Couples experiences of using DemPower in everyday life

<table>
<thead>
<tr>
<th>Journal</th>
<th>Quality in Ageing and Older Adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manuscript ID</td>
<td>QAOA-10-2019-0059.R2</td>
</tr>
<tr>
<td>Manuscript Type</td>
<td>Research Paper</td>
</tr>
<tr>
<td>Keywords</td>
<td>Application, Couples, Dementia, Information and Communication Technology, Intervention, Self-management</td>
</tr>
</tbody>
</table>
Couples experiences of using [app name] in everyday life

Introduction: Interventions aimed at couples where one partner has dementia are often targeting burden, depression and cognitive function and do not focus on relationship and interpersonal issues. Furthermore, interventions within this population do not seem to have embraced a salutogenic and authentic dyadic approach where both partners’ experiences are considered. In order to address this gap, we developed a couple-management app, [app name], which was piloted and tested among couples where one partner has dementia living at home. Aim: This study explores couples’ experiences of engaging with the app [app name]. Methods: Semi-structured interviews with couples were analysed using thematic analysis. Findings: The findings resulted in the themes Growth of the relationship; We are not alone; and Positive approach. Discussion: The findings indicated that the experiences of a salutogenic and dyadic intervention can contribute to feelings of empowerment, satisfaction of couples’ achievements and a sense of support through peers and with the app itself.

Keywords: Application; Couples; Dementia; Information and Communication Technology; Intervention; Self-management

Introduction

In Sweden, it is estimated that around 160,000 people are living with dementia and this demographic trend will nearly double in the next 20 years (National Board of Health and Welfare, 2014). Most people with dementia in Sweden live at home and require homecare services and support (Official Report of the Swedish Government, 2016). This trend also applies to other high-income countries where two-thirds of people with dementia live in their own homes (Alzheimer’s Disease International, 2013).
Many people with dementia live together with their partner who often becomes an informal caregiver. According to Alzheimer’s Disease International (2009), 85% of couples where one partner has dementia living at home, need some form of support to manage their daily life. However, support provided for couples is often task-oriented, and often focused on psychosocial support for the partner without dementia, such as via support groups and education-based material (Alzheimer’s Disease International, 2016). Much of the support for people with dementia and partners, including couple-based support, is largely absent and where it does exist, it seems to lack a genuine dyadic approach where relationship factors are acknowledged (Author, 2017a). Furthermore, couples’ relationships where one partner has dementia are often described negatively (see for example Ablitt, Jones & Muers, 2009; Allen, Curran, Duggan, Cryan, Chorcora et al. 2017) with outcomes of interventions focussed on measuring caregiver burden, depressive symptoms and cognitive functioning (Purkis & Ceci, 2015).

Although the aspect of reducing negative outcomes are important, and that symptoms of dementia are a threat to wellbeing as a couple, arguably it is of greater importance to target support towards the positive elements of the couple’s relationship and everyday life. In fact, relationship quality has been highlighted as a key factor for the prevention of negative outcomes (Ablitt et al. 2009; Allen et al. 2017), including in three recent reviews of the literature on this topic area (Author, 2017 a, b; Conway, Watson, Tatangelo & McCabe, 2018). This makes one wonder why relationship quality and support in couples’ day-to-day life together are not the sole targets of the intervention(s) (see also Heehyul, Townsend, Whilatch, Dilworth-Anderson, 2017; Sinclair, Auret, Gersbach, Hogan, Bucks, Clayton, Agar & Kurrle, 2018).

Over the past decade, the focus on a salutogenic approach (from the term salutogenesis, i.e focus on health not illness) within the treatment of chronic conditions,
has rapidly increased. Alongside this, an ever increasing number of self-management resources have become available for people living with chronic conditions. Here, self-management aims to improve health for those concerned and is targeted for use at the time and place it best suits the person (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002). Many of the available self-management resources are digital, such as those accessible online (Chiu & Eysenbach, 2011; Grady & Gough, 2015), although self-management and digital interventions have not yet been implemented as an integral part of the care of people with dementia (Huis in het Veld, Francke, Verkaik & van Meijel, 2018). Some of the reasons for this might be that the views of self-management techniques are clearly linked to medicine and symptom control (Martin, Turner, Wallace, Choudhry & Bradbury, 2013) with Ibrahim et al. (2017) recently suggesting that people living with dementia should not be given too much responsibility over their personal situation due to their on-going cognitive decline. However, this restricted application completely misses the point, as a core philosophy of self-management is that it should not solely focus on symptom control alone and, instead, target the individual's relationships in order to meet the challenges of everyday life (Author 2017b; Martin et al, 2013). Accordingly, there is a clear gap in both the literature and knowledge about a dyadic, salutogenic and self-management approach directed towards couples where one partner has dementia living at home. It is to this area that this article will now turn.

