



# Living Life and Doing Things Together: collaborative research with couples where one partner has a diagnosis of dementia

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# Qualitative Health Research

## **Living Life and Doing Things Together: collaborative research with couples where one partner has a diagnosis of dementia**

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## Abstract

The aim of this study is to identify relevant content for a self-management guide by using the outcomes of previous research in combination with knowledge and experiences from couples where one partner has a diagnosis of dementia. The study was carried out in three phases: 1) Literature search of previous research related to wellbeing and couplehood in dementia; 2) Interviews with couples with dementia based on the findings of the literature search; 3) Further authentication of the findings within expert groups of people with dementia and carers. For analysis of data we used a hybrid approach of thematic analysis with combined deductive and inductive approaches. The findings of this study indicated that the four main themes “Home and Neighborhood”, “Meaningful activities and Relationships”, “Approach and Empowerment” and “Couplehood” with related sub themes could be appropriate targets for a self-management guide for couples where one partner has a diagnosis of dementia.

## Introduction

In this article, we report on the progress of the “Living Life and Doing things Together” study, an international project with the overall aim of developing an empirically-based self-management guide for couples living at home and where one partner has a diagnosis of dementia. The “Living Life and Doing Things Together” study is one of eight work programs which form the five year (2014-2019) ESRC/NIHR “Neighbourhoods and Dementia” mixed methods study (Keady, 2014; and see: [www.neighbourhoodsanddementia.org](http://www.neighbourhoodsanddementia.org)). The Neighbourhoods and Dementia study is funded as part of the first UK Prime Minister’s Challenge on Dementia (Department of Health, 2012) with a focus on the everyday connection of people with dementia to spaces, places and people. The study “Living Life and Doing Things Together” addresses couples where one partner has a diagnosis of dementia and has the overall objective to develop, and test, a self-management guide which will be delivered via an application called “DemPower” in a feasibility trial conducted in Sweden and the UK during 2018.

As a first step of the “Living Life and Doing Things Together” study, the research team undertook a narrative review (Bielsten & Hellström, 2017a) and a scoping review (Bielsten & Hellström, 2017b) of the literature with the aim to map interventions for couples where one partner has a diagnosis of dementia. The reviews provided an overall view of types and objectives of couple-based interventions and to what extent they addressed the couple’s relationship. Salient findings of the reviews indicated that most dyadic interventions, including joint interventions (both partners participating together), lack a relational focus and a genuine dyadic approach, which is a phenomenon highlighted by several other authors (see for example: Moon & Adams, 2012; Van’t

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2  
3 Leven et al. 2013; Merrick, Camic & O’Shaughnessy, 2016); most interventions required  
4 participating couples to travel to the location of the intervention and/or that the  
5  
6 intervention was dependent on the delivery by professionals, which indicated a lack of  
7  
8 easily accessible support; the absence of a salutogenic approach in which the couples’  
9  
10 resources and strengths were the main focus. The lack of relationship- and strength based  
11  
12 support guided our overall approach to the development of the self-management guide,  
13  
14 which is inspired by salutogenesis (Antonovsky, 1979, 1987) and self-management in  
15  
16 dementia (Martin, Turner, Wallace & Bradbury, 2013). As an authorship and research  
17  
18 team, our stance has been to view the couple as a ‘unit’ interdependent on each other’s  
19  
20 wellbeing and resources. In the present article we will report on the process of identifying  
21  
22 relevant content for the self-management guide, and demonstrate how the study design of  
23  
24 collaborative research enhanced the trustworthiness of the findings.  
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## 31 Background

