Exploring Life Story Books in Dementia Care

the potential of digital reminiscence interventions

Teuntje Elfrink

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Teuntje Rian Elfrink

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De promotor
Prof. dr. ir. G.J. Westerhof

De copromotoren
Prof. dr. S.U. Zuidema
Prof. dr. M. Kunz

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Prof. dr. ir. G.J. Westerhof – Universiteit Twente

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“Ik vond het heel erg interessant om weer eens met mijn eigen leven kennis te maken.”

CONTENT

1

General Introduction

GENERAL INTRODUCTION

Everyone has a story to tell. The older we get, the more memories we collect to shape our very own – unique – life story. We all have our milestones, our ups and our downs. Along the way we learn from our experiences, and they enable us to grow. Some memories will last forever, some will fade into the background, and some will suddenly float up to the surface again and bring us back to that precious moment.

Persons living with dementia are confronted with more and more gaps in their story, as they deal with progressive memory loss. Recollecting memories (*reminiscing*) and creating a life story can improve one's well-being. Besides, life stories can be used to enhance person-centered care: knowing more about the person in front of you can help you understanding them, and allow you to match the provided care with their needs and values. But what if one's memory deteriorates? How to create a life story for these persons? Can creating a life story help them? And what about the informal caregivers? Aiming to answer these questions, this thesis describes an exploration of the use of (digital) life story books in dementia care by using a multi-method approach.

Dementia

According to the World Alzheimer Report, in 2021 an estimated number of 55 million people lived with dementia globally, and this number is expected to increase to 78 million by 2030 (Gauthier et al., 2021). In their report, Alzheimer's Disease International defines dementia as: *''a condition that groups symptoms of impaired memory, thinking, behaviour and emotional control problems resulting in a loss of autonomy.''*(p. 15). The diseases causing dementia and the manifested symptoms differ amongst persons. In all, dementia interferes with one's activity of daily living and persons living with dementia often need support or care.

Dementia has a profound impact on everyone involved: it directly affects the quality of life of the patient, and of all diseases it has the highest burden of disease for persons over 65 (Conde-Sala et al., 2016; Alzheimer Nederland, no date; McKeith & Cummings, 2005). Dementia also results in a higher burden for informal caregivers and a lower quality of their lives (De Vugt et al., 2003; Peeters et al., 2012; Prince et al., 2013; Conde-Sala et al., 2016). In the Netherlands, 53% of the informal caregivers of persons living with dementia experience a high burden, and 3% even report to be overburdened (Alzheimer Nederland, no date). This burden is of physical, emotional and financial nature (World Health Organization, 2021). Additionally, dementia affects society as a whole: direct medical and social care costs, and the costs of informal care make dementia the most costly disease in the Netherlands, and one of the most costly diseases worldwide (Prince et al., 2015; World Health Organization, 2021; Alzheimer Nederland, no date). In the Netherlands, about two thirds of persons with dementia is estimated to live at home, but as society is rapidly ageing this number will increase (Alzheimer Nederland, no date). Staying at home is not only the ‘’wish’’ of society, but also the general preference of persons with dementia and their informal caregivers (Peeters et al., 2014). However, living at home with a good quality of life is not self-evident, mainly due to the fact that accompanying neuropsychiatric symptoms (NPS; such as apathy, agitation, depression, anxiety, and delusions) can make the care at home too burdensome (Gaugler et al., 2009).

Dementia care and support predominantly focus on preserving quality of life and preventing or reducing psychosocial problems, as there is currently no ‘’cure’’ for dementia (Koopmans et al., 2009). This care can be of pharmacological and non-pharmacological nature; the current thesis focusses on the latter. To prevent, reduce and cope with (behavioral) changes caused by dementia, behavioral interventions are most frequently applied and can target persons with dementia, their caregivers and their care environment (Magai et al., 2002; Cohen-Mansfield, 2001; Brodaty et al., 2003; Mittelman et al., 1996). A systematic review of Olazarán and colleagues (2010) shows that NPS can be prevented and reduced by behavioral interventions, and hereby improve well-being of those concerned. It is of great importance that these behavioral interventions match the experiences, perceptions, and understanding of persons with dementia so that they can contribute to and meet the needs of the persons with dementia and their informal caregivers (Van der Roest et al., 2009). Koren (2010) supports this thought and describes the shift from medical and routine-driven care towards personalized and individualized care as the ‘’cultural change movement’’. This is in line with the ideas and beliefs of Higgs and Gilleard (2017). They argue a more personalized approach in dementia care is needed, summarized in the term *person-centered care* (PCC). In 2016, the American Geriatrics Society Expert Panel defined PCC as follows (p. 16):

> “Person-centered care” means that individuals’ values and preferences are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals. Person-centered care is achieved through a dynamic relationship among individuals, others who are important to them, and all relevant providers. This collaboration informs decision-making to the extent that the individual desires (AGS, 2016).

Reminiscence

One way to enhance PCC is by using a person's biography and memories (Clarke, 2000; Clarke et al., 2003). Reminiscence is widely used in dementia care and is defined as *the use of written or oral life histories to improve psychological well-being* (McKeown et al., 2006; VandenBos, 2007). Westerhof and colleagues (2010) – who built on Haight and Burnside (1993) – distinguish between reminiscence, life review and life review therapy. Reminiscence concerns *retrieving* and *sharing* memories, whereas life review (therapy) aims at *processing* those memories as well. They state "*The central activity [of reminiscence] is positive autobiographic storytelling that activates the social functions of reminiscence*" (Westerhof et al., 2010, p. 713). Multiple systematic reviews and meta-analyses show that reminiscence (activities) could positively affect the mental health, depressive symptoms, quality of life, and cognitive functioning of persons with dementia (Woods et al., 2005; Subramaniam & Woods, 2012; Blake, 2013, Huang et al., 2015). Reminiscence can be offered on a group or individual level, and in the care or home setting. Often, props such as music, videos, objects or pictures are being used to support the reminiscence process. Mostly, these props are attuned to the target group, but are not personalized – thus more general in nature. The process might result in a tangible product, such as a poster, short story or album. Since research has shown that remembering and reliving precious personal memories can create feelings of pleasure, familiarity, and assurance, reminiscence interventions are included in the Dutch standard for dementia care (Huijsman et al., 2020).

Personal memories are part of the autobiographical memory system, which remains intact for a relatively long time despite the progress of dementia (Dempsey et al., 2014; Caddell & Clare, 2010). This means that most persons with early dementia can still retrieve and share personal memories. In later phases of dementia, they can even relive the positive feelings connected to their precious memories. This makes reminiscence a suitable and valuable approach for persons with dementia.

Life story books

It is assumed that the positive effects of reminiscence are especially achieved when applying it in a specific and personalized way, such as by creating a life story book (LSB). Creating a LSB is a common approach in reminiscence, which provides a rich and tangible object to support the process of retrieving and sharing memories (McKeown et al., 2006). A LSB can entail milestones, important life events and specific personal precious memories. Creating a LSB with personal memories *together* with the person with dementia is believed to be especially promising (Subramaniam & Woods, 2012). Next to recollecting important personal memories, patients appreciate actually processing their life story into a (tangible) book – which they receive in the end (Morgan & Woods, 2010).

E-health

The use of technology, or e-health, in dementia care is rising. One can think of domotics (home automation), remote care, or mobile apps (Nijhof et al., 2009). In their literature review, Pappadà and colleagues (2021) classified three main categories of technology targeting persons with dementia: monitoring and security purposes, sustaining daily life, and therapeutic interventions. The increase in the use of technology for persons with dementia is in line with the expanding computer and internet skills of older persons (Van Deursen & Van Dijk, 2015). In 2019, about 58% of the Dutch persons between 65 and 75 years reported having basic or more than basic computer knowledge and skills, an increase of almost 11% compared with 2015. For persons older than 75 this percentage rose from 19 in 2015 to 27.9 in 2019 (CBS, no date). So it's evident persons over 65 years old are feeling more and more comfortable using a computer.

Reminiscence and LSB interventions could benefit from the use of technology in several ways (Lazar et al., 2014; Zhang & Ho, 2017). To start with, it allows users to document, retrieve and add personal memories in an easy manner. The story can always be changed and updated – also when the dementia progresses. Next, multimedia can prime the senses in order to elicit (more or other) memories. One can think of using videos, music and photos – next to written cues. Furthermore, using technology can make the reminiscence process more interactive and hereby support social interaction. For example, relatives or friends can cooperate (from distance) and add memories to the story of their loved one. Lastly, a big advantage is that technological interventions can be used in the home setting as well as in institutional care – and can be easily shared when the need for care changes (e.g. in case of nursing home admittance).

The Online Life Story Book

Thus, the first steps are taken in the field of using digital LSBs in dementia care. Building on the hopeful possible benefits of LSB interventions and the use of technology in reminiscence interventions, for this dissertation the *Online Life Story Book (OLSB)* was developed, implemented on a small scale and evaluated. The OLSB makes use of an existing e-health application to which we added our method in the context of persons with early dementia. The application allows users to document and share their memories. All kinds of memories can be added on a timeline, e.g. life events, such as a wedding or a birth of a (grand) child, but also recipes from a (grand) mother, or one's favorite song can be included. Memories can be added as a text/story, photo, audio or video. Besides, both personal materials and documents available for public use – for example retrieved from municipal archives – can be included as well. A detailed description about the OLSB, with example fragments can be found in intermezzo 1.

The OLSB has several distinctive features. It is one of the first LSB interventions in dementia care using technology, and employed in the home situation. Besides, informal caregivers are actively involved in this intervention. As informal caregivers are looking for meaningful activities that allow them to take some distance from their caring role for a moment, (mutual) reminiscence in the form of the OLSB might also benefit them. Another unique element of the OLSB is that trained volunteers create the OLSBs together with the dyads (in our case being the person with dementia together with their spouse). Deploying volunteers in interventions like the OLSB is becoming increasingly necessary, given the fact that persons with dementia will live longer, and at home. An advantage for care institutes is that interventions executed by volunteers are more cost-effective and easier to organize than interventions employed by care professionals (Richters et al., 2015). Besides, an intervention led by a volunteer can feel less stigmatizing for the user compared to care by a professional caregiver, as a volunteer can become a new link and contact with society (Westerhof et al., 2008). Benefits for volunteers involved in such a project might be that volunteering can enhance both their well-being and that of the people they are helping, they are getting the possibility to create something that really matters to the dyads, and they can learn new skills and competencies (Wheeler et al., 1998; Hwang et al., 2005; Chen & Morrow-Howell, 2015).

The intervention *''The Online Life Story Book''* entails the (1) application itself, a (2) training for volunteers (both on how to use the application and on how to stimulate persons to retrieve and select memories), (3) a printed tangible book, (4) suggestions on how to use the (digital and printed) book and (5) guidelines for implementing the intervention in care. In short: the OLSB is a reminiscence intervention for persons with (early) dementia and their informal caregivers, with technological elements, guided by trained volunteers and employed in the home situation.

Aim and outline of this thesis

Currently, there is no overview on the use of (digital) LSBs in dementia care and little is known about the effects, content and implementation of an intervention with the characteristics like the OLSB. The overall aim of this thesis is therefore to explore the use and potential of (digital) LSBs in dementia care. Why and how are they being used? And how can they be used? This, in order to contribute to a better understanding of how such reminiscence interventions can be implemented in dementia care.

Our multi-method exploration entails a systematic review on current use, a randomized controlled trial (RCT) to investigate the effectiveness of our OLSB intervention, a content analysis on created LSBs of our intervention, and a process evaluation to examine the implementation of our intervention. The following questions are addressed to guide our exploration:

○ **What is known about (digital) life story book interventions in dementia care?**

Chapter 2 entails a systematic review, which gives an answer to the sub question *''What is known about (digital) life story book interventions in dementia care?''*. LSBs are used in multiple settings and for diverse purposes within the field of dementia care, but an overview of how LSBs are actually being used and the effectiveness of these interventions was lacking. In order to get this overview, we looked at both characteristics of the intervention itself and study characteristics (e.g. target group, type and characteristics of the LSB, the aims and designs of the studies). Conducting this systematic review helps positioning our own intervention in the field of reminiscence – and more specific LSB – interventions in dementia care.

○ **What are the quantitative effects of the Online Life Story Book for persons with early dementia and their informal caregivers?**

Chapter 3 describes the design of our study and the OLSB intervention. To investigate the sub question *''What are the quantitative effects of the Online Life Story Book for persons with early dementia and their informal caregivers?''* chapter 4 focusses on the actual RCT conducted on the OLSB. The objective of the RCT was to investigate the effectiveness of the OLSB on neuropsychiatric symptoms in persons with (very) mild dementia and to assess the distress and quality of life of their primary informal caregivers – in comparison to care as usual (wait list control condition).

○ **What is the content of Online Life Story Books of persons with early dementia?**

Chapter 5 answers the sub question *''What is the content of Online Life Story Books of persons with dementia?''* with a content analysis of eight OLSBs created in our study. During the systematic review of chapter 2, it became clear that there is a dearth of information when it comes to structure and content of created (digital) LSBs in dementia care. This content analysis provides more insight in how the content could support the process of reminiscence and thereby increase the effectiveness of such interventions.

○ **How was the process of creating and implementing Online Life Story Books evaluated by the different stakeholders?**

Chapter 6 describes the process evaluation of the OLSB in which three sub questions are addressed. Firstly, in addition to the quantitative effects of the OLSB (see chapter 4), we were also interested in any other perceived effects of the intervention. So the sub question ‘’*What are the perceived and potential effects of the OLSB for and of persons involved in creating and using the OLSB?’’* will be answered. Next, we wondered ‘’*How did persons involved in the OLSB experience its implementation?’’,* to strengthen future implementation within this target group. Lastly, we asked the question *‘’How did persons involved in the OLSB perceive the use of technology in the intervention?’’.* Since the use of technology is new and promising for interventions like the OLSB information about how stakeholders perceived the possibilities and barriers of using technology will give us relevant information for future practice. To obtain information needed to answer these three questions, semi-structured interviews were conducted with different types of stakeholders.

Next to the process evaluation, an interactive seminar with eighteen persons from different types of organizations – all with a connection to the topic of LSBs – was organized during the project. The goal was to exchange knowledge about and experiences with implementing LSBs in care. In two interactive rounds participants worked with, thought about and discussed LSBs. A report of this meeting can be found in intermezzo 2.

○ **What have we learned?**

Chapter 7 is a general discussion to reflect on the entire research project “The Online Life Story Book”. All studies and questions of this thesis are integrated, strengths and limitations are shared, and both future practical and research implications are discussed.

Life Story Books for People with Dementia

a systematic review

2

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ABSTRACT

Objectives:
There is an increasing evidence that reminiscence therapy is effective in improving cognitive functions and reducing depressive symptoms in people with dementia. Life story books (LSBs) are frequently used as a reminiscence tool to support recollecting autobiographical memories. As little is known about how LSBs are used and what type of studies have been employed to evaluate LSB interventions, we conducted a systematic review.

Methods:
The electronic databases Scopus, PubMed, and PsychINFO as well as reference lists of existing studies were searched to select eligible articles. Out of the 55 studies found, 14 met the inclusion criterion of an original empirical study on LSBs in people with dementia.

Results:
The majority of the LSBs were tangible books, although some digital applications were also found. The LSBs were created mostly in individual sessions in nursing homes with a median of six sessions. Some studies only focused on the person with dementia, while others also examined (in)formal caregivers. Most studies used qualitative interviews, case studies, and/or (pilot) randomized controlled trial (RCTs) with small sample sizes. Qualitative findings showed the value of LSBs in triggering memories and in improving the relation with the person with dementia. Quantitative effects were found on, e.g. autobiographical memory and depression of persons with dementia, quality of relationship with informal caregivers, burden of informal caregivers, and on attitudes and knowledge of formal caregivers.

Conclusions:
This systematic review confirms that the use of LSBs to support reminiscence and person-centered care is promising, but larger RCTs or implementation studies are needed to establish the effects of LSBs on people with dementia.

INTRODUCTION

In 2015, the number of people living with dementia worldwide was estimated at 46.8 million. This number is expected to increase to 74.7 million in 2030 and 131.5 million in 2050 (Prince et al., 2015). Dementia is often accompanied by neuropsychiatric symptoms (NPS). Dementia and the related NPS not only affect the quality of life of the person with dementia, but also result in a higher burden of informal caregivers and a lower quality of their lives (De Vugt et al., 2003; Peeters et al., 2012; Conde-Sala et al., 2016). Dementia often leads to disability and a high and expanding need for care and support of a caregiver (Prince et al., 2013). Overall, dementia is among the top five with the highest burden of disease for persons over 65 years and it belongs to the diseases with the highest burden for informal caregivers (McKeith & Cummings, 2005). This burden includes physical, emotional, and economic aspects (World Health Organization, 2017). Furthermore, dementia is one of the most costly diseases worldwide (Prince et al., 2015; World Health Organization, 2017).

Higgs & Gilleard (2017) plead for a shift to a more person-centered approach in dementia care: person-centered care (PCC). The shift from medical, routine-driven care to personalized, individualized care – regardless of the cognitive or functional capacity of the patients – is called ''the culture change'' (Koren, 2010). In 2016, the American Geriatrics Society Expert Panel developed a summarizing definition of PCC: *"Person-centered care" means that individuals' values and preferences are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals. Person-centered care is achieved through a dynamic relationship among individuals, others who are important to them, and all relevant providers. This collaboration informs decision-making to the extent that the individual desires* (AGS, 2016).

PCC can be enhanced by using a person's biography and memories (Clarke, 2000; Clarke et al., 2003). The use of written or oral life histories to improve psychological well-being is described as reminiscence and is often used with people with dementia (McKeown et al., 2006; VandenBos, 2006). Several (systematic) reviews have shown that reminiscence activities can contribute to the mental health and quality of life of persons with dementia (Woods et al., 2005; Subramaniam & Woods, 2012; Blake, 2013). A recent meta-analysis of Huang and colleagues (2015) concluded that reminiscence therapy has a small effect on improving cognitive functioning and a moderate effect on reducing depressive symptoms in older persons with dementia, predominantly for those living in institutions.

The creation of a life story book (LSB) is a common approach in reminiscence (McKeown et al., 2006). The use of LSBs with personal memories that are constructed together with the person with dementia is especially promising (Subramaniam & Woods, 2012). Besides the recollection of personal memories, receiving a tangible output in the form of a LSB is highly valued by patients (Morgan & Woods, 2010). In recent years, LSBs are used for multiple purposes and in multiple settings, while studies that evaluate LSB interventions for people with dementia are emerging. To provide an overview of how LSBs are used and what is known from research, we conducted a systematic review with two guiding questions:

1. How are LSBs used in dementia care?
2. What are the designs and findings of studies on the use of LSBs?

METHODS

This systematic review was conducted according to the preferred reporting items for systematic reviews and meta-analyses statement (Moher et al., 2015).

Inclusion and exclusion criteria

Population

This review concerns people with mild cognitive impairment (MCI) or dementia.

Types of interventions

Interventions that use LSBs were eligible for inclusion. There had to be a clear description of the LSB, and the LSB had to contain not only biographical facts but also autobiographical elements or memories.

Outcomes of interest

The outcomes of interest were (1) the use of LSBs and (2) the designs and findings of qualitative and quantitative studies on their use.

Types of evidence

In order to answer the two research questions, all empirical study designs were considered. Academic peer reviewed full-text papers published in printed or electronic format in academic journals or conference proceedings were deemed eligible for inclusion. No language restrictions were applied. Theses, book chapters, non-empirical studies, or unpublished work were excluded.

Data sources and search strategy

Academic databases Scopus, PubMed, and PsycINFO were searched. Additional sources included reference lists of relevant articles and reviews and expert consultation. In the search, strategy terms on “LSB” were combined with terms on dementia. All following terms were being searched in titles, abstracts, and keywords: “life story book” or “life story album” or “storybook” or “life album” or “memory book” or “memory album” or “reminiscence book” or “reminiscence album” or “biography book” or “autobiography book” or “life history book” AND “dementia” or “Alzheimers” or “mci” or “mild cognitive impairment”. Two authors (TE and GW) performed the last search run on October 19, 2017.

Study selection

The flow diagram of the search and selection procedure of studies is illustrated in Figure 1. Two data extractors (TE and GW) assessed the eligibility independently in a standardized manner. The 55 retrieved records from the search were screened by title and abstract. An interrater reliability check on the 55 articles was performed, resulting in an agreement of 98% and a Cohen’s κ of 0.96, which is considered as ‘’almost perfect’’ (McHugh, 2012). The disagreement was resolved by consensus, in this case by excluding the article (since no LSBs were used in the intervention). After this first screening, a total of 33 full articles were assessed for eligibility. The extractors read these 33 articles independently. For this second round, the agreement was 91%, with a Cohen’s κ of 0.82, which is considered as the upper bound of ‘’strong.’’ The remaining three discrepancies were resolved by consensus to exclude the articles (based on the third criterion of insufficient information about the LSB).

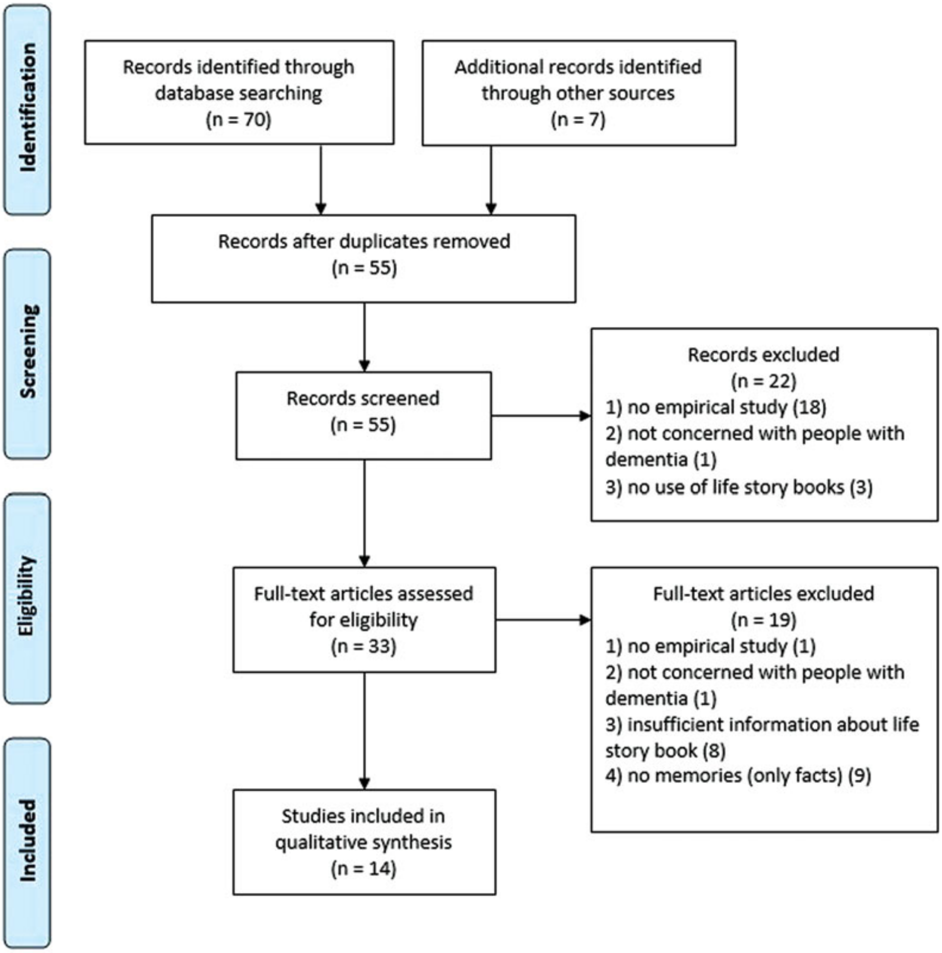


Figure 1. Flow diagram of the search and selection procedure of studies.

Data extraction

In order to answer the first research question How are LSBs used in dementia care? the following information was extracted from the articles: target group; type and characteristics of the LSB; implementation of the LSB; and time to create the LSB. To answer the second research question What are the findings of studies on the use of LSBs? the following factors were extracted: aim of the study; type of study; sample size; instruments and/or outcome variables; and findings.

RESULTS

Study identification and selection

Figure 1 summarizes the databases hits, exclusion, and final inclusion in a flow diagram. A total of 70 records were found from Scopus (34), PubMed (22), and PsycINFO (14). Reference lists searches and expert consultation added seven studies. After removing duplicates, 55 studies remained and were screened for title and abstract. Based on title and abstract, 22 were discarded as the studies did not meet the inclusion criteria. The full texts of the remaining 33 studies were assessed for eligibility. Of these 33, 19 studies did not meet the inclusion criteria. Finally, a total of 14 studies met the inclusion criteria and were included in the systematic review. Out of the 14 included studies, 12 were identified through database searching.

Study characteristics

All 14 studies were empirical studies published in peer-reviewed journals or conference proceedings. The studies were published between 2003 and 2017. Ten of the 14 studies were conducted in the last five years between 2013 and 2017. In total, 243 persons with dementia participated in the studies.

Research question 1: How are life story books used in dementia care?

To answer this question, first, a general description of the different target groups and type and characteristics of the LSBs are presented in Table 1. Second, Table 2 shows descriptions of the implementation processes and the time needed to create a LSB.

Target group

All included studies concerned people with dementia: Ten studies concerned people with mild to moderate dementia, one study very mild to mild, one mild to severe, one different stages, and one severe dementia. In the study of Crook et al. (2016), the participants suffered from mild to moderate dementia and had Down syndrome. A total of nine LSB interventions were carried out for individuals, whereas the other five were dyadic interventions. The mean age varied between 58.6 (Crook et al., 2016) and 92.8 years (Andrews-Salvia et al., 2003). Eleven studies involved both men and women, three only women. The countries in which the studies took place where North Wales (two), United States (solely four; combined with Japan one), United Kingdom (three), Malaysia (two), Korea (one), and Northern Ireland (one). A majority of eight studies was performed in a care home setting, whereas three studies took place at the home situation and two studies in both settings. In one study (Hashim et al., 2013), the setting was not clear.

Table 1. Overview of target group and type and characteristics of the life story book

Author	**Target group**					
	Condition of dementia	*Individual or dyadic*	*Mean age*	*Gender*	*Country*	*Living situation*
Kwak, Ha, Hwang, Ingersoll-Dayton and Spencer (2017)	Very mild to mild	Dyadic	76.5	M+F	South Korea	Home and care home
Subramaniam and Woods (2016)	Mild to moderate	Individual	82	M+F	North Wales	Care home
Ingersoll-Dayton, Spencer, Campbell, Kurokowa and Ito (2016)	Mild to moderate	Dyadic	74 (US) 77.4 (J)	M+F	United States and Japan	Home
Crook, Adams, Shorten and Langdon (2016)	Mild to moderate and Down Syndrome	Individual	58.6	M+F	United Kingdom	Care home
Hashim, Ismail, Rias and Mohamed (2015)	Mild form of AD	Individual	74	F	Malaysia	With family
Subramaniam, Woods and Whitaker (2014)	Mild to moderate	Individual	86	M+F	North Wales	Care home
Scherrer, Ingersoll-Dayton and Spencer (2014)	Mild to moderate	Dyadic	74	M+F	United States	Home
Hashim, Rias and Kamaruzaman (2013)	Mild form of AD	Individual	67	F	Malaysia	Unknown
Ingersoll-Dayton, Spencer, Kwak, Scherrer, Allen and Campbell (2013)	Mild to moderate	Dyadic	75.7	M+F	United States	Home and care home
McKeown, Ryan, Ingleton and Clarke (2013)	Different stages	Individual	84.5	M+F	United Kingdom	Care home
Morgan and Woods (2010)	Mild to moderate	Individual	82.5	M+F	United Kingdom	Care home
Haight, Gibson and Michel (2006)	Mild to moderate	Individual	60-99	M+F	Northern Ireland	Care home
Andrews-Salvia, Roy and Cameron (2003)	Severe	Individual	92.8	F	United States	Care home
Haight, Bachman, Hendrix, Wagner, Meeks and Johnson, (2003)	No too late	Dyadic	Unknown	M+F	United States	Care home

Type and characteristics of the life story book

Type of LSB	*Materials used*	*Order of memories*	*Pages/ no of memories*
Book	Unknown	Unknown	Unknown
Movie	Photographs and other visual materials augmented with background music, favorite songs and narration	Chronological with division in six segments	Average length: 18 minutes
Traditional (US) and digital book (J)	Photos, stories, blank pages for the future	Chronological	Unknown
Book and rummage box	Photographs and memorabilia	Unknown	Unknown
Digital application	Pictures, details and voice of family members and photographs and descriptions of past events	Unknown	Unknown
Book	Pictures and quotations	Chronological	50-70 pages
Book	Photographs, cards, news items, blank pages for the future	Chronological (assumed)	Unknown
Digital application	Information and photos of Myself, My Family and Performing prayer	Unknown	Unknown
Book	Ten photographs or mementoes per chapter (five chapters)	Chronological (assumed)	Max. 50 photos
Book or pen picture	Book: photographs and text Pen picture: writing account	Chronological	Pen picture: 2 pages
Book	Photographs and other materials	Chronological (assumed)	Unknown
Book	Photographs and explanatory captions	Chronological (assumed)	Unknown
Book	Division between My life and My family with photographs and declarative sentences	Chronological (assumed)	20 pages
Book	Pictures, words and other memorabilia	Unknown	Unknown

Table 2. Description of the implementation and the time needed to create a life story book

Author	**Implementation of life story book**	
	Those involved	*Role of researcher(s)*
Kwak, Ha, Hwang, Ingersoll-Dayton and Spencer (2017)	Participant and partner	Engaging participant in process and compiling the book
Subramaniam and Woods (2016)	Participant and relative	Co-editor of the movie
Ingersoll-Dayton, Spencer, Campbell, Kurokowa and Ito (2016)	Participant and partner	Compiling the life story
Crook, Adams, Shorten and Langdon (2016)	Participant and family member or other consultee	Facilitating interaction and delivering intervention
Hashim, Ismail, Rias and Mohamed (2015)	Participant and caretaker	Explaining and demonstrating the use of the application
Subramaniam, Woods and Whitaker (2014)	Co-creation: participant and therapist Gift: relative and researcher	Co-creation: therapist as compiler Gift: working close together with relative
Scherrer, Ingersoll-Dayton and Spencer (2014)	Participant, partner and social worker	No role in the actual intervention
Hashim, Rias and Kamaruzaman (2013)	Participant, caretaker and doctor	Interviewing caretaker and doctor in order to develop content of the application
Ingersoll-Dayton, Spencer, Kwak, Scherrer, Allen and Campbell (2013)	Participant, partner and social worker	No role in the actual intervention
McKeown, Ryan, Ingleton and Clarke (2013)	Participant, multi-professional staff and/or family carers	Facilitating the life story work intervention
Morgan and Woods (2010)	Participant and carer or relative	Engaging participant in process and compiling the book
Haight, Gibson and Michel (2006)	Participant and care staff (family slightly)	No role in the actual intervention
Andrews-Salvia, Roy and Cameron (2003)	Family members and researcher	Compiling the book together with family members
Haight, Bachman, Hendrix, Wagner, Meeks and Johnson, (2003)	Condition 1: both caregiver and care receiver participated separately, but simultaneously Condition 2: only caregiver (without participant)	Condition 1: two reviewers visiting the home Condition 2: unknown

Approach	*Time to create*
The Couples Life Story Approach which makes use of life review techniques from Haight (1992)	5 weekly sessions
The life story movie is based on a previously completed conventional book	Creation of movie: on average 8.3 weeks. Test prototype: on average 3 sessions
The Couples Life Story Approach	5 weekly sessions
Unknown	9 daily sessions of 30 minutes
Unknown	8 weekly sessions of 15-30 minutes
Co-creation: based on Haight's Life Review model and Life Review Experiencing Form (LREF; Haight, 1992)	Co-creation: 11-16 sessions in 12 weeks Gift: 5-6 sessions in 12 weeks
The Couples Life Story Approach with reminiscence sessions with the social worker and the dyad	5 weekly sessions
Unknown	Test prototype: 4 sessions in 4 weeks
The Couples Life Story Approach with reminiscence sessions with the social worker and the dyad	Five weekly sessions with an average time span of 76 minutes (40-120) per session
Life story work	Unknown
Haight's Life Review Experiencing Form (LREF; Haight, 1992)	Approximately 12 weekly sessions of 30-60 minutes
Haight's Life Review model and Life Review Experiencing Form (LREF; Haight, 1992)	6 weekly sessions of 60 minutes
Unknown	12 sessions in 3 weeks, varying from 7.5-22.5 minutes
Haight's Life Review model and Life Review Experiencing Form (LREF; Haight, 1992)	6 weekly sessions of 60 minutes

Type and characteristics of the life story books

In eight studies, a tangible LSB was created. In three studies, both a traditional and another type of LSB was formed, namely a digital book (Ingersoll-Dayton et al., 2016), a rummage box (Crook et al., 2016), and a pen picture (McKeown et al., 2013). In three studies, only a digital version was created: both studies by Hashim et al. (2013; 2015) worked with a digital application and the study of Subramaniam and Woods (2016) used previously constructed tangible LSBs as input to create a digital life story movie. A wide variation of materials was used to create the LSBs: photographs, music, narration, stories, blank pages, quotations, and news items. The order of the stories told in the LSBs, when known, was chronological. The length of the books varied from 2 pages (the pen picture) to 70 pages (Subramaniam et al., 2014). The average length of the movies of the Subramaniam and Woods (2016) study was 18 minutes.

