC**) Skills (D) Motivation (R*) (P*) <i>P: 'I saw people enjoyed the activity. The goal is reached when you see people enjoy life. It is really beautiful to see what people are still capable of.'</i> (DC**) 	<p>Recommendations:</p> <ul style="list-style-type: none"> Keep overview (P) Skills (D) Keep the activity easily accessible (P) Create good atmosphere (P)
<p>Location:</p> <ul style="list-style-type: none"> Right table height (P) Quiet environment (P) Safe environment (P) 	<ul style="list-style-type: none"> Shady garden (P) Also inside gardening (P) More quiet location (P) Use standing work tables (D) <i>'I used to work a lot in the garden, but it is not possible for me to bend over anymore. So it is good for me to work at a table.'</i> (DC)
<p>Weather:</p> <ul style="list-style-type: none"> Sunny weather (D) 	<ul style="list-style-type: none"> Better weather (D) <i>'It would be nice if the weather was better.'</i> (MC)
<p>Used material:</p>	<ul style="list-style-type: none"> Large plants (D) Variety in plants (D) Work with flowers (D)
<p>Time:</p> <ul style="list-style-type: none"> Enough time available (P) Duration (45-60 min) OK (P) 	<ul style="list-style-type: none"> Plants were too small (D) (P) Garden not suitable (D) <i>'A better spot, the small portable vegetable garden is full of plastic. These are not the best conditions for gardening.'</i> (MC) Duration too short (D) <i>'Too short, I could do this all day!'</i> (MC) Duration too long (because of bad weather) (D) No time for preparation (by professional) (P)

Table 4a. (continued)

Gardening	
Facilitators	Barriers
Group:	Recommendations:
<ul style="list-style-type: none"> • Positive group dynamic (P) • Being together (P) <p><i>'Being together contributes to the success of the activity. Everyone was relaxed and everyone had their own job.'</i> (MC)</p> <ul style="list-style-type: none"> • Select people with experience in gardening (P) <p><i>'It was nice to see the knowledge of plants and gardening emerging and that people enjoyed talking about it.'</i> (MC)</p>	<ul style="list-style-type: none"> • Bad preparation by professional (P) (R) <p><i>P: 'The preparation could have been better, for example enough gardening tools. Now we had to walk away from the activity too often.'</i> (DC)</p> <ul style="list-style-type: none"> • Decision tree was not read by professional (R) • Personalization cards were not read by professional (R) • Personalization cards read by professional beforehand, but not used during activity (R) • Explanation of activity to participants difficult (P) <ul style="list-style-type: none"> • Not used to work in personalised way (R) • Attitude: no change needed (P) • Low education level (P)
<p>Preparation:</p> <ul style="list-style-type: none"> • Good preparation (P) • Sufficient professionals (P) • One on one supervision (P) 	<ul style="list-style-type: none"> • Use of volunteers (P) • Make use of a personal plan (P)
<p>Care culture:</p>	<ul style="list-style-type: none"> • Time needed to change culture (R) • Give professionals and volunteers training and information (R) • Keep personnel motivated (R)

*D = Person with dementia, P = Professional, R = Researcher, **MC = Meeting Centre, DC = Day Care, NH = Nursing home

Table 4b. Evaluation of facilitators, barriers and recommendations for personalised nature activities – nature walk

Nature Walk	
Facilitators:	Barriers:
<p>Professional:</p> <ul style="list-style-type: none"> • Skills (D) • Affinity with nature (D) • Slow walking pace (P) • Motivation (R) (P) <p><i>P: 'It is not about distance, but about quality.'</i>(NH**)</p> <p><i>P: 'Some participants did not want to join beforehand, but became very enthusiastic during the walk.'</i>(NH)</p>	<p>Recommendations:</p> <ul style="list-style-type: none"> • More knowledge of nature (D) (P) • Sufficient depth regarding to nature (D) <i>'Walking around the neighbourhood a bit, I expected more of it. That the guide explains the names of the trees and plants.'</i> (MC)
<p>Location:</p> <ul style="list-style-type: none"> • Specific route, passing nature (P) • Enough nature available (D) 	<ul style="list-style-type: none"> • Not enough nature available in the immediate environment (D) • Walk in the park (D) <i>'Another location would have been nice, for example the park would have been better. It is a bit noisy, but nice to walk through. You see more of the country and also a lot of birds. Which is also nice.'</i> (MC) • Use of different routes (D) • Drink a cup of coffee during the walk (D)
<p>Weather:</p> <ul style="list-style-type: none"> • Prepare for bad weather (rain coats) (P) • Spring (P) 	<ul style="list-style-type: none"> • Duration of activity too short (D) (P) • No time for rest (D) (P) <i>P: 'We planned one hour for the nature walk, but in the end we only had 45 minutes. It was not very disturbing, but if we had had a bit longer, we could have sat down for a while.'</i>(MC)
<p>Time:</p> <ul style="list-style-type: none"> • Duration activity OK (D) 	<ul style="list-style-type: none"> • Plan sufficient time to rest (D) (P)

Table 4b. (continued)

Nature Walk		
	Barriers:	Recommendations:
<p>Group:</p> <ul style="list-style-type: none"> • Familiar people (D) <i>'I enjoy it. With people you know. Walking alone is also nice, but I prefer to walk with people I know. Talking a little.'</i>(MC) • Select different participants every time (P) 	<ul style="list-style-type: none"> • Lacking a person (D) <i>'Actually, I think (name) should have come with us. He knows a lot about the neighbourhood.'</i> (MC) 	<ul style="list-style-type: none"> • More information about nature, thematic content. (D) (P) <i>P: 'A little more knowledge and background information about nature could be added to the instruction. You can make use of a theme, for example with a book about Spring or about animals. Then you can talk about it afterwards.'</i>
<p>Preparation:</p> <ul style="list-style-type: none"> - Make sure everybody is ready on time (P) 	<ul style="list-style-type: none"> • Bad preparation by professional (P) (R) <i>P: 'I could have done more with the assignment cards and I could have prepared more.'</i> (MC) • Decision tree not read by professional (P) (R) • Personalisation cards were not read by professional (P) (R) • Personalisation cards read by professional beforehand, but not used during activity (P) (R) • No time for preparation (by professional) (P) <i>It is not that I don't want to, it's a lack of time. I am a volunteer and only work two days a week in the care institution.'</i> (MC) 	

*D = Person with dementia, P = Professional, R = Researcher; **MC = Meeting Centre, DC = Day Care, NH = Nursing home

DISCUSSION

The aim of this exploratory study was to find out which aspects of being in nature or outdoor spaces people with dementia find important for their wellbeing and quality of life (question 1), which activities in nature they appreciate (question 2), what tool could be used to support activities in nature in a person-centred way (question 3) and whether personalised nature activities are appreciated by people with dementia (question 4.A.) and feasible according to professionals in care practice (question 4.B).

Research question 1

From the focus groups eight themes emerged on the aspects of being in nature people with dementia find important for their quality of life: pleasure, relaxation, feeling fit, enjoying the beauty of nature, feeling free, the social aspect of nature, feeling useful and memories. Most of these aspects of experiencing nature have been mentioned in previous studies (Duggan et al., 2008; Olsson et al., 2013; Whear et al., 2014). However, the relevance of connecting to the past by recollecting and sharing memories and the importance of feeling fit and staying healthy were both mentioned in only one of the three studies about nature experiences (Duggan et al., 2008; Whear et al., 2014). Although the relationship between maintaining self-confidence and outdoor activities was identified by Olsson et al. (2013), the importance of feeling useful was not emphasised here, or in the other studies.

Research question 2

From the focus groups also became clear that people with dementia appreciate a variety of activities: active activities (e.g. walking, cycling and swimming), passive activities (e.g. sitting outside, looking at nature and talking about nature), social activities, activities involving animals, activities with flowers and plants, and inside nature activities. Interestingly, although the passive activities mentioned here are in line with the meaningful activities named by people with dementia in Raske (2010), the active activities identified here were not mentioned in that study, while, according to the focus groups, walking was, in all care settings, the most desired and popular nature activity.

Research question 3

Based on the aspects of nature and activities derived from the focus groups, we developed an approach which can be used to personalise nature activities, and

three (examples of) easy applicable nature activities to explore the feasibility and appreciation of personalised nature activities.

Research question 4.A

Not all example activities were tried out in the pilot study: the sensory activation activity appeared not to fit with the wishes of the persons who participated in the pilot. Trying out the activities showed that all participants positively appreciated the activities: they enjoyed the activity and almost all of them would like to do the activity again. This matched with our findings that participants showed high levels of positive behaviours and low levels or absence of negative behaviours during the activities. When negative behaviours occurred, the frequency was very low. This is notable since the participants did show a great variation of behaviour problems in the month before the activity. The results correspond with the findings of Milligan et al. (2004) and Maller et al. (2005) who indicated that both nature in general and outdoor spaces can be beneficial in dementia care. Whear et al. (2014) even found quantitative evidence of decreased agitation associated with garden use. Because the current study was an exploratory pilot evaluation focused on the development and trying out of an approach for person-centred nature activities, the effects of the nature activities on specific outcome measures in people with dementia were not investigated. However, the positive reactions of the participants are sufficient reason for further investigation. Furthermore, as connecting to personal needs is considered a starting point for treating behaviour problems, and Algase et al. (1996) and other studies suggest nature activities may have positive effects on behaviour and mood problems (Connell et al., 2007; Detweiler et al., 2008), it would especially be interesting to investigate the effects of nature activities that are personalised according to this approach on challenging behaviour of people with dementia.

Research question 4.B

Regarding the practical feasibility of the nature activities, eight themes for the successful implementation of nature activities were identified: preparation, guidance, location, weather, material, duration, group conditions and cultural aspects of the organisation. We found that the most crucial factor for successful implementation of nature activities was a good preparation of the activity. Often the instruction was not thoroughly read, which resulted in a less person-centred setting. We also noted a barrier regarding the care culture. We found that most professionals and volunteers were not used to working in a person-centred way. One

professional, working in a day care institution, observed that many of her colleagues felt no change was needed in the way they work. This barrier was also mentioned in a study about the implementation of Snoezelen Multi-Sensory Environment (Van Weert et al., 2004): “It is not always easy to achieve or to adhere to the new working style”. To overcome these barriers, it is important that the professionals and volunteers receive information and training to adopt the personalised way of working and to keep them motivated. The importance of staff training for successful implementation of psychosocial interventions was also emphasised by Boersma et al., (2015). No large differences were found in facilitators and barriers to implementation between the different care settings.

Limitations

Limitations of the pilot study were the small number of participants and that the activities were not always executed according to the outcomes of the decision tree. As a result the setting not always optimally matched the interests, wishes, abilities and nature experiences of the person with dementia. This should be taken in account when preparing an effect study. General training regarding the principles of person-centred care is necessary to use the person-centred approach as intended. Also, the weather was not always optimal for outside activities. This may have influenced the execution and appreciation of some activities. In the future, this could be encountered by adding weather conditions to the decision tree, allowing different types of activities, depending on different weather conditions. For some people with dementia it appeared to be quite difficult to answer the open-ended questions of the decision tree, the closed questions were easier. To overcome this problem the decision tree could be extended with more closed questions to make sure the person's interests, wishes, abilities and experiences with nature become clear.

Because of the physical movement during the nature walk, performing the observations was sometimes experienced as somewhat challenging by the researchers. This may have influenced the reliability of the observations. A way to improve this in future effect studies, might be to let two researchers observe each participant. We also noticed that some participants had difficulty quantifying their satisfaction with the activity on a scale from one to ten: sometimes a participant evaluated the activity positively, while he/she gave a low grade, and vice versa. In future studies it is therefore advised to check if the person understands the method

of scoring beforehand, or the scoring method might be improved using visual cues such as smiley faces.

Scientific and societal impact

This study contributes to the development of knowledge regarding the implementation of person-centred care activities for people with dementia living in different care settings. For the first time, a tool was developed to adapt nature activities to the personal wishes, needs and experiences of people with dementia. This was done in co-operation with people with dementia and health care professionals. The promising experiences in practice emphasise the need for further research into the effects on behaviour, mood and quality of life of person-centred nature activities for people with dementia in different care settings, preferably by means of controlled studies, with a pre-test post-test design. Our primary intention was to study the person-centred nature approach as a means to prevent and treat mood and behaviour dysregulations of people with dementia. We therefore conducted a pilot study within this group. In future studies it would be very interesting to also investigate the effects of person-centred nature interventions on the quality of life of people with dementia without specific behaviour and mood problems.

CONCLUSION

This study resulted in a tool that can be applied by health care professionals and other caregivers to personalise nature activities for people with dementia in meeting centres, day care centres and long-term care settings. The tool shows promising accessibility and user-friendliness. However, independently of the care setting, training in the application of the person-centred approach, including the use of materials, is needed. With some adaptations, it may also be possible to use this approach for other psychosocial interventions for people with dementia, which could be of great value in promoting person-centred work in dementia care.

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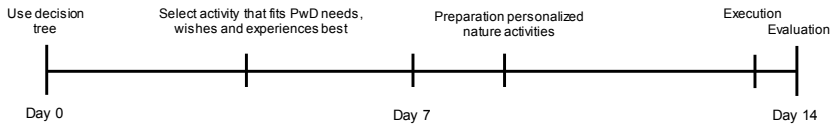
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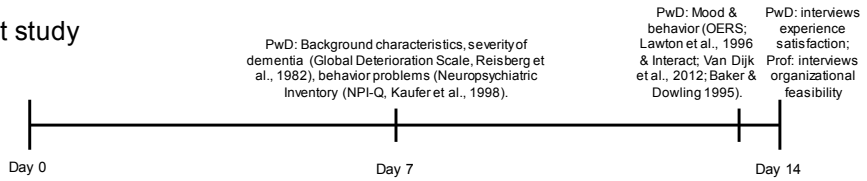
APPENDICES

Appendix A. Figure clinical approach pilot study

Nature activity



Pilot study



PwD: Person with dementia
Prof: Health care professional

Appendix B. Table scores on the Interact

INTERACT (range 0-4)*	Gardening (n=7)	Nature Walk (n=6)
	Mean group score (range)	Mean group score (range)
Mood		
Tearful/sad	0.00 (0-0)	0.00 (0-0)
Happy/content	2.86 (0-4)	3.50 (3-4)
Fearful/anxious	0.00 (0-0)	0.00 (0-0)
Confused	0.57 (0-2)	0.33 (0-2)
Laughing	1.29 (0-2)	2.00 (1-3)
Enthusiasm	3.00 (2-4)	2.67 (2-4)
Speech		
Talked spontaneously	2.00 (0-4)	1.83 (1-2)
Recalled memories	0.43 (0-2)	2.00 (2-2)
Spoke clearly	3.29 (1-4)	2.50 (1-4)
Spoke sensibly	3.57 (2-4)	2.67 (1-4)
Spoke in normal-length sentences	3.43 (1-4)	2.33 (0-4)
Relating to professional/volunteer		
Held eye contact appropriately	2.71 (0-4)	2.40 (0-3)
Touching	0.00 (0-0)	0.80 (0-2)
Related well	3.57 (2-4)	3.67 (3-4)
Co-operated	3.71 (3-4)	4.00 (4-4)
Listened to voice/noise	3.86 (3-4)	3.83 (3-4)
Responded to speaking	3.29 (1-4)	3.00 (1-4)

Appendix B. (continued)

INTERACT (range 0-4)*	Gardening (n=7)	Nature Walk (n=6)
	Mean group score (range)	Mean group score (range)
Relating to other participants		
Held eye contact appropriately	2.57 (0-4)	3.00 (2-4)
Touching	0.00 (0-0)	0.00 (0-0)
Related well	2.71 (0-4)	3.67 (2-4)
Co-operated	3.00 (0-4)	3.33 (2-4)
Listened to voice/noise	3.29 (1-4)	3.67 (3-4)
Responded to speaking	3.00 (0-4)	3.17 (2-4)
Relating to environment		
Tracked observable stimuli	3.57 (1-4)	3.50 (2-4)
Touched objects/equipment appropriately	3.71 (3-4)	4.00 (4-4)
Attentive to/focused on activity/objects	3.57 (2-4)	3.33 (2-4)
Responding to activity or objects	3.43 (1-4)	3.00 (2-4)
Comments/questions about activities/objects	2.00 (0-3)	1.67 (0-3)
Need for prompting		
Did things on own initiative	2.57 (1-4)	1.67 (1-2)
Stimulation level		
Wandering/restless	0.00 (0-0)	0.67 (0-4)
Enjoying self	3.14 (1-4)	3.33 (2-4)
Bored/inactive	0.43 (0-2)	1.17 (0-4)
Alert/active	3.43 (2-4)	2.33 (0-4)
Relaxed/content	3.43 (2-4)	3.33 (0-4)
Verbal anger (talk angrily)	0.00 (0-0)	0.00 (0-0)
Verbal anger (yelling)	0.00 (0-0)	0.00 (0-0)
Aggressive	0.00 (0-0)	0.00 (0-0)
Negativism/complaining	0.14 (0-1)	0.00 (0-0)
Reluctance	0.00 (0-0)	0.00 (0-0)
Repetitious mannerism	0.29 (0-2)	0.33 (0-2)

From 0: Not at all to 4: Nearly all the time





CHAPTER 3

**EVALUATION OF THE
'UNFORGETTABLE' ART
PROGRAMME BY PEOPLE
WITH DEMENTIA AND
THEIR CAREGIVERS**

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ABSTRACT

Background: Art programmes have been shown to contribute to the quality of life of people with dementia. To understand how people with dementia benefit from art programmes it is important to evaluate them. 'Unforgettable' is an interactive museum programme for people with dementia and their caregivers in the Netherlands. This study examined how it is experienced and appreciated by its users. It also investigated whether the user experience and appreciation are linked to their specific background characteristics.

Method: A single-group design was used. A 'take home' survey was conducted to collect the participants' background characteristics and their experience and appreciation of the programme. A before and after intervention measurement took place, using a smiley face scale, to measure the change in mood of participants.

Results: Participants evaluated the programme very positively. Social interaction proved a key factor in their appreciation. The mood of the persons with dementia (n = 95) and caregivers (n = 104) improved after participation in the Unforgettable programme.

Conclusion: The Unforgettable programme is experienced and evaluated positively. The results of this evaluation may contribute to the quality of art programmes in museums.

INTRODUCTION

The idea that art can be important and beneficial for people's health has deep roots in the past. A connection between poetry and the restoration of health was already made in Ancient Greece (Clift & Camic, 2015). However, the growing interest in the therapeutic value of arts is quite recent. In their literature review Perruzza and Kinsella (2010) suggest that 'the use of creative arts occupations in therapeutic practice could have an important qualitative value related to health and wellbeing'. In the last few years there has been increasing interest in cultural and art programmes specifically for people with dementia, aiming to improve their social engagement and quality of life (Gould, 2013; Mittelman & Epstein 2009). Different types of art programmes exist, for example visual art programmes (e.g. paintings, drawings, ceramics, photography), performing arts (e.g. music, dance, theatre) or literary arts (e.g. prose, drama, poetry). Art programmes offer people with dementia the opportunity to communicate and express themselves (Swinnen, 2016), and often involve active participation and interaction (Cohen et al., 2006) thus promoting their social engagement. They can also be a good way to spend leisure time in a meaningful way. Visual art programmes, like museum visits for people with dementia and caregivers, have been found to be beneficial. For example, MacPherson et al. (2009), found that participants with dementia taking part in discussions of artworks at the National Gallery of Australia became animated, were able to discuss and interact about the artworks and gained confidence. However, these effects were not found to be lasting. Another study (Johnson et al., 2017) demonstrated that museum activities positively impacted subjective wellbeing and were more effective than a control intervention consisting of offering refreshments and conversation. Flatt et al. (2015) studied an art museum engagement activity and concluded that museums offer a special setting that is engaging and may improve social wellbeing. Camic et al. (2016) sought to better understand how gallery programmes play a role in the lives of people with dementia. They found that four components were important: a) the art gallery is seen as a valued place, b) it provides intellectual stimulation, c) it promotes social interaction and inclusion, and d) it can change the perception of dementia among caregivers and gallery facilitators.

Some art programmes are meant for both the person with dementia and his or her (informal) caregiver. Informal caregivers often experience stress and burden due to their continuous care task (Ringer et al., 2017). As art programmes enable emotional connection (Bober et al., 2002) and stimulate communication (Young et al., 2016),

they are expected to also have a positive impact on the caregiver. Indeed, the few studies that report on the impact of combined art programmes on caregivers suggest that art programmes may be beneficial not only for the persons with dementia, but also for their caregivers. For instance, Mittelman and Epstein (2009) evaluated the 'Meet Me at MoMA' programme that provides interactive museum tours for people with dementia and their caregivers. They found that the participants' mood, measured by the Smiley Face Assessment Scale (SFAS), in both groups had improved after participating in the museum tour. Moreover, caregivers indicated that, after participation in the programme, the number of people they felt close to increased. In another study into three art museum-based programmes for people with dementia and their caregivers, Lamar and Luke (2016) demonstrated an alleviation of caregiver stress associated with participation in the museum programmes. A positive change in mood for both the people with dementia and the caregivers was found in the pilot study of the 'Awakened Art Stories' programme, a creative expression intervention (Loizeau et al., 2015).

When implementing visual art programmes for people with dementia, besides investigating their effects, it is also important to understand how they are experienced by their participants. A few visual art programmes were evaluated on self-reported participant satisfaction. Mittelman and Epstein (2009) reported that the overall satisfaction with the guided museum tours was very high. Of the 29 participants 75.9% rated the programme with the highest possible rating. Listening to the educators was mentioned most often as an aspect they liked best about their museum visit. Also noted were discussing and looking at the artwork, socialising with others and the private atmosphere. Similarly, participants joining the 'Awakened Art Stories' programme were highly satisfied with the content and organisation of the programme (Loizeau et al., 2015). Sharing the experience with relatives and others as well as experiencing positive feedback in a museum were mentioned as elements that positively influenced the participants' mood. Flatt et al., (2015) found that both the participants with dementia and the caregivers rated the art museum engagement activity highly with a 4.5 out of 5. They most enjoyed the art making, followed by the group interactions and the guided art discussion. Previous experience of art appeared to be associated with greater overall programme satisfaction.

However, the research into visual art programmes and dementia to date has mainly been done with small study samples (Windle et al., 2016), and with a focus on the

effectiveness of and satisfaction with art programmes and to a lesser extent on the experiences of the programmes by participants.

In this paper we report results of a larger exploratory study on experiences and appreciation of interactive guided museum tours, and the relations between these outcomes and specific background characteristics. How people with mild to moderate dementia responded differently to different types of art was published elsewhere (Hendriks et al., 2019). The current study was conducted in the Netherlands in the context of a study into the national implementation of the so called Unforgettable programme in twelve Dutch museums in different parts of the country. This programme was modelled after the 'Meet Me at MoMA' programme of the Museum of Modern Art in New York, where the effects among people with dementia and caregivers were studied in a smaller pilot study (Mittelman & Epstein 2009).

Aim of the study

The study was intended to contribute to optimisation of the programme for the target group.

More specifically, the study focused on the following questions:

1. What are the background characteristics of people with dementia and caregivers participating in the Unforgettable programme?
2. How do participants of the Unforgettable programme, people with dementia and caregivers, experience and appreciate it?
3. Are the experience and appreciation of the Unforgettable programme reflected in mood changes after the guided museum tours (compared to before the tours)?
4. Are the experience, appreciation and (possible) change in mood related to specific background characteristics of the participants?

METHODS

Design

A single-group design was used. To investigate the background characteristics of the participants and their experience and appreciation of the programme, a questionnaire was used after the intervention. To investigate the (change in) mood of the participants, a measurement before- and after the intervention took place. The local Medical Ethics Review Committee reviewed the study protocol and information

letters and stated that the study was not subject to the Medical Research Involving Human Subjects Act.

Setting and participants

The data were collected in twelve museums in different parts of the Netherlands. Two museums developed and started the Unforgettable programme in 2013, the other ten implemented the programme sequentially during the three-year period either through a three-month training programme (for the first two museums) or a two-month training programme (for the last eight museums).

Over the period June 2014 to December 2016 study data were collected from people with dementia and (informal and formal) caregivers participating in the programme. The inclusion criteria for the persons with dementia were: participating in the whole museum tour and being diagnosed with dementia. Participants included couples consisting of people living at home and their informal caregivers, as well as community-dwelling people with dementia who visited day care centres or Meeting Centres for people with dementia and their caregivers and individuals from residential care settings accompanied by formal caregivers. For the accompanying informal and formal caregivers the inclusion criterion was participation in the whole museum tour programme. There were no specific exclusion criteria.

The Unforgettable guided museum tour programme and its implementation

The Unforgettable programme, which is offered monthly on a set day and time, comprises a 90-minute museum tour for people with dementia and their caregivers. Depending on the size and logistics of the museum, the preferred maximum group size varies from 10 to 14 participants (5-7 dyads). The programme is led by a specially trained guide and one or two trained hosts (volunteers). The museum tour guides and the hosts were trained by a project coordinator who worked in each museum for two to three months to implement the programme. The training included information about dementia, information about the guiding method based on the Enquiry Based Learning method (University of Manchester, n.d.), and one pilot tour per trainee. After the training period, the programme was started in each museum.

Each guided tour is organised around a theme, e.g. 'portrait', 'home' or 'love', and comprises a selection of four to six different art works. The guide asks open questions about the art works and gives small creative assignments, such as making a collage

or a portrait of the person with whom they take the tour. At the end of the tour all participants receive a souvenir (generally a postcard with one of the museum's artworks on display) to take home. The price of the tour ranged between 7.50 and 8.50 euro per person.

Measurements

The take home questionnaires were handed out to the participants (one for the person with dementia and another one for the caregiver) directly after the end of the museum tour. The questionnaire for the caregiver included questions on the background characteristics of the caregiver (e.g. age, gender, relationship with person with dementia, experiences with caregiving) and the person with dementia (e.g. age, gender, diagnosis, previous experience with museums/art). Furthermore, experiences with caregiving were measured using the Positive Experience Scale (PES; De Boer et al. 2012). The PES consists of six statements such as 'By caring I learned to be happy with the little things in life'. The respondent is asked, taking into account the past month, to indicate on a 3-point Likert scale to what level they agree with the statements (I agree, I do not agree/I do not disagree, I disagree). This instrument has been shown to have good psychometric properties (De Boer et al. 2012).

To assess the experience and appreciation of the museum tour the questionnaires contained both open and closed questions about, for example, the overall satisfaction with the programme, consideration to undertake other activities because of the experience with the museum tour, and self-reported effect on conversation, mood, appetite and sleep of the person with dementia. These questions were based on the questions of the survey used in the Mittelman and Epstein (2009) study. They found that people with mild dementia could, for the most part, complete the questionnaires by themselves. Those who were in a slightly more advanced stage of dementia needed to have one-on-one support to answer the questions. For the study into the Unforgettable programme some extra questions were added, e.g. 'Did your contact with the person with dementia change during the programme?' (for the caregivers) and 'What do you think about the price of Unforgettable?'

Visual analogue scales have been shown to be a valid tool for evaluation of mood among people with dementia (Temple et al., 2004). The SFAS used in the study into the 'Meet Me at MoMA' programme (Mittelman & Epstein, 2009) and in other studies

on art programmes (Livingston et al., 2016) was translated into Dutch. The SFAS was applied to measure the mood of the people with dementia and their caregivers before and immediately after the art tour. This visual analogue scale consists of a one-item 5-point self-report Likert scale with five faces icons ranging from very unhappy to very happy (SFAS; Mittelman & Epstein, 2009).

Procedure

A few days before the Unforgettable tour was to take place, the contact person at the museum sent the participants an e-mail with information about the study. People who were willing to participate in the study were asked to arrive 15 minutes before the start of the tour. The researcher then briefly repeated the aim and procedure of the study, and asked the persons with dementia and their caregivers whether they would like to participate. If they were willing, the researcher invited them to sign a consent form. If the people with dementia indicated they wanted to participate but were not able to sign the form themselves, the caregiver signed the form on their behalf. Immediately before the start and immediately after the end of the guided tour, the participants were asked to indicate their current mood using the SFAS. The majority of people with dementia were able to fill in the SFAS independently. Those who had difficulty filling in the SFAS independently were supported by their caregiver. After the tour the participants received the two take home questionnaires, one to be filled out by the person with dementia and one to be filled out by the caregiver. To encourage reliable answers and to prevent non-responders, the participants were asked to fill out these questionnaires at home within three days and then send them to the researcher in the provided return envelope.

Data analysis

The background characteristics and the experience of and appreciation with the programme of the people with dementia are described separately for people with dementia attending in groups from care facilities and people with dementia attending in dyads. For the caregivers this information is described separately for the informal and for the formal caregivers.

The open-ended questions in the take home questionnaires were analysed by a researcher (IH) using inductive thematic analysis to extract themes from the answers. The open-ended questions were entered into an Excel datasheet, and identification of themes was undertaken. In the final stage the themes were grouped. The groups

were carefully inspected to ensure that the clustered themes were representative of the original data and initial assigned themes. For pragmatic reasons only themes that were mentioned by at least three participants are reported. Descriptive analyses on the quantitative data were conducted using SPSS (version 22). Data were checked for normality with the Shapiro-Wilk test.

Differences between the pre- and post-intervention scores on the SFAS (mood) scale were tested using the Wilcoxon signed rank test with a significance level of $\alpha \leq 0.05$.