32  
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34 The progressive nature of dementia brings challenges to couples’ relationships by  
35  
36 demanding constant adaptation to new situations and roles. Relationship quality might  
37  
38 deteriorate as a result of the transition from a mutually interdependent relationship toward  
39  
40 a caregiver-care-receiver relationship (Ingersoll-Dayton, Spencer, Kwak, Scherrer, &  
41  
42 Campbell, 2013; Hellström, Nolan & Lundh, 2007). This transition is often at the  
43  
44 expense of the sense of “couplehood”, a concept described as feelings of belonging to a  
45  
46 “We” (Kaplan, 2001, p. 87). Low relationship quality in couples has shown to have a  
47  
48 negative impact on wellbeing in several dimensions, for example it: accelerates cognitive  
49  
50 and functional decline (Norton, Piercy, Rabins, Green, Breitner & Ostbye et al. 2009);  
51  
52 predicts the need of moving to a special accommodation (Spruytte, Van Audenhove &  
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3 Lammertyn, 2001; Brodaty, Gresham & Luscome, 1997); increases the risk of depression  
4  
5 in both the person with dementia and the partner; increases strain; and decrease self-  
6  
7 efficacy in partners (Ablitt, Jones & Muers, 2009). Despite all the evidence of  
8  
9 relationship quality as a crucial factor for wellbeing, and for the prevention of negative  
10  
11 consequences, support aimed at couples' relationships is scarce. Accessible support for  
12  
13 couples, including dyadic support, are often based on the individual which leads to  
14  
15 barriers in acknowledging needs for relationship based support (Bielsten & Hellström,  
16  
17 2017a,b).  
18  
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20

21 In recent years, several authors have highlighted the urgent need for interventions  
22  
23 that support couples' relationships and interaction (see for example Ablitt et al. 2009;  
24  
25 Bielsten & Hellström, 2017a,b; McGovern, 2011; Balfour, 2014). Support aimed at  
26  
27 couples where one partner has a diagnosis of dementia would be advised to target the  
28  
29 couples' interaction, communication and closeness in the context of everyday life, as  
30  
31 communication and interaction often become problematic areas for couples living with  
32  
33 dementia and has a significant impact on relationship quality (Reilly, Relkin & Zbrozek,  
34  
35 2006; Boots, de Vugt, Withagen, Kempen & Verhey, 2016; Werthon & Monk, 2008).  
36  
37  
38 Whilst most couples will face difficulties and losses in these areas, the impact of negative  
39  
40 experiences can be reduced with maintained mutuality and positive interaction within the  
41  
42 relationship (Balfour, 2014). Developing this point further, Balfour (2014) highlights the  
43  
44 importance of everyday life and to help the couple to "find new meaning and new ways  
45  
46 of thinking precisely grounded in the couple's daily living" (p. 314). Balfour's  
47  
48 "therapeutic couple work" thus demands a professional guiding the sessions, resulting in  
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3 limitations for everyday use and for the couple to engage in continuously and when it  
4  
5 suits them best.

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8 Couple's relationship in dementia is often assumed to be burdensome, which  
9  
10 reflects the predominant problem-based and symptom-oriented support accessible for  
11  
12 couples with dementia. The targets of the support are most commonly focused on the  
13  
14 caregiver-care-receiver roles, cognitive function of the person with dementia, and the  
15  
16 partners strain and burden (Bielsten & Hellström, 2017a, b; Purkis & Ceci, 2015; Martire,  
17  
18 Schulz, Helgeson & Saghafi, 2010). This position is the complete opposite to the  
19  
20 approach within most other chronic diseases where the goal is to learn how to live as well  
21  
22 as possible with the disease (Robinson, 2017), learn self-management skills, promote  
23  
24 coping strategies and gain self-efficacy (Martin, Turner, Wallace, Stanley, Jesuthasan &  
25  
26 Bradbury, 2015; Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002).