Implementation of the life story books

Both the participant and a partner or relative were involved in the process of creating the LSB in five studies. A professional caregiver was additionally helping in five cases. The participant created the book with the professional caregiver – so without a relative – in two cases and in the two remaining cases, it was the other way around: the participant was not involved in the process and the book was created by the relative and a professional caregiver. The researcher helped creating the LSB in the study of Andrews-Salvia et al. (2003) and in the control condition of the Subramaniam and Woods study. In five studies, Haight's life review model or life review experience form (LREF; Haight, 1992) was used in the sessions to create the LSB. A total of four studies used the couples life story approach (once combined with techniques from Haight). The number of sessions involved in creating a LSB varied from 3 (Subramaniam & Woods, 2016) to 16 (Subramaniam et al., 2014) with a median of six sessions, while the amount of weeks it took ranged from 9 days (Crook et al., 2016) to 12 weeks (Morgan and Woods, 2010; Subramaniam et al., 2014) and the time per session variated between 15 minutes (Hashim et al., 2015) and 120 minutes (Ingersoll-Dayton et al., 2013). No information was found about actual use, e.g. whether it has been used daily or weekly, for how long, and by whom, of the LSBs after the process of creating it.

Research question 2: What are the designs and findings of studies on the use of life story books?

To answer this question, the main characteristics of the study designs (aims, types of studies, and sample sizes) are presented in Table 3. Table 4 shows the instruments and/or outcome variables used in the studies and presents the findings (qualitative and/or quantitative) of the different studies.

Aim of study

The aims of the studies can be divided into two main categories: (1) getting insight in the challenges and possibilities of implementing LSB interventions in dementia care by evaluating the process and (2) gaining (initial) evidence on the effectiveness of the LSB interventions on participants (e.g. on autobiographical memory and quality of life and mood) and/or their (in)formal caregivers (e.g. on relationship and burden). Seven studies focused on the first aim, three on the second aim, and four had a combination of both aims. Hence, there were 11 studies with the first aim and seven with the second aim in total.

Type of study

The 11 studies that evaluated the implementation process used a multiple qualitative case study (three), single case study (two), case-study vignette (three), or another qualitative approach (three). Regarding the seven studies that examined the effectiveness of the LSB interventions, two multiple baseline designs and five (preliminary) (randomized) controlled trial designs were used. Four of these studies compared the LSB intervention to care as usual or no treatment. Of those four, one study compared a LSB with both a no intervention and a rummage box condition (Crook et al., 2016) and another had the following three conditions:
(1) life review work carried out separately – but simultaneously – with the person with dementia and the caregiver; (2) life review carried out with the caregiver alone; and (3) an untreated control group (Haight et al., 2003). The fifth controlled trial study compared a co-creation of a LSB with receiving a LSB as a gift (Subramaniam et al., 2014). Participants were randomly assigned to the conditions, except for the Haight et al., 2003 study, for which it remains unclear whether allocation was random.

Sample size

The sample sizes ranged from 1 (the case studies) to 56 (multiple case study; Kwak et al., 2018). For the controlled trials, the average sample size was 20 (with a range from 5 to 31). In four studies, only the persons with dementia were involved in the study, in nine studies informal caregivers, formal caregivers, or other staff were part of the study, and in one study, it was unclear.

Table 3. Overview of study characteristics

Author	Aim of study
Kwak, Ha, Hwang, Ingersoll-Dayton and Spencer (2017)	Adaptation of ''Couples Life Story Approach'' in South Korea
Subramaniam and Woods (2016)	Acceptability and efficacy
Ingersoll-Dayton, Spencer, Campbell, Kurokowa and Ito (2016)	Development of ''Couples Life Story Approach''
Crook, Adams, Shorten and Langdon (2016)	Initial evidence on well/ill-being and behavior
Hashim, Ismail, Rias and Mohamed (2015)	Evidence on management of everyday tasks, reminiscence and cognitive function
Subramaniam, Woods and Whitaker (2014)	Effect of different pathways for developing a life story book
Scherrer, Ingersoll-Dayton and Spencer (2014)	Mapping challenges of conducting narrative-based interventions
Hashim, Rias and Kamaruzaman (2013)	Developing a Digital Memory Book Application to the need of the patient
Ingersoll-Dayton, Spencer, Kwak, Scherrer, Allen and Campbell (2013)	To help individuals who have dementia and their spouses or partners communicate and reminisce about their life and develop a book that incorporates mementoes of their life
McKeown, Ryan, Ingleton and Clarke (2013)	To understand experiences of people with dementia, family carers and care staff in using life story work and to explore the process taken for life story work to be implemented
Morgan and Woods (2010)	To gain empirical evidence on the impact of life review therapy with people with dementia
Haight, Gibson and Michel (2006)	To test the effectiveness of a structured life review/life storybook process
Andrews-Salvia, Roy and Cameron (2003)	To assess the effect of memory books on the number of on-topic facts stated for three topics (life, family and day)
Haight, Bachman, Hendrix, Wagner, Meeks and Johnson, (2003)	Reviewing the application of reminiscence with people with dementia

Type of study	Sample size
Multiple qualitative case study design	56
Multiple baseline design & qualitative study	6
Qualitative study	29
Randomized multiple baseline design with three conditions: 1) life story book 2) rummage box 3) no-intervention condition	5
Qualitative case study	1
Preliminary RCT with two conditions: 1) receiving 12 individual life review sessions and co-creating a LSB 2) receiving a personal LSB created by their relatives as a 'gift' & two case study vignettes	23 11 12
Multiple baseline single case design	20
Qualitative case study	1
Qualitative study	24
Multiple baseline design	4
Preliminary RCT with two conditions: 1) life review which culminated in the creation of a LSB 2) treatment as usual & two case study vignettes	17 8 9
Controlled pilot RCT with two conditions: 1) life review/life storybook 2) care as usual	31 15 16
Multiple baseline design	4
Study with three conditions: 1) life review work carried out separately – but simultaneously – with the person with dementia and the caregiver 2) life review carried out with the caregiver alone 3) an untreated control group & two case study vignettes	22 ? ? ?

Table 4. Overview of instruments and findings

Author	Instruments/Outcome variables
Kwak, Ha, Hwang, Ingersoll-Dayton and Spencer (2017)	Primary data: session notes written by interventionists. Supplementary data: interviews with participants and weekly team meeting notes
Subramaniam and Woods (2016)	Quantitative: Quality of life-Alzheimer's disease scale (QOL-AD); Autobiographical memory interview extended version (AMI-E; subscales PSS and AIS); Geriatric depression scale residential (GDS-12R); Quality of the caregiving relationship questionnaire (QCPR). Qualitative: Open-ended questions.
Ingersoll-Dayton, Spencer, Campbell, Kurokowa and Ito (2016)	Clinical analysis of the progress of the couples discussed by members of the Japanese and American teams. Based on these discussions, four themes emerged that characterized how the couples experienced this intervention
Crook, Adams, Shorten and Langdon (2016)	Dementia care mapping (DCM), divided into Behavior Category Code (BCC) and Mood-Engagement Value (ME), calculated into Well/Ill-being (WIB). The questionnaires were filled out on two days before baseline and on nine consecutive days during the intervention conditions
Hashim, Ismail, Rias and Mohamed (2015)	An evaluation form that contains a set of questions related to presentation, motivation, understanding, memorability, learnability and usability
Subramaniam, Woods and Whitaker (2014)	Quality of life–Alzheimer's disease (QOL–AD); Autobiographical memory interview extended version (AMI-E); The Geriatric Depression Scale (Residential) (GDS-12R); Quality of the caregiving relationship questionnaire (QCPR participant and relative); Approaches to Dementia Questionnaire (ADQ); Staff knowledge of care-recipient questionnaire. The questionnaires were filled out on baseline and on follow-up at 12 and 18 weeks. Description of two cases
Scherrer, Ingersoll-Dayton and Spencer (2014)	During team meetings, social workers described the positive changes that they observed in their weekly meetings with couples, as well as the challenges they encountered. These challenges were discussed as the project leaders and other members of the project team considered strategies to address them
Hashim, Rias and Kamaruzaman (2013)	Interviews with caretaker and doctor to assess needs; Observation of behavior during sessions; Testing of long and short term memory (unclear how)
Ingersoll-Dayton, Spencer, Kwak, Scherrer, Allen and Campbell (2013)	Questionnaires with open-ended questions about their reactions to the approach (participants and caregivers) and observations
McKeown, Ryan, Ingleton and Clarke (2013)	Semi-structured interviews, observation, conversations, field notes
Morgan and Woods (2010)	Geriatric Depression Scale - Short Form (GDS-SF); Autobiographical Memory Interview (AMI). The questionnaires were filled out on baseline and on follow-up at six weeks Descriptions of two cases
Haight, Gibson and Michel (2006)	Mini Mental Status Exam (MMSE); Cornell Scale for Depression (CSDD); Alzheimer's Mood Scale N & P (neg. and pos.); Functional Independence Measure (FIM); Communication Observation Scale for Cognitively Impaired (CS); Memory and Behavior Problems Checklist (MBS). The questionnaires were filled out one week before and one week after the intervention (of six weeks)
Andrews-Salvia, Roy and Cameron (2003)	Number of on-topic facts made by the subjects during conversation with the experimenters using the memory books as memory aids
Haight, Bachman, Hendrix, Wagner, Meeks and Johnson, (2003)	Mini-Mental State Exam (MMSE); Alzheimer Mood Scale (extracted from transcribed interviews); Revised Memory and Behavior Problem Checklist; Burden Interview. The questionnaires were filled out on baseline and on follow-up at two months. Descriptions of two cases

Findings
Cultural themes identified: (1) dealing with negative memories in early years of marriage; (2) communication styles and patterns; (3) ways to incorporate difficult life events into the Life Story Book; and (4) complex dynamics of hierarchy in the relationship between older couples and the interventionist
Digital LSB > LSB. Positive average improvement on quality of life, autobiographical memory (subscale PSS), depression and quality of caregiving relationship
Those involved viewed digital life story books as a very useful tool stimulating memories, triggering positive emotions and encouraging conversation and interaction
Themes found: partner affirmation (highlighting each other's strengths), improved engagement; handling losses; fullness of a life as a couple
Reminiscence conditions > no intervention condition. Higher WIB, but not consistent across all participants. Both reminiscence conditions tended to be associated with an increase in communicative, expressive and intellectual behaviors. No significant difference was found between the LSB and rummage box
Positive feedback and user-satisfaction. Patient felt motivated and enjoyed using the application that supported managing her daily activities, reminiscence and cognitive function
Both LSB-conditions (co-creation and gift) show significant improvements on quality of life ($p=0.035$) and autobiographical memory ($p=0.001$-0.005) at post-intervention, and on quality of relationship at 6-week follow-up ($p=0.046$). Staff attitude ($p<0.001$) and knowledge ($p<0.001$) was improved at 6-week follow-up. No difference was found between the two LSB-conditions
The book appeared to play a role as a maintenance tool after the completion of the life review process and helped the participants to look back on their life
Recommendations are given on how to (1) construct a narrative from disparate stories, (2) tell a mutual story, (3) tell the story of a couple that has been in a shorter relationship, (4) incorporate others in the story, (5) include difficult life moments, and, (6) end the story
The results show that by using the application, not only the patient's reminiscence is improved regarding to performing prayer (short term memory), but it also upgrades the social interaction and communication between the patient and caretaker
Positive aspects mentioned by participants are: enjoyed reliving story of life together; communication tips were useful; enjoyed the life story book; planned to share the life story book with others; meaningful engagement; helped memory
Private memories were sometimes recalled by the person with dementia that were not for inclusion in any written product; enabling the person with dementia to tell their own life story could be a challenge; quality of the life story books was variable and; at times, life story work may be overused with the person with dementia
LSB>treatment as usual. Significant improvement on depression ($p=0.009$) and autobiographical memory ($p=0.016$) during follow-up
Although the life review process and creation of the LSB was difficult, the participants enjoyed it
LSB>care as usual. Significant improvement on cognitive functioning ($p<0.0005$), depression ($p<0.015$) positive mood ($p<0.008$) and communication ($p<0.005$). Improvement (not significant) on independence and memory and behavior problems
All subjects stated more on-topic facts using the memory books than during the baseline condition
Dyadic < caregiver only & no treatment. Significant decrease on cognition ($p<0.03$). Dyadic > caregiver only & no treatment. Significant improvement on mood ($p<0.04$). Dyadic & caregiver only > no treatment. Significant increased burden ($p<0.06$) and behavior problems ($p<0.05$) in no treatment
The case studies helped to elucidate the process

Instruments/Outcome variables

A large number of different instruments or outcome variables were used. A distinction can be made between qualitative and quantitative measurements. To explore the implementation process of the interventions, qualitative instruments, such as (semi-structured) interviews, observations, open questions, conversations, and field notes, were used. To assess the effectiveness of the interventions, multiple questionnaires and observational instruments were used on different stakeholders. Participant-focused outcomes were, e.g. autobiographical memory, depression, and quality of life. Furthermore, questionnaires on the quality of the caregiving relationship and communication between the informal caregiver and person with dementia were assessed. Informal caregiver measures were on caregiver burden and formal caregiver measures were on knowledge and attitudes. The outcome measures in the controlled trial studies were applied on baseline as well as during the intervention (Crook et al., 2016) or after the intervention with a maximum of 18 weeks (Subramaniam et al., 2014).

Findings

Qualitative findings

All those involved looked back on the interventions as an enjoyable process and they viewed a LSB as a useful tool triggering memories and – largely positive – emotions. Participants, relatives, and care staff saw the value of the LSB mainly in improvements in relationships: partner affirmation, engagement, fullness of life as a couple, social interaction, and communication. Furthermore, several (cultural) themes were identified and recommendations for implementing a LSB intervention were given, e.g. on how to incorporate difficult life events in the LSB, how to tell a mutual story, and how to end the story. No negative effects were reported.

Quantitative effects

In the five controlled trial studies, the LSB interventions showed significant improvements in autobiographical memory, mood, depression, and quality of life of the persons with dementia compared with care as usual or no treatment. Furthermore, the communication and quality of relationships between participants and their informal caregivers improved significantly. Finally, significant improvement on staff attitudes and knowledge was found. In one study, two reminiscence intervention conditions (one being a LSB intervention and the other a rummage box) showed significant improvement compared to the no intervention condition, but no difference was found between the LSB condition and the rummage box condition (Crook et al., 2016). Moreover, some positive non-significant changes in independence and behavior problems in favor of the LSB intervention were reported (Haight et al., 2006).

One study reported a mixed outcome: the persons with dementia in the dyadic LSB condition showed a significant decrease in cognition compared to the caregiver only and no treatment condition, while mood and burden improved in both the dyadic and caregiver only condition (Haight et al., 2003).

DISCUSSION

Reminiscence can be used to enhance PCC and has proven to be effective for persons with dementia (Woods et al., 2005; Subramaniam & Woods, 2012; Blake, 2013; Huang et al., 2015). The creation of a LSB is a specific form of reminiscence that is the result of a life review process that illustrates the biography of a person.

This systematic review of 14 studies showed that most LSBs were tangible books that were created in about six individual sessions in nursing homes with persons with varying degrees of dementia as well as with their informal and formal caregivers. Process evaluations showed the value of LSBs in triggering memories and positive emotions and in improving the relation with the person with dementia. Quantitative evaluations supported this value as significant improvements were found on autobiographical memory, depression, mood, and quality of life of the persons with dementia, as well as on the quality of relationships and communication between the person with dementia and the informal caregiver. Furthermore, effects on burden of the informal caregivers and on attitudes and knowledge of formal caregivers were found in comparison to care as usual.

The findings for persons with dementia are in line with earlier reviews and a meta-analysis that have shown that reminiscence activities can contribute to cognitive functioning, depression, and quality of life of persons with dementia (Woods et al., 2005; Subramaniam & Woods, 2012; Blake, 2013; Huang et al., 2015). The findings for caregivers and their relation to persons with dementia indicate that LSBs can contribute to the culture change towards more PCC (Koren, 2010; AGS, 2016; Higgs & Gilleard, 2017). The relationship between persons with dementia and their formal and informal caregivers appears to be improved and the expression of values and preferences of persons with dementia in LSBs can further contribute to support their health and life goals. This also aligns with previous findings that reminiscence has the potential to enable care staff to see the person behind the patient and enable the patient’s voice to be heard, verbally and non-verbally (Woods et al., 2005).

According to the framework for trials of complex interventions created by the Medical Research Council (MRC, 2000), the research on LSBs is ranged between the phase of modelling and the phase of exploratory trails (phase I and phase II). The use of LSBs and the qualitative studies provides insight in the components and underlying mechanisms of LSBs (phase I). The main mechanism is the recollection and sharing of autobiographical memories. The components are an individual or dyadic life review that results in a tangible (digital) life story. The quantitative studies in this review apply to the exploratory trial phase (phase II). In this phase, the components are tested in different designs. Small sample sizes and non-random allocation of participants are characteristic for this phase. Despite the fact that the majority of the controlled trials in this review were randomized, we need to interpret the significant improvements found on several outcomes in this review with caution, especially due to the small sample sizes. The next phase (phase III) would be to conduct larger randomized controlled trial (RCT) studies to establish the effects of LSBs on people with dementia. This phase asks for a good choice of intervention characteristics in relation to outcome measures. Given the diversity in aims and methods of the included interventions, it is hard to state one as the best practice at this moment in time. Hence, when conducting a larger trial, a clear formulation of the aims of the LSB intervention and how the specific components contribute to the aims is necessary.

Overall, the research in the field of the use of LSBs in dementia care is in the first phases of providing evidence. However, one has to realize that research on LSBs in dementia care is a fairly new area of interest, hence the lack of good, solid RCTs with large sample sizes. Given the current state, the small RCTs, pilot studies, and qualitative case studies of this review do provide insights and help future research.

This review shows that an intervention may focus more on the person with dementia and try to improve autobiographical memory, mood, depression, and/or quality of life or, alternatively, focus more on the relationships of (in)formal caregivers with the person with dementia. The process of creating a LSB may be different for both purposes, for example, in terms of the persons who are involved in the process, or in the use of individual forms like Haights LREF (Haight, 1992) versus a dyadic approach like the couples life story approach (Ingersoll-Dayton et al., 2013). Technology might contribute to the first aim due to multimedia effects like music or movies that may more strongly involve the person with dementia in the process of recollecting memories and improving mood. Technology might contribute in another way to the second aim as different persons can contribute to the creation and use of digital LSBs more easily, also making the LSB more interactive. Is it only after conducting good trials that the last phase (phase IV) of long-term implementation can be realized?

This review is the first to provide an overview on the use of LSBs as a specific domain within the field of reminiscence in dementia care. The studies included were diverse in their aims and consequently in their methods, which makes it difficult to compare the studies in a consistent way. However, the diversity does show that creating LSBs needs to be a tailored process. Especially in a time when the need for more PCC is greater than ever, one could question whether there is one golden standard since it always will be a personal, individualized process to create one's life story. Nevertheless, it is worthwhile to investigate the effect of personalized LSBs on larger studies.

Since 12 of the 14 included studies were identified through database searching, it is assumed that the constructed search strategy was sufficient and all relevant studies were identified. The majority of studies in this review report on positive findings or effects, although some studies do mention less positive outcomes. Failed attempts on studies on LSBs may not have been published. This systematic review shows indications of effects of creating LSBs and possible ways to implement LSBs in dementia care, but information on their actual use after the creating process and long-term effects after implementation is lacking.

This systematic review shows that research on LSB interventions for people with dementia is emerging and confirms that the use of LSBs to support reminiscence and PCC is promising.

Intermezzo 1

Supplementary information about the intervention ”the Online Life Story Book”

The Online Life Story Book (OLSB) is an e-health application in which memories can be placed on a dynamic timeline. All kinds of memories can be added to the OLSB, e.g. life events such as a wedding, anecdotes of a certain person, and a recipe from a grandmother. Memories can be included as text, photo, audio or video. Not only materials in possession of the dyads (a person with cognitive impairment and their informal caregiver) can be used to fill the OLSB, but documents available for public use can be included as well.

Trained volunteers supported the dyads in creating the OLSB. The volunteers had to meet the following criteria: having affinity with ageing people, being motivated to learn more about the intervention, being willing to follow the training, being capable to use computers and internet, having social skills, being flexible, and having a minimum of secondary vocational education. After a positive intake conversation with the researcher(s) and a psychologist, volunteers received a training in small groups. This training, spread over two half days, consisted of information about the intervention, dementia and conversational skills. By means of role plays, they practiced drawing a time line of each other's life, asking for specific memories, having (difficult) conversations, and working with the application. During the project, monthly intervision meetings guided by the researcher(s) and psychologist were organised, in which experiences were exchanged. In case of any questions, the project team was always available for the volunteers.

After a first visit to make acquaintance and draw a global time line of the life of the participant, the volunteer visited the dyads four additional times within a period of 8–10 weeks. The volunteers were trained to ask for specific memories and to make them as explicit and lively as possible. Together with the person with dementia and his or her caregiver, the volunteer searched for the themes and questions that best matched the life story of the participant. The volunteer strived for a variation in themes and life phases across the four visits. After each visit, the volunteer added the memories to the timeline. After the five visits and when the OLSB was completed, it was printed in a tangible version so the participants could leaf through it and could use it more easy in their everyday life. Dyads also received a manual with tips and tricks on how to keep on using the application and on how to incorporate the OLSB in their everyday contact, for example by talking about favorite memories, listening to music, or doing preferred activities.

The initial application that was used in this study was developed by Hellomydear in Belgium, which allowed placing the memories on a dynamic timeline. The timeline was easily marked with historical years and expanded when new memories were added. After the unexpected termination of the co-operation, a switch to another application, Albelli, was made. This commercial application is freely accessible and is being used to create all kinds of albums, although no timeline is generated. The digital version of the book can be accessed afterwards, but the main aim of this application is to create an album. See below for screenshots from OLSBs created with Hellomydear (1a and 1b) and Albelli (2). As part of the project, a comprehensive toolkit with a description of the intervention and a scenario to implement the intervention (with information about the training for volunteers and the course book with guidelines for them) was created (Elfrink, Ullrich et al., 2018).

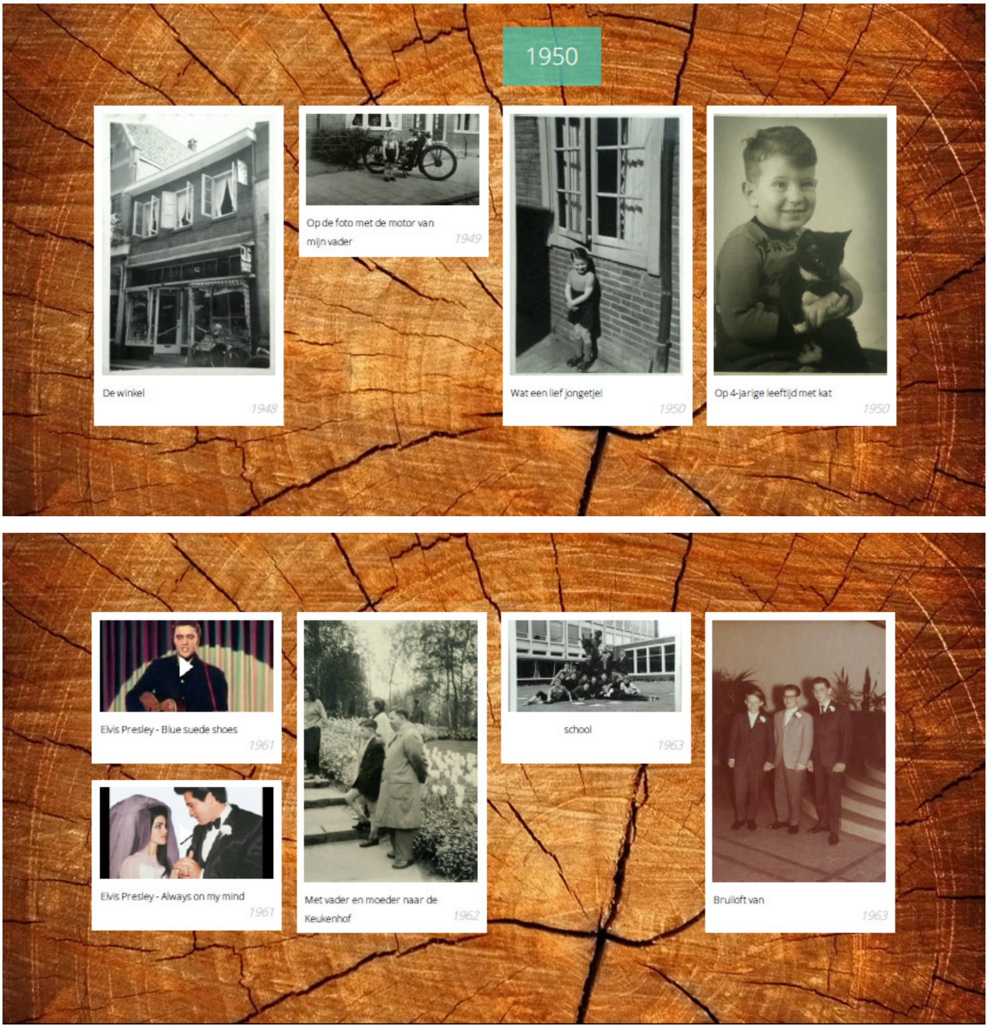
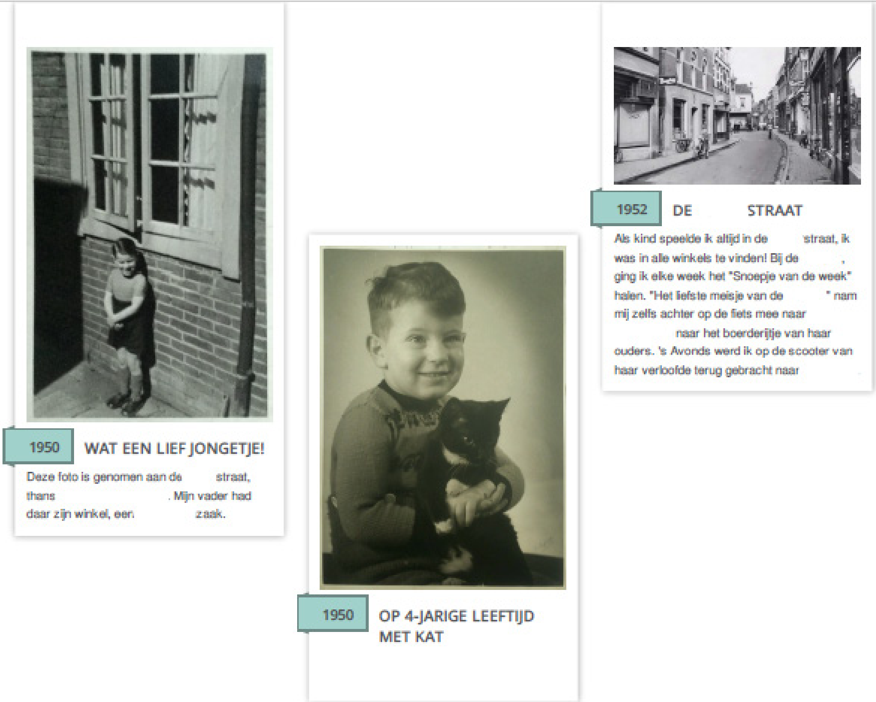


Figure 1a. Fragments from a general timeline (as printed in the tangible version) created with Hellomydear (anonymized)



1950 **WAT EEN LIEF JONGETJE!**

Deze foto is genomen aan de straat, thans . Mijn vader had daar zijn winkel, een zaak.

1950 **OP 4-JARIGE LEEFTIJD MET KAT**

1952 **DE STRAAT**

Als kind speelde ik altijd in de straat, ik was in alle winkels te vinden! Bij de , ging ik elke week het "Snoepje van de week" halen. "Het liefste meisje van de " nam mij zelfs achter op de fiets mee naar naar het boerderijtje van haar ouders. 's Avonds werd ik op de scooter van haar verloofde terug gebracht naar

Figure 1b. Fragments from the digital book (as printed in a tangible version) created with Hellomydear (anonymized)

1933-1935

Een carriere als tennisser is aan mij verloren gegaan. Op de tweede foto sta ik met Opie en moeder bij de sluizen van . Mijn opa was machinist op de een sleepboot, en ik vond dat, zo klein als ik was, heel interessant.

Op de derde foto sta ik met mijn moeder in het

MUZIEKFRAGMENTEN

Goldbergvariaties-
Bach BWV 998
Glenn Gould

Chopin Nocturnes
Arthur Rubinstein

West Side Story
Symphony o.l.v.
Bernstein

Figure 2. Fragments from the digital book created with Albelli (anonymized)

The Effectiveness of Creating an Online Life Story Book on Persons with Early Dementia and Their Informal Caregivers

a protocol of a randomized controlled trial

3

Elfrink, T. R., Zuidema, S. U., Kunz, M., & Westerhof, G. J. (2017).
BMC geriatrics, 17(1), 1-11.
doi: 10.1186/s12877-017-0471-y

ABSTRACT

Background:
Dementia has a high burden for patients, informal caregivers and society. Given changes in care systems, more persons with dementia will live longer at home. However, living at home (with dementia) with a good quality of life is not easy to achieve. Dementia is often accompanied by neuropsychiatric symptoms like apathy, agitation, depression, and anxiety, which have a negative impact on quality of life. Whereas cognitive deterioration can hardly be influenced, it is possible to reduce neuropsychiatric symptoms. As autobiographical memories remain intact for a relatively long time in dementia, reminiscence interventions can promote feelings of pleasure and trust. The Online Life Story Book (OLSB) allows to digitally share memories (stories, pictures, video or audio fragments). The main objective is to study the effects of the OLSB on neuropsychiatric symptoms. The study has four secondary objectives: 1) to study the effectiveness of the intervention on the burden and quality of life of the primary informal caregiver; 2) to provide a preliminary health-economic evaluation; 3) to study the (time to) nursing home admittance as a longer term effect; 4) to provide a process evaluation.

Methods and design:
A randomized controlled trial with individual randomization to one of two conditions is conducted: 1) intervention “Online Life Story Book”; 2) control condition (care as usual). Participants are persons with early dementia and their primary caregivers. In the intervention OLSB, a trained volunteer guides the participants through the process of putting together a timeline of their lives during 5 meetings within a period of 8-10 weeks. To assess the effects of the intervention on the primary outcome, neuropsychiatric symptoms, the Neuropsychiatric Inventory (NPI) will be assessed at three time points: before the intervention (baseline, T0), 3 months (T1) and 6 months (T2) post baseline.