For all the questions about outcomes (appreciation, experience and change in mood) that showed at least some variation in answers by respondents, we investigated if these answers were associated with background characteristics (e.g. education, experience of art, severity of dementia of the people with dementia, and age, type of caregiver, positive experience with caring of the caregiver). These associations between background characteristics and outcomes were calculated using the Spearman rank correlation coefficient. Group differences were calculated using the Mann-Whitney-U-test, Kruskal-Wallis test, Chi Square Rank test and Fisher's Exact test (FET), depending on the type of variable.

RESULTS

Background characteristics participants

Of the 117 people with dementia and 128 caregivers (of whom 85 were informal caregivers), 65 (55.6%) people with dementia and 76 (59.4%) caregivers returned the take home questionnaires. In 11 cases, only the caregiver filled out the take-home questionnaire. They indicated the persons with dementia were incapable of filling out the questionnaire themselves. Nine persons with dementia did not fill in the questionnaire because they joined the tour without a personal caregiver. Twenty caregivers did not fill in the questionnaire because they joined the tour as second or third caregiver. The delay to returning questionnaires ranged from 0 to 11 days for persons with dementia (median 0 days) and from 0 to 23 days for caregivers (median 0 days). Not all questions on background characteristics were answered, which was partly due to the formal caregivers' and volunteers' lack of knowledge about the background of the person with dementia.

The groups of participants varied in size (median: 12, range: 5-19) and composition. Most participants with dementia living at home participated with informal caregivers, some participated with formal or voluntary caregivers. Some people with dementia participated in a group from a care institution or day care facility and were accompanied by formal, voluntary and/or informal caregivers.

Prior experience

The vast majority (73.1%) of the people with dementia and of the caregivers (93.2%) had visited a museum before. An overview of the background characteristics of the participants can be found in Tables 1 and 2.

Regarding the caregiver characteristic '*experience of caring in the last month*' nearly all of the 54 informal caregivers indicated that they enjoyed nice moments together with the person they cared for (96%). Also, 89% said that caring for the person with dementia made them feel good. About half of the informal caregivers (49%) reported getting closer to the person since they cared for them, while 74% said they learned to be happy with the little things in life by caring for the person with dementia, and 80% learned new things about themselves through caring. 63% of the informal caregivers got to know new people in the last month as a result of caring for the person with dementia.

Table 1. Background characteristics of people with dementia

Characteristics	Persons with dementia				
	N	All	N	participating in dyads	N participating in groups*
Gender	117		88		29
Female		70 (59.8%)		49 (55.7%)	21 (72.4%)
Male		47 (40.2%)		39 (44.3%)	8 (27.6%)
Age (years), mean (SD)	95	81 (7.55)	72	82 (7.29)	23 81 (8.43)
Diagnosis PwD	60		57		3
Alzheimer's		32 (53.3%)		29 (50.9%)	3 (100%)
Vascular		10 (16.7%)		10 (17.5%)	-
Other		7 (11.6%)		7 (12.2%)	-
Dementia NOS		11 (18.3%)		11 (19.3%)	-

Table 1. (continued)

Characteristics	N	Persons with dementia		
		All	N participating in dyads	N participating in groups*
Severity of dementia	68		63	5
Mild		13 (19.1%)	13 (20.6%)	-
Moderate		36 (52.9%)	33 (52.4%)	3 (60%)
Moderately severe		19 (27.9%)	17 (27.0%)	2 (40%)
Marital status	70		65	5
Married/living together		34 (48.6%)	34 (52.3%)	-
Widowed		20 (28.6%)	17 (26.2%)	3 (60.0%)
Divorced		12 (17.1%)	11 (16.9%)	1 (20.0%)
Not married		4 (5.7%)	3 (4.6%)	1 (20.0%)
Living situation PwD	73		66	7
Independent (with spouse)		21 (28.8%)	21 (31.8%)	-
Independent (with domestic/ personal care)		17 (23.3%)	17 (25.8%)	-
Care home/nursing home		25 (34.2%)	19 (28.8%)	6 (86.7%)
Small-scale living		3 (4.1%)	2 (3.0%)	1 (14.3%)
Other		7 (9.7%)	7 (10.6%)	-
Education	63		60	3
Low		29 (46.0%)	27 (45%)	2 (66.7%)
Middle		11 (17.5%)	10 (16.7%)	1 (33.3%)
High		23 (36.5%)	23 (38.3%)	-
Former profession PwD in/as	57		53	4
Economy & management		18 (31.6%)	17 (32.1%)	1 (25.0%)
Education		8 (14.0%)	8 (15.1%)	-
No profession/housewife		10 (17.5%)	7 (13.2%)	3 (75.0%)
Health care		4 (7.0%)	4 (7.5%)	-
Social work		4 (7.0%)	4 (7.5%)	-
Art		4 (7.0%)	4 (7.5%)	-
Engineering		3 (5.3%)	3 (5.7%)	-
Retail		3 (5.3%)	3 (5.7%)	-
Craftsman		3 (5.3%)	3 (5.7%)	-
Visited a museum before	67		63	4
No		18 (26.9%)	15 (23.8%)	3 (75.0%)
Less than once per year		16 (23.9%)	15 (23.8%)	1 (25.0%)
1 – 5 times a year		25 (37.3%)	25 (39.7%)	-
6 – 11 times a year		5 (7.5%)	5 (7.9%)	-
12 times per year or more		3 (4.5%)	3 (4.8%)	-

Notes: SD: standard deviation. NOS: not otherwise specified. Totals may not equal 100 per cent because of rounding. *From care facilities

Table 2. Background characteristics of informal and professional caregivers

Characteristic	Caregivers					
	N	All	N	Informal	N	Professional and volunteers
Gender	128		85		43	
Female		95 (74.2%)		58 (68.2%)		37 (86%)
Male		33 (25.8%)		27 (31.8%)		6 (14%)
Age (years), mean (SD)	113	63 (14.14)	76	67 (14.13)	37	56 (11.80)
Marital status	73		55		18	
Married/living together		57 (78.1%)		44 (80%)		13 (72.2%)
Widowed		2 (2.7%)		1 (1.8%)		1 (5.6%)
Divorced		4 (5.5%)		4 (7.3%)		-
Not married		10 (13.7%)		6 (10.9%)		4 (22.2%)
Caregiver lives together with PwD	75		56		19	
Yes		22 (29.3%)		22 (39.3%)		-
No		53 (70.7%)		34 (60.7%)		19 (100%)
Education	74		56		18	
Low		15 (20.2%)		12 (21.5%)		3 (16.9%)
Middle		27 (36.5%)		19 (34%)		8 (44.5%)
High		32 (43.3%)		25 (44.6%)		7 (38.9%)
Visited a museum before	74		56		18	
No		5 (6.8%)		5 (8.9%)		-
Less than once per year		10 (13.5%)		6 (10.7%)		4 (22.2%)
1 – 5 times a year		35 (47.3%)		25 (44.6%)		10 (55.6%)
6 – 11 times a year		14 (18.9%)		13 (23.2%)		1 (5.6%)
12 times per year or more		10 (13.5%)		7 (12.5%)		3 (16.7%)
Caregiver participated in Unforgettable before	74		56		18	
Yes		24 (32.4%)		19 (33.9%)		5 (27.8%)
No		50 (67.6%)		37 (66.1%)		13 (72.2%)
Caregiver has been taking care of PwD since	55	3.9 years (range 0-17)	44	4.0 years (range 0-11)	11	3.3 years (range 0-17)
Caregiver is primary caregiver for PwD	74		55		19	
Yes		40 (54.1%)		40 (72.7%)		-
No		34 (45.9%)		15 (27.3%)		19 (100%)

Notes: SD: standard deviation. Totals may not equal 100 per cent because of rounding

Experience and appreciation of the Unforgettable programme and association with background characteristics

An overview of the answers to the structured questions of the take-home questionnaire is presented in Appendices A and B. For the questions that showed at least some variation in answers by respondents we investigated if these answers were associated with background characteristics. We checked if the background characteristics were related to overall satisfaction with the programme and answers to the questions 'was there anything bad about your museum visit?' and 'did your contact with the person with dementia change during the programme?' (only for caregivers). Below the results concerning the experience and appreciation of Unforgettable are summarised descriptively.

Experience of the programme

Of the 52 informal caregivers 40.4% said their contact with the person with dementia changed, of the 17 formal caregivers the percentage was 29.4%. Some explained this was because they appreciated doing this activity together.

'The return of interest and therefore a stronger sense of shared experience of the tour.'
(Informal caregiver)

The answer to the question 'did your contact with the person with dementia change during the programme' appeared to be linked with the years of caring for the person with dementia ($p < 0.01$, FET). The longer people had been caring for the person with dementia, the more likely it was that they experienced a different type of contact during the tour. No relationship was found between the answer to this question and other caregiver characteristics.

It was found that 26.9% of the 52 informal caregivers and 29.4% of the 17 formal caregivers were surprised by the reaction of the person with dementia, which changed their perceptions of the person with dementia for whom they cared. One informal caregiver explained being surprised

'By his concentration and interest. Nowadays he quickly loses interest in doing things.'

After joining the tour, 22 out of 55 (40%) people with dementia indicated that they were inspired to undertake other activities together with their caregiver. 35 (51.5%)

caregivers would also like to do other activities, like visit other museums or go to a concert. They also mentioned going to the zoo, painting and going out for a walk.

Besides a better mood (n = 13; 24.1%), being tired (n = 7; 16.4%), being more talkative (n = 4; 6.2%), having a better appetite (n = 3; 4.6%), being more active (n = 3; 4.6%), and having more problems sleeping (n = 1; 1.5%) the people with dementia did not report any changes in themselves after the tour. Besides a more positive mood that was mentioned seven times (9.2%) in the open-ended question regarding changes in the person with dementia, five caregivers (6.6%) mentioned that the person with dementia was tired after the tour. The tiredness appeared to be related to the answer to the question 'was there anything bad about your museum visit?' ($p = 0.000$; *FET*): five of the seven people with dementia (71.4%) who reported being tired after the tour also mentioned something unpleasant about their museum visit, such as the group being too large or the duration of the tour being too long. The caregivers did not see much change in the person with dementia's appetite and speech after the tour (see 'Changes in mood and behaviour, Appendix B). According to their caregivers, 26% (n = 13) and 23% (n = 3) of the persons with dementia joined by informal and formal caregivers respectively did show an improved mood after the museum visit. It was difficult to measure changes in sleep after the tour as most of the participants filled out the questionnaire the same day.

Appreciation of the programme

The answers to the questions regarding the appreciation of the programme in the take home questionnaire were predominantly positive. Most of the persons with dementia and the (in)formal caregivers enjoyed the museum visit (a lot) and the majority of the participants reported that they would like to do the tour again. The persons with dementia and caregivers rated the programme with a mean score of 8 on a scale from 1 to 10. Overall satisfaction with the programme was not related to background characteristics, neither for persons with dementia or caregivers.

Elements of the programme that were most appreciated by the persons with dementia were: social interaction (n = 10), looking at art (n = 6), the clear explanation of the guide (n = 5), the engagement of the guide and hosts (n = 3), and the museum in terms of the building (n = 3). The elements that were appreciated most by the (in)formal caregivers were: the engagement, kindness and motivation of the guide and hosts (n = 20), the social interaction (n = 10), the clear explanation of the guide (n = 8), the

friendly welcome (n = 6), the good pace during the tour (n = 6), seeing the reaction of the person with dementia (n = 5), and the small group (n = 3).

The following quotes explain the appreciation of the participants:

'Changing topics. Discussing personal opinions!' (Person with dementia)
'Looking at beautiful art, together with others.' (Person with dementia)
'Being addressed as a person.' (Person with dementia)
'Seeing how my mother makes contact with others and seeing how careful she is.'
 (Informal caregiver)
'Looking at art in a quiet and, for my husband, inviting environment and sharing that moment with others.' (Informal caregiver)
'My mother was stimulated to look at the images and she associated lovely with it, it was very activating.' (Informal caregiver)
'It was very nice to hear what everyone noticed in an artwork.' (Informal caregiver)

The answers to the question 'Was there anything bad about your museum visit?' can be summarised in the following themes that were mentioned at least three times by the caregivers: poor accessibility of the museum; poor accessibility of the toilet; unrest during the tour because of noises; technical problems (e.g. lift out of order); and/or a tour guide having difficulty creating a calm atmosphere. There were no negative factors mentioned three or more times by the persons with dementia; duration too long and chaotic beginning of the tour were mentioned twice. Highly educated caregivers were more likely to say that there was something bad (negative/unpleasant aspects of the visit) than caregivers with less education ($\chi^2 = 13.00$; degrees of freedom (df) = 2; $p < 0.01$). No relationships were found between the other background characteristics of the caregiver and the answer to this question. For the people with dementia the answer to the question 'Was there anything bad about your museum visit?' was not associated with their background characteristics.

The vast majority of the participants (people with dementia and caregivers) responded positively to the question 'Did you think the tour was stimulating/informative?'

'You also hear other people's views.' (Person with dementia)
'I would like to do it more often: it is good to focus on something that centres on your own feelings and to share them with the group.' (Informal caregiver)

'Everyone was involved and addressed individually. The interactivity was nice.'
(Informal caregiver)

Most people with dementia did not make suggestions to improve the programme. Some would like the group to be smaller. A smaller group was also mentioned by the (informal) caregivers. In addition, they suggested creating a calmer atmosphere:

'Smaller group, having a large group made it chaotic. The start in the restaurant was chaotic because of the environment.' (Informal caregiver)

Mood and association with background characteristics

In general, the participants started the guided tour in a good mood: the median score on the SFAS scale increased significantly from 4 (somewhat happy) before the guided tour to 5 (very happy) after the tour, for both persons with dementia ($n = 95$) and the caregivers ($n = 104$) ($p = 0.02$ and $p < 0.01$ respectively).

Regarding the results about the associations between the person with dementia's and caregivers' background characteristics and their change in mood, we found a significant association ($H = 6.01$; $df = 2$; $p = 0.05$) between change in mood of the person with dementia and their diagnosis: after the tour, a more positive mood was more often found in people with another or unknown type of dementia ($n = 12$; 66.7%), compared to six people (25%) diagnosed with Alzheimer's, and three people (37.5%) with vascular Dementia. A significant association ($U = 620.50$; $z = -2.21$; $p = 0.03$) was found between change of mood of the person with dementia and the type of caregiver (formal or informal) with whom he or she joined the tour: those attending the tour with an informal caregiver were more likely to improve their mood ($n = 26$ individuals; 44.1%), compared to those who attended with a formal caregiver ($n = 8$, 27.6%). No associations were found between the other characteristics of the persons with dementia and their changes in mood after the museum tour.

For the caregivers we found that the older they were the more their mood improved ($Rho = 0.26$, $p = 0.01$). We also found a relation between the type of caregiver (informal or formal) and changes in mood ($U = 839.00$; $z = -2.65$; $p = 0.01$): The informal caregivers more often experienced an improved mood ($n = 32$; 45.6%), compared

to formal caregivers (n = 7; 20.5%). No associations were found between the other caregiver characteristics and changes in mood.

DISCUSSION

This paper reports on the results of a user evaluation study of the Unforgettable museum programme for people with dementia and their caregivers which was carried out within the framework of an implementation study into this programme in twelve Dutch museums. The evaluation investigated the participants' perspective, which resulted in information that may optimise the guided museum tours for people with dementia and their caregivers. Moreover, analysis of the background characteristics of participants provides insight into which of these might influence the experience of participants.

The Unforgettable programme was originally developed for people with dementia and their informal caregivers living at home. However, this study has shown that the programme also appeared to attract others, such as community dwelling people with dementia accompanied by formal or voluntary caregivers (e.g. from a day care facility or Meeting Centre), and groups from long-term care facilities with formal as well as voluntary and informal caregivers. Looking at the reported 'positive care experiences' by caregivers who joined the Unforgettable programme, we found higher scores than reported by De Boer et al., (2012) who studied a broader sample of caregivers of different patient groups, including people with dementia. One possible explanation for these higher scores could be that the museum programme selectively attracts people with a more positive attitude towards caring. An alternative explanation could be that the experiences during the Unforgettable programme positively influenced the caregivers' answers on the PES. Further study of this difference would be interesting.

Overall, the Unforgettable programme was very positively evaluated by the participants. Comparable results were found for similar programmes such as 'Meet Me at MoMa' (Mittelman & Epstein, 2009) in New York and the 'here:now' programme of the Frye Museum in Seattle (Burnside et al., 2017). Social connection is often found to be one of the most important elements of art programmes (Burnside et al., 2017; Camic et al., 2016). The Unforgettable programme is no exception: social interaction and meeting others appeared to be key factors in the appreciation of the programme by both people with dementia and their caregivers. Social engagement is recognised

as one of the most important components of wellbeing of older adults (Cherry et al., 2013) and social health (Dröes et al., 2017). Recent research has shown that older adults with cognitive impairments are significantly less likely to be socially active than older adults without cognitive impairments (Johnson et al., 2014). Art can be seen as a facilitation tool for expressing emotions (Wang & Li, 2016). Moreover art often reflects generic life themes and experiences which are recognisable for a broad public, while it is generally accepted that people can have different opinions about the aesthetic value of it and that it can evoke different feelings. The open atmosphere that is created by the guides during the tours can contribute to a safe environment in which participants feel free to speak openly about their emotions and feelings. Museum programmes such as Unforgettable can therefore be seen as a valuable addition to other activities that stimulate social interaction for people with dementia.

The people with dementia appreciated the art in general and the museum building itself. The latter finding supports the added value of joining an activity in a community building rather than an activity in a long-term care facility or at home. This is also in line with the findings of Brieber et al. (2015) that artworks are seen as more interesting in a museum than in a laboratory. Another important aspect of the programme mentioned by the persons with dementia as well as the caregivers was the role of the guide and hosts. Personality, especially kindness and involvement, and the guide's knowledge of art were very much appreciated. Chancellor et al. (2014) also found the role of the art therapist to be critical in creating a comfortable environment for people with dementia. Poor accessibility of the museum and of the toilet were mentioned as negative aspects of the museum visit. To improve the tour, the participants recommended smaller groups and a calmer atmosphere during the tour.

In contrast to the persons with dementia, the caregivers did not specifically mention looking at art or the museum building. For them seeing the reaction of the person with dementia was what they appreciated most. Caregivers' changed perceptions about the person with dementia were also found in the study of Camic et al. (2016). We may therefore conclude that the positive evaluation by the caregivers may not specifically be attributed to the art or the museum itself. However, the programme seems to fit the needs of a specific group of caregivers who enjoy going to a museum. In our study, participants could apply for the study themselves, they were not randomly selected.

The overall satisfaction of both the people with dementia and the caregivers did not appear to be related to their background characteristics. However, more educated caregivers were more likely to be critical about the museum visit. Previous experience with museums did not appear to be a precondition for enjoying the Unforgettable programme. Moreover, enjoying the programme was not limited to people in the mild or moderate stage of dementia living at home, as it also appeared to be valued positively by people with moderately severe dementia living in long-term care facilities.

Besides mood improving and being tired, the participants with dementia did not report changes within themselves after the tour. People with dementia who reported being tired after the tour were more likely to have experienced something bad about the museum visit, such as the group being too large or the duration of the tour being too long. The caregivers did not report much change in behaviour after the tour either, although some also noticed tiredness in the person with dementia. A different type of contact with the person with dementia was experienced more often by carers who had been a caregiver for a longer period of time.

The positive experience and appreciation of the Unforgettable programme were reflected in the improved mood of both the persons with dementia and the (in) formal caregivers, as measured by the SFAS. This positive impact is in line with outcomes of other studies into museum programmes, such as 'Meet me at MoMA' (Mittelman & Epstein, 2009) which also reported improved mood, and the 'Artful Moments' programme in Canada (Hazzan et al., 2016), which reported decreased stress experienced by the participating caregivers. For the people with dementia we found a significant association between their change in mood and the type of caregiver they joined the tour with; people with dementia attending the programme with an informal caregiver were more likely to experience improved mood. This might be explained by the persons with dementia's familiarity with that person. The familiarity of a social environment has been shown to promote involvement in activities (Phinney et al., 2007). Also, people with types of dementia other than Alzheimer's disease or vascular dementia were more likely to have an improved mood. This latter finding may be explained by the very good mood of the people with Alzheimer's disease at the start of the tour (ceiling effect). Concerning the caregivers' change in mood we found that older caregivers and informal (as compared to formal) caregivers experienced more improvement in mood. This difference between

informal and formal carers might be explained by the fact that the mood of formal caregivers was already very good before the start of the tour. No associations were found with other background characteristics of people with dementia or caregivers.

Limitations

This study had some limitations: first, participants of the Unforgettable programme were self-selected and the vast majority of them had previous experience of art, which makes it impossible to generalise the outcomes to groups of people with dementia in general and people without experience of art. Also, this self-selection of people to participate in the programme might have resulted in bias because they might have had a positive attitude to this intervention beforehand and may have been more inclined to give positive feedback afterwards; or, for them, just taking part in research may have resulted in giving positive feedback (Hawthorne effect). Second, almost half of the participants did not return the take home questionnaire. These were relatively more people who joined the tour in a group from a care institution or as professional or voluntary caregiver. A lack of time of the professionals, or the fact that the participants were asked to return the questionnaire within three days after the tour, could be reasons for not filling out the questionnaires. By offering the participants the possibility to choose between filling out the questionnaires themselves at home or a (telephone) interview by one of the researchers one day or a few days after the tour, a higher response rate could possibly be achieved. The length of the questionnaire, especially the one for the caregiver, could be another reason for not returning the questionnaire. To improve feasibility, we had mainly questions with up to three answering possibilities, which could have had a negative effect on the sensitivity. The same holds for the easy-to-administer-five-response SFAS questionnaire that we used. For future studies a good trade-off needs to be made between the length of the questionnaire and answering possibilities on the one hand and the feasibility of filling out the questionnaire on the other. The number of times people participated in the Unforgettable programme could be an indicator of (dis)satisfaction. However, as the Unforgettable programme was not set up as a series of museum tours, information on the participation frequency after having participated in the museum tour for the first time was not collected. Moreover, we used a one-group design: the lack of a control group makes it difficult to determine whether the appreciation of the programme and the improvements in mood of people with dementia and caregivers were specifically related to the art and the art programme itself or to other factors. The appreciation, experience and mood of the participants

in the museum activity were not compared to the appreciation, experience and mood of participants in other non-art activities. So it remains unclear if the outcomes are specific for the museum programme. The qualitative data, however, suggest that the majority of the participants indeed highly appreciated the guided tours and had relatively few suggestions for improvement. For future research it would be interesting to investigate the added value of art programmes, including the duration of the effect on mood, compared to other (social) activities for people with dementia. Because of the explorative character of our study no multiple testing correction was done when calculating the associations between the user experience and appreciation of the programme and their background characteristics. Our aim was to explore potential associations with background characteristics, that could be further investigated in future studies.

The fact that data in this implementation study were collected in different museums with very different collections all over the Netherlands, can be seen as an advantage. However, this did make the evaluation of the appreciation of the museum tour programme complex. The numbers of participants who visited the different museums were too small to investigate the effects of these variations. Finally, most of the participants in this study were diagnosed with Alzheimer's disease and/or vascular dementia, there were too few people with other types of dementia to fully investigate differences in appreciation of the programme and impact on mood by diagnostic sub-groups of people with dementia. As people with different types of dementia have different disabilities, it would be interesting to focus future research on how different sub-groups appreciate the guided museum tours and what adaptations might be necessary to meet the needs of these sub-groups.

Scientific and societal impact

The results of this study can stimulate and support other museums to set up similar programmes and thus promote the further dissemination and availability of museum programmes for people with dementia and their caregivers; both for those living in the community as well as in long-term care facilities. Based on the findings of our study we recommend museums to implement the Unforgettable programme, while explicitly taking into account the participants' experiences and suggestions, such as small groups and a calm environment, in their implementation plan. Insight into what aspects the participants appreciate more or less can help to improve art programmes for people with dementia and their caregivers, which is likely to

increase the benefit for its users. The most appreciated aspects mentioned in our study, such as the social interaction and the engagement of the well-informed guides and hosts, may also help to explain the positive impact of museum programmes. The positive experiences with the Unforgettable programme may encourage people with dementia and their informal and formal caregivers to participate in the programme.

CONCLUSION

In this exploratory study we demonstrated that the Unforgettable programme is experienced and evaluated positively by its participants, i.e. both people with dementia and informal and formal caregivers. Furthermore, we found some background and environmental factors that were related to the appreciation, experience and changes in mood. Taking notice of these may help further improve museum programs for people with dementia and carers. We recommend to investigate if our study findings are confirmed in larger, preferably randomised controlled trials.

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APPENDICES

Appendix A. Table appreciation and experience Unforgettable programme by person with dementia

	N	Persons with dementia – total	N	Persons with dementia – participating in dyads	N	Persons with dementia – participating in groups*
Appreciation						
Did you enjoy the museum visit?	62		58		4	
A lot						
A little bit		48 (77.4%)		45 (77.6%)		3 (75.0%)
No		13 (21.0%)		12 (20.7%)		1 (25.0%)
		1 (1.6%)		1 (1.7%)		-
How was the atmosphere during the tour?	44		42		2	
Open		37 (84.1%)		35 (83.3%)		2 (100%)
Neutral		6 (13.6%)		6 (14.3%)		-
Distant		1 (2.3%)		1 (2.4%)		-
	58		55		3	
Pleasant		53 (91.4%)		50 (90.9%)		3 (100%)
Neutral		4 (6.9%)		4 (7.3%)		-
Unpleasant		1 (1.7%)		1 (1.8%)		-
Did you think the tour was stimulating/informative?	54		51		3	
Yes		51 (94.4%)		48 (94.1%)		3 (100%)
No		3 (5.6%)		3 (5.9%)		-
Was there anything bad about your museum visit?	57		54		3	
Yes		6 (10.5%)		5 (9.3%)		1 (33.3%)
No		51 (89.5%)		49 (90.7%)		2 (66.7%)
Would you like to participate in an Unforgettable tour again?	60		57		3	
Yes		55 (91.7%)		52 (91.2%)		3 (100%)
No		5 (8.3%)		5 (8.8%)		-
Overall satisfaction with Unforgettable (mean)	63	8 (range 1-10)	60	8 (range 1-10)	3	8 (range 8-9)
Experience						
Did you discuss the museum visit after you left the museum?	59		56		3	
Yes		49 (83.1%)		47 (83.9%)		2 (66.7%)
No		10 (16.9%)		9 (16.1%)		1 (33.3%)

Appendix A. (continued)

	N	Persons with dementia – total	N	Persons with dementia – participating in dyads	N	Persons with dementia – participating in groups*
Are you considering other activities with your relative because of the tour?	55		53		2	
Yes		22 (40.0%)		20 (37.7%)		2 (100%)
No		33 (60.0%)		33 (62.3%)		-
What do you think about the price of Unforgettable?	51		50		1	
Too low		2 (3.9%)		2 (4.0%)		-
Good		47 (92.2%)		46 (92.0%)		1 (100%)
Too high		2 (3.9%)		2 (4.0%)		-

Totals may not equal 100 per cent because of rounding; *From care facilities

Appendix B. Table appreciation and experience Unforgettable programme by informal and professional caregivers and volunteers

	N	Caregivers – all	N	Informal caregivers	N	Professional caregivers and volunteers
Appreciation						
Did you enjoy the museum visit?	68		53		15	
A lot		58 (85.3%)		45 (84.9%)		13 (86.7%)
A little bit		9 (13.2%)		7 (13.2%)		2 (13.3%)
No		1 (1.5%)		1 (1.9%)		-
Did you find the tour stimulating/informative?	66		49		17	
Yes		57 (86.2%)		43 (87.8%)		14 (82.4%)
No		9 (13.8%)		6 (12.2%)		3 (17.6%)
Was the guide able to attract attention and was he/she understanding?	69		52		17	
Yes		64 (92.8%)		47 (90.4%)		17 (100%)
A bit		4 (5.8%)		4 (7.7%)		-
No		1 (1.4%)		1 (1.9%)		-
Did you appreciate the contact with the other participants during the tour?	66		49		17	
Yes		62 (93.9%)		45 (91.8%)		17 (100%)
No		4 (6.1%)		4 (8.2%)		-

Appendix B. (continued)

	N	Caregivers - all	N	Informal caregivers	N	Professional caregivers and volunteers
Was there anything bad about your museum visit?	66		50		16	
Yes		17 (25.8%)		11 (22%)		6 (37.5%)
No		49 (74.2%)		39 (78%)		10 (62.5%)
Do you plan to participate in an Unforgettable tour again?	70		53		17	
Yes		63 (90.0%)		48 (90.6%)		15 (88.2%)
No		7 (10.0%)		5 (9.4%)		2 (11.8%)
Would you recommend the tour to other people?	68		51		17	
Yes		63 (92.6%)		48 (94.1%)		15 (88.2%)
No		5 (7.4%)		3 (5.9%)		2 (11.8%)
Overall satisfaction with Unforgettable (mean)	73	8 (range 3-10)	55	8 (range 3-10)	18	8 (range 6-9)
Experience						
Did your contact with the PwD change?	69		52		17	
Yes		26 (37.7%)		21 (40.4%)		5 (29.4%)
No		43 (62.3%)		31 (59.6%)		12 (70.6%)
Were you surprised by the response of the PwD?	69		52		17	
Yes		19 (27.5%)		14 (26.9%)		5 (29.4%)
No		50 (72.5%)		38 (73.1%)		12 (70.6%)
Did you discuss the museum visit after you left the museum?	70		53		17	
Yes		55 (78.6%)		42 (79.2%)		13 (76.5%)
No		15 (21.4%)		11 (20.8%)		4 (23.5%)
Are you considering other activities with the PwD because of the tour?	68		52		16	
Yes		35 (51.5%)		24 (46.2%)		11 (68.8%)
No		33 (48.5%)		28 (53.8%)		5 (31.3%)
What do you think about the price of Unforgettable?	57		44		13	
Too low		1 (1.8%)		1 (2.3%)		-
Good		52 (91.2%)		39 (88.6%)		13 (100%)
Too high		4 (7.0%)		4 (9.1%)		-

Appendix B. (continued)

	N	Caregivers - all	N	Informal caregivers	N	Professional caregivers and volunteers
Appreciation and experience of PwD according to CG						
Do you think the PwD enjoyed the museum visit?	69		53		16	
A lot		43 (61.4%)		33 (39.3%)		10 (62.5%)
A little bit		24 (34.3%)		18 (21.4%)		6 (37.5%)
No		2 (2.9%)		2 (2.4%)		-
Changes in Mood and Behaviour PwD:						
Conversation	66		51		15	
More than usual		9 (13.6%)		7 (13.7%)		2 (13.3%)
Unchanged		56 (84.8%)		43 (84.3%)		13 (86.7%)
Less than usual		1 (1.5%)		1 (2%)		-
Appetite	61		49		12	
More than usual		4 (6.6%)		4 (8.2%)		-
Unchanged		56 (91.8%)		44 (89.8%)		12 (100%)
Less than usual		1 (1.6%)		1 (2%)		-
Mood	63		50		13	
More than usual		16 (25.4%)		13 (26%)		3 (23.1%)
Unchanged		45 (71.4%)		35 (70%)		10 (76.9%)
Less than usual		2 (3.2%)		2 (4%)		-
Sleep that night	47		41		6	
More than usual		7 (14.9%)		7 (17.1%)		-
Unchanged		38 (80.9%)		32 (78%)		6 (100%)
Less than usual		2 (4.3%)		2 (4.9%)		-

Totals may not equal 100 per cent because of rounding



CHAPTER 4

HOW DO PEOPLE WITH DEMENTIA RESPOND TO DIFFERENT TYPES OF ART? AN EXPLORATIVE STUDY INTO INTERACTIVE MUSEUM PROGRAMMES

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ABSTRACT

Objectives: Various art programmes are available for people with dementia. These have been shown to contribute to their quality of life. But are all types of art suitable for this purpose and for the target group? This study investigated whether responsiveness during museum programmes depends on the type of art work shown and/or characteristics of the person with dementia, such as severity of dementia or specific cognitive impairments.

