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Positive Psychology and Technology

Dementia, how we forget about ourselves and what we can do about it

- The evaluation of an online life story book

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Abstract

Purpose – The purpose of the study is to report on a process evaluation of the making process of an online life story book (OLSB). The book has been created by a patient that has been diagnosed with beginning dementia, his informal caregiver, that at the same time is his wife, a trained volunteer from the University of Twente. The process has been accompanied by a health care professional from the Dutch institution ‘Livio’ from a more distant point of view. It is the aim of the study to analyze the content of one life story book and look at motivations, point of view and considerations of the participant, and other stakeholders that have been involved in creating the book. The process evaluation will be carried out as part of a RCT research that the University of Twente is carrying out.

Design/Methodology/Approach – The study has been separated into two major parts. First, three interviews have been held with all people that have been involved in the creation of the live story book. Second, a content analysis of the online life story book has been applied to get an insight on how the book is filled.

Findings – The findings of the interviews reveal a largely positive attitude towards the making process of the life story book. The findings of the content analysis provide an insight in the personal life of the patient.

Discussion & Conclusion – The process evaluation showed that the OLSB intervention enhanced the relationship between all participant and presented an added value for all people involved. Especially the fostering of mutual understanding among each other is an important achievement that is necessary in a world where society is aging and where the number of people with dementia dramatically increases. The shift to a more person-centred approach is, according to literature, the most promising approach to address the changes and to make sure that quality care can be delivered to patients. However, as earlier implied, research on life story books is scarce and it is therefore crucial to further investigate its use. Particularly research on online versions of life story books is rare in present-day literature, what makes this study an important contribution to present and future research.

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1. Introduction

The following review focuses on reminiscence therapy with the use of life story books, directed at people with dementia. By applying a process evaluation to an online life story book, it is aimed to discover its diversity. By applying semi-structured interviews to all people involved in the making process of the book, it is intended to learn about the motivations of the participants.

1.1 Problem definition

Dementia is a phenomenon that will have an increasing impact on society, not only today, but also in the future. According to an evaluation of 'Alzheimer's Disease International' there have been 46.8 million people worldwide living with dementia in 2015. This number will almost double every 20 years and will reach approximately 74.7 million people in 2030. By 2050, an estimated 131.5 million people will be living with dementia (Alzheimer's Disease International, 2017). Due to the most recent research of the Dutch organisation 'Stichting Alzheimer Nederland' there live around 260.000 people with dementia in the Netherlands. This number is expected to rise rapidly during the following years (Alzheimer Nederland, 2014).

The evolving increase in the number of people with dementia is driven by a worldwide population growth and demographic aging (Prince, et al., 2013). Demographic aging is a process that represents the success of an improved health care system over the last century. Due to superior healthcare, many people live longer and healthier lives, which results in a greater proportion of older people around the world (Peters, Ossebaard, & Gemert-Pijnen, 2013; United Nations, 2015). Dementia has been identified as being at the heart of the problem of the aging society.

The epidemiological data arising from recent statistics are an indicator for rising costs in health care. The associated costs of dementia care were US\$818 billion in 2015 and are likely to rise over US\$1 trillion by 2030 (Prince, 2015). Therefore, mental fragility in later life, as a cause of dementia, is not only a source of fear for many, but also a major policy concern to all those concerned with health and welfare services (Higgs & Gilleard, 2017). As dementia is one of the major causes of disability and dependence among older people worldwide, it also presents an overwhelming challenge, not only for the patients, but for their caregivers, family and friends. The impact can be physical, as well as psychological, social or even economic. Cognitive, functional and compromises, associated with the course of disease of dementia, reduces the quality of life for patients and caregivers, increases the costs and distress

associated with care, may precipitate institutionalisation, and eventually lead to the death of the patient (World Health Organisation, 2016).

1.2 Dementia

The word ‘dementia’ derives from the Latin word *de mens* and means “from the mind”. It has been mentioned in the Bible, and ancient Egyptian, Greek and Roman writings, which suggests that it has affected human kind since the beginning of time (Rabins, Lyketsos, & Steele, 2006; English Oxford Living Dictionaries, 2017). The World Health Organisation describes dementia as “a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing.” (World Health Organization, 2016). According to the latest version of the Diagnostic and Statistical Manual, dementia is described as ‘major cognitive disorder’ that affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement, but not consciousness (American Psychiatric Association, 2013; World Health Organisation, 2016).

Another important aspect that needs to be considered when talking about dementia is depression. Depression is not only a frequent symptom of dementia, but also seems to be an important precursor to the illness. Snowden, et al. (2015) describe depression as a chronic condition in elderly patients, that carries its own risks for mortality, higher health care costs, and disability, and that often accompanies other chronic conditions, such as dementia. Through recent research robust evidence has been found, that cognitive impairment is associated with significantly higher rates of depression and even though individual studies are not universally consistent, recent reviews demonstrated that depression can be referred to as risk factor for dementia (Snowden, et al., 2015).

However, Gilleard & Higgs (2014) name a long life as the best predictor for developing dementia. Although there is a growing awareness for cases of dementia in people under the age of 65, mainly older people are affected by this ‘major neurocognitive disorder’ (American Psychiatric Association, 2013; Alzheimer’s Disease International, 2017). Several epidemiological studies that have been applied over the last four decades indicate an exponential risk for the development of dementia that is triggered by increasing deterioration (Hofman, et al., 1991; Jolley & Jorm, 1998; Corrada, Brookmeyer, Paganini-Hill, Berlau, & Kawas, 2010).

With an increase in demographic aging the term “fourth age” moves in the foreground. The “fourth age”, starting at about 80 to 85 years of age, describes the last years of adulthood

(Barnes, 2011). As one of the first Laslett (1991) mentioned the social change from the 'third age' to the 'fourth age'. While the 'third age' is the era of personal fulfilment, the 'fourth age' is described as an era of final dependence, decrepitude and death. Barnes (2011) specifies this phenomenon as the transition between the span of time of retirement, and the beginning of age-imposed physical, emotional, and cognitive limitations. He describes the "third age" as period of adulthood, roughly between the age of 65 and 80, when a person is experiencing less responsibilities regarding family or career than before, and is typically coupled with sufficient financial resources and good physical and emotional health. The fourth age is more accurately characterized as time span of biological and functional decline, in which most older people will experience nonpathological cognitive deterioration and what Barnes (2011) calls 'age-related cognitive decline' (ARCD). Research suggests that the frequency of dementia increases dramatically among the old-old as the 'fourth age' is often termed. Through demographic aging this population, 'the fourth age', is one of the fastest-growing populations of society (Rabins, Lyketsos, & Steele, 2006).

The growing population of people with cognitive impairments demands health care, as well as clinicians with expertise in the segment of dementia. Recent research suggests that a shift to a more person-centred, thus a more individual approach, is the key to an improved dementia care. When caring for people with severe Dementia, the concept of the person being central is increasingly advocated in clinical practice, as well as in academia. The aim of person-centred care can be seen as an approach to deliver high quality care that acknowledges the personhood of the patients in all aspects of their care (Edvardsson, Winblad, & Sandman, 2008). Brooker & Latham, 2016 specify four parts as the elements of person-centred care, the VIPS: **valuing** people with dementia and those who care from them, treating people as **individuals** and accept their unique histories, looking at the world from the **perspective** of the person with dementia, and recognising that all human life, including that of people with dementia, is grounded in relationships, and that people with dementia need an enriched **social environment** that both compensates for their impairment and fosters opportunities for personal growth. However, even if person-centred care has been linked to quality care, it stays a challenge to implement it to care practice (McKeown, Clarke, Ingleton, Ryan, & Repper, 2010).

1.3 Reminiscence therapy

It is currently known, that the effectiveness of pharmacological treatments in dementia care is limited (donepezil, rivastigmine, galantamine and memantine), and that such treatments have

symptomatic effects in only a small group of patients (Cotelli, Manenti & Zanetti, 2012). The lack of available drug treatments for people with dementia has led researchers to investigate the potential efficacy of non-drug treatment. Especially exercises and cognitive based interventions have received great attention in recent years (Huntley & Howard, 2016.)

Literature distinguishes different forms of interventions ranging from multi-strategy approaches to psychosocial interventions and cognitive training. Non-pharmacological interventions may play a role in developing multidimensional models for dementia care by addressing the treatment of cognitive, functional, behavioural and affective aspects of dementia. Psychosocial interventions however aim on the improvement of quality of life for people with dementia and their caregivers. Still, the effects of non-drug treatment need to be studied, as research is a long way from understanding whether any of the approaches can offer real benefit to patients with dementia (Charlesworth et al., 2016).