**Bridging the dyadic, salutogenic and self-management approach together through [app name]**

Our aim with the [app name] application was to develop a home-based intervention constructed from self-management techniques and with a dyadic and salutogenic approach that couples could engage in when it suited them best. This intervention is referred to as a couple-management app. The objectives of [app name]
were threefold: i) to help couples focus on the everyday activities they can still do rather on what they are no longer able to do; ii) to reflect upon the strengths of the couples relationship and help couples to find ways to tackle daily activities together’ and iii) to archive reflections, meaningful moments, and memories the way they would like them to be remembered and stored. The contents of [app name] are structured under the four themes “Home and Neighbourhood”, “Meaningful activities and Relationships”, “Meeting, Sharing and Caring in your neighbourhood” and “Managing emotions, Communication and Approach” with related sub-headings and sections. The four themes and sections in [app name] are introduced using storyboard techniques with a voiceover, followed by video clips of couples sharing their experiences of living with dementia as a couple. The video clips are based on real-life experiences of couples living with dementia where they share their relationship and everyday life. [app name] makes suggestions for activities under each section. Examples of some activities include games, links to useful information, taking photographs, writing reflections, and discussing emotions and the couples’ approach to their relationship and daily life. For more information about the development and content of the [app name] see Author (2018a) and Author (2018b).

Aim

The aim of this study was to explore the experiences of using the application [app name] among couples where one partner has dementia living at home.

Method

Participants and procedure

Twelve Swedish couples tested the [app name] delivered via tablets, in the feasibility
study (Author, 2018a). Inclusion criteria were: couples where one partner has a diagnosis of dementia living at home and who have been in a long-term relationship for two or more years. When follow-up data collection was conducted for the feasibility study, couples were asked if they were interested in participating in an interview study about their experiences of using [app name] [the present study]. Couples received an information sheet about the study at that occasion and a new appointment for the interview was scheduled. Recruitment was made by asking the couples to participate in the order that they completed the feasibility study. In total, eight couples agreed to participate, although two couples later declined due to traveling at the time for the interviews. Six couples therefore participated in the present study and their characteristics are displayed in Table 1.

Please insert table 1 here

**Data collection**

Interviews took place approximately one week after the information sheet was handed out. All six couples chose to do the interview in their own homes. Interviews varied in length between 20 – 45 minutes. Data consisted of six semi structured interviews and the interview guide is displayed in Table 2. The first author, with several years of experience of communication with people with dementia and their family members, conducted all the interviews. Written informed consent was collected from all individuals before the interview started. Interviews were audio recorded and transcribed verbatim by the first author.

Please insert table 2 here
Analysis

Thematic analysis was used to analyse the data (Braun & Clarke, 2012). Thematic analysis was conducted by following the stepped process; step 1, where we read the transcribed data several times to gain an overall view of the raw data – here, we marked initial ideas for codes; step 2 refers to coding the data and where we applied descriptions of the data to sequences in order to organise it; in step 3 we clustered codes together in order to form subthemes of the extracts associated to each other; in step 4 we reviewed and refined the subthemes and created main themes as overarching a titles for the corresponding sub themes; step 5 is the last step where the data is reported.

Interviews were held in Swedish and data were initially discussed between the Swedish authors to ensure transparency and consistency. After the data had been translated into English the data were discussed within the whole research group.

