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Effects of a digital reminiscing intervention on people with dementia and their care-givers and relatives

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Abstract

Dementia is a source of growing concern globally, and often impacts on social and communicative functioning. INdependent LIving Support Functions for the Elderly (IN LIFE) was a project carried out within the European Commission Research and Innovation programme Horizon 2020 that resulted in the development of two digital communication aids for reminiscence intervention for elderly people with dementia and their communication partners. The purpose of this intervention study was to investigate the effects on quality of life for people with dementia when using these aids. People with dementia (N = 118) and their formal care-givers (N = 187) and relatives (N = 9) were given the communication aids for a period of 4–12 weeks. To assess a range of outcomes, questionnaires developed within the project were used along with the EQ-5D (European Quality of Life – 5 Dimensions) and QoL-AD (Quality of Life in Alzheimer's Disease) questionnaires. Quality of life improved among people with dementia when measured using EQ-5D ($p < 0.05$). There was also a correlation between the impact on the participants' health and wellbeing, the carers' rating of the usefulness of the digital communication aids and the care-givers' satisfaction with using technology ($p < 0.05$). These results indicate that digital communication aids may be useful in social interaction where one partner has dementia.

Introduction

Worldwide, 55 million people are living with dementia and it is now the 7th leading cause of mortality (Gauthier *et al.*, 2021). Dementia has a major impact on the individual's quality of life and the symptoms can lead to communication difficulties, frustration and sadness (Clare *et al.*, 2008; Prince *et al.*, 2015). As the world population grows older, the number of people living with dementia is likely to double every 20 years, which will lead to one of the greatest global challenges for public health-care to solve (Prince *et al.*, 2015).

Dementia is a collective name and a diagnosis for a set of symptoms caused by neurodegeneration affecting the ability of synapses to communicate. Depending on the location, cause and extent of the damage, the disease manifests itself in a variety of ways and to a varying degree. Common cognitive symptoms are memory problems, word-finding difficulties, anomia, and difficulty planning and performing daily life activities, as well as psychiatric symptoms such as anxiety, depression and other behavioural changes (Tang and Robinson, 2013). Overall, people with dementia often need support from their relatives or care-givers (Prince *et al.*, 2013) and their quality of life may be negatively affected by reduced opportunities for social contact (Hoe *et al.*, 2006).

There are several definitions of quality of life. The most widely used definition is from the World Health Organization, which describes quality of life as a state of being in full physical, mental and social wellbeing (Fayers and Machin, 2000). Another definition is HRQoL (Health-Related Quality of Life) (Sloane *et al.*, 2005) which involves an assessment limited to the effects on a person's state of health and overall wellbeing, and how it can influence their ability to live a good life (Azoulay *et al.*, 2008; Wolak-Thierry *et al.*, 2014). EQ-5D (European Quality of Life – 5 Dimensions) was created by Brooks (1996) to measure HRQoL and deals with physical, mental and social functioning (Herdman *et al.*, 2011). A further definition is disease-specific quality of life, which focuses on a particular disease or diagnosis and the aspects of a person's life that are affected most (Sloane *et al.*, 2005). QoL-AD (Quality of Life in Alzheimer's Disease) is designed specifically for people with dementia and was developed by Logsdon, Gibbson, McCurry and Teri in 1999 (Wolak-Thierry *et al.*, 2014).

Background

Social interaction with other people is essential for the preservation of identity and self-esteem (Pearce *et al.*, 2002; Ericsson *et al.*, 2011). In order to feel understood and positive, people with dementia need the opportunity to communicate with family, friends, health-care professionals and strangers (Preston *et al.*, 2007). It is important that those around people with dementia initiate and maintain conversations to stimulate social interaction (Ericsson *et al.*, 2011).

Quality of life increases when people with dementia attain social inclusion and have access to activities that they find meaningful (Abrahamson *et al.*, 2012). The

possibility to tell others about one's life and past experiences is also important as it can compensate for the loss of current abilities (Clare *et al.*, 2008). It is common for the diagnosis of dementia to cause a lack of insight into one's difficulties, which can create frustration and a sense of hopelessness among relatives and informal care-givers (Ducharme and Geldmacher, 2011). Dementia therefore not only results in reduced quality of life for a person with the disease but also among relatives or informal care-givers (Ducharme and Geldmacher, 2011; Välimäki *et al.*, 2016). When a person with dementia moves to a care home, relatives and informal care-givers may experience a sense of reduced responsibility and improved HRQoL (Bleijlevens *et al.*, 2015). However, people with dementia living in care homes often experience feelings of insecurity, loss, isolation, loneliness and fear (Clare *et al.*, 2008).

Good relationships between people with dementia and their care-givers are important to preserve wellbeing and quality of life for both parties (Clare *et al.*, 2008). To achieve this, the care-givers and relatives need training in strategies that can create conditions where people with dementia do not feel socially isolated and instead experience improved quality of life (Bourgeois and Hickey, 2007; Smith *et al.*, 2011).