Discussion:
When proven effective, the Online Life Story Book can be a valuable addition to the existing provision of care for persons with dementia and their informal caregivers.

BACKGROUND

At present, the number of people living with dementia worldwide is estimated at 47.5 million. This number will increase to 75.6 million in the coming 15 years. Dementia is among the top-5 with the highest burden of disease for persons over 65 years and it belongs to the diseases with the highest burden for informal caregivers. This burden includes physical, emotional and economic pressure. With costs over 604 billion US dollars it is one of the most costly diseases as well (World Health Organization, 2016).

In the Netherlands, about two thirds of persons with dementia is estimated to live at home, but given the impact of the ageing population this number will increase. This is also in line with the preferences of persons with dementia and their informal caregivers (Peeters et al., 2014). However, living at home with a good quality of life is not easy to achieve.

Dementia is often accompanied by the presence of neuropsychiatric symptoms (NPS), like apathy, agitation, depression, anxiety, and delusions. A systematic review of studies on the course of NPS in community-dwelling patients with dementia found a cumulative prevalence of any neuropsychiatric symptom between 49% and 95% (Borsje et al., 2015). Delusions, agitation, aberrant motor behavior and apathy are the most common NPS (Borsje et al., 2015). Neuropsychiatric symptoms not only affect the quality of life of the patient (Conde-Sala et al., 2016), but also result in a higher burden of informal caregivers and a lower quality of their lives (Conde-Sala et al., 2016; De Vugt et al., 2003; Peeters et al., 2012). NPS are among the most important reasons for nursing home admittance, as they often make the care at home too burdensome (Gaugler et al., 2009). Whereas it is still not possible to treat dementia, dementia care focuses mainly on maintaining quality of life and preventing psychosocial problems (Koopmans et al., 2009).

There is evidence that neuropsychiatric symptoms can be prevented or diminished by behavioral interventions (Olazarán et al., 2010). However, it is important that such interventions fit the experiences and life world of persons with dementia well so that they can contribute to the needs of the persons with dementia and their informal caregivers (Van der Roest et al., 2009).

The Online Life Story Book (OLSB) is such an intervention that nicely ties in with changes in care systems that promote persons with dementia to be living longer at home instead of moving to a nursing home. The Online Life Story Book has a different approach than most existing applications as it focuses on the unique life story rather than on specific complaints and symptoms. The OLSB builds on research on reminiscence (Westerhof et al., 2010). Research has shown that remembering and reliving precious personal memories can create feelings of pleasure, familiarity, and assurance. Hence, reminiscence interventions are part of the Dutch standard for dementia care (Alzheimer Nederland & Vilans, 2013). Personal memories belong to the autobiographical memory system, a part of memory that remains intact in dementia for a relatively long time (Dempsey et al., 2014; Caddell & Clare, 2010). Most persons with early dementia are able to retrieve personal memories and share them. And even in later phases of the disease, they can still relive the positive feelings associated with precious memories. When the disease progresses and memory further deteriorates, it becomes more and more important to offer multisensory cues for memories in a structured way that fits the unique life story of the person with dementia. Under these conditions, reminiscence interventions can contribute to the psychosocial functioning of persons with dementia (Woods et al., 2005).

Several systematic reviews have shown that reminiscence activities can contribute to the mental health and quality of life of persons with dementia (Woods et al., 2005; Subramaniam & Woods, 2012; Blake, 2013, Huang et al., 2015). The use of life story books with personal memories that were constructed together with the person with dementia is especially promising (Subramaniam and Woods, 2012). Besides the recollection of personal memories, the collection of a person’s life story in a book adds to this (Morgan & Woods, 2010).

The current study aims to test the effects of the OLSB in comparison to care as usual. The current study adds in three ways to the existing knowledge about the use of life story books for persons with dementia: 1) by assessing effects on NPS in the home situation; 2) by using technology; 3) and by employing volunteers in the intervention.

Assessing effects in the home situation

The current project is one of the first to use life story books in the home situation. Informal caregivers are in need of meaningful activities that allow them to step out of the caring role (Touwen, 2014). Mutual reminiscence is such an activity that can also give rise to further activities in everyday life such as listening to music together, or cooking an all-time favorite recipe. This helps to decrease NPS and promote quality of life of the person with dementia. Moreover, it aids in reestablishing a more personal relation with the person with dementia. It diminishes the burden of the informal caregiver and improves his or her quality of life.

Using technology

The current project is innovative as it assesses the use of life story books that have been created with modern information and communication technology. Technology plays an increasing role in dementia care, whether in domotics, remote care, or mobile apps (Nijhof et al., 2009). This also fits the increasing competences of older persons to use computers and the internet (Van Deursen & Van Dijk, 2015). About 85% of the Dutch persons between 65 and 75 years already use the computer and the internet at least once a week (CBS, no date). The use of technology has three major advantages (Lazar et al., 2014). First, technology makes it easier to document and retrieve personal memories that match the idiosyncrasies of individual life stories. Second, technology provides multimedia for the storage and retrieval of memories. Sound, music, photos, and movies can be easily added, besides anecdotes and verbal cues. Indirectly smell, taste, and touch can be used, for example by cooking a favorite recipe or doing preferred activities together. This becomes even more important when it becomes more difficult for the person with dementia to retrieve memories through verbal stimuli. Third, technology makes it possible to use the life story book in an interactive way. Informal caregivers and family members and friends can add new memories or remarks on memories that were especially vivid to them. Hereby, it is possible to update and adjust the life story book even when the dementia progresses. A recent review shows that the use of technology for reminiscence intervention is promising, but that there is still a lack of systematic studies in this field (Lazar et al., 2014).

Employing volunteers

Given the changes in healthcare systems around the world in which more people will live longer at home instead of moving to a nursing home, not only informal caregivers but also volunteers play an increasing role and are expected to participate more and more to provide care in everyday life. For care institutes the delivery of the intervention will become more efficient than care provided by a professional (Richters et al., 2015). For older adults, an intervention delivered by a volunteer will be less stigmatizing than care by a healthcare professional such as a psychologist, in particular while volunteers provide a new contact with society (Westerhof et al., 2008). It is well-known that volunteering supports both the volunteer's mental health and well-being and that of the people they serve (Wheeler et al., 1998). Volunteers like to contribute to projects with a concrete goal, limited time investment, and possibilities for training (Arcon, 2011). The current project suits both altruistic and self-oriented motivations of volunteers as it offers the possibility to create something of personal value to the person with dementia and the informal caregiver, whereas it also allows them to learn new competences in the training (Hwang et al., 2005; Chen & Morrow-

Howell, 2015). The volunteer provides the necessary structure and the needed social and technological competences that serve to ease the task for the informal caregiver. As the intervention is based on reminiscence as a naturally occurring process in later life, volunteers can easily stimulate conversations about personal memories with the help of a well-defined protocol (Westerhof et al., 2010).

In summary, the primary objective of the study is to assess the effectiveness of the intervention “Online Life Story Book” on neuropsychiatric symptoms of persons with early dementia, in comparison to care as usual. The study has four secondary objectives: 1) to study the effectiveness of the intervention OLSB on the burden and quality of life of the primary informal caregiver; 2) to provide a preliminary health-economic evaluation by analysing the effects on the quality of life and care consumption of the person with early dementia; 3) to study the (time to) nursing home admittance as a longer term effect; 4) to provide a process evaluation.

METHODS AND DESIGN

Study design

A randomized controlled trial with individual randomization to one of two conditions is conducted:

1. The intervention condition: participants in the intervention “Online Life Story Book”
2. The control condition: participants receive care as usual.

The participant flow can be found in Fig. 1. The study takes 6 months for each individual participant with a baseline measurement (T0) as well as measurements after three (T1) and 6 months (T2). The intervention, creating an OLSB, takes about 8–10 weeks. The study takes place at the home of the person with early dementia who participates in the study. A trained volunteer will support the construction of the OLSB. Trained student assistants and the primary researcher will carry out the measurements.

This study has been approved by the Twente Medical Ethics Committee under the file number p16-04 (Dutch Trial Register: NTR5939). Participation is voluntary and all respondents will provide written informed consent before inclusion.

Participants

Recruitment

We include persons with early dementia who are living at home and are being cared for by informal caregivers. In Enschede and Haaksbergen (two medium size cities in the Eastern part of the Netherlands) alone, there are 2500 persons with dementia. Livio, a large organization providing elderly care in this region, is in contact with about 575 of them through home care and living facilities for independently living older persons. Stichting Informele Zorg Twente, a local welfare organization, is in contact with about 650 informal caregivers. If the inclusion of 106 participants poses problems, participants can be recruited through other large care groups of the University Network for Elderly Care (UNO-UMCG), a network consisting of 16 large care organizations in the Northern and Eastern part of the Netherlands. We will recruit participants via so called Alzheimer Café's, meeting centers for persons with early dementia, general practitioners and advertisements in newsletters for elderly people in the region.

Assessment of inclusion and exclusion

Inclusion and exclusion criteria In order to be eligible to participate in this study, a subject must meet the following criteria:

- (Very) mild dementia;
- Living at home and receiving informal care;
- Being mentally capable to provide informed consent.

A potential subject who meets the following criterion will be excluded from participation in this study:

- Past psychotrauma.

Inclusion criteria

The main inclusion criterion is (very) mild dementia (Clinical Dementia Rating 0.5 or 1). This will be assessed with the Clinical Dementia Rating Scale (Morris, 1993). This is a semi-structured interview that is carried out partly with the person with dementia and partly with the informal caregiver. The part for the person with dementia focuses on memory (10 items), orientation (8), and judgment/problem solving (9). The part for the caregiver asks for memory (15 items), orientation (8), judgment/problem solving (6), community affairs (10), home & hobbies (5), and personal care (4). The answers are used to compute a score ranging from 0 = none, 0.5 = very mild, 1 = mild, 2 = moderate to 3 = severe. Participants are included when they score 0.5 or 1. The other inclusion criteria are checked by the researcher during the baseline measurement.

Exclusion criterion Psychotrauma is studied with the module posttraumatic stress disorder (PTSD) of the Mini International Neuropsychiatric Interview (MINI) that enables classification in DSM-categories (Sheehan, 1998). The module consists of 14 dichotomous questions and 3 open questions that address current and lifetime PTSD. Participants are excluded when they report current or lifetime PTSD.

Sample size calculation

Based on systematic reviews, a small significant effect is expected for the primary outcome at follow-up (Woods et al., 2005; Blake, 2013; Subramaniam & Woods, 2012). Hence, 74 participants are needed (GPower: f = 0.15; alpha = .05; power = .80; repeated measures anova with 2 groups and 3 measurement points; r = .50 between measurements). Given the vulnerability of the participants and a high mortality rate, we expect a drop-out of 30% (Woods et al., 2005; Blake, 2013; Subramaniam & Woods, 2012). Hence, 106 participants need to be included, 53 per condition.

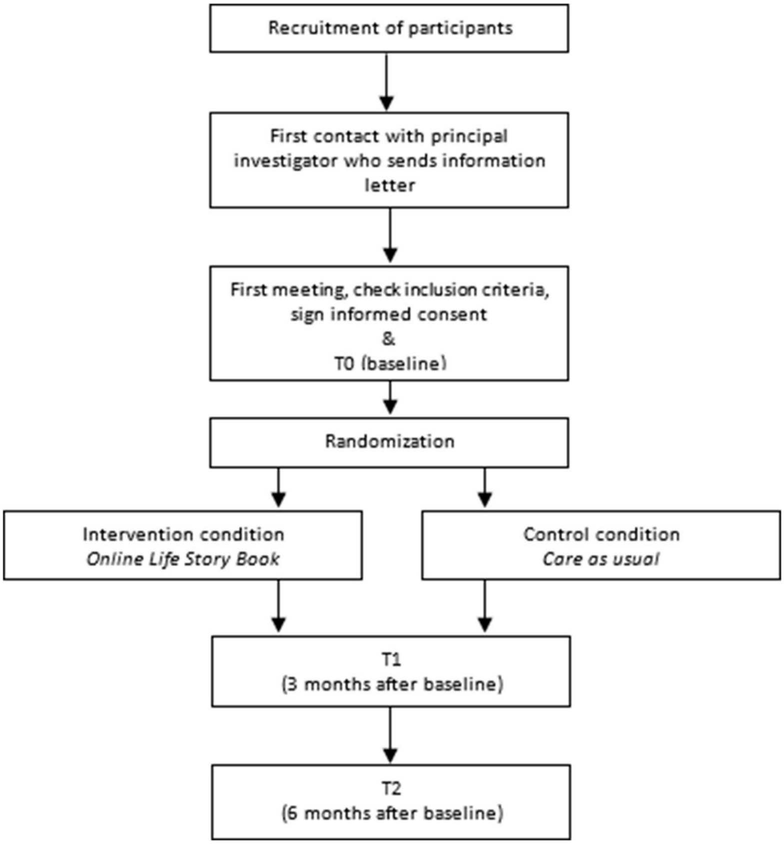


Figure 1. Study Flowchart.

Randomization

After the participant is included in the study, signed the informed consent, and participated in the baseline measurement, randomization will be carried out. Randomization will be done by an independent researcher at the University of Twente, based on a computer-generated list of random numbers.

Description of the intervention: the online life story book

The Online Life Story Book is an e-health application that allows placing personal memories on a dynamic timeline. The timeline is easily marked with historical years. Memories like life events, anecdotes, photos, movies, voice fragments, music, recipes, preferences, and activities can be placed on the timeline. To make the application safe and warrant privacy, all information is stored on a secured server. The application is developed by Hellomydear in Belgium (Hellomydear, no date).

OLSB materials

The application allows storage of materials that are directly relevant to the life story of the participant. Multimedia material can be used: text, photos, movies, sound, music, and indirectly smell, taste, touch, and movement, e.g. by adding recipes or preferences for activities. Subsequently, the participant and caregiver(s) can carry out these activities. The material may consist of personal information, such as photos of the participant at school, holidays, marriage, or with family and children. Material can also be added that bears a direct relation to the life story of the participants, such as an old picture of the street where someone lived, a logo of the firm for which the participant worked, a song or piece of music the participant liked. The subjective life story of the participant provides the necessary guidance. For a participant who liked football the history of his favorite club might be documented, whereas for a person who loved technology, reminders of technological innovation could be used. The material might be in possession of the participant or informal caregivers. Sometimes, it will be necessary to digitalize these materials, which is nowadays most easily done with the use of smartphones or tablets. Digital materials can also be found in other ways. Good websites document the social-cultural history of the Netherlands and/or its regions (e.g. Geheugen van Nederland; NPO Geschiedenis; Beeld en Geluid; Stadsarchief Enschede; Online Luisteren). Pictures or documents available for public use can be added to the timeline. The OLSB allows including links to these online materials if they are not available for public use.

Making the OLSB

Trained volunteers will support persons with dementia and their informal caregivers. After a first visit to make acquaintance and draw a global time line, the volunteer will visit the participant four additional times in 8–10 weeks. The volunteers follow guidelines that are based on existing scientific and practical insights into reminiscence and dementia (O'Shea et al., 2011; Kindell et al., 2014). The volunteers are trained to ask for specific memories and to make them as explicit and lively as possible. Together with the person with dementia and his or her caregiver, the volunteer searches for the themes and questions that best match the life story of the participant. The volunteer strives for a variation in themes and life phases across the four visits. After each visit, the volunteer adds memories to the timeline. After the five visits and when the online life book is completed, it will be printed to a tangible version. We expect that it will take approximately 3 months from the first visit of the volunteer to the delivery of the printed book. After the initial construction of the online life book by the volunteer, it remains possible to add memories to the timeline as well as commentaries to memories. The participant will get access for the duration of 1 year. After this year, one gets the opportunity to lengthen the registration for €10,- per year. The necessary guidelines will be made available to the participants. The person with dementia and the caregiver can allow others, like children, families, or friends to contribute to the book.

Everyday use

The use of the OLSB in everyday life is very easy and pleasant. More competences than scrolling the timeline and clicking on memories is not needed. Besides the online version that is available on a computer or tablet, every participant will receive a printed version to make it easier to use in everyday life. Codes in the book make it possible to assess online material that cannot be printed, such as sound, music, or movies. Participants and their caregivers can make use of the online or printed version to recollect personal memories of the participant. Participants and caregivers receive a manual with tips and tricks how to use the application to this end and how they can make use of the memories in their everyday contact, for example by talking about favorite memories, listening to music, or doing preferred activities.

Time investment

A trained volunteer will aid the person with dementia in making the life-story book during five visits of 1 h. Based on existing reminiscence interventions (Woods et al., 2005; Blake, 2013; Subramaniam & Woods, 2012), participants – and their informal caregiver and involved family – are advised to spend at least 1 h a week in using the book to recollect personal memories. Participants are instructed that this is a minimum requirement and that it is better to spend several shorter periods (e.g. 10-15 min several days a week) rather than 1 h on a separate day. Via the manual the participants also receive tips and tricks how to make use of the memories in planning everyday activities (e.g. listening to music, visiting the old primary school, baking ones favorite cookies, reading a rhyme). The time investment of these activities will vary depending on the kind of activities.

Control condition

Participants in the control condition receive care as usual. They have access to all existing treatments, interventions, and support, such as medical treatment, home care, memory centers, case management, activities organized by Alzheimer Nederland, support for informal caregivers. To allow for an optimal use of usual care, participants will be informed through a booklet about existing care possibilities. Participants in the control condition are allowed to create an OLSB after the study.

Measurements

Overview

Table 1 gives an overview of all measurements. Participants are asked to fill out the questionnaires at baseline (T0); 3 months after the baseline measurement (T1); and 6 months after the baseline measurement (T2).

Primary outcome

Neuropsychiatric symptoms (NPS) To assess the effect of the intervention on the primary outcome, neuro-psychiatric symptoms, the Neuropsychiatric Inventory (NPI) will be used at all three time points in all participants. The NPI is a reliable and valid measure that is filled out by the primary informal caregiver (Cummings et al., 1994). The NPI is often used to measure neuropsychiatric symptoms, also in pharmacological and psychosocial intervention studies. The instrument is developed by Cummings (1994) and translated in Dutch by De Jonghe, Borkend and Kat (1997). The NPI measures the frequency, severity and distress of twelve neuropsychiatric symptoms (Delusions, Hallucinations, Agitation/ Aggression, Depression/Dysphoria, Anxiety, Elation/Euphoria, Apathy/Indifference, Disinhibition, Irritability/ Lability, Aberrant motor behavior, Sleep and Nighttime Behavior Disorders, and Appetite and Eating Disorders). The frequency (F) is provided on a scale from 0 = never to 4 = daily, the severity (S) on a scale from 0 = not to 3 = severe. The score for each of the twelve symptoms is computed as the frequency multiplied by the severity, resulting in a score ranging from 0 to 12. An FxS score of 4 or higher is seen as clinically relevant symptoms. The twelve FxS scores are added to a total score (0-144) or to four scores of symptom clusters: hyperactivity, psychosis, affective symptoms, and apathy (Aalten et al., 2003).

Table 1. Overview of study parameters, measurement instruments and measurement points

Measure	Instrument	Filled out by	
		Person with dementia	**Informal caregiver**
Inclusion criterion			
(Very) Mild dementia	CDR	T0	T0
Exclusion criterion			
Trauma	MINI Psychiatric Interview, module PTSD	T0	
Primary outcome measure			
Neuropsychiatric symptoms of person with dementia	NPI, total score		T0, T1, T2
Secondary outcome measures			
Caregiver burden	NPI, module Distress		T0, T1, T2
	EDIZ		T0, T1, T2
	TOPICS-MDS, modules Time investment and Burden		T0, T1, T2
Quality of life of caregiver	TOPICS-MDS, modules CarerQol and Quality of life (RAND-36 and variant of Cantril's Self Anchoring Ladder)		T0, T1, T2
Health of caregiver	TOPICS-MDS, module Health (RAND-36)		T0, T1, T2
Health-economic evaluation			
Care consumption	TOPICS-MDS, module Use of care		T0, T1, T2
Health-related quality of life of person with dementia	TOPICS-MDS, module EQ5D+Cognitive	T0, T1, T2	
Personal Information			
Socio-demographics	TOPICS-MDS, module General data		T0
Personal functioning of person with dementia	TOPICS-MDS, modules Daily functioning (Katz-15) and Social functioning (RAND-36)	Daily functioning: T0, T1, T2	Daily functioning & Social functioning: T0, T1, T2
Health of person with dementia	TOPICS-MDS, modules Health and Multimorbidity	Health: T0, T1, T2	Multimorbidity: T0, T1, T2
Psychological well-being of person with dementia	TOPICS-MDS, module Psychological well-being	T0, T1, T2	
Quality of life of person with dementia	TOPICS-MDS, module Quality of life (RAND-36 and variant of Cantril's Self Anchoring Ladder)	T0, T1, T2	
Longer term outcome			
Nursing home admittance	Addressed in month 18 with general practitioner		
Process evaluation			
Other (reminiscence) activities	Open question		T1, T2
Use of OLSB	Open question		T1, T2

Secondary outcomes

The majority of the secondary outcomes and the personal information is assessed with parts of The Older Persons and Informal Caregivers Survey Minimum DataSet (TOPICS-MDS) (Lutomski et al., 2013). The TOPICS-MDS was developed to examine the effects of the initiatives that are part of the Dutch National Care for the Elderly Programme.

Caregiver Burden Caregiver burden is a secondary outcome measure. It is measured with a Dutch questionnaire (Ervaren Druk door Informele Zorg or EDIZ; De Boer et al., 2012). This instrument has been used in informal caregivers with dementia and proved to be reliable and valid in this group. The informal caregiver rates the subjective burden on nine items with a five-point scale ranging from 1 = no! to 5 = yes!. The answers are dichotomized per item and then added up to a score between 0 and 9.

Caregiver burden is also measured with the distress scales of the NPI (Cummings et al., 1994; De Jonghe et al., 1997). The caregiver rates the distress for each of the twelve neuropsychiatric symptoms on a scale from 0 = none to 5 = severe. These twelve distress scores are summarized to a total score, ranging from 0 to 60. This sum score provides an indication of the emotional distress caused by all neuropsychiatric symptoms. Thirdly, the modules Time investment and Burden of the TOPICS-MDS are used to assess caregiver burden.

Quality of life of the caregiver The care-related quality of life of the caregiver is measured with the CarerQol (Brouwer et al., 2006). This reliable and valid instrument asks seven questions that are rated on a three-point scale (0 = none to 3 = many). Caregivers also answer a general question on happiness on a visual analogue scale ranging from 0 to 10. The total score provides an indication of the care related quality of life of the informal caregiver. The CarerQol is part of the TOPICS-MDS. In addition, the general quality of life of the caregiver is assessed with the module Quality of life of the TOPICS-MDS. The latter module consists of questions of the RAND-36 and a variant of Cantril's Self Anchoring Ladder in which persons are asked to rate their life on a scale from 1 to 10 (Van der Zee & Sanderman, 1993; Cantril, 1965).

Health of caregiver The general health condition of the caregiver is measured with the module Health of the TOPICS-MDS. This consists of two questions of the RAND-36 (Van der Zee & Sanderman, 1993).

Health-economic evaluation

Care consumption of the person with dementia will be used in the preliminary health-

economic evaluation that provides a time window of 6 months, parallel to the RCT. Care consumption is measured in the TOPICS-MDS (Lutomski et al., 2013). Care consumption includes medical costs (e.g. visits of general practitioner, specialist physicians, and hospital care) as well as indirect non-medical costs (e.g. home care, travel costs). Costs will be evaluated, based on the manual of Tan et al. (2012).
Health-related quality of life of person with dementia To measure health-related quality of life, the EQ5D + Cognitive will be used (Brooks, 1996), a short questionnaire with 6 items that is also part of the TOPICS-MDS. This study will use Dutch tariffs to calculate the quality adjusted life years (QALYs) to obtain a utility score.

Personal information
Socio-demographics The following socio-demographics of both the persons with dementia as well as their caregivers are assessed: sex, age, education, marital status and cultural background. These questions are part of the TOPICS-MDS, module General Data (Lutomski et al., 2013). Additionally, the name of their general practitioner is also asked, so they can be informed about the participation in the study.

Personal functioning of person with dementia Personal functioning is measured with the modules Daily functioning and Social functioning of the TOPICS-MDS. This module consists of the Katz-15-ADL (Weinberger et al., 1992) and a question of the RAND-36 (Van der Zee & Sanderman, 1993).

Health of person with dementia The general health condition and the multimorbidity are assessed with the modules Health and Multimorbidity of the TOPICS-MDS. The latter consists of a list of 17 common diseases.

Psychological well-being of person with dementia The psychological well-being is measured with the module Psychological well-being of the TOPICS-MDS. This module consists of questions (5) of the RAND-36 (Van der Zee & Sanderman, 1993).

Quality of life of person with dementia The module Quality of life of the TOPICS-MDS is being used to measure the quality of life of the person with dementia. This module consists of two questions of the RAND-36 about quality of life in general and at this moment and a variant of Cantril's Self Anchoring Ladder in which persons are asked to rate their life on a scale from 1 to 10 (Van der Zee & Sanderman, 1993; Cantril, 1965).

Longer term outcome

Nursing home admittance The longer term outcome is (time to) admittance to a nursing home. This will be assessed for all participants in month 18 of the study together with the general practitioner.

Process evaluation

The intervention will be evaluated in two ways: a content analysis of Online Story Books and through qualitative interviews. Participants will be asked for renewed informed consent for this part of the study, after they constructed the Online Life Story Book, as they can only then judge whether or not they want to share it with the research team. A content analysis of twenty randomly chosen Online Life Story Books will be carried out.

Qualitative interviews will be conducted using an existing narrative method (Adler et al., 2008). after the study has been completed. Stakeholders (professionals (care manager, psychologist, coordinator of volunteer work, social worker), volunteers, participants and their informal caregivers) will be asked to provide stories about specific moments before, during, and after the intervention. Each interview will last about 1 h.

Next to the content analysis and interviews, at T1 and T2 participants are asked questions regarding:

Reminiscence Activities In order to ascertain whether persons in the control group did not create an online life story book or have undertaken similar activities during the study, the informal caregivers are asked a question about which reminiscence activities the person with dementia has undertaken.

The use of the Online Life Story Book Participants are asked how often and how long the book in general and the online version of the book is used.

Statistical analyses

Descriptive statistics

First, a CONSORT flow diagram will be made that shows the flow of the participants as well as the number of participants and the reasons for dropping out of the intervention or the study. Descriptive analyses will provide insights in the major characteristics of the persons with early dementia and the informal caregivers that participated in the study. These include personal information and functioning (TOPICS-MDS), neuropsychological complaints (NPI), caregiver burden (NPI and EDIZ) as well as quality of life of the person with dementia (EQ5D + Cognitive) and the caregiver (CarerQol). Comparison with existing data of the TOPICS-MDS will give more information about the group that was actually reached.

Randomization check

Chi-square tests and t-tests will be used to check whether the randomization has succeeded in terms of personal information and functioning (TOPICS-MDS), neuropsychological complaints (NPI), caregiver burden (NPI and EDIZ), quality of life of the person with dementia (EQ5D + Cognitive), and quality of life of the caregiver (CarerQol). When significant differences are found at baseline, we will assess whether these attenuate the outcomes later in time. If that is the case, we will control for these confounding variables in later analyses on the effects of the intervention.

Missing values

Multiple imputation (five data sets) will be used to replace missing values and carry out the analyses on the pooled data set. Hence, all participants who were randomized can be included in the statistical analyses. The results from this imputed intention-to-treat sample will be compared to the results of the observed data only.

Effects

To analyze the effects on the primary outcome (total neuropsychiatric symptoms), repeated measures MANOVA will be used to assess the group differences across time. The condition (intervention vs. control) is the independent variable and the outcome measures across the three measurements are the repeated dependent variables. Simple contrasts will be used post-hoc to compare the post-intervention and follow-up measures with the pre-intervention measures. Effect sizes at post-intervention and follow-up will be calculated as Cohen’s d. Effect sizes between .56 and 1.2 are interpreted as large, between .33 and .55 as moderate, and below .33 as small (Lipsey & Wilson, 1993).

We will also tentatively study the effects of the intervention on the four clusters of neuropsychiatric symptoms (hyperactivity, psychosis, affective symptoms, and apathy). As these measures are often not normally distributed, we will use a dichotomized outcome (clinically relevant symptoms or not, based on a FxS score of 4 and higher) (Aalten et al., 2003). We will carry out four logistic regression analyses with condition (intervention versus control) and presence of clinically relevant symptoms within the respective clusters at baseline as independent variables and presence of clinically relevant symptoms at follow-up as dependent variable. The odds-ratios will be used to provide estimates of the effect sizes in terms of Cohen’s d.

For the secondary outcome measures, three repeated measures MANOVA’s will be conducted, similar to the analysis for the primary outcome. The effect sizes will be given in Cohen’s d.

Health-economic evaluation The preliminary health-economic evaluation will be done from a healthcare perspective. It is expected that the costs of the intervention will be earned back through the reduction in care consumption. The health-economic evaluation will be carried out according to the intention-to-treat principle. Bootstrapping techniques with 95% confidence intervals will be used to compare the differences in costs between the intervention and the control condition. The incremental cost-utility ratios (ICERs) will be computed. These indicate the extra costs per QALY (measured with the EQ5D + C) gained. A sensitivity analysis will be conducted to assess the robustness of the results by assessing the mean costs (plus or minus a standard deviation) for the most important expenses.

Nursing home admittance The longer term effect of (time to) nursing home admittance will be analysed by comparing the intervention and control condition in a Cox's hazard regression analysis.

Process evaluation A *content analysis* of twenty randomly chosen Online Life Story Books will be carried out. The analysis focuses on aspects of life stories and autobiographical memories that are known to be related to mental health (Westerhof & Bohlmeijer, 2014): the number of memories, the specificity of the memories (memories that refer to events that took place on a single day are considered specific memories), the variance of memories across life domains (family, friends, work, care, and household, leisure, health, historical events), the variance across life phases (childhood, adolescence, young adulthood, middle adulthood, older adulthood) and the variance across media (text, photos, movies, sounds, music). The codes will be quantified into a measure of the complexity of the Online Life Story Book. Descriptive statistics of the complexity measure as well as its correlation with change in neuropsychiatric symptoms between baseline and follow-up will be calculated.
Qualitative interviews will be analysed through story line analysis (Murray & Sools, 2014). Story line analysis allows assessing the most important personal values that are at stake in a story. A qualitative description of its results will be provided.

DISCUSSION

The first strength of this project is that the Online Life Story book is an intervention that builds on existing knowledge about reminiscence (Westerhof et al., 2010). The last decade there is more evidence that reminiscence interventions are effective in improving cognitive functions and in decreasing feelings of depression in persons with dementia (Huang et al., 2015). Life story books are often used as a tool to ease the process of recollecting autobiographical memories. However, little is known about the effects of using a life story book as reminiscence therapy for people with early dementia. We are conducting an RCT for persons with early dementia or mild cognitive impairment so that they can contribute to the book themselves. The OLSB utilizes the natural process of recollecting memories and stimulates this process. It is known that in an early stage of dementia, people can still retrieve and share memories from the past (Dempsey et al., 2014; Caddell & Clare, 2010). However, our research focuses on a relatively short time period of 6 months. Some effects or changes, especially in care consumption, might only take place later in time, also because care institutions do not quickly adjust their provisions. An important question for future research is also how the competence to retrieve autobiographical memories changes over the course of the disease and how the book can be used to stimulate memory recollection when persons with dementia have less control over this process.

Another strong aspect of this project is that the OLSB intervention nicely ties in with changes in care systems promoting persons with dementia to be living at home for a longer period. Professional support will not follow this trend, so persons with dementia will depend more and more on informal caregivers and volunteers. We expect that the OLSB not only contributes to the NPS and quality of life of the person with dementia living at home, but also to the care burden and quality of life of informal caregivers. The current study mainly focuses on the effects for persons with dementia and their caregivers. Important questions for future research are how the intervention affects the well-being for volunteers and how the deployment of volunteers can be made sustainable when the intervention is implemented on a larger scale.