Ethical considerations

The study was given ethical approval by the [name of ethics committee]. Participating couples received relevant oral and written information about the study and that they could withdraw from the study at any time. Written and verbal consent was collected from the couples and all data were kept confidential (World Medical Association, 2013). To ensure that both individuals in the dyad consented to take part in the study, it was important that the first author actively asked for consent throughout the study, a process that enabled couples to make informed decisions from the start to the completion of the study (Dewing, 2008). This required that the researcher was responsive and sensitive to changing needs. This was important as despite information about voluntary participation, there could be underlying power structures within the relationship that may have influenced the couples’ contribution and agreement to take
part (Braybrook, Mróz, Robertson, White & Milnes, 2017). Moreover, the first author and the couples taking part in this separate follow-on study had already met during the feasibility study of [app name] and it was therefore important that each person within the dyad was given time to reflect upon their decision to take part.

Findings

The findings of this study resulted in three themes: (1) Growth of the relationship, (2) We are not alone and (3) Positive approach.

Theme 1: Growth of the relationship

Couples shared that dementia is a condition that affected them both within all perspectives of their everyday life together and their relationship. They discussed that they considered it somehow as a dyadic condition that could be addressed by discussing their situation in [app name]:

“The app handles a lot of issues related to couple relationship and it is without doubt that you are two with the disease in this disease” Couple 1 (C1)

“In the situation that we are in now, we must help each other to come to terms” C2

As seen in the above quotations, it seemed to be secondary as to who had the dementia, and more importance was placed upon supporting one another and adjusting to the changing roles and routines that came with the onset of dementia. Couples expressed that the underlying structures of the relationship had changed. Within some couples, both partners felt that their relationship had developed and become more equal, and that the love that was present in their relationship was a powerful force in helping to adjust
to changing circumstances. Sharing such emotions had an affirming and empowering affect and couples validated each other’s experiences, as the following slice of data attests:

“Now that you have this dementia, we have reached out to each other and are very close, we have both been able to be vulnerable. And support each other, we have no power struggle or prestige that one can have, we have released it now” C5

One of the wives, of the two couples described above (C5), said that before her husband had been diagnosed with dementia, he was always ‘a leader’ and always knew ‘what to do’ and how ‘to solve things’. In their current situation, his wife had now taken over many decisions and contacts with authorities that her husband used to manage. In this particular relationship, the husband reported this new-found situation as ‘pleasant’ and seemed to welcome this mutually supportive act. Within the other couple mentioned above (C3), the husband had a hard time accepting change in roles in the beginning but had now accepted it and found it peaceful to not have to be in charge all the time.

Couples in the study discussed the fact that they had rarely sat down to talk and reflect upon their situation before using [app name]. Sitting down together to talk could, in itself, contribute towards a sense of closeness and openness. Both partners could then share their frustration about the situation with one another, and not keep things to themselves or share their real feelings outside of the dyadic relationship. The couples felt that using the app had helped their personal relationship and had been a positive experience although it had initially felt ‘a bit uncomfortable’ (C3). By focussing on [app name], the app seemed to free up the couple’s emotions and enable them to talk openly
and honestly together about their real feelings and emotions about living with dementia and the consequences it had for them both, as summarised below:

“I have talked to others about it but it’s not that you and I have been sitting like this ... more than with the doctor... but not with you in that way...why ... I don't know. We haven't talked about the disease in that way before, you and I ... it has been helpful” C3

“That you really sit down and think about all this…. We sit and talk sometimes when he discovers how he forgets and so but otherwise it doesn't get so often that you sit down and talk around these things” C4

Couples expressed that they benefited from discussing their communication. They described it as useful and satisfying to be able to talk about communication in a conflict-free situation. Recognizing frustration and own shortcomings could be liberating:

“We talked about conflicts and stress, the fourth chapter. And how we experience that ... I have not dared before ..., I have occasionally said that I am sorry because I am irritated and yes, it is ... Yes, I feel calmer in some way ... now” C3

Couples had tried new things through the activities of [app name]. Several activities contributed to closeness, especially the suggestion of choosing a song from a music list and express their love for each other. Couples that chose to dance during their selected song expressed that the dance took them back in time and they felt that nothing had really changed in the foundation of their relationship:

“And the dance, as we did, was to come back to this feeling, and you were very happy and this I hope we do again...that we actually decide that we are taking a dance, because it's getting back to the closeness we once had” C3
The fact that the couple sat next to each other when engaging in [app name] gave them physical closeness and the questions in the app could contribute towards a reflection upon the strength of their relationship:

“When we went through it (the app), then it was like this, that I was sitting on that chair and you were sitting on that, and then it was the questions then, so we became closer, I think” C3

**Theme 2: We are not alone**

The data suggested that couples enjoyed watching the videos of other couples in the [app name] app as it made them feel that they were not alone with the situation. Furthermore, couples also found comfort in the videos as a learning experience in how to manage their everyday life, getting tips and advice on how this may be achieved, as these two quotations reveal:

“When you saw these videos of the couples who were talking, you did not feel alone, you could learn from that they say so and that they have solved it like that, they do so to each other…” C5

“Yes, they (videos) calmed us a little, I think. Although there were actors in videos, it calmed me anyway. And they were so nice to each other, I think it gave a lot about how I, as a relative, should behave” C3

Couples felt that they were cared for through the support in [app name] and that “someone” really had made an effort to help them in their daily life. They also found [app name] helpful overall and that the app had introduced them to a lot of information and advice, some of which they could use in the present day and some that they could return to in the future:
“Many things are good to know that they exist and it is good that someone has thought about it and comes up with suggestions, practical suggestions that can be a seed for something that you can use later. I think, there were plenty of seeds” C1

Theme 3: Positive approach

Couples had embraced the strategy of living in the moment and when discussing this in [app name], it gave them an assurance that their strategy was the right way to go. They saw “living in the moment” as their best tip for other couples and also to normalise and to embrace the future:

“Much of what the app said was to live in the present and that's the thing”
C2

“Our tip is to live in the present and make the most of the time. Then, it (dementia) is not something you die from in two days so you do not have to hurry and you do not have to change everything” C1

Couples also found it important to prioritise and document what quality of life meant to them. This contributed to reflections about the positive things in life. In other words, to think about the good before the bad and not to worry in advance. Interestingly, one couple felt that contact with healthcare professional were too focused on identifying and teasing out problems rather than on health promoting activities:

“I think it is very important to think positively. It means very much to both of us that we think of what quality of life means to us and to think how good we really have it” C4

“I thought it was very nice that it [app name] was not problem-oriented because when you get to the hospital you get a little depressed but this was a
thing where you highlight the positive and all that you can do. One does not have to be depressed in advance... It's a lot of good tips I think” C4

Participation in the intervention contributed to positive emotions and couples felt that they had been involved in something valuable to other couples facing a similar situation. The intervention and the follow-up study were perceived as a positive element in themselves and a feeling of being important:

“I can't say that it is only this…but the app is part of this …It has felt good that we have been valuable in research ... that we can perhaps do something… for others who get a diagnosis” C3

Discussion

The aim of this study was to explore the experiences of the [app name] by couples where one partner has dementia living at home. The findings resulted in the themes: Growth of the relationship, We are not alone, and Positive approach. The themes are clearly linked to couples recognition of their transition as a couple living with dementia. Here, transition can be defined as a passage from one life phase to another and describes a developing and often empowering change process as a consequence (Chick & Meleis, 1986). In the presented study, the six couples’ experiences of transition could be seen to have its starting point with the diagnosis of dementia, or when they suspected that something was wrong (the disconnectedness caused by the disruption), followed by phases of coping and adjustment to change (patterns of response), and the endpoint where couples have reached more stability relatively to the situation during the process (see also: Chick & Meleis, 1986). However, dementia is a progressive condition which implies multiple transitions for couples and, perhaps, parallel transitions at the same time. The intensity of the influencing factor in a transition, in this case dementia,
may also vary over the process and so might the patterns of response (Chick & Meleis, 1986). However, the experiences of engaging in [app name] salutogenic and couple-based approach to dementia and everyday life have positively impacted on couples and their transition through the lived experience of dementia.

A growth of the couples’ relationships comes from within an evolving process and time span, couples in our study shared that dementia had changed their relationship in both good and bad ways. Since this study targeted the present situation, we were interested in how couples experienced everyday life whilst engaging with [app name]. Consequently, the theme ‘Growth of the relationship’ included a “we are in this together” style of approach. Here, couples viewed dementia as a dyadic condition that affected them both equally. Partners’ interdependence on one another had also become clearer over time and where the well-being of both mattered. Coping with the present, and the future, as a unit was an important outcome in engaging with the [app name].