Reminiscence intervention involves conversations about past events and experiences with the goal of reviving memories and stimulating cognition for people with dementia and improving their health and wellbeing. Reminiscence intervention can include the use of videos, images and objects, either in groups or individually. A systematic review (Woods *et al.*, 2018) showed that reminiscence intervention did not have any clinically significant long-term effects. However, there are identified benefits of 'in the moment' enjoyment of a shared social experience and some effect on cognitive function, communication, interaction, quality of life and mood. A study by Lopes *et al.* (2016) showed that an individual reminiscence programme resulted in significant improvement in mental health, reduced anxiety and greater ability to access autobiographical memory for people with dementia, but further research is needed to clarify long-term effects. Reminiscence intervention can help care-givers who are competent communication partners to improve the quality of interaction with people with dementia (Bourgeois *et al.*, 2001).

With the development of digital technology, there is greater potential for it to be used for health-related purposes. Having a digital system for reminiscence intervention in place can promote the use of reminiscence intervention as a form of therapy. It supports multiple users, and the health-care provider has the potential to store both generic material and the personal material of the people with dementia (Anderson *et al.*, 2014). Research has shown that people with dementia and their care-givers can easily adapt to computer-based reminiscence interventions, and suggests that it is beneficial when used between people with dementia and their care-givers (Alm *et al.*, 2004). In comparison with more traditional reminiscence interventions, such as photograph albums, multimedia interventions can increase the opportunity for shared attention and social interaction between people with dementia and their communication partners (Astell *et al.*, 2005, 2010). The general increase in internet use has created a greater need for and interest in mobile and internet-based health and medical care applications, termed collectively as E-health (Kerkhof *et al.*, 2016). Touchscreen devices such as tablets are commonly available and developing tablet applications is now relatively easy. This has led to a growing interest within health-care organisations in extending the use of tablets to specific target groups, such as people with dementia (Kerkhof *et al.*, 2016).

The IN LIFE project

This present study was part of the three-year research and development project IN LIFE (INdependent LIving support Functions for the Elderly), carried out within the European Commission Research and Innovation programme Horizon 2020 (European Commission, 2018). Nine European countries were involved in the task of improving opportunities for elderly people to lead an efficient and independent everyday life. The two Swedish partners, Dart, a regional centre for assistive technology and augmentative and alternative communication at Sahlgrenska University Hospital, and CEDER, a dementia research centre at Linköping University, collaborated to investigate the effects of elderly people with dementia using digital communication aids in conversation with their communication partners (Astell *et al.*, 2018; European Commission, 2018).

Two digital communication aids were developed within the context of reminiscence intervention and they can be used on any type of tablet or computer. These Web-based aids, called CIRCA and CIRCUS, were aimed for use by people who have difficulty communicating and their relatives and care-givers (University of Sheffield, 2018).

CIRCA was created to support socialisation and interaction, and it contains generic material presented within three general categories (film, photos and music) all from different time periods (Astell *et al.*, 2010). The content presented within the categories at any given time is randomised. The randomisation varies each session to give novelty without placing a burden on the care-giver to plan and organise in advance. CIRCA builds upon software from the University of Sheffield. It has been used in previous studies for people with dementia (Gowans *et al.*, 2004; Astell *et al.*, 2010; Ferm *et al.*, 2020). Results revealed that using CIRCA increased interaction for people with dementia and their care-givers. In summary, the interaction while using CIRCA was more relaxed and enjoyable, and care-givers felt that they became better acquainted with the people with dementia and that it improved their relationship (Astell *et al.*, 2010). The IN LIFE project has transformed CIRCA into a Web application suitable for modern platforms and devices such as tablets and smartphones (*see* Figure 1). The project also translated the existing material from English into Swedish, and supplemented the British content with photos and music suitable for a Swedish context. The layout, however, remains very similar to previous versions.