A third strength of the OLSB is the use of technology. Technology plays an important role in society – and dementia care – and the use of technology also fits the increasing competences of older persons to use computers and the internet (Van Deursen & Van Dijk, 2015). People do not only receive a tangible book at the end but the lasting online exemplar will be available and gives the persons the opportunity to adjust its content as well as to use the multimedia sources to stimulate memory retrieval (e.g. watching a movie or listening to a specific song that is included in the book). Another advantage of the technology in the OLSB is the opportunity for nearest and dearest to give input and work along on the life story from a distance. Although we provide participants with a manual for the use of the OLSB, it will be important to monitor in future studies the actual use of the OLSB, for example by analyzing log data. The technology would also make it possible for professional caregivers to learn more about the life stories of the persons with dementia. This may support them in providing person-centered care. The OLSB can improve the relationship between care staff and persons with dementia and can contribute to fulfilling the needs of the client. These possibilities of technology ask for further research on how professionals should obtain access to the OLSB and how they can make use of the OLSB in their everyday care.

Most of the studies conducted in this research area consist of small samples (Woods et al., 2005; Huang et al., 2015). Our study is the first to carry out an RCT on an online life story book among persons with dementia living at home. The study closely follows everyday care practices in its recruitment. To reach the targeted number of participants it will be of great importance to work closely together with the partners to make sure that every potential channel for recruitment is being used. As the 'online' aspect might generate resistance among those who do not have much experience with computers, we stress that the participants receive a hard copy of the book and that they can leave the online tasks to the volunteer. People might also be reluctant to admit their cognitive complaints. We try to overcome this possible threshold by a positive recruitment strategy that focuses on the value and potential of the OLSB, rather than on the complaints. To gain insight in the recruitment procedures, we will keep track of the success of the recruitment. Furthermore, we will compare our sample to the Dutch population with dementia, based on data of the TOPICS-MDS, in order to gain more knowledge about the participants we reached. This is also important as the study is carried out in only one region (the eastern part of the Netherlands).

If proven to be effective, the Online Life Story Book may be offered as a standard intervention for persons with early dementia, living at home. As a follow up project, we want to address the implementation process of the Online Life Story Book in (care) practice.

The Online Life Story Book

a randomized controlled trial on the effects of a digital reminiscence intervention for people with (very) mild dementia and their informal caregivers

4

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ABSTRACT

This paper describes a randomized controlled trial on the Online Life Story Book (OLSB), a digital reminiscence intervention for people with (very) mild dementia living at home. The aim of the study was to investigate the effectiveness of the OLSB on (i) neuropsychiatric symptoms (NPS) in persons with dementia and (ii) the distress and quality of life (QOL) of primary informal caregivers. A randomized controlled trial with individual randomization to one of two conditions was conducted: 1) intervention "Online Life Story Book"; 2) wait list control condition. In the intervention OLSB, a trained volunteer guided the participants through the process of creating an OLSB in approximately 5 meetings within a period of 8–10 weeks. Participants in the control condition received care as usual while they waited for 6 months before starting. Outcomes on NPS and distress and QOL of the informal caregiver were assessed at baseline (baseline, T0), 3 months (T1) and 6 months (T2) post baseline. Of the 42 persons with dementia, 23 were female and 19 were male. They had a mean age of 80 years, ranging from 49 to 95. The total drop-out rate was 14.3 percent. Small but insignificant effects on NPS, caregiver distress and QOL of caregivers were found with the exception of self-rated caregiver distress that reduced significantly during the intervention. One reason to explain the results might be that the included participants were in relatively good health. Practical challenges during the intervention could have affected the results as well. It might also be that the intervention caused effects on other outcomes than NPS and caregiver distress. In future research, it is important to study the effects in persons with more complaints and higher distress and to be careful in the selection of outcome variables in relation to the reminiscence functions served by the intervention.

INTRODUCTION

As there is still no treatment for dementia, dementia care mainly focuses on maintaining quality of life and reducing psychosocial problems (Koopmans et al., 2009). The most applied non-pharmacological care consists of behavioral interventions for persons with dementia as well as their caregivers and care environment in order to reduce – and respond to – behavioral changes due to dementia and accompanying neuropsychiatric symptoms (NPS) (Magai et al., 2002; Cohen-Mansfield, 2001; Brodaty et al., 2003; Mittelman et al., 1996). NPS have a high prevalence amongst persons with dementia (Borsje et al., 2015). Dementia and the related NPS not only affect the quality of life of persons with dementia, but also lead to a higher level of distress and a lower quality of life of informal caregivers (Conde-Sala et al., 2016; Peeters et al., 2014; De Vugt et al., 2003). This distress includes physical, emotional and economic aspects (WHO, no date). NPS are among the most important reasons for nursing home admittance, as they often make the care at home too burdensome (Gaugler et al., 2009). A systematic review of Olazarán and colleagues shows that NPS can be substantially diminished by behavioral interventions (Olazarán et al., 2010). It is important that such behavioral interventions are person-centered, so that they can meet the needs of persons with dementia and their informal caregivers (Van der Roest et al., 2009). This paper describes a randomized controlled trial on such a person-centered behavioral intervention for people with (very) mild dementia: the Online Life Story Book (OLSB).

Reminiscence, which involves the active retrieval of personal memories, is a person-centered behavioral approach (Westerhof & Bohlmeijer, 2014). Personal memories are shaped by the autobiographical memory system, which remains intact for a relatively long time despite the progress of the disease (Dempsey et al., 2014; Caddell & Clare, 2010). Previous research has shown that reminiscence activities can contribute to the mental health and quality of life of persons with dementia (Huang et al., 2015; Blake, 2013; Subramaniam & Woods, 2012; Woods et al., 2005). The creation of a life story book (LSB) is a common approach in reminiscence McKeown et al., 2006). Important life events, milestones and specific precious personal memories can be included in a LSB. A recent systematic review on LSBs for people with dementia shows an increase in studies in this field and first effects on autobiographical memory, mood, quality of life and relationships (Elfrink, Zuidema et al., 2018). It also gave insight in the diversity of approaches to create a LSB. For example, the LSBs were created mostly in on average six individual sessions in nursing home settings with a range from 3 to 16 sessions. Whilst some studies only focused on the person with dementia, others also examined (in)formal caregivers and found potential effects on the caregiver distress and quality of life.

Only three of the most recent studies incorporated a form of technology: one consisted of a movie and the other two of (basic) digital applications with pictures and sounds. This systematic review seems to confirm the previous conclusion of Lazar and colleagues that using technology in reminiscence interventions is promising, but that there is a lack of systematic studies (Lazar et al., 2014).

The Online Life Story Book (OLSB) is a new reminiscence intervention that allows the user to digitally share memories using multimedia and multisensory cues which might become more important to elicit memories when the disease progresses (Lazar et al., 2014). Next to the novelty of using technology, our current project is one of the first to conduct an RCT that examines a LSB intervention in the home situation and involves trained volunteers who support creating the digital LSBs. Moreover, effects on the person with dementia as well as their informal caregivers are assessed. Hence, the aim of this study was to investigate the effectiveness of the OLSB on neuropsychiatric symptoms in persons with (very) mild dementia and the distress and quality of life of their primary informal caregivers.

METHODS

Design

A two-arm randomized controlled trial with individual randomization and three measurements at baseline (T0), 3 months (T1) and 6 months (T2) after baseline was conducted. A detailed description of the study design, intervention and outcome measures is published in a research protocol (Elfrink et al., 2017). This study has been approved by the Twente Medical Ethics Committee under the file number p16-04 (Dutch Trial Register: NTR5939, date of registration: 14 March 2016).

Experimental condition: Online Life Story Book

The Online Life Story Book is an e-health application that allows placing personal memories on a dynamic timeline. The timeline is easily marked with historical years and expands as more memories are added. Memories like life events, anecdotes, photos, movies, voice fragments, music, recipes, preferences, and activities can be placed on the timeline. The initial application that was used in this study was developed by Hellomydear. Since this application – unexpectedly – was no longer available during the last couple of months of the study, some participants had to switch to another application. We used Albelli, a commercial application that can be used to create several kinds of photo albums. In Albelli, no timeline is generated, but books were still made in chronological order. Both applications allowed to print the online books. QR-codes made it possible to access the online multisensory memories.

The website of Hellomydear is no longer operational.

Trained volunteers supported the persons with dementia and their caregivers (in the following referred to as dyad) in making the OLSB. This is more cost-effective for care institutes and easier to organize compared to care provided by professionals like psychologists (Westerhof et al., 2018). Furthermore, an intervention delivered by a volunteer instead of a care professional can be less stigmatizing, as volunteers provide a contact with society rather than with health care professionals Westerhof et al., 2008). The volunteers visited the dyads approximately five times within a period of 8–10 weeks. The volunteers followed communication guidelines with regard to dementia and reminiscence. They asked dyads about specific milestones and important memories, and nudged them to tell about it as explicit as possible. The volunteers tried to get a variety of memories from different phases of life. Persons with dementia and their family members collected materials that the volunteer digitized when necessary and uploaded in the OLSB.

Thirteen volunteers – 9 women and 4 men – were recruited through local organizations in care and social work. Their age ranged from 28 to 60 years. They had different professional backgrounds in either health care, social work, or technology. The volunteers received four hours training on reminiscence, dementia, conversation techniques, and on how to use the application. The training was led by TE, CU and a senior psychologist. After the switch in application, volunteers were retrained to use the new application and given an updated manual with instructions. During the intervention, volunteers could ask questions and share their experiences via telephone or email or at monthly supervision meetings (led by TE and CU). By excluding persons with a past psychotrauma, having all conversations with both the person with dementia and their informal caregiver so they would feel more safe, and the possibility for the volunteers to consult the researchers and a senior psychologist during the intervention, the potential for distress for the person with dementia was accounted for.

Control condition: Wait list with care as usual

The dyads in the control condition received care as usual and were offered to create an OLSB after a period of six months. They were handed out an information letter with possible support and activities for persons with (mild) dementia in the region of Twente. In the Netherlands, usual care for persons with mild dementia consists of care provided by the general practitioner, case management (by the general practice or a nurse practitioner), medication (if indicated) and access to formal care. During this study, no restrictions were placed regarding the care or support dyads requested for.

Participants

Each person with dementia was accompanied by an informal caregiver; together they formed a dyad.

Recruitment and setting. Persons with (very) mild dementia living at home in the region of Twente and being cared for by an informal caregiver were included. The dyads were recruited through local organizations that work with persons with dementia and their informal caregivers (care and social work; general practitioners; memory clinic; informal meetings with peers). Furthermore, articles in local newspapers and door-to-door papers, and a promotional video were used.

Inclusion and exclusion criteria. In order to be eligible to participate in this study, a person with dementia had to meet the following criteria: (1) living at home and receiving informal care; (2) having (very) mild dementia (scoring 0.5 or 1 on the Clinical Dementia Rating (CDR) (Morris, 1993)); (3) being mentally capable to provide informed consent (assessed by researcher during intake). A potential participant was excluded when past psychotrauma was present (assessed with the module posttraumatic stress disorder of the Mini International Neuropsychiatric Interview (MINI) Sheehan, 1998)).

Power analysis. A small effect was expected for the primary outcome at follow-up (Subramaniam & Woods, 2012; Woods et al., 2005).

The power calculation indicated 74 participants (GPower: f = 0.15; alpha = .05; power = .80; repeated measures ANOVA with 2 groups and 3 measurement points; r = .50 between measurements). Given the vulnerability of the participants and a high mortality rate, a drop-out of 30% was expected Blake, 2013; Subramaniam & Woods, 2012; Woods et al., 2005). Hence, 106 participants needed to be included, 53 per condition.

Procedure

Most people were approached by informed care professionals who brought them into contact with the researchers. The persons with dementia or informal caregivers who were interested in the project or care professionals who knew people who might be eligible, sent their contact information to the primary investigator (TRE). Then, an information letter about the aim of the project, the eligibility, the process of participation, the benefits and investment of participating, data-management and contact information was sent and an intake was planned. The intake as well as all further meetings for data collection took place at the participants home and were conducted by the researchers. During intake, the project was explained again, questions were being answered and if the participant was still willing to participate, an informed consent was signed (by both the person with dementia and the informal caregiver). This took about 30–40 minutes. Directly after the participant was screened on the inclusion and exclusion criteria, the baseline (T0) measurement was assessed. The total duration of the three assessments was estimated between 90–120 minutes, for both the person with dementia and the informal caregiver.

Eligible dyads were randomized to either the intervention or the wait list control condition. The random allocation sequence was created a priori by a computer-generated randomized number list with stratification on gender of the person with dementia (randomizer.org). When randomized to the experimental group, a volunteer was assigned to the dyads. When allocated to the wait list control group, a volunteer was assigned six months after intake after all study measurements had ended. The first inclusion measurement was assessed in June 2016 and the last measurement took place in December 2017. The trial ended because the project lasted from February 2016-February 2018, so all data needed to be gathered before February 2018.

From both an ethical and practical point of view, it was impossible to keep the dyads blinded to the allocation. As stated above the persons in the wait list control condition received care as usual and were handed out an information letter with possible support and activities for persons with (mild) dementia in the region.

Measures

Characteristics of participants. The sociodemographic and health characteristics of the participants were assessed with parts of The Older Persons and Informal Caregivers Survey Minimum DataSet (TOPICS-MDS (Lutomski et al., 2013). The following socio-demographics of both the persons with dementia and their informal caregivers were assessed: sex, age, education, and marital status. Health for persons with dementia was measured with a questionnaire on the presence or absence of 17 common diseases; the Katz-15-ADL that asks for the need for support for activities of daily living; a question of the RAND-36 that measures interference of physical and emotional problems with social activities; a single question on subjective health; five questions of the RAND-36 that measure psychological well-being; one question of the RAND-36 about quality of life in general; and a variant of Cantril's Self Anchoring Ladder in which persons were asked to rate their life satisfaction on a scale from 0–10 (Weinberger et al., 1992; Van der Zee & Sanderman, 2002; Cantril, 1965). Health for informal caregivers was measured only with a single question on subjective health.

Primary outcome. *Neuropsychiatric symptoms* (NPS). To assess the effect of the intervention on the primary outcome, neuropsychiatric symptoms, the Neuropsychiatric Inventory (NPI) was assessed at all three time points in all participants (Cummings et al., 1994; De Jonghe et al., 1997). The NPI is a reliable and valid measure that assesses the frequency, severity and distress of twelve neuropsychiatric symptoms: delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability, motor disturbance, nighttime behaviors, and appetite/eating. The frequency (F) is provided on a scale from 0 = never to 4 = daily, the severity (S) on a scale from 0 = not to 3 = severe. The score for each of the twelve symptoms is computed as the frequency multiplied by the severity, resulting in a score ranging from 0 to 12. An FxS score of 4 or higher is considered as clinically relevant. The scores on the individual symptoms were also summed towards scores on four symptom clusters: hyperactivity, psychosis, affective symptoms, and apathy (Aalten et al., 2003). Last, the twelve FxS scores were added to a total score (0–144 (Aalten et al., 2003)). For the NPI symptom clusters and the total score there is no clinical cut-off score, because of the many disparate behaviors (Cummings et al., 1994).

Secondary outcomes. *Caregiver Distress. General caregiver distress* was measured with a scale on the perceived distress in informal care (EDIZ (De Boer et al., 2012)). The informal caregiver rated the subjective distress on nine items with a five-point scale. The answers were dichotomized per item (no! and no = 0; more or less, yes and yes! = 1) and then added up to a score between 0 and 9.

Caregiver distress due to neuropsychiatric symptoms was measured with the distress scales of the NPI (Cummings et al., 1994; De Jonghe et al., 1997). The caregiver rated the distress for each of the twelve neuropsychiatric symptoms on a scale from 0 = none to 5 = severe. These twelve distress scores were summarized to a total score, ranging from 0–60. This sum score provides an indication of the emotional distress caused by all neuropsychiatric symptoms.

The questions on Distress and Time investment of the TOPICS-MDS were used to assess caregiver distress (Lutomski et al., 2013). *The self-rated distress* was measured with a single question where caregivers rated the distress of care to the person with dementia on a scale from 0 to 100. The *time investment* is the total hours per week that the informal caregiver spent to assist the person with dementia with household tasks, personal care, and moving outside the house.

Quality of life of the caregiver. The quality of life was assessed with parts of the TOPICS-MDS (Lutomski et al., 2013). The *care-related quality of life* of the caregiver was measured with the CarerQol, which consists of seven questions that are rated on a three-point scale (1 = none to 3 = many) as well as a visual analogue scale on happiness ranging from 0 to 10 (Brouwer et al., 2006). *The general quality of life* of the caregiver was assessed with a question of the RAND-36 and life satisfaction was measured with a variant of Cantril's Self Anchoring Ladder, in which persons were asked to rate their life on a scale from 1–10 (item: '*What grade do you give your life at the moment?*') (Van der Zee & Sanderman, 2002; Cantril, 1965).

Statistical analyses

All statistical analyses were performed using SPSS 25.0 (IBM SPSS Statistics). All tests were two-tailed using a 95% confidence interval. First, frequency distributions were made of all sociodemographic and health characteristics as well as the baseline assessments of neuropsychiatric symptoms, caregiver distress, and caregiver quality of life. Second, in order to assess the success of the randomization, the baseline characteristics between the two conditions were analysed with x2 tests and t-tests. Third, to assess selective drop-out, x2 tests and t-tests were used to compare persons who did or did not complete the whole study.

To analyze the primary and secondary outcomes of the intervention, we used a mixed model analysis that allows to take all existing information into account, even in spite of the fact that some participants dropped out. A random within-subjects effect was modeled as a repeated measure with correlated residuals. We specified two fixed factors: condition (intervention versus control) and time (baseline, 3 months, 6 months). Because of the differences between the two applications we also conducted analyses with three condition levels (Hellomydear, Albelli, and control). We tested several covariance types for the within-subjects factor and used the model fit (Akaike Information Criterion and Baseysian Information Criterion) to find the best fitting type. This was either the unstructured or the heterogeneous first-order autoregressive type. We report the expected marginal means and used those at six months follow-up to compute the Cohen's d between the conditions (below .33 is interpreted as small; between .33 and .55 is moderate; above .55 is large) (Lipsey & Wilson, 1993). We also carried out repeated measures analyses (General Linear Model) with completers only, with 'time' as within subject factor, 'condition' as between subject factor as well as the interaction between the two. As these analyses showed the same significant findings, we decided to only report the results of the mixed model analyses.

RESULTS

Participant flow

Figure 1 presents the details on the participant flow. Of the 47 participants assessed for eligibility, 42 were included and randomized. One person was excluded because of no dementia (CDR score of 0) whereas three were excluded because of too severe dementia (CDR score above 1). Before randomization, one informal caregiver reported a too high burden for the person with dementia to take part in the study.

The actual drop-out of participants during the entire project was 14.3 percent. There was no significant difference between the intervention and the control condition (x2 (1) = 0.4; p = .527). Of the 23 participants randomized to the intervention condition, four (17.4%) did not complete the intervention and the study, because of several reasons: one had a fast cognitive decline, so it would be too much of a burden to create the online life story book; one had to wait for too long to be assigned to a volunteer; one changed his mind because he found it too private to share memories; and one person passed away before the follow-up measurement. Of the 19 participants allocated to the control condition, two (10.5%) did not complete the measurements at three and six months, because of a too high burden for the informal caregiver and the participant.

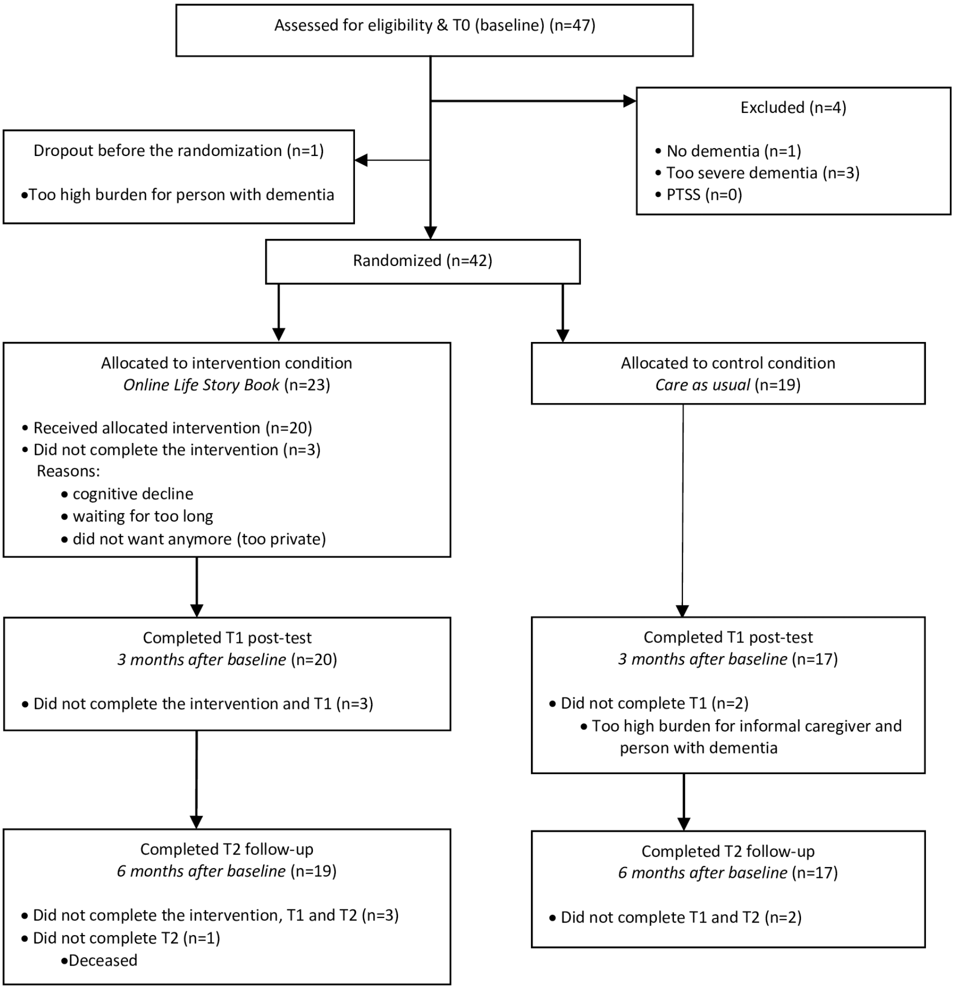

Figure 1 - Participant flow

Participant characteristics

Persons with dementia. Table 1 presents the baseline characteristics of the persons with dementia. Of the 42 participants, 23 were female and 19 were male. They had a mean age of 80.6 years (SD = 9.4), ranging from 49 to 95 years. Fifty percent had finished primary or lower vocational education, 30% secondary or middle vocational education, and 20% higher education. Participants were married (69%) or widowed (31%). They had very mild (26%) or mild dementia (74%) according to the clinical dementia rating scale. They indicated on average to have 4.1 (SD = 1.8) out of 17diseases and to need help on 6.9 (SD = 4.0) out of 15 domains of functioning. Their social activities were sometimes impeded because of physical or emotional problems (mean = 3.2; SD = 1.2; scale 1–5 with 1 being continuously impeded and 5 being never). Their subjective health was rated as moderate to good (mean = 2.5; SD = 0.8; scale 1–5); their psychological well-being score was on average 23.6 (SD = 3.3; scale 5–30); their life satisfaction was 7.5 (SD = 1.0; scale 0–10); and their self-rated quality of life was good (mean = 3.0; SD = 0.9; scale 1–5). With regard to the primary outcome measure, they scored on average 9.2 (SD = 10.1; scale 0–144) on the frequency by severity scale of the Neuropsychiatric Inventory. For hyperactivity, the average score was 0.6 (SD = 1.0), for psychosis 0.6 (SD = 0.8), for affective symptoms 1.1 (SD = 1.3) and for apathy 1.1 (SD = 1.7). Few participants scored above the cut-off for clinically relevant complaints (0 on delusions, 0 on hallucinations, 4 on agitation/aggression, 2 on depression/dysphoria, 3 on anxiety, 1 on elation/euphoria, 4 on apathy/indifference, 2 on disinhibition, 4 on irritability/lability, 4 on motor disturbance, 5 on nighttime behaviors, and 9 on appetite/eating). However, 48% of the participants with dementia had clinically relevant symptoms on at least one of the twelve symptoms.

Table 1. Demographical data and personal information of persons with dementia at baseline

Variable	**All (N=42)**	**OLSB (N=23)**	**Control (N=19)**	**t/ x (df)**
Age, mean in years (SD)	80 (9.4)	79.5 (8.1)	81.2 (11.2)	0.6 (40)[a]
Female N (%)	23 (55.8%)	16 (69.6%)	7 (30.4%)	4.5 (1)[a]
Educational level N	40	22	18	
Primary and lower vocational education	20 (50.0%)	13 (59.1%)	7 (38.9%)	1.9 (2)[b]
Secondary and middle vocational education	12 (30.0%)	6 (27.3%)	6 (33.3%)	1.9 (2)[b]
Higher education	8 (20.0%)	3 (13.6%)	5 (27.8%)	1.9 (2)[b]
Marital status				
Married	29 (69.8%)	14 (60.9%)	15 (79%)	1.6 (1)[b]
Widowed	13 (30.2%)	9 (39.1%)	4 (21%)	1.6 (1)[b]
Cultural background				
Born in the Netherlands	39 (93%)	21 (91.3%)	18 (94.7%)	0.2 (1)[b]
Born abroad	3 (7%)	2 (8.7%)	1 (5.3%)	0.2 (1)[b]

Note.

[a] No significant differences between intervention and control condition (t-test with p> 0.05)

[b] No significant differences between intervention and control condition (x2-test with p> 0.05)

* Significant differences at baseline between both groups (p< 0.05).

Informal caregivers. Table 2 presents the baseline characteristics of the informal caregivers. Of the 42 informal caregivers, 31 were female and 11 were male. They had a mean age of 62.8 years (SD = 13) ranging from 38 to 88 years. Twenty of the informal caregivers were a spouse who lived together with the person with dementia, whereas twenty-two were family members, such as a child, niece or nephew, who did not live together with the person with dementia. Their subjective health was good to very good (mean = 3.4; SD = 1.0; scale from 1–5). With regard to the measures of caregiver distress at baseline, their general distress was on average 4.0 (SD = 2.5; scale from 0–9), the average distress due to neuropsychiatric symptoms was 5.9 (SD = 6.1, scale 0–60), and the average self-reported distress was 39.7 (SD = 26.9; scale 0–100). Caregivers spent on average 11.8 hours per week (SD = 15.2) caring for the person with dementia. With regard to caregiver quality of life, they rated their quality of life at baseline as good to very good (mean = 3.7; SD = 0.9; scale from 1–5) and their average life satisfaction as 7.5 (SD = 1.2 on a scale from 0–10

Table 2. Demographical data of informal caregiver

	All (N=42)	**OLSB (N=23)**	**Control (N=19)**	**t/ x (df)**
Age, mean in years (SD)	63 (13)	63 (13)	63 (14)	0.1 (36)[a]
Female N (%)	31 (73.8)	15 (65.2)	16 (84.2)	1.9 (1)[b]
Spouse and living together	20 (47.6)	12 (52.2)	8 (42.1)	0.8 (2)[b]
Health, 1-5 (SD)	2.5 (1.0)	2.6 (1.0)	2.5 (1.0)	-0.1 (40)[a]

Note.
[a] No significant differences between intervention and control condition (t-test with p> 0.05)
[b] No significant differences between intervention and control condition (x2-test with p> 0.05)

Randomization check. Except for the gender of the person with dementia, there were no significant differences between the intervention and control condition on any of the demographic and health variables of the persons with dementia and their caregivers (all x2 tests and t-tests had p>.05). There were also no significant differences in the total baseline scores and the four domain baseline scores of neuropsychiatric symptoms between the intervention and the control condition (t-tests with p>.05). Last, there were no significant differences in any of the measures of distress or quality of life of the caregivers at baseline (t-tests with p>.05).

Drop-out analyses. There were no significant differences between the persons who did (n = 36) or did not (n = 6) complete all study measurements on any of the demographic and health variables of the persons with dementia and their caregivers (x2 tests and t-tests with p>.05). There were also no significant differences in neuropsychiatric symptoms at baseline, nor in caregiver distress or caregiver quality of life at baseline (t-tests with p>.05). In sum, there was no selective drop-out.

Primary outcome

Table 3 presents the estimated marginal means of the mixed model analyses for the primary outcome neuropsychiatric symptoms. There were no significant effects of time, condition, or their interaction. The significant difference in gender of the person with dementia between the two conditions at baseline did not affect these outcomes: no significant effects of time, condition, or their interaction were found. As not all participants in the intervention condition received the same kind of online life story book, we also carried out a mixed model analysis on three conditions (Hellomydear, Albelli, and control). Again, there were no significant effects of time, condition, or their interaction. When analyzing the different clusters of neuropsychiatric symptoms

Table 3. Results on primary outcome neuropsychiatric symptoms (estimated marginal means)

		Baseline Mean (SE)	3 Months Mean (SE)	6 Months Mean (SE)
Neuropsychiatric Symptoms	Intervention	8.7 (2.4)	9.8 (2.5)	12.2 (2.6)
	Control	9.8 (2.7)	13.6 (2.7)	12.5 (2.8)
Neuropsychiatric Symptoms	Hellomydear	8.8 (3.4)	7.3 (4.0)	13.4 (4.3)
	Albelli	8.6 (2.8)	11.9 (3.4)	10.9 (3.8)
	Control	9.8 (2.4)	13.6 (2.8)	12.5 (3.1)
Hyperactivity	Intervention	3.4 (1.1)	4.4 (1.3)	4.3 (1.7)
	Control	3.0 (1.0)	3.3 (1.2)	4.0 (1.6)
Psychosis	Intervention	1.2 (0.5)	1.9 (0.7)	0.9 (0.4)
	Control	2.1 (0.5)	1.7 (0.6)	1.5 (0.4)
Affective Symptoms	Intervention	4.7 (1.2)	6.6 (1.4)	5.8 (1.3)
	Control	4.4 (1.1)	4.6 (1.3)	6.1 (1.2)
Apathy	Intervention	5.1 (1.5)	6.4 (1.6)	6.1 (6.1)
	Control	3.5 (1.4)	5.1 (1.4)	7.0 (1.6)

No significant differences

Table 4. Results on secondary outcomes caregiver distress and caregiver quality of life (estimated marginal means)

		Baseline Mean (SE)	3 Months Mean (SE)	6 Months Mean (SE)
General distress	Intervention	3.8 (0.5)	3.8 (0.6)	3.9 (0.6)
	Control	4.1 (0.6)	3.3 (0.7)	3.5 (0.7)
Distress neuropsychiatric symptoms	Intervention	5.5 (1.3)	5.4 (1.5)	6.6 (1.8)
	Control	6.4 (1.4)	7.3 (1.6)	7.7 (1.9)
Self-rated distress	Intervention	38.9 (5.8)	31.8 (5.9)	44.7 (6.1)
	Control	40.7 (6.3)	41.4 (6.5)	41.1 (6.5)
Time investment	Intervention	12.3 (3.2)	13.9 (3.7)	16.7 (4.8)
	Control	11.3 (3.5)	13.2 (4.1)	10.7 (5.3)
Care-related quality of life	Intervention	17.5 (0.5)	17.5 (0.6)	17.2 (0.6)
	Control	17.1 (0.6)	17.7 (0.7)	17.6 (0.6)
General quality of life	Intervention	2.5 (0.2)	2.5 (0.2)	2.5 (0.2)
	Control	2.8 (0.2)	2.9 (0.2)	2.8 (0.2)
Life satisfaction	Intervention	7.7 (0.2)	7.8 (0.2)	7.5 (0.3)
	Control	7.4 (0.3)	7.6 (0.3)	7.5 (0.3)

* p<.05

6 Months Cohen's d	Condition F(1)	Time F(2)	Interaction F(2)
-0.03	0.3	1.9	1.1
0.09	0.1	1.6	1.8
-0.07			
-0.04	0.1	1.1	1.2
0.40	0.5	2.2	0.8
0.07	0.2	0.9	1.4
0.18	0.1	2.0	1.8

6 Months Cohen's d	Condition F(1)	Time F(2)	Interaction F(2)
0.20	0.1	1.1	1.6
-0.18	0.4	1.0	1.4
0.18	0.1	2.8	3.2*
0.37	0.2	1.0	1.3
-0.20	0.0	0.9	1.0
-0.43	1.8	0.0	0.0
-0.02	0.3	0.8	0.3

(Hyperactivity, Psychosis, Affective Symptoms and Apathy) separately, no significant differences were found for condition, time, or their interaction. All effect sizes were small at six months follow-up with the exception of the effect size for psychosis which was moderate.