One promising psychosocial intervention that is commonly used in dementia treatment is reminiscence. Different studies describe that the use of reminiscence therapy has a positive effect to facilitate cognitive functioning and decrease depressive emotions in people with dementia (Huang, et al., 2015). Reminiscence Therapy (RT) usually involves the discussion of past activities, experiences and events with another person or in a group of people. In RT, different media and tangible prompts, such as photographs, household and other familiar items from the past, music and archive sound recordings, are used to encourage the participants to talk. In RT group meetings people typically come together once a week to share past events. Life review in contrast typically involves individual sessions in which the person is guided chronologically through life experiences, encouraged to evaluate them, and may produce a life story book.

An important component of RT are family care-givers, that are increasingly involved (Woods, Spector, Jones, Orrell, & Davies, 2005). Informal evidence suggests that the inclusion of family carers in groups with people with dementia improves relationships between the patients and their caregivers, and benefits both parties. RT is one of the most popular psychosocial interventions in dementia care, and highly rated by staff and participants (Woods, et al., 2012).

Research suggests that there is evidence that RT is effective in improving mood in older people diagnosed with dementia (Woods, Spector, Jones, Orrell, & Davies, 2005). One of the most recent researches on the field of RT has been carried out by Huang, et al. (2015) and confirms the effectiveness of reminiscence therapy in reducing depressive symptoms and improving cognitive functions in elderly people with dementia. The study indicates that the

inclusion of reminiscence therapy should be considered as routine care for the improvement of depressive symptoms and cognitive functions, particularly in institutionalized residents with dementia. A study from Subramaniam & Wood (2012) showed, that reminiscence therapy, that includes life review processes and results in the production of a life story book (LSB), shows great potential in the field of dementia care. The research indicates, that therapy that focuses on developing a LSB can be associated with preserving autobiographical memory.

1.4 Life story books

Life story books were initially developed for children in foster care, to aid their identity through continuous change (Haight, et al., 2006). A life story book (LSB) is the result of a life review process that illustrates the history of an individual in chronological order. The LBS can contain memory in the form of pictures, captions, and personal memorabilia (Haight, et al., 2003; Subramaniam, Woods & Whitaker, 2013). According to Haight et al. (2003) it is important that a life story book only contains information that is approved by the individual that it is meant for.

LSBs can be used in care settings to help staff understand more about the individual and their experiences. Subramaniam, Woods, & Whitaker (2013) studied the effect of different pathways for developing a life story book (LSB) for people with dementia. They found that the creation – either through a life review process or by relatives without involving the person with dementia – has benefits for anyone concerned, including relatives and staff. However, they also concluded that undertaking a life review requires training and supervision. Furthermore, Haight et al. (2003) states that the process of developing a life story book can be real demanding for people with dementia, due to their condition.

A study from Woods, Spector, Jones, Orrell, & Davies (2005) found that life story work has the potential to enable care staff to see the person behind the patient, allow family carers to uphold their relatives' personhood, enable the voice of the person with dementia to be heard, verbally and non-verbally; be enjoyable for all concerned and enable the person with dementia to feel proud about themselves and their lives, and in that way built a bridge to a more person-centred approach. They state that life story work has the potential to enhance person-centred care not only for older people with dementia, but also for their families.

It is believed, that technology can help to deliver reminiscence therapy that is able to better engage with dementia patients through its ability to deliver more vibrant and richer content. Through rapid advances in E-health (electronic health) and M-health (mobile health)

technologies, there have been technology driven solutions to address therapeutic options to approach cognitive and non-cognitive symptoms of dementia. These devices are considered to deliver music or images to patients and get them to think and talk about their past, to distract them from their non-cognitive symptoms and increase cognitive symptoms (Zhang & Ho, 2017).

According to Subramaniam & Woods (2012) it can be assumed that over five years it is normal to have a digital version of a LSB which can contain music, pictures and videos. Research states that the online life story book (OLSB), compared to the regular paper version, has additional benefit for patient's due to its enhanced range of possibilities, such as music and videos (Subramaniam and Woods, 2016). Research suggests, that there is continuous improvement in the field of LSBs. However, further research, especially on the field of OLSBs is essential to explore its potential and possible effectiveness on people with dementia (Subramaniam & Woods, 2012).

1.5 Aim of the study

To sum it up, reminiscence therapy with the use of OLSBs has great potential for interventions directed at people with dementia. As research on OLSBs is scarce it is crucial to further investigate its use.

In collaboration with the Dutch institution 'Livio', the University of Twente is researching the effects of reminiscence and life review therapy on people that are diagnosed with a mild neurocognitive impairment or early dementia. For this purpose, an OLSB is created in cooperation with relatives or close friends of the patient, and a trained volunteer from the University of Twente. It is expected that the project will reduce neuro-psychiatric symptoms that are associated with dementia, such as depression and apathy, and thus improve the quality of life not only for the patient, but also for all people concerned. To measure the effect of the project the University of Twente is carrying out an RCT study.

At the same time, a process evaluation is to be carried out, to gain more insight in the whole constructing process of the life story book. In this complex process, qualitative data gives a more adequate view on the inside of the project. Each participant might have several reasons to participate in the study and take part in the individual process of constructing an OLSB. The aim of the study is to analyse the content as well as the diversity of one life story book and look at motivations, point of view and considerations of the participant, and other stakeholders that have been involved in creating the book.

The following research will be concerned with the process evaluation, as a part of the RCT research that the University of Twente is carrying out.

1.6 Research questions

Based on the previous research and the outline of the study two research questions have been formulated.

I. How did the patient, the informal caregiver, the volunteer and the health care professional experience the making process of the online life story book?

- i. Which impact does the online life story book has on the relationship between health care professional, patient and informal caregiver; volunteer, patient and informal caregiver; patient and informal caregiver among each other?
- ii. Does the online life story book have an added value for the patient; the informal caregiver; the volunteer; the health care professional?

II. How is the online life story book filled?

2. Method

2.1 Research design and sample

A process evaluation was employed to investigate the making process of an OLSB. The qualitative study has been separated into two major parts. Firstly, three interviews have been held with all major participants that accompanied the process of creating the life story book, including the patient and his informal caregiver, a health care professional from 'Livio', and a volunteer from the University of Twente. Secondly the created life story book has been analysed for its content in detail.

2.1.1 Participants

The patient is a 71year old man that has been diagnosed with beginning dementia. Due to privacy reasons, he will be referred to as Mr. S. in the following study. He was born in Enschede, the Netherlands in 1946 and has been living there since. He is married to his wife, who happens to be his informal caregiver, since 1973. In the following study, she will be referred to as Mrs. S. Mrs. S. was born in Gelderland, the Netherlands in 1950 and lives in

Enschede, the Netherlands since the marriage to Mr. S. Together the couple has two adult children, a daughter, and a son. Both, Mr. and Mrs. S. are retired. Mr. S. visits a meeting centre for people with dementia twice a week.

The volunteer that has been assigned to the patient is a young woman that will be referred to as Miss H. Her precise age is not known. She has been trained by the University of Twente to get familiar with the program with which the OLSB has been created, and to gain basic knowledge on the topic of dementia.

The health care professional that has been involved in the case of Mr. S. works as a case manager at 'Livio' in Enschede, an organisation that is active in the field of health, care and living. Her precise age is not known. She will be referred to as Mrs. B. in the following study. Mrs. B. pointed out the life story book project to the couple S. and encouraged them to participate in it. However, during the study it turned out, that Mrs. B stopped working with Mr. S. before they started the project, due to money restrictions at 'Livio'.

2.2 Instruments

2.2.1 Interviews

In total, three interviews have been held: an interview with the patient and his informal caregiver, an interview with the volunteer that helped creating the OLSB, and an interview with the health care professional that was involved in the process from a more distant point of view. The interviews have been applied to gain insight on two different aspects: the making process of the OLSB and its future use. To get as much information as possible semi-structured interviews have been applied, to leave more space for the researchers' questions. However, for each interview an interview-schema has been created to provide a basic guideline. They have been developed in consultation with various researchers to ensure that they cover all important issues. The interview-schemas can be found in appendix A. All interviews have been recorded on an audio device for research purposes. Before the interview, the procedure and purpose was explained to all participants, and they were asked to sign an informed consent. The participation in the interview was completely voluntary and could be interrupted or stopped at any time. A blank version of the informed consent can be found in appendix B.