CIRCUS is a personal digital communication aid that is designed to support memory and conversation and contains films and photos uploaded by people with dementia and their care-givers (*see* Figure 2). CIRCUS also has additional features. One of these is the sharing function, which means that a user can add another user of CIRCUS and then share selected photos or other items with this user. This function is designed to allow users of CIRCUS to communicate and share their experiences with care-givers who may live far away and likewise for care-givers to easily be able to add content remotely to a user they support. This allows the user to easily convey simple phrases about their personal lives and opinions to the care-givers with whom they are interacting. A study by Goffe and Karlsson (2017) found that the use of CIRCUS as a communication aid contributed to a more positive experience for people with dementia and their care-givers compared, for example, with using a photograph album. They were able to interact on more equal terms with CIRCUS, and the care-givers who participated felt that inclusion of personal material facilitated the conversation. An interaction study with three
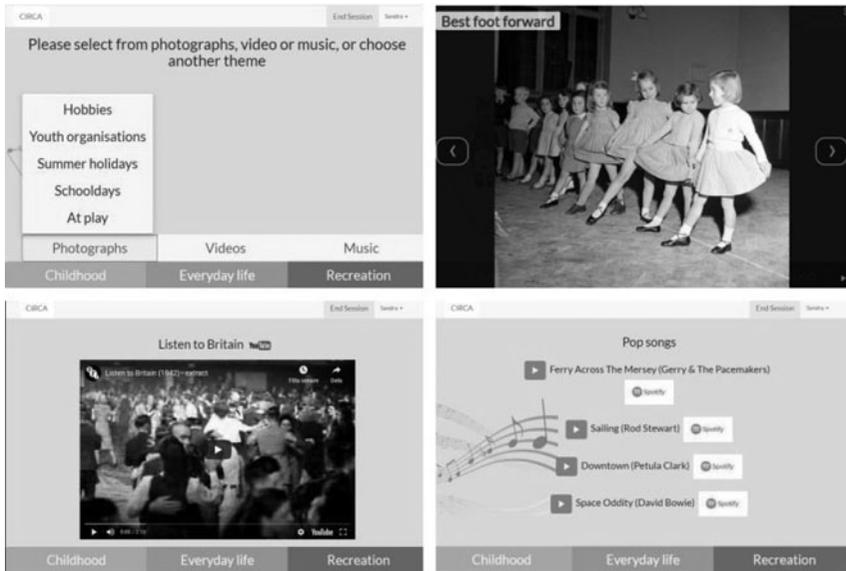
Figure 1. CIRCA is filled with generic material and is divided into three general categories, photos, films and music, and their sub-categories (topics). When choosing a topic, a picture, film clip or music tune is randomly shown on the screen to enjoy and talk about.

Figure 2. CIRCUS can be filled with personal material, such as photos and films, in different folders. It also contains speech synthesis and a sharing function.

dyads of women with dementia and their carers, all using both CIRCA and CIRCUS, also found evidence that people with dementia and their carers would benefit from this technology (Ferm *et al.*, 2020).

However, there is still a knowledge gap regarding the effects of using digital reminiscence interventions, such as CIRCA and CIRCUS, that are designed to support elderly people with cognitive difficulties, such as dementia, and their communication partners.

The main purpose of this intervention study was to investigate the effects on all participants and on quality of life for people with dementia. The purpose is thus divided into two parts, with associated research questions:

(1) Investigate the extent to which quality of life for people with dementia differed before and after the use of digital communication aids, measured using EQ-5D and QoL-AD, respectively.
(2) Examine the effect of using digital communication aids, divided into the following sub-questions:
    (a) What was the impact on the health and wellbeing post-intervention for people with dementia, care-givers and relatives?
    (b) Is there any correlation between the perceived usefulness of the digital communication aid and the impact on the health and wellbeing of people with dementia, care-givers and relatives?
    (c) Is there any correlation between the care-givers' rating of the usefulness of the digital communication aid and their overall satisfaction with technology?

Methods

The inclusion criteria of this study were that people with dementia should (a) be over the age of 55, (b) not have previous cognitive difficulties following another diagnosis, (c) have experienced cognitive difficulties or been given an age-related dementia diagnosis, (d) need support in their daily lives from a care-giver or relative, (e) have access to at least one care-giver or relative to support their participation, and (f) be capable of giving their informed consent after receiving accessible information about the study. Determination of the sample size was guided by the study funder and by the project's budget parameters and experience with former surveys. A convenience sample was used, comprising participants recruited through various channels. To reach management and staff, all local representatives in a regional network for dementia nurses were informed about the study and spread the information to care homes and daily activity centres throughout the region where people with dementia participated. To reach people with dementia and their relatives individually, information was spread through Dart's Web and social media channels as well as through open lectures and workshops where interested care-givers and relatives got in direct contact with the project team. Recruitment of participants commenced after ethical approval. All participants matching the inclusion criteria were invited to participate in the study. The type or degree of dementia of the participants was not taken into account, although the majority of the participants received some type of dementia care, which means that a prior dementia assessment was made. The inclusion criterion for the care-givers and relatives was that they had regular contact with the people with dementia who participated in the project.

In total, 253 people signed up to participate in the study. Out of these, 50 people with dementia, 66 care-givers and two relatives had to be excluded for one of two reasons: (a) the participants had given their written consent to participate, but did not complete all the questionnaires, or (b) their data had been collected before the official questionnaires of the IN LIFE project were supplemented by Horizon 2020, the European Union's research and innovation framework programme, which meant that data from these participants did not comply with the project's data collection and could not be compared.