Secondary outcomes

Table 4 presents the estimated marginal means of the mixed model analyses for the secondary outcomes caregiver distress and caregiver quality of life. With regard to the secondary outcome measures, only the interaction effect for self-rated distress is significant (F(2) = 3.2; p = .045). At three months follow-up caregivers in the intervention condition report somewhat less distress than caregivers in the control condition, but at six months slightly more. The effect sizes at six months follow-up are small with the exception of moderate effect sizes for time investment and general quality of life.

DISCUSSION

This study is one of the first to conduct an RCT to examine the effects of an Online Life Story Book created in the home setting by volunteers for people with (very) mild dementia and their caregivers. Contrary to expectations the results show no significant differences between the experimental condition and the wait list control condition with self-rated distress of informal caregivers being the only exception.

There could be several reasons to explain these results. To start with, persons with dementia reached in our study appeared to have few neuropsychiatric symptoms whereas caregivers did not perceive much distress and reported a relatively high quality of life compared to other studies with the same target group (Gonfrier et al., 2012; Froelich et al., 2009; Aalten et al., 2005; Cortes et al., 2005). This may have caused floor and ceiling effects so there was almost no room for improvement. The preventive effect of the OLSB could have become visible if an extra follow-up at 12 months was assessed, as normally NPS are expected to develop over the course of time. Related to this, our open recruitment may have led to reaching a specific group of persons with (very) mild dementia and their informal caregivers: only people that were initially motivated and felt capable enough to participate did sign up. The setting might have been important too: a meta-analysis on reminiscence therapy found greater improvement on depressive symptoms for institutionalized people with dementia than community-dwelling people with dementia and according to a recent Cochrane systematic review on reminiscence therapy for dementia the impact on quality of life appeared most promising in care home settings (Huang et al., 2015; O'Philbin et al., 2018). So it could be that it is harder to measure change in people with dementia living at home than in relatively more standardized and homogenous care home settings. Hence, the question remains how the intervention would have worked for people with more severe complaints, or who did not feel the competence to participate in such a project.

Next, outcomes might not have been significant because less persons participated than initially anticipated, even though the Cohens d corresponded to the small effect sizes that were assumed in the power analysis. Finding participants that suffered from i) mild dementia, ii) were living at home iii) had an informal caregiver that wanted to actively contribute iv) felt the space and competence and v) wanted to talk about personal matters appeared to be a real challenge. Despite the smaller number of participants, the drop-out during the intervention was substantial lower than expected, resulting in 85.7% completers versus the anticipated 70%.

The persons that withdrew, did so mostly because of reasons that were not related to the intervention itself. The switch in application could have biased the results as the time periods between baseline and T1 were extended for those dyads. However, only one person refrained because of waiting too long before the new application could be used. Most dyads did not mind the change in application to create the OLSB and controlling for type of application did not show any difference in significant levels over time. Having said that, the change was time consuming, people had to wait somewhat longer to start, or people who were already in the process of making the OLSB had to wait and start over with the new application.

Another reason for the unexpected outcome of no effect, could also be due to the kind of outcome variables that have been used. As can be seen in the review of Elfrink and colleagues, existing research on LSBs for persons with dementia focused on different types variables such as cognition, mood (depression), quality of life and communication/quality of caregiving relationship (Elfrink, Zuidema et al., 2018). Many of those variables have also been evaluated on their effectiveness in the Cochrane systematic review on reminiscence and dementia, but due to the diversity of study designs (group vs individual approach; care home vs home setting) and outcome measures a proper comparison was hard to make. That may have caused the small and inconsistent effects that the researchers found in their review (O'Philbin et al., 2018). Most of these outcomes have not been covered in our study, since we were especially interested in NPS and caregiver distress which can be seen as more distal outcomes, as it takes more time to see an effect in those variables. Nevertheless, we strongly believe that incorporating outcomes on caregiver distress and quality of life of the caregiver is a strength in our research since dementia not only affects the person with dementia but the family or system as a whole. In line with this, research has shown that reminiscence can have different functions (i.e. identity construction, problem solving, and death preparation, bitterness revival, boredom reduction, and intimacy maintenance, conversation and teaching or informing) and that is important to match these functions with the aim of the reminiscence intervention and consequently the outcome measures (Westerhof & Bohlmeijer, 2014). It could be that the OLSB predominantly serves the social functions and less explicitly the more therapeutic functions. To summarize, the question remains which kind of outcome variables should be included in reminiscence interventions for persons with dementia, how to assess them and what time-frame of measurement fits best for which variable.

Next to the effectiveness of this intervention it is also important to take a look into the usefulness and feasibility. For instance, it can be a real advantage that persons with dementia low on burden of disease – like in our study – are able to actively contribute to their own life story book, which may result in a more personal story of their own. The fact that there was a very low drop-out rate and that those dyads that withdrew did so mainly because of reasons that were not related to the intervention itself, would suggest that the dyads accepted the intervention.

Including experienced changes by those involved could help to get a better understanding of the potential benefits of reminiscence interventions. To gain better insight in the perceived efficacy and implementation from the perception of different stakeholders (participants, informal caregivers, volunteers and care professionals) a process evaluation was conducted parallel to this RCT. These complementary results will be described in a following paper (in preparation).

Conclusion

Despite the absence of significant effects on the use of an Online Life Story Book for people with (very) mild dementia and their informal caregivers, this study contributes to the research on LSBs and does provide valuable implications. It shows that in future research, it is important to study the effects in persons with more complaints and higher burden and to be careful in the selection of outcome variables in relation to the reminiscence functions served by the intervention.

Ethical approval

This study has been approved by the Twente Medical Ethics Committee under the file number p16-04 (Dutch Trial Register: NTR5939, date of registration: 14 March 2016). The study was carried out according to the principles of the Declaration of Helsinki (59th WMA General Assembly, Seoul, October 2008) and the Medical Research Involving Human Subjects Act (WMO).

Online Life Story Books

exploring the content of digital life story books for people with cognitive impairment

5

Elfrink, T. R., Ullrich, C., Kunz, M., Zuidema, S. U., & Westerhof, G. J.
Submitted

ABSTRACT

Background and objectives:
Creating a life story book seems to be a promising reminiscence intervention for persons with cognitive impairment. However, little is known about the nature of memories that are included in life story books. The goal of this exploratory content analysis of Online Life Story Books was to gain insight into the structure and content of memories that persons included in their digital life stories in order to see to what extent the books can stimulate reminiscence and to make implications lessons for future interventions.

Research design and methods:
Eight Online Life Story Books of Dutch people with cognitive impairment living at home were analysed for both the structure of the books and content of the memories.

Results:
Structure-wise, a book consisted on average of 75 memories that were each represented by approximately two photos and/or texts. Content-wise, the majority of the components were of a positive, recurrent nature from an unknown perspective, and fell under the themes of vacation, family or home. Most components belonged to the life phase from 45 to 64-years-old and were without text or of a descriptive nature.

Discussion and implications:
This content analysis showed that the created books were rich in both structure and content. Multiple characteristics of reminiscence were represented and the content seemed to fit with the social function of reminiscence. The exact content of (online) life story books is determined by the availability of (multimedia) materials, and the focus or choices of the volunteer, family and persons themselves.

BACKGROUND AND OBJECTIVES

The creation and use of a life story book – a well-known approach to support reminiscence – can enhance mood, quality of life, relationships, and autobiographical memory of persons with dementia (Elfrink, Zuidema et al., 2018; McKeown et al., 2006). A systematic review of studies on life story books in dementia care showed not only a variety of instruments, outcome measures, and sample sizes used, but also a variety of target groups, and type and characteristics across the fourteen included life story book interventions (e.g. being an individual or dyadic intervention and the number of sessions; Elfrink, Zuidema et al., 2018). One encouraging finding was that studies that used a form of technology (e.g. a digital application) showed that the users felt comfortable and motivated to work with digital life story books and that social interaction and communication with the professional caregiver was improved through the use of these digital life story books (Hashim et al., 2013; Hashim et al., 2015). However, there seems to be a dearth of information on the structure and content of created – digital and non-digital – life story books. In eight of the fourteen studies included in the review by Elfrink et al. (2018), the total number of pages and/or memories were rarely described. Furthermore, and most importantly, little was reported about the actual nature of the memories included in the life story books, e.g. the theme of the memory or when it took place. Therefore, what life story books actually contain and how they are structured remains undocumented and, to the best of our knowledge, is missing from the current research. Such insights into the content of (digital) life story books in dementia care and how this content could support the process of reminiscence has the potential to increase the effectiveness of such interventions.

The current article describes a content analysis of the Online Life Story Book (OLSB), a digital life story book intervention for persons with cognitive impairments and their informal caregivers that was executed at home.

The OLSB was invented as a reminiscence intervention, as defined by Westerhof et al. (2010) who extended the work of Haight and Burnside (1993). Westerhof and colleagues (2010) differentiate between reminiscence, life-review, and life-review therapy. Reminiscence is about retrieving and sharing memories, whereas the latter two focus on processing those memories as well. According to their categorization, the main aim of reminiscence is to enhance positive feelings and social interaction: *“The central activity [of reminiscence] is positive autobiographic storytelling that activates the social functions of reminiscence”* (p. 713). The social function implies that persons create and maintain social bonds by retrieving and sharing memories. Besides, it allows persons to get to know each other and pass on experience to others (Westerhof

& Bohlmeijer, 2021). The OLSB intervention was thus designed to include memories that can enhance the social function of reminiscence and/or the goal of stimulating positive feelings.

Several characteristics were found to be important for this goal, namely: addressing a wide scope of themes, including the person's whole lifespan, using multisensory cues, eliciting positive memories, stimulating specificity in memories, and reminiscing from the first-person perspective. The first characteristic is the scope of themes addressed during the recollection. There seem to be some universal themes used in reminiscence interventions as described in, for example, Stinson's Protocol for Structured Reminiscence (Stinson, 2009). Examples of these recurring themes are families, friends, school, work/home life, holidays, and love. The second characteristic is to focus on the whole lifespan from childhood to later life in order to help persons elicit memories about life phases which might not arise spontaneously (Bohlmeijer et al., 2011; Westerhof et al., 2010). The third characteristic is to prime the senses in a multisensory way; adding photographs, music, videos and text can support people in eliciting their personal memories (Lazar et al., 2014; Zhang & Ho, 2017). Next, the focus on specific, positive memories is of importance, as persons – especially those with psychological complaints such as depressive symptoms – are inclined to recall negative memories over positive, and general over specific ones (Ono et al., 2016; Serrano et al., 2004; Sumner et al., 2010). Recollecting specific positive memories can also reinforce self-identity, improve mood, and reduce both physiological and emotional consequences of acute stress (Blagov & Singer, 2004; Speer & Delgado, 2017). Lastly, assuming the first-person perspective is of importance when describing memories (Iriye & Jacques, 2020). Iriye and Jacques argue that describing a memory from the first-person perspective – from one's own eyes – can improve the vividness of the memory (and thereby strengthen the effect of reminiscence), compared to describing it from a third-person or observer-like perspective.

In order to enhance the social function of reminiscence, creating rich life story books (in terms of number of memories, themes, life phases, and multisensory elements) that are filled with specific, positive and vivid memories is of great importance. This content analysis explored what persons actually included in their OLSB, in order to gain insight into the extent to which the OLSB includes the characteristics of a reminiscence intervention and to see what lessons can be learned to improve future reminiscence interventions.

RESEARCH DESIGN AND METHODS

Design

This content analysis is part of a larger study on the effects and use of the OLSB. A randomized trial showed small but insignificant effects on neuropsychiatric symptoms, caregiver distress and the quality of life of the caregivers, and a significant reduction of self-rated caregiver distress during the intervention (Elfrink et al., 2021). More information on both the study and intervention can be found in the research protocol and the article on effectiveness (Elfrink et al., 2017; Elfrink et al., 2021). A content analysis of eight OLSBs was performed to explore what persons actually included in their life stories.

Intervention

The Online Life Story Book (OLSB) is an e-health application to compile memories in a digital manner. Memories can be added in the shape of a text, photo, movie or audio. The initial application that was used in this study was developed by Hellomydear, an organization in Belgium, in which memories could be placed on a dynamic timeline. Since this application was no longer available midway through this study, a switch to Albelli was made. This commercial application is freely accessible and is being used to create all kinds of albums, though no timeline is generated. Volunteers supported the persons with cognitive impairment and their informal caregivers (dyads) in creating the OLSB. All volunteers were trained to ask for specific rather than general memories across different themes and life phases of the participant. They could use a manual suggesting the following themes and life phases: young adulthood and family, adolescence and maturation, work and care, love and friendships, creativity and hobbies. To make the memories as vivid and specific as possible, volunteers were instructed to ask for any audio visuals that could support the memories and to ask follow-up questions (e.g. What did you do? Where? With whom?) A set up that was suggested (but not obliged) was as follows: The volunteer visited the dyads on average 5 times within a period of 8 to 10 weeks, after which the OLSB was completed. In the first meeting, a general timeline with important milestones could be created to serve as a foundation for the remaining conversations. In remaining four visits, the volunteer could then help the person to expand the number of memories and deepen them. Volunteers and participants could work chronologically, thematically, or via any other structure they preferred.

Participants and procedure

Participants were persons living at home, receiving informal care and having mild cognitive impairment (MCI) or (very) mild dementia – scoring 0.5 or 1 on the Clinical Dementia Rating (CDR, Morris, 1993). Persons with past psychotrauma – assessed with the module posttraumatic stress disorder of the Mini International Neuropsychiatric Interview (MINI, Sheehan, 1998) – were excluded. In total, 18 volunteers created OLSBs together with 42 participating dyads, resulting in 34 completed OLSBs. For this content analysis, eight books were analysed, selected via convenience sampling based on the OLSBs that were finished first. The books of five female and three male participants were studied, with an age range from 71 to 87 years (M=80). In six cases, the informal caregiver that helped creating the OLSB was a spouse and lived together with the person with dementia, whereas in the two remaining cases, a daughter and grandson were involved respectively. Four female and three male volunteers assisted the dyads during the creation process (one male volunteer was involved in two cases). Five of the OLSBs were created with the original application of Hellomydear and the other three by using the program of Albelli. Participants were approached via phone by the same researcher that collected the data in the effectiveness study (Elfrink et al., 2017). They signed a new informed consent for this part of the study in which they gave the researchers permission to access and save their OLSB.

Coding scheme and analysis

A coding scheme was developed for the content analysis of the OLSBs. The initial scheme was created by three researchers (TRE, CU & GJW). The codes were categorized into two main sets regarding 1) the structure and 2) the content found in an OLSB. The elements we identified in both structure and content where theory driven (directed, top-down), whereas the actual codes were derived directly from the data itself and were determined inductively (conventional, bottom-up; Hsieh & Shannon, 2005).

The first set of elements was about structure. The first element was the *total number of memories*, in order to determine the amount of memories people included. The second element was the *number of components*; multiple components (e.g. a photograph together with text) could be added to one memory, indicating the richness of a certain memory. For example a memory of a wedding consisting of three or more components could include a photograph of the wedding announcement in the newspaper, a photograph of the wedding invitation and photographs or a video of the actual wedding. Then the *density of components* was determined by calculating the average number of components per memory. The fourth element was the (multimedia) *type of component*: a component could be displayed as text only, a photograph, a video or as music. This was of importance with regard to whether people included multimedia aspects in their life story. As pointed out in the Introduction, using multisensory cues can enhance reminiscence (Lazar et al., 2014; Zhang & Ho, 2017). All of these structure elements were countable.

The second set of elements concerning the content of the memories were listed for every component. First, *themes* were identified. Two researchers (TRE & CU) identified the following four themes after independently analysing all of the components of one OLSB: home, family, friends, and vacation. These match the universal themes identified by Stinson (2009). Additional themes that became visible whilst analysing the remaining OLSBs were career, hobby, and trip. In the end, all eight books were coded using this final classification of themes. Regarding the code theme, we set up the following rules when a memory fell into multiple themes:

- Home: Memories about situations at home – alone or with someone one's household.
- Family: Memories about one's family (when not at home, on vacation or on a trip).
- Friends: Memories about loved ones that are not family – in diverse situations, e.g. a birthday party (when not at home, on vacation or on a trip).
- Vacation: Memories about vacations regardless with whom – so vacations shared with others were coded as vacation instead of 'friends' or 'family'.
- Trip: Memories about an activity away from home, regardless with whom. Trips are not considered vacations.
- Career: Memories about education, job(s) and volunteer work.
- Hobby: Memories about one's hobby.

For example, if a person included a memory of being with friends or family on vacation, it was coded as 'vacation'; a memory with the family at home was coded as 'home'; a memory of being with distant relatives (even if they were at the home location) belonged to the subject of 'family'. When it was unclear or irreducible to which theme a memory belonged, it was coded as 'unknown'.

Next, the number of memories within a specific period of time, referred to as *life phase* was coded since addressing the entire life course can support the reminiscence process (Bohlmeijer et al., 2011; Westerhof et al., 2010). Six phases were categorized by years: pre-birth, 0-14, 15-24, 25-44, 45-64, and 65+. When there was no date or it was not possible to deduce when a memory took place, it was coded as "unknown". To determine the *richness* of the books and to see whether the books were varied in both themes and life phase, it was checked how many of the seven themes and six life phases were represented in each book. Per book we calculated a total score for both elements. A book could reach a maximum score of 7 on themes, as we identified seven codes on thematic level (home, family, friends, vacation, trip, career, and hobby). A book could receive a maximum score of 6 on the life phase element (pre-birth, 0-14, 15-24, 25-44, 45-64, and 65+ years).

Subcodes for *specificity* were specific and general. A memory was coded as specific when it was a memory “filled with unique details and traceable to a precise moment in time” (Singer et al., 2007, p. 887). A memory was coded as general when it represented “a series of events over several days weeks or months” or when “similar events separated in time [blended] into a single recollection” (Singer et al., 2007, p. 887). So a recurring event like a birthday was coded as general, unless something unique was described (e.g. a 50th birthday jubilee with a special celebration).

The *valence* was coded as positive (i.e., a good/fond memory) or negative (a bad memory); positive memories can enhance the social function of reminiscence (Serrano et al., 2004; Sumner et al., 2010; Ono et al., 2016). The valence either emerged from the words used by the participant or was interpreted by the researcher. For example, a photograph with a smiling person or a photograph from a vacation with no further text, caption or explanation, was coded as positive (assuming nothing negative happened during that holiday). A memory of a negative life event such as the disease or loss of a loved one was coded as negative – unless the accompanying text suggested otherwise.

Lastly, we added *perspective* to the scheme, which was coded from the way memories were described. Memories were coded as first-person when written from the perspective of the participant him/herself (such as “When I had my 50th birthday…”), as third-person when written about the person (“When she had her 50th birthday…”), as descriptive when the memory was described in a general way (“50th birthday”) and as “unknown” when there was no text.

At the end of this developing process, the scheme was used for the content analyses of all eight OLSBs. Since the created coding scheme was straightforward and the rules about hierarchy were tight and did not leave much room for interpretation, the main investigator (TE) coded all the books and consulted the second investigator (CU) in case of doubt so that a consensus might be reached.

RESULTS

Structure

Firstly, we analysed the eight OLSBs on the average number of memories and the components belonging to those memories (see Table 1). Those components were, for example, text elements or multimedia elements. On average a book consisted of 75 memories with a range from 25 to 214. The number of components per book was on average 142 with a range from 49 to 275. The density of the number of components per memory was on average 1.89. Consequently, in general, a memory was represented by more than one text/photograph/video/music fragment. A large majority (94.4%) of the components were photographs, followed by text (4.9%). In all eight books together, a total of seven music fragments (range 0-3) and one video was included.

Content

The results with regard to the content of the memories can be found in Figure 1 (themes and life phases) and Table 1 (all other characteristics). The three most frequently included themes were vacation, family and home, whilst trips and hobbies were least represented. The range varied across all themes, for example, some people included only one component about their career, whilst others included multiple components – with a maximum of 28. The range of richness of themes represented in the books varied from 5-7 (mean:6.1; SD:1.0). Subsequently, we examined in which of the six different phases of life a memory took place. The phase that was represented most was 45-64 (40.5%). Memories prior to birth were included as well. Of course, those were not memories of the persons themselves, but, for example, a wedding photo of their parents, a family tree or family book. Overall, the range of the richness of the included life phases was 5-6 (mean: 5.4; SD: 0.5).

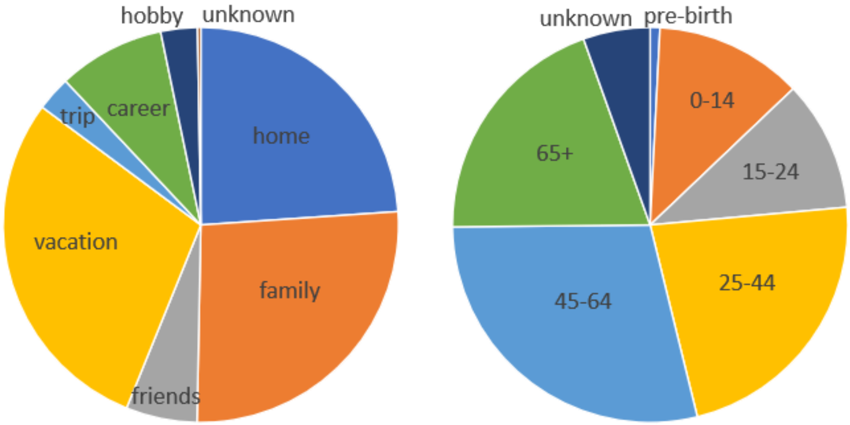

Figure 1. Distribution of themes (left) and life phases in years (right) across all components

Table 1. Overview of the content of eight Online Life Story Books

	N	**%**	**Mean**	**Range**
Structure				
Number of memories	601	-	75.13	25-214
Number of components	1133	-	141.63	49-275
Density of components	1.89	-	1.89	1.23-3.88
Type	*Components*			
Text	56	4.9	7.00	0-37
Photo	1069	94.4	133.63	44-264
Music	7	0.6	0.88	0-3
Video	1	0.1	0.13	0-1
Content	Components			
Theme				*Richness range: 5-7*
Home	271	23.9	33.88	12-60
Family	299	26.4	37.37	11-105
Friends	66	5.8	8.25	0-33
Vacation	329	29.0	41.13	4-134
Trip	32	2.8	4.00	0-13
Career	99	8.7	12.38	1-28
Hobby	34	3.0	4.25	0-12
Unknown	3	0.3	0.38	0-2
Life phase				*Richness range: 5-6* [a]
Pre-birth	9	0.8	1.13	0-5
0-14	137	12.1	17.13	3-31
15-24	121	10.7	15.13	5-26
25-44	256	22.6	32.00	3-67
45-64	325	28.7	40.6	2-154
65+	223	19.7	27.88	6-63
Unknown	62	5.5	7.75	0-45
Specificity				
Specific	419	37.0	52.38	11-211
General	714	63.0	89.25	38-227
Valence				
Positive	1107	97.7	138.4	88.3%-100%
Negative	26	3.3	3.25	0%-11.7%
Perspective				
First-person	144	12.7	18.00	0-87
Third-person	57	5.0	7.13	0-24
Descriptive	407	35.9	50.88	4-104
Unknown/no text	525	46.3	65.63	2-216

Note. [a] In the OLSBs with a score of 5, the pre-birth phase was not represented and thus the only ‘missing’ phase.

Next, the specificity of the components was analysed. The majority of memories were general, covering a longer period of time (e.g. when persons included multiple photographs about their time in school but did not refer to one specific memory from that period) or recurring events, such as birthdays or Christmas. However, a substantial number (almost 37%) were specific unique events which occurred only once, such as a farewell party at work, a wedding or the birth of a (grand)child.

With regard to valence, most of the components (97.7%) were positive. Negative memories were mostly about the death of loved ones or career matters such as dismissal.

The final element was perspective. The majority of the components were without text (46.3%) or of a descriptive nature (35.9%). The first-person perspective was used in 12.7% of the books and the third-person was used the least number of times (5%).

To conclude, there was a focus on specific positive memories represented by photographs with certain themes (vacation, family, and home) during a particular life phase (45-64 years).

DISCUSSION AND IMPLICATIONS

Creating a (digital) life story book seems to be a promising reminiscence intervention for persons with cognitive impairment as it can enhance mood and stimulate conversation (Elfrink, Zuidema et al., 2018; McKeown et al., 2006). However, a diversity of approaches leads to a wide variety of life story books created. Currently, little is understood about what life story books precisely contain and thereby how they can contribute to different reminiscence functions and outcomes (Elfrink, Zuidema et al., 2018). The aim of this explorative content analysis was to gain more insight into the memories that persons included in their life story books and thus better understand the actual structure and content of the OLSBs that could stimulate reminiscence and the social function of retrieving and sharing memories (Westerhof et al., 2010; Westerhof & Bohlmeijer, 2021). As addressed in the Introduction, this study included the following characteristics of reminiscence: a wide scope of themes, the whole lifespan, the use of multisensory cues, the elicitation of positive memories, stimulation of specific memories and the use of the first-person perspective.

In this study, the richness of the OLSBs is shown by the total number of memories (the smallest book consisted of no less than 25 important memories to reminisce about), the high density of components per memory, and the high number of themes and life phases. Apart from the rich nature of the books, there seemed to be a preference for photographs of specific moments with a positive valence that represented the theme of vacation, family or home and took place in the life phase of 45-64 year. Overall, this result supports the use of reminiscence, but it also shows that there are selection processes involved in creating the OLSBs.

The photographical material available to persons in this age group might have influenced the selection, as nearly 95% of all included components were photographs. Of the 1133 components, only seven were music fragments and one was a video. It is known that multisensory cues can be beneficial in the reminiscence process (Woods et al, 2005). On the one hand, although the OLSB enables a variety of multisensory cues, evidently this function was not often used. On the other hand, photographs are, of course, part of multimedia and can prime more vivid memories than texts alone. Therefore, the fact that little text only was used (less than 5%) and that the vast majority of components the OLSBs consisted of photographs is a sign that participants found their way around the multimedia aspect of the intervention. The nature of the most represented themes could be explained by the fact that people tend to take and/or select photographs of family and friends, vacations and special events (Van House et al., 2004). The representation of different life phases could also have been influenced by the availability of photographic material since the 1980s. This might explain why the reminiscence 'bump' (15-24 years) found in previous research was not visible in this study's OLSBs (Jansari & Parkin, 1996).

The photo selection might also have affected the high amount of positive memories that was included, which also fits with the purpose of reminiscence. People are inclined to take photos of special and specific events – and are more inclined to remember positive happenings over negative ones. However, even without photographical support, persons could have chosen to include text about a sad memory, such as the loss of a loved one. The so called "positivity effect" in ageing could also have played a role in the amount of positive memories included. This effect implies a preference for positive information in later life (Carstensen & DeLiema, 2018; Carstensen & Mikels, 2005). Another relevant point related to the high percentage of photographs included in the OLSBs is that the role of photography is changing. Whereas taking photographs was something special and persons took photos to capture one's heritage, it is becoming a means to shape identity and enhance communication. Currently, there is a shift occurring from photography being used as a memory tool to that of a communication tool (Van Dijck, 2008). Social media is rising and can support and prompt reminiscence, for both younger as well as older persons (Thomas & Briggs, 2016). The older persons of today are in the centre of this digital transition, which includes digital photography, smart devices and social media. Hence, it is likely that the older persons of 2040 will compile completely different LSBs, as they are continually documenting their life story in their daily lives aided by their increased use of social media and smartphones. This transition will empower the social function of future reminiscence interventions even more, but can also result in an overload of materials that in hindsight are considered less relevant (Thomas & Briggs, 2016).

The selection of the memories included could have also been affected by the choices of the volunteer, family, and persons themselves. Volunteers were instructed to collect as many important memories as possible by covering a broad range of different life phases and themes, and this might have resulted in the distribution of both themes and phases. Another explanation could be the connection between the participant and the informal caregiver, and how active the participant was involved in creating his or her own book. For example, if the informal caregiver was a daughter or grandson (as in this study) who has brought in the majority of the memories, then she or he would know more about recent events in that person's life than former events, compared to a spouse. An alternative factor could be the aim of the OLSB for the participants; it is possible that they created the books to retain recent memories, seeing the book as a tool for when their memory loss might deteriorate further. Alternatively, they might have participated because they simply enjoyed the activity. While volunteers were not instructed to solely focus on and ask for positive memories, such memories can be a side effect of the process and the availability of (mostly photographical) materials that served as input. Lastly, the first-person perspective was not frequently used, which may affect the vividness of the memories. In this study it was unknown whether the choice for perspective was the participant's own preference, or those of the volunteer or informal caregiver; perhaps this was an unconscious preference of whomever entered the descriptions.

Strengths and limitations

This content analysis focused on one specific intervention, so it is evident that the results cannot be generalized to other interventions. However, it provides a unique approach as to how the content of life story books can be analysed and interpreted. The fact that the intervention was not strictly protocolized and persons were free to include whatever they wanted, could be seen as both a limitation and a strength. It is a limitation in the sense that the participants were not actively stimulated to address all the themes or life phases. It is a strength as the autonomy of participants was respected. It would be interesting to know more about the motives of the participants in their selection of content for their OLSB: Why did they include the memories they did and the components? Was it based on the availability of photographs, were they prompted by the questions of the volunteer, did their spouse or another family member make suggestions, or did they consider the included memories as the most valuable ones in their life? And how did they view the purpose of the OLSB? Did they have a function in mind before starting and how did they actually use the OLSB? Knowing more about these motives could provide further insights into how to tailor the creation process.

Recommendations

Based on our findings, we suggest a number of recommendations for future interventions like the OLSB. First of all, one should consider what the instructions are given regarding the creation of the OLSB, for example, how to select the memories that should be included in the book. It is encouraging that a combination of positive and specific memories was included in the eight books. However, it might be advisable to encourage or specifically guide participants to remember even more positive and specific memories, depending on their intended use of the book, without neglecting other important memories that might elicit negative emotions (e.g. last photo of one's deceased parents). Negative life events are also a part of life; and ultimately, these sad or difficult memories can be valuable as they might have shaped someone's identity. However, integrating these memories into the life story needs to fit the participant's overall purpose of his or her life review. All in all, it is recommended to pay attention to positive and specific memories, but to also be considerate of less positive events and to attempt to find a balance. The same is true for stimulating persons to include memories from their entire life and from all themes by asking for important milestones for each life phase and certain themes. Next, motivating persons to include textual descriptions next to photographs, audio or videos could be beneficial later when one's memory further deteriorates. It is helpful to have textual support for the memories, so that information can be used to stimulate autobiographical memory and conversation. Therefore it might be advisable to include not only visuals but to write a description of the memory as well.