The interview with the patient and his informal caregiver has been held by two researchers of the University of Twente. As they met the patient earlier, it has been decided that he might feel more comfortable with familiar faces while talking about intimate details of

his life. The interview took part at the patient's home in Enschede, the Netherlands and took about 23minutes.

As the volunteer moved to Amsterdam, the Netherlands recently, it was not possible to talk to her in person. Therefore, all correspondence with her took place via e-mail or skype.

The interview, that was held via skype, took about 30minutes.

The interview with the health care professional took place in an office room at 'Livio' in Enschede, the Netherlands. It was held together with another bachelor student who is conducting research on a second OLSB. Consequently, questions about both books have been discussed during the interview, that took about 42minutes in total.

2.2.2 Content analysis.

For the content analysis, the OLSB of Mr. S. has been analysed. The book has been created by the patient, in cooperation with the informal caregiver and the volunteer. Mr. S's online version consists of 188 pages filled with experiences, achievement and history. All material included in the book has been provided by the patient. The OLSB is a personal document that is only accessible for the patients and the ones he wishes to share it with.

2.3 Analysis

2.3.1 Interviews

The results of the semi-structured interviews have been analysed by using the Atlas.ti software. After transcribing the interviews, a coding schema, based on the main topics of the interviews, was developed for each interview, together with another student. An overview of the coding schemas can be found in appendix C. Both researches created the codes individually. They have been inspired by the topics of the semi-structured interviews. Finally, they have been assembled to see if there is potential overlapping or difference between the disposed codes and to minimize subjectivity of the researcher. During consideration of both researchers, consensus has been reached and all codes have been declared convenient and covering. The codes that have been used are as followed:

Interview patient and informal caregiver

For the interview of the patient and informal caregiver in total 19 codes have been created. An overview of all codes and their grouping is displayed in table 1.

Table 1*Overview of all codes used for the interview with the patient and informal caregiver*

Categories	Codes
Experience making process	Consideration participation Making process generally Experiences making process Negative life events Use Schedule time Satisfaction Suggestion for improvement
Relationship participants	Relationship couple among each other Contact with volunteer Relationship couple and volunteer Relationship couple and health care professional
Added value	Added value of book patient Added value book generally Retrospection participation
Use of technology	Use music in album Use videos in album Advantage use of technology during process
Topics irrelevant to the research	Others

Interview volunteer

For coding the interview of the volunteer in total 17 codes have been created. An overview of all codes and their grouping can be found in table 2.

Table 2*Overview of all codes used for the interview with the volunteer*

Categories	Codes
Experience making process	Reasons and expectations Making process generally Use hardcopy Use online version Training and peer consulting Time management Role-allocation couple-volunteer Role-allocation Mr.-Mrs. Suggestion for improvement
Relationship participants	Relationship first meeting

	Change in relationship through book
Added value	Added value participants Added value volunteer Retrospection participation
Use of technology	Use technology during making process Added value technology for participants
Topics irrelevant to the research	Others

Interview health care professional

For the interview with the health care professional in total 18 codes have been created. An overview of all codes and their grouping can be seen in table 3.

Table 3

Overview of all codes used for the interview with the health care professional

Categories	Codes
Experience making process	Contact with project Previous knowledge book Making process album Motivation application participants Opinion about book generally Opinion couple about book Opinion about book of couple Opinion respective future use Difficulties Potential
Relationship participants	Relationship health care professional and patient Change of relationship through book
Added value	Added value for target group Added value for couple Added value for health care professional
Use of technology	Added value technology for target group Added value technology for health care professional
Topics irrelevant to the research	Others

All interviews have been coded by two different students and have been discussed among each other afterwards. It was possible to give more than one code to the same unit. A unit

could be one word, a whole sentence or a complete passage. In the end, the coded material has been reflected on the hand of direct quotes, to make the analysis as reliable as possible.

2.3.2 Content analysis

To analyse the content of the OLSB a schema has been created by two researchers. It was set up prior to the analysis and coordinated with one another. The topics were defined after skimming the content of the OLSB and have not been changed later. It can therefore be concluded that the content analysis has been a top down process. An overview of that schema can be found in Appendix D.

In total 5 codes have been designed to label each memory, including: *Home*, for memories that took place at home, for example a birthday party or a Christmas dinner. *Family*, for memories that display members of the family, including parents, the spouse, children and grandchildren. *Friends*, for memories that show old friends from school or an evening out with contemporary friends. *Vacation*, for all memories that have been made during a vacation, and *Career* for memories concerning the academic path like school certificates or memories from a business. Sometimes it was not quite clear which code fits best to what memory, as some pictures show overlapping content. Since it was only possible to assign one code per memory, some general rules were applied. Photos of vacation trips with friends or family for example, also fall under the label *Vacation*. Memories that show family members at home, at a birthday party, Christmas dinner, or comparable event, are summarized under the label *Family*. To sum it up, the label *Family* stands above the label *home*, while the label *Vacation* stands above the labels *Family* and *Friends*. With the label *Career*, no overlap has been found, which is why there was no need for applying an additional rule.

Furthermore, the content of the OLSB has been analysed for its text. As it was possible to add a headline and explanation to each memory, it has been looked at the amount of text and the personal form it has been written in. A text could be labelled either as 'short text', 'long text', 'title only', or even 'no text at all'. To define which text belongs to either the category 'short text' or 'long text', a general rule has been applied. All texts that have been three sentences or shorter have been considered as short texts. In addition, all memories have been screened to see if they were shared or personal ones, or general facts. A personal memory would for example be a photo, that only shows the patient alone, while a shared memory would contain him and for example family and friends. Memories have been considered as general facts if the patient did not experience it by himself, as for example the birth or marriage of his parents. Also, the denseness and chronological order of all photos has

been recorded by noting the year dates of all memories. Finally, it has been analysed which materials have been used to display a certain memory. A memory could for example be a normal photo, an article, a music frequency or a video. However, all memories are displayed as photos in the OLSB. An overview of the entire content analysis is displayed in appendix E.

3. Results

3.1 Interviews

To answer the first research question: “How did the patient, the informal caregiver, the volunteer and the health care professional experience the making process of the Online Life Story Book?” the interviews with all stakeholders have been analysed. All results relevant to the research question are listed here. The results also will be used to answer the sub-questions, that are: “Which impact does the Online Life Story Book has on the relationship between; a) the health care professional, the patient and the informal caregiver; b) the volunteer, the patient and the informal caregiver?” and “Does the life story book has an added value for the patient, informal care giver, volunteer, and health care professional?” All results were grouped under the following categories: a) Experience making process, b) Relationship participants, c) Added value, and will be discussed per stakeholder using the previous formulated code schema (see appendix C).

3.1.1 Participant and informal caregiver

Experience making process

Making process generally. One of the matters of interest during the interview with the participant Mr. S. and his informal caregiver and wife Mrs. S. was the process of making the OLSB in general. When asking both about it Mrs. S. stated: “I think, that we have been really open and told everything from what we thought is important. And she (volunteer) picked good points from it. If you see the book we are really happy with it.” Referring to the volunteer she added: “Of course, she was a stranger when she came here first, so you can tell a lot of confidential things, she does not know anyone we know. So, no one is going to talk about it. So, you can tell confidential things very easily [...] I don’t think there was something were we said we don’t want to talk about it.” The interviewer then asked Mr. S. if he also had the feeling to be able to speak freely and he replied: “Yes”. All in all, it can be summarized that the general making process went well because both, Mr. and Mrs. S. had the feeling that they could talk about everything they wanted to talk about. Also, they enjoyed recovering old memories together, and talk about them.

Experience making process. Furthermore, the couple was asked more detailed about their experiences during the making process of the book. Mrs. S. explained, addressing the

volunteer: “Yes, was also very good. We proposed something and she understood what we were talking about, and she did it. “The next time she showed us what we were asking form her, actually.” “Very satisfied.” Mr. S. complemented: “Yes. We had no complains”. As there were no negative comments about their experience of the making process from the couple, it can be said that the making process went well. That is in large parts because of the good cooperation and communication between the volunteer and the couple.

Use of music in album. An important question concerning the making process of the OLSB was the use of music fragments in the album. When asked about this topic Mr. S. states:” I liked it. I was not busy with music in my life. I am the man of the books and not of the music.” Mrs. S. adds: “It is nice that the music is in the book but I think you are going to use it less than the videos.” To sum it up it can be concluded, that both Mr. and Mrs. S. liked the music they incorporated in the book. However, especially Mrs. S. stresses the fact, that the videos will be used more.

