Couples experiences of using DemPower in everyday life

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Couples experiences of using DemPower in everyday life

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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, Whitlatch, Dilworth-Anderson, 2017; Sinclair, Aret, 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]

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2
3 75 were threefold: i) to help couples focus on the everyday activities they can still do rather
4
5 76 on what they are no longer able to do; ii) to reflect upon the strengths of the couples
6
7 77 relationship and help couples to find ways to tackle daily activities together' and iii) to
8
9 78 archive reflections, meaningful moments, and memories the way they would like them
10
11 79 to be remembered and stored. The contents of [app name] are structured under the four
12
13 80 themes "Home and Neighbourhood", "Meaningful activities and Relationships",
14
15 81 "Meeting, Sharing and Caring in your neighbourhood" and "Managing emotions,
16
17 82 Communication and Approach" with related sub-headings and sections. The four
18
19 83 themes and sections in [app name] are introduced using storyboard techniques with a
20
21 84 voiceover, followed by video clips of couples sharing their experiences of living with
22
23 85 dementia as a couple. The video clips are based on real-life experiences of couples
24
25 86 living with dementia where they share their relationship and everyday life. [app name]
26
27 87 makes suggestions for activities under each section. Examples of some activities include
28
29 88 games, links to useful information, taking photographs, writing reflections, and
30
31 89 discussing emotions and the couples' approach to their relationship and daily life. For
32
33 90 more information about the development and content of the [app name] see Author
34
35 91 (2018a) and Author (2018b). .
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43

44 **Aim**

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46 93 The aim of this study was to explore the experiences of using the application [app
47
48 94 name] among couples where one partner has dementia living at home.
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51

52 **Method**

53 *Participants and procedure*

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57
58 97 Twelve Swedish couples tested the [app name] delivered via tablets, in the feasibility
59
60

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

120 **Analysis**

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

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

132

133 **Ethical considerations**

134 The study was given ethical approval by the [name of ethics committee]. Participating
135 couples received relevant oral and written information about the study and that they
136 could withdraw from the study at any time. Written and verbal consent was collected
137 from the couples and all data were kept confidential (World Medical Association,
138 2013). To ensure that both individuals in the dyad consented to take part in the study, it
139 was important that the first author actively asked for consent throughout the study, a
140 process that enabled couples to make informed decisions from the start to the
141 completion of the study (Dewing, 2008). This required that the researcher was
142 responsive and sensitive to changing needs. This was important as despite information
143 about voluntary participation, there could be underlying power structures within the
144 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

195 and honestly together about their real feelings and emotions about living with dementia
196 and the consequences it had for them both, as summarised below:

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

201
202 “That you really sit down and think about all this.... We sit and talk
203 sometimes when he discovers how he forgets and so but otherwise it doesn't
204 get so often that you sit down and talk around these things” C4

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

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

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

218 “And the dance, as we did, was to come back to this feeling, and you were
219 very happy and this I hope we do again...that we actually decide that we are
220 taking a dance, because it's getting back to the closeness we once had” C3

221 The fact that the couple sat next to each other when engaging in [app name] gave them
222 physical closeness and the questions in the app could contribute towards a reflection
223 upon the strength of their relationship:

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

227 ***Theme 2: We are not alone***

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

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

236
237 “Yes, they (videos) calmed us a little, I think. Although there were actors in
238 videos, it calmed me anyway. And they were so nice to each other, I think it
239 gave a lot about how I, as a relative, should behave” C3

240 Couples felt that they were cared for through the support in [app name] and that
241 “someone” really had made an effort to help them in their daily life. They also found
242 [app name] helpful overall and that the app had introduced them to a lot of information
243 and advice, some of which they could use in the present day and some that they could
244 return to in the future:

245 “Many things are good to know that they exist and it is good that someone
246 has thought about it and comes up with suggestions, practical suggestions
247 that can be a seed for something that you can use later. I think, there were
248 plenty of seeds” C1

249 ***Theme 3: Positive approach***

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

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

256
257 “Our tip is to live in the present and make the most of the time. Then, it
258 (dementia) is not something you die from in two days so you do not have to
259 hurry and you do not have to change everything ” C1

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

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

268
269 “I thought it was very nice that it [app name] was not problem-oriented
270 because when you get to the hospital you get a little depressed but this was a

271 thing where you highlight the positive and all that you can do. One does not
272 have to be depressed in advance... It's a lot of good tips I think" C4

273

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

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

281 Discussion

282 The aim of this study was to explore the experiences of the [app name] by couples
283 where one partner has dementia living at home. The findings resulted in the themes:
284 *Growth of the relationship, We are not alone, and Positive approach.* The themes are
285 clearly linked to couples recognition of their transition as a couple living with dementia.
286 Here, transition can be defined as a passage from one life phase to another and describes
287 a developing and often empowering change process as a consequence (Chick & Meleis,
288 1986). In the presented study, the six couples' experiences of transition could be seen to
289 have its starting point with the diagnosis of dementia, or when they suspected that
290 something was wrong (the disconnectedness caused by the disruption), followed by
291 phases of coping and adjustment to change (patterns of response), and the
292 endpoint where couples have reached more stability relatively to the situation during the
293 process (see also: Chick & Meleis, 1986). However, dementia is a progressive condition
294 which implies multiple transitions for couples and, perhaps, parallel transitions at the
295 same time. The intensity of the influencing factor in a transition, in this case dementia,

296 may also vary over the process and so might the patterns of response (Chick & Meleis,
297 1986). However, the experiences of engaging in [app name] salutogenic and couple-
298 based approach to dementia and everyday life have positively impacted on couples and
299 their transition through the lived experience of dementia.