The high representation of photographs in the OLSBs raises the question whether creating the OLSBs was more a matter of memory production through photography than of memory recollection – and whether this is problematic. On the one hand, the selection of a photograph is the choice of the participant. On the other hand, it might be advisable to let the volunteers focus more on other (underrepresented) themes and periods by asking questions and being creative in including other kinds of materials. Besides (and this corresponds with the aforementioned), one must reflect upon who chooses the memories included in the OLSB. Who will be in charge, and who can be in charge? As undermining autonomy and creating biases could be risks, the main question remains: To what extent should one direct these interventions? Therefore, we would advise not to over direct the participants, but rather to stimulate them in creating a rich and complete overview of their life which might enable them to keep on reminiscing on their lives, without undermining their autonomy. Especially when their memory later deteriorates, it can be valuable to have multiple entry points (media, themes and life phases), instead of solely one.

For future research, it would be worthwhile to explore and compare other life story books on their content level in order to draw more general conclusions for improving the use of (online) life story books or comparable reminiscence interventions. Next, it could be interesting to investigate life story books over time, for example, to see whether the books that focus more on the social function can indeed enhance relationships and lead to the aim of better or deeper connections. Another point of interest would be to examine the added value of using these life story books in later stages of cognitive decline.

Conclusion

In summary, the created OLSBs contained multiple characteristics based on reminiscence and its social function. The exact content of an (online) life story book is determined by the availability of (multimedia) materials, and the focus or choices of the volunteer, family and person him or herself. Creating a rich book not only provides the possibility to create meaning in one's life, but could also help in enhancing reminiscence and social interaction. The recommendations offered as a result of this study will hopefully be valuable not only for the persons concerned, but also for their informal and professional caretakers, now and in the future.

Online Life Story Books

perceived effectiveness, implementation and use of technology in a digital life story book intervention for people with cognitive impairment and their informal caregivers

6

Elfrink, T. R., Ullrich, C., Kunz, M., Gerritsen, D.L.,
Zuidema, S. U., & Westerhof, G. J.
Submitted

ABSTRACT

Background:

This paper describes a process evaluation of the Online Life Story Book (OLSB), a digital reminiscence intervention for people with cognitive impairment who are living at home. The aim of this evaluation was to obtain insights into the perceived effectiveness and implementation of the OLSB and use of the technology within the OLSB intervention.

Methods:

Semi-structured interviews were conducted with persons with mild cognitive impairment (MCI) or early dementia and their informal caregivers, as well as with volunteers, formal caregivers and care professionals. Supplementary information about the actual implementation was obtained from log books.

Results:

The perceived effectiveness of the OLSB predominantly demonstrated social outcomes like interaction, relationship and acquiring a holistic view of the person with the cognitive impairment. The current implementation was facilitated by the usability of the application whilst barriers were the time-consuming digitalization of the photographs and the intervention being part of a research project. Monitoring the process and inviting family members to use the application so they could help from a distance were perceived as positive functions of the technology. People saw possibilities to integrate the digital OLSB into the client's overall care, for example, by linking it to the client's electronical medical record.

Discussion and conclusion:

This study provides insight into the implementation of a digital life story intervention for older individuals with cognitive impairments and how to measure its effectiveness. The findings demonstrates that such interventions provide promising benefits and allow for better person-centered (dementia) care.

BACKGROUND

According to a meta-analysis reminiscence can affect cognitive functioning and reduce depressive symptoms in older persons with dementia (Huang et al., 2015). Several reviews have also shown the potential of reminiscence for improving psychosocial outcomes for persons with dementia, such as an improved mood and well-being (Blake, 2013; O'Philbin et al., 2018; Subramaniam & Woods, 2012; Woods et al., 2005). Those effects are especially reached when using specific and personalized reminiscence material, such as a life story book (LSB).

The creation of a LSB is a common approach that provides a rich and tangible object to support reminiscence (McKeown et al., 2006). The use of LSB interventions in dementia care is promising. A recent systematic review indicates that LSB interventions in dementia care can be effective and helpful for outcomes like autobiographical memory, mood, quality of life, and particularly in improving relationships. Among the included studies, inconsistent effects were influenced by a number of factors including: instruments used, sample sizes and substantial differences in outcome measures (Elfrink, Zuidema et al., 2018). Some studies also showed that people with dementia felt motivated and comfortable using a digital LSB and that this improved social interaction and communication with the professional caregiver (Hashim et al., 2013; Hashim et al., 2015).

Reminiscence and LSB interventions could benefit from the use of technology, as it more readily allows users to document, retrieve and add personal memories, can provide possibilities to prime the senses in order to elicit memories, and can make the process more interactive (Lazar et al., 2014; Zhang & Ho, 2017). Furthermore, technological interventions can be used in the home setting as well as in institutional care. In 2012, Subramaniam and Woods predicted that by 2017 digital life stories for persons with dementia would become standard. Whereas digital LSBs are promising, that prediction has yet to be realized. Hence, it is important to gain more insight into the creative process and actual use of digital LSBs in dementia care. The current article describes a process evaluation of the Online Life Story Book (OLSB), a digital LSB intervention executed in the home setting by persons with mild cognitive impairment or early dementia alongside their informal caregivers.

The OLSB is a reminiscence intervention that uses technology and allows digital sharing of memories (stories, pictures, video and/or audio fragments). OLSB was one of the first LSB interventions used in the home setting and to involve trained volunteers who created the life stories. Contrary to our expectations, a previous study with a randomized controlled trial (RCT; N=42 persons with dementia and their informal caregivers) with a waiting list control group showed that the OLSB had no significant effects on neuropsychiatric symptoms (NPS) of the person with cognitive impairment, nor on burden and quality of life (QOL) of the informal caregiver (Elfrink et al., 2021). The lack of effects might be due to the relatively low presence of NPS and relatively high QOL of the participants, the outcome variables used (targeting more long-term outcomes instead of short-term effects like social interaction, mood and communication) as well as the possible suboptimal quality of the implementation of the intervention (Elfrink et al., 2021).

Adding a process evaluation on the OLSB to this trial provides further possibilities to derive lessons from working with a (digital) LSB intervention in dementia care. First, it would be meaningful to assess how those involved perceived the effectiveness of the OLSB. By asking the stakeholders about the added value of the intervention, one could receive more insight into relevant outcome measures for future studies. Besides, it is important to establish what works not only theoretically, but more importantly, from the user perspective. Second, concerning the implementation of LSB interventions, there appears to be a lack of stakeholder involvement in the studies included in the systematic review about LSBs in dementia care – such as by the persons with dementia and their (in)formal caregivers (Elfrink, Zuidema et al., 2018). Hence the question remains how to best implement LSB interventions for people with cognitive impairment and related stakeholders. Third, technology has some theoretical advantages, but little is known on how users perceive the technology's possibilities and barriers. With this process evaluation, we hoped to answer these questions.

After our first study on the effectiveness of the OLSB, the present study reports on the process evaluation of the OLSB. The aim was to gain insight into the: 1) perceived effectiveness and 2) implementation of the OLSB and 3) stakeholders' perceived use of technology within the OLSB.

METHODS

Design

This process evaluation is part of a larger project on OLSB's in care institutions in the Netherlands. This larger project is described in a research protocol and includes the previously mentioned RCT as well as the current process evaluation (Elfrink et al., 2017; Elfrink et al., 2021). The process evaluation was conceived as a new study, collecting additional interview data of persons with cognitive impairment and their informal caregivers who also participated in the RCT. In the following it will be referred to as a *dyad* when it concerns a person with cognitive impairment together with his or her informal caregiver. Interviews were also conducted with other stakeholders: the volunteers who created the OLSBs together with the dyads and the most involved formal caregivers. A total of eight complete cases were analysed. Additionally four (uninvolved) care professionals with positions that could be important when it comes to implementing innovations in elderly care were interviewed.

Intervention

The Online Life Story Book is an e-health application to bundle memories such as life events, anecdotes, recipes, and poems. Memories can be included as text, photos, movies or audio recordings. In our study, trained volunteers assisted the dyads in creating the OLSBs. They visited the participants for 5 conversations within a period of 8-10 weeks. During those conversations, they asked for memories of different life phases and themes, and collected (and if needed digitalized) materials to include in the OLSBs. The initial application that was used in this study was developed by Hellomydear in Belgium, but since the developers terminated the co-operation during the study, a change to another application, Albelli, was made. The application of Hellomydear had a digital timeline to scroll through the years and a function to invite others to the album, whereas Albelli doesn't have those functions. More information about the intervention can be found in intermezzo 1.

Participants

Semi-structured interviews were conducted with the dyads, the volunteers, formal caregivers and four care professionals. During the effectiveness study, 18 volunteers created an OLSB together with 42 participating dyads, resulting in 34 completed OLSBs. The eight evaluated cases were selected via convenience sampling based on the OLSBs that were finished first. Five of the OLSBs were created with the original application of Hellomydear and the other three by using the program of Albelli. Table 1 provides an overview of the persons involved per case. A total of 26 interviews were conducted with dyads (n=8), volunteers (n=7), formal caregivers of the persons with cognitive impairment (n=7) and uninvolved care professionals (n=4).

Table 1. Persons involved per case.

	Person with cognitive impairment			*Informal caregiver*	*Volunteer*	*Formal caregiver*
	Gender	Age	Educational level			
1	M	71	Secondary vocational education	wife	F	F, case manager dementia
2	F	76	Primary and lower vocational education	husband	M	F, case manager dementia (same as case 1)
3	M	81	Higher vocational education	wife	M	F, owner daycare center
4	F	84	Secondary vocational education	husband	M	F, case manager dementia
5	F	73	Secondary vocational education	husband	M (same as case 4)*	F, case manager dementia
6	M	87	Higher vocational education	wife	F	F, daycare supervisor
7	F	84	Primary and lower vocational education	daughter	F	F, home care worker
8	F	87	Primary and lower vocational education	grand-son	F	F, first responsible nurse

* Due to personal circumstances, the volunteer that created two OLSBs was asked questions via a digital form instead of via an interview

The selected group of persons (n=8) were having mild cognitive impairment (MCI) or (very) mild dementia (scoring 0.5 or 1 on the Clinical Dementia Rating [CDR]; (Morris, 1993)). Similar to all the other participants of the prior effectiveness study, the dyads were recruited through, for example, the one collaborating home care institution, general practitioners, informal meetings with peers, local newspapers and door-to-door papers. Potential participants were interviewed together with their informal caregiver. In six of the cases, the informal caregiver that helped to create the OLSB was a spouse and lived together with the person with cognitive impairment, whereas in the other two cases, the daughter or grandson was involved.

For this process evaluation seven volunteers were asked for their experiences, as one volunteer was involved in two cases.
Three of the formal caregivers were case managers, the others were an owner of a daycare center, a daycare supervisor, a home care worker, and a first responsible nurse.

Next to the eight complete cases, four uninvolved care professionals working at the collaborating home care institution were interviewed, namely: a psychologist (F), a senior psychologist (F), a manager (treatment and paramedical services, M) and an elderly-care physician (M).

Procedure

Dyads were approached via phone by the same researcher that collected the data in the prior effectiveness study. The dyads signed a new informed consent for this part of the study and were visited at their home for the interview. All interviews were audio-recorded after approval of the participants. The duration of the interviews was between twenty and fifty minutes. After the interview with a dyad, the volunteer and the most involved formal caregiver were approached by phone by trained and supervised psychology bachelor students. Interviews with volunteers (n=6; due to personal circumstances the volunteer that was involved in two cases was sent a digital form with questions instead of participating in an interview) took between thirty and seventy-five minutes and those with formal caregivers (n=7) between sixteen and thirty-six minutes. Interviews with the four uninvolved care professionals lasted between thirty and fifty minutes. All the interviews were conducted between March 7 and December 13, 2017.

Materials

Per stakeholder group, a semi-structured interview with a topic list was created by three different researchers after discussion and consensus (TRE, CU and GJW). Elements of Nielsen and Randall's process evaluation model were used as a guidance for the topic lists (Nielsen & Randall, 2013). This model offers a framework with three different levels of elements that are important for a sound process evaluation: 1) the mental models – perceptions – of all stakeholders, 2) the intervention itself and 3) the context in which the intervention took place. The first aim of this process evaluation was to get more insight into the perceived effectiveness of the OLSB. In order to do so, specific questions about the perceptions of the stakeholders on added value were included. This covers the first element of the Nielsen and Randall model. The second aim, namely to learn about the implementation of the OLSB, is connected to the second and third element of the model: stakeholders were asked about the intervention and the context (facilitators and barriers) of the implementation and ideas for future implementation. In addition, log books completed by the volunteers were used to gather information about the creation process of the OLSB together with the dyads. Lastly, the third aim was to get insight in the stakeholders' perceived use of technology within the OLSB. Therefore, specific questions about the use of

technology within the intervention itself were incorporated in the topic lists.
Topics covered in the interviews were among others: motivation to participate, creating process, collaboration, time investment, added value, the use of technology, and the possibilities of an OLSB intervention in (future) care. See additional file 1 for the topic list per type of stakeholder (dyad, volunteer, formal caregiver, care professional).

In the logbooks, volunteers noted down the following items after each conversation with the dyad: preparation time, the actual time of the conversation, and the time it took to process it into the OLSB. They were also asked to rate their satisfaction with each conversation (i.e., “Overall, are you satisfied with the course of this conversation? Please rate it on a scale from 0-10.”), and they could give an optional explanation. Information from the log books of 24 conversations was available.

Analysis

A thematic analysis was performed on the answers to the semi-structured interviews using the ATLAS.ti software (ATLAS.ti Scientific Software Development GmbH, version 8.4.20) (Clarke et al., 2015). After transcribing the interviews, a coding scheme was developed by two researchers (TRE and CU). In line with the research questions and the interview topics, three main themes were derived deductively: perceived effectiveness, implementation, and technology. As interviews did not strictly follow the topic list, it was necessary to first code the theme of each unit of analysis. Units of analysis consisted of single or multiple sentences. The subthemes were then derived inductively from the data by jointly analyzing four interviews (one per type of stakeholder: dyad, volunteer, formal caregiver and care professional). After doing so, the coding scheme was finalized. The three main themes consist of 17 sub themes which will be described in the results section (see Table 2). Two interviews, consisting of 51 units of analysis, were coded independently by two researchers which led to a Cohen’s κ of 0.89 on sub theme level which is considered almost perfect (Landis & Koch, 1977). After this agreement, one researcher (TRE) coded the remaining interviews.

RESULTS

Table 2 shows the frequency of the mentioned themes and sub themes with an explanatory quote for each sub theme. Sample quotes from the interviewees are provided with an abbreviation of the person concerned followed by a case number (if applicable). In the following sections, a paraphrased summary is provided for the sub-aims perceived effectiveness of the OLSB, implementation of the OLSB and the use of technology within the OLSB.

Perceived effectiveness of the OLSB

The theme perceived effectiveness of the OLSB consisted of seven sub themes, based on the value of the intervention for different stakeholders: the persons with cognitive impairment, their informal caregivers and families, couples, volunteers, formal caregivers, care institutions/care in general, and society. To be clear, interviewees were not only asked about perceived effectiveness for themselves, but for other stakeholders as well. The group (subcode) for whom it is an added value appears in the text below in italics.

The different stakeholders agreed that the OLSB is an instrument to enhance social interaction, reminiscence, conversation, and cognition of the persons *with cognitive impairment*. Persons with cognitive impairment (and others) felt as if their memory had been refreshed. Overall, creating an OLSB was viewed as a meaningful and fun activity, especially by the dyads themselves. Some persons emphasized the importance of having an OLSB for when the condition of the person with the cognitive impairment might deteriorate. The added value for *informal caregivers and family* was that working on the OLSB created more involvement and input for conversation with their family member who was cognitively impaired. The creation of the OLSB was seen as a valuable process to involve family members in the life of the person with the cognitive impairment and to strengthen communication. Next to this, the OLSB could act as a family genealogy, and people found it a valuable way to pass on their family history to next of kin. Some participants gained new information about their family by creating the OLSB. One informal caregiver mentioned the relationship with the volunteer – that continued after the project – as a benefit.

For the *couples*, the added value was the meaningful shared activity of creating the book, and it helped them in their communication. *Volunteers* appreciated the contact and the trust they received. For some, the project ended with the volunteers establishing a lasting valuable contact with the participants. Participating as a volunteer and helping the persons creating an OLSB was perceived as making a contribution to society and to one's own personal development. An OLSB can help *formal caregivers* obtain a holistic view of the person instead of knowing only facts that mostly concern only medical conditions. Formal caregivers said that this can lead to an improved relationship, which in turn can result in providing improved and more person-centered care. According to the interviewees, the OLSB can support formal caregivers in starting a conversation – which was a similar outcome for the families. For *care institutions*, the OLSB can reinforce their vision of knowing their clients well and it can enhance person-centered care. Next to this, professional caregivers mentioned the OLSB can be used as a tool to stimulate collaboration

Table 2. Frequencies and explanatory quotes per main theme and sub theme.

Main theme and sub theme	Frequency	Explanatory quote
Perceived effectiveness	**251**	
Persons with cognitive impairment	108	*It was very nice to do. You even come in touch with your own history again, and it was very pleasant to relive all that. (PWCI1)*
Informal caregivers and families	19	*We gave the children the book as well. And they liked that very much. They could see for themselves where they participated in it. Intuitively they participated, of course, and they liked it. (IC4)*
Couples	26	*It's just such a beautiful document for yourself … I noticed how much joy it gave both couples to dive in to their history again […] and to do that just with the two of them. That just gives so much joie de vivre. I saw that in both couples. It was very nice. (FC1&2)*
Volunteers	41	*It's an enrichment for yourself. You get the opportunity to have a look into somebody's life. They are somewhat older, so they have been through so much, and of course you will learn something from that. … It just gave me a very nice feeling, because it gave them a nice feeling. And I'm still in touch with them. And I could easily connect to them, I believe that was very pleasant for them. I think they are very grateful that I helped them and well, yes that it [the relationship] actually still continues (V1)*
Formal caregivers	41	*When more caregivers are involved, it's very important that they know the life story as well. And that's not the case right now. The caregivers have absolutely no background information about somebody's life. And you can easily and beautifully get that via such an album. And that could be an absolute benefit … for the client, because if the caregivers know the client very well, then they can provide care in a good way. (FC5)*
Care institution/care in general	11	*I also believe that providing quality care in nursing will be improved when we know the life story of a person. Not only the pleasant moments, but the less pleasant ones as well. The collaboration between care and family will be improved by that as well. (P)*
Society	5	*When xxx proposed to create a life story we thought that we should do that, because maybe you can contribute something to the research about Alzheimer's, and how people respond to it [the OLSBs]. (IC2)*

Implementation	**223**	
Process of creating the OLSB	106	*The contact with the volunteer was very nice as well. After two visits she already was an acquaintance, like “Come on, let’s continue where we left off.” And meanwhile, we had selected the photos and stories. The volunteer made it into a coherent book. (IC1)*
Context (facilitators and barriers)	28	*The better the connection, the better the book! (V4&5)*
Target population	7	*What is the right moment to conduct this? Maybe an even better moment is when the older person is still just healthy and functioning well, so they can take part in it. (SP)*
Task division	15	*Well, the question is: Do they all have to be care professionals? … I believe you just have to have a good look at it [the task division], because right now, persons with a background in care are mostly involved. And I think that you should deploy people with a pedagogical or psycho-social background for activities like this. (ECP)*
Activities	18	*You can ask “Where is the collectivity?” … So people have something in common that they can talk about, and in that way you can reminiscence together or do an activity together, or you can connect it to current events. (ECP)*
Conditions	32	*If I have to be honest, I think that if I want to keep my autonomy and my identity, then part of it is that I can decide what I share with whom. (M)*
Risks	17	*As a barrier I think that it is time consuming to create such a book and perhaps to sort all the material as well. You are dependent on the informal caregivers who are already very busy nowadays. Often it takes lots of effort to motivate informal caregivers to, well, yes, do something meaningful. (P)*
Technology	**84**	
Usability	64	*That is a video fragment that I don’t watch that often, and since it is in the life story book, you come across it regularly. (PWCI1)*
User needs	12	*Of course, when the family is living in Australia, you can have contact and add videos of the grandchildren. That speaks for itself. (ECP)*
Integration in care	8	*When you have it in a digital version, nowadays you can create all kind of links. So you can integrate it into the [medical] record. (M)*
Total	**558**	

PWCI = person with cognitive impairment; IC = informal caregiver; V = volunteer; FC = formal caregiver; P = psychologist, SP = senior psychologist, M = manager (treatment and paramedical services); and ECP = elderly-care physician.

between institutions and families. Furthermore, using the OLSB could lead to reducing costs (according to the psychologist). Two transcending themes were reported as added value for *society*: contributing to research about dementia and creating a more cohesive society.

Implementation of the OLSB

The second aim was to obtain a better understanding of both the current and possible future implementation of the OLSB. The theme *implementation* consisted of seven sub themes: *process of creating the OLSB, context, target population, task division, activities, conditions* and *risks*. Here, the thematic analysis of the interviews was complemented with the volunteers' log books.

Both dyads and volunteers were pleased with the collaboration during the *process of creating the OLSB.* In general, the dyads provided the stories and materials to incorporate into the OLSB while the volunteers were responsible for retrieving the stories, digitalizing the photos, and uploading them into the application. Whereas the dyads retrieved the memories and the volunteers mainly created the OLSB, the coordination and decision-making were shared. The exact division of the tasks differed amongst the cases. In one case, for example, the informal caregiver created the past 20 years of the OLSB together with his wife with cognitive impairment, whilst in other cases the volunteer did almost all the work. The time investment of the people involved varied across the cases as well. On average, persons were quite satisfied with the amount of time it took to create the OLSB. The predicted time span was 5 conversations in 10 weeks. For some the frequency of 5 conversations was perfect, whilst others said they needed less or more conversations to complete the OLSB. This was confirmed by reviewing the volunteers' log books, in which the range of total conversations was between 5 and 8. One volunteer mentioned that the frequency of the visits intensified due to the unanticipated accelerated deterioration of the person with the cognitive impairment. The prior estimated duration of one hour per conversation seemed to be appropriate as well. Most of the volunteers said the time spent in conversations was flexible. If a participant felt tired, a conversation was shortened, and if the dyad felt more energetic, a conversation could be somewhat longer. This was partly confirmed by the volunteers' log books, in which the average duration of a conversation was around 76 minutes (range 45-120 minutes; median 67.5 minutes). The average preparation time per conversation reported in the logs was almost 53 minutes (range 0-300 minutes; median 30 minutes) and the average time it took volunteers to process all the information into the OLSB was 147 minutes (range 0-600 minutes; median 120 minutes). In total, the volunteers rated the conversations between them and the dyads with an average of 7.58 (range 6-9).

The next sub theme of the current implementation was *context*, indicating the facilitators and barriers during the implementation of the OLSB. Since the volunteers were the main executors of the intervention, they were the participant group with the most input for this sub theme. During the interviews, they mentioned the training and supervision they received from the project team as facilitating factors. Next to that, the application of Hellomydear to create the OLSB was also seen as facilitating and supportive during the process. Finally, the connection with the dyad was sometimes perceived as a facilitator: a good relationship between the volunteer and dyad was seen as constructive in creating the OLSB. Barriers were the amount of time it took some volunteers to digitalize all the photographs. The setting of the OLSB as being part of a research study was perceived as both a facilitator and a barrier. It was seen as facilitator in that the participants had the opportunity to create an OLSB for free, but as a barrier as participants had to fill out several questionnaires before and after the intervention and at follow-up in the effectiveness study.

Possibilities for future implementation were discussed during the interviews with the formal caregivers and care professionals. Interviewees thought that the *target group* of an OLSB could be expanded: the OLSB does not have to be only implemented specifically for persons with dementia. Although involved care professionals do see the relevance of an OLSB for people with cognitive impairment, some of them wondered whether it might be too late to create an OLSB once cognitive decline is already present.

According to the stakeholders, a clear *task division* is needed for a more profound implementation, and care professionals suggested different divisions of tasks. In general, they agreed on the added value of volunteers. Some believed that volunteers not only can have a role in creating but also in coordinating the OLSB project. Others saw a function for the volunteer in promoting and informing future OLSB users. Furthermore, the OLSB was considered to be a collaboration between the care provider and the family.

The implementation could differ across types of institutions. Creating an OLSB – and using it when finished – could also become a group *activity* in care homes allowing clients to become more acquainted with each other and reminisce together and/or as an incentive to doing a shared activity about topics that they have in common (e.g. being born and raised in the same region).

Key values that were seen as *conditions* and possible *risks* for implementing were privacy and ownership or autonomy. Autonomy was mentioned as being a condition in the sense that the person needs to be in charge and decide what to share with whom – and is, therefore, closely related to privacy. The next thing stated was having an ‘ambassador’ within the institution who could be a leader to ensure that the OLSB would remain in use. Another condition was having enough time so one could actually work with the intervention. Furthermore, the technology of the institution should be up-to-date in order to be able to use an intervention like the OLSB in care practice. Next, it was suggested that insurance companies might have a role in paying for the extra time needed once they understood that care can be more efficient when caregivers have the chance to know their clients through their stories generated by the OLSB.

Use of technology within the OLSB

The third sub-aim of this study was to find out more about the use of technology within the OLSB, for both current and future implementation. The corresponding theme included the subthemes *usability, user needs*, and *integration in care*.

Regarding *usability* and the functions of the OLSB during the current implementation, people responded that they were generally able to work with both applications. Specifically with regard to Hellomydear, dyads appreciated the function of having access during the creation process so they could monitor the volunteer’s progress. In addition, inviting and adding family members to the online book was valued as a very positive function of the technology. Lastly, adding not only pictures or photographs, but also audio and video fragments was perceived as a real advantage by some persons.

For the *user needs* for future implementation, several formal caregivers saw advantages for the client as well as for themselves in using a digital life story application. The first advantage is that other persons, such as family members, can be invited to work on the OLSB from a distance. A possible function to sort the stories not only by year but also by theme can be helpful for caregivers to easily identify important themes about which they can start conversations with their clients in a targeted way. Lastly from the reminiscence perspective, adding audio and video is seen as a definite advantage.

The formal caregivers saw possibilities for *integration in care* by linking an OLSB with the electronical medical record, so that they can see not only medical but personal information as well, allowing them to provide better person-centered care. One formal caregiver could imagine the OLSB being an in vivo screening instrument for the autobiographical memory of a client.

DISCUSSION AND CONCLUSION

Online Life Story Books (OLSBs) seem promising for dementia care, but little is known about stakeholders' perceptions of its benefits, use and integration in dementia care. The aim of this process evaluation was, therefore, to gain insight into the stakeholders' perceived effectiveness and implementation of the OLSB, and the use of technology within the OLSB. The results are discussed in light of general developments in elderly and person-centered care, and of implementation and development of interventions in long-term care.

Firstly, regarding the perceived effectiveness of the intervention, persons with cognitive impairment (and others) reported that they felt their memory was refreshed and that creating the OLSB was seen as a meaningful and intimate process that enhanced connection and interaction between them and their informal caregivers and family members, volunteers and professional caregivers. Hence, the OLSB seems to predominantly serve the social functions of reminiscence during the intervention (Webster, 2003; Westerhof et al., 2010).

This corresponds with findings reported in the systematic review on life story books (LSBs), in which participants, relatives, and care staff saw the value of LSBs mainly in the improvement of their relationships and, to be more specific, in partner affirmation, engagement, fullness of life as a couple, social interaction, and communication (Elfrink, Zuidema et al., 2018). Furthermore, this process evaluation showed that the OLSB can help caregivers to obtain a holistic view of the person instead of knowing only facts that are mostly related to the person's medical conditions or diagnoses. This can lead to an improved relationship, which in turn can result in providing improved and more person-centered dementia care. Subsequently, it was stated the OLSB can be used as a tool to stimulate collaboration between the institution and family. This result corresponds with two other findings. First, Fazio and colleagues' recommended in their review article one of the fundamentals of person-centered dementia care is to "know the person living with dementia" (Fazio and al, 2018, p. S18). And the second is formulated by Levy-Storms in a literature review stating that the key value of person-centered dementia care is "the person is not their dementia illness" (Levy-Storms, 2013, p18).

The finding that most of the added values mentioned in our interviews can be categorized as empowering the social function of reminiscence adds to the discussion about which outcomes to use to study the effectiveness of reminiscence – and more specifically – LSB interventions in dementia care, since to date, there is an inconsistency between effects and instruments used in research (Elfrink, Zuidema et al., 2018). This finding is underlined in the RCT, in which we focused on neuropsychiatric symptoms (NPS) of the persons with cognitive impairment, and burden and quality of life (QOL) of the informal caregivers. None of the NPS were mentioned in the interviews as possible benefits (added value) of the OLSB. Burden and QOL of informal caregivers were indirectly addressed (e.g. the creation of a OLSB as being a fun and meaningful activity to do together as a couple). This seems to confirm that, in hindsight, we might not have measured the right outcomes in our RCT, and this might account in general for research conducted with this target group. In our opinion, more person-centered outcome measures, such as communication and social interaction, should be used to assess the effectiveness of LSB interventions for people with dementia or cognitive impairment and their informal caregivers. It also might be helpful to conduct a process evaluation before investigating the effectiveness of an intervention, so one has better insight into the intended and most valuable – and thereby the most person-centered – effect.

In addition to the outcome measures used, one could question whether the OLSB enhances reminiscence in the long term. On the one hand, the quotes from the interviews show that the creation of an OLSB innately is reminiscence. In order to create the OLSB, persons have to recollect memories in an active manner and talk about them, and the interview responses confirm that memories are triggered during the intervention. On the other hand, we do not know if this reminiscence function of the OLSB continues across the course of the dementia. Reminiscence seemed to be the working mechanism of the OLSB, resulting in improved social aspects. For future research, it would be interesting to focus more on the actual use of the OLSB after its completion to see whether the OLSB remains an instrument to reminisce and to see whether the mentioned benefits on social functions and memory still persist. For future implementation, more emphasis could be placed on the possible reminiscence function of the conversations and the creating process of the OLSB. This means that the volunteer – or whoever is assisting the dyad – should be aware of this function in order to reinforce reminiscence.

Secondly, evaluating the implementation of the OLSB also provided some insights for future execution of LSB interventions in dementia care. In general, the usability of the application was appreciated, however, a barrier for the volunteers was the time-consuming digitalization of the photographs. Currently, older persons are less confident when using the internet, computers, smartphones or other electronics, but acceptance of technology is increasing and, therefore, using technology in creating LSBs is expected to be less of an issue in future implementations (Anderson et al., 2017). The collaboration and task division between volunteers and dyads was positively evaluated, while it was also valued that persons could actively contribute to their own story. This corresponds with the finding that the more an activity is tailored to the interests and abilities of persons with dementia (in nursing homes), the more they will be engaged (Trahan et al., 2014). Moving beyond the clinical setting, perhaps it would be even a further advantage to aim implementation at older persons in general. Consequently, an intervention like the OLSB would not only be of great importance when one has beginning stages of memory loss, but also before any potential memory deficit.

One could question what the best division of tasks is for an intervention like this. Informal caregivers of persons with dementia can perceive a high burden, so it might be helpful to unburden them. At the same time, professional caregivers often do not have, or feel as if they do not have, the time to be involved in such interventions (Conde-Sala et al., 2016; De Vugt et al., 2003; Peeters et al., 2014). As Groot Kormelinck and colleagues found in their systematic review on barriers and facilitators of complex interventions in long-term dementia care, the perceived work and time pressure of care staff could hinder implementation (Groot Kormelinck et al., 2021). Therefore, we believe that motivated volunteers can provide valuable assistance in creating (O)LSBs, although adequate training and guiding is necessary, as is effective coordination between those involved.

Another interesting finding regarding the implementation was that filling out multiple questionnaires for the effectiveness study before and after the intervention was perceived as a barrier for some of the dyads. In this study, the burden of the research was not that high, but for future and especially more complex interventions, it is important to not demand too much from participants in terms of collecting research data so not to influence the implementation. A part of the solution could be to find a way of measuring themes that is not burdensome on the participants of the study. While some participants found the research setting a hindering factor to the deployment of the OLSB, other participants regarded the setting as a facilitating factor, as they were given the opportunity to create an OLSB for free. Besides, some people felt that by taking part in this study, they were contributing to research about dementia, which gave them satisfaction. A general issue of eHealth interventions is that they seem to disappear once project funding has ended. More structural support from the government would be advisable in order to embed such interventions into (dementia) care (Nieuwenhuis, 2018).