Use of video in album. Following the previous question the couple was then asked about the use of video material in the album. Mrs. explains: “The video is more about us. I mean the music you hear almost every day on the radio, I mean in the car we always have radio. And then we have a CD with music that we both like, with Elvis Presley and Louis Armstrong and that's the music we like. So, I think that is less used in the book. But the video is very special.” Mr. S. states: “[...] It is a video that I usually don't see that often. But in the book, I see it even more often.” Both Mr. and Mrs. S. really appreciate the incorporation of the videos in the OLSB. Both argue, that music can be heard in the car or on the radio, but that the videos are something special that they don't see every day.

Satisfaction. Finally, the satisfaction of the couple relating to the making process is of interest for the interviewer: Mr. S. said: “Regarding contents very good only the quality...”, “The cover was already nice.”. Mrs. added: “[...] We are very happy with it. Fantastic book.” During the whole interview, the couple nearly exclusively talks positive about the making process and the life story book as the result. Both, Mr. and Mrs. S. seem to be happy about their participation of the project and emphasise the added value of the book that they finally got from it.

Relationship participants

Relationship couple among each other. Later in the interview Mr. S. was asked about how he experienced to work with his wife on the life story book. He said: “Yes, it is really nice to do the work together. Better than alone.” Due to his condition, it would have been difficult for

him to participate in the project alone. He therefore especially enjoyed working together with his wife.

Contact couple and volunteer. When asked about the general contact with the volunteer Mrs. S. stated: „The contact with the volunteer was also very nice. After two weeks, she was well known [...]” Mr. S. adds: “[..] A friendly contact.” The interviewer was interested in how Mr. S.’s impression on the volunteer was, as she came as a stranger into the couples’ house. He did not really have much to say about that, except that it was a nice contact.

Relationship couple and volunteer. When, the couple is questioned about the relationship with the volunteer in more detail. Mrs. S. said: “I think that we are lucky that we were such a good match from both sides.” Both, Mr. and Mrs. S. had the feeling that there was equally a good bond between them and the volunteer. Mrs. S. emphasises that the good contact was an important contribution to the success of the project.

Relationship couple and health care professional. Furthermore, the couple was asked about Mrs. B the case manager that was occupied with the case of Mr. S., and their relationship to her. Mrs. S. explained: “She was our case manager. She initially advised us with the book. But over time, Mr. S. got people from the district nursing, and they had to take over everything. I totally disagree with that. We still see Mrs. B on Twekkelerveld, we still have the contact details, we can call her if there is anything but she is no longer our case manager.” Even if the health care professional was no longer involved in the case of Mr. S. when the couple started the making process of the OLSB, she was still approachable to the couple in case of questions. This finding indicated, that the bond between the couple and her was a good one.

Added value

Added value of book patient. At the end of the interview Mr. and Mrs. S. are asked if they think that the OLSB is or could be an added value for them. Mrs. S. replied: “Yes, I really think it's a property. It's just so beautiful, so nice to look at it and I really hope if Mr. S. is further in the process, that it is adding something to his memory. That's what it is all about.” When the interviewer turns to Mr. S. he responds: “I like it a lot. It brings back many memories. Gorgeous, really.” Summing up it can be recapitulated that Mr. and Mrs. S. are happy about the life story book as it brings back memory. Especially Mrs. S. hopes that it will help Mr. S. to remember when the dementia further progresses.

Retrospection participation. To gain more knowledge about the added value of participating in the project, the couple is asked about how they look back on the participation in the project. Mr. S. said: “I was very excited to do that. You even get in touch with your past and it was nice to get it all up again.” Mrs. S. supplemented: “I think it's just been a very fun time. That you get old memories and look back at old photo albums. I think it was very important to Mr. S.” Even if Mrs. S. believes that making the book was especially important to her husband, both had a good time recovering old memories and putting them together in the OLSB.

3.1.2 Volunteer

Experience making process

Making process generally. When Miss H. was asked about how she experienced the making process of the OLSB in general she states: “Everything sounds too perfect, but it went really well!” She explains that all stories to the photos came easily during the meetings and that there was so much material that they could fill a complete book. She adds: “This was maybe a little bit less good for me, well less good, it was a lot of work to insert everything, but therefore we could make a complete book.” “It is, of course, if they have a lot of photos, then you are going to talk about them much more easily. I mean it is not that I had to choose photos, or anything like that. They already a lot and so I was able to ask questions and from this came stories automatically, so yes, that was simple.” All in all, the volunteer is positive about the making process and explains how easy it was to make a start to everything.

Time management. Furthermore, the time that the volunteer needed to put into the project was a matter of interest during the conversation. When asked about her time management she explains: “I needed a lot of time to process the photos, because it was a lot. So, I was working on that some hours each time. Scan and place everything to put it in there nicely [...] I had more meetings than previously planned. I don't remember how much, but more [...]. That was not a problem, but more.” When asked about the project and if it was a burden to put that much time and effort in it the volunteer stated: “No, I do not think it was too much pressure. Especially the meetings were great, that could have been more, does not matter. The only thing that costed a lot of time was scanning everything in. But okay, I did not think it was annoying.” So, even the volunteer had to put more time and effort in the project than previously expected, she is positive about it and doesn't think of the project as a burden.

Role allocation couple-volunteer. Also, Miss H. was asked about the role allocation between her and the couple. She replied: “They were also interested in my story. I was not

there for that of course, but you do get a nice social interaction. That it does not get monotonous, let's say. Very, very natural. Not as an interview or something very strict. Bit according to feeling." So even if the meetings with the volunteer were about the patient, the relationship was mutual and there was interest in the other person on both sides.

Role allocation Mr.-Mrs. When asked about the role allocation between Mr. and Mrs. S. Miss H. mentioned: "I have to say that his wife made a start with a lot of things. Mr. S. Often did not know what we were doing and why. So, she prepared the photos, but with considering him. So that it would be his album. But he wanted it to be everyone's album [...]" "Even though Mrs. S. needed to take the lead in the project, she considered her husband with all decisions. Mr. S. was occasionally not able to remember his participation, due to his medical conditions. However, Mrs. S. could compensate his impairments and make sure that his voice is heard. While Mrs. S. made sure that it becomes Mr. S.'s book, he wanted it to be a book for everyone.

Relationship participants

Relationship first meeting. The volunteer was asked about her first impression on the relationship with the couple. She said: "It was from day one that they put everything on the table for me, but also, it felt a little as if they, as if I was a daughter or something. That they said 'yes, you can do all of that', but not only that, also outside the life album, that they just trusted me with certain things, and still we have contact and yes, just very nice". To sum it up, the volunteer had a good bond with the participants from day one on. She stresses, that the relationship went beyond the work-relationship and still goes on at the present day.

Change in relationship through book. Also, it was matter of interest if making the OLSB, together with the patient, changed her view on him. Miss H. stated: "Yes, I think so. If I met Mr. on the street, I would have thought that he was not interesting, say it like that. Like everyone else of course. But if you meet someone like that, it is way different. Depending on what you can get then to tell you. That, of course, changes your view." The volunteer added: "We just have a good band now. That is mainly through his wife. I do not know if he still knows that I made the life album. That relationship is of course a bit difficult. For him, of course, it is more difficult because of the disease. But with his wife, there really is a change from not knowing each other to get to know each other well." All in all, the development of the OLSB has improved the relationship between everyone as all participants have met each other in a very personal way. However, the volunteer stressed that especially the relationship with Mrs. S. developed as the connection with Mr. S. was difficult due to his condition.

Added value

Added value for participants. The volunteer was asked if she thought the OLSB has an added value for the patient. She told: "I think so, yes. During the project, they are spitting through their lives, bringing back memories where they have not stood still, but also see the positive aspects of their lives. The things they've made and the beautiful moments they've shared. I think so." The volunteer concluded that the OLSB is an added value to the participants because it brings back old memories and lets them experience their past once more.

Added value for volunteer. The volunteer also was asked if the project has an added value for herself. To this question she replied: "Yes, I think so. And, that I still have contact with those people. Also, that I could feel very well with them, that's also very nice for them I think. I think they are very grateful that I helped and, well, that it is still happening now." Miss H. is positive about the project and emphasises that the relationship between her and the couple S. did not end after the life story book was finished, but that they still talk to each other.

Retrospection participation. Finally, Miss H. was asked about her opinion of the project after it is finished. She explained: "Well, I think that it was even better than expected because I expected to bond a little, not too tight, but I have to say that it really got a tight bond." She explained that family S. was open and welcoming to her from the beginning. "It was from day one on that they put everything on the table, but also, yes, it felt a little as if I was their daughter or something like that." To sum it up, the volunteer was very positive about the whole project, and the enrichment that the relationship to the participants has given her.