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

309 However, whilst dementia had brought partners closer to each other insofar as
310 they spent more time together, it also resulted in a heightened sense of togetherness and
311 mutual respect for their relationship (Hellström, Nolan, & Lundh, 2005). For example,
312 in our study couples now described their relationship as 'more equal' and 'accepting'
313 and this was achieved by sharing responsibilities in areas that could previously be seen
314 as stereotypical gender role around the home, such as cooking and cleaning. Changes in
315 social and domestic roles have been studied by several researchers where relationships
316 often are described in terms of loss in relationship quality and former roles of the
317 relationship (Ablitt et al. 2009; Allen et al. 2017; Conway et al. 2018; Watson,
318 Tatangelo & McCabe, 2018; Brodaty & Donkin, 2009). However, the couples in our
319 study who expressed greater togetherness and role equality since the onset of dementia,
320 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

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2
3 346 impacted on each other. Awareness is a key component in the concept of transition and
4
5 347 relates to the definitions and redefinitions of self and the situation (Chick & Meleis,
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7 348 1986). Indeed, 'talking things through' with each other as a couple has been highlighted
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9 349 as an important part for growth of the relationship within couples where one partner has
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11 350 dementia (Hellström et al. 2017) and data from this study would appear to support this
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13 351 assertion.
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18 352 The salutogenic approach to guide health and wellbeing and the focus on what couples
19
20 353 can do, rather on what they cannot do, permeated couple's discussions. Couples liked
21
22 354 the idea of focusing on positive resources and stated that there was currently too much
23
24 355 negativity around dementia. When documenting their inner resources and strengths
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26 356 (included in [app name]), couples often came to the conclusion that they planned to do
27
28 357 more of the activities they like and know that they can manage. However, through the
29
30 358 use of [app name], couples also tried to learn new things, which meant that they
31
32 359 embraced a self-management approach and the everyday technology that made it
33
34 360 meaningful in their lives. Couples found it empowering to have performed tasks in the
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36 361 app, both together and on their own. For people living with dementia as part of the
37
38 362 couple relationship, independent use of the [app name] depended upon the symptoms of
39
40 363 dementia and how advanced it was. According to LaMonica et al. (2017), older people
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42 364 and people with cognitive decline, are often curious of internet and digital interventions
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44 365 and how it might be possible to improve their situation. Furthermore, Stockwell-Smith
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46 366 (2019) has examined couples' where one partner has dementia conditions for self-
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48 367 management and found that with the support from healthcare staff, self-management
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50 368 interventions can improve self-efficacy and independence.
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2
3 370 The use of everyday technology has been highlighted to positively influence people
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5 371 with dementia and partners in their daily life (Gibson, Dickinson, Brittain & Robinson,
6
7 372 2015), especially when people with dementia and their care partners have a sense of
8
9 373 familiarity to the technology, such as through a smartphone or tablet (Gibson et al.
10
11 374 2015; Newton, Dickinson, Gibson, Brittain & Robinson, 2016). However, the
12
13 375 personalisation of technology and how it is used should be individually adapted (Gibson
14
15 376 et al. 2015), particularly when that technology helps the person with dementia to
16
17 377 maintain activity (Rosenberg, Kottorp & Nygård, 2012). Whilst this study did not focus
18
19 378 on the technology behind [app name], but on the self-management approach that is
20
21 379 often delivered via technology, the findings demonstrated that technology can be used
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23 380 to support both couple relationships and activity.
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29 381 The awareness of the progressive nature of dementia, and that couples know that
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31 382 they probably are going to meet challenges (and transitions) over time, did not seem to
32
33 383 affect them in the present. In line with the findings of (Author, 2018a), couples often
34
35 384 live in the 'here and now' as a deliberate coping strategy to push to one side anxieties
36
37 385 and self-doubts. Couples involved in our study also pointed out that life is not over just
38
39 386 because a diagnosis of dementia is received. Whilst there is no denying that dementia is
40
41 387 a serious condition, people with dementia and their partners would perhaps benefit
42
43 388 more from the implementation of a salutogenic approach in healthcare.
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47

48 389 This study has some limitations to consider. We interviewed six couples that
49
50 390 tested the app. According to Guest et al. (2006), there is no consensus in how many
51
52 391 participants required for a qualitative study. The recommendation is six to eight
53
54 392 participants as a minimum. This could contribute to a narrower picture of the
55
56 393 experiences of testing [app name] as a couple. Another limitation, is that we conducted
57
58 394 dyadic interviews (Sohier, 1995). Dyadic interviewing can result in fragmented data in
59
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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.

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1

2 Table 1. Participant characteristics

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

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

5 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?)

6