Method: A cross-sectional observational study was conducted in which the responsiveness of people with dementia to different types of art was investigated as part of a study into the implementation of the 'Unforgettable' programme, interactive guided museum tour programme in Dutch museums for people with dementia.

Results: The appreciative and active responsiveness and interaction with others during the programme appeared related to the severity of dementia, to specific cognitive impairments, and to type of artworks. People with more severe dementia responded less to art than people with mild dementia. Artworks with more natural elements revealed less interaction with others. Artefacts (i.e. objects not originally meant as artworks) evoked more reactions than artworks.

Conclusion: The study results are important to take into account when designing and offering art programmes for people with dementia. Knowing which type of art works appeals most to (subgroups of) people with dementia will contribute to the optimisation of art programmes for this target group and to their active participation in such programmes.

INTRODUCTION

Dementia is a global health concern. The number of people living with dementia worldwide is expected to increase from 47 million in 2015 to 131,5 million people in 2050 (Alzheimer Disease International, 2015). Until dementia can be cured or prevented there is an increasing demand for the development of appropriate psychosocial interventions to improve and/or maintain mental and social health of people with dementia (Vernooij-Dassen & Jeon, 2016). Various psychosocial interventions, such as life story interventions, music-based interventions and animal-assisted therapy have been shown to contribute to the wellbeing of people with dementia (Patel et al., 2014). Over the last few years art programmes have increasingly been offered to this target group, with the primary goal of creating meaningful personal experiences for the participants (De Medeiros & Basting, 2013). Art programmes may also satisfy the sense of aesthetics (Leder et al., 2004), which is considered a subdomain of quality of life (Brod et al., 1999). Although the evidence base of the effects of art programmes on people living with dementia has still been relatively small thus far, research suggests benefits on quality of life (Camic et al., 2014; Johnson et al., 2015). Furthermore, it can provide a means of communication with people who have language problems (Peisah et al., 2011). The results of the study into the Memories in the Making art programme indicated that the participants with dementia demonstrated significantly more interest, sustained attention, pleasure and self-esteem compared to the people participating in more traditional adult day care activities (Kinney & Rentz, 2005). Comparable results were found in the study of Windle et al. (2018) into a twelve-week visual art programme. In their research into the Meet Me at MoMA programme for persons with dementia and their caregivers of the Museum of Modern Art in New York, Mittelman and Epstein (2009) found that the mood of both the persons with dementia and the caregivers improved. Also, the number of people to whom the caregivers indicated they felt close to increased. These results indicate that art programmes can also provide emotional support to caregivers.

However, whether the evoked reactions and positive impacts of art programmes apply to all people with dementia remains unclear. It could be that this depends on certain conditions, such as the severity of their dementia or specific cognitive impairments, or on the type of artwork shown. For example, MacPherson et al. (2009) suggested that different types of visual art, such as representational, abstract, or conceptual art, may impact the effectiveness of a programme.

Windle et al. (2014) suggest that visual art programmes should be built on dynamic and responsive artistic practice, and should create a provocative and aesthetic experience to trigger the mechanisms that lead to quality of life. Knowing this, the question arises: 'What are the active components of visual art programmes that evoke these effects?'. Although the previously mentioned studies provided important insights into the possible impact of art on the quality of life of people with dementia, not much is known about the mechanisms behind the effectivity of art programmes. Many studies in the field of art and dementia concerned the production of art (Fornazzari, 2005; Liu et al., 2009). They showed that creativity remains preserved or even emerges when people get dementia. Some studies focussed on the neural aspects of art experience, for example on the activation of brain areas when viewing art works (Vartanian & Skov, 2014), and changes in art preference in people with brain damage (Bromberger et al., 2011). The Aesthetic triad model (Chatterjee & Vartanian, 2014) describes different neural systems that are thought to contribute to the aesthetic experience: the sensory motor system, the emotional valuation system and the knowledge meaning system. These systems are all involved in different stages of dementia (Chancellor et al., 2014). Based on the research on neural correlates of art, it can be speculated that some attributes of art, such as colour (Wijk et al., 1999; 2002), natural elements (Kaplan, 1995; Possin, 2010) or complexity of the art work (Biederman & Vessel, 2006; Krupinski & Locher, 1988), may impact the reactivity to art for particular types or severity of dementia.

By our knowledge, no research has been done on how specific attributes of artworks and/or severity of dementia and other characteristics of the person may impact the responsiveness to artworks. Results of such research contributes to composing individually tailored art programmes that optimally match the person's abilities and may subsequently impact their wellbeing.

In this study, we explored this theme as part of a comprehensive implementation study into the 'Unforgettable' programme in Dutch museums. This programme consists of interactive guided museum tours for people with dementia and their caregivers to provide them with a joint pleasant activity. It was modelled after the Meet Me at MoMA programme of the Museum of Modern Art in New York. In the Netherlands, the programme started in 2013 in two museums, the Stedelijk Museum Amsterdam and the Van Abbemuseum in Eindhoven. Because of the success of the

Unforgettable programme, the two museums developed an implementation project to disseminate the programme to ten other museums across the Netherlands.

This article reports on the explorative study into the responsiveness to art of people with dementia based on the studies of Kroeze (2015) and Slotwinska (2017). The following research questions were studied:

1. Is there a relationship between responsiveness to art and severity of dementia, specific cognitive impairments, or other characteristics of persons with dementia?
2. Is there a relationship between responsiveness and specific types or features of art?
3. Is there a relationship between responsiveness and specific types or features of art when controlling for the severity of dementia, specific cognitive impairments, or other characteristics of persons with dementia?

METHODS

Design

A cross-sectional observational study was conducted with people with mild to moderate dementia who were shown several artworks consecutively during guided tours in museums (see setting and participants). The observations were done as part of a study into the implementation of the Unforgettable programme for people with dementia and their caregivers.

The local Medical Ethics Review Committee stated that the study was not subject to the Medical Research Involving Human Subjects Act. An informed consent procedure was followed to make sure that people with dementia were well informed before confirming their willingness to participate in this study.

Setting and participants

The data for the study reported on in this paper were collected in the ten museums in different parts of the Netherlands that participated in the implementation study into the Unforgettable programme (2014-2017) and in one of the two museums that had started with the programme a year before the start of the implementation study (in 2013). The museums had different art collections, ranging from historical objects to modern art and mounted animals. Each museum offered the Unforgettable

programme after a training and implementation period. The Unforgettable programme consists of an interactive, 90 minutes museum tour, designed for people with dementia and their informal and professional caregivers. It is led by a specially trained museum guide and one or two hosts. The training for the guides and hosts was given two to three months prior to the launch of the programme in each museum and was conducted by the project coordinator of the Unforgettable programme. The training included an introduction to dementia, information about how dementia is experienced by people with dementia themselves and their caregivers, background information about the theory behind the programme and one pilot tour per trainee. The Unforgettable programme is offered once a month and is organised around a theme, for example 'animals' or 'family'. For each tour four to six different art works are selected around the theme and presented. The guide asks open questions (e.g. about the colours, aesthetic preferences), stimulates interaction between the people with dementia and their caregivers and between the participants, and gives small assignments to be executed in couples. The assignments fitted within the theme of the tour, were executed individually or in pairs, and ranged from simple drawing assignments, to 'adopt the same pose as a figure in the artwork' or 'talk about the object in couples'.

All observations for this study took place during these guided interactive tours in museums. To test the different hypotheses of this study it was intended to collect observations of at least 128 people with dementia. This number was based on an a-priori power analysis (effect size $f = .25$, desired power .8 and α of .05), expecting moderate differences in responsiveness of people with mild to moderate dementia, taking into account their background characteristics, when shown different types of art works.

In the period between May 2014 and December 2016 data was collected among the participants of the Unforgettable programme. Inclusion criteria were: having a dementia diagnosis and participating in the whole tour. There were no specific exclusion criteria.

Measurements

To categorise and compare the different attributes of the artworks shown the *Assessment of Art Attributes (AAA) scale* (Chatterjee et al., 2010) was used. Chatterjee et al. (2010) identified six formal-perceptual attributes (balance, colour saturation, colour temperature, depth, complexity and stroke) and six conceptual-

representational attributes (abstraction, animacy, emotion, realism, objective accuracy, and symbolism) that could be scored on a 5-point Likert scale. This instrument was tested by artistically naïve and experienced groups who assessed art attributes with a high level of agreement (Chatterjee et al., 2010). This indicates that the AAA is a reliable way of assessing art attributes. Moreover, in order to categorise the artworks on the art attribute 'nature', a Nature scale (Appendix A) was developed and used. Based on the assumption of Kaplan et al. (1972), that the difference between natural and man-made scenes can be seen as a continuum ranging from nature to man-made aspects exclusively, a Nature 5-point Likert scale was created that was used to categorise the artworks ranging from 5 (highest in nature) to 1 (highest in man-made aspects).

The *Interact instrument* as adapted by Van Dijk et al. (Baker & Dowling 1995; Van Dijk et al., 2012) was used by trained observers to systematically observe the participants responsiveness to the artworks during the guided tour as an indicator for art experience and social participation. The Interact instrument consists of five subscales: mood, speech, relating to person, relating to environment and need for prompting. The six 'relating to person' items were scored from three perspectives, i.e. relating to the caregivers, relating to the guide and relating to the other participants. The adapted Interact observation scale consists of 47 items in total. The items are scored on a 5-point Likert-type scale rating the frequency of occurrence of relevant behaviour: 'not at all', 'a bit of the time', 'some of the time', 'most of the time' and 'nearly all the time'. The Interact has previously been used in (Dutch) dementia care research and has been shown to have good psychometric properties (Van Weert et al., 2005). Results of the Interact are commonly reported per item; no total score is calculated (Van Dijk et al., 2012; Van Weert et al., 2005).

Background characteristics of the person with dementia (e.g. age, sex, experience with museums/art, diagnosis, specific cognitive impairments) were collected with a 'take home questionnaire', composed specifically for the study, that had to be filled out by the caregiver. The caregivers also filled in a short questionnaire to assess the cognitive functioning of the person with dementia, based on the Global Deterioration Scale (Reisberg et al., 1982) and the Brief Cognitive Rating Scale (BCRS; Reisberg & Ferris, 1987). The questionnaire consisted of eight items measuring ability to concentrate, short-term memory, long-term memory, orientation, language, daily functioning, motor functioning, and 'mood and behaviour' on a 4-point Likert scale

varying from hardly any (visible) impairment to severe impairment. In general, questionnaires filled out by caregivers have been proven to give a reliable assessment of dementia (e.g. Monnot et al., 2005).

Procedure

A few days before the Unforgettable tour, the participants (persons with dementia and their informal and professional caregivers) received an email from the contact person of the museum with information about the study. Just before the start of the art tour the observer(s) invited the participants to participate in the study into the Unforgettable programme. If they decided to participate, they were asked to sign an informed consent form. Of these participants, two to four persons, depending on the number of observers, were randomly selected for observation as they could not all be observed due to practical reasons. People got a number (1-6) in order of arrival. This number corresponded with the numbers (1-6) on a dice. The dice was rolled to decide who was to be observed. The people with dementia and the caregivers did not know who was to be observed. The observers were trained by IH and supervised by RMD in using the Interact observation scale first by observing film recordings of people with dementia in a care institution, and by discussing what was observed afterwards until consensus was reached. Second, the observers joined a museum tour, both observed the same participants independently and discussed their assessments afterwards.

The artworks shown during each guided tour were photographed and described. Afterwards, a researcher and an art historian independently categorised these artworks according to the AAA-scale and Nature scale. On most artworks consensus was reached. Of the artworks for which no consensus was reached, the view of the art historian prevailed. After the tour the participants received the take home questionnaire and were asked to fill it out and to return it by post within three days.

Data Analysis

As participants were presented different art works during the different guided tours and in different museums, the observations cannot be seen as repeated measures, but should be seen as single measures. All collected data were entered in a coded anonymised database. Using IBM SPSS Statistics 23.0, descriptive analyses were conducted on the quantitative data (characteristics, cognitive impairments). The kappa coefficient was used to assess the interrater reliability of the observed mood and behaviour as measured by the Interact observation scale.

Associations between characteristics of the people with dementia (e.g. education, experience with art, severity of dementia) and their responsiveness, and between types or features of art and the responsiveness to them, were calculated using the Spearman rank correlation coefficient. Group differences were calculated using the Mann Whitney U test or the Kruskal Wallis test, depending on the type of variable.

The scores on the AAA-scale (1-5) and on the Nature scale (1-5) were divided into 'low' and 'high' by a researcher. The artworks that were scored 3 by the art historian were excluded from the analysis as they did not clearly fit into the, for example, figurative or abstract, or warm or cold colours, categories. This was not the case for the Nature scale as the score of 3 was regarded as 'high in nature' and therefore no artworks were excluded.

To test the effects of art attributes on the responsiveness ANCOVA's were conducted, with the characteristics that were associated with the responsiveness as covariate. Only characteristics and art attributes with a correlation coefficient (Spearman's rho) of at least 0.200 were selected to test the effects. Normality was tested with the Kolmogorov-Smirnov test. The assumption of homogeneity of variance was tested with Levene's test.

RESULTS

Participants

A total sample of 72 participants were observed during the guided tours, their background characteristics are shown in Table 1. Each participant saw three to six artworks, adding up to 432 observations. On average people viewed five artworks, 6% saw only three artworks and 11% saw six art works. The majority of the people with dementia (70%) joined the tour with an informal caregiver, a minority (29%) joined the tour in a group from a care facility (e.g. Meeting Centre or Nursing Home) together with care professionals (22%) or volunteers (7%), who also answered the questions about the persons with dementia. For 1% the accompanying person was unknown. The average number of people participating in the tour (including people with dementia, caregivers, guide and volunteers) in one group was 13, ranging from 5 to 19 people. The average number of people with dementia in one group was 4, ranging from 1 to 8 people with dementia.

Table 1. Characteristics of the participants (N=72)

Characteristic	N*
Gender	
Female	43
Male	29
Age (mean, SD)	81.33 (7.64)
Severity of dementia	
Mild	10 (20%)
Moderate	27 (54%)
Moderately severe	13 (26%)
Type of dementia	
Alzheimer's	20 (46.5%)
Dementia NOS	9 (20.9%)
Vascular	7 (16.3%)
FTD	2 (4.7%)
Other	5 (11.7%)

*n varies due to missing data

Totals may not equal 100% because of rounding

Extracting dependent variables from Interact instrument

To extract dependent variables from the Interact instrument a Principal Components Analysis was applied with Varimax rotation. Six items (*verbal anger, yelling, aggressive, wandering/restlessness, negativism/complaining and reluctance*) had little or no variability (almost always scored zero) and were therefore removed from the analysis. Appendix B shows the correlation matrix with components. Based on the statistical significance, clarity of interpretation and relevance to the research questions, four components were chosen as dependent variables in the analysis (the items they consist of are presented in parentheses):

- **appreciation** (*attentive/focused, listened to voice/noise of guide, tracked observable stimuli, held eye contact with guide, relaxed/content, alert/active, enjoying self, listened to voice/noise of others, happy/content, not bored/inactive, not confused, not fearful/anxious, and not tearful/sad*);
- **active responsiveness** (*did things from own initiative, comments/questions about activities/objects, talked spontaneously, responded to speaking of others, recalled memories*);
- **interaction with caregiver** (all items in relation to caregiver: *co-operated, related well, listened to voice/noise, responded to speaking and held eye contact*);

- **interaction with others** (*related well and co-operated well with guide and with others, responded to speaking of guide and responded to activities/objects*).

Together these four components comprise 58.27% of the total variance.

The interrater reliability of the Interact observation scale was substantial (Kappa = .612, $p < .001$) (Cohen, 1960).

Association responsiveness to art and background characteristics

The dependent variables ‘appreciation’, ‘active responsiveness’, ‘interaction with caregiver’ and ‘interaction with others’ were non-normally distributed. Table 2 shows the associations between the background characteristics of the persons with dementia and their responses to art.

The responsiveness of the people with dementia as measured by *appreciation* was associated with measures such as the severity of dementia ($\rho = -.23$; $p = .00$), recent memory ($\rho = -.15$; $p = .02$), daily functioning ($\rho = -.19$; $p = .01$), language functioning ($\rho = -.27$; $p = .00$), motor functioning ($\rho = -.23$; $p = .00$) and mood and behaviour ($\rho = -.17$; $p = .01$) of the people with dementia. For these correlations it applies that the less severe dementia or the lower the cognitive impairment is, the higher the appreciation.

The *active responsiveness* also appeared to be related to the diagnosis ($H = 14.74$; $df = 2$; $p = .00$). People diagnosed with vascular dementia had the highest mean score (1.77) on active responsiveness compared to people with Alzheimer’s (.94) and other types of dementia (.95). Moreover, the severity of dementia ($\rho = -.32$; $p = .00$), recent ($\rho = -.21$; $p = .00$) and long term memory ($\rho = -.27$; $p = .00$), orientation ($\rho = -.19$; $p = .01$), daily functioning ($\rho = -.32$; $p = .00$), language functioning ($\rho = -.42$; $p = .00$) and mood and behaviour ($\rho = -.19$; $p = .01$), were associated with active responsiveness. People with less severe dementia or who were less cognitively impaired were more likely to show more active responsiveness.

Interaction with caregiver: People with worse motor functioning ($\rho = -.27$; $p = .00$) and more problems in mood and behaviour ($\rho = -.14$; $p = .05$) were more likely to have less interaction with their caregiver.

Interaction with others was found to be associated with the diagnosis ($H = 7.46$; $df=2$; $p = .02$). People diagnosed with vascular dementia had the highest mean score (3.51),

people with Alzheimer's the lowest (3.13), and people diagnosed with another type of dementia scored in between (on average 3.26). Also the severity of dementia ($\rho = -.19$; $p = .01$), recent ($\rho = -.14$; $p = .04$) and long term memory ($\rho = -.20$; $p = .00$), daily functioning ($\rho = -.18$; $p = .01$), language functioning ($\rho = -.31$; $p = .00$), and mood and behaviour ($\rho = -.17$; $p = .02$) appeared related to interaction with others. People with less severe dementia or who were less cognitively impaired were more likely to interact more frequently with others. No relationships were found between the person with dementia's sex, age, education, previous experience with art and their responsiveness regarding interaction with others.

Table 2. Associations between responsiveness to art and background characteristics

Characteristic	Appreciation	Active responsiveness	Interaction with caregiver	Interaction with others
Sex	U = 11810.50; z = -.12; p = .90	U = 10326.50; z = -1.86; p = .06	U = 8996.00; z = -1.40; p = .16	U = 10365.00; z = -1.30; p = .20
Age (years), mean (SD)	$\rho = -.04$; p = .54	$\rho = .05$; p = .38	$\rho = -.05$; p = .41	$\rho = -.02$; p = .74
Education	$\rho = .06$; p = .40	$\rho = -.11$; p = .11	$\rho = .01$; p = .92	$\rho = .05$; p = .47
Previous experience with art	U = 4206.00; z = -.78; p = .43	U = 4060.50; z = -.99; p = .32	U = 3909.00; z = -.61; p = .55	U = 4231.00; z = -.29; p = .77
Diagnosis	H=4.95; df=2; p = .08	H=14.74; df=2; p = .00	H=.02; df=2; p = .99	H=7.46; df=2; p = .02
Severity of dementia	$\rho = -.23$; p = .00	$\rho = -.32$; p = .00	$\rho = -.07$; p = .35	$\rho = -.19$; p = .01
Concentration	$\rho = -.09$; p = .21	$\rho = -.05$; p = .45	$\rho = .51$; p = .47	$\rho = -.05$; p = .51
Recent memory	$\rho = -.15$; p = .02	$\rho = -.21$; p = .00	$\rho = .03$; p = .65	$\rho = -.14$; p = .04
Long term memory	$\rho = -.10$; p = .14	$\rho = -.27$; p = .00	$\rho = .12$; p = .07	$\rho = -.20$; p = .00
Orientation	$\rho = -.01$; p = .94	$\rho = -.19$; p = .01	$\rho = .06$; p = .38	$\rho = -.09$; p = .21
Daily functioning	$\rho = -.19$; p = .01	$\rho = -.32$; p = .00	$\rho = -.03$; p = .65	$\rho = -.18$; p = .01
Language functioning	$\rho = -.27$; p = .00	$\rho = -.42$; p = .00	$\rho = -.09$; p = .24	$\rho = -.31$; p = .00
Motor functioning	$\rho = -.23$; p = .00	$\rho = -.10$; p = .14	$\rho = -.27$; p = .00	$\rho = -.08$; p = .24
Mood and behaviour	$\rho = -.17$; p = .01	$\rho = -.19$; p = .01	$\rho = .14$; p = .05	$\rho = -.17$; p = .02

Significant in bold $p < 0.05$ - Mann Whitney U test, Spearman Rho and Kruskal Wallis test

Association responsiveness to art and specific types or features of art

Table 3 shows the associations between the different types or features of art and the people with dementia's responses to art.

The more natural elements in the artwork, the less responsiveness as measured by appreciation ($\rho = -.12$; $p = .04$), and less interaction with others ($\rho = -.21$; $p = .00$) were observed. The more abstract an artwork, the less interaction with others ($\rho = -.18$; $p = .00$) and less responsiveness as measured by appreciation ($\rho = -.13$; $p = .02$) were found. Artworks which were considered to be more emotional provoked more active responses than less emotional artworks ($\rho = -.11$; $p = .05$). Also increased colour saturation of artworks appeared to be associated with increased active responsiveness ($\rho = -.12$; $p = .05$). Moreover, artefacts (i.e. objects not originally meant as artworks, such as historical objects, clothing or crockery) revealed more active responsiveness than artworks originally meant as art ($\rho = -.20$; $p = .00$). Artworks which were more balanced evoked less interaction with caregivers ($\rho = -.12$; $p = .04$).

Table 3. Associations between responsiveness to art and types or features of art

Characteristic	Appreciation	Active responsiveness	Interaction with caregiver	Interaction with others
Abstraction	$\rho = -.13$; $p = .02$	$\rho = .06$; $p = .34$	$\rho = -.02$; $p = .73$	$\rho = -.18$; $p = .00$
Balance	$\rho = -.08$; $p = .19$	$\rho = -.07$; $p = .26$	$\rho = -.12$; $p = .04$	$\rho = -.10$; $p = .08$
Emotionality	$\rho = .06$; $p = .27$	$\rho = .11$; $p = .05$	$\rho = .02$; $p = .75$	$\rho = .09$; $p = .11$
Complexity	$\rho = .07$; $p = .22$	$\rho = -.08$; $p = .19$	$\rho = .04$; $p = .53$	$\rho = .02$; $p = .18$
Colour saturation	$\rho = -.02$; $p = .78$	$\rho = .12$; $p = .05$	$\rho = -.03$; $p = .68$	$\rho = .08$; $p = .18$
Colour temperature	$\rho = -.03$; $p = .59$	$\rho = -.08$; $p = .20$	$\rho = -.02$; $p = .78$	$\rho = -.04$; $p = .50$
Natural elements	$\rho = -.12$; $p = .04$	$\rho = -.05$; $p = .37$	$\rho = -.01$; $p = .90$	$\rho = -.21$; $p = .00$
Artefact	$\rho = .06$; $p = .34$	$\rho = -.20$; $p = .00$	$\rho = .00$; $p = .99$	$\rho = -.04$; $p = .55$

Significant in bold $p < 0.05$

Influence background characteristics on relationship between responsiveness and specific types or features of art

In a two-way ANCOVA a significant difference in 'interaction with others' was found when looking at artworks with a lot of natural elements (mean = 3.02) compared

to artworks with few natural elements (mean = 3.43), whilst adjusting for long term memory impairment ($F(1,205) = 13.791, p = .00$). Levene's test showed that the error variances were unequal, $F(1, 206) = 5.838, p = .02$. A significant difference in interaction with others was also found when looking at artworks with many natural elements (mean = 2.30) compared to artworks with few natural elements (mean = 3.38), whilst adjusting for language impairment ($F(1,190) = 13.618, p = .00$). The results of the Levene's test showed that the error variances were equal, $F(1,191) = .326, p = .57$. Moreover, a significant difference in responsiveness was found for artworks scoring high (mean = 2.99) and low (mean = 3.49) in natural elements, when controlling for diagnosis ($F(1,188) = 16.166, p = .00$). The error variances were unequal, $F(1,189) = 8.23, p = .01$.

DISCUSSION

This paper reports on the results of a sub-study within the implementation study into the Unforgettable museum programme for people with dementia and their caregivers. This sub-study investigated whether individuals with mild to moderate dementia react differently to various types of art, whether their responsiveness to art is associated with certain background characteristics and whether the relationship between responsiveness to art and specific types or features of art is influenced by these characteristics.

The associations found between characteristics of the people with dementia and their responsiveness to art were small to moderate. People with less severe dementia, or with fewer cognitive impairments were found to show more appreciative and active responsiveness. People diagnosed with vascular dementia showed more active responsiveness than people with Alzheimer's and other types of dementias. An explanation for this difference may be that, as people with vascular dementia in general have less problems with episodic memory than people with Alzheimer's (Graham et al., 2004), the artworks evoke more personal memories in people with vascular dementia, which subsequently may lead to more active responsiveness. People with worse motor functioning were more likely to have less interaction with their caregiver. It is notable that no other background characteristics, such as the severity of dementia, are found to be related to the interaction with the caregiver. When looking at interaction with others, people with less severe dementia or who were less cognitively impaired were more likely to interact more with others. People diagnosed with vascular dementia showed the most interaction with others while

people with Alzheimer's showed the least interaction with others. No relationships were found between the person with dementia's sex, age, education and their responsiveness, which could mean these characteristics simply do not influence the responsiveness of people with dementia. The finding that the responsiveness to art is not influenced by previous art experience indicates that the programme is suitable for both people with and without experience with museums or art.

The associations between types or features of art and the responsiveness to them were found to be small. Artworks with more natural elements and more abstract artworks revealed less appreciative responsiveness and less interaction with others. The latter is not in line with the findings of Camic et al. (2015), who found that the general responses of participants with mild to moderate dementia in art programmes were similar for conceptual and installation art in a contemporary art gallery, which is generally more abstract, compared to a traditional art gallery, where 16th and 17th century European art, generally figurative, dominated. Artworks which were more balanced evoked less interaction with caregivers. The finding that artworks which were considered to be more emotional provoked more active responses than less emotional artworks is in line with the study results of LaBar et al. (2000), who found a relation between emotionality of art and the reactions to it. They found that photos with emotionally arousing scenes attracted more viewing time than photos with non-emotionally arousing scenes. However, they found this not only in people with early stage Alzheimer's disease, but also in the young and aged controls who participated in their study. More active responsiveness was also seen for artworks with more saturated colours and for artefacts. The outcome that artefacts, objects not originally meant as artworks, evoke more reactions than artworks, may be explained by the familiarity of such objects. Familiar objects help people with dementia to feel more comfortable and increase their social and functional abilities (Son et al., 2002). No associations were found between the complexity of the artwork, the temperature of the colours used in the artwork and the responsiveness to them.