Finally, the third aim was to gain insight into the use of technology within the OLSB. User friendliness, autonomy and privacy emerged as important values. With regard to user friendliness, functions that were appreciated were a timeline, the option to add physically distant family members to the OLSB, and the use of multimedia. An additional function to incorporate in a future digital LSB intervention is an option to sort the memories according to theme. Some reservations regarding the use of technology were that care institutions should account for privacy issues, keep the technology up-to-date and invest sufficient funds and time allocation in the technology. A final important point is concerned with the integration of an OLSB intervention into care. Caregivers saw advantages to linking clients' OLSB with their electronical medical record (EMR) in order to gain knowledge of the person's life story and to provide better care. However, discussions about the pros and cons of linking the OLSB with the EMR are not easily resolved. Issues with privacy and autonomy could be conflicting with person-centered care. This matches with the ethical principles for eHealth – trust, privacy, ownership, dignity, equity, and proportionality – as pointed out by the European Health Telematics Association in 2012. To avoid medicalizing the OLSB and retain it as a person-centered tool, we feel hesitant to directly link or incorporate the OLSB to the EMR. Ultimately, the person with cognitive impairment and their informal caregiver should always have the deciding vote on what to share with whom. We feel that we need to think about ways in which the OLSB could be more a part of daily care practice, allowing it to contribute to person-centered care. Therefore, solid design studies with attention for ethical questions are of great importance to secure issues like user friendliness, autonomy and privacy.

Strengths and limitations

The eight cases used in this study were selected by means of convenience sampling based on the OLSBs that were completed first. Since we cannot know whether these eight were representative for all 34 cases, this may have led to potential bias. For example, these might have been the cases with the most enthusiastic participants or volunteers. We do know that the persons who withdrew from the intervention and study did so because of non-intervention-related reasons (Elfrink et al., 2021). By questioning multiple stakeholders, we believe to have included a diversity of participants which resulted in a wide range of different viewpoints. According to Guest and colleagues data saturation can be reached by using only six interviews (Guest et al., 2006). However, it is difficult to establish when saturation is reached, since it is not about the number per se but more about the depth of the data (Fusch & Ness, 2015). In our study, all themes and sub themes were identified after the first round of coding. A strong point of this study is that we quickly attained an almost perfect Cohen's κ when analyzing the themes. Lastly, complementing the information from the interviews with the volunteers' log book entries helped in obtaining a better view of conversations between volunteers and dyads and the time it took the volunteers to create the OLSB.

Conclusion

This process evaluation provides a better understanding of the creation process and the possibilities of a digital LSB intervention in dementia care. It seems to confirm the need for a broader discussion on which type of outcome measures to use to assess effectiveness, the task division, user friendliness, use of technology and the ethical questions regarding privacy and autonomy of reminiscences as well as more specific life story book interventions in dementia care. We believe that this process evaluation can be used as a starting point for developing a solid, complete and functioning application for every possible end user and a future with better person-centered (dementia) care.

Additional file 1: Topic lists stakeholders

Dyads

Participation

- Motivation to participate to project
- Motivation to participate to research

Creation process

- Time span (every two weeks, 5x one hour)
- Experiences: looking back in general; doing it together with loved one
- What went well?
- Possible obstructions/dealing with negative memories/events
- Contact with volunteer: first contact; collaboration; trust; conversations; shared all relevant information/could you speak freely; clarity about agreements
- Advantage of online aspect: own contribution online; others that assisted (who and what)

Usability/functionality

- Frequency use of life story book general: last week; weeks before
- Use lsb general: conversations, activities, other
- Hellomydear: advantages and disadvantages of online functions
- Albelli: what would you think if the following functions were possible: creating it online; using it online; creating it together with family; sharing it with family, relatives or caregivers; ability to keep on adding memories after it's printed; multimedia (photo, movie, music)
- Actual use Hellomydear: online functions (keep on adding, sharing, music & video): what functions did you actually use? what would you want to keep on using?
- Actual use Albelli: did you use the link; what functions would you like to use?

Final result

- General satisfaction with final result
- What do you like/what works for you?
- Points of improvements

Added value

- What and why
- Other possibilities how it can add to your life?
- How could it add to the care you receive?
- Added value for future
- Activities undertaken in response to the OLSB (e.g. visited places or friends, picking up a hobby, cooked something from an old recipe); difference before and after OLSB

Engagement caregivers/care professionals

- Who is involved in your care and did he or she do something with the OLSB (talk about it, look in it)

Volunteers

Participation

- Motivation to participate to project
- Expectations & came true

Creation process

- How was it to create a life story for somebody?
- What were the conversations about (describe how a conversation went)?
- What did it bring you?
- Is there an added value for yourself?
- Is there an added value for the participant?
- What went well?
- What made it easy for you during the creation of the album?
- What didn't went well?
- Was there anything you would have done differently, in retrospect?
- What was the task division between participant and informal caregiver?
- What was the task division between you and the dyad?
- What was the input/contribution of the dyad?
- Presence informal caregiver during conversations (Was he/she present at each meeting?)

Time investment

- 5 conversations: realistic?
- 1 hour per conversation: realistic?
- Frequency of 1 conversation every two weeks: did you deviate from it?
- Time needed to prepare a conversation
- Time needed to process a conversation afterwards
- Subjective impression of time investment

Contact with participants

- First meeting, impression
- General impression contact between you and participants
- Clarity about agreements (division of tasks/home work/how often you visited)
- How easy was it to start the conversation and to keep it going?
- What went smoothly in the collaboration?
- What went less smoothly in the collaboration?

- Do you think something changed in the relationship of the dyad during the process?
- Do you think something changed in the participant's ability to recollect memories during the process?

Training and intervision
- Did you feel prepared well enough by the training?
- What were positive things about the training?
- Did you miss something in the training?
- How did you experience the meetings with the other volunteers?

Technology
- Experience using technology
- Did you use internet for finding materials, or was everything you included in the possession of the participant?
- Did you digitalize existing documents or photo's? (How many?)
- Do you feel that technology is an added value to create an OLSB? For the participant; for yourself
- Do you feel that technology/the application is an added for looking in the album? (for the participant)

Contact volunteer-participant
- Did the OLSB change your impression of mr/ms?
- (How) did the relationship between you change during the process?

Formal caregivers

General – about the project
- How did you get in touch with the project?
- What did you know on beforehand of this project?
- What where your thoughts about the project?

(if applicable: what was your motivation to sign the dyad(s) up)

Album of participant
- Did you see the album already?
- Did you use the album (if yes: how, which activities)?
- Impression of album?
- What is convenient about the album (benefits)?
- Added value for client?
- Added value for care professionals?
- Did your relationship with x changed by knowing the personal story of x? What might be

positive changes; what might be negative changes?

Technology

- Added value of technology for client (if yes, how) and yourself and other care professionals (if yes, how)

Future use

- Added value OLSB care for older persons in general
- Could it improve care for persons with dementia?
- Could creating an OLSB enhance the relationship between care professionals and clients?
- Possibilities implementing and applying in care: how; what is needed; possibilities to integrate; developments in care that could support the idea of life story books; what would support you to use it; what is missing; how would you want to use it; possibilities in everyday work and did you already do this; other possibilities of using OLSB; does it connect to existing technology in care?
- Possible barriers or obstacles when implementing the OLSB in care; what do you encounter
- Possible benefit of using the OLSB in care (could it be supportive when persons need to live at home for longer)

Care professionals

Added value

- What is the added value of this intervention for: care institution; department; care professional; client; family/informal caregivers; volunteers?
- Do you think the intervention works well like this?
- What are advantages and disadvantages of this intervention?

Quality of the intervention

- What works well when using life story books?
- What doesn't work well when using lsbs?
- What are possible points of improvement?
- What do you think about deploying volunteers?

Technology

- Added value of technology to the album; for who is technology a benefit?
- Benefits of online function to clients, family/informal caregivers, care professionals?
- Which functions would you use?
- How important is the function to print the book?
- Connection medical record: desirable? Possible?
- Other digital functions

Future

- What is your vision about using life story books in care?
- How could it be used in your care institution?
- How could it be integrated/implemented easily in your care institution?
- What is missing at the moment?
- Task division: guarantees, coordination (e.g. for matching volunteers and participants), role for yourself, role for informal caregivers
- Tasks of management to implement it well
- Hindering factors for sound implementation
- Current developments in care that could support the idea of life story books
- What would support you to use it?
- Which factors could benefit a sound implementation?

Intermezzo 2

Interactive seminar with stakeholders

i.2

Aim

As part of the Online Life Story Book project an interactive seminar was organized by Teuntje Elfrink, Gerben Westerhof and Christina Ullrich from the University of Twente on 20 October 2017. The meeting took place during the trial, but was detached from the studies performed on the OLSB. The aim of this meeting was the exchange of knowledge about and experience with the implementation of life story books, to strengthen its position in elderly care.

Attendance

Eighteen persons with different backgrounds and functions participated, all with a link to life story books. Organizations represented were (applied) Universities, care institutions, funding agency and private initiatives (Universiteit Twente, Livio, ZonMw (Memorabel), de GeluksBV, Mijn Leven Als Verhaal, Tangenborgh, ZorgAccent, ROC van Twente, Nationaal Ouderenfonds, Vrije Universiteit Amsterdam, Evenmens, and Stichting Het Levensverhaal En Suite). Specific positions represented included GZ psychologist (licensed psychologist), elderly-care physician, researcher, manager and teacher.

Set up and results

The seminar had a duration of 3 hours and consisted of two interactive rounds, concluded with a plenary closure.

Round 1

In the first round, the participants were divided into subgroups of 4-5 people. First of all, a kind of mini-reminiscence was undergone to experience what it is like to share and ask for personal memories (with strangers): everyone made a minor timeline of his or her life on the basis of 5 photos or other materials. The timelines were then shared and explained to the group members. The guiding question for the discussion was: *What elements are needed in a life story book in order to shape person-centered care?* Important themes were noted on sticky notes; each group had its own color. The memo sheets of all groups were then clustered on a large sheet and discussed.

Themes that emerged from this last step:
Senses: How do you appeal to your senses to reminisce?
Themes: What themes can you address?
Values: Who is a person? What are interests, habits, idiosyncrasies?
Shape: Will it be an online book with an offline/tangible variant? How do you ensure as much experience and sensation as possible?
Order/structure: Do you make a chronological or thematic life story (book)?

Difficult themes: What to do with secrets, difficult memories or traumas?
Who: Who decides/is in charge? Who creates the life story book?
Privacy: Who can see what? (difference between family and care professionals) Connected to that:
Function and aim: Is it something to share amicably, is it a good use of time, does it have a therapeutic function, is it discussed in groups, do you link it to daytime (care) activities? The function and purpose determine the design of a life story book and the questions you ask persons.

Recurring and overarching, **autonomy** emerged as the central theme. It is important that the person in question has control over their own life story and has ownership over what is included and who can view or use it for what purpose(s).

Round 2

Groups of 4-5 people have been formed, in a different composition. During this second round, the participants considered the following practical question: How can we integrate the use of online life story books or life stories in care?
Ingredients were collected on the basis of cards with questions: what do you come across, what do you have to take into account, what are important elements? Subsequently, a recipe was made per group using the collected ingredients: how do you make it into a good dish?
The recipes made were discussed plenary. The main findings:

What are the **basic ingredients**? (what are the conditions?)

- Respect, ownership, autonomy, privacy
- Time and policy
- Connecting to the needs and wishes of the person concerned
- A flexible display of the story (both chronological and thematic)

What does the **mixing bowl/the kitchen/the worktop** look like? (what is the context?)

- Aim (person itself, caregiver, loved ones)
- Functionality (sense of purpose/meaning, (emotional) release, conversation material)
- Embedding on a technical and organizational level
- Sufficient amount of financial resources and manpower
- Intramural, dementia care, individually, independently/together with an informal caregiver or volunteer

What **temperature** do you set the oven to? (how do you organize it?)
- Securing, time, budget, continuity
- Involvement
- Connect with what is already being done; integrate

What makes it **sweet**? (human, person-centered elements)
- Passing on knowledge
- Contact, empathy, reciprocity, deepening, trust, collaboration
- Not only include texts (poems, photographs, recorded text, videos)
- Pop-ups on important dates

What makes it **spicy**? (how do you provide structure; how do you promote enthusiasm?)
- Give autonomy
- Listen carefully, patience, step by step
- Pay attention for social and conversational skills in training (persons who assist in creating)
- Deployment of (grand)children, use of multimedia, integrate in daily practice

What makes it **bitter**? (what are possible stumbling blocks, hindering factors?)
- Time, money, laws and regulations, measuring effectiveness
- Filling in for someone (take away autonomy)
- unfamiliarity, scepsis, burdening/overloading informal caregiver

The dishes were given names such as *stew/genuine curiosity, gourmet, to be continued and I… [hobby/passion] so I am.* Flavors mentioned were *nutritious, happy, delicious for everyone and longing for more*. Lastly, expectation management, family participation, the fact that many parties can benefit from it and that it is an investment in well-being ensured the balance.

Main conclusion of this seminar

There are multiple ways to apply life stories in care and in both rounds, autonomy emerged as the most important condition to take into account.

General Discussion

This thesis explores the use of (digital) LSBs in dementia care by using a multi-method approach. In this final chapter, the most important findings of our studies are summarized and contextualized. Next, strengths and limitations are discussed. Lessons learned are shared and elaborated on – as it provides valuable information for both future research and practice. This will be illustrated by means of a practical guideline for both researchers and practitioners.

Summary of key findings

Chapters 2-6 answer the research questions posed in the general introduction. Below, the key findings of these studies are summarized.

○ **What is known about (digital) life story book interventions in dementia care?**
The use of LSB interventions in dementia care is emerging, but there is a lack of (consistent) studies and information reported about the implementation and content of the LSBs.

In our comprehensive systematic review in chapter 2 (Elfrink, Zuidema et al., 2018) we searched original empirical studies on LSBs for people with dementia. In total, 14 studies were included. The systematic review displayed an increase in studies on LSBs in dementia care. It also exposed a wide variety between the identified interventions and studies, which made it difficult to compare and draw general conclusions. Some of the studies were solely directed at the person with dementia, whilst others included (in)formal caregivers as well. The most frequently used methods to assess intervention effectiveness were qualitative interviews, case studies, and/or (pilot) randomized controlled trial (RCTs) with small sample sizes. Qualitative findings showed LSBs could prompt memories and could enhance the relation with the person with dementia. Quantitative effects were reported on, e.g. autobiographical memory and depression of persons with dementia, burden of informal caregivers, quality of relationship with informal caregivers, and on attitudes and knowledge of formal caregivers. The majority of the LSBs was created during 3-16 individual sessions (median of six sessions), in nursing homes. Only three of the studies used a form of technology: one was a life story movie and the other two interventions were (basic) digital applications with pictures and sounds. Not all studies included a sufficiently detailed description of intervention and the ‘’end products”: what did the created books look like? Intermezzo 1 of this thesis therefore provides a detailed description of our own digital intervention.

○ What are the quantitative effects of the Online Life Story Book for persons with early dementia and their informal caregivers?

Self-rated caregiver distress was reduced during the OLSB. Small but insignificant effects on neuropsychiatric symptoms, caregiver distress and quality of life of caregivers were observed.

A digital LSB intervention executed together with the informal caregiver in the home setting and deployed by a trained volunteer had not been evaluated yet. Chapter 3 describes the protocol of our study (RCT and process evaluation) that examined the OLSB (Elfrink et al., 2017). The subsequent chapter 4 presents the results of the RCT (Elfrink et al., 2021). The aim of the RCT was to investigate whether the OLSB is more effective than a wait list control condition on neuropsychiatric symptoms (NPS) in persons with early dementia and the distress and quality of life (QOL) of their primary informal caregivers. Outcomes were measured at baseline (T0), and 3 months (T1), and 6 months (T2) later. In total, 42 participants were included, of which 23 were female and 19 were male. The mean age of the persons with early dementia was 80 years (range 49-95). The total drop-out rate was 14.3 percent. A total of 18 volunteers guided the participants in both conditions, in approximately 5 meetings spread over 8-10 weeks. Small but insignificant effects on NPS, caregiver distress and QOL of caregivers were found over time. There was one exception: self-rated caregiver distress dropped significantly during the intervention (at three months), but increased at six months. Reasons for our results might be the relatively good health of the participants, practical challenges during the intervention, and the focus of our outcomes.

○ What is the content of Online Life Story Books of persons with early dementia?

The created books were rich in both structure and content, and the content seemed to match with the social function of reminiscence.

Our systematic review (chapter 2) showed that studies mainly reported quantitative and qualitative outcomes of the LSB interventions, while little was shared about the end result of these interventions: the created (digital) books. Therefore, chapter 5 describes a content analysis of eight of the books created in our study. We created a coding scheme and identified two main themes: the structure and the content of the OLSBs. In terms of its structure, a book comprised of 75 memories on average, each represented by approximately two photos and/or texts (i.e., components). Regarding the content, the majority of the components were of a positive, recurrent nature, from an unknown perspective, and belonged to the themes of vacations, family, or home. Most components took place in the life phase from 45 to 64-years-old and were either without text or of a descriptive nature. The fact that specific positive memories were included in all eight books, is promising and seems to indicate that the content matches with the social function of reminiscence. The exact content of the OLSBs seems to depend on the availability of materials, and the choices of the creators (persons concerned, family and volunteers). All in all, we concluded that the analysed OLSBs were rich in both their structure and content.

○ **How was the process of creating and implementing Online Life Story Books evaluated by the different stakeholders?**

Participants mentioned (potential) benefits of the OLSB, not only for themselves but also for other types of stakeholders. They also gave insight into the process of creating OLSBs when it comes to context, target population, task division, activities, conditions and risks. With respect to the technology used in the OLSB, they shared information about usability, user needs, and integration in care.

Our systematic review (chapter 2) also showed that little was reported about the implementation of LSB interventions in dementia care. Hence, in chapter 6 we performed a process evaluation to gain insight into the perceived effectiveness and the implementation of OLSB and the use of technology.. In total, 26 semi-structured interviews were conducted with four different types of stakeholders. The first three types derived from eight ‘’cases’’, being: 1) the person with dementia together with their informal caregiver, 2) the volunteer that guided them, 3) and their primary formal caregiver). Additionally, four care professionals that were not directly involved in creating OLSBs were interviewed (i.e., psychologist, senior psychologist, manager, elderly-care physician). Additional information about the implementation was derived from logbooks kept by the volunteers. Perceived and potential benefits of the OLSB mentioned by stakeholders were mainly on social outcomes such as interaction, relationship and getting a holistic view on the person with dementia. The usability of the OLSB was perceived as positive, whilst the time it took to digitize the materials and the fact that the OLSB was part of a bigger research project were named as negative aspects. Stakeholders appreciated the technological functions of monitoring the process and inviting family members so they could assist from a distance, and the potential integration into the client’s overall care (e.g. by connecting it to the electronical medical record).

Discussion of key findings

The use and potential of (digital) life story books in dementia care

The results described above contribute to existing knowledge about LSBs in dementia care. In order to say something about the relevance of and future directions for LSBs in dementia care, we have to weigh up the various studies. In the following, the key findings of our studies will be discussed in relation to the literature.

We know from previous reviews and meta-analyses that reminiscence is a promising approach in dementia care, as it can decrease depressive symptoms for persons with dementia, and enhance their mental health, QOL, and cognitive functioning (Woods et al., 2005; Subramaniam & Woods, 2012; Blake, 2013, Huang et al., 2015). A specific form of reminiscence is creating a LSB; McKeown et al., 2006). Our systematic review (chapter 2, Elfrink, Zuidema et al., 2018) supported and complemented the findings of the studies on reminiscence in general, as there was no overview of the use and effectiveness of LSBs specifically in dementia care yet. Our review showed that the use of LSB interventions is emerging, and that a variety of interventions is employed. We looked at both characteristics of the interventions and at study characteristics. Quantitative as well as qualitative effects were reported, e.g. on depression, burden of informal caregiver, quality of relationship with informal caregivers, prompting memories and autobiographical memory. This is in line with evidence found for reminiscence interventions in general, and of course very promising. At the same time, our systematic review also revealed that there is an inconsistency in how the LSB interventions are reported on. Besides, we encountered missing information, especially about the actual intervention (how many sessions, who executed it, which framework was used, how did the created books look like).

This motivated us to develop, implement and evaluate our own intervention, and to report on it: The Online Life Story Book (OLSB). To gather as much information as possible, we performed an RCT, content analysis and process evaluation. Below, our interpretations will be discussed in light of the basic psychological needs and the use of technology.

Basic Psychological Needs

The social function of reminiscence seems to play a relevant role in the OLSB, autonomy appears to be an important condition to keep in mind when implementing an intervention alike and the OLSB seems to support the ability of persons with dementia to retrieve memories. A theory that matches these conclusions is the Basic Psychological Needs Theory (BPNT; Ryan & Deci, 2017). According to this theory, well-being can be increased when the three basic psychological needs of relatedness, autonomy and competence are supported (Ryan & Deci, 2000). In the following, our findings are discussed considering these three basic psychological needs.

Relatedness

Relatedness refers to the need of feeling connected to others, of having a sense of belonging, and of feeling supported (Ryan & Deci, 2000). Perceived and potential benefits of the OLSB mentioned by the stakeholders we interviewed as part of the process evaluation (chapter 6) centered around social outcomes, for example interviewees shared that our digital application predominantly can enhance the relationship between the person with dementia and their family, volunteers and informal and formal caregivers. This was in line with the findings of our systematic review, which showed that the interaction and the relationship with the person with dementia were important outcomes. Furthermore, our content analysis (chapter 5) exposed that the created books were rich (in terms of number of memories, themes, life phases, and multisensory elements) and included specific and positive memories: all characteristics supportive of the social function of reminiscence (Westerhof et al., 2010). This social function is described as follows by Westerhof and Bohlmeijer ''By retrieving and sharing memories, people create and maintain social bonds. They get to know each other, maintain relationships and pass on experience to others.'' (Westerhof & Bohlmeijer, 2021, p. 272). Overall, OLSB – and LSBs in general – may support the need of relatedness as LSBs can empower the relationships and the sense of belongingness of the person concerned.

Autonomy

Autonomy concerns the need of having control – and having a choice – over one's life and more specific about one's behaviour and actions (Ryan & Deci, 2000). Dementia is referred to as ''a condition that groups symptoms of impaired memory, thinking, behaviour and emotional control problems resulting in a loss of autonomy.'' (Gauthier et al., 2021). In our process evaluation and in the interactive seminar (intermezzo 2), autonomy came forward as the most important requirement when implementing a LSB intervention in (dementia) care. LSBs could support the need of autonomy of persons with dementia, both during and after the creation of their life story. In the creation process, they can be actively involved and make choices on what to include. When the life story is completed, they can choose who can have access to it. When used by care professionals a personal (O)LSB can provide better insight in their personal values and preferences, which enables autonomy-supportive care when people become unable to communicate their choices. By involving persons actively in their care process, they are giving more control – autonomy – over the care they receive (Clarke, 2000; Clarke et al., 2003; AGS, 2016).

Competence

Competence is about the need of expressing and building one's abilities (Ryan & Deci, 2000). In our project most of the persons with early dementia had a meaningful contribution to the creation of their OLSB, supported by family and volunteers. The set-up of the intervention allowed for a flexible division in tasks and the participants were actively involved in this. In the perceived effects, it appeared valuable to ''live their life again" and that memories emerged when working on their story. As dementia is a progressive disease, persons living with it will encounter impairments and loss of fulfillment of their needs when the disease develops. However, most persons with early dementia are still able (competent) to reminisce and share personal memories, as the autobiographical memory remains intact for a relatively long time regardless of the progress of dementia (Dempsey et al., 2014; Caddell & Clare, 2010). This, in combination with the stimulating function of using multisensory cues to elicit memories and the involvement of the social system, makes the OLSB a suitable reminiscence approach for persons with dementia (Lazar et al., 2014; Westerhof et al., 2010). Besides, an advantage of the OLSB is that it can serve as a kind of external autobiographical memory which remains available for family and carers even if the person concerned is no longer able to actively retrieve one's memories.

Technology

Next to the basic psychological needs, the use of technology is a key point in discussing our studies. It is known that technology can support reminiscence and thus LSB interventions in multiple ways: users can easily document, retrieve and add personal memories; it can prime the senses in order to elicit memories; and technology can make the process more interactive (Lazar et al., 2014; Zhang & Ho, 2017). Furthermore, technological reminiscence interventions can be used in the home setting as well as in institutional care. In 2012 Subramaniam and Woods expected that digital life stories for persons with dementia would become standard by 2017. It is evident this prediction has not come true yet. As only three of the fourteen studies included in our review (chapter 2) had a technological element, and the use of digital components other than digital photographs in our eight analysed OLSBs was scarce (chapter 5), the digital revolution in the use of LSBs has yet to start. This is somewhat contradicting with the benefits of technology of the OLSB stakeholders mentioned during the interviews: not only did they appreciate the technological functions of the OLSB (such as easily placing memories on a timeline or inviting family members to join from a distance), but possibilities for future deployment of technology in such interventions (linking it to the client's electronical medical record) were posited as well (chapter 6). Besides, literature on the use of technology in (general) dementia care shows a rise in the use of e-health in dementia care (Nijhof et al., 2009; Pappadà, 2021). This increase matches the growing computer and internet competencies and skills of older persons (Van Deursen & Van Dijk, 2015; CBS, no date). At the same time, the use of technology in (dementia) care also comes with ethical concerns and challenges, such as safeguarding ones privacy and autonomy.

To conclude, our studies show potential in using – digital – LSBs in dementia care. When implementing a LSB intervention relatedness, autonomy and competence must be considered, just as the opportunities and obstacles of using technology (e.g. multisensory cues; privacy).

Strengths, limitations and implications

The strengths and limitations for each study were addressed in the respective chapters. Below, we discuss the strengths and limitations of this thesis on a meta-level, and make recommendations for both future research and practice.

Multi-method approach

This thesis contains a multi-method approach to explore LSBs in dementia care. A multi-method approach refers to using multiple methods (mostly quantitative and qualitative) in order to discover more than only whether an intervention works or not (Creswell & Creswell, 2017). A multi-method approach is especially suitable for exploring broad research aims – like ours – and by giving more nuanced insights it can help in providing a holistic understanding of the (psychological) phenomenon investigated (Frost & Shaw, 2015). We feel all our studies complement each other: the literature review exposed both benefits and gaps and thus the potential of existing LSB interventions in dementia care; the RCT focused on quantitative effects of our intervention; the content analysis gave insight in what was included in the created LSBs; and the process evaluation revealed stakeholders' perspectives. Employing different types of studies helped us in expanding our scope and weighing the outcomes. For example, the answers in the interviews from the process evaluation put the (lack of) effects of the RCT into perspective. Altogether, using multiple methods enabled us to explore the use of LSBs in a complementary way.

However, there is more potential in combining the multiple methods, but this was out of the scope of this thesis. Firstly, diving deeper into individual cases could have given us further insight. *How did person x experience the process, what was included in this particular book, what were qualitative perceived benefits and does that match the quantitative outcomes for this specific person? Do the persons of whom the burden decreased share several characteristics in their books or perceived effectiveness?* Secondly, focusing more on using logdata could have given us more information about the actual use of the OLSB (both in the creation process and once finalized). Thirdly, more follow-up measures would have enabled us to monitor the longitudinal developments of possible effects, for example to see whether the books that focus more on the social function can indeed enhance relationships and lead to better or deeper connections as is aimed for.

With our multi-method approach we tried to find a balance between comparing and drawing conclusions on the effectiveness of the OLSB at group level on the one hand and understanding the perceived effectiveness and the content of the books on the other hand. In our quantitative RCT the process of the persons disappeared; in our qualitative process evaluation that process became apparent on a group level; in our content analysis we still focused on drawing conclusions based on multiple books rather than diving into one case. We experienced the tension between the nomothetic and idiographic approach: when you start comparing or putting together different cases to draw general conclusions (nomothetic), the uniqueness (idiographic) devalues (McAdams, 2008). However, one could also see these two approaches as complementary rather than conflicting, as both perspectives allow to understand human behaviour and can be used (and reinforce each other) in implementation science (Lyon et al., 2017). So while we could have strengthened our approach even more by paying further attention to the uniqueness through zooming into one specific case, we feel the observed uniqueness of the created books contributes to (and is even essential for) providing PCC.

Practical context

Next to employing using a multi-method approach, another strength of this thesis is that it was set up in a practical context and thus reflects a real life setting, which contributes to the ecological validity (Andrade, 2018). Besides, in our studies we primarily focused on the person with dementia, but we also included other relevant stakeholders – being informal caregivers, volunteers, professional caregivers and other care professionals. We feel involving all those concerned in creating a LSB enabled us to obtain a more complete picture. Using multiple methods in practical research and including different stakeholders can increase person-centered care (Ivankova, 2017). But doing research in the field also comes with challenges. For instance, we had difficulties with the recruitment which was a time consuming process to say the least – and therefore it was hard to reach the needed power for our RCT. There were enthusiastic formal caregivers who suggested and approached possible participants, but we also met carers who did not see the potential of the project or did not feel the time to be involved. This corresponds with findings of a systematic review of Groot Kormelinck and colleagues (2021), in which the perceived work and time pressure of care staff was found to be a hindering factor in implementing complex interventions in long-term dementia care. Due to the better-than-expected adherence and thus a lower drop-out rate than we estimated, we managed to get a sufficient power for our RCT. Then, our participants appeared to be in relatively good health when starting the intervention, which may have contributed to the lack of significant effects. As goes for the recruitment, collecting data (both quantitative and qualitative) was time consuming as well. Especially conducting the questionnaires for the RCT took more time than we anticipated. A further drawback was the unexpected termination of the hosts of the application we initially used – in the middle of the RCT. Discussing possibilities to keep on using the application and looking for suitable alternatives when the termination was definite was a challenge. Projects in a practical context strongly depend on cooperation and communication between different parties (Groot Kormelinck et al, 2021). Besides, some of the aims of the project could not be realized due to practical issues. There were struggles with studying the (time to) nursing home admittance as a longer term effect of the OLSB and with conducting a health economic evaluation of the intervention, both due to a lack of data. However, for the final report for the grant provider we did perform a minimal cost-benefit analysis with the data we did obtain. This showed no differences in healthcare consumption/ expenditure (measured by means of the cost manual, van Hakkaart-van Roijen et al., 2016) and health related quality of life (measured with EQ5D; Brooks, 1996) between the intervention and control condition. We also calculated the costs for implementing (training and supervision of volunteers, printing the books) and assuming a volunteer creates three books, it cost around €150,- per book (so per person with dementia).

All in all, it became clear that we were working with humans and had to deal with unforeseen issues like these. However, by expanding the process evaluation and content analysis, we feel we extracted supplementary relevant information. Besides, we learned valuable lessons for the future. In the following, we will summarize our key research and practical implications.

Research and practical implications

As we see possibilities for (digital) LSBs to enhance the social relationships, autonomy and competence of the person concerned, one can say that it might support the three basic psychological needs as described in the BPNT (Ryan & Deci, 2017). Paying attention to autonomy and competence seem to be conditions one need to take into account when employing a LSB intervention, whereas relatedness seems to be both a condition and an outcome of the LSB intervention. For future research on LSB interventions in dementia care, it would be interesting to focus on these needs more explicitly and see how these needs play a role. For example, does reminiscing about a time in which a person was competent (e.g. in their work or caring for their family) enhances the fulfilment of the current feel of competence?

Next to the four studies, we also organized an interactive seminar with eighteen stakeholders to exchange of knowledge and experience, to strengthen the future of life books in elderly care (see intermezzo 2). Based on our studies, the seminar and previous research we learned there are important points to keep in mind when developing, implementing and evaluating an intervention like the OLSB in (person-centered) dementia care. In this part, we listed down the key points with accompanying questions and considerations, which we summarized into a schematic representation at the end of the paragraph.