The participants who completed initial demographic questionnaires comprised 118 people with dementia, 187 care-givers and nine relatives. The majority of

Table 1. Background data of participants, including the living situation of the people with dementia

	People with dementia	Care-givers	Relatives
N	118	187	9
Gender:			
Male	41	13	2
Female	77	174	7
Age range	57–101	17–66	51–67
Mean age	84	45	56
Living situation:			
Live alone	40		
Live with family	2		
Live with partner	2		
Care home	13		
No information	20		

Note: N = 314 (56 male, 258 female).

participants in all groups were women. The participants with dementia had a mean age of 84 while the care-givers and relatives had one of 45 and 56, respectively (*see* Table 1). Participants with dementia were asked about their living situation. A significant number were living alone, but all participants with dementia needed support in their daily life and had various kinds of services.

IN LIFE intervention

Participants were assigned to either the CIRCA or the CIRCUS digital communication aid for a trial period. This period lasted between 4 and 12 weeks depending on the supporting care-givers or relatives' possibility of devoting time to the project. The project provided the participants with a tablet with an internet connection and a personal login code. The elderly people with dementia, their care-givers and their relatives all participated when testing CIRCA. The CIRCUS testing had to commence late due to unforeseen delays in the application development. Because of this delay, the project limited testing to a few people with dementia and their care-givers who expressed interest in CIRCUS specifically.

All participants in the study received oral, written and Web-based information regarding the IN LIFE project, along with information about how they could use the digital communication aids. The information was in an easy-to-read format and included pictorial support. Care-givers and relatives received an initial workshop with demonstrations of the communication aids. All the participants used the digital communication aids at care homes, day care facilities, hospitals or homes.

Procedure

All participants were provided with information about the study, both orally and in easy-to-read format with pictorial support, before the intervention period started.

All participants gave their informed consent, either in writing or orally witnessed by a staff member. Questionnaires were distributed both before and after participation in the project. The participants could choose to fill them in directly online on the tablets used in the trials or on paper which was collected by the researchers. Only the EQ-5D survey could not be digitalised due to copyright issues. The questionnaires developed for people with dementia had pictorial support and were written in an easy-to-read format. Carers and relatives provided support as the participants with dementia answered the questions. The questionnaires were completed immediately after the trial period to make sure as much as possible of the experiences was captured.

In three of the questionnaires, the questions covered satisfaction with technology, the rating of the digital apps, their usefulness, and their impact on health and wellbeing. Five-point scales were used.

Following guidelines from Horizon 2020, two additional surveys were used to measure the quality of life of people with dementia, the EQ-5D and QoL-AD questionnaires. Using two surveys is recommended as they complement each other, one being generic and the other disease-specific (Ades *et al.*, 2013).

EQ-5D contains five dimensions: Mobility, Self-care, Usual activities, Pain/discomfort and Anxiety/depression, where a low score indicates good quality of life. The answers are given on a scale of 1–5, which produces a score of 5–25 (Fayers and Machin, 2000). A 20-centimetre visual analogue scale from 0 to 100, where the respondents mark their current state of health, is also part of the survey, with a high score indicating good quality of life. An overall improvement was not anticipated, for instance in the dimension of mobility, in view of the neurodegenerative nature of dementia.

QoL-AD contains 13 dimensions, with each dimension rated on a four-point scale (poor, fair, good and excellent). The dimensions in QoL-AD are: Physical health, Energy, Mood, Living situation, Memory, Family, Marriage, Friends, Self as a whole, Life as a whole, Ability to do chores around the house, Ability to do things for fun and Money (Selai *et al.*, 2001; Sloane *et al.*, 2005). The survey produces a total score of 13–52, with a high score indicating good quality of life (Sloane *et al.*, 2005; Wolak-Thierry *et al.*, 2014).

Given the nature of the trial setup and the way the questionnaires were conducted, the results show the participant's self-reported perceptions of usefulness rather than an external measure that would have required observations from the researchers.

Data analysis

The Statistical Package for the Social Sciences version 25.0 was used for data and statistical analyses. Since ordinal data were present and we suspected that data were not normally distributed, non-parametric data analysis tests were conducted. For all the statistics, $p < 0.05$ or $p < 0.01$ was selected. When analysing quality of life of people with dementia, the Wilcoxon signed-rank test was used for the total pre-intervention and post-intervention scores. For people with dementia who did not fill in one to two dimensions out of a total of 13, the missing dimensions were supplemented by average scores, which were then added to calculate the total score (Hoe *et al.*, 2006).

To analyse the impact on all the participants' health and wellbeing after using the digital communication aids, descriptive statistics were used based on the

CIRCA and CIRCUS evaluation questionnaires. Chi-square test and Spearman's correlation analysis were used when analysing the relationship between the participants' rating of the usefulness of the digital communication aids and their impact on their health and wellbeing, as well as the relationship between the care-givers' rating of their satisfaction with technology and their rating of the usefulness of the communication aids.