The negative association between frequency of interaction with others and the number of nature elements in artworks appeared not to be influenced by impairments in long term memory or language, nor to diagnosis.

It may be that the differences in responsiveness to different types of art are not related to cognitive processes or other personal characteristics, but that they are

the result of other factors, such as working method of the guide, but also personal preferences or personal experiences. This is in line with what De Medeiros and Basting (2013) call the ‘incredibly individual nature of cultural art’. They argue that ‘What could be meaningful for one person, could not mean anything to another’. According to De Medeiros and Basting (2013), people are likely to be affected in different ways, even when participating in the same intervention. Not finding differences in reactions might also be related to the setting in which the art works were shown. The setting used in this study; a group art tour for people with dementia, might not have been completely suitable for measuring the reactions to the art itself. According to Windle et al. (2018) ‘visual art programmes are by their nature ‘complex’ because they contain several independent interacting components (e.g., settings, people receiving and delivering, their behaviours and responses)’. This may have influenced the reactions to the art. The lack of finding other associations between responsiveness and types or features of art may also be caused by too little differences between the included art works. They were selected to fit within the theme of the tour rather than on their specific characteristics, for example being typically abstract or typically figurative. For future studies, in order to further study possible effects of artworks a more selective sample of artworks should be considered by using artworks that are previously selected on their features. Also, it is recommended for future studies to include larger samples in which more possible influencing confounders are accounted for like aspects of the physical environment, personality factors, group composition and the skills and working method of the guide to get further insight into what other factors possibly influence the positive experience of art in people with dementia.

Limitations

To test whether there is a relationship between responsiveness and specific types or features of art when controlling for characteristics of persons with dementia ANCOVA's were conducted. However, because the dependent variables were non-normally distributed and some of the error variances were unequal, the results of these analyses should be interpreted with caution. Therefore non-parametric tests were done to test whether there is a relationship between responsiveness to art and characteristics of persons with dementia, and whether there is a relationship between responsiveness and specific types or features of art. In this study we did not control for the group setting (different participants with different types and severity of dementia) and time available for the participant to respond to art works

(dependent of the number of art works shown). Neither did we include environmental factors, such as noise level in the museum or lighting/size of art works. We therefore don't know if these factors influenced the responsiveness to the art works. It might be relevant to investigate this in future studies. We also did not control for the sequence of presentation of the art works, because intermediate analyses showed that there was no relation between the sequence of the art work and responsiveness. In future studies, however, it may be interesting to also take this potentially influencing factor into account. Caution is also needed in interpreting the results of this study, as it was underpowered and the observations were not fully independent from each other due to the fact that participants were presented several artworks consecutively, which means that all participants were counted several times. In this study we used an existing classification method to categorise different types of art. In future studies it would be interesting to further investigate which other elements of art works may possibly influence the responsiveness in people with dementia. The responsiveness to the art shown during the tours was assessed by observations of researchers. This means that, for example, mood reactions were subjectively interpreted from facial and verbal expressions. In future research, it could be interesting to let the participants fill out a short Visual Analog Scale after each presented art work (Johnson et al., 2015). Sometimes an artwork was discussed for too short to be able to score all observation items for every person that was observed during the tour. This may have influenced the reliability of the observations. In future studies, it would be advisable to use an observation instrument with less items and, if possible, video recordings may be considered to more thoroughly evaluate the behaviour and to observe participants individually and for a longer time. However, in our project it was considered too intrusive. Finally, most of the participants in this study were diagnosed with Alzheimer's disease and vascular dementia. This sample thus represents the majority of people with dementia, which makes the findings more generalisable. There were too few people with other types of dementia to investigate differences in reactions by other diagnostic subgroups of people with dementia. As the museums not only differed in art collection, but also in type of building, size and number of visitors, for future research we recommend to include these factors in the analyses to investigate whether the museum setting and characteristics influenced the responsiveness to art. In this explorative study, the subgroups were too small to investigate this properly.

Scientific and societal impact

This study provides insight into the characteristics of both the participants and the artworks that may impact the experience of art programmes. This study's findings contribute to the development of person-centred care activities for people with dementia: Insight into what responses are evoked by different types of artworks in people with mild to moderate dementia, can help to select art works that are more likely to appeal to different subgroups of people with dementia. It is expected that this will not only contribute to the increase of social participation and quality of life of people with dementia, but will also affect the family caregiver positively: If the art programme is more attractive for the person with dementia, it is also likely to be a more positive experience for the caregiver participating in the art programme.

Looking at the effect of dementia severity, this study's results indicate that the more severe the dementia, the less responsiveness was observed. In general, it is assumed that art programmes for people with more severe dementia require certain adjustments (Livingston et al., 2016). Since people with more severe dementia react less to art in general, - which could mean they have less associations with art -, it would be interesting to compare their responsiveness to viewing art with their responsiveness in a creative art assignment programme.

From research done by Boutoleau-Brettonnière et al. (2016) we know that, for example, people with frontotemporal dementia, despite retaining aesthetic judgement, have difficulties with abstraction, attention and emotional processes when looking at art. Therefore, it would be interesting for future research to also focus on other types of dementia. Furthermore, it would be interesting to study differences in reactivity to art between healthy elderly persons, persons with cognitive impairments and persons with other disorders like depression.

CONCLUSION

The relationships between types of art or background characteristics of the people with dementia and their responsiveness to artworks were found to be small to moderate. The appreciative and active responsiveness and interaction with others during the programme appeared to be related to the severity of dementia and to specific cognitive impairments. In general, responsiveness when looking at art was lower in people with more severe dementia. The relationships between types or features of art and the responsiveness to them were found to be limited. Artworks

with less nature elements and more figurative artworks revealed more appreciative responsiveness and more interaction with others. Artefacts, objects not originally meant as artworks, evoked more reactions than artworks. To sum up, these findings are important to take into account when designing and offering art programmes for people with dementia. Knowing which type of artworks appeals most to (subgroups of) people with dementia will contribute to the optimisation of art programmes for this target group and their active participation in such programmes.

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APPENDICES

Appendix A. The Nature Scale

5 (*nature clearly dominates*)- landscapes dominate, no people,

4 (*a lot of nature but doesn't dominate*)- nature aspects are substantial but not exclusively predominating

3 (*some nature but not in natural settings*)- portraits, people in rooms, still life with predominant nature, single animal or plant pictures, stuffed animals

2 (*very little nature*)- abstract human/animal figures, cityscapes with no/very little nature involved, still art with some reference to nature

1 (*man-made aspect clearly dominates*)- abstract art, man-made objects , ceramic, abstract installations, clothing

From: Slotwinska, K. (2017)

Appendix B. Table component matrix with varimax rotation from principal component analysis

Variables	Components									
	1	2	3	4	5	6	7	8	9	10
Attentive to/focused on activity/objects	.915									
Listened to voice/noise_G ^a	.912									
Tracked observable stimuli	.871									
Held eye contact appropriately_G	.843									
Bored/inactive	-.776									
Relaxed/content	.749									
Alert/active	.735									
Confused	-.729									
Enjoying self	.703									
Listened to voice/noise_O ^b	.645									
Fearful/anxious	-.639									
Happy/content	.594									
Co-operated_CG ^c		.948								
Related well_CG		.941								
Listened to voice/noise_CG		.907								
Responded to speaking_CG		.856								
Held eye contact appropriately_CG		.776								
Related well_G			.858							
Co-operated_G			.842							
Related well_O			.624							
Co-operated_O			.581							
Responding to activity or objects			.573							
Responded to speaking_G			.541							
Did things from own initiative				.919						
Comments/questions about activities/ objects				.842						
Talked spontaneously				.838						
Responded to speaking_O				.575						
Recall memories				.558						
Talked with normal length sentences					.802					
Spoke clearly					.799					
Spoke sensibly					.797					
Laughing						.682				
Enthusiasm						.580				
Held eye contact appropriately_O						.517				
Touched objects appropriately							.738			
Tearful/sad		-.537						-.677		
Touching_G									-.832	
Repetitious mannerism										-.747
Touching_O										.822
Touching_CG										.562

^a G= guide

^b O= other participants

^c CG= caregiver

From: Slotwinska, K. (2017).

How do people with dementia respond to different types of art?





CHAPTER 5

**IMPLEMENTATION AND
IMPACT OF UNFORGETTABLE:
AN INTERACTIVE ART
PROGRAMME FOR PEOPLE
WITH DEMENTIA AND
THEIR CAREGIVERS**

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ABSTRACT

Background: Previous research shows that museum programmes can be beneficial for the quality of life of people with dementia. This study evaluated the implementation of ‘Unforgettable’, an interactive museum programme for people with dementia and their caregivers in the Netherlands, and investigated the impact of the programme’s implementation on the museums as an organisation and on the attitudes towards dementia of the museum staff.

Method: Semi-structured interviews were held with 23 stakeholders to identify facilitators and barriers to the implementation of the Unforgettable programme in twelve Dutch museums. Based on the model of Meiland et al., (2004) an overview is made of factors influencing the different levels and phases of the implementation process. The impact of Unforgettable on the attitudes of the museum staff was assessed using the Approaches to Dementia Questionnaire (n = 176).

Results: The training in the Unforgettable method, regular evaluation with the programme guides and hosts, and cooperation with other organisations appeared essential for successful implementation of Unforgettable. A lack of promotional activities was an impeding factor. Compared to before the implementation, the museum employees’ attitudes towards people with dementia became more positive.

Conclusion: Both successful dissemination of the Unforgettable programme and the more positive attitudes towards dementia of employees in museums implementing this programme can contribute to the social participation of people with dementia and thereby to their quality of life.

INTRODUCTION

Every three seconds someone in the world develops dementia. Due to a growing and greying population worldwide, the number of people with dementia is estimated to almost triple in the coming decades: In 2050 over 131 million people are expected to be living with dementia worldwide (Prince et al., 2016).

In addition to cognitive decline, people with dementia can experience changes in their behaviour and mood, such as increased aggression, agitation, anxiety and depression. These changes can negatively affect their quality of life and that of their caregivers. Optimising the quality of life of people with dementia is the focal point of their care. Several studies have shown that psychosocial interventions, such as cognitive stimulation therapy, reminiscence and physical exercise can be beneficial for people with dementia (Olazarán et al., 2010). Also, different art activities such as handling museum objects (Johnson et al., 2015), music-based interventions (Van der Steen et al., 2017) and visual art programmes (Windle et al., 2017) have shown positive effects on the wellbeing of people with dementia.

Connecting with others is one of the principal components of psychosocial interventions that benefit people with dementia (Lawrence et al., 2012). This social aspect, including social inclusion, is important for the general wellbeing of people with dementia (Dröes et al., 2017). Raising general awareness about dementia can help to promote social inclusion. In many countries worldwide (World Health Organization, 2012) this is done by developing national dementia policies (e.g. Scheltens et al. 2012, Deltaplan Dementie, 2012) and/or campaigns for a dementia-friendly society. Increasing public knowledge is also expected to help improve the attitudes towards dementia and so tackle the stigma that is still experienced by people with dementia and their carers (Gerritsen et al., 2014). Research has shown that education programmes aiming to improve the knowledge and understanding of dementia result in more positive attitudes towards people with dementia and more empathy (Hattink et al., 2015). Art interventions can lead to more positive attitudes towards dementia, as was found in the study of Roberts and Noble (2015) among medical students who participated in an art programme together with people with dementia, and in the study of Fritsch et al., (2009) among care professionals who participated in the TimeSlips programme. Little is known, however, about the effect of such interventions on the attitude towards dementia of people not primarily working in care practice.

The Unforgettable museum programme implementation study

In 2013 two Dutch museums, the 'Stedelijk Museum Amsterdam' and the 'Van Abbemuseum' in Eindhoven implemented the Dutch 'Unforgettable' programme consisting of interactive guided museum tours for people living with dementia and their caregivers. The programme was modelled after the successful Meet Me at MoMA programme of the Museum of Modern Art in New York, which showed positive effects on people with dementia (positive change in mood, higher self-esteem) and their caregivers (positive change in mood, increased feeling of social support, less emotional problems) (Mittelman & Epstein, 2009). Based on these positive results further dissemination of the programme was desirable. However, little was known at that time about the conditions for successful implementation of the programme, and possible necessary adaptations to be made, when applied in other countries and cultures. After having first very positive experiences with the programme in their own museum, the two Dutch museums decided to start a national implementation study.

Because implementation of psychosocial interventions appears to not always be adequate in care practice (Vernooij-Dassen & Moniz-Cook, 2014), and successful implementation of psychosocial support often requires adaptive implementation (Meiland et al., 2004), one of the aims of the implementation study was to get insight into the facilitators and barriers of successful implementation and possible solutions for barriers. These findings were expected to support further successful implementation and dissemination of the Unforgettable programme. To explore whether the implementation of Unforgettable influenced the museum programming or inspired museums to organise similar activities for other target groups, the impact of the programme on the museums was also studied. The implementation project was led by a national project coordinator who was appointed by the Stedelijk Museum and the Van Abbemuseum. The implementation study was designed and conducted by the department of Psychiatry of the VU University Medical Centre.

This paper reports on the study that was carried out into the implementation of the Unforgettable programme in twelve museums across the Netherlands. The study had the following research questions:

1. Which factors influence the implementation process of the Unforgettable programme during the preparation phase, the starting phase and the continuation phase?

2. What is the impact of the implementation of the Unforgettable programme on the museums as an organisation and on other museums not involved in the Unforgettable project?
3. What is the impact of the implementation of the Unforgettable programme on the attitude towards dementia of the people working and volunteering at the museums?

During this implementation study we also explore how Unforgettable is experienced and appreciated by its users. The results of this study are reported separately (Hendriks et al., 2021).

The methods and results are discussed separately for questions 1 and 2 and for question 3.

METHODS

The local Medical Ethics Review Committee has declared that the study was not subject to the Medical Research Involving Human Subjects Act.

Intervention: the Unforgettable programme

The Unforgettable programme comprises an interactive guided museum tour, especially designed for people with dementia and their informal caregivers. Professional caregivers can also participate together with a person or group of persons with dementia. The goal is to provide the participants a pleasant activity together.

Each Unforgettable tour is constructed around a theme, for example ‘rituals’, ‘humans and animals’ or ‘colour’. Four to six art works that fit into the theme are selected and discussed by the participants. The programme is offered once every month.

The Unforgettable programme is led by a specially trained museum guide, who leads the discussion during the tour, and one or two trained hosts, who assist the guide and/or support the participants. The training was given by the project coordinator of the Unforgettable programme. For the guides, the training started with a two-day introduction in which information about the occurrence, symptoms and consequences of dementia, and information about the Unforgettable method were provided. In the weeks following the two-day introduction each trainee guided one pilot tour with people with dementia and caregivers participating. The hosts received

a one-day introduction course about dementia and the Unforgettable method and joined a pilot tour. Besides some small adaptations, for example the Dutch guides do not start each new art work with one minute of silent observation, the Unforgettable programme is similar to the Meet Me at MoMA programme.

Question 1 and 2: factors influencing implementation and impact on museum as organisation and on museums not involved in the Unforgettable project

Design

A qualitative multiple case study was conducted. Semi-structured interviews were conducted with key figures involved in the implementation of the Unforgettable programme in twelve museums regarding the experienced facilitators and barriers during the preparation, starting and continuation phases of the implementation, and regarding the impact of the programme on their organisation.

Setting and participants

In the period between August 2014 and January 2017 data were collected through semi-structured interviews with stakeholders (n = 23) involved in the implementation of the Unforgettable programme in the twelve museums. These stakeholders were purposively selected (Barbour, 1999). All stakeholders were interviewed once, each at different moments of implementation. A stakeholder was eligible for inclusion if he or she was a representative of an organisation involved in one or more of the implementation phases (preparation, execution, and continuation) of the Unforgettable programme. There were no specific exclusion criteria.

Measurements and procedure

To collect the data a semi-structured interview schedule was used in order to assess the impact of the programme on the museums and to identify facilitating and impeding factors during the preparation (two to three months before the official start of the programme), starting (zero to six months after the official start) and continuation phases (seven or more months after the official start) of the implementation. Regarding the continuation phase, also expected facilitators and barriers were inventoried. This schedule was based on the theoretical framework for tracing facilitators and barriers of adaptive implementation developed by Meiland et al. (2004). This framework distinguishes different levels: the micro or primary process/user level, the meso or inter-organisational level and the macro or societal level (health care system, legislation and policy). In addition, it includes (pre)

conditions existing at the start of the implementation process, i.e. features of the programme in general and human and financial conditions.

Based on this theoretical framework an interview schedule with open-ended questions was composed with topics that were potentially associated with factors facilitating or impeding the implementation process during the different phases of implementation and levels. The same interview schedule was used for all museums. However, for each key figure, different topics were selected in the interview that matched their expertise and involvement in the implementation process.

The interviews were conducted by a researcher who emphasised the guarantee of anonymity. The interviews were conducted between 1 and 18 months after the start of the implementation period of the Unforgettable programme in the museums and lasted between 38 and 115 minutes, with a mean length of 60 minutes. Besides the interviews, logbooks that were kept by the project coordinator for each museum were checked for additional information. To answer the question about the impact on the museums as an organisation, in addition to the interviews, the researchers kept a list with (plans for) new initiatives inspired by the Unforgettable programme. This list contained initiatives in the museums involved in the Unforgettable project, as well as in other museums who were not involved in the Unforgettable project.

Data analysis

All interviews were recorded on tape and transcribed verbatim. Using ATLAS.ti, content analysis (Hsieh & Shannon, 2005) of twelve of the interviews was carried out by two independent researchers to ensure reliability. When the researchers disagreed on a code, they discussed it until consensus was reached. The framework of Meiland et al. (2004) was used as a coding schedule for analysing the interviews. New codes were added to this schedule when factors appeared relevant for the implementation and were not yet included in the coding schedule. Next, the factors influencing the implementation were clustered by theme and described.

Question 3: impact on attitudes of museum staff

Design

A pre-test-post-test one-group design was used. Pre-test data were collected among museum employees before the start of the training in the Unforgettable method, three to two months before the official start of the Unforgettable programme (T0), depending

on the duration of the training period. Post-test data were collected one to three months after the official start of the Unforgettable programme in the museum (T1).

Setting and participants

In the period between March 2014 and January 2017 data were collected in ten museums among employees who followed a training to provide the Unforgettable museum tours and among employees and volunteers who did not receive this training. All employees were invited to participate in the survey; there were no specific exclusion criteria.

Measurements and procedure

The employees and volunteers of the museums, who were to receive the training as well as other employees and volunteers of the museums who were not, were asked to fill out the Approaches to Dementia Questionnaire (ADQ, Lintern, 2001) to measure their attitudes towards dementia. This measure was originally developed to assess the attitudes towards people with dementia of staff working in dementia care. The scale consists of two subscales: 'recognition of personhood' (eleven items) and 'hope' (eight items). The total ADQ consists of 19 questions that can be answered on a 5-point scale ranging from 'completely agree' to 'completely disagree'. The total score on the scale ranges from 19 to 95. The higher the score, the more positive the attitude towards dementia. The ADQ has been shown to be reliable and valid (Lintern, 2001), and has been used previously among professionals, informal caregivers and lay people caring for people with dementia (Hattink et al., 2015).

Data analysis

For data analysis SPSS version 22 was used. Descriptive analyses were performed to describe the baseline characteristics of the study participants. Differences in background between the trained and the not-trained group and between completers and dropouts were analysed with Mann-Whitney U tests, Chi-Square Rank tests and Fisher's Exact tests, depending on the type of variable. Associations between the background characteristics that differed between the trained and not-trained people and their baseline ADQ score were analysed using the Spearman rank correlation coefficient, the Mann-Whitney U test and the Kruskal-Wallis test, depending on the type of variable. Differences between pre-scores and post-scores on the ADQ were analysed with a t-test. A one-way ANCOVA was conducted to compare the scores of the trained and not-trained groups while controlling for the background characteristics

that significantly differed between the groups and were associated with the baseline ADQ score. Associations between change in score and the background characteristics were calculated using the Spearman rank correlation coefficient and the Mann-Whitney U test dependent of the type of variable. The used significance level for all tests was $\alpha < 0.05$.

RESULTS

Question 1

Participants

From the museums we interviewed seven educational staff members/programme coordinators, four tour guides, one PR staff member, one museum director and one Unforgettable programme host. From the care sector two persons from informal caregiver organisations, two persons working in a Meeting Centre, one Dementia Network coordinator and one person from a memory clinic in an Alzheimer Centre were interviewed. Additionally, we interviewed the three Unforgettable project coordinators who successively led the implementation during the study period.

Facilitators and barriers to implementation

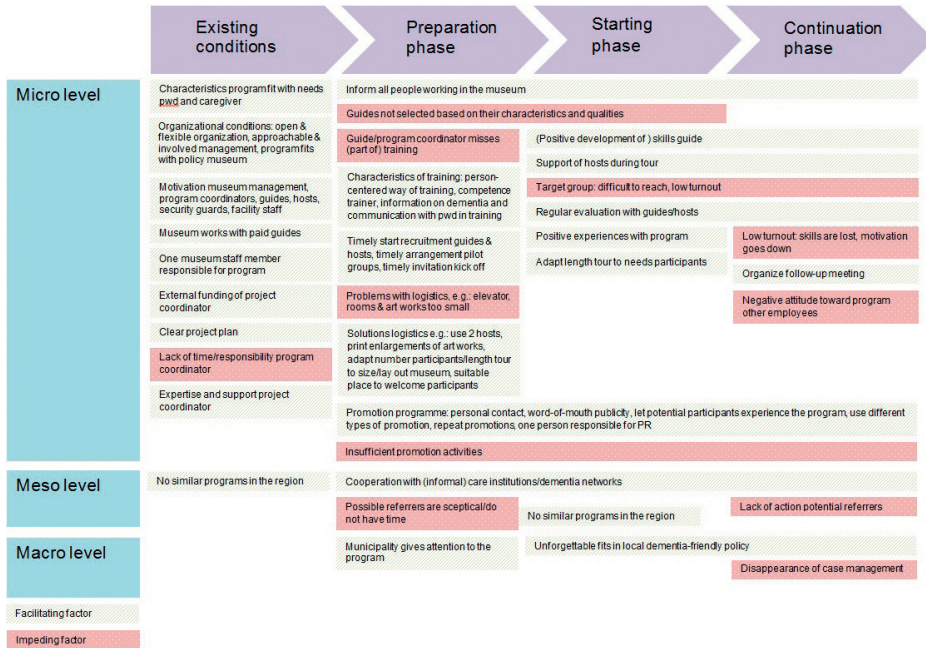
Figure 1 provides an overview of the experienced facilitators and barriers on the micro, meso and macro levels for the existing conditions before the start of the implementation and in the three subsequent phases of implementation: the preparation, starting and continuation phases.

Micro level

Operational and organisational conditions

As to the existing conditions, *clear project plan* was seen as a facilitator for successful implementation by most key figures. However, some of them would have liked to have received the budget plan beforehand so they could have anticipated costs involved in the project. An *open and flexible organisation* and the experience that the *programme fits with the vision and policy of the museum* were found to be facilitating for the implementation, just as an *approachable and involved management*.

Figure 1. Overview facilitators and barriers



Recruitment guides and hosts

In the preparation phase many facilitating factors for successful implementation had to do with the *recruitment of the guides and hosts*. Making a profile of *the characteristics required for a guide* and selecting them on their qualities, characteristics and previous experience with dementia was seen as a facilitator. In some museums the (voluntary) hosts quit during the training period because of the requested commitment. Organising an information meeting beforehand and a not too intensive training with respect to the requested amount of time that should be spent on the training, were therefore suggested as a solution. To make sure the guides were motivated for the programme it also proved helpful to let the *guides sign up themselves* instead of the programme coordinator preselecting them. Moreover, it appeared to be easier to work with *paid guides* than with voluntary guides as the former felt more responsible.

Training guides and hosts

Concerning the training, which took place in the preparation phase, the *personal approach and competence of the project coordinator* who trained the guides and hosts was often mentioned as a facilitator. Also the content of the training, including the provided *information on dementia and the contact with people with dementia*, as well

as the open atmosphere during the training sessions were seen as facilitators. In some cases the programme coordinator of the museum did not take part in the training, which was experienced as a barrier. The mandatory nature of the training was experienced as facilitating the implementation of the programme, while *guides and programme coordinators who missed (parts of) the training* impeded successful implementation. In one museum, due to extreme weather conditions, the training had to be provided on one day, which was also experienced as impeding a successful implementation.

Other museum employees

In all phases of the implementation it appeared to be important to *inform and continue to inform other employees of the museum*, such as security guards, people working at the reception desk and in the museum restaurant. *Personal contact* in informing them or letting them *experience the programme* themselves was experienced as helpful for the implementation.

Promotion of the programme

Personal contact was a factor that was mentioned not only as facilitating in informing the people working in the museum, but also in relation to the promotion of the programme. *Continuous promotion* appeared to be of great importance in all phases of the implementation. Letting possible users and referrers *experience the programme* appeared to be essential. Some programme coordinators *lacked time* to prioritise activities for the programme which often led to less promotion and consequently to lower turnout.

Low turnout

In the start and continuation phase, in some museums the lack of promotion and the *difficulty of reaching people with dementia living at home and their caregivers* led to *fewer participants* than expected. As a consequence in some cases this led to *decreased motivation and decreased skills of the guides and hosts*. *Regular evaluation* with guides and hosts as well as the organisation of a *follow-up meeting* with the project coordinator in the continuation phase were seen as helpful to keep up the skills and motivation of the guides and hosts.

Meso level

Cooperation with other organisations

Collaboration with and making use of the networks of other organisations such as *(informal) care or support organisations* and caregiver organisations helped in the promotion of the programme and recruitment of participants throughout all phases of implementation. *Referrers not taking action* to inform possible participants about the programme was experienced as a barrier to the implementation.

Macro level

Attention for the programme on a regional level

Support or *attention for the programme by the local municipality or a municipality/region with aspirations to become a dementia-friendly community* was seen as facilitating the implementation of Unforgettable.

Question 2

Impact of the programme on the museum

Six months after the implementation of the Unforgettable programme in all museums the programme was still offered as part of the museum programming. In some museums the implementation of the Unforgettable programme led to plans for new programmes for other groups of people with special needs, such as: tours for blind people, people with hearing disabilities, people with Down syndrome, elderly people in general, or a tour exclusively for caregivers. One museum worked with the Unforgettable method outside the museum: they brought the art works inside a care institution and used the Unforgettable method to start conversations on the art works with the residents. Another museum also made plans to do this. Some key figures mentioned that the museum guides, who offered the interactive tours, also used the Unforgettable communication method in other groups visiting the museum, such as elderly people without dementia, young children and teenagers. Because of the positive experiences with the Unforgettable method in one of the museums, they let the Unforgettable guides train other guides to apply a more interactive way of working according to the method used in the Unforgettable programme.

The Unforgettable museums met yearly in a meeting organised by the project coordinator of Unforgettable. In this meeting they could share experiences and ideas, which was highly appreciated. According to the key stakeholders, besides these meetings, there was not much contact or collaboration between the museums

that implemented the Unforgettable programme. However, one of the museum programme coordinators experienced interest in their programme by other museums in their region not involved in the implementation project. Another museum already shared its knowledge and experience with a museum in their region. Two Unforgettable museums planned to share their knowledge with other museums through a platform and through a one-time meeting respectively. Also, the Unforgettable project coordinator was approached by museums that were not involved in the implementation project, both from the Netherlands and from abroad, expressing their interest in Unforgettable.

Question 3

Participants

A total of 256 employees and volunteers of the museums participated in this study. Of these 120 persons were trained in the Unforgettable method, the 136 other employees and volunteers were not directly involved with the Unforgettable programme. The background characteristics of trained and untrained museum employees and volunteers that completed the pre-test of the ADQ are detailed in Table 1.

Significant differences between gender, age, position in museum, years of employment, hours of work per week, being informed about dementia and experience with dementia were found between the trained and not-trained persons. No significant differences in marital status and education were found. Associations between the characteristics that differed between the groups and their baseline scores on the (subscales of the) ADQ can be found in Table 2.

A total of 176 people filled out the post-test questionnaire, the response at post-test was 69%. The reasons for dropout are unknown, the dropouts did not respond to repeated requests to fill out the questionnaires. No significant differences were found in age, marital status, education, years of employment and experience with dementia between the dropouts and completers. There were, however, significant differences in gender, position, hours of work per week and being informed about dementia.