3.1.3 Health care professional

Experience making process

Opinion about book generally. At the beginning of the interview Mrs. B. was asked about her opinion on the OLSB in general. She explained: "Yes, I was equally enthusiastic. Sure, yes. Yes, yes. I just think it's very beautiful. I also said to people, "you're crazy if you're not participating". It's just such a beautiful document for yourself, it just gives you, I've seen that with both couples, how much joy it has given them to dive back in the past. What beautiful stories they came across, pictures, and especially for those with dementia, it is very nice. Their short-term memory is just very bad, you should not ask them "what did you eat yesterday?" But from earlier they still know a lot and they like to talk about that and that's

just, eh, that just gives a lot of joy to life. I have seen that with both, yes, sure.” Furthermore, she added to her answer: “It is such a nice project, and you don’t have to pay anything. Something like this is a once in a lifetime opportunity, you don’t come across something like that again that easily. Of course, you must have photos, you must want it, you must want it together, but people don’t see that as a problem. If they don’t have any circumstances in their past, because that is important. If they had a good and pleasant childhood and they had a good marriage, then I think it should be absolutely no problem to participate.” To sum it up it can be stated that the health care professional is positive about the project and even encouraged her patients to participate in it. She thinks that the online life story book is a document that gives a lot of joy to the couples who participated and is especially important for someone with Alzheimer’s, as it does address the long-term memory and brings back old memory. However, she emphasizes that the book is not supposed to bring up bad memories, so it must be clarified if that is possible to happen before starting the project.

Opinion couple about book. When Mrs. B. was asked about the couple’s first opinion on the book she said: “I must say, that Mr. and Mrs. S. had to think about it [...]” “Like, ‘do we really want to go back, do we think it is fun, does it add something’.” The health care professional explained, that the couple S. at first doubted their participation in the project. She mentions that the couple struggled with the idea of going back in time and recover old memories.

Opinion about book of couple. Following the previous question Mrs. B. was asked about her opinion on the OLSB of Mr. S. and she mentioned: “I did not see the final version [...]” During the interview it became apparent that Mrs. B. stopped working on the case of Mr. S. due to money cutbacks at ‘Livio’, and that she therefore never saw his OLSB.

Relationship participants

Relationship health care professional and patient. Later in the interview, Mrs. B was asked about the relation between her and the patient. She said:” With both I had the feeling that the relationship was okay [...]”. She added: “I had the feeling that we bonded well.” To sum it up, the health care professional had the feeling that she bonded well with the couple, while she was working with them.

Change of relationship through book. Also, it was of interest if the health care professional detected a change in the relation with the patient through the OLSB. She stated: “Yes, yes. Because you share such a whole line of life. More than you already knew. Yes, sure yes.” Even if the health care professional was not involved in the making process of the

OLSB and did not see the result, she assumed that through sharing personal memory and talk about a person's past, one gets to know a person well, what fosters a better relationship.

Added value

Added value target group generally. Finally, Mrs. B. was asked about the added value of the OLSB for people with dementia in general. She explained: "[...] It is your whole lifeline. That is nice [...]" "People like to tell about their past, because they still know a lot about it. Sure." The health care professional names the exchange of past events as the main added value of the OLSB intervention. As people with dementia still know a lot about their past, the intervention encourages them to recover memory.

Added value for couple. Also, the health care professional was asked about her opinion on the added value for the couple that makes the book. She said: "Well, I already said, it has given a lot of life happiness, eh. Of course, that was of course, sometimes you see people with it, they have Alzheimer's disease, that's also a bit individual, "that's no longer possible and that's no longer possible". Well, and here you could, they could be very nice together." Mrs. B. refers to the fact that patients with dementia start, not only to forget things, but start to forget how to do things. To sum it up, the health care professional thinks that especially working together with the partner is an added value of the life story book as it gives joy.

Added value for health care professional. The added value of the life story book for the health care professional was an important matter of the conversation as well. When asked about her opinion in this, Mrs. B. mentioned: "Eh very short, lately, I had a neighborhood nurse on the phone who said that it was so hard to connect with this lady, vascular dementia. I told her that this madam had just a great grandchild and that there are pictures in the kitchen and that she should take her up on that picture. Later she said, 'what a good tip of yours, she started to smile smoothly, I equally felt a connection'. Well, that's sure, through implement such an online life album, you just get better contact." The health care professional uses a work example to demonstrate the added value of OLSB in health care. She explained that the use of personal memories of a patient can help both, professional care person and patient to better bond with one another.

3.2 Content analysis

To answer the second research question: "How is the Online Life Story Book filled?", a content analysis has been applied to the OLSB of Mr. S. In total 215 memories have been labelled with one code out of five topics, including family, friends, home, vacation and career.

It appears that especially the topic ‘family’ is frequently represented in the book. The label ‘family’ has been attributed to 41% of the memories, which is far more than all other codes. However, also the codes ‘home’ (22%) and ‘vacation’ (19%) have been applied oftentimes, while the codes ‘Friends’ (11%) and ‘Career’ (7%) are used less frequently. An overview of all codes and the times they were used is represented in table 4.

Table 4

Overview of all topics and their frequency.

Topic	Frequency	Data in percent
Family	88	41%
Friends	24	11%
Home	48	22%
Vacation	41	19%
Career	14	7%
Total	215	100%

Furthermore, all memories have been analysed for the following features each: either personal or shared memory, positive or negative memory, everyday life or unique memory. The examination has shown that Mr. S. has almost exclusively used positive memories in this book. Only one single memory has been labelled as negative. Also, it appears that most of the memories are unique memories that are shared with one or more other people. An overview of the precise numbers the features have been used can be seen in table 5.

Table 5

Overview of the features and their frequency.

Personal or shared, positive or negative, everyday life or unique	Frequency	Total
Personal	72	215
Shared	141	
General fact	2	
Positive	214	215
Negative	1	
Everyday life	43	215
Unique	172	

In addition, it has been considered what kind of materials have been used in the life story book. As the book has been made online all materials are displayed as photos. In total,

187 of 215 memories are original photos. However, the book also contains photos of other materials, for example invitations, documents, or a photo of a flag. An overview of all materials used is shown in table 6.

Table 6

Overview of all materials used and their frequency.

Kind of material	Frequency
Photo	187
Document	3
Book cover	2
Ceramic doll	2
Certificate of marriage	2
Invitation	2
Music	2
Video	2
Certificate	1
Drawing	1
Emblem of Enschede	1
Flag	1
Magazine article	1
Newspaper article	1
Plate	1
Portrait	1
Poster	1
Postcard	1
Stamp	1
Story	1
Telegram	1
Total	215

After that, all memories have been analysed for its text. The participant could give a headline to each memory and add a text to explain it. A difference has been made between a long text, a short text, a headline only, and no text at all. To determine if a text is short or long a general rule has been applied. All text that is longer than three sentences has been labelled with 'long'. All text that was three sentences or shorter has been labelled with 'short'. Furthermore, it has been analysed in which personal form the text, if present, has been formulated. According to the analysis the participant usually only gave short explanations of his memories. Only in nine cases the explanations are somewhat longer. In two cases, neither text nor title was used. An overview of the amount of text used is stated in table 7.

Table 7*Spelling style and their frequency.*

Spelling style	Frequency
Long	9
Short	37
Title only	167
No text at all	2
Total	215

The participant predominantly formulated his texts in first person. Also, he uses a descriptive writing style, to describe a person, place or thing and the first-person plural. An overview of the personal forms used in the life story book of Mr. S. is displayed in table 8.

Table 8*Personal form and their frequency.*

Personal form	Frequency
First person	16
First person plural	1
Third person	2
Descriptive	27
Title only or no text at all	196
Total	215

Finally, the denseness of all memories has been analysed. Usually the participant used one photo per memory. Only 19 times Mr. S. decided to attach more than one photo to a memory. However, in some cases there are photos marked with different headlines, but represent the same memory. An overview of the number of the used photos per memory can be seen in table 9.

Table 9*Frequency of photos used per memory*

Photos per memory	Frequency	Data in percent
One photo per memory	177	82%

More than one photo per memory	19	9%
Different headline but photos represent same memory	19	9%
Total	215	100%

When looking at the dates of when the photos have been taken, it can be concluded that there are memories from almost all years between 1946 and 2016. Also, it can be stated that the distribution of the photos within the years is even. Especially memories from the years between 2001 and 2010, as well as between 2011 and 2016 have been added. An overview of the denseness of the photos is summarized in figure 1.