Results

### Quality of life for people with dementia measured using EQ-5D

The total EQ-5D score, where a low score indicates good quality of life, revealed a significant improvement in quality of life with the result: N = 45, $z = 2.87$, $p < 0.05$. Prior to participation in the IN LIFE project, the people with dementia scored median (Md) = 13 (standard deviation (SD) = 0.06) and after participation they scored Md = 12 (SD = 4.48). For the five individual dimensions in the questionnaire, *Mobility* ($p = 0.073$), *Self-care* ($p = 0.505$), *Usual activities* ($p = 0.060$), *Pain/discomfort* ($p = 0.973$) and *Anxiety/depression* ($p = 0.653$), reduced scores were also revealed, although the reduction was not significant. People with dementia were also required to rate their *current state of health* according to a visual analogue scale in percentage terms from 0 to 100, where a high rating indicates a better state of health. The results showed that there was an increase in the ratings of people with dementia before and after participation in the IN LIFE project, although the difference was not significant ($z = 1.536$, $p = 0.125$).

Quality of life for people with dementia measured using QoL-AD

The total score using QoL-AD, where a high score indicates good quality of life, revealed an improvement in quality of life for people with dementia although the results were not significant (N = 30, $z = 0.496$, $p = 0.620$). Prior to participation in the IN LIFE project, people with dementia scored Md = 31.0 (SD = 4.4) and after participation they scored Md = 31.0 (SD = 4.9).

For three of the 13 dimensions, there were significant differences between the results. For people with dementia (N = 49), the result for *Memory* before participation was Md = 1.0 (SD = 0.73) and after participation the result was Md = 1.0 (SD = 0.67), which was a significant memory deterioration ($z = 2.556$, $p = 0.011$). The result for *Physical health* (N = 56) before participation was Md = 2 (SD = 0.82) and after participation the result was Md = 2 (SD = 0.59), which is also a significant deterioration ($z = 3.087$, $p = 0.002$). The result for *Ability to do things for fun* (N = 43) before participation was Md = 2 (SD = 0.6) and after participation it was Md = 2 (SD = 0.69), which represents a significant increase in the potential to do things for fun ($z = 2.13$, $p = 0.033$).

The results for other dimensions were not significant: *Energy* (N = 57, $p = 0.866$), *Mood* (N = 59, $p = 0.64$), *Living situation* (N = 57, $p = 0.127$), *Family* (N = 55, $p = 0.634$), *Marriage* (N = 17, $p = 0.272$), *Friends* (N = 39, $p = 0.355$), *Self as a whole* (N = 52, $p = 0.317$), *Life as a whole* (N = 52, $p = 0.317$), *Ability to do chores around the house* (N = 30, $p = 0.805$) and *Money* (N = 28, $p = 0.237$).
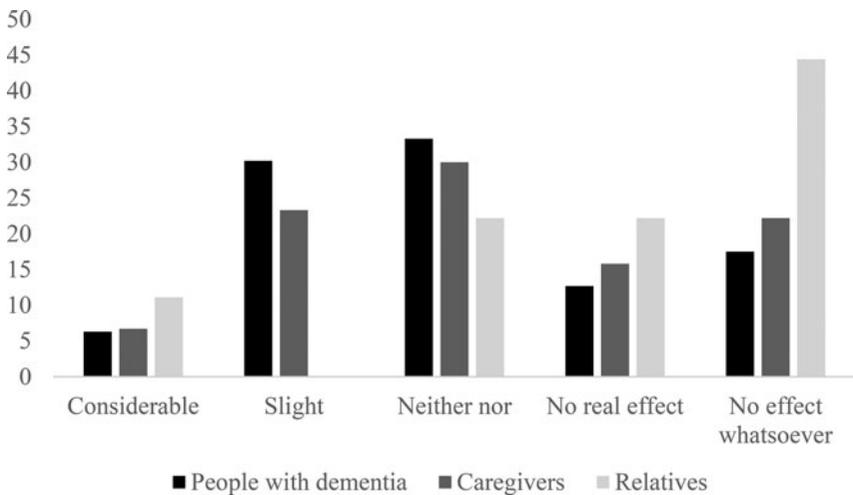
Figure 3. Frequency spread for the participants' rating of the effect of CIRCA on their health and wellbeing.

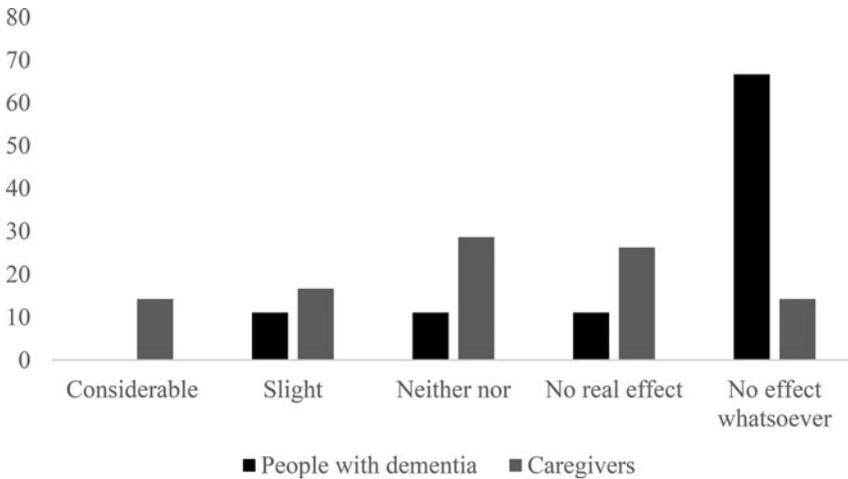### The effects on the participants' health and wellbeing following use of the Web-based communication aids