Table 1. Background characteristics of trained and untrained museum employees and volunteers at baseline

Characteristic	Trained people N=120*	Untrained people N=136*	Test statistic
Sex, n (%)			
Female	82.5%	69.1%	$\chi^2 = 6.15$; $df = 1$; p = 0.01
Male	17.5%	30.9%	
Age (years), mean (SD)	57 (14.46)	48 (13.75)	$U = 4676.00$; $z = -5.06$; p = 0.00
Marital status			
Married/living together	68.1%	66.2%	$p = 0.72$ FET**
Widowed	8.4%	5.3%	
Divorced	10.1%	1.5%	
Not married	13.4%	27.1%	
Education	73.4%	74.0%	$p = 1.00$ FET**
Highly educated			
Position in museum			
Guide	36.8%	4.8%	$\chi^2 = 117.83$; $df = 2$; p = 0.00
Volunteer	50.4%	9.5%	
Educational department	6.0%	11.9%	
Curator	0.9%	8.7%	
Internship	0.9%	6.3%	
Other (marketing, HR, hospitality)	5.1%	54.8%	
Works in museum			
Less than 1 year	9.5%	16.9%	$U = 6464.00$; $z = -2.59$; p = 0.01
1 – 5 years	56.9%	27.9%	
5 – 10 years	16.4%	19.9%	
10 years or more	17.2%	28.7%	
Not applicable	-	6.6%	
Hours of work per week			
Less than 10 hours	83.6%	18.4%	$U = 2446.50$; $z = -9.71$; p = 0.00
10 – 24 hours	8.6%	18.4%	
24-32 hours	1.7%	22.8%	
32 or more hours	6.0%	33.8%	
Not applicable	-	6.6%	
Informed about dementia			
Yes	64.2%	52.9%	$\chi^2 = 14.368$; $df = 1$; p = 0.00
No	35.8%	47.1%	
Experience with dementia			
Yes	70.8%	.4%	$\chi^2 = 8.605$; $df = 1$; p = 0.00
No	29.2%	59.6%	

* n may vary among the different descriptives, **Fisher's Exact Test

Significant in bold $p < 0.05$, totals may not equal 100% because of rounding

Table 2. Associations between characteristics of museum employees and volunteers and baseline ADQ score

Characteristic	Person-centred score	Hope-score	Total score
Sex	U = 5167.00; z = -1.05; p = 0.29	U = 4724.50; z = -1.98; p = 0.05	U = 4509.00; z = -1.81; p = 0.07
Age (years), mean (SD)	ρ (rho) = -0.10; p = 0.14	ρ (rho) = -0.32; p = 0.00	ρ (rho) = -0.29; p = 0.00
Position in museum	H = 3.00; df = 2; p = 0.22	H = 3.42; df = 2; p = 0.18	H = 0.43; df = 2; p = 0.81
Works in museum since	ρ (rho) = -0.04; p = 0.59	ρ (rho) = -0.03; p = 0.60	ρ (rho) = -0.03; p = 0.63
Hours of work per week	ρ (rho) = -0.14; p = 0.03	ρ (rho) = 0.17; p = 0.01	ρ (rho) = 0.02; p = 0.81
Informed about dementia	U = 4434.00; z = -5.54; p = 0.00	U = 6746.50; z = -1.35; p = 0.18	U = 4527.50; z = -4.64; p = 0.00
Experience with dementia	U = 5265.00; z = -3.50; p = 0.00	U = 6754.00; z = -0.64; p = 0.52	U = 5338.00; z = -2.52; p = 0.01

Significant in bold $p < 0.05$

Attitudes to dementia

Table 3 shows the pre-test and post-test scores on the ADQ questionnaires for the trained and untrained museum employees and volunteers. For the trained people an increase was found in both hope ($T(91) = -3.07$; $p = 0.00$) and person-centredness ($T(91) = -6.15$; $p = 0.00$), and thus on the overall attitude toward dementia ($T(86) = -6.81$; $p = 0.00$). A statistically significant increase in overall attitude towards dementia (total score) was also found for the untrained employees and volunteers ($T(74) = -2.87$; $p = 0.00$), and more specifically in person-centredness ($T(75) = -3.41$; $p = 0.01$). No significant difference was seen in hope ($T(76) = 0.41$; $p = 0.69$). As shown in Table 4, the trained group scores significantly higher on the person-centred score than the not-trained group. There was a significant difference between the trained and not-trained individuals in person-centred score, when controlling for hours of work per week, being informed about dementia, and experience with dementia ($F(1,153) = 6.01$; $p = 0.02$). A significant difference between these groups was also found for the total score, when controlling for age, being informed about dementia, and experience with dementia ($F(1,153) = 10.03$; $p = 0.00$). No significant difference was found between the hope score of the trained and not-trained group when controlling for gender, age

and hours of work per week ($F(1,149) = 2.03$; $p = 0.16$). At post-test the trained group scored significantly higher on both the person-centred subscale and the total score.

Table 3. Change in attitude to dementia in trained and not-trained museum employees and volunteers

ADQ	Pre-test mean (SD)	Post-test mean (SD)	df	T	p
Trained people					
Total (19-95) (n=87)	70.22 (5.26)	73.43 (5.35)	86	-6.81	.00
Hope (8-40) (n=92)	24.78 (3.59)	25.82 (3.19)	91	-3.07	.00
Person-centred (11-55) (n=92)	45.21 (3.56)	47.52 (3.72)	91	-6.15	.00
Non-trained people					
Total score (19-95) (n=75)	70.12 (6.04)	71.65 (6.01)	74	-2.87	.00
Hope (8-40) (n=77)	25.96 (3.12)	25.83 (3.11)	76	0.41	.69
Person-centred (11-55) (n=76)	44.39 (3.90)	45.79 (4.22)	75	-3.41	.01

* *n* varies due to missing data

underlined scores represent more positive values

Table 4. Differences in attitude trained and not-trained museum employees and volunteers

ADQ	Trained people	Not-trained people	df	F	p	Partial eta
Post-Test Adjusted means (SD)						
Total score ^a (19-95) (n=75)	73.42 (5.35)	71.65 (6.01)	1,153	10.03	.00	0.06
Hope ^b (8-40) (n=77)	25.99 (3.13)	25.82 (2.96)	1,149	2.03	.16	0.01
Person-centred ^c (11-55) (n=76)	47.60 (3.74)	45.61 (4.20)	1,153	6.01	.02	0.04

underlined scores represent more positive values

^acontrolled for age, being informed about dementia, experience with dementia

^bcontrolled for gender, age and hours of work per week

^ccontrolled for hours of work per week, being informed about dementia, experience with dementia

Employees and volunteers who were informed about dementia before the start of the implementation more often showed a more positive person-centred attitude at post-test than people who were not informed about dementia ($U = 2830.00$; $z = -1.98$; $p = 0.05$). A small negative correlation was found between hours of work per week and change in hope ($r_s = -0.19$; $p = 0.02$) and overall score ($r_s = -0.17$; $p = 0.03$). No association was found between change in overall attitude, hope or person-centredness and other

characteristics of the museum employees and volunteers: gender, age, education or previous experience with dementia.

DISCUSSION

This study aimed to evaluate the implementation process of the Unforgettable programme for people with dementia and their caregivers in twelve museums in the Netherlands. Furthermore, this study investigated the impact of the programme on the attitudes toward dementia of the museum staff in ten museums. An important starting point was that good implementation of evidence-based interventions is crucial to enable replication of the positive effects. Also, a better understanding of how the programme works within different types of museums was expected to contribute to the quality of the programme.

Regarding the implementation process the study showed that, despite differences in art collection and organisation, successful implementation of the Unforgettable programme in different museums is very feasible.

To our knowledge, this is the first study into the implementation process of an art programme for people with dementia and their caregivers. However, literature from other disciplines is consistent with our findings and shows that the implementation of an intervention can be affected by personal factors, such as the beliefs and behaviours of the implementers, by factors related to the organisational context such as the attitudes and behaviours of other stakeholders, and by the external environment of the implementing organisation (Domitrovich et al. 2008; Forman et al. 2009). The importance of a clear project plan at the start of the implementation is consistent with the findings in the implementation studies of Meiland et al. (2005) and Mangiaracina et al. (2016). Difficulties with recruiting people with dementia and informal caregivers were also found to be a barrier in the study of Van Haeften-Van Dijk et al. (2015).

The implementation of Unforgettable impacted on the museums as an organisation: For example, the museums had plans to implement the Unforgettable programme for other groups of people with special needs or started to use the Unforgettable communication method in regular tours with children or elderly people. Many museums experienced interest in Unforgettable, both from the Netherlands and from abroad. In all museums the programme was still offered six months after

the start in of the programme in each museum. The expansive use of a specific intervention for people with dementia was also seen in the study of Van Haeften-Van Dijk et al. (2015) about the implementation of the Veder theatre method. After implementation, plans arose to also use the method, besides as a group activity, in one-on-one communication in 24-hour care.

Regarding the impact on the attitude of the museum staff this study showed that after the implementation of the Unforgettable programme the trained people had an increased understanding of dementia and/or increased recognition of people affected by dementia as unique individuals with the same value as any other person. The increase in hope was small but significant. This indicates that the museum employees and volunteers became more optimistic about the capacities and future of people affected by dementia (Lintern, 2001).

The trained persons had a higher increase in the overall and in the person-centred score than those who were not trained. This difference could be explained by the findings of Nagle et al. (2013) and Lüdecke et al. (2016), who found that personal contact with individuals with dementia and/or their caregivers may help to increase knowledge about dementia. The changes in views about dementia were also found in the study of Windle et al. (2018) and Camic et al. (2015). In this latter study art gallery facilitators expressed changed attitudes toward participants with dementia. These changes 'were related to the opportunity to share an engaging experience and to witness people with dementia making capable contributions in an intellectually challenging setting'.

The finding that also untrained staff had a more positive attitude toward dementia suggests that getting even a little information about dementia or having just some contact with people with dementia may already influence the attitudes about dementia in a positive way. An alternative explanation is that the people who did not fill out the post questionnaire had less 'connection' with Unforgettable and dementia than the people who did, which may have introduced an overrepresentation of those with a more positive attitude.

This study shows that people who worked less hours in the museum were more likely to have increased their hope for people with dementia and overall their positive attitudes towards dementia. This may be explained by the larger change in hope

and overall score of the volunteers, who on average worked fewer hours per week than the museum employees.

The attitudes toward dementia appeared not to be associated with gender, age, education or previous experience with dementia. This is consistent with other studies that found no differences in dementia knowledge according to gender (Lokon et al., 2017; Lüdecke et al., 2016) and with the study of Kada et al. (2009) in which no association between demographic variables and attitudes toward dementia of dementia care staff was found.

Strengths and limitations of the study

This study had several strengths: The stakeholders who were interviewed about the implementation had different professional backgrounds and different functions and tasks within the implementation process. This ensured a broad view of possible factors influencing the implementation. Concerning the attitudes towards dementia, not much research has been done about attitudes towards dementia of people not working in care. Studies that were done among this group were often aimed at the knowledge of symptoms or predictors of dementia (McParland et al., 2012).

Besides strengths, this study also had some limitations. One of them is that the interviews with stakeholders were mainly held in the starting phase. Only two interviews were conducted in the continuation phase. As a result, the mentioned facilitators and barriers for the continuation phase were partly based on expectations of stakeholders. The responders and dropouts of the ADQ differed in gender, position, hours of work per week and being informed about dementia, which can be seen as a limitation. As a result, the changes in attitudes toward dementia cannot be generalised for all museum employees and volunteers. Other limitations are that this study used an uncontrolled one-group design and was conducted in the Netherlands. Therefore, the study should be seen as explorative and one should be cautious when generalising the results, which may not be generally applicable for all museums and in other countries.

Scientific relevance

The scientific relevance of this study is that it provides insight into the facilitators and barriers to the adaptive implementation of an art programme for persons with dementia and their caregivers outside the usual care environment. It might be

interesting to study whether early consultation of key figures in the region - having them think about possible facilitators and barriers, and about effective strategies to address potential barriers before the start of the implementation - would benefit the implementation. As there has been little research on this topic so far, the results of this study could be useful for future research into adaptive implementation of interventions for people with dementia outside the usual care environment in general. This study also adds to the knowledge about attitudes toward dementia of the general public, who are not professionally involved in care. It would be interesting to further examine the exact elements that led to the changes in attitude: for the trained people it would be interesting to investigate what contributed most to the changes; the contact with people with dementia in the tours or the education about dementia in the training.

Societal relevance

This research was initiated in actual practice and is an expression of a growing general awareness of the importance of a dementia-friendly society. The identification of specific factors that impact the implementation will help to successfully disseminate the Unforgettable programme further. In particular, careful selection of the tour guides and hosts, regular evaluation of the Unforgettable programme and continuous promotion through different means were found to facilitate successful implementation. Moreover, cooperation with care institutions and attention for the programme by the local municipality dementia networks were found to be helpful in promoting and recruiting participants.

In this study attitude was operationalised by the ADQ which measures two aspects of attitude towards dementia: hope and person-centredness. The training with information about dementia and meeting people with dementia in the guided tours may both have contributed to a more positive attitude towards dementia. According to the Theory of Planned Behaviour of Ajzen (1991), which suggests that attitude is one of the predictors for social behaviour, knowledge and understanding about dementia is essential for a more dementia friendly society.

CONCLUSION

Besides the fact that this study provides a good understanding of the adaptive implementation of an art programme for people with dementia and their caregivers in different museums in the Netherlands, it also shows that Unforgettable is associated

with a more positive attitude of museum employees and volunteers toward dementia. The experienced facilitators and barriers to the implementation of Unforgettable will help other museums to determine an effective strategy to implement similar programmes. In this way the programme can be further disseminated. Both the further dissemination of (programmes similar to) Unforgettable and the positive effect on attitudes toward dementia of museum employees and volunteers can contribute to a better understanding and less stigmatisation of dementia and consequently to an enhancement of social inclusion of people with dementia and their caregivers. This will promote their well-being.

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CHAPTER 6

VALUE OF PERSONALISED VERSIONS OF DEMENTIA- SPECIFIC QOL SCALES: AN EXPLORATIVE STUDY IN THREE EUROPEAN COUNTRIES

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ABSTRACT

Purpose: Measuring Quality of Life (QOL) can be difficult due to its individual character. To explore the value of personalised QOL measurement for people with dementia, personalised versions of two dementia-specific QoL scales (DQoL and QoL-AD) were constructed. This study investigated whether the personalised measures are more valid to detect variations in QOL than their standard versions for people with mild to moderate dementia, with sufficient internal consistency. Moreover, the relationship between the personalised QoL measures and severity of dementia was investigated. Finally, the study explored the differences between countries regarding the personalised overall QOL and differences in the importance of QOL domains.

Methods: This explorative one-group design study used baseline data from the MEETINGDEM study into the implementation of the Meeting Centres Support Programme in Italy, Poland and the UK.

Results: The personalised versions of the DQoL and QoL-AD were reliable, but not more valid than their standard versions. No relationship between severity of dementia and personalised QOL was found. While no differences were found between countries for the overall QOL score, some QOL domains were valued differently: people with dementia from the UK rated self-esteem, mood, physical health, energy level and the ability to do chores around the house significantly less important than people from Italy and Poland.

Conclusion: The personalised versions of the DQoL and QoL-AD may offer dementia care practice important insights into what domains contribute most to an individual's QOL.

INTRODUCTION

Patient-reported outcome measures are important in assessing the effectiveness of disease-modifying and psychosocial interventions. An outcome that is often used in patients with chronic diseases is Quality of Life (QOL). QOL is defined by the WHO (2017) as ‘the individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns’. It is affected by the person’s physical health, psychological state, personal beliefs, social relationships, and by their relationship to relevant features of their environment. In the last two decades QOL is being recognised increasingly as an important construct and outcome (Aspden et al., 2014; Bowling et al., 2015; Dröes et al., 2006; Ettema et al., 2007; Moniz-Cook et al., 2008; Orgeta et al., 2015; Ready & Ott, 2003). In their review Van Leeuwen et al. (2019) identified nine QOL domains that older adults consider important: ‘Health perception’, ‘Autonomy’, ‘Role and activity’, ‘Relationships’, ‘Attitude and adaptation’, ‘Emotional comfort’, ‘Spirituality’, ‘Home and neighbourhood’, and ‘Financial security’, and that vary in different situations. Albeit in slightly different terms, these domains are mentioned by people with dementia as well (Dröes et al., 2006). In dementia the main focus in care is the promotion of optimal QOL, as there is no cure available (Ettema et al., 2005a). At the same time, there appear to be discrepancies in views regarding the relevance of QOL domains among people with dementia (Stewart-Archer et al., 2016), and between people with dementia, carers and theoretical models. For example, a study by Dröes et al. (2006) showed that several QoL domains, such as ‘safety and privacy’, ‘self-determination and freedom’, ‘being useful/giving meaning to life’ and ‘spirituality’, which were mentioned as relevant by community-dwelling people with dementia and by people with dementia living in nursing homes, were not represented in QOL instruments at that time. Today the latter two are more often included (Perales et al., 2013). ‘Sense of aesthetics in living environment’, ‘financial situation’ and ‘being useful/giving meaning to life’ were not mentioned by the professional caregivers as relevant and they paid very little attention in care practise especially to the latter two domains (Gerritsen et al., 2007), although these are experienced as relevant by people with dementia. Disease-specific QOL instruments, including dementia-specific QOL scales, aim to target the domains most relevant to the condition and are therefore more likely to capture how the disease impacts the experienced wellbeing over time (Schölzel-Dorenbos et al., 2012). Furthermore, personalised instruments allow for a better (Meier et al., 1999) and feasible assessment of the individual’s QOL, as Schölzel-Dorenbos found in

her study on the SEIQOL (Schölzel-Dorenbosch, 2000) and Selai et al. (2001) in their work on the QOLAS, offering persons the opportunity to indicate the importance of different life domains (Bowling et al., 2015; Ettema et al., 2005b).

Several factors may affect self-reported QOL in dementia (Schölzel-Dorenbos et al., 2009), including behavioural and non-cognitive symptoms as well as symptoms caused by the progressive cognitive decline, such as difficulties in abstract thinking and anosognosia. Hence, there has been a long-standing discussion about who should rate the QOL of people living with dementia. Cognitive limitations may affect people's ratings. On the other hand, family carers typically rate the QOL of the person with dementia lower than people with dementia do themselves, due to factors inherent to caring for a person with dementia (e.g. burden, depressed mood, projection) (Schölzel-Dorenbos et al., 2009); and scoring by professional caregivers tends to be more moderate (Leontjevas et al., 2016). A study by Conde-Sala et al. (2014) showed that several factors were particularly associated with greater discrepancies between patient and carer ratings of QOL, i.e. severity of dementia, anosognosia, depression, as well as cognitive status in patients and female sex in carers. Also, Schifarczyk (2012) found a relationship between the difference in QOL assessments of proxies and people with dementia and the severity of dementia, even in mild dementia stages. Given the subjective nature of QOL, the general opinion is that self-reported QOL is preferred for as long as possible (Beattie et al., 2015; Ettema et al., 2005b) and that reliable, sensitive scales should enable this until late dementia stages. Indeed, studies suggest that people with mild to moderate dementia are able to understand and answer questions regarding their lives (Brod et al., 1999; Logsdon et al., 1999) and there is evidence for reliability of some scales in severe dementia (Logsdon et al., 1999; Logsdon et al., 2002; Moniz-Cook et al., 2008).

The relationship between severity of dementia and QOL is complex due to the progressive cognitive decline, but also due to the disability paradox (Albrecht et al., 1999), whereby people with a chronic disease report a higher QOL than proxies because they adapt to their illness. Although negative correlations were shown between proxy-rated observed QOL aspects (e.g. having social relations and being isolated) and severity of dementia (Ettema et al., 2007), several studies into self-reported QOL suggested that the perceived QOL is not related to severity of dementia (Logsdon et al., 2002; Hoe et al., 2009). In contrast with these findings Conde-Sala (2014) showed that patients with the lowest QOL ratings had a better cognitive status,

more depression, and less anosognosia. Conversely, the highest QOL was reported by patients with a poorer cognitive status, less depression, and greater anosognosia. To our knowledge no studies were conducted into the relationship between outcomes of personalised QOL measurement and severity of dementia.

Several self-report disease-specific instruments have been developed to assess QOL in dementia. Two of the most used scales are the Dementia Quality of Life instrument (DQoL) (Brod et al., 1999) and the Quality of Life in Alzheimer's Disease scale (QoL-AD) (Conde-Sala et al., 2014). To explore the added value of personalised QOL measurement, we constructed personalised versions of the DQoL and QoL-AD. The development of personalised, dementia-specific, self-report QOL scales aims to enable a more valid measurement of QOL and, consequently, more effective decision making with regard to interventions, allocation of health care resources and tailored dementia care.

The present study aimed to examine whether the personalised versions of DQoL and QoL-AD are more valid to detect intra- and interpersonal variations in QOL than their standard versions for people with mild to moderate dementia, while still being sufficiently reliable. It is hypothesised that there is a higher correlation between the personalised versions of the instruments and overall perceived QOL by persons with dementia. The study also intended to identify whether there is a relationship between the severity of dementia and self-reported QOL as measured with the personalised and standard versions of DQoL and QoL-AD. Although, as mentioned, previous research is not unambiguous about this relationship, it could be that the personalised QOL scales are more sensitive than the standard versions and therefore may confirm a positive association between severity of dementia and QoL. Insight into the association between personalised self-reported QOL and dementia severity may provide information on the changing impact that dementia has in specific life domains as the condition progresses. This may be helpful to guide personalised support and care.

Finally, the study intended to explore whether there are differences between three European countries in the self-reported overall QOL as well as in the importance of QOL domains as assessed by people with mild to moderate dementia when they rate their QOL with the personalised DQoL and QoL-AD. Country differences in the importance of domains will aid the development of country-specific care policies and strategies to adaptively implement existing care methods and innovations.

METHODS

Design

This study was part of the European MEETINGDEM project, funded by the Joint Programming Neurodegenerative Diseases. MEETINGDEM investigated the adaptive implementation and evaluation of the Meeting Centres Support Programme (MCSP) for people with dementia and their carers in Italy, Poland and the United Kingdom (Dröes et al., 2017). For the evaluation study a controlled trial with a pre-test-post-test control group design was conducted, in which the MCSP (a community-based combined support programme offered in socially integrated community centres) was compared to usual care (UC) in each country. Measurements were performed at baseline (Month 0) and after 6 Months. For the present study on QOL measurement only data from the baseline measurement were used. Ethical approval for the study was obtained from the relevant ethics committee in each country. An informed consent procedure was followed to make sure that people with dementia and their carers were well informed before confirming their willingness to participate in the study.

Setting and participants

Participants were community dwelling people with mild to moderate dementia and no age limit, recruited from meeting centres for people with dementia and their carers and via GPs, regular day care, home care or other in Italy, Poland and the United Kingdom. If the researcher considered possible participants physically or mentally unable to fill in the questionnaire or at risk of being overstrained by filling in the questionnaire, they were not included. Data were collected between May 2015 and December 2016 (Dröes et al., 2017).

Measurements

Background characteristics, such as sex, age, marital status, educational level and co-morbidities were obtained for each participant. The severity of dementia was assessed using Reisberg's Global Deterioration Scale (GDS) (Dröes et al., 2017), in which stages 1-3 are the pre-dementia stages, 4-5 refer to mild and moderate dementia, and stage 6 and 7 refer to moderately severe and severe stages of dementia. Self-reported quality of life was measured with the DQoL (Brod et al., 1999) and the QoL-AD (Logsdon et al., 1999). The DQoL (29 items) measures both positive and negative behaviours across five domains: positive affect (6 items), negative affect (11 items), feelings of belonging (3 items), self-esteem (4 items) and sense of aesthetics (5

items), which are all scored on a 5-point Likert scale. Scales were reversed so that for all scales higher scores indicate a better QOL. The QoL-AD consists of 13 items that measure the domains of physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self, and life as a whole. The items are rated on a 4-point scale ranging from poor (1) to excellent (4). The psychometric properties of the DQoL (Brod et al., 1999) (Cronbach's alpha 0.80 for self-esteem, 0.83 for positive affect, 0.89 for negative affect, 0.67 for feelings of belonging and 0.77 of sense of aesthetics respectively) and QoL-AD (Thorgrimsen et al., 2003) (Cronbach's alpha 0.82; interrater reliability kappa >0.70; correlated (Pearson's r) 0.69 with DQoL) have been shown to be good. The DQoL can be completed by people with MMSE-scores of 12 or higher (Brod et al., 1999), the QoL-AD can be completed by people with an MMSE-score as low as 3 (Hoe et al., 2005).

Both Italian and Polish versions of the DQoL and QoL-AD were translated through a process of back and forth translation from the original English versions.

Personalised QOL measures

To personalise the measurement of QOL, so-called 'pre-questions' were added to the instruments about the value of the quality of life domains included in the DQoL and the QoL-AD as described in Brod et al. (1999) and Logsdon et al. (1999) respectively. People were asked to indicate on a visual analogue scale ranging from one (completely unimportant) to ten (extremely important) how important each QOL domain was for their quality of life.

Personalised DQoL

The pre-questions added for the domains of the DQoL concerned self-esteem, mood, feelings of belonging and experiencing nature and music (which refers to the domain sense of aesthetics). The response option on a scale from 0 to 10 was chosen following The Older Persons and Informal Caregivers Survey Minimum DataSet (TOPICS-MDS) questionnaire, which uses one overall assessment of QoL on a scale of 0-10. The pre-question for mood accounted for both positive and negative affect domains as the distinction between these two aspects might not be well understood by the participants.

Personalised QoL-AD

The pre-questions for the QoL-AD concerned the 12 items/domains of the QoL-AD (physical health, energy level, mood, living situation, memory, family, marriage/

closest relationship, friends, self-image, ability to do chores around the house, ability to do things for fun and money/financial situation). For the 13th item (assessment of life as a whole) no pre-question was included as it refers to an overall assessment of the participant's quality of life.

Procedure

All person with dementia-carer dyads who started participating in the newly developed Meeting Centres Support Programme (MCSP) in Italy, Poland and the UK were invited to participate in the MEETINGDEM evaluation study by the Meeting Centre's (MC) Manager within the first two weeks of attendance. People in the UC group were recruited via e.g. GPs, home care organisations or regular day care centres within the same locality but outside the MC catchment area. Participation in the research was entirely voluntary.

Except for the GDS, which was administered by the manager of the MC or by a professional who knew the person in the UC group, all questionnaires were administered by trained researchers. Participants of the UC group were interviewed face-to-face at the MC or in their own homes. The trained researchers applied the pre-questionnaires in a standardised way according to the instructions (see Appendix). Before posing the pre-questions, the interviewer made sure the participant understood the method. All data were collected and cleaned in each country and subsequently sent to the research team in the UK for integrating all the data.

Data analysis

To calculate the relative contribution of each domain to the overall quality of life, the standard score on each domain of the DQoL was multiplied by its corresponding pre-question rating. This created weighted scores for the personalised domains of the DQoL. This procedure was used for all five domains of the DQoL, where the rating for the Mood pre-question was used in both Positive Affect and Negative Affect domains. Ratings could range from 0-50, with higher scores representing higher quality of life.

Scores for each item of the standard QoL-AD measure were multiplied by their corresponding pre-question rating. For the 13th item a weight was calculated as the average of the 12 pre-questions scores, in order to maintain the contribution of this item in the calculation of the total QoL-AD score. A total score for the personalised QoL-AD questionnaire was computed as the sum of all weighted scores. The total

personalised QOL scores could range from 0-520, with higher scores representing higher quality of life. Similar to the procedure used for the standard questionnaire, for up to two missing values the mean score of the remaining items was imputed. If more than two scores were missing, the entire measure was considered missing.

In order to compare standard and personalised measures, scores were normalised. The transformation re-scaled all scores of the standard and personalised DQoL and QoL-AD to a 0-10 scale per formula, $E_i = (e_i - E_{min}) / (E_{max} - E_{min}) * 10$ (Where E_i =Normalised score; e_i =standard score; E_{min} =minimum value of the variable; E_{max} =Maximum value of variable).

To test the reliability (internal consistency) of the standard and personalised QoL-AD Cronbach's alphas were calculated. For the DQoL we only calculated the Cronbach's alphas for the domains of the standard version. There was no point in calculating them for the personalised DQoL domains, as all items within a domain received the same weight and thus the internal consistency was not expected to change.

The difference in validity between the personalised and standard DQoL was tested using the following procedure: 1) calculating for both the Spearman rank correlation coefficients between the five (personalised) domain scores of the DQoL and the scores on the DQoL item 'overall rated quality of life' which is a separate item in the questionnaire. For the QoL-AD the difference in validity between the personalised and standard QoL-AD was tested by calculating for both the Spearman rank correlation coefficients between the (personalised) QoL-AD score (12 items) and the unweighted QoL-AD item 13 'assessment of life as a whole' and 2) testing whether the correlation coefficients for the standard and personalised versions of DQoL and QoL-AD differed significantly, using a Fisher Z-Transformation.

The relationship between the severity of dementia and QOL in people with dementia as measured with the personalised and standard versions of DQoL and QoL-AD was calculated using Spearman rank correlation coefficients.

The median scores on the pre-questions (domain weights) were described for the three countries. Kruskal Wallis tests were done to test for differences between the three countries in the overall QOL as well as in the importance of different QOL domains.

RESULTS

Participants

A total sample of 227 participants joined the MEETINGDEM study. Of those, 138 were included in this QOL study because they met the inclusion criterion of a GDS score 4-5. Their mean age was 81.1 years (SD = 6.78, range 63-95). Table 1 shows a detailed overview of their background characteristics.