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30  
31 The term salutogenesis originates from Antonovsky's (1979, 1987) health-  
32  
33 oriented paradigm with the core concept of Sense of Coherence. Sense of Coherence  
34  
35 involves the three components, namely comprehensibility, manageability, and  
36  
37 meaningfulness, which are seen as crucial factors for successful coping.  
38  
39 Comprehensibility implies the experience of perceived predictability, order and  
40  
41 "cognitive sense" of stimuli. Manageability implies the extent to which the individual  
42  
43 perceive that s/he has the resources (personal and social) to face and cope with demands.  
44  
45 Meaningfulness, the most important factor according to Antonovsky, refers to sense of  
46  
47 meaning, purpose and motivation to deal with demands (Antonovsky, 1979, 1987.  
48  
49 Lillekroken, Slettebo & Hauge, 2015). The concept of Sense of Coherence is originally  
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51 applied to the individual, but one could argue for it to be applicable to couple's  
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3 relationship when/if the couple is seen as a unit that needs to perceive dyadic  
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5 comprehensibility, manageability, and meaningfulness. Perceived meaningfulness of the  
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7 loving relationship and everyday life may be the most important factors that motivate  
8  
9 couples, where one partner has a diagnosis of dementia, to face the on-going challenges  
10  
11 to their relationship (Keady & Nolan, 2003; McGovern, 2011). This, in turn, highlights  
12  
13 the need for new types of support with a dyadic approach and with the aim to support  
14  
15 couples' efforts in sustaining everyday relationship quality and wellbeing.  
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## 20 The study

### 21 Aim

22  
23 The aim of this study is to identify relevant content for a self-management guide by using  
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25 the outcomes of previous research in combination with knowledge and experiences from  
26  
27 couples where one partner has a diagnosis of dementia.  
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### 32 Methodology

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34 Drawing on the work of Fereday and Muir (2006), we used Alfred Schutz's (1973)  
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36 framework of first- and second order constructs as an overall methodology for the study,  
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38 and their hybrid approach of thematic analysis for analysis of the data.  
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45 Alfred Schutz's (1973) framework of first- and second order constructs was used as an  
46  
47 overall methodology. Schutz refer to the subjective meaning as the *first-order* constructs,  
48  
49 meaning that first-order constructs are information and knowledge from people with lived  
50  
51 experience. The *second-order* constructs are the scientific interpretation and reproduction  
52  
53 which trustworthiness is dependent on whether the first-order constructs has been  
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3 safeguarded or not. In addition to the demand for subjective meaning, second order  
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5 constructs also need to be connected to existing scientific theory and common sense.  
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7 Schutz (1973) has formulated three postulates for scientific constructs, which guided our  
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9 process:

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12  
13 *Logical consistency:* The system of typical constructs designed by the researcher  
14  
15 has to be clear and distinct and fully compatible with formal logic, which is linked  
16  
17 to universal meaning, objectivity and rationality.

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20 *Subjective interpretation:* The model must grasp the subjective meaning of the  
21  
22 actor.

23  
24 *Adequacy:* The constructs of the researcher must have consistency with common-  
25  
26 sense experience and be recognizable and understandable for actors in everyday life  
27  
28 (Schutz, 1973; Fereday & Muir, 2006).  
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## 31 32 33 Method

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35 The study involved three phases:

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39 (1) Phase 1 was a comprehensive literature search of previous research related to  
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41 couplehood and wellbeing in dementia. The literature search informed a draft  
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43 framework of themes outlined to be potential targets for the self-management  
44  
45 guide.  
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48 (2) Phase 2 involved ten interviews, guided by the draft framework, with five couples  
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50 where one partner has a diagnosis of dementia in Sweden. In this phase the  
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52 predetermined themes were presented to the couples with the purpose of  
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54 confirming or rejecting the relevance of the themes. This phase also enabled the  
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process of adding subjective meaning to the themes and allowed for couples to add new themes of relevance.

- (3) Phase 3 involved authentications of the findings within expert groups of people with dementia and carers in Sweden and in UK. This phase enabled testing of the empirical validity of the themes as sensitizing concepts, and the transferability to a UK context. Meetings with expert groups also enabled the collaborative approach to be maintained throughout the study.

### Phase 1. Literature search

A literature search of previous research related to couplehood and everyday wellbeing in dementia was conducted. Fourteen recurrent themes were identified in the literature and outlined as potential targets for the self-management guide. The identified themes formed a draft framework that guided the data collection in the second phase of the study.