As seen in Figure 3, the average rating of CIRCA's effect on their health and wellbeing for people with dementia (N = 63) was *Neither nor* (mean = 3.05, SD = 1.18). The average rating of the care-givers (N = 120) produced the same result *Neither nor* (mean = 3.28, SD = 1.25) and that of relatives (N = 9) was *No real effect* (mean = 3.89, SD = 1.36).

Figure 4 shows that for people with dementia (N = 9), the average rating of the effect of CIRCUS on their health and wellbeing was *No real effect* (mean = 4.33, SD = 1.12). For the care-givers (N = 42), the average rating was *Neither nor* (mean = 3.1, SD = 1.27). As the relatives did not undergo CIRCUS testing, no similar analysis was made for the remaining participants.

Correlation between the participants' rating of the usefulness of the Web-based communication aids and the effect on their health and wellbeing

Using Spearman's correlation analysis, the rating by people with dementia (N = 63) of the usefulness of CIRCA (mean = 2.57, SD = 1.12) and the effect on their health and wellbeing following intervention with CIRCA (mean = 3.05, SD = 1.18), showed a positive correlation ($r = 0.743$, $p < 0.01$). A chi-square test also revealed a positive correlation between usefulness and effect on the health and wellbeing of people with dementia ($\chi^2 = 62.419$, degrees of freedom (df) = 16, $p < 0.01$). In the case of people with dementia (N = 9) who used CIRCUS, there was no significant correlation ($r = 0.640$, $p = 0.063$) between their rating of usefulness (mean = 3.44, SD = 1.51) and the effect on their health and wellbeing (mean = 4.33, SD = 1.12). With Spearman's correlation analysis, the care-givers' (N = 120) rating of the usefulness (mean = 2.37, SD = 1.23) and the effect on their health and wellbeing following use of CIRCA (mean = 3.28, SD = 1.25) showed a significant correlation, and

Figure 4. Frequency spread for the participants' rating of the effect of CIRCUS on their health and wellbeing.

it was slightly positive ($r = 0.370$, $p < 0.01$). In the case of the chi-square test, a significant correlation was also noted between the usefulness of CIRCA and the effect on the care-givers' health and wellbeing ($\chi^2 = 32.846$, df = 16, $p < 0.01$). The correlation between the care-givers' (N = 42) rated usefulness of CIRCUS (mean = 1.78, SD = 1.09) and the effect on their health and wellbeing (mean = 3.1, SD = 1.27) was not significant ($r = 0.034$, $p = 0.830$).

As seen in Table 2, relatives' (N = 9) rating of the usefulness of CIRCA (mean = 3.22, SD = 1.2) and the effect on their health and wellbeing (mean = 3.05, SD = 1.18) did not reveal any significant correlation ($r = 0.436$, $p = 0.240$) with Spearman's correlation analysis. Neither did the chi-square test ($p = 0.116$).

Correlation between the care-givers' rating of the usefulness of the Web-based communication aids and a rating of their satisfaction with the technology

The care-givers' (N = 113) rating of the usefulness of CIRCA was *Usable to some degree* (Md = 2, SD = 1.23) and the rating of their satisfaction with the technology was *Quite satisfied* (Md = 3, SD = 0.89). Using Spearman's correlation analysis, a significant positive correlation was noted between the care-givers' rating of their satisfaction with technology and their rating of the usefulness of CIRCA ($r = 0.301$, $p = 0.001$). In the case of the chi-square test, a correlation was noted between the care-givers' rating of usefulness and their satisfaction with the technology ($\chi^2 = 28.087$, df = 16, $p < 0.05$). Table 3 shows the details of the care-givers' rated usefulness and the covariation with their satisfaction with the technology.

The care-givers' (N = 49) rating of the usability of CIRCUS was *Usable to some degree* (Md = 1, SD = 1.09) and the rating of their satisfaction with the technology was *Satisfied* (Md = 2, SD = 0.71). Spearman's correlation analysis revealed no correlation between the care-givers' satisfaction with the technology and their rating of the usability of CIRCUS ($r = 0.167$, $p = 0.252$), and neither did the chi-square test ($\chi^2 = 11.182$, df = 8, $p = 0.192$).

Table 2. Correlation between the participants' health and wellbeing and the usefulness of CIRCA with Spearman's correlation analysis and chi-square test

Participants	r	p
People with dementia	0.720	0.000*
Care-givers	0.370	0.000*
Relatives	0.436	0.240

Significance level: * $p < 0.01$.