Table 1. Characteristics of the participants (N=138)

Characteristic	N*
Country	
Italy	70 (50.7%)
Poland	25 (18.1%)
U.K.	43 (31.2%)
Sex	
Male	55 (42.6%)
Female	74 (57.4%)
Partnership	
Yes	71 (55.5%)
No	57 (44.5%)
Relationship to carer	
Spouse	67 (51.9%)
Off-spring	53 (41.1%)
Grandchild	2 (1.6%)
Other family	2 (1.6%)
Friend	2 (1.6%)
Other	3 (2.3%)
Educational level ^a	
Higher	28 (22.0%)
A-Level	29 (22.8%)
GCSE	29 (22.8%)
Level 1	25 (19.7%)
No education	15 (11.8%)
Co-morbidities	
Yes	77 (60.2%)
No	51 (39.8%)
Cognitive Impairment (GDS)	
Mild Dementia (GDS=4)	90 (65.2%)
Moderate Dementia (GDS=5)	48 (34.8%)

*N may vary because of missing values; ^aHighest grade completed;
Totals may not equal 100% because of rounding

Reliability and validity of (personalised) DQoL and QoL-AD

The DQoL domains proved reliable in our sample (Cronbach's alpha 0.67 for self-esteem, 0.84 for positive affect, 0.85 for negative affect, 0.51 for feelings of belonging (an acceptable level for a three-item scale) and 0.75 of sense of aesthetics respectively). This calculation was performed without the multiplication of the corresponding pre-question score as they are the same for every item within the subscale. Therefore, these values are equal for both the standard and personalised versions. Both the standard (13 items; $\alpha = 0.80$), and the personalised QoL-AD (13 items; $\alpha = 0.86$) were found to be highly reliable.

Table 2. Correlations between DQoL and 'overall rate of quality of life' and between QoL-AD and 'life as a whole' for the standard and personalised versions of the instruments and results of the difference tests

	n	r_s	p	z	Difference between S & P (Sig. (2-tailed))
DQoL-Feelings of belonging-S	121	.294**	.001		
DQoL-Feelings of belonging-P	116	.331**	.000	-.31	.757
DQoL-Sense of aesthetics-S	122	.061	.505		
DQoL-Sense of aesthetics-P	115	.195*	.038	-1.04	.298
DQoL-Self-esteem-S	121	.323**	.000		
DQoL-Self-esteem-P	117	.242**	.009	.67	.503
DQoL-Positive affect-S	124	.429**	.000		
DQoL-Positive affect-P	118	.331**	.000	.88	.379
DQoL-Negative affect-S	124	.440**	.000		
DQoL-Negative affect-P	118	.375**	.000	.60	.549
QoL-AD-S	123	.442**	.000		
QoL-AD-P	116	.319**	.000	1.1	.271

S = standard version; P = personalised version

Table 2 shows the correlations between the domains of the DQoL and the DQoL item 'overall rating quality of life', and between the score of the 12 QoL-AD items and the QoL-AD item 'life as a whole'. The correlations vary from weak ($r_s = .10$) to moderate ($r_s = .44$). The difference tests between correlation coefficients did not show significant differences between the standard and the personalised DQoL and QoL-AD (see Table 2).

Relationship between severity of dementia and QoL

Neither the personalised nor the standard DQoL revealed correlations between severity of dementia and the five domains of the DQoL. Also, no correlations were found between severity of dementia and the total score of the personalised or standard QoL-AD.

The mean score on the item 'Overall rating quality of life' of the standard DQoL, was in the total sample 3.34 (range = 1-5; SD = .965); for the GDS 4 group the mean score was 3.34 and for the GDS 5 group 3.35. The mean score on the item 'life as a whole' of the standard QoL-AD was 2.85 (range = 1-4; SD = .648); for the GDS 4 group the mean score was 2.83 and for the GDS 5 group 2.88.

Differences between the three countries

Table 3 shows an overview of the medians of the pre-question ratings on the importance of each quality of life domain per country. Although not all domains were assessed as equally important, the relatively high medians demonstrate that in general all domains included in the DQoL and QoL-AD were assessed as important for quality of life. The most important domains appeared to be family and marriage/closest relationship. Other domains that appeared to be of high importance to the persons with dementia were physical health, living situation and memory. The ability to do chores around the house was found to be the least important, even though this domain was still ranked as relatively important for QOL.

No difference was found between the countries for the self-measured QOL score as measured by the personalised QoL-AD ($H(2) = 2.833, p = .243$). A statistically significant difference between countries was found for the importance of the domain *mood*, as measured by the pre-questions of the DQoL ($H(2) = 6.476, p = .039$), with a mean rank of 64.48 for Italy, 68.92 for Poland, and 49.38 for the UK. Differences between Italy, Poland and the UK were also found as measured by the pre-questions of the QoL-AD for *physical health* ($H(2) = 26.174, p = .000$), with mean ranks of 68.31, 77.92, 40.19 respectively; and for *energy level* ($H(2) = 6.007, p = .050$), with mean ranks of 67.19, 59.92 and 49.91.

Table 3. Median scores on the pre-questions of DQoL and QoL-AD per country

	Italy (median, range) n = 55*	Poland (median, range) n = 25*	UK (median, range) n=39*
DQoL			
Mood	8.5 (0-10)	9 (5-10)	8 (3-10)
Self-esteem	8 (1-10)	9 (4-10)	8 (2-10)
Feelings of belonging	9 (0-10)	9.5 (3-10)	8 (5-10)
Sense of aesthetics	9 (0-10)	8 (5-10)	8 (2-10)
QoL-AD			
Physical health	10 (5-10)	10 (6-10)	9 (5-10)
Energy level	9 (5-10)	8 (4-10)	8 (4-10)
Mood	9 (5-10)	9 (5-10)	8 (2-10)
Living situation	9 (5-10)	9 (5-10)	10 (5-10)
Memory	10 (5-10)	9 (5-10)	8 (2-10)
Family	10 (5-10)	10 (6-10)	10 (8-10)
Marriage/closest relationship	10 (5-10)	10 (6-10)	10 (8-10)
Friends	8 (0-10)	8 (2-10)	9 (3-10)
Self-image	8 (3-10)	8 (2-10)	8 (3-10)
Ability to do chores around the house	8 (0-10)	8 (4-10)	7.5 (1-10)
Ability to do things for fun	8 (0-10)	8 (3-10)	8 (3-10)
Money/financial situation	9 (4-10)	8 (0-10)	8.5 (0-10)

*N may vary because of missing value

DISCUSSION

To our knowledge, there are no dementia-specific instruments that measure self-reported QOL in a personalised way. We therefore constructed additional pre-questions that can be used together with the DQoL and/or QoL-AD to assess personalised QOL. Personalised QOL does not merely reflect satisfaction with the different domains of quality of life, but also how these domains are valued by the person.

The reliability of the positive affect, negative affect and sense of aesthetics domains of the DQoL were found to be high and comparable with the reliability of these domains found in the study of Brod et al. (Brod et al., 1999). The feelings of belonging and self-esteem domains however, were found to be moderately reliable, and less reliable than in the study of Brod et al. (1999). Both the standard and personalised

versions of the DQoL proved to be reliable in our study as well as in the study by Thorgrimsen et al. (2003).

All domains of both DQoL-versions, besides sense of aesthetics, were correlated with the DQoL item 'overall quality of life'. The twelve items of both the personalised and standard QoL-AD were correlated with the QoL-AD item 'life as a whole'. As the correlation coefficients did not significantly differ for the standard and the personalised DQoL and QoL-AD, we must conclude that there is no indication that the personalised versions of the instruments are more valid than the standard versions.

No correlations were found between severity of dementia and the five domains of the DQoL or the total score of the QoL-AD, neither for the personalised nor for the standard version. For the standard version of the QoL-AD, this is consistent with the findings of Logsdon et al. (2002), Conde-Sala et al. (2014) and Hoe et al. (2009) and could be an indication that the overall QOL as measured with the QoL-AD is indeed not related to severity of dementia, contrary to what is found in caregivers' evaluations of QOL of persons with dementia (Conde-Sala et al., 2014). However, having only included people with mild to moderate dementia may have been the reason no potential relationship was detected.

Overall, all domains of the standard DQoL and QoL-AD were considered to be highly important by people with dementia, which underlines the validity of these instruments (Logsdon et al. 2002; Thorgrimsen et al., 2003). Nevertheless, some variability in importance of domains was found, which is in line with findings of Van Leeuwen et al. (2015) where older adults expressed their preference for a QOL measure that reflect their personal concerns in life. No difference was found between countries for overall QOL as measured by the personalised QoL-AD. This is not in line with the findings of the European RightTimePlaceCare study of Beerens et al. (2014), as they found that people with dementia in the northern and western countries of Europe scored higher on the QoL-AD compared to people with dementia in the eastern and southern European countries.

A statistically significant difference was found for the importance of the domain self-esteem, with the people from the UK rating this less important than people from Italy and Poland. Differences between countries were also found for how people valued the domain mood of the DQoL and the QoL-AD, with the people from the UK rating this

less important than people from Italy and Poland. Also, the physical health, energy level and the ability to do chores around the house were rated as less important by people in the UK as compared to the other two countries. These differences may be related to differences in the background characteristics of the participants in the three countries. In the MEETINGDEM project (Brooker et al., 2018), where the data were collected for this QOL study, participants in the UK were on average older, and more likely to be male than in Italy and Poland (Brooker et al., 2018).

Limitations

The results of this study should be interpreted carefully because of some limitations. This study reported on a specific sample of people with dementia: All participants had mild to moderate dementia. As a result, our findings may not be generalisable to people in a more severe stage of dementia. Having a sample of only people with mild and moderate dementia also limited the investigation of the relation between severity of dementia and QOL. A second limitation is that within the MEETINGDEM study, potential participants that were considered physically or mentally unable to fill in the questionnaires, including the QOL scales, or were at risk of being overstrained by filling in the questionnaires, were not included in the study. This may have led to selection bias. A third limitation is that the study was insufficiently powered to detect small to moderate differences between the countries regarding self-reported QOL and importance of QOL-domains and that the sample was not large enough to investigate in more detail what background characteristics determine the country differences in opinions on importance of QOL domains. A fourth limitation is the use of Cronbach's alpha to calculate the reliability of the personalised scale as it is bound to be lower than with standard measures due to the additional variance that is obtained with the personal weights.

Scientific and societal impact

Measuring QOL can be difficult because of its individual character: aspects of life which are important to one person may have little or no relevance to another (O'Boyle et al., 1993). The results of this study underscore that the importance of items/domains of QoL scales can vary between individuals (De Medeiros & Basting, 2013) and countries. As expected from the literature (Dröes et al., 2006), social relationships are ranked highly by all people in all countries: the most important QOL domains appear to be family and marriage/closest relationship. Some domains were valued less in the UK compared to the other countries. Further research into

what determines the importance of QOL domains and intercultural differences is recommended.

This study can be relevant for clinical practice where the pre-questionnaires can be used together with the DQoL and the QoL-AD to select objectives of care and to monitor treatment based on the domains indicated to be relevant by the individual person. The results of this explorative study may also contribute to the knowledge about cultural differences in Europe regarding the importance of domains that contribute to QOL. This information can be of interest when adapting and implementing care methods and innovations in different countries.

Dröes et al. (2006) found that the domains that are relevant for an individual's QOL were not limited to the domains measured with the DQoL and the QoL-AD. Therefore, in future studies, the pre-questions method could also be used together with other QOL measures that include other, or more, QOL domains. It is important to further study the acceptability and feasibility of the pre-questions by examining the perceptions of the users and interviewers regarding their use. It would be interesting to also study the applicability of the pre-questions of the QoL-AD in people with moderately severe to severe dementia. They might have more difficulties in expressing the importance of the domains, which may influence the reliability and validity of this instrument.

CONCLUSION

Although both the standard and personalised versions of the DQoL and QoL-AD were found to be reliable, the personalised versions of the DQoL and QoL-AD were not found to be more valid to detect intra- and interpersonal variations in QOL than the standard versions. However, the results of this study offer insights into the individualised QOL of people with dementia, which may have important implications for care practice. To properly design and apply personalised interventions for individuals with dementia, it is essential to understand which life domains contribute most to their QOL.

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APPENDIX

Pre-questions for quality of life measurement

Pre-questions for quality of life measurement (DQoL and QoL-AD)

Instructions for interviewers

Please administer these questions in interview format to individuals with dementia, following the instructions below:

[Place the paper with the scale from 0 to 10 on the table in a way that the person is able to see it properly as you give the following instructions:]

'I am going to ask you some questions about what is important in your life. I will ask you to describe how important you find a number of topics. You can respond on a scale from 0 to 10, in which '0' means 'completely unimportant', 5 means moderately important, and '10' means extremely important' [Point to 0, 5 and 10 on the form as you say it.]

Please check if the person understood the instruction by asking: 'For example, how would you indicate on this scale that eating healthily is very important to you? If the instruction is not understood, repeat the instruction and check again. If the instruction is still not understood, skip this part of background information and continue to the following questionnaire (DQoL).

'I would like to know from you how important you find the following subjects: [name subjects].'

If the person shows a lack of understanding, please repeat or clarify the question. However, under no circumstances should the interviewer suggest a specific response.

Write down her/his answer on the score form. If a participant is unable respond to a particular question, this should be noted in the comments at the bottom of the score form.

Background information

These questions were developed by using the domains listed in Brod et al. 1999 and Logsdon et al. 1999.

DQoL domains (Brod et al 1999):

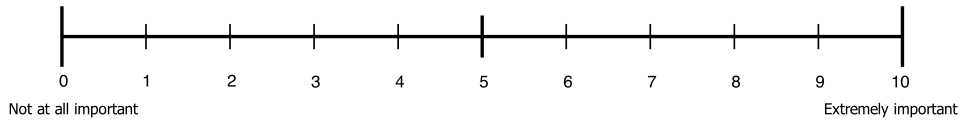
- Self-esteem
- Positive affect/humor
- Negative affect
- Feelings of belonging
- Sense of aesthetics

QoL-AD domains (Logsdon et al. 1999):

The QoL-AD has 13 items covering twelve domains of physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self, as well as life as a whole.

Pre-questions for quality of life measurement (DQoL and QoL-AD)

Interview according to standard instructions.



Pre-questions DQoL

1. **Self-esteem** (e.g. feeling useful, feeling confident, satisfaction with yourself)
2. **Mood** (e.g. feeling content, not feeling worried, anxious)
3. **Feelings of belonging** (e.g. feeling lovable, feeling that people like you)
4. **Experiencing nature & music** (e.g. listening to music, watching animals or birds)

Pre-questions QoL-AD

5. **Physical health**
6. **Energy level** (e.g. having enough energy)
7. **Mood** *please fill out the same score as on question 2*
8. **Living situation** (e.g. the place you live)
9. **Memory**
10. **Family** (e.g. relationship with family members)
11. **Marriage/closest relationship** (e.g. relationship with spouse, partner, closest person)
12. **Friends**
13. **Your self-image** (e.g. positive experience of whole self)
14. **Ability to do chores around the house**
15. **Ability to do things for fun** (e.g. do things that you enjoy)
16. **Money/financial situation**





CHAPTER 7

GENERAL DISCUSSION



INTRODUCTION

The aim of the research presented in this thesis was to contribute to the further development, evaluation and implementation of person-centred psychosocial interventions in dementia care. For this purpose we conducted five studies, which all focused on person-centred care and quality of life (QOL). In person-centred care the experiences and needs of the person are central (Brooker & Latham, 2016). Quality of life is related to the persons wellbeing and includes people's subjective perceptions of the most important parts of their lives (Cai et al., 2021).

In the first study the development of a person-centred psychosocial nature intervention was examined (chapter 2), three subsequent studies concerned the evaluation and implementation of the Unforgettable art intervention (chapter 3,4,5), and in the last study the psychometric properties of two personalised quality of life instruments, which measure QOL in a person-centred way, were evaluated (chapter 6). The two interventions (nature and art intervention) are intended both for people with dementia living at home and people with dementia living in a long-term care setting. The interventions as well as the QOL instrument regard people with mild to moderate dementia.

This final chapter describes the main findings of the five conducted studies and addresses their methodological limitations. The scientific, clinical and societal value of the studies is described and recommendations for future research, clinical practice, and policy makers are made. The chapter ends with general conclusions.

MAIN FINDINGS AND CONCLUSIONS

Nature and dementia: development of a person-centred approach (Chapter 2)

The aim of this study was to develop and pilot an approach for person-centred nature activities for people with dementia. The study had the following research questions: Which aspects of being in nature or outdoor spaces do people with dementia find important for their quality of life? What types of activities in nature do people with dementia prefer? What tool can be developed to support the realisation of nature activities for people with dementia living in the community and in long-term care settings in a person-centred way? Do people with dementia who experience behaviour and mood disruptions appreciate personalised nature activities? Are personalised nature activities feasible according to professionals in care practice?

From the focus groups among people with dementia, eight key aspects/themes of experiencing nature were identified as being important for quality of life (relaxation, freedom, pleasure, feeling fit, enjoying the beauty of nature, social interaction, feeling useful and memories), as well as six categories of preferred activities (active, passive and social activities, activities involving animals, activities with flowers and plants and indoor nature activities). Based on these themes and categories, an approach was developed to design nature activities according to the personal wishes, needs, and quality of life experiences of people with dementia. During the personalised nature intervention, participants of the pilot study showed many positive and few negative behaviours. All participants enjoyed the activity and almost all of them would like to do the activity again. As regards organisational feasibility, eight themes for successful implementation of nature activities were identified, i.e.: preparation, guidance, location, weather, material, duration, group conditions, and cultural aspects of the organisation.

Evaluation of the ‘Unforgettable’ art programme by people with dementia and their caregivers (Chapter 3)

This study examined how the Unforgettable art programme was experienced and appreciated by the participants in twelve museums in the Netherlands. This programme, which originally has been developed by the Museum of Modern Art in New York, consists of guided, interactive museum tours in which art works are shown and discussed with participants using a person-centred method. The focus of the programme lies on the participants’ personal opinions and experiences evoked by the art. The personal interpretation of the art is stimulated. This study also investigated whether the participants’ experience and appreciation are linked to their specific background characteristics.

Participants evaluated the programme very positively. Social interaction, between the participants but also the warm and welcoming attitude of the guide and hosts proved to be a key factor in their appreciation. Also the museum setting was appreciated. The mood of the persons with dementia and caregivers was improved directly after participation in the Unforgettable programme compared to before the start of the museum tour. For the people with dementia a significant association between their change in mood and type of caregiver with whom they joined the tour was found: people attending the programme with an informal caregiver as compared to a professional caregiver were more likely to experience improved mood.

How do people with dementia respond to different types of art? An explorative study into interactive museum programmes (Chapter 4)

The study aimed to answer the question ‘are different types of art equally suitable to be used in an art programme for people in different stages of dementia?’ This was investigated by looking at the responsiveness to art during the Unforgettable tour, and relating this to the type of artwork shown and/or characteristics of the person with dementia, such as severity of dementia or specific cognitive impairments.

The appreciative and active responsiveness as well as the interaction with others during the museum tours appeared to be related to the severity of dementia, cognitive impairments, and type of artworks: people with more advanced dementia or more severe cognitive impairments responded less to art and interacted less frequently with others than people with mild dementia. Artworks with more natural elements revealed less interaction with others. Artefacts (i.e. objects not originally meant as artworks, such as historical objects, clothing or crockery) evoked more reactions than artworks.

Implementation and impact of Unforgettable: an interactive art programme for people with dementia and their caregivers (Chapter 5)

This study evaluated the nationwide adaptive implementation of the Unforgettable museum programme, for people with dementia and their caregivers in twelve museums in the Netherlands.

Additionally, to explore whether the implementation of Unforgettable influenced the museum staff, the impact of the programme on the attitudes toward dementia of the staff and volunteers was investigated. Also the impact on the museums as an organisation was investigated as well as whether the programme inspired museums to organise similar activities for other target groups (flywheel effect).

The following factors appeared essential for successful implementation of Unforgettable: the training in the Unforgettable method, regular evaluation with the programme guides and hosts, committed and motivated staff and management, sufficient time spent on the programme by the programme coordinators, and cooperation with other organisations. A lack of promotion activities proved an impeding factor. Compared to before the implementation of Unforgettable, after introducing the programme the museum employees’ attitudes toward people with

dementia turned out to be more positive. The programme also had a flywheel effect: in some museums the implementation of the Unforgettable programme led to plans for new programmes for other groups of people with special needs. One museum used the Unforgettable method also outside the museum: they brought the art works inside a nursing home.

Value of personalised dementia-specific QOL-scales: an explorative study in three European countries (Chapter 6)

For evaluating QOL in person-centred interventions, mostly standardised QOL measures are used, while we know that there are personal differences in the relevance of the different domains and items. To explore the value of personalised QOL measurement for people with dementia, personalised versions of two dementia-specific self-report QOL scales (DQoL and QoL-AD) were constructed by means of prioritising the different domains. It was investigated whether these measures were more valid to detect variations in QOL of people with mild to moderate dementia than their standard versions. Also, the reliability was investigated. Moreover, it was examined if severity of dementia was associated with personalised QOL. Finally, the study explored the differences between countries regarding the personalised overall QOL outcome and regarding the indicated importance of the individual QOL domains.

Although the personalised versions of the DQoL and QoL-AD were sufficiently reliable, the scales proved not to be more valid than their standard versions. No relationship between severity of dementia and personalised QOL was found. No differences were found between countries for the overall QOL score and for most of the domains, i.e. feelings of belonging, sense of aesthetics, living situation, memory, family, marriage/closest relationship, friends, self-image, ability to do things for fun, money/financial situation. However, some QOL domains were valued differently: people with dementia from the United Kingdom rated self-esteem, mood, physical health, energy level and the ability to do chores around the house significantly less important than people from Italy and Poland.

ANALYSIS AND DISCUSSION OF THE FINDINGS

Psychosocial interventions are most effective when tailored to the person's needs, wishes and abilities (Fazio et al., 2018; Lawrence et al., 2012; Vernooij-Dassen & Moniz-Cook, 2014). Already in 1996 Kovach and Henschel (as cited in Lawrence et al., 2012) observed that 'activity groups with less structure, smaller numbers and more flexibility in the

delivery, allowed greater opportunities for self-expression and a focus on individual needs and abilities'. Psychosocial interventions that are tailored to a person's needs and wishes can be beneficial for the quality of life of people with dementia. However, as mentioned in the introduction of this thesis, even though person-centred care is generally recommended worldwide, it is not yet implemented in all countries, cultures and care settings. This thesis therefore focused on the systematic development, evaluation and implementation of person-centred dementia care, more specifically the development of a person-centred approach of nature-based interventions, the evaluation and implementation of an art-based intervention and a personalised approach of QOL assessment. What did our research contribute to the state of the art described in the scientific literature and what are the lessons learned from our research?

Development

Person-centred care is the preferred approach in dementia care (Brooker & Latham, 2016; De Lange, 2004; World Health Organization, 2017). For many professionals in healthcare, however, the central question is, how do you do this? Tools that can promote person-centred care by supporting and guiding professionals in providing it are therefore very important.

The user-centred method that was applied in this thesis to develop a tool to compose personalised nature activities, resulted in a user-friendly and useful aid. This tool can be used by caregivers to set up nature activities in line with the personal wishes, needs, and values of people with dementia. According to the principles of participatory design and co-design (Hendriks et al., 2015; Rodgers, 2018), people with dementia and professional caregivers were involved in all phases of the development of the tool. This type of design seems to be more likely to reflect the perspectives and preferences of the users, and the chances to end up with a successful design outcome are higher (Hendriks et al., 2013).

In the first phase of development, focus group interviews were conducted to explore which aspects of nature or outdoor spaces people with dementia find important for their quality of life. To maximise the diversity of views of people with dementia in different stages of dementia and contexts, these focus groups were organised in different healthcare settings in different regions of the Netherlands. A recent study of Evans et al. (2019), in which people living with dementia were asked about their experiences in nature, showed that connecting with nature also appeared to

be important for people's self-identity. This supplements the aspects of experiencing nature that were found in our study.

Secondly, a first prototype was designed based on the aspects of experiencing nature, and preferred outdoor activities that people with dementia mentioned as important for their quality of life. Attuning the nature activity to what the individual person finds relevant is, of course, crucial for personalised care.

Next, feedback from professionals with different backgrounds in the field of (dementia) care or nature education helped to further shape and improve the tool, the examples of nature activities and its instructions (*'the approach'*). The user-centred method of development as was used in the personalised nature activities study may be also applied to develop tools for personalising other types of psychosocial activities or interventions. In the last decade user-centred and participatory design methods were also successfully applied in the designing of assistive technology for people with dementia (Kerkhof et al., 2019; Meiland et al., 2014). Nevertheless, the development of tools to personalise psychosocial interventions is still in its infancy.

Finally, to see whether the developed approach was useful in care practice it was applied by care professionals undertaking personalised nature activities with people with dementia, including those with behaviour or mood problems. The findings of this pilot study, showing that people with dementia participating in the person-centred nature activities had many positive behaviours and few negative, are in line with the findings of the systematic review of Zhao et al. (2020). They concluded that people with dementia benefit from participatory horticultural activities as these reduce agitated behaviour, improve communication and promote positive emotion and engagement. However, whether person-centred nature-based interventions are more effective than *non*-person-centred nature interventions needs further evaluation research. Considering the Medical Research Council Framework for the development of complex interventions (Craig et al., 2008), this would then be the next step after concept development and piloting/feasibility testing.

Evaluation

The past years more and more research has been done into different art programmes. These studies indicate that art can play a valuable role in dementia care. A recent review into art and museum interventions for people with dementia shows that visual

art therapy can reduce depressive symptoms and anxiety and can provide pleasure and enjoyment (Masika et al., 2020). The findings of the evaluation study into the Unforgettable art programme are in line with this; both participants with dementia and their caregivers enjoyed the Unforgettable art programme and it had a positive impact on their mood as measured directly after the programme.

Unforgettable is a group art activity in which the interactivity is stimulated and personal observations and interpretations are encouraged. These are important features of the Unforgettable programme. Cohen-Mansfield (2018) found that the mood and engagement of people with dementia improved in group activities as compared to people who participated in individual activities. This is no surprise as positive social interactions are generally important for people with dementia (Jao et al., 2018). The positive social interaction stimulated by, and deriving from the Unforgettable programme and its facilitators, was indeed highly appreciated by the participants. The social interaction also appeared to be essential for the satisfactory experience of people with dementia visiting the Prado Museum in Madrid: Sharing the exhibition halls with the general public provided positive elements and participants enjoyed watching other groups of visitors (Belver et al., 2018).

Another key feature of the Unforgettable programme is that it is an activity designed for dyads: people with dementia and their caregivers. The tour guides treat the participants, whether they have dementia or not, equally. Research shows that because couples can no longer share all their thoughts and experiences, caregivers often feel that they are losing their partners (Swall et al., 2020). For the well-being of informal caregivers, it is important not to get completely caught up in the caregiving role. A meaningful connection between people with dementia and their informal caregivers is important for both of them (Van Corven et al., 2021). Informal caregivers especially appreciated joining the Unforgettable tour because they enjoyed being able to do it together. Also, people with dementia who joined the Unforgettable tour together with an informal caregiver were more likely to be in a better mood afterwards as compared to people who joined the tour together with a professional caregiver. The positive impact of dyadic art activities, on for example communication between persons with dementia and their caregivers, was also found in the review into psychosocial outcomes of dyadic art interventions of Bourne et al. (2020). Based on their findings they suggest that dyadic activities could support 'couplehood' by strengthening relationships.

In line with our study which showed that museum artefacts proved to stimulate social interaction most, Camic et al. (2019) found that handling of museum objects had a positive impact on the wellbeing of people with dementia. More specifically, they found that the positive impact was larger in people with mild dementia, compared to people in the moderate stage of dementia. The stimulation deriving from artefacts might be explained by their recognisability, as compared to other types of art. Our study also found that people with milder cognitive impairments or mild dementia responded more to art than people with more severe dementia. In their study, Luyten et al. (2018) examined the responses of nursing home residents with dementia towards the interactive art installation 'VENSTER'. They found that sessions in which calming scenes were shown evoked less responses than activating and interactive scenes. Sessions with semi-abstract, interactive content were more difficult to understand for the users. Care providers had to invite them to interact and to keep the interaction going. The researchers therefore raised questions about the use of abstract interactive art for nursing home residents. Given the findings of our study that more abstract artworks revealed less appreciative responsiveness and less interaction with others, it might be an interesting question to further investigate. However, based on the findings of our study and the relevant literature, it can be concluded that it is important to keep the background characteristics of the participants in mind when selecting the art works for museum programmes.

The study into the personalised evaluation of QOL showed that both standardised and personalised measures were valid ways to assess QOL. The choice of type of measure therefore depends on the goal of the QOL assessment. For individual person-centred care planning personalised QOL measures may be preferred above standardised. For evaluation of interventions on a group level, for instance within research, standardised QoL measures are preferred as these will take less administration time.

Implementation

Good implementation of evidence-based interventions is crucial to achieve positive effects. Interventions that have been shown to be successful, are not always successfully implemented in other sites or environments (Vernooij-Dassen & Moniz-Cook, 2014).