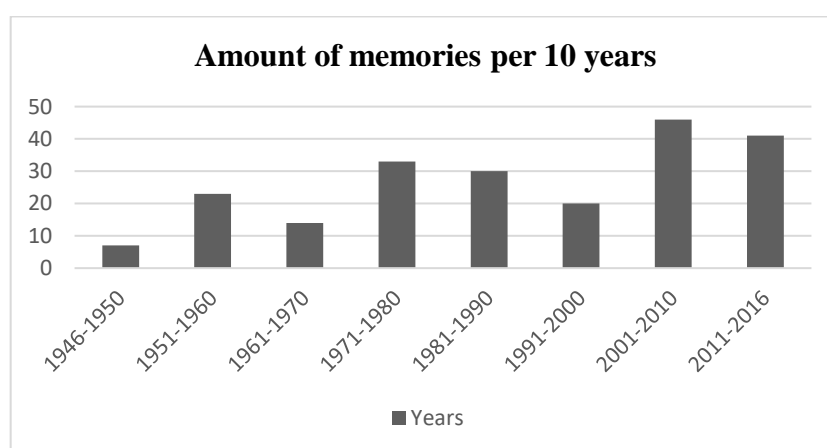


Figure 1. The amount of memories per 10 years

4. Discussion

This process evaluation was applied to learn about the motivations and experiences of the participants that were involved in the making process of the OLSB and to capture its content.

The first question central to this study was how all participants (patient, informal caregiver, volunteer, and health professional) experienced the making process of the OLSB. To answer this question, it was investigated which impact the LSB has on the relationship between all participants and whether the book was an enrichment for the different parties. Second it was considered how the book was filled.

All participants experienced the participation in the project as extremely positive and joyful. In addition, each participant confirmed that the engagement in the study, as well as the final version of the book is, in various ways, an enrichment for all people concerned.

The results from the process evaluation showed that the close involvement of the caregiver, either informal or in the form of the volunteer, had a beneficial value for the patient and was essential in the process of developing an OLSB. At this point, no statement can be made about the health care professional since she was no longer involved in the making process of the book. All participants, including the patient, the informal caregiver and the volunteer experienced the making process as an enjoyable task. Research found that the inclusion of family carers and care staff in people with dementia improves relationships between them, and benefits both parties (Woods, et al., 2012). Furthermore Subramaniam, Woods & Whitaker (2013) stress the possibility of using LSB's in care settings to support help staff understand more about the individual patient and his experiences. These results support the findings of the process evaluation. All sides, informal caregiver, patient and volunteer indicated that they have established a special relationship with each other, that goes far beyond a professional relationship. It was stated that the couple and the volunteer were still in contact with each other when the official project ended. It can be deducted, that the development process had a huge influence on the relationship of the participants among themselves.

In his book Mr. S. chronologically used memories from his birth on, until the present day. The volunteer indicated that it was an added value for her, to get to know the life of the patient and share the wonderful experiences he made within his life. Subsequently, Woods, Spector, Jones, Orrell & Davis found that life story work has the potential to enable care staff to see the person behind the patient and enable the patients voice to be heard, verbally and non-verbally. To underline these findings, another aspect needs to be considered. During the content analysis, it became apparent, that almost all texts used in the book have been written from the first-person perspective. This suggests, that even if the texts were mostly short, the patient was indeed the person who wrote them and therefore could tell his own story. During the making process the role allocation between patient, informal caregiver and volunteer was equally distributed. Even if the informal caregiver made a start with preparing the photos, she always considered the patient when making decisions. She wanted the book to be Mr. S's book, while he himself wanted the document to be for everyone. As the book incorporates mostly shared memories, it can be assumed that in the end Mr. S. wishes were considered, as the book is not only about himself. Especially photos of family members and shared vacations

are included in the book frequently, which might give the patient the opportunity to exchange experiences with other participants in the photo. However, it can be supposed that the patients voice has been heard when developing the OLSB, what might build a bridge to a more person-centred approach

The use of a trained volunteer to accompany the making process of the OLSB was a novelty to this study. Haight et al. argued that creating a life story book can be demanding for people with dementia, due to their condition. In accordance Subramaniam, Woods & Whitaker stated that undertaking a life review process requires training and supervision. When the patient was asked how he liked working with the volunteer and the informal caregiver he explained that he enjoyed the joined work, as it would have been difficult for him to do everything on his own. These findings underline both previous mentioned studies.

In their research Brooker & Latham (2016) mentioned the importance of a more person-cantered, thus more individual approach, as a key to improved dementia care. They introduced four parts as the elements of person-cantered care, the VIPS: **V**aluing people with dementia and those who care for them, treating people as **I**ndividuals and accept their unique histories, looking at the world from the **P**erspective of the person with dementia, people with dementia need an enriched **S**ocial environment that both compensates for their impairment and fosters opportunities for personal growth. To some extent, the developing process of the OLSB is directly linked to these points. The volunteer emphasized that she perceived it as an added value that she developed a relationship to both, the patient and the informal caregiver. She stressed that she would have perceived Mr. S. as a completely different person, a person like anyone else, as she had not met him through the OLSB. She learned to value the patient and his informal caregiver, by accepting the person behind the illness and his unique history. Also, she got the chance to see the world through his eyes, listen to his life story and support him in his life review process, not least through preparing the OLSB.

Based on this finding, it can be assumed that the use of OLSB's does enable care staff to bond to the patient and therefor enable a more personalized quality care. Adding to this topic the health care professional stated that OLSB offer a wonderful opportunity to get to know the patient better and to find connecting points. Also, she emphasised that especially working together with the partner is an added value of the project, as it gives joy and brings back old memories. Although she has not seen the book of Mr. S. personally, she indicates that OLSB should, in the long term, be linked to the medical report of patients, to improve the relationship between care staff and patients. In this respect, the development of OLSB's not

only has benefits for the patient and his informal caregiver, but also allows care staff to see the person behind the disease.

Another innovation of this study is the implementation of an OLSB instead of an ordinary LSB. Since information on the field of digital LSB's is scarce, only a few studies deal with this topic.

The results from one of those studies showed that elderly people diagnosed with dementia felt motivated and comfortable using an OLSB (Abu Hashim, et al., 2015). A study from Subramaniam & Woods (2016) states that the OLSB, compared to a regular paper version, has additional benefits for patient's due to its enhanced range of possibilities, such as videos and movies. Consistently Zhang & Ho (2017) found that technology can deliver reminiscence therapy that is able to better engage with the patient through deliver more rich and vibrant content. These devices are considered to present music, images or videos to the patient and get them to think and talk about their past.

In his OLSB Mr. S. also incorporated two music fragments and two videos. The patient and his wife thought that it was nice that the music was in the book, but both emphasized the added value of the video. They argued that the music is something they can hear every day, on the radio or a CD, but that the video is something that don't see very often and therefore appreciate even more. Also, they underline the fact that the videos awaken old memories which they are happy to exchange with each other.

In accordance with these findings, the study from Subramaniam & Woods (2016) showed, that people with dementia enjoyed viewing their own life story movies. Also, they indicate that family members and staff alike reported a positive effect of the life story movie on them as well as on the person they cared for. A result that is consistent with the findings of this process evaluation. However, they furthermore state that music stimulated the memories of people with dementia. These findings cannot be supported by the current study as neither the patient nor the informal caregiver see the music as an added value. Nevertheless, it cannot be completely ruled out that the music fragments have no or only a little effect on the patient. Since the study is directed at a single participant and his opinion no conclusions can be made for a larger target group. Also, the study did not look for changes in cognitive functioning or improvements of depressive symptoms, which may have taken place unconsciously.

The findings from the present study and the comparison to present day literature underline the potential of OLSB's for future dementia care. Subramaniam & Woods (2012) it can be assumed that over five years it will be normal to have digital versions of LSB's. In this respect, it gets clear how important the implementation of OLSB can be for future dementia

care. The process evaluation showed that the OLSB intervention enhanced the relationship between all participant and presented an added value for all people involved. Especially the fostering of mutual understanding among each other is an important achievement that is necessary in a world where society is aging and where the number of people with dementia dramatically increases. The shift to a more person-centred approach is, according to literature, the most promising approach to address the changes and to make sure that quality care can be delivered to patients. As in present-day literature there is little known about interventions that help people with dementia to retain or even regain a sense of the self. The approach used in this study might therefore be a new of addressing dementia in the future. However, as earlier implied, research on life story books is scarce and it is therefore crucial to further investigate its use. Particularly research on online versions of life story books is rare in present-day literature, what makes this study an important contribution to present and future research.