Table 3. Covariation of care-givers' satisfaction with the technology and their rating of the usefulness of CIRCA

Rating of usefuless	Satisfaction with technology				
	Very satisfied	Satisfied	Quite satisfied	Not particularly satisfied	Not at all satisfied
N	26	24	59	3	1
	Percentages				
Very usable	50	54.2	18.6	33.3	0
Usable to some degree	11.5	25	20.3[1]	0	0
Neither nor	23.1	16.6	39	66.7	0
Not very usable	7.7	4.2	13.6	0	100
Not usable at all	7.7	0	8.5	0	0

Note: 1. The most commonly reported rate.

Discussion

The first purpose of this study was to investigate the extent to which quality of life for people with dementia differed before and after the use of digital communication aids, measured using EQ-5D and QoL-AD, respectively. As a consequence of dementia, both memory and general health deteriorate as the disease progresses (Tang and Robinson, 2013). Hypothetically, this was also the case for the participants in the present study during the intervention period. However, it was noted in this study, when measured using EQ-5D, that quality of life improved for people with dementia, and when measured using QoL-AD, that the ability to do things for fun improved. It is reasonable to assume that the number of opportunities for social interaction and activities for people with dementia increased as they were involved in the present intervention using CIRCA or CIRCUS.

The second purpose of this study was to examine the effect of using digital communication aids, and the first sub-question was: What was the impact on the health and wellbeing post-intervention for people with dementia, care-givers and relatives? The participants in the study reported that use of Web-based communication aids had

a neutral effect on health and wellbeing. Previous research shows that Web-based aids that were intended to promote communication and interaction between people with dementia and their communication partners resulted in improved health and wellbeing for all (Alm *et al.*, 2004; Astell *et al.*, 2010; Lopes *et al.*, 2016; Goffe and Karlsson, 2017). The use of technology can enable and stimulate interaction between people with dementia and those who care for them (Ferm *et al.*, 2020). A possible explanation for the lack of significance in the present study is that care-givers or relatives of people with dementia did not have enough time or felt stressed in conjunction with the intervention, and thus did not have the opportunity to reflect on whether it had any effect on their own health and wellbeing. Research has shown that there is a correlation between improved quality of life for people with dementia and when the people around them feel less stressed (Orgeta *et al.*, 2015).

More time to use the Web-based communication aids together with people with dementia might have had a more positive effect on the care-givers' health and wellbeing.

The second sub-question was: Is there any correlation between the perceived usefulness of the digital communication aid and the impact on the health and wellbeing of people with dementia, care-givers and relatives? In the present study, a correlation was noted between the participants' rating of the usefulness of CIRCA and the effect of CIRCA on their health and wellbeing. However, the results showed no corresponding significant effect on health and wellbeing related to the use of CIRCUS. The main reason for the results relating to the effect of the Web-based communication aids on the participants' health and wellbeing could be explained by their ability to use the aids. This correlation has also emerged in previous research (Astell *et al.*, 2010; Goffe and Karlsson, 2017). This could explain the differences between the effect on health and wellbeing of intervention with CIRCA and intervention with CIRCUS. As stated previously, CIRCUS is a personal Web-based communication aid where the participants themselves are required to add their own material. There are thus greater demands on the users of this intervention compared with the users of CIRCA, which is already filled with generic material. Care-givers already have a high workload and they generally have low-paid jobs, long working days, few benefits, and are subject to occupational injury and depression (Deutschman, 2000). A potential risk of intervention via a tablet or a computer could be that it leads to new demands on the care-givers or relatives of people with dementia, which could increase their burden instead of alleviating it (Kerkhof *et al.*, 2016).

The third sub-question was: Is there any correlation between the care-givers' rating of the usefulness of the digital communication aid and their overall satisfaction with technology? Previous research into reminiscence intervention has reported that there are several benefits with the digital multimedia format. This is particularly the case when the care-givers feel that the people they care for can make use of the system, which was shown in previous research into CIRCA (Alm *et al.*, 2004). Our study shows that there was no significant correlation for CIRCUS, which may be due to the previously discussed requirement of individual adaptions. The correlation for CIRCA was deemed higher, which may have to do with the fact that it can be used without preparations in different settings.

Qualitative research into CIRCA has revealed that CIRCA supports relationships between care-givers and people with dementia by creating situations that involve

engaging in social interaction (Astell *et al.*, 2010). Qualitative research into CIRCUS has produced similar results, where all care-givers who participated in the study were positively disposed to using CIRCUS, although it was difficult for people with dementia to interact with the system independently (Goffe and Karlsson, 2017). It was previously believed that people with dementia were not capable of using new technology, or they would find it very difficult to learn how to use it, as it was assumed that the technology is too complicated or that elderly people are not familiar with it (Orpwood *et al.*, 2010). However, several studies have shown that people with dementia are capable of learning how to use new technology (Thivierge *et al.*, 2008; Imbeault *et al.*, 2013).