However, whilst dementia had brought partners closer to each other insofar as they spent more time together, it also resulted in a heightened sense of togetherness and mutual respect for their relationship (Hellström, Nolan, & Lundh, 2005). For example, in our study couples now described their relationship as ‘more equal’ and ‘accepting’ and this was achieved by sharing responsibilities in areas that could previously be seen as stereotypical gender role around the home, such as cooking and cleaning. Changes in social and domestic roles have been studied by several researchers where relationships often are described in terms of loss in relationship quality and former roles of the relationship (Ablitt et al. 2009; Allen et al. 2017; Conway et al. 2018; Watson, Tatangelo & McCabe, 2018; Brodaty & Donkin, 2009). However, the couples in our study who expressed greater togetherness and role equality since the onset of dementia, had come to terms with the situation and the ongoing transitional impact on their
everyday lives. Accordingly, our study has demonstrated that there are positive aspects
of change in social roles and that this impacts upon relationship quality: a positive when
perhaps for too long, the experience of living with dementia has been socially
constructed as one of a diminishing number of contacts and connections (see for
example: Duggan, Blackman, Martyr, Van Shaik, 2008; Ward, Clark, Campbell,
Graham, Kullberg et al. 2018).

Interesting, the discussion about reaching a more equal relationship mainly came
up with couples where the husband had dementia, which might relate to former
structures of the domestic relationship (Boyle, 2017). Interestingly, older caregiving
husbands to a wife with dementia often felt that they had to give up some of their
masculine identity in order to take over “female chores” (Hellström, Håkansson,
Eriksson & Sandberg, 2017). On the other hand, another experience of [app name] that
contributed towards a growth of the relationship, was when couples shared their
emotions and experiences of the impact of dementia on their relationship with each
other. It was a surprise that they had not done this before, a finding which we were not
expecting. Fear of revealing emotions to one another was one reason the couples gave
for this non-disclosure. However, by sitting down together with their mutual “task” of
talking about their feelings, the exercise gave the couple a neutral and accepting space
to talk about emotions; an experience that brought them closer together with a greater
understanding about different responses to coping with changing situations. This was
also the case when they discussed their communication and interaction with each other.
Talking about ‘what works’ and ‘what does not work’ and what contributes to conflicts
in their relationship helped couples to identify situations they could avoid and strategies
to put into place to enhance their quality of life and wellbeing. This brought a greater
awareness of their responses to situations which occur, and how their responses
impacted on each other. Awareness is a key component in the concept of transition and
relates to the definitions and redefinitions of self and the situation (Chick & Meleis,
1986). Indeed, ‘talking things through’ with each other as a couple has been highlighted
as an important part for growth of the relationship within couples where one partner has
dementia (Hellström et al. 2017) and data from this study would appear to support this
assertion.

The salutogenic approach to guide health and wellbeing and the focus on what couples
can do, rather on what they cannot do, permeated couple’s discussions. Couples liked
the idea of focusing on positive resources and stated that there was currently too much
negativity around dementia. When documenting their inner resources and strengths
(included in [app name]), couples often came to the conclusion that they planned to do
more of the activities they like and know that they can manage. However, through the
use of [app name], couples also tried to learn new things, which meant that they
embraced a self-management approach and the everyday technology that made it
meaningful in their lives. Couples found it empowering to have performed tasks in the
app, both together and on their own. For people living with dementia as part of the
couple relationship, independent use of the [app name] depended upon the symptoms of
dementia and how advanced it was. According to LaMonica et al. (2017), older people
and people with cognitive decline, are often curious of internet and digital interventions
and how it might be possible to improve their situation. Furthermore, Stockwell-Smith
(2019) has examined couples’ where one partner has dementia conditions for self-
management and found that with the support from healthcare staff, self-management
interventions can improve self-efficacy and independence.
The use of everyday technology has been highlighted to positively influence people with dementia and partners in their daily life (Gibson, Dickinson, Brittain & Robinson, 2015), especially when people with dementia and their care partners have a sense of familiarity to the technology, such as through a smartphone or tablet (Gibson et al. 2015; Newton, Dickinson, Gibson, Brittain & Robinson, 2016). However, the personalisation of technology and how it is used should be individually adapted (Gibson et al. 2015), particularly when that technology helps the person with dementia to maintain activity (Rosenberg, Kottorp & Nygård, 2012). Whilst this study did not focus on the technology behind [app name], but on the self-management approach that is often delivered via technology, the findings demonstrated that technology can be used to support both couple relationships and activity.