Strengths and limitations

Looking back, it can be concluded that the study had both, its weak and strong sides. In this study, the use of OLSB's has been proven to be an enjoyable activity for all people concerned. Also, it came forward that the life story work including the patient, family carers and care staff has the potential to enhance aspects of person centred care. Therefore, one of the most important strength of the study is getting to know the patient with dementia in a very personal way. Seeing the person behind the dementia is fundamental to the process of developing an OLSB, and not least a central feature to person-centred care. Furthermore, the intervention has been carried out in an environment that allowed opportunities for facilitation, supervision, development and active involvement of the person with dementia, his family and care staff. Another positive aspect that needs to be highlighted is therefore the inclusion of the patient in his own care where he recovers old memories, feels proud and gets the possibility to be heard.

Nevertheless, especially one limitation of the study needs to be mentioned. The findings presented in this study relate to only one OLSB. It is not possible to say whether the outcomes can be generalized to a larger target group; that is, people with beginning dementia that participate in a life review process which results in the making of an OLSB. However, it can be assumed, that the depth of knowledge that has been gained about the person with dementia and the making process of the OLSB was greater, than if a more general approach would have been applied. Furthermore, the study did not investigate possible changes in cognitive functioning or the increase of depressive symptoms, as it was focused on a more

qualitative approach. In the long term, however, it would be interesting to know how life story work affects this.

Implications

Terminal to the study several implications can be made for future research.

First, the work with OLSB's is a promising method that provides a range of opportunities for person-centred care outcomes to be met in dementia care. This sort of life story work should be implemented within certain conditions, to make sure that it stays person-centred; that is, within an environment that compensated for possible impairments of the patient, fosters opportunities for personal growth, and where education and supervision are integrated. To meet this, only participants with a beginning dementia should be recruited, to make sure that the patients voice can really be heard.

Second, the development of an OLSB is a way to include family carers in the patients' cause of disease and enables them to contribute to the preservations of his personhood. It is an enjoyable approach that fosters relationships and has the potential to create a transition to a more person-centred care in dementia care practice.

5. Conclusion

To sum it up, projects with life story books show a great potential in helping people with dementia, their caregivers, and relatives. The process evaluation indicates that life story books can have a beneficial value for people with dementia and their care givers, as they encourage personal relations and bring back old memories. Especially the integration of digital life story books is very promising in a word where technology plays an increasingly important role, as it can lead a path to a more person-centred approach. However, further research is urgently required.

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7. Appendix

Appendix A: Overview of all three interview schemas used for the semi-structured interviews, in the original Dutch version

Interview schema deelnemers

Deelname:

- Overweging om deel te nemen project
- Overweging om deel te nemen onderzoek
- Terugblikken

Maakproces:

- Tijdsbestek (twee weken, 5 keer een uur)
- Ervaringen
- Algemeen om terug te kijken
 - Om met naaste samen te doen
 - Mogelijke belemmeringen/omgaan met negatieve gebeurtenissen
 - Contact met vrijwilliger
 - Eerste contact
 - Samenwerking
 - Vertrouwen
 - Gesprekken
 - Alle belangrijke informatie kunnen delen/vrijuit kunnen vertellen (werd er goed geluisterd)
 - Duidelijkheid over afspraken
- Voordelen van online maken
 - Zelf online meegeholpen?
 - Anderen die hebben meegeholpen? Wie?
 - Wat hebben anderen toegevoegd?

Geïndividualiseerde vragen (op basis van inhoudsanalyse)

- Overwegingen voor de vormgeving (bv geen muziek, bepaalde thema's veel etc.)

Eindresultaat OLA

- Algemene tevredenheid met het eindresultaat
- Wat bevat goed
- Verbeterpunten
- Gebruik van online-versie
 - Ja/nee, hoe vaak
 - Mogelijke belemmeringen
 - Voordelen van online-versie
 - Gebruiksvriendelijkheid van online-versie
 - Uiterlijk van online-versie

Toegevoegde waarde Online Levensalbum

- Waarom toegevoegde waarde (wat en waarom)
- Activiteiten naar aanleiding van het levensalbum (bijv. plekken of vrienden van vroeger bezocht, een hobby weer opgepakt, een recept gebakken/gekookt, etc.)

Betrokkenheid zorgprofessional

- Wie van de zorg is erbij betrokken (verzorgende, thuishulp of casemanager)
- Wat diegenen hiermee doet (erover praten? Al bekeken?)

Interview schema Vrijwilliger

Motivatie deelname

- Wat was de reden voor u om deel te nemen aan dit project?
- Wat waren uw verwachtingen?
- Hoe kijkt u hierop terug?
- Zijn de verwachtingen uitgekomen?

Het maakproces van het OLA

- Hoe heeft u het beleefd om een levensboek voor iemand te maken?
- Waar gingen de gesprekken over? (Kunt u beschrijven hoe zo'n gesprek ging?)
- Wat neemt u voor uzelf hiervan mee? / wat heeft u ervan geleerd?
- Heeft het project voor u zelf toegevoegde waarde?
- Heeft het project volgens u toegevoegde waarde voor de deelnemer?

- Wat liep er goed?
- Wat liep er minder goed?
- Waren er dingen die u anders had willen doen?
- Zou u de rolverdeling tussen de beide partners kunnen omschrijven?
 - Doorvragen naar inbreng?
- Zou u iets kunnen vertellen over de rolverdeling tussen het koppel en uzelf?
 - Doorvragen naar inbreng?
- Hoe hebben deelnemer en mantelzorger er zelf in meegeholpen?
- Was de mantelzorger bij elk gesprek aanwezig of zijn er ook gesprekken met de deelnemer alleen geweest? (Zo ja; hoe vaak en waren deze gesprekken anders?)

Tijdsindeling

- Hoe realistisch was het om in 5 gesprekken te doen?
- Hoe realistisch om telkens 1 uur per gesprek te plannen?
- Wat vindt u van de frequentie 1 keer per twee weken een gesprek?
 - Bent u hiervan afgeweken?
- Hoe veel tijd had u nodig voor de voorbereiding per gesprek?
- Hoe veel tijd had u nodig voor de verwerking na elk gesprek?
- Hoe belastend/ tijdsintensief ervaarde u het in het algemeen?

Het contact met de deelnemers

- Hoe was de kennismaking?
- Hoe heeft u het contact tussen u en de deelnemers in het algemeen ervaren?
- Was er voldoende duidelijkheid over afspraken? (Takenverdeling/ huiswerk/ hoe vaak u langs komt)
- Hoe makkelijk was het om het gesprek op gang te laten komen en te houden?
- Wat ging er makkelijk af in de samenwerking?
- Wat ging er moeilijker af in de samenwerking?
- Heeft u het idee dat er mogelijk iets veranderd is in relatie tussen beide partners gedurende het proces?

De training en intervisie

- Voelde u zich voldoende voorbereid door de training?
- Wat was er goed aan de training?

- Wat miste u mogelijksterwils nog?
- Hoe heeft u de bijeenkomsten samen met de andere vrijwilligers ervaren? (Indien ze niet geweest zijn; heeft u op een andere manier ervaringen uitgewisseld?)

Technologie

- Hoe heeft u het gebruik van technologie ervaren?
- Heeft u technologie, bijvoorbeeld internet, gebruikt voor het vinden van herinneringen of waren de gebruikte documenten reeds in het bezit van de deelnemer?
- Heeft u veel bestaande documenten/foto's gedigitaliseerd?
- Denkt u dat de technologie een meerwaarde is bij het maken van het levensalbum?
 - Voor de deelnemer
 - Voor uzelf
- Denkt u dat de technologie/de applicatie een meerwaarde is bij het bekijken van het levensverhaal door de deelnemer?

Relatie

- Heeft het levensalbum uw beeld van meneer/mevrouw veranderd?
- Zijn er gesprekken geweest waarbij de mantelzorger niet aanwezig was?
 - Waren deze gesprekken verschillend van de gesprekken waarbij de mantelzorger we aanwezig was? Zo ja, hoe?
- Is uw relatie met de deelnemer gedurende het project veranderd?
 - Zo ja: Hoe?

Interview schema health care professional

Algemeen over het project:

- Hoe bent u met het project in aanraking gekomen?
- Wat wist u van tevoren al van het project?
- Hoe keek u hiertegen aan?
- Wat is uw beweegreden om deze koppels op te geven voor dit project?

Album meneer S.

- Heeft u dit album al gezien?