To examine how the Unforgettable art program is best implemented in other museums, the nationwide implementation was evaluated. The experienced impor-

tance of a clear project plan at the start of the implementation of the Unforgettable programme, was also found in the implementation studies of Mangiaracina et al. (2017), Van Mierlo et al. (2016) and Meiland et al. (2005) into several other psychosocial interventions. The importance of the skills and characteristics of the guide facilitating the museum tour is in line with the findings of Camic et al. (2016) and Flatt et al. (2015). Literature from other disciplines is also consistent with the findings of our implementation study and show that the implementation of an intervention can be affected by execution factors such as the active engagement of staff and family, by factors relating to the organisational context such as the beliefs and expectations of the stakeholders within the organisation, and by the external environment of the implementing organisation (Forman et al., 2009; Lawrence et al., 2012). Limited managerial support and insufficient time are often found to be barriers to implementation of best care practices in different healthcare disciplines (Lourida et al., 2017). Difficulties with recruiting people with dementia and informal caregivers to a new activity or intervention, as was experienced in some of the museums, were also found to impede successful implementation of easy access day care centres in the study of Van Haeften-Van Dijk et al. (2015). Even though the implementation of Unforgettable overall was successful, looking back at the research on the implementation of the Meeting Centres Support Programme of Meiland et al. (2004), the support for the programme in the different museums might have been stronger if even more attention had been paid to the specific contexts of the different museums.

In the pilot study into the personalised nature activities, we also investigated the organisational feasibility of the personalised nature intervention approach from an implementation perspective. It was found that the most crucial factor for successful implementation of person-centred nature activities was a good preparation of the activity sessions by the professional caregiver. A barrier to successful implementation was that some professionals and volunteers were not used to working in a person-centred way. The importance of a trained professional is underlined by Schneider (2018). She emphasizes that the quality and thereby the efficacy of the intervention depend primarily on who delivers the intervention and their qualities. Is the facilitator trained in delivering the intervention in a person-centred way? What is their knowledge about dementia? Training and information about the principles of person-centred care are thus recommended.

Information and training about dementia care was also proven to be important in the study into the Unforgettable art programme. The museum staff and volunteers who received information about dementia and were trained in the Unforgettable method, had a more positive and a more person-centred attitude towards people with dementia than those who were *not* trained. Also, other research has shown that education programmes aiming to improve the knowledge and understanding of dementia result in more positive attitudes towards people with dementia and more empathy (Hattink et al., 2015; Scerri et al., 2020;). The training of the staff and volunteers included having conversations with people with dementia and caregivers and joining a pilot tour. This indicates that not only information, but also personal contact with individuals with dementia and/or their caregivers may help to increase a positive attitude towards dementia. The importance of personal experience with dementia for the change of attitude towards dementia was also found in the study of Cheston et al. (2019). Similar changes in views about dementia and attitude of the museum staff after implementation of the museum programme for people with dementia were found among art gallery facilitators in the study of Camic et al. (2016). These changes appeared to be related to ‘the opportunity to share an engaging experience and to witness people with dementia making capable contributions in an intellectually challenging setting’.

Patient and public involvement in research

Involving people with dementia in the development, implementation and evaluation of psychosocial interventions contributes to their feeling of not ‘just’ being a person with dementia but being seen as equal to the team of researchers and professionals developing the intervention (Roberts et al., 2020). In recent years patients and the public have been increasingly involved in dementia care research as it is recognised that this can increase the relevance and effectiveness of research as it promotes that the research findings are appropriate for the target group (Shippee et al., 2015; Staley, 2009). Our study into a personalised approach for nature activities provides insight into the involvement of people with dementia in the development of a tool that can be used to personalise nature activities. By using the aspects of nature experience that people with dementia consider as important to their quality of life, the tool (*‘decision tree’*) and consequently the outcome of the person-centred nature activity are more likely to be effective. In the evaluation study into the Unforgettable programme, the participants in the successive museums were asked about their suggestions for

improvement. These were taken into consideration in the further dissemination of the programme into other museums.

METHODOLOGICAL CONSIDERATIONS

Several methodological considerations regarding the studies have to be made.

Sample size and generalisability

The studies into Unforgettable reported on a specific sample of people with dementia which limits the generalisability of the outcomes: all participants had mild to moderate dementia. In addition, most of the participants in this study were diagnosed with Alzheimer's disease and/or vascular dementia. There were too few people with other types of dementia to investigate differences in reactions between diagnostic subgroups. Moreover, participants of the Unforgettable programme were self-selected, which makes it difficult to generalise the outcomes to groups of people with dementia in the general population.

The small number of participants or subgroups of participants, and thereby the generalisation of the results, was a limitation in the studies. The numbers of participants who visited the different museums with very different art collections were too small to investigate the effects of the variations between museums on the outcomes. In the study into the personalised QOL instrument, the number of study participants per country was too small either to investigate in more detail what background characteristics may have determined the country differences in views on importance of QOL domains. The small number of participants or subgroups of participants, and thereby the generalisation of the results, was a limitation in all studies. However, the studies describe novel or explorative interventions or instruments, and not a definitive trial in which larger samples would be used (Moore et al., 2015).

Because of the lack of a control group in the Unforgettable study it is difficult to determine whether the appreciation of the programme and the improvements in mood of people with dementia and caregivers were specifically related to the art and the art programme itself or to other factors. Because of the explorative nature of this study no multiple test correction was applied in calculating the associations between the user experience and appreciation of the Unforgettable programme and the background characteristics of the participants. Also, the study into the personalised QOL used an uncontrolled one-group design and should be considered exploratory.

In the study into the implementation of Unforgettable, the interviews with stakeholders were mainly held in the starting phase. As only two interviews were conducted in the continuation phase (seven or more months after the official start of the programme in a museum), we have gained less insights about the longer-term implementation issues. The respondents to the Approaches to Dementia Questionnaire, which assessed staff attitudes towards people with dementia, differed from dropouts in gender, position, hours of work per week, and being informed about dementia, which may have led to biased outcomes. As a result, we do not know if the improved attitude towards dementia can be generalised to all museum employees and volunteers.

Reliability

The behaviour of participants during the Unforgettable programme and the nature activity was assessed by observations of researchers using the (adapted) INTERACT observation scale (Baker & Dowling, 1995). Participant observation has strengths, as it allows measuring in the moment and during the activity. However there are also weaknesses, such as the fact that mood reactions are subjectively interpreted from facial and verbal expressions. There were also some practical limitations in the use of this observation scale: the adapted version of the INTERACT observation scale had many items and the time to fill them out was sometimes short, especially during the museum tour whereby the scale was filled in after viewing each artwork. This may have influenced the reliability of the observations. In future studies, in such contexts it would be advisable to use an observation instrument with less items and, if possible, video recordings to allow more thorough evaluation of behaviour and to observe participants individually and over a longer period of time.

Instruments

To ensure patient participation in studies, it is important to ask participants themselves about their experiences with an intervention. However, measuring outcomes in vulnerable people, such as people with dementia and their caregivers, leads to specific challenges such as simplicity versus specificity and short and feasible, but maybe incomprehensive, versus long and tiring yet more comprehensive. In the study into the personalised nature activities, we noticed that some participants needed help with quantifying their satisfaction with the activity on a ten-point scale and answering open-ended questions. The low response rate of the take home questionnaire among participants in the Unforgettable study might be explained by the length of this questionnaire, especially the one for the caregiver. A higher response rate could possibly

be achieved by using shorter interviews. For future studies a good trade-off needs to be made between the length of the questionnaire, the number of response options, and psychometric properties on the one hand and the feasibility of filling out the questionnaire on the other. However, this may be a challenge. For example, to improve the feasibility of the study into the appreciation of the Unforgettable programme, we had mainly questions with up to three response categories. This obviously provided a less nuanced picture than questions with more response categories would have had and may have negatively affected sensitivity to finding effects.

SCIENTIFIC, CLINICAL AND SOCIETAL VALUE

The research reported in this thesis contributes to the scientific knowledge regarding the development, implementation and evaluation of person-centred psychosocial interventions and interventions for subgroups of people with dementia and their formal and informal caregivers by delivering a successfully pilot-tested person-centred approach for designing nature interventions; by providing knowledge on effectively implementing person-centred nature and art interventions in a community-based and residential care setting and by delivering a reliable and valid new method for personalised QOL measurement.

The tool that resulted from the study into the personalised nature activities can be useful for healthcare professionals and other caregivers to personalise nature activities for people with dementia in meeting centres, day care centres, and long-term care settings. With some adaptations, it may also be possible to use this tool for other psychosocial interventions for people with dementia, which could be of great value in promoting person-centred work in dementia care.

The art and nature interventions were designed for all people with dementia, not for specific subgroups. However, as they will mainly attract people who like to be involved in these kind of activities they can be seen as meaningful activities for interested subgroups. These programmes will provide a greater variety of meaningful activities for people with dementia. The more choices there are, the more likely it is that some activities will suit the interests and wishes of individual persons. In the end, that is what contributes to people's quality of life (Kim & Park, 2017). Moreover, the method used during the interactive museum tours is person-centred, in the sense that it highly encourages and values the personal views and contributions of each individual participant.

The results of the evaluation studies of the Unforgettable programme show that when designing and implementing (art) programs for people with dementia it is important to take into account their background and environmental/contextual factors. Moreover, knowing which type of artworks appeals most to (subgroups of) people with dementia can contribute to the optimisation of art programmes for this target group and their active participation in such programmes. If the art programme is more appealing to the person with dementia, it is also likely to be a more positive experience for the caregiver participating in the art programme. This may subsequently impact both of their wellbeing.

The identification of conditions for successful implementation of the nature and art interventions described in this thesis may help to disseminate these interventions further so that more people with dementia and caregivers can benefit from them. Opportunities for social participation are essential in realising a dementia-friendly society. The more positive attitude towards dementia of the museum staff and volunteers after the introduction of the Unforgettable programme indicates that museums offering a dementia programme, and therewith getting in touch with people with dementia and increasing their knowledge and understanding about dementia, can contribute to a more dementia-friendly society.

Finally, to properly design, apply and evaluate personalised interventions for individuals with dementia, it is essential to understand which life domains contribute most to their QOL. The use of a personalised QOL measurement seems therefore relevant for clinical practice. The personalised versions of the DQoL and the QoL-AD may be used to determine care goals for individual persons with dementia and to monitor treatment based on the domains as indicated as relevant by the person. The study into the personalised QOL measures also makes people aware that there may be cultural differences regarding the importance that people with dementia attach to the individual domains of QOL. This information may be important when adapting and implementing care methods and innovations in different countries.

RECOMMENDATIONS FOR FUTURE SCIENTIFIC RESEARCH

Several recommendations for future research can be given. Before implementing psychosocial programmes on a wider scale, the added value of the programmes should be evaluated in research with a greater evidential value. Relatively little research has been done into personalised interventions for people with dementia,

especially little is known about the personalisation of nature activities for this target group. Further research into the application, effectiveness and implementation of the developed personalisation tool for nature interventions is therefore recommended.

Not much research has been done into adaptive implementation of interventions for people with dementia in community settings (Meiland et al., 2004; Van Mierlo et al., 2018). Further research is needed into community-based activities that provide opportunities for people with dementia to participate socially in activities that match their needs, wishes and possibilities. Also, recently a lot of research has been done into art interventions for people with dementia, although most of them focus on the person with dementia rather than on the dyad (Bourne et al., 2020). Considering the burden of informal caregivers and the importance of a meaningful relationship between the person with dementia and his or her caregiver, research on the impact of dyadic art interventions on the person with dementia, his or her family caregiver and their relationship are of particular importance.

The approach we developed to personalise dementia specific QOL instruments was new. The results of the explorative study underscore that the felt importance of domains of QOL may vary between individuals with dementia and also between countries and cultures. Further research into what determines people's experience on the importance of QOL domains and intercultural differences is recommended.

Most studies described in this thesis can be seen as explorative because of their small sample size. However, the promising outcomes emphasise the need for further research into the effects on behaviour, mood, and quality of life of person-centred nature activities and museum programmes for people with dementia in different (care) settings. This should preferably be done by means of controlled studies, with a pre-test–post-test design. It would also be interesting to look at subgroups of people with different types and severity of dementia to see if these factors influence the outcomes and experiences.

Medical research into progressive diseases or syndromes such as dementia is often aimed at prevention, diagnostics and cure. Less attention is paid to the psychosocial perspective of how to live well with such diseases in our society. According to the Dutch Ministry of Health, Welfare and Sport more attention, also in the research field, should be given to the question how we organise our society accordingly

(Ministry of Health, Welfare and Sport, 2020); a recommendation that urgently needs to be followed up in the design and funding of research in the coming decades.

RECOMMENDATIONS FOR CLINICAL PRACTICE

Even though the positive impact of person-centred care is well-known, and care staff is very willing to support the person in a personalised way, there is still a lack of knowledge on how to personalise activities (Hamiduzzaman et al., 2020). Moreover, research shows that for nurses, delivering person-centred care to people with cognitive impairment is challenging (Grealish et al., 2019). Personalisation tools such as the decision tree that was developed in the study into the personalised nature activities can help care personnel with this.

As was found in the study into the personalised nature activities and the study into the Unforgettable art programme, besides information and education about dementia, the culture of the organisation and thereby organisational support is essential in the realisation of person-centred interventions. Personalised activities are often underused due to a lack of organisational support (Lawrence et al., 2012). If the new intervention is not supported widely in the organisation, there is a high risk that the implementation will fail.

Inspired by exciting experiences of others, organisations often copy-paste interventions that have been shown to be successful in another organisation. However, for an intervention to be effective in a new context, it should be implemented in an adaptive way (Meiland et al., 2004). Cooperation with other care, welfare and societal organisations appeared essential for successful implementation of the Unforgettable museum programme. Collaboration with and making use of the networks of these other organisations, such as (informal) care or support organisations and caregiver organisations proved crucial in the promotion of this person-centred programme throughout all phases of implementation. Therefore, museums who intend to implement the Unforgettable programme are advised to include collaboration with local relevant care, welfare and societal organisations as one of the main strategies in their implementation plan. When implementing an intervention, all organisational levels should be taken into account and the people who will work with the programme should embrace it and understand the importance.

Measuring QOL is complex because of its individual character: aspects of life which are important to one person may have little or no relevance to another person. Care personnel should be made aware of that, when making use of standardised quality of life measures, not all elements may be equally important to the person. It is therefore recommended that care staff are encouraged to use individualised QOL measures to gain insight into what is important for the individual person with dementia's QOL. This information may help them to prioritise specific quality of life domains in the treatment and care of their clients.

RECOMMENDATIONS FOR PUBLIC POLICY

For the further dissemination of person-centred activities for people with dementia public policy is crucial. The World Health Organization sets the development of knowledge and skills of healthcare professionals in dementia care as a priority (World Health Organization, 2017). Training in using person-centred care is recommended to be added to the curriculum of dementia care education in general. In the Netherlands the 'Zorgstandaard Dementie 2020', the guideline for dementia care, puts the needs and wishes of people with dementia and their informal caregivers central in dementia care (Dementiezorg voor elkaar, 2020). For policy makers it is important to realise that there may be a tension between strict quality regulations and efficacy on the one hand, and the delivery of person-centred care on the other, which intends fulfilling personal needs and wishes. The latter asks for a more holistic view rather than segmented care (Sharp et al., 2018). Therefore in this respect, flexibility in the execution of regulations for care organisations may be required to facilitate providing personalised care (Van de Bovenkamp et al., 2020).

In recent decades a trend towards remaining at home for as long as possible and shifting away from institutionalisation is seen in policy. Also, people with dementia prefer to remain living at home for as long as possible (Gibson & Richardson, 2017; House of Commons, 2018). Therefore, the focus should lie on keeping people with dementia active participants in their local communities as long as possible (Alzheimer Disease International, 2018; World Health Organization, 2017). Consequently, it is more and more important, besides supporting personalised care and activities inside the care institution, to also support opportunities for meaningful engagement for people with dementia living at home. With an emphasis on *meaningful for the person*, as the quality of life of people with dementia is linked to their personal needs and interests being satisfied as well as experiencing a sense of being useful (Cahill et al., 2004; Dröes

et al., 2006). The person who cares for the person with dementia plays a major role in enabling the person with dementia to continue living at home. Often the caregivers experience mental burden due to their caregiving task (Etters et al., 2008). Their relationship with their partner, parent or friend has changed (Quinn et al., 2009). To undertake an inspiring activity together, such as the Unforgettable museum tour, can provide them with a joint meaningful and joyful experience rather than just caring for their loved one. Therefore in the provision and (financial) support for meaningful activities for people with dementia, the informal caregiver should not be forgotten.

How people perceive and portray dementia has impact on how they act towards people with dementia (Gerritsen et al., 2018). This has implications for how the issue of dementia within society is addressed. The perception of people with dementia as a group rather than as individuals with diverse characteristics, abilities and needs is problematic. The risk of a homogenised response is higher in a group-based approach (Gerritsen et al., 2018). By offering more personalised activities, such as art or nature interventions, in the care institution and in the community, people can continue their lives and associated activities for as long as possible. For community activities, a dementia friendly society can be seen as a prerequisite, and at their turn, these initiatives will also contribute to the social inclusion of people with dementia. It gives them the opportunity to be part of the community.

In general, but especially for professionals and volunteers working with people with dementia outside the care practice, information on dementia and its consequences is recommended. The finding of our study that also the *untrained* staff of the museums where the Unforgettable programme was implemented had a more positive attitude towards dementia suggests that even getting little information about dementia or having just some contact with people with dementia may already influence the attitudes towards dementia in a positive way. This underlines the importance of knowledge transfer about dementia and getting in touch with people with dementia. In the Netherlands, like in many other countries, a national dementia strategy and dementia-friendly communities have been and are being developed (Alzheimer Europe, n.d.). These campaigns help creating awareness of dementia and of the importance of a person-centred approach and will contribute to a dementia friendly society (Gerritsen et al., 2018). Therefore, public policy should continue investing in campaigns that contribute to promoting the general knowledge on the disease and its consequences. It can be expected that with more publicity and familiarity

with dementia in our society it will be easier for people with dementia and their (in) formal caregivers to continue to participate in society and to experience the joy that activities in nature, art and being with other people can bring.

OVERALL CONCLUSION

This thesis contributes to the knowledge regarding the development, implementation and evaluation of person-centred psychosocial interventions for people with dementia. The focus in dementia care should not merely be on healing and symptom management, but also on the wellbeing of people living with dementia. It is not about what others find important for the person, but what the person himself wants and needs. Person-centred care, in which people with dementia's need for social interaction and activities matching their wishes and abilities are fulfilled, should have priority in dementia care. Moreover, to properly design and apply personalised interventions for individuals with dementia, it is essential to understand which life domains contribute most to their quality of life. To make sure the intervention fits the needs and wishes of people with dementia, it is essential to involve people with dementia in all stages of research, from the development and evaluation to the implementation and dissemination. In case of more severe dementia, family members, even though they cannot represent the true perspective of the person living with the disease, should be involved. Taking notice of the background of people with dementia and the societal and environmental factors may help to further improve programmes for people with dementia and their (informal) caregivers, including nature and art programmes. For an intervention to be effective, it must be successfully implemented. For the consolidation of personalised care activities, continuous organisational support and promotion is important. Both the further, adaptive implementation of nature and arts programmes and the positive effect on attitudes towards dementia can contribute to a better understanding and less stigmatisation of dementia. This may lead to an enhancement of social inclusion of people with dementia and their caregivers which will consequently promote their well-being. Overall, the (explorative) studies reported in this thesis underline the importance of person-centred psychosocial interventions for maintaining or improving the quality of life of people with dementia and confirm the crucial role that people with dementia themselves can play in the development, implementation and evaluation of such interventions.

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SUMMARY
SAMENVATTING
LIST OF PUBLICATIONS
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SUMMARY

Psychosocial interventions are most effective when they fit the needs, wishes and abilities of the person. Also in the care for people with dementia, person-centred care is recommended worldwide. However, this is not yet daily practice, also because of the lack of knowledge and tools about how to give shape to person-centred care. Therefore, his dissertation focuses on the development, evaluation and implementation of person-centred psychosocial interventions in dementia care. The subject of this dissertation is introduced in Chapter 1. More specifically, research was done into the development of person-centred nature interventions (Chapter 2), into the evaluation (Chapters 3 and 4) and implementation (Chapter 5) of Unforgettable, an art programme for people with dementia and their loved ones, and into an instrument to measure quality of life in a person-centred way (Chapter 6). The final chapter (Chapter 7) describes the main results and limitations of the studies. Also, recommendations for further research, care practice and policy makers are given in this chapter. Based on the main research questions, a chapter-by-chapter summary is provided below.

Chapter 1: Introduction

Dementia is a syndrome. There are several types of dementia. The most common are Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy Body dementia. The number of people with dementia worldwide is currently around 50 million and is expected to triple by 2050. Because of this, dementia has the full attention of researchers, healthcare professionals and policy makers. To this date dementia cannot be cured. Dementia care therefore focuses on optimising the quality of life of people with dementia and supporting those around them. Psychosocial interventions, non-medical interventions that aim to improve social functioning, can help with this. Psychosocial interventions are most effective when they are tailored to the individual wishes, needs and abilities of the person with dementia. A systematic approach to the development, evaluation and implementation of person-centred psychosocial interventions is therefore important.

Chapter 2: Nature and dementia: development of a person-centred approach

Which aspects of nature do people with dementia find important for their quality of life? Which activities in nature do people prefer?

To answer these two questions, focus groups with people with dementia were conducted in different types of care institutions (meeting centres, day care centres, nursing homes), in different regions in the Netherlands. When asked which aspects of nature participants found important for their quality of life, eight themes emerged: pleasure, relaxation, feeling fit, enjoying the beauty of nature, the social aspect of nature, feeling free, feeling useful and memories. When asked what activities in nature they preferred, participants mentioned active activities, such as walking, cycling, swimming and doing exercises; passive activities, such as sitting outside, looking at nature, talking about it; social activities, such as drinking coffee together outside, watching children play, activities with animals; activities with flowers and plants and indoor nature activities, such as watching a nature film or flower arranging.

What tool can be developed to support the personalised delivery of nature activities for people with dementia?

Based on the results of the focus groups and literature research on nature experiences of people with dementia, a draft version of a person-centred methodology was developed. This first version of the methodology included two variants of a tool (a decision tree and a checklist), combined with three macro activities (gardening, nature walk and a sensory stimulating activity). This tool can help caregivers and volunteers to find activities that suit the person with dementia and help to personalise the chosen activities. The decision tree, checklist and macro activities have been presented for feedback to a number of people with dementia and to a group of professionals from different backgrounds (care or nature organisation) and have been adjusted accordingly. The decision tree was generally preferred. Most professionals were positive about the feasibility of the method. Some indicated that staff in their own institution would not have enough experience and expertise to guide personalised nature activities. Requesting guidance from nature organisations or additional training in guiding such activities was suggested as a possible solution.

Are these personalised nature activities feasible and how are they valued by people with dementia and professionals in dementia care practice?

The tool and macro activities were tested on a small scale for user-friendliness and usability among people with dementia and their caregivers. Care professionals and/or volunteers of the care institution guided the nature activities which they adapted as much as possible to the personal preferences, needs and possibilities of the people with dementia participating in the activity. During the activities their behaviour was observed. Participants showed little 'negative' behaviour (such as sadness, fear, confusion) during the activity and much 'positive' behaviour (such as happy/satisfied, alert, spontaneous talking, focus on the activity and interaction with others). After the activity, all participants indicated that they had enjoyed participating and almost all would like to do the activity again. From the interviews with professionals, volunteers and people with dementia after the activities, eight themes for successful implementation of personalised nature activities emerged: a motivated facilitator with affinity to nature, a suitable and calm location, good weather, suitable materials, appropriate duration of the activity, good composition of the group, open-minded care culture and good preparation. This last factor proved to be the most crucial. Not preparing the activity properly resulted in less attention for the participants and caused disturbance the activity. Not reading the instructions for the activity resulted in a less person-centred and less stimulating setting.

Chapter 3: Evaluation of the 'Unforgettable' art programme by people with dementia and their caregivers

The Unforgettable programme consists of interactive museum tours for people with dementia and their loved ones. The Stedelijk Museum Amsterdam and the Van Abbemuseum in Eindhoven started offering this programme in 2013. Later, the Unforgettable programme was implemented in ten other museums in the Netherlands. Unforgettable is based on the Meet Me at MoMA programme of the Museum of Modern Art in New York. These museums are not alone in this. In recent years, more and more attention has been paid to art programmes in various settings for people with dementia. This is not without reason: art programmes, such as music making, theatre and museum visits, appear to have positive effects on the well-being of people with dementia.

How is the Unforgettable programme experienced and appreciated by the participants?

Both the people with dementia who participated in this museum programme and their participating family and professional caregivers appeared to be in a better mood immediately after the tour than before. A few days after the tour, people with dementia and their caregivers indicated how they had experienced the programme. In particular the social interaction during the tour and the involvement and friendliness of the tour guides and hosts were appreciated. People with dementia also appreciated looking at art and the museum building itself. A number of family caregivers found the response of their family member with dementia the most rewarding part of the tour, for example seeing how caring he or she was and how they enjoyed the tour. Some family caregivers were surprised by their relative's reaction: their involvement in the tour, their enthusiasm or spontaneity. Some of the family caregivers indicated that they experienced a different type of contact than usual with their loved one during the tour. They had more eye contact or talked about the tour they had experienced together. People with dementia and their caregivers appreciated the programme and would like to take part in such a tour again. Previous experience with art or museums was not a prerequisite for enjoying the Unforgettable tour; people with and without experience of art rated the tour equally positively. Although Unforgettable was originally intended for people with mild dementia, it was also positively evaluated by people with moderate to severe dementia living in care facilities.

Chapter 4: How do people with dementia respond to different types of art? An explorative study into interactive museum programs (Unforgettable)*Are there differences in reaction to different types of art?*

This chapter investigates whether people with dementia react differently to different types of art. It was also investigated whether specific background characteristics of people with dementia influence this. During the museum tour, participants were observed by the researchers. They looked at the interaction between the people with dementia and their caregiver, tour guide and other participants, but also at their alertness, involvement in, and reaction to the various works of art discussed. Works of art with less nature, such as cityscapes or abstract installations, produced more social interaction than works of art that showed a lot of nature, such as landscapes or animals. A difference was found when looking at objects that were not originally intended as art, for example tableware and clothing, versus looking at works of art that were originally intended as art: there were more reactions to the objects not

intended as art than to works of art. People with mild to moderate dementia generally reacted more spontaneously and interacted more with others than people with more severe dementia. In terms of responses to the works of art, it made no difference whether the work was discussed at the beginning or at the end of the tour.

Chapter 5: Implementation and impact of Unforgettable: an interactive art program for people with dementia and their caregivers

Which factors influence the implementation of Unforgettable?

To answer this question, interviews were held with those involved in the implementation of Unforgettable in twelve Dutch museums, such as tour guides, Unforgettable programme coordinators of the museums and employees of involved chain or family care organisations. Despite the differences in collection and organisation, the implementation of Unforgettable in all museums proved to be quite feasible. A number of factors that were present in the museums beforehand appeared to ease the implementation, such as the expertise and support of the project coordinator, the motivation of the different museum staff members and the extent to which the Unforgettable programme fitted in with the museum's policy. Little time for the programme due to a busy schedule of the programme coordinator hindered a good implementation. Another important point of attention for a successful implementation of Unforgettable at the operational level was the recruitment of tour guides and hosts. They should be selected on their qualities and characteristics. Also important was the training for tour guides and volunteers in which information was given about dementia, contact was made with people with dementia, and the Unforgettable method was practised. In addition, informing other museum staff members helped with the implementation; it awakened their enthusiasm for and commitment to the programme. Regular evaluation proved to be important in maintaining the skills and motivation of the tour guides. The promotion of the programme was very important. People living at home with dementia were particularly difficult to reach. Repeated attention for and promotion of the programme in different ways to relevant organisations in the region, preferably through personal contact, were essential for successful implementation. At the organisational level, working with and making use of the networks of other organisations such as family care organisations or dementia networks was important. At the societal level, the implementation was enhanced if the municipality paid special attention to dementia, for example in the context of a dementia-friendly municipality. This contributed to the support for the programme within the region.

What is the impact of Unforgettable on the museums?

As a result of Unforgettable, a number of museums have plans to set up programmes for other groups of people with special needs, such as people with severe vision impairment or people with Down's syndrome. For the museums, Unforgettable not only underlined the importance of inclusion and offering programmes for people with disabilities, but also of interactive guiding. Tour guides from Unforgettable now also use the Unforgettable method in other public tours. Some museums experienced that the implementation of Unforgettable contributed to the general development of the guides and the strengthening of the internal relationships within the museum and therefore to the professionalisation of the museum. Unforgettable has also contributed to the cooperation and exchange of knowledge with other museums and social organisations.

What is the impact of the implementation of the Unforgettable program on the museum staff and volunteers?

Museum staff and volunteers completed a questionnaire on how they perceive people with dementia. This was done before Unforgettable was implemented in their museum, and a few months later, after the programme had been implemented. About half of the museum staff and volunteers who participated in the study were trained in guiding the Unforgettable programme as a tour guide or host. It was striking that both those who had been trained and those who had not had any training had a more positive image of people with dementia in their museum a few months after the start of the programme. They saw people with dementia more as individuals with the same value as any other person. However, this positive change was larger in the trained people than in the non-trained people. The trained people were also more optimistic about the possibilities and future of people with dementia.