The awareness of the progressive nature of dementia, and that couples know that they probably are going to meet challenges (and transitions) over time, did not seem to affect them in the present. In line with the findings of (Author, 2018a), couples often live in the ‘here and now’ as a deliberate coping strategy to push to one side anxieties and self-doubts. Couples involved in our study also pointed out that life is not over just because a diagnosis of dementia is received. Whilst there is no denying that dementia is a serious condition, people with dementia and their partners would perhaps benefit more from the implementation of a salutogenic approach in healthcare.

This study has some limitations to consider. We interviewed six couples that tested the app. According to Guest et al. (2006), there is no consensus in how many participants required for a qualitative study. The recommendation is six to eight participants as a minimum. This could contribute to a narrower picture of the experiences of testing [app name] as a couple. Another limitation, is that we conducted dyadic interviews (Sohier, 1995). Dyadic interviewing can result in fragmented data in...
case partners feel limited to speak freely in front of each other (Zahrin, 2018). However, the method also help the partners with dementia to speak when they can be supported by the partner.

**Conclusion**

The findings of this study indicate that couples where one partner has dementia value interventions that focus on a salutogenic approach to their everyday life and relationship. This dyadic intervention contributed to feelings of empowerment, satisfaction of couples’ achievements and a sense of support through both peers and the intervention itself. The focus on strengths, resources and quality of life can give couples insight into the growth of their relationship and the evolving transitions during the trajectory of dementia. Furthermore, this study can serve as a starting point for the type of support couples need and wish to receive. We therefore propose that further research into couples where one partner has dementia sets out to embrace a more salutogenic approach, one that is rooted in the couples’ relationship and everyday life in order to enhance overall well-being.
References


Author, 2017a

Author, 2017b

Author, 2018a

Author, 2018b


Chick, N., & Meleis, A.I. (1986). *Transitions: A Nursing Concern*. [https://repository.upenn.edu/cgi/viewcontent.cgi?article=1008&context=nrs](https://repository.upenn.edu/cgi/viewcontent.cgi?article=1008&context=nrs) (last accessed 19 August).


Table 1. Participant characteristics

<table>
<thead>
<tr>
<th>Couple</th>
<th>Gender</th>
<th>Age PwD/P</th>
<th>Diagnosis</th>
<th>Length of relationship (Years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Couple 1</td>
<td>F/M</td>
<td>66/64</td>
<td>Alz</td>
<td>40</td>
</tr>
<tr>
<td>Couple 2</td>
<td>M/F</td>
<td>81/83</td>
<td>Alz</td>
<td>60</td>
</tr>
<tr>
<td>Couple 3</td>
<td>M/F</td>
<td>70/66</td>
<td>FTP</td>
<td>45</td>
</tr>
<tr>
<td>Couple 4</td>
<td>M/F</td>
<td>79/78</td>
<td>Alz</td>
<td>60</td>
</tr>
<tr>
<td>Couple 5</td>
<td>M/F</td>
<td>74/69</td>
<td>UNS</td>
<td>40</td>
</tr>
<tr>
<td>Couple 6</td>
<td>M/F</td>
<td>72/68</td>
<td>Alz</td>
<td>50</td>
</tr>
</tbody>
</table>

PwD = Person with Dementia, P = Partner, Alz = Alzheimer’s, FTP = Fronto Temporal Dementia, UNS = Un Specified Dementia

Table 2. Interview guide

- How did you experience testing xx together?
- Did you find anything positive about xx?
- Did you find anything negative about xx?
- Has xx contributed (good or bad) to your relationship, as a couple?
- Did you use any information from xx, (how did you use it?)