- Wat is uw indruk van het album?
- Wat is handig aan dit album (voordelen)
- Denkt u dat het album van toegevoegde waarde is voor de cliënt?
- Denkt u dat het album van toegevoegde waarde is voor zorgprofessionals?
- Heeft het levensalbum uw beeld van meneer/mevrouw veranderd?
- Is de relatie tussen patiënt en zorgprofessional (op emotionele basis) veranderd door het persoonlijk verhaal van meneer S.?
 - Wat zijn hier de eventuele positieve punten van?
 - Wat zijn hier de eventuele negatieve punten van?

Album mevrouw O.

- Heeft u dit album al gezien?
- Wat is uw indruk van het album?
- Wat is handig aan dit album (voordelen)
- Denkt u dat het album van toegevoegde waarde is voor de cliënt?
- Denkt u dat het album van toegevoegde waarde is voor zorgprofessionals?
- Is de relatie tussen patiënt en zorgprofessional (op emotionele basis) veranderd door het persoonlijk verhaal van mevrouw O.?
 - Wat zijn hier de eventuele positieve punten van?
 - Wat zijn hier de eventuele negatieve punten van?

Technologie

- Denkt u dat technologie een toegevoegde waarde heeft?
 - Voor de deelnemer zelf?
 - Voor de zorgprofessionals?

Toekomstige inzet

- Wat zijn de toegevoegde waarde van het album voor de ouderenzorg in het algemeen?
- Zou het levensalbum bij kunnen dragen aan de zorg voor mensen met dementie?
- Zou het maken van een levensalbum volgens u bij kunnen dragen aan de relatie tussen zorgprofessional en cliënt?
- Wat zijn mogelijke moeilijkheden/ beperkingen
- Waar lopen we in de zorg nog tegen aan?
- Wat zou een toegevoegde waarde kunnen zijn van het album binnen de zorg?

- Bij specifiek langer thuis wonen (zou het ondersteunend kunnen zijn?)
- Wat zou u als zorgprofessional hiermee willen doen? Hoe zou u het willen gebruiken?
- Wat zijn de mogelijkheden voor het gebruik in u dagelijkse werk?
- Wat heeft u eventueel al hiermee gedaan? / hoe heeft u al eventueel gebruik hiervan kunnen maken?
- Welke toepassingen ziet u hiervoor?
- Denkt u dat een online levensalbum aan zou kunnen sluiten bij de technologie die reeds gebruikt wordt in de zorg? Indien ja, hoe?
- Ziet u mogelijkheden om het te koppelen aan het zorgdossier?

Appendix B: Blank version of the informed consent used for the semi-structures interviews, in the original Dutch version

Toestemmingsverklaringformulier (informed consent)

Titel onderzoek:

Verantwoordelijke onderzoeker:

In te vullen door de deelnemer

Ik verklaar op een voor mij duidelijke wijze te zijn ingelicht over de aard, methode, doel en [indien aanwezig] de risico's en belasting van het onderzoek. Ik weet dat de gegevens en resultaten van het onderzoek alleen anoniem en vertrouwelijk aan derden bekend gemaakt zullen worden. Mijn vragen zijn naar tevredenheid beantwoord.

[Indien van toepassing] Ik begrijp dat film-, foto, en videomateriaal of bewerking daarvan uitsluitend voor analyse en/of wetenschappelijke presentaties zal worden gebruikt.

Ik stem geheel vrijwillig in met deelname aan dit onderzoek. Ik behoud me daarbij het recht voor om op elk moment zonder opgaaf van redenen mijn deelname aan dit onderzoek te beëindigen.

Naam deelnemer:

Datum:

Handtekening deelnemer:

In te vullen door de uitvoerende onderzoeker

Ik heb een mondelinge en schriftelijke toelichting gegeven op het onderzoek. Ik zal resterende vragen over het onderzoek naar vermogen beantwoorden. De deelnemer zal van een eventuele voortijdige beëindiging van deelname aan dit onderzoek geen nadelige gevolgen ondervinden.

Naam onderzoeker:

Datum:

Handtekening onderzoeker:

Appendix C: Overview of the coding schemas used to analyse the interviews in the original Dutch version

Codeerschema interview deelnemers

Thema: deelname

- Labels:
 - Overweging deelname
 - Terugblik deelname

Thema: maakproces

- Labels:
 - Maakproces algemeen
 - Tijdsbestek maken
 - Ervaring maakproces
 - Vrijwilliger
 - Voordelen gebruik technologie bij maakproces

Thema: content analyse (specifieke vragen over de content van het desbetreffende album)

- Labels:
 - Gebruik video's in album
 - Gebruik muziekfragmenten album

Thema: eindresultaat

- Labels:
 - Tevredenheid
 - Verbeterpunten
 - Gebruik
 - Toegevoegde waarde album voor cliënt (ongeacht de vorm online/hardcopy)
 - Toegevoegde waarde online album

Thema: betrokkenheid zorgprofessional

- Label:
 - Betrokkenheid zorgprofessional

Thema: relatie

- Label:

- Veranderingen in relatie door levensalbum met:
 - Vrijwilliger
 - Zorgprofessional

Thema: overige:

- Labels:
 - Relatie koppel onderling
 - Negatieve levensgebeurtenissen

Codeerschema Interview Vrijwilliger

Thema: deelname in het algemeen

- Labels:
 - Redenen en verwachtingen
 - Terugblik

Thema: maakproces

- Labels:
 - Maakproces in het algemeen
 - Verbeterpunten

Thema: toegevoegde waarde

- Labels:
 - Toegevoegde waarde voor cliënt
 - Toegevoegde waarde voor vrijwilliger
 - Toegevoegde waarde mantelzorger

Thema: rolverdeling en relaties

- Labels:
 - Rolverdeling meneer-mevrouw
 - Rolverdeling koppel-vrijwilliger
 - Relatie kennismaking
 - Relatie veranderd door levensalbum

Thema: tijdsindeling en training/intervisie

- Labels:
 - Tijdsindeling
 - Training en interventie

Thema: technologie

- Labels:
 - Gebruik technologie tijdens maakproces
 - Meerwaarde technologie voor cliënt

Thema: gebruik eindproduct

- Labels:
 - Gebruik onlineversie

- Gebruik hardcopy

Codeschema interview Zorgprofessional

Thema: deelname project

- Labels:
 - Aanraking project
 - Voorkennis levensalbum
 - Motivatie opgave deelnemers
 - Mening t.o.v. levensalbum in het algemeen

Thema: albums koppel van E. en koppel S.

- Labels:
 - Mening over resultaat levensalbum koppels
 - Mening koppels t.o.v. levensalbum
 - Toegevoegde waarde voor koppel

Thema: toegevoegde waarden

- Labels:
 - Toegevoegde waarde voor doelgroep in het algemeen
 - Toegevoegde waarde zorgprofessional
 - Relatie zorgprof – cliënt

Thema: technologie

- Labels:
 - Meerwaarde technologie voor doelgroep
 - Meerwaarde technologie voor zorgprofessional

Thema: toekomstige inzet levensalbum

- Labels:
 - Mening betreft toekomstige inzet
 - Moeilijkheden
 - Mogelijkheden

Thema: relatie

- Labels:
 - Verandering relatie door levensalbum

Appendix D: Overview of the schemas used to apply a content analysis to the OLSB in the original Dutch version

Schema content analyse online-levens-album

Kwantitatief:

- Aantal herinneringen
- Aantal thema's
- Aantal herinneringen per thema
- Dichtheid van herinneringen
- Valentie: Aantal positieve herinneringen/Aantal negatieve herinneringen
- Verhouding foto's en tekst

Kwalitatief

- In welke persoonsvorm is het album geschreven?
- Soort gebeurtenissen (*per gebeurtenis* → *vorm: terugkerend of eenmalig* → *positief of negatief* → *of gedeeld* → *Thema*)
 - Terugkerend of eenmalig? /alledaags of uniek/ overstijgend
 - Eigen persoonlijke herinnering vs. algemeen gegeven
 - Positief of negatief
 - Persoonlijke herinnering of gedeelde herinnering
- Thema's
 - Vakantie
 - Thuis
 - Loopbaan (opleiding/werk)
 - Familie
 - Vrienden
- Welke materialen (algemeen foto's van gebeurtenissen, afbeeldingen, krantenknipsels, oorkonden, geboortekaartjes, specifieke voorwerpen, recepten of bijvoorbeeld gedichten)
- In welke vorm zijn herinneringen opgeslagen? (Foto's, teksten, audio of video)
- Schrijfstijl: korte statements of langere verhalen