Themes, shortened rationales and supporting literature are displayed in table 1.

Table 1. Identified themes and supporting literature

Name of themes	Rationale	Supporting Literature
The meaning of home	Having the opportunity and support to age in place, in the own home, neighborhood and in a community.	Wiles et al. 2012; Gillsjö et al. 2011; Soilemezi et al. 2017; Ward et al. 2017; Keady et al. 2012; Keady et al. 2014; Nygård, 2004
Comfort/safety inside home Comfort/safety outside home	Being able to stay in familiar environments. Importance of facilitating daily activities and chores to promote independence and activity inside the home and in the neighborhood.	Tanner et al. 2008; Torrington, 2009; Werthon & Monk, 2008; Soilemezi et al. 2017; Mitchell & Burton, 2010; Keady et al. 2012; Ward et al. 2017; Keady et al. 2014
Physical wellbeing	Physical activity as a source of doing things together as a couple and to promote healthy aging, cognitive function and physical wellbeing.	Dal Bello-Haas et al. 2014; Bowes et al. 2013; Lamotte et al. 2017; Hernández et al. 2015; Wei-Wei et al. 2016; Duggan et al., 2008; Pitkälä et al. 2010; World Health Organization, 2010
Mental wellbeing	Cognitive stimulation with the aim to improve or sustain ability to communicate and interact with each other.	Woods et al. 2012; van Nes, 2013; Genoe & Dupuis, 2014; Hill et al. 2017; Mondini et al. 2016; Spector et al., 2017
Individual activities	Individual activities as a source to gain strength and to nurture social relationships.	van Nes, 2013; Robinson et al. 2005; Hellström et al. 2007; Bergman et al. 2016; Solum et al. 2013;
Meeting with peers	Having the opportunity to share experiences with people in a similar situation.	Söderhamn et al. 2014 Clare et al. 2008; Leung et al. 2015; Toms et al. 2015; Keyes et al. 2016

Informing others	Preventing isolation due to stigma and negative feelings. Disclosure.	McRae, 2008 & 2011; Genoe & Dupuis, 2014; Hellström & Torres, 2013; Alzheimer's Association; Quinn et al. 2008
Stress	Avoiding stressful situations that have negative impact on cognitive function and sense of self.	Alzheimer's association, 2015; Brodaty & Donkin, 2009; Groat and Weems, 2009; Lindsay et al., 2012
Future and planning	Planning ahead for future impact of the condition with the aim of increased sense of control.	Robinson et al. 2015; Grand et al. 2011; SCIE, 2015; Alzheimer's Association; Hellström & Torres, 2016
Adapting activity to capability	Adapting capability to activity (and goals of activities), in order to feel that activities are manageable and successful.	Genoe & Dupuis, 2014, McGovern, 2015; Groat and Weems, 2009; McRae, 2010
Doing things together	Everyday chores and activities are meaningful and an important source of pleasure and opportunity to do things together.	Hellström et al. 2007; Balfour, 2014; Genoe & Dupuis, 2014; Reilly et al. 2006.
Being active and supportive	The balance between support and keeping sense of independence. Supporting personhood and meaningful activity.	McRae, 2011; Nygård, 2004; Vernooij-Dassen & Moniz-Cook, 2016
Communication and interaction	Being able to spend time together, interact and have a joy-full time, to maintain value in the relationship. Learning strategies to manage communication and interaction.	Reilly et al. 2006; Boots et al. 2016; Werthon & Monk, 2008; Bigonnesse et al. 2014; Tanner et al. 2008; Berry, 2014. McGovern, 2011
Avoiding conflicts	Prevention of conflicts and sustaining positive communication.	Hellström et al. 2007; McGovern, 2011; Ingebretsen & Solem, 1998

Key words used for literature search: "couple", "spouses", "dementia", "wellbeing", "