Chapter 6: Value of personalised versions of dementia-specific QOL scales: an explorative study in three European countries*Are personalised quality-of-life instruments more suitable for measuring variation in quality of life than 'standard' quality-of-life instruments?*

To answer this question, so called 'pre-questions' were added to two commonly used quality of life instruments for people with dementia: the DQoL and the QoL-AD. In the personalised instrument, the person with dementia denotes for the domains/items of the DQoL and the QoL-AD (e.g. family, money, physical health) how important they are to him or her on a scale of one to ten. How people feel about

those domains/items is then asked according to the instructions of the DQoL and/or the QoL-AD. A weighted value is calculated based on the priorities and the answers given to the domains/items. Finally, the results of the personalised versions were compared with those of the standard versions. Although the personalised versions of the DQoL and the QoL-AD were reliable in measuring quality of life, they did not find more variation in the experienced quality of life of people with dementia than the standard versions.

Is there a relationship between the self-reported quality of life and severity of dementia?

No relationship was found between severity of dementia and quality of life as measured by the personalised quality of life instrument.

Are there differences between countries in the importance given to different domains of quality of life?

The research on the personalised quality-of-life tool was conducted in three different countries: Poland, Italy and the United Kingdom. People with dementia in these countries rated all domains of the DQoL and items of the QoL-AD as important for their quality of life. Some domains/items were considered more important than others, for example living situation and memory. Family and marriage/nearest relationship were considered most important for quality of life in all countries. The ability to do chores around the house was generally found to be the least important for quality of life. A number of domains/items of quality of life as measured by the personalised versions of DQoL and the QoL-AD were considered less important for quality of life by people with dementia from the UK than by people with dementia from Poland and Italy. These were physical condition, mood, self-esteem, energy level and ability to do chores around the house. These differences may also be explained by the difference in background; the participating people with dementia from the UK were on average older and relatively more often male than in Italy and Poland.

Chapter 7: General discussion

The final chapter of this thesis summarises and discusses the main results of the studies described. Also, important limitations of the studies are presented. For example, in the studies of the Unforgettable programme and the personalised quality of life instrument, there were too few participants per subgroup to be able to carry out further analyses. There were also limitations with regard to the measuring instruments used. For example, some participants in the studies of the personalised

nature activities and the study of the personalised quality of life instrument found it difficult to express their experience on a ten-point scale.

This chapter also describes the value of the research to practice, society and science. This dissertation contributes to scientific knowledge on the development, evaluation and implementation of personalised psychosocial interventions for people with dementia. The tool ('decision tree') that was developed to personalise nature activities can be used in care practice. Also the method used to create the tool, by involving people with dementia and professionals in the different development phases, can be used in (care) practice to develop other tools for person-centred activities. The research into the Unforgettable programme provides insight into the impact that the programme has on people with dementia, their loved ones and professional caregivers, and on museum staff and volunteers. Knowing which types of art evoke the most reactions can help optimise art programmes for people with dementia. Understanding factors that promote or hinder the implementation of nature and museum programmes may help design effective strategies to implement similar programmes. Personalised quality of life instruments may be used to determine care goals for individual persons with dementia and to monitor treatment based on the domains or items as indicated as relevant by the person.

Chapter 7 also provides a number of recommendations. For future research these are: further research into the application and effectiveness of the methodology to personalise nature activities; conducting controlled studies into personalised nature and museum interventions for people with dementia; further research into the (intercultural) differences in importance of quality of life domains; and involving people with dementia in the development, evaluation and implementation of an intervention to ensure that the intervention meets the needs and wishes of future users. In addition, within the care practice it is important that a personalised approach in dementia care is encouraged and supported by the management of care organisations and that knowledge and training on personalised working is offered. Finally, there are recommendations for policy makers: to pay attention to the psychosocial perspective and the personal wishes and needs of people with dementia (living at home and living in an institution); to set up campaigns to create more awareness and knowledge about dementia and to reduce the stigma around dementia; to support programmes that contribute to the social integration of people with dementia, such as Unforgettable.

SAMENVATTING

Psychosociale interventies zijn het meest effectief als ze passen bij de behoeften, wensen en mogelijkheden van de persoon. Ook in de zorg voor mensen met dementie, wordt persoonsgerichte zorg wereldwijd aanbevolen. Toch is dit nog geen dagelijkse praktijk, mede vanwege het ontbreken van kennis en hulpmiddelen over hoe persoonsgerichte zorg vorm kan krijgen. Dit proefschrift focust daarom op de ontwikkeling, evaluatie en implementatie van persoonsgerichte psychosociale interventies in de dementiezorg. Dit onderwerp wordt in hoofdstuk 1 ingeleid. Meer specifiek is er onderzoek gedaan naar de ontwikkeling van persoonsgerichte natuuractiviteiten (hoofdstuk 2), naar de evaluatie (hoofdstuk 3 en 4) en implementatie (hoofdstuk 5) van Onvergetelijk, een kunstprogramma voor mensen met dementie en hun naasten, en naar een meetinstrument om kwaliteit van leven op een persoonsgerichte manier te meten (hoofdstuk 6). Het laatste hoofdstuk van dit proefschrift (hoofdstuk 7) beschrijft de belangrijkste resultaten en beperkingen van de studies. Ook worden er in dit hoofdstuk aanbevelingen voor nader onderzoek, de zorgpraktijk en beleidsmakers gedaan. Aan de hand van de belangrijkste onderzoeksvragen wordt hieronder een samenvatting per hoofdstuk gegeven.

Hoofdstuk 1: Inleiding

Dementie is een syndroom. Er zijn verschillende typen van dementie. De meest voorkomende zijn de ziekte van Alzheimer, vasculaire dementie, fronto-temporale dementie en Lewy Body dementie. Het aantal mensen met dementie wereldwijd is momenteel ongeveer 50 miljoen en naar verwachting zal dit aantal verdrievoudigd zijn in 2050. Dementie heeft dan ook de volle aandacht van onderzoekers, zorgprofessionals en beleidsmakers. Omdat dementie op dit moment niet te genezen is, ligt de aandacht in de zorg op het optimaliseren van de kwaliteit van leven van mensen met dementie en op het bieden van ondersteuning aan de mensen om hen heen. Psychosociale interventies, niet-medicamenteuze interventies die tot doel hebben om het psychosociale en sociale functioneren te verbeteren, kunnen hierbij helpen. Psychosociale interventies zijn het meest effectief als ze worden afgestemd op de individuele wensen, behoeften en mogelijkheden van de persoon met dementie. Een systematische aanpak in de ontwikkeling, evaluatie en implementatie van persoonsgerichte psychosociale interventies kan hierbij helpen.

Hoofdstuk 2: Natuur en dementie: ontwikkeling van een persoonsgerichte methodologie

Welke aspecten van de natuur vinden mensen met dementie belangrijk voor hun kwaliteit van leven? Aan welke soorten natuuractiviteiten geven mensen met dementie de voorkeur?

Om deze twee vragen te beantwoorden zijn focusgroepen met mensen met dementie gehouden in verschillende soorten zorginstellingen (ontmoetingscentra, dagbehandelingen, verblijfsafdeling van verpleeghuizen), in verschillende regio's in Nederland. Op de vraag welke soort aspecten van de natuur de deelnemers belangrijk vinden voor hun kwaliteit van leven, kwamen acht thema's naar voren: plezier, ontspanning, zintuigelijke beleving, vrijheid, sociaal, herinneringen, je fit voelen en je nuttig voelen. Op de vraag aan welke activiteiten in de natuur zij de voorkeur gaven, noemden deelnemers actieve activiteiten, zoals wandelen, fietsen, zwemmen en oefeningen doen; passieve activiteiten zoals buiten zitten, naar de natuur kijken, erover praten; sociale activiteiten zoals samen buiten koffie drinken, kijken naar spelende kinderen, activiteiten met dieren; activiteiten met bloemen en planten en natuuractiviteiten binnenshuis, zoals het kijken van een natuurfilm of bloemschikken.

Welke methodologie kan worden ontwikkeld om het gepersonaliseerd uitvoeren van natuuractiviteiten te ondersteunen?

Gebaseerd op de resultaten van de focusgroepen en van literatuuronderzoek naar natuurbeleving van mensen met dementie, is een conceptversie van een persoonsgerichte methodiek ontwikkeld. Deze eerste versie van de methodiek omvatte twee varianten van een tool (een beslisboom en een checklist), gecombineerd met drie macroactiviteiten (tuinieren, natuurwandeling en een zintuig stimulerende activiteit). De tool kan zorgmedewerkers en vrijwilligers helpen bij het vinden van activiteiten die bij de persoon met dementie passen en bij de personalisatie van de gekozen activiteiten. De beslisboom, checklist en macroactiviteiten zijn voor feedback voorgelegd aan een aantal mensen met dementie en aan een groep professionals vanuit verschillende achtergronden (zorg of natuurorganisatie) en zijn op basis hiervan aangepast. De algemene voorkeur ging uit naar de beslisboom. De meeste professionals waren positief over de uitvoerbaarheid van de methodiek. Sommigen gaven aan dat personeel in hun eigen instelling niet genoeg ervaring en expertise zou hebben om gepersonaliseerde natuuractiviteiten te begeleiden. Het

vragen van begeleiding door natuurorganisaties of extra training in het begeleiden van dergelijke activiteiten werd gesuggereerd als een mogelijke oplossing daarvoor.

Zijn deze gepersonaliseerde natuuractiviteiten uitvoerbaar en hoe worden ze gevalueerd door mensen met dementie en professionals in de dementiezorg?

De tool en macroactiviteiten zijn op kleine schaal getest op gebruiksvriendelijkheid en bruikbaarheid bij mensen met dementie en hun begeleiders. Medewerkers en/of vrijwilligers van de zorginstelling begeleidden de natuuractiviteit die zij zoveel mogelijk aanpasten aan de persoonlijke voorkeuren, behoeften en mogelijkheden van de deelnemers met dementie. Tijdens de activiteiten werd het gedrag van de deelnemers geobserveerd. Deelnemers lieten weinig 'negatief' gedrag (zoals verdriet, angst, verwarring) zien tijdens de activiteit en veel 'positief' gedrag (zoals blij/tevreden, alert, spontaan praten, focus op de activiteit en interactie met anderen). Na afloop van de activiteit gaven alle deelnemers aan dat zij het leuk hadden gevonden om mee te doen en bijna alle deelnemers zouden de activiteit nog een keer willen doen. Uit de interviews met zorgmedewerkers, vrijwilligers en mensen met dementie na afloop van de activiteiten, kwamen acht thema's voor een succesvolle implementatie van gepersonaliseerde natuuractiviteiten naar voren: een gemotiveerde begeleider met affiniteit met natuur, geschikte rustige locatie, goed weer, geschikte materialen, juiste duur van de activiteit, goede samenstelling groep, open-minded zorgcultuur en een goede voorbereiding. Deze laatste factor bleek ook de meest cruciale. Het niet goed voorbereiden van de activiteit resulteerde in minder aandacht voor de deelnemers en verstoorde de rust tijdens de activiteit. Het niet goed lezen van de instructie van de activiteit resulteerde in een minder persoonsgerichte en minder stimulerende setting.

Hoofdstuk 3: Evaluatie van het 'Onvergetelijk' kunstprogramma door mensen met dementie en hun mantelzorgers en professionele begeleiders

Het Onvergetelijk programma bestaat uit interactieve museumrondleidingen voor mensen met dementie en hun naasten. Het Stedelijk Museum Amsterdam en het Van Abbemuseum in Eindhoven zijn in 2013 gestart met het aanbieden van dit programma. Later is het programma in nog tien andere Nederlandse musea geïmplementeerd. Onvergetelijk is gebaseerd op het Meet Me at MoMA programma van het Museum of Modern Art in New York. De musea staan hierin (inter)nationaal gezien niet alleen, de laatste jaren is er steeds meer aandacht voor kunstprogramma's in verschillende settings voor mensen met dementie. Dit is niet voor niks:

kunstprogramma's, zoals muziek maken, theater en museumbezoeken blijken positieve effecten te hebben op het welzijn van mensen met dementie.

Hoe wordt het Onvergetelijk programma ervaren en gewaardeerd door de deelnemers?

Zowel de mensen met dementie die deelnamen aan dit museumprogramma als hun deelnemende mantelzorgers/professionele begeleiders, bleken direct na de rondleiding beter gestemd te zijn dan daarvoor. Een paar dagen na de rondleiding gaven mensen met dementie en mantelzorgers/begeleiders aan hoe zij het programma hadden ervaren. Met name de sociale interactie tijdens de rondleiding en de betrokkenheid en vriendelijkheid van de rondleiders en gastvrouwen- en heren werden gewaardeerd. Mensen met dementie waardeerden ook het kijken naar kunst en het museumgebouw. Een aantal mantelzorgers vond de reactie van hun naaste het mooiste aan de rondleiding, bijvoorbeeld om te zien hoe zorgzaam hij of zij was en hoe hun naaste genoot van de rondleiding. Sommige mantelzorgers waren verrast over de reactie van hun naaste: hun betrokkenheid bij de rondleiding, hun enthousiasme of spontaniteit. Een deel van de mantelzorgers gaf aan een ander soort contact dan gebruikelijk met hun naaste te hebben ervaren tijdens de rondleiding. Ze hadden meer oogcontact of praatten na over de rondleiding die ze echt samen beleefd hadden. Mensen met dementie en hun mantelzorgers en begeleiders waardeerden het programma en zouden graag nog een keer meedoen. Eerdere ervaring met kunst of musea bleek geen voorwaarde voor het genieten van de Onvergetelijk rondleiding; mensen met en zonder ervaring met kunst beoordeelden de rondleiding even positief. Hoewel Onvergetelijk oorspronkelijk bedoeld is voor mensen met een lichte vorm van dementie, werd het ook door mensen met matige tot matig ernstige dementie, wonend in zorginstellingen, positief beoordeeld.

Hoofdstuk 4: Hoe reageren mensen met dementie op verschillende typen kunst? Een exploratieve studie naar een interactief museum programma (Onvergetelijk)

Zijn er verschillen in reactie op verschillende typen kunst?

In dit hoofdstuk wordt onderzocht of mensen met dementie verschillend reageren op verschillende typen kunst. Daarbij is ook gekeken of specifieke achtergrondkenmerken van mensen met dementie hierop van invloed zijn. Tijdens de rondleiding werden deelnemers geobserveerd door de onderzoekers. Er werd onder andere gekeken naar de interactie tussen de mensen met dementie en hun begeleider, rondleider en andere deelnemers, maar ook naar hun alertheid, betrokkenheid bij, en reactie op, de verschillende besproken kunstwerken.

Kunstwerken met minder natuur, bijvoorbeeld stadsgezichten of abstracte installaties, leverden meer sociale interactie op dan kunstwerken waarop juist veel natuur te zien was, bijvoorbeeld landschappen of dieren. Een verschil werd ook gevonden bij het kijken naar voorwerpen die oorspronkelijk niet als kunst waren bedoeld, bijvoorbeeld servies en kleding, versus het kijken naar kunstwerken die wel oorspronkelijk waren bedoeld als kunst: er werd meer gereageerd op de voorwerpen dan op kunstwerken. Mensen met lichte tot matige dementie reageerden over het algemeen vaker spontaan en hadden meer interactie met anderen dan mensen met ernstiger dementie. Voor de reacties op de kunstwerken maakte het niet uit of een kunstwerk aan het begin of juist aan het eind van de rondleiding werd besproken.

Hoofdstuk 5: Implementatie en impact van Onvergetelijk: een interactief kunstprogramma voor mensen met dementie en hun mantelzorgers en professionele begeleiders

Welke factoren zijn van invloed op de implementatie van Onvergetelijk?

Om deze vraag te beantwoorden zijn interviews gehouden met betrokkenen bij de implementatie van Onvergetelijk in twaalf musea, zoals de rondleiders, Onvergetelijk programmacoördinatoren van de musea en medewerkers van betrokken keten- of mantelzorgorganisaties. Ondanks de verschillen in collectie en organisatie bleek implementatie van Onvergetelijk in alle musea goed mogelijk. Op uitvoeringsniveau bleken een aantal op voorhand aanwezige factoren in de musea de implementatie te bevorderen, zoals de expertise en ondersteuning door de projectcoördinator, de motivatie van de verschillende museummedewerkers en de mate waarin het Onvergetelijk programma paste bij het beleid van het museum. Weinig tijd voor het programma door een drukke agenda van de programmacoördinator belemmerde een goede implementatie. Een ander belangrijk aandachtspunt voor een succesvolle implementatie van Onvergetelijk op uitvoeringsniveau bleek de werving van rondleiders en gastvrouwen en -heren, hierbij was de selectie op vaardigheden en eigenschappen belangrijk. Ook belangrijk was de training voor rondleiders en vrijwilligers waarin informatie werd gegeven over dementie, contact werd gemaakt met mensen met dementie, en geoefend werd met de Onvergetelijk methode. Daarnaast hielp het informeren van andere museummedewerkers bij de implementatie; het wakkerde hun enthousiasme voor en betrokkenheid bij het programma aan. Regelmatige evaluatie bleek belangrijk om de vaardigheden en de motivatie van de rondleiders op peil te houden. Heel belangrijk bleek de promotie van het programma. Met name thuiswonende mensen met dementie waren lastig

te bereiken. Herhaalde aandacht voor en het op verschillende manieren promoten van het programma bij relevante organisaties in de regio, het liefst via persoonlijk contact, bleken essentieel voor een succesvolle implementatie. Op organisatieniveau was de samenwerking met en het gebruikmaken van de netwerken van andere organisaties zoals mantelzorgorganisaties of dementie netwerken belangrijk. Op maatschappelijk niveau was het bevorderend voor de implementatie als er door de gemeente speciale aandacht werd gegeven aan dementie, bijvoorbeeld in het kader van een dementievriendelijke gemeente. Dit droeg bij aan het draagvlak voor het programma binnen de regio.

Wat is de impact van Onvergetelijk op de musea?

Een aantal musea heeft naar aanleiding van Onvergetelijk plannen om programma's op te zetten voor andere groepen mensen met speciale behoeften, zoals ernstige visuele beperkingen of mensen met het syndroom van Down. Voor de musea heeft Onvergetelijk niet alleen het belang onderstreept van inclusie en het aanbieden van programma's voor mensen met een beperking, maar ook van interactief rondleiden. Rondleiders van Onvergetelijk gebruiken de Onvergetelijk methode nu ook in andere publieke rondleidingen. Sommige musea ervoeren dat de implementatie van Onvergetelijk een bijdrage leverde aan de algemene ontwikkeling van de rondleiders en de versterking van de interne relaties binnen het museum en daarmee aan de professionalisering van het museum. Ook heeft Onvergetelijk bijgedragen aan de samenwerking en kennisuitwisseling met andere musea en maatschappelijke organisaties.

Wat is de impact van de implementatie van Onvergetelijk op de museummedewerkers en vrijwilligers?

Museummedewerkers en -vrijwilligers vulden een vragenlijst in over hoe zij tegen mensen met dementie aankijken voordat Onvergetelijk in hun museum werd geïmplementeerd, en een paar maanden later, nadat het programma geïmplementeerd was. Ongeveer de helft van de museummedewerkers- en vrijwilligers die deelnamen aan het onderzoek werd getraind in het geven of begeleiden van het Onvergetelijk programma. Opvallend was dat zowel degenen die getraind waren als degenen die niet getraind waren een paar maanden na de start van het programma in hun museum een positiever beeld hadden van mensen met dementie. Ze zagen hen meer als individuen met dezelfde waarde als elk ander persoon. Deze positieve verandering was bij de getrainde mensen wel groter dan

bij de niet-getrainden. De getrainde mensen waren bovendien ook optimistischer geworden over de mogelijkheden en toekomst van mensen met dementie.

Hoofdstuk 6: De waarde van gepersonaliseerde versies van dementie-specifieke kwaliteit-van-leven-meetinstrumenten: een exploratieve studie in drie Europese landen

Zijn gepersonaliseerde kwaliteit-van-leven-instrumenten meer geschikt om variatie in kwaliteit van leven te meten dan 'standaard' kwaliteit van leven instrumenten?

Om deze vraag te beantwoorden zijn extra vragen toegevoegd aan twee veelgebruikte kwaliteit van leven instrumenten voor mensen met dementie: de DQoL en de QoL-AD. In het gepersonaliseerde instrument geeft de persoon met dementie voor de domeinen/items van de DQoL en de QoL-AD (bijvoorbeeld familie, geld, fysieke gezondheid) aan hoe belangrijk die voor hem of haar zijn op een schaal van één tot tien. Daarna wordt uitgevraagd hoe men zich voelt met betrekking tot die domeinen/items conform de instructies van de DQoL en/of de QoL-AD. Vervolgens wordt er een gewogen waarde berekend op basis van de prioriteiten en de gegeven antwoorden op de domeinen/items. Daarna zijn de uitkomsten van de gepersonaliseerde versies vergeleken met die van de standaardversies. Hoewel de gepersonaliseerde versies van de DQoL en de QoL-AD betrouwbaar waren om kwaliteit van leven te meten, vonden zij niet meer variatie in de ervaren kwaliteit van leven van mensen met dementie als de standaardversies.

Is er een relatie tussen de kwaliteit van leven zoals gemeten met het gepersonaliseerde kwaliteit-van-leven-instrument en ernst van dementie?

Er werd geen relatie gevonden tussen de ernst van dementie en kwaliteit van leven zoals gemeten met het gepersonaliseerde kwaliteit-van-leven-instrument.

Zijn er verschillen tussen landen wat betreft het belang dat wordt gehecht aan verschillende domeinen van kwaliteit van leven?

Het onderzoek naar het gepersonaliseerde kwaliteit-van-leven-instrument werd uitgevoerd in drie verschillende landen: Polen, Italië en het Verenigd Koninkrijk. Alle domeinen van de DQoL en items van de QoL-AD werden in de drie landen door mensen met dementie beoordeeld als belangrijk voor hun kwaliteit van leven. Sommige domeinen/items werden meer belangrijk gevonden dan anderen, bijvoorbeeld de leefsituatie en het geheugen. Familie en het huwelijk/meest nabije relatie werden in alle landen als meest belangrijk gevonden voor de kwaliteit van

leven. De mogelijkheid om huishoudelijke klusjes te doen werd over het algemeen het minst belangrijk voor de kwaliteit van leven bevonden. Een aantal domeinen/items van kwaliteit van leven zoals gemeten door de gepersonaliseerde versies van DQoL en de QoL-AD werden door mensen met dementie uit het Verenigd Koninkrijk minder belangrijk geacht voor de kwaliteit van leven dan door mensen met dementie uit Polen en Italië. Dit waren fysieke gesteldheid, stemming, het gevoel van eigenwaarde, energieniveau en de mogelijkheid om huishoudelijke klusjes te doen. Deze verschillen zijn mogelijk ook te verklaren door het verschil in achtergrond; de deelnemende mensen met dementie uit het Verenigd Koninkrijk waren gemiddeld ouder en relatief vaker man dan in Italië en Polen.

Hoofdstuk 7: Algemene discussie

In het laatste hoofdstuk van dit proefschrift worden de belangrijkste resultaten van de beschreven studies samengevat en bediscussieerd. Ook worden belangrijke beperkingen aan de studies weergegeven. Zo waren er in de studies naar het Onvergetelijk programma en het gepersonaliseerde kwaliteit van leven instrument te weinig deelnemers per subgroep om daar nadere analyses op te kunnen doen. Ook waren er beperkingen wat betreft de gebruikte meetinstrumenten. Zo bleken sommige deelnemers aan de studies naar de gepersonaliseerde natuuractiviteiten en de studie naar het gepersonaliseerde kwaliteit van leven instrument het lastig te vinden om hun ervaring uit te drukken op een tienpuntsschaal.

In dit hoofdstuk wordt ook de waarde van het onderzoek voor de praktijk, maatschappij en wetenschap beschreven. Dit proefschrift draagt bij aan de wetenschappelijke kennis over het ontwikkelen, evalueren en implementeren van gepersonaliseerde psychosociale interventies voor mensen met dementie. De tool ('beslisboom') die ontwikkeld is om natuuractiviteiten te personaliseren, kan in de zorgpraktijk worden gebruikt. Ook de methode die gebruikt werd om de tool te creëren, waarbij mensen met dementie en professionals in de verschillende ontwikkelfasen werden betrokken, kan in de (zorg)praktijk gebruikt worden bij de ontwikkeling van andere hulpmiddelen voor persoonsgerichte activiteiten. De onderzoeken naar het Onvergetelijk programma geven inzicht in de impact die het programma heeft op mensen met dementie, hun dierbaren en professionele begeleiders en op museummedewerkers en vrijwilligers. Weten welke typen kunst de meeste reacties oproepen, kan helpen bij het optimaliseren van kunstprogramma's voor mensen met dementie. Inzicht in factoren die de

implementatie van natuur- en museumprogramma's bevorderen dan wel belemmeren, kan helpen effectieve strategieën op te stellen om vergelijkbare programma's te implementeren. Gepersonaliseerde kwaliteit-van-leven-instrumenten kunnen in de klinische zorgpraktijk worden gebruikt om kwaliteit van leven op een gepersonaliseerde manier in kaart te brengen en zo meer inzicht te krijgen in de behoeftes van de individuele persoon.

In hoofdstuk 7 worden ook een aantal aanbevelingen gedaan. Voor toekomstig onderzoek betreffen die: nader onderzoek naar de toepassing en effectiviteit van de methodologie om natuuractiviteiten te personaliseren; uitvoeren van gecontroleerde studies naar gepersonaliseerde natuur en museuminterventies voor mensen met dementie; nader onderzoek naar de (interculturele) verschillen in belang van kwaliteit van leven domeinen; en het betrekken van mensen met dementie bij de ontwikkeling, evaluatie en implementatie van een interventie om er zeker van te zijn dat de interventie past bij de behoeftes en wensen van de toekomstige gebruikers. Daarnaast is het binnen de zorgpraktijk van belang dat een gepersonaliseerde aanpak in de dementiezorg wordt aangemoedigd en ondersteund vanuit het management van zorgorganisaties en dat kennis en scholing over gepersonaliseerd werken wordt aangeboden. Ten slotte zijn er aanbevelingen aan beleidsmakers: aandacht voor het psychosociale perspectief en de persoonlijke wensen en behoeften van (thuiswonende en in een instelling verblijvende) mensen met dementie; het opzetten van campagnes om meer bewustwording en kennis over dementie te creëren en daarmee het stigma rondom dementie te verminderen; het ondersteunen van programma's die bijdragen aan de sociale integratie van mensen met dementie, zoals Onvergetelijk.

LIST OF PUBLICATIONS

Hendriks, I. H., Van Vliet, D., Gerritsen, D. L., & Dröes, R. M. (2016). Nature and dementia: development of a person-centered approach. *International Psychogeriatrics*, 28(9), 1455–1470. <https://doi.org/10.1017/s1041610216000612>

Description of author roles: Iris Hendriks and Deliane van Vliet conducted the data collection and analyses and wrote the paper. Debby Gerritsen and Rose-Marie Dröes designed the study, supervised the data collection, and analyses and contributed to writing of the paper.

Hendriks, I., Meiland, F. J. M., Gerritsen, D. L., & Dröes, R. M. (2019). Evaluation of the ‘Unforgettable’ art programme by people with dementia and their care-givers. *Ageing and Society*, 41(2), 294–312. <https://doi.org/10.1017/s0144686x19001089>

Description of author roles: Rose-Marie Dröes and Franka Meiland were involved in the conception, design, analysis and interpretation of data and in revising the article; Iris Hendriks was involved in the collection, analysis and interpretation of data and in drafting the article; Debby Gerritsen was involved in the interpretation of data and revising the article. All authors approved the version to be published.

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Hendriks, I., Meiland, F. J. M., Gerritsen, D. L., & Dröes, R. M. (2018). Implementation and impact of Unforgettable: an interactive art program for people with dementia and their caregivers. *International Psychogeriatrics*, 31(3), 351–362. <https://doi.org/10.1017/s1041610218000959>

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ABOUT THE AUTHOR

Iris Hendriks was born in 1989 in Beuningen. After obtaining her VWO diploma Iris studied ‘Nederlands Recht’ at the Radboud University in Nijmegen. She also took several courses at the University Luiss Guido Carli in Rome and at the University of Amsterdam. During the last period of her studies Iris worked at the research group ‘Care and support in dementia’ of Prof.dr. Rose-Marie Dröes at the department of Psychiatry of the VUmc (now Amsterdam UMC, location VUmc). As a work student she was co-responsible for the organisation of a congress on psychosocial care for people with dementia. After earning a master’s degree in ‘Burgerlijk recht’ in 2013, Iris joined the research group of Rose-Marie Dröes in 2014 as a junior researcher. Initially she studied the implementation of the ‘Unforgettable’ programme of the Stedelijk Museum Amsterdam and the Van Abbemuseum in Eindhoven in ten other Dutch museums. Later, the study into person-centred nature activities was added to her work. In researcher and project management roles, Iris also contributed to the European MEETINGDEM project, that focussed on the implementation of Meeting Centres for people with dementia in three European countries. Together, these studies resulted in a PhD thesis. Currently, Iris works as policy officer at the ‘Nederlandse Vereniging voor Toezichthouders in Zorg en Welzijn’ (NVTZ) in Utrecht. Iris lives with her partner and their three children in Culemborg.

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