We are aware that multiple theoretical models exist when it comes to developing, implementing and evaluating (e-)health interventions, such as the CeHRes Roadmap, the ASCE model or Intervention Mapping (van Gemert-Pijnen et al, 2011; Wiering et al., 2011; Fernandez et al., 2016). The first has even been applied in the context of dementia care and is reported on by means of a case study of an interactive web-based system to support shared decision-making in care networks of people with dementia (van Gemert-Pijnen & Span, 2016). In our case, the OLSB made use of an existing application, to which we added our method in the context of persons with early dementia living at home. So we did not develop the technology or application itself, but tailored the use of existing applications to the goal of our project. For further development of an intervention like ours and its support by technology, it might be worthwhile to investigate whether an existing model, such as the ones listed above, can assist.

Based on our findings, we identified four general recommendations, being about formulating aims, intervention design, implementation plan, and evaluation. Most of the recommendations apply to both researchers and practitioners (and we can imagine there might be a double role as well); some are more relevant for researchers and others for practitioners.

Formulating aims

What is the main aim or what are the aims: what is the purpose of your LSB intervention, what do you hope to achieve in the end? Who is your target group?
First of all, it is important to take the intended use of the books into account, whether you are a practitioner or a researcher – or both. For example, is it ‘’just’’ an activity to spend time or does it have a therapeutic function? Do you want to use it as a tool

to reminisce, to support the social relationships, to improve cognition, to decrease NPS, to strengthen the identity or to provide PCC? Or perhaps a combination? Each intended use asks for a different approach.

A question to keep in mind when formulating aims: Who is your target group? Are you focusing on persons with (early) dementia or perhaps before potential memory loss (so they could contribute more to their LSB)? What about involving informal caregiver(s), formal caregivers, care professionals, volunteers, or other persons?

Intervention design

What does your intervention need in order to meet your aim(s)?

This is important for both researchers and practitioners. It follows on the previous, on your formulated aim(s). Considerations for intervention design:

What are the main elements of the intervention?

Do you want to create digital or handwritten books? Do you want to use video's, photographs, audio, or a combination? What is the basic idea you have in mind?

How to align this to the needs, skills and competencies of the user(s)?

Who will use the intervention? What do they need? What are their skills and competencies? How can you facilitate them? Users can be: persons concerned, family, volunteers (like we did), professionals, or perhaps a combination.

What are pro/cons of technology (if applicable)?

Technology was an added value in our intervention. Possible functions to consider when developing a future LSB intervention, are a timeline and making connection with the electronical medical record. You can create a flexible display of the story (both chronological and thematic), so persons can sort their memories in both ways. But when it comes to using technology, be aware of privacy, hosting, maintenance, and costs of using the technology. Another consideration: do you want to keep track of the use for research purposes, so include logdata? Think about how technology can serve your target group, but also think about possible downsides of using technology. Pilot test your intervention with those who are going to work with it before implementing it on a larger scale.

Implementation plan

How to properly implement it into practice? What is the context?

Things to keep in mind whilst creating an implementation plan:

Who will facilitate (/pay for) the intervention?

For example, it can be financed by the care institution, government, insurance company or paid privately.

What is the setting, where does it take place?
Are you going to deploy it in an intramural setting, at home, at a care institute? Will it be individually or in groups, independently/together with an informal caregiver or volunteer?

Who will execute the intervention?
Think about deploying volunteers (like we did), professionals, family, or perhaps a combination.

Set up/time line
Make a realistic one; as experienced during the implementation of the OLSB, it's people work and all steps just take (more) time, especially when it comes to recruitment, particularly when the intervention is accompanied by a study. Be patient, take your time.

General costs
Calculate other costs like training (conversational and technological skills) and take actual time to create the books into account.

Conversational and social skills
Pay attention to conversational and social skills in order to align with the person(s) you (or volunteers, carers, whomever) are working with. A special training for the persons who are involved in creating the (digital) LSB (informal caregivers, formal caregivers and/or volunteers) might be necessary.

Questions to ask/what to include
Depending on the aim: what questions are you going to ask? Do you want to include only happy memories or also more difficult ones? In our study in which we focused on reminiscence as main aim, we screened for past psychotrauma as reminiscence can cause reliving past traumas and can be dangerous. But when you want to use the LSB to support (person-centered) care, it might be helpful to know about these more negative life events.

Autonomy and privacy
Next, we feel special attention must be paid to autonomy and privacy – which are connected. To start with autonomy, we believe you have to be aware of supporting

autonomy on three levels: on what to include, on how to create the life story book, and on what to share with whom. When it comes to what to include, there needs to be a balance in steering. You need to ask questions to prompt memories. At the same time you need to let them decide in the end; after all it is their story. The same goes for guiding them through the process of creating the book: there needs to be a global guideline and timeline, but you need to be flexible to adjust it to the preferences of the person concerned. For example, retrieving memories and talking about the past can be very exhausting, so you might need to shorten the sessions. Plus, keep on talking about the division of tasks: what does the person want to do (and what is possible), and how can you support that? The question on what to share with whom is connected to privacy issues. For example, one can lay it on their own table and only use it in their home but it could also be linked to the electronical medical record. You as researcher and/or practitioner need to be aware of privacy matters, but you must inform the person concerned as well.

Again, the themes mentioned here are dependent on the previous considerations. For example, there is a big difference between using the intervention (book) to initiate conversations between spouses/children and using it in a nursing home where 20 staff members will read it.

Evaluation

How to evaluate the intervention and/or implementation? Which information from whom are you going to collect when and how?

This is relevant for researchers, but might also be of interests for practitioners. The evaluation totally depends on the aims and target group you previously identified. A question that might guide you: Who are involved (persons with dementia, informal caregivers, formal caregivers, …) and what do you want to know from them, which outcomes are relevant? Think about collecting quantitative and/or qualitative data, on the short and/or long term.

So it depends on your aim(s), target group(s) what you are going to assess (NPS, memory, social interaction, …), from whom (persons with dementia, caregivers, …), in which manner (questionnaire, interview, focus group, content, logdata, …), and when (before, during – for example about implementation, so you can anticipate –, right after, after x months, long term). Based on our experience during the OLSB project, we believe social outcomes should be considered when evaluating a similar intervention, for example by using the Quality of the carer-patient relationship questionnaire (QCPR: Spruytte et al., 2002).

Key points and considerations mentioned above, are visualized in a schematic representation:

Key point		***Considerations***
Formulating aims	*What is the main aim or what are the aims: what is the purpose of your LSB intervention, what do you hope to achieve in the end?*	What are your aims? activity to spend time stimulating reminiscence supporting social relationships improving cognition decreasing NPS strengthening identity enhancing PCC (or a combination)
	Who is your target group?	Who is your target group? person with no memory loss-severe dementia informal caregivers formal caregivers volunteers … (or a combination)
Intervention design	*What do does your intervention need in order to meet your aim(s)?*	What are the main elements of the intervention? How to align this to the needs, skills and competencies of the user(s)? What are pro/cons of technology (if applicable)?
Implementation plan	*How to proper implement it into practice? What is the context?*	Who will facilitate (/pay for) the intervention? What is the setting, where does it take place? Who will execute the intervention? What is the set up/time line? (take your time!) What are the expected costs? Do you need to pay special attention to conversational and social skills? What kind of memories to include and which questions to ask? Autonomy Privacy
Evaluation	*How to evaluate the intervention and/or implementation? Which information from whom are you going to collect when and how?*	What outcomes are you going to measure? From whom do you need the information? When do you need the information? Which methods are you going to use?

Example
Suppose, we want to develop an intervention alike and we choose the same target group as in this project, as persons with early dementia are relatively capable to retrieve and formulate autobiographical memories. Given the experiences gained during this project, we would shift the focus of the aim from reducing NPS and caregiver burden to enhancing the social relationships of the person living with dementia and the possibilities to improve PCC. Design and implementation wise, we would use the same set-up for creating the LSBs, but would like to involve the most involved professional caregiver more, in order to enhance PCC. It would be interesting to get insight in what these primary professional caregivers ‘’need”: what kind of information would they like to have in order to be able to provide care that better matches the values and needs of their clients? This could be asked during interviews or focus groups. Then, of course we would like to know whether the intervention actually leads to an improvement in relationships and PCC. A way to evaluate this is by conducting the Quality of the carer-patient relationship questionnaire (QCPR: Spruytte et al., 2002), the Client-centred care questionnaire (CCCQ: de Witte et al., 2006) and the Staff knowledge of care-recipient questionnaire (Subramaniam et al., 2014), in combination with semi-structured interviews for both clients are carers.

This short example is just one possibility of a follow-up, as we feel the opportunities of employing LSB interventions are endless. Overall, keep in mind that working with persons (with or without dementia) and implementing and studying reminiscence or LSB interventions is customized, and most of all people work. This means that the intervention must be aligned with the person with dementia and the persons who are going to implement it (volunteers, informal caregivers, care professionals, …). Therefore, we suggest to use a participatory design model in which different stakeholders are actively being involved in every phase.

This overview with suggested considerations arose from our experiences during this project and might not be complete, but we hope it can provide guidelines for both future research and implementation of interventions like the Online Life Story Book.

Conclusion

To explore life story books in dementia care, this thesis described a systematic review, a study protocol, an RCT, a content analysis, and a process evaluation. The studies give valuable insights in the possible benefits of an intervention like the OLSB in dementia care. The systematic review showed potential effects of LSBs on autobiographical memory and depression of persons with dementia, quality of relationship with informal caregivers, burden of informal caregivers, and on attitudes and knowledge of formal caregivers. Quantitative data gathered during the RCT showed no significant effects on neuropsychiatric symptoms and quality of life and burden of informal caregivers, except for self-rated caregiver distress which dropped during the intervention. The exploration of eight created OLSBs gave extra insight in the actual content of such books and is something that has never been done before, as far as we know. In the interviews of the process evaluation all stakeholders reported perceived and potential effects such as improved relationship and interaction with, and providing a holistic view of the person with dementia. The latter is especially important when it comes to enhancing PCC. According to the stakeholders the use of technology is promising, but one has to keep questions about autonomy and privacy in mind.

Based on all studies, it can be said that (digital) LSBs have an added value in dementia care. This thesis provides considerations for future research and practice, categorized in four main recommendations: formulating aims, intervention design, implementation plan and evaluation. We hope this dissertation contributes to the future of (digital) LSB interventions and hereby to enhancing person-centered dementia care.

Appendices

Abbreviations
References
Samenvatting
About the author
Publications
Dankwoord

Abbreviations

BPNT – Basic Psychologial Needs Theory
CDR – Clinical Dementia Rating
EDIZ – Ervaren Druk door Informele Zorg
EMR – Electronical medical record
ICERs – Incremental cost-utility ratios
LSB – Life story book
MCI – Mild cognitive impairment
MINI – Mini International Neuropsychiatric Interview
NPI – Neuropsychiatric Inventory
NPS – Neuropsychiatric symptoms
OLSB – Online Life Story Book
PCC – Person-centered care
PTSD – Posttraumatic stress disorder
QALYs – Quality adjusted life years
QOL – Quality of life
RCT – Randomized controlled trial
SD – Standard deviation
TOPICS-MDS – The Older Persons and Informal Caregivers Survey Minimum Data Set

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Samenvatting

In de algemene inleiding, **hoofdstuk 1**, wordt de context van de verschillende studies en hoofdstukken van dit proefschrift geschetst. De begrippen dementie, reminiscentie, levensboeken en e-health staan centraal en worden toegelicht, waarna onze eigen interventie – het Online Levensalbum (Online Life Story Book) – wordt geïntroduceerd. We sluiten dit eerste hoofdstuk af met het doel van het proefschrift en de onderzoeksvragen die in de overige hoofdstukken beantwoord worden.

Dementie is een verzamelnaam van ruim 50 hersenziektes. Kenmerkend is dat de informatieverwerking van de hersenen is aangetast. Dit kan invloed hebben op het geheugen, het denkvermogen, het gedrag en de emotionele controle, wat kan resulteren in een verlies van autonomie. Het wordt geschat dat er wereldwijd 55 miljoen mensen met dementie leven en de verwachting is dat dit op zal lopen tot 78 miljoen in 2030. De ziektes die ten grondslag liggen aan de dementie en de uiting van symptomen verschilt van persoon tot persoon. Wel is het zo dat dementie over het algemeen zorgt voor belemmeringen bij algemene dagelijkse levensverrichtingen (ADL) en dat mensen met dementie vaak hulp of zorg nodig hebben.

Dementie heeft invloed op iedereen die betrokken is. Allereerst natuurlijk op de persoon met dementie zelf; het beïnvloedt de kwaliteit van diens leven. Van alle ziektes heeft het de hoogste ziektelast voor mensen ouder dan 65 jaar. Bovendien zorgt dementie voor een hoge belasting en een lagere kwaliteit van leven van mantelzorgers. Deze belasting kan van fysieke, mentale en financiële aard zijn. Daarnaast is het ook een ziekte die hoge zorgkosten voor de maatschappij met zich meebrengt. In Nederland woont ongeveer twee derde van de mensen met dementie thuis en de verwachting is dat dit gezien de vergrijzing zal toenemen. Naast dat het de ‘‘wens’’ van de maatschappij is dat mensen langer thuis wonen, is het ook de voorkeur van de mensen met dementie en hun mantelzorgers zelf om zo lang mogelijk thuis te blijven wonen. Echter is het niet vanzelfsprekend om met een goede kwaliteit van leven thuis te blijven wonen, omdat de neuropsychiatrische symptomen (NPS; zoals apathie, agitatie, depressie, angst en wanen) die gepaard kunnen gaan met dementie de zorg te belastend kunnen maken.

Omdat dementie momenteel nog niet genezen kan worden, richt de ondersteuning en zorg zich vooral op het behouden van kwaliteit van leven, en het voorkomen of terugdringen van psychosociale problemen. Deze zorg kan van farmacologische of niet-farmacologische aard zijn: dit proefschrift richt zich op het laatste. Om (gedragsmatige) veranderingen veroorzaakt door dementie te voorkomen of af te remmen – en om er mee om te gaan – worden in de meeste gevallen gedragsinterventies toegepast, die gericht kunnen zijn op de persoon met dementie, mantelzorgers en de zorgomgeving. Het is belangrijk dat dergelijke interventies goed aansluiten bij de ervaringen, beleving en het begrip van de persoon om wie het gaat, zodat het kan bijdragen aan de wensen en behoeften. Dit komt terug in de beschrijving van persoonsgerichte zorg, een aanpak die in opkomst is binnen de dementiezorg.

Reminiscentie is zo'n persoonsgerichte gedragsmatige aanpak die binnen de dementiezorg wordt ingezet. Reminiscentie wordt beschreven als *''het gebruik van geschreven of gesproken levensgeschiedenissen om psychologisch welbevinden te verhogen''*. De kern van reminiscentie is het ophalen en delen van positieve autobiografische verhalen. Uit onderzoek is gebleven dat reminiscentie(activiteiten) een positieve bijdrage kunnen leveren aan de mentale gezondheid, depressieve gevoelens, de kwaliteit van leven en het cognitief functioneren. Persoonlijke herinneringen kunnen relatief lang worden opgehaald door mensen met dementie en in latere fases van de ziekte kan het ophalen van dierbare herinneringen zelfs nog zorgen voor het herleven van de positieve gevoelens die bij de herinnering horen. Dit maakt reminiscentie een geschikte en waardevolle benadering binnen de dementiezorg.

Het wordt aangenomen dat de positieve effecten van reminiscentie vooral worden behaald wanneer het in een specifieke en persoonlijke manier wordt aangeboden, bijvoorbeeld door het creëren van een levensboek. Bovendien resulteert het maken van een levensboek vaak in een rijk en tastbaar object dat verdere reminiscentie kan stimuleren. Vooral het maken van een levensboek *samen* met de persoon met dementie is veelbelovend.

Er wordt steeds meer gebruik gemaakt van technologie, of e-health, binnen de dementiezorg. Hierbij kan gedacht worden aan domotica, zorg op afstand of mobile applicaties. Deze toename van het gebruik van technologie binnen de dementiezorg past bij de toenemende bekwaamheid en vaardigheden van oudere mensen om met internet en computers om te gaan. Reminiscentie en – meer specifiek levensboekinterventies – kunnen op meerdere manieren profiteren van technologie. Zo kan technologie het opslaan, ophalen en toevoegen van persoonlijke herinneringen vergemakkelijken. Ook kan het verhaal veranderd of geüpdatet worden. Bovendien kunnen er herinneringen toegevoegd worden in de vorm van geluid, foto's en video, om zo (meer of andere) herinneringen aan het licht te kunnen brengen. Ook kan technologie het reminisceren meer interactief maken, doordat familieleden bijvoorbeeld op afstand mee kunnen werken en iets kunnen toevoegen. Tot slot kunnen technologische interventies zowel in de thuissituatie als binnen de institutionele zorg worden gebruikt – en worden gedeeld wanneer de zorgbehoefte verandert (bijvoorbeeld wanneer mensen niet meer thuis kunnen blijven wonen).

We weten dus dat levensboeken ondersteunend kunnen zijn voor mensen met dementie. Er is echter nog weinig bekend over het gebruik van digitale levensboeken in de dementiezorg. Daarom hebben we het Online Levensalbum in het leven geroepen. Dit is een – de naam zegt het al – digitale applicatie waarin mensen hun herinneringen kunnen opslaan en delen. Herinneringen zoals een huwelijk of geboorte, maar ook recepten van iemands (groot)moeder, of iemands favoriete lied kunnen worden opgenomen op een digitale tijdslijn. Herinneringen kunnen worden toegevoegd als tekst/verhaal, foto, geluid of video.

Vernieuwend aan het Online Levensalbum is dus het gebruik van technologie. Daarnaast is het uitgerold in de thuissituatie. Ook zijn mantelzorgers betrokken, omdat we weten dat dergelijke interventies ook voor hen waardevol kunnen zijn. Tot slot hebben getrainde vrijwilligers de boeken samen met de koppels (persoon met dementie en mantelzorger) gemaakt. We hebben hiervoor gekozen omdat het minder stigmatiserend kan zijn dat een vrijwilliger mensen helpt dan wanneer een zorgmedewerker een dergelijke activiteit op zich neemt, het kostenbesparend kan zijn en het een waardevolle tijdbesteding voor de vrijwilliger kan zijn.

Omdat een dergelijke interventie nog niet eerder is onderzocht en er over het algemeen weinig bekend is over het gebruik van (digitale) levensboeken in de dementiezorg, zal dit worden verkend in dit proefschrift.
In de introductie worden vijf vragen gesteld, die in de daaropvolgende hoofdstukken worden beantwoord.

Wat is er bekend over (digitale) levensboeken binnen de dementiezorg?

In onze uitgebreide systematische review in **hoofdstuk 2** hebben we de elektronische databases Scopus, PubMed en PsychINFO en referentielijsten doorzocht, om empirische studies over levensboeken bij mensen met dementie te selecteren. In totaal voldeden 14 van de 55 geïdentificeerde onderzoeken aan de inclusiecriteria. De systematische review liet een toename zien van studies over levensboeken in de dementiezorg. Het onthulde ook een grote verscheidenheid tussen de 14 geïdentificeerde interventies en onderzoeken. Sommige onderzoeken waren uitsluitend gericht op de persoon met dementie, terwijl andere zich ook op (in)formele zorgverleners richtten. De meest gebruikte methoden waren kwalitatieve interviews, casestudy’s en/of (pilot) randomized controlled trial (RCT’s) met kleine steekproefgroottes. Kwalitatieve bevindingen toonden aan dat levensboeken herinneringen kunnen oproepen en de relatie met de persoon met dementie kunnen versterken. Kwantitatieve effecten werden gerapporteerd op bijvoorbeeld autobiografisch geheugen en depressie van personen met dementie, belasting van de mantelzorgers, kwaliteit van de relatie met mantelzorgers en op attitudes en kennis van formele zorgverleners. De meerderheid van de levensboeken werd gecreëerd tijdens individuele sessies, in verpleeghuizen met een mediaan van zes sessies (variërend van 3-16). Slechts drie van de onderzoeken bevatten een vorm van technologie: één was een levensverhaalfilm en de andere twee interventies waren (basale) digitale toepassingen met beeld en geluid. Niet alle studies rapporteerden alle (wat wij beschouwden als) relevante informatie. Er is vooral weinig beschreven over de daadwerkelijke interventie en de ‘’eindproducten’’: hoe zien de gemaakte boeken eruit? Bovendien maakte de grote verscheidenheid aan interventies het moeilijk om te vergelijken en algemene conclusies te trekken. Dit versterkte onze motivatie om onze eigen digitale interventie te ontwikkelen, implementeren en evalueren.

Wat zijn de kwantitatieve effecten van het Online Levensalbum voor personen met beginnende dementie en hun mantelzorgers?

Een digitale levensboekinterventie uitgevoerd samen met de mantelzorger in de thuissetting en ingezet door een getrainde vrijwilliger is nog niet eerder geëvalueerd. In **hoofdstuk 3** wordt het onderzoeksprotocol van onze studie beschreven waarin de het Online Levensalbum is onderzocht. In het daaropvolgende **hoofdstuk 4** worden de resultaten van de randomized controlled trial (RCT) gepresenteerd. Het doel van de RCT was om te onderzoeken of de OLSB effectiever is dan een wachtlijstcontroleconditie op (i) neuropsychiatrische symptomen (NPS) bij personen met beginnende dementie en (ii) de belasting en de kwaliteit van leven van hun primaire mantelzorgers. De resultaten werden gemeten bij baseline (T0), na 3 maanden (T1) en na 6 maanden (T2). Er zijn 42 mensen met beginnende dementie geïncludeerd, waarvan 23 vrouwen en 19 mannen. Het totale uitvalpercentage was 14,3%. In totaal hebben 18 vrijwilligers de deelnemers (in beide condities), in ongeveer 5 bijeenkomsten verspreid over 8-10 weken begeleid. De gemiddelde leeftijd van de personen met beginnende dementie was 80 jaar (range 49-95). Kleine maar niet-significante effecten op NPS, belasting van de mantelzorger en kwaliteit van leven van de mantelzorger werden over de tijd gevonden. Er is één uitzondering: de zelf beoordeelde belasting van de mantelzorger (‘’hoe zwaar is de zorg’’ op een schaal van 0-100) daalde significant tijdens de interventie (na drie maanden), maar nam toe na zes maanden. Redenen voor deze resultaten kunnen de relatief goede gezondheid van de deelnemers, praktische uitdagingen tijdens de interventie en de focus van onze uitkomstmaten zijn.

Wat is de inhoud van Online Levensalbums van personen met beginnende dementie?

Zoals duidelijk werd na het uitvoeren van onze systematische review (hoofdstuk 2), was de informatie over de gecreëerde levensboeken schaars. Studies richten zich vooral op en rapporteren over (kwantitatieve en kwalitatieve) uitkomsten van de interventies en er wordt weinig gedeeld over het daadwerkelijke eindresultaat van deze interventies: de gemaakte (digitale) boeken. Daarom hebben we een inhoudsanalyse uitgevoerd. In **hoofdstuk 5** wordt de inhoud van acht gecreëerde Online Levensalbums verkend. Om dit te doen, hebben we een coderingsschema gemaakt en daarbinnen twee hoofdthema's geïdentificeerd: het eerste gaat over de *opbouw* en het tweede gaat over de *inhoud* van de boeken. Qua opbouw bevat een boek gemiddeld 75 herinneringen, elk vertegenwoordigd door circa twee foto's en/of teksten (zijnde *componenten*). Qua inhoud waren de meeste componenten positief en terugkerend van aard, beschreven vanuit een onbekend perspectief en behorende tot de thema's vakantie, gezin of thuis. De meeste componenten hadden betrekking op de levensfase van 45 tot 64 jaar en waren zonder tekst weergegeven of van beschrijvende aard. Dat in alle acht boeken specifieke positieve herinneringen zijn opgenomen, is veelbelovend en lijkt erop te wijzen dat de inhoud aansluit bij de sociale functie van reminiscentie. De sociale functie van reminiscentie houdt in dat mensen door herinneringen op te halen en te delen sociale banden kunnen creëren en onderhouden. Bovendien kunnen mensen elkaar door reminiscentie leren kennen en ervaringen doorgeven aan anderen. De exacte inhoud van de boeken lijkt af te hangen van de beschikbaarheid van materialen, en de keuzes van de makers (persoon om wie het gaat, familie en vrijwilligers). Al met al kunnen we concluderen dat de geanalyseerde Online Levensalbums rijk waren in zowel hun opbouw als inhoud.

Hoe werd het proces van het maken en implementeren van Online Levensalbums geëvalueerd door de verschillende betrokkenen?

Evenals dat er beperkte informatie beschikbaar is over de inhoud van levensboeken, is er weinig gerapporteerd over de implementatie van levensboekinterventies in de dementiezorg. Daarom hebben we in **hoofdstuk 6** een procesevaluatie uitgevoerd waarin we inzicht wilden krijgen in de ervaren effectiviteit, de implementatie en het gebruik van technologie binnen het Online Levensalbum. In totaal zijn er 26 semigestructureerde interviews gehouden met vier verschillende typen stakeholders, oftewel betrokkenen. De eerste drie typen zijn binnen acht gehele casussen geïnterviewd, en betroffen: 1) de persoon met dementie samen met diens mantelzorger, 2) de vrijwilliger die hen begeleidde, 3) en hun primaire formele zorgverlener). Als vierde type betrokkene zijn vier zorgprofessionals geïnterviewd die niet direct betrokken waren bij de totstandkoming van Online Levensalbums (te weten een psycholoog, GZ-psycholoog, manager en specialist ouderengeneeskunde). Aanvullende informatie over de uitvoering is ontleend aan logboeken die de vrijwilligers hebben bijgehouden. De ervaren en potentiële voordelen van het Online Levensalbum die door betrokkenen werden genoemd, hadden voornamelijk betrekking op sociale uitkomstmaten, zoals interactie, verbeteren van relaties en het krijgen van een holistisch beeld van de persoon met dementie. De gebruiksvriendelijkheid van de interventie werd als positief ervaren, terwijl de tijd die nodig was om de materialen te digitaliseren en het feit dat het deel uitmaakte van een groter onderzoeksproject als negatieve aspecten werden genoemd. Betrokkenen waardeerden de technologische functies om het proces te kunnen monitoren en het kunnen uitnodigen van familieleden zodat ze op afstand konden helpen. Verder werd wat technologie betreft potentie gezien in het integreren van het Online Levensalbum in de totale zorg van de cliënt (bijvoorbeeld door deze te koppelen aan het elektronisch medisch dossier). Al met al, heeft deze procesevaluatie ons waardevol inzicht gegeven in de implementatie van het Online Levensalbum.

Wat hebben we geleerd?

Hoofdstuk 7 bevat de algemene discussie waarin wordt gereflecteerd op het gehele onderzoeksproject ‘’Het Online Levensalbum” om meer te kunnen zeggen over het gebruik en de potentie van (digitale) levensboeken in de dementiezorg. Alle studies en vragen van dit proefschrift worden geïntegreerd, waarna sterke punten en beperkingen worden gedeeld. Tot slot worden er aanbevelingen gedaan voor zowel de onderzoeks- als praktijkcontext.

Volgens de Basic Psychological Needs theory kan het welzijn worden vergroot als de drie psychologische basisbehoeften – te weten verbondenheid, autonomie en competentie – worden ondersteund. Deze drie basisbehoeften sluiten aan bij de conclusies van ons project. Zo lijkt de sociale functie van reminiscentie een relevante rol te spelen bij het OLA, lijkt autonomie een belangrijke voorwaarde te zijn om in gedachten te houden bij het implementeren van een dergelijke interventie en lijkt het OLA personen met dementie te ondersteunen bij hun vermogen (competentie) om herinneringen op te halen.

Naast de psychologische basisbehoeften is het gebruik van technologie een belangrijk punt in de bespreking van onze studies. Het is bekend dat technologie reminiscentie en dus levensboekinterventies op meerdere manieren kan ondersteunen: gebruikers kunnen gemakkelijk persoonlijke herinneringen documenteren, ophalen en toevoegen; het kan de zintuigen prikkelen om herinneringen op te roepen; en technologie kan het proces interactiever maken. Bovendien kunnen technologische reminiscentie-interventies zowel in de thuissituatie als in de institutionele zorg worden gebruikt.

Omdat slechts drie van de veertien onderzoeken in onze systematische review een technologisch element bevatten en het gebruik van andere digitale componenten dan digitale foto's in onze acht geanalyseerde OLA's schaars was, lijkt het alsof de digitale revolutie in dit veld nog moet beginnen. Dit is enigszins in tegenspraak met de voordelen van technologie die tijdens de interviews werden genoemd: niet alleen werden de technologische functies van het OLA (zoals het eenvoudig plaatsen van herinneringen op een tijdlijn of het uitnodigen van familieleden om op afstand mee te doen) gewaardeerd, maar werden ook mogelijkheden gezien voor toekomstige inzet van technologie bij dergelijke interventies (zoals het koppelen ervan aan het elektronisch medisch dossier van de cliënt). Tegelijkertijd brengt het gebruik van technologie in de (dementie)zorg ook ethische zorgen en uitdagingen met zich mee, zoals het waarborgen van de privacy en autonomie.

Het feit dat onze studie in de praktijkcontext is uitgevoerd en we gebruik hebben gemaakt van verschillende methodes (systematische review, RCT, procesevaluatie, inhoudsanalyse en seminar) waarbij we niet enkel de persoon met dementie zelf hebben betrokken, is een sterk punt. Wel zien we voor toekomstig onderzoek potentie in het nog sterker combineren van de verschillende methoden (denk aan het gebruik van logdata, langere follow-up, het bekijken van waargenomen effecten op casusniveau), het doen van een uitgebreidere kosten-baten studie en het onderzoeken van de rol van de drie basisbehoeften bij een dergelijke interventie. Tevens bracht onze aanpak ook uitdagingen met zich mee, waarvan de grootste was dat het tijdrovender was dan we van tevoren hadden verwacht (denk aan werving van zowel deelnemers als vrijwilligers, afname vragenlijsten, afstemming).

Op basis van onze bevindingen hebben we vier algemene aanbevelingen opgesteld voor zowel de onderzoeks- als de praktijkcontext. Deze aanbevelingen hebben betrekking op het formuleren van doelstellingen, het interventie-ontwerp, het implementatieplan en de evaluatie.

Concluderend kunnen we stellen dit proefschrift meer inzicht heeft gegeven in het gebruik en de mogelijkheden van (digitale) levensboeken in de dementiezorg, zowel voor de mensen met dementie zelf als voor andere betrokkenen.

About the author

TEUNTJE ELFRINK (1989)

Teuntje Elfrink was born in Deventer, the Netherlands and grew up in Bathmen. She graduated from high school in Deventer (gymnasium), at the Etty Hillesum Lyceum in 2007. In 2008, she moved to Enschede to study Psychology at the University of Twente, and she earned both her bachelor's and master's (specialization: mental health promotion - cum laude) degree. After graduation she worked as a psychologist at Tactus (addiction care) and as junior researcher at the department of Psychology Health and Technology (PHT) at the University of Twente. Over the years, she has been involved in projects as Voluit Leven, Op Verhaal Komen, Compassie als Sleutel tot Geluk and Positief Educatief Programma, prior to the Online Levensalbum/Online Life Story Book, which started in 2016. The latter was a two-year project which was extended to a PhD-trajectory. Next to her PhD-research, Teuntje worked – and works – as a teacher at PHT. The last few years, she is an internship coordinator and involved in the course Personal Reflection and Development – both part of the Positive Clinical Psychology and Technology master.

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Elfrink, T. R., Ullrich, C., Kunz, M., Zuidema, S. U., & Westerhof, G. J. (2021). The Online Life Story Book: A randomized controlled trial on the effects of a digital reminiscence intervention for people with (very) mild dementia and their informal caregivers. *Plos one, 16*(9), e0256251. doi: 10.1371/journal.pone.0256251

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