Limitations of the study

A number of limitations arose in the present study when analysing the participants' experiences of Web-based communication aids. The first limitation was the absence of a control group and lack of power analysis as well as sensitivity analysis, which impedes the potential to distinguish the true effect.

The second limitation for the analysis was the drop-out rate, the main reasons being the care-givers' and relatives' ability to complete the questionnaires and the fact that the questionnaire had already been changed to some extent when data collection commenced. The high number of excluded participants and drop-outs in the case of the QoL-AD questionnaire could be the reason the results were not significant. EQ-5D and QoL-AD correlated significantly with each other with regard to their reliability. However, EQ-5D demonstrates stronger inter-assessor reliability between people with dementia and their representatives, *i.e.* when the quality of life questionnaire for the person with dementia is filled in by other people (Aguirre *et al.*, 2016). Since this was the case in the present study, EQ-5D may work better than specific quality-of-life questionnaire metrics.

The third limitation was a lack of data in the present intervention study relating to the type and degree of dementia among the participants which is a key factor in distinguishing with which group the intervention works best. The lack of this information could thus affect the results as there could be major differences in how people with dementia rated their quality of life depending on their difficulties. This could mean that the results obtained in the present study are not representative of all people with dementia. The inclusion criteria for participating in the study mean that all participants were assessed to have dementia, but no individual assessment was possible to carry out in the parameters of this study. Furthermore, dementia is a degenerative disease and assessing improvements in disease status reported through quality-of-life questionnaires completed by people with dementia with the aid of supportive care-givers or relatives is problematic (Arons *et al.*, 2013).

A fourth limitation was that the study did not distinguish the results according to the setting in which the participant used the digital communication aid (*e.g.* at a care home or in their own home), which could have given more information whether or not the setting was a key factor for the intervention. These limitations are all related to the fact that the present study was part of a larger project, where the design and methodology were set and not possible to adjust for a single partner.

A fifth limitation was that this study aimed to investigate both the experiences of relatives and care-givers, but got a large overweight of care-givers among the

participants. One reason for this was that the main part of the recruitment was obtained through networks of professionals. It was difficult to reach the people with dementia themselves and their family members, even though efforts were made through user organisations, social media, and open lectures and workshops. The participants with dementia received care in their home or lived in care homes and the contact with the researchers was mediated via the carers. Even though carers were encouraged to invite relatives to participate, there was a sparse response. The reason for this is unknown to us but we can suspect that this information got lost in the communication between the staff and the relatives, or that people with dementia in care homes may not have frequent contact with relatives.

There could be a number of reasons why the effect on health and wellbeing was reported as neutral in comparison with the quality-of-life results for people with dementia. One reason could be that they interpreted health and wellbeing in line with the World Health Organization's 1949 classification, in which good health is described as a condition of complete physical, mental and social wellbeing. According to previous research, this could be problematic as complete wellbeing is difficult to achieve and health-promoting activities, as is the case with the Web-based communication aids in the present study, could be easily misinterpreted as helping to counteract the disease rather than promoting the person's health and wellbeing (Card, 2017). Another reason could be that the intervention was not sufficiently intensive to have any effect on the participants' health and wellbeing.

Future studies

Clear intervention guidelines are important as the intervention results may be affected by many factors, for instance, the intensity of the intervention. Both the degenerative nature of dementia and the involvement of support from carers and relatives must be considered in order to design robust intervention studies. To exclude any bias, future research is needed in order to focus on identifying factors that affect the health and wellbeing of people with dementia and their communication partners. For example, we suggest conducting separate studies to analyse session data and investigate whether the intensity of usage correlates to the level of self-reported satisfaction. Furthermore, future research ought to place more emphasis on CIRCUS and investigate whether the results would be different if the users had received more training in how to use the different functions in CIRCUS. In future studies, it would be relevant to look at the appropriate length of intervention period for the use of digital reminiscing aids to give effect. It would also be interesting to evaluate if the living situation and setting for intervention affected the results.

Conclusion

The present intervention study is a contribution to highlighting the significance of Web-based communication aids for people with dementia and their care-givers and relatives. It has provided further information about positive effects of Web-based communication aids on quality of life for people with dementia. A correlation between the usefulness of Web-based communication aids and their perceived effect on the participants' health and wellbeing was also noted. The study thus

provides further knowledge to professionals and care-givers in relation to people with dementia. The study highlights that Web-based communication aids may be beneficial as they have a positive effect on quality of life for people with dementia. The Web-based communication aids in the study appear to be useful and have a perceived impact on the health and wellbeing of people with dementia and their care-givers and relatives. Web-based communication aids therefore appear to support and promote social interaction between people with dementia and their communication partners. The results of the present intervention study provide a basis for the use of Web-based communication aids to support social interaction and to become an integral part of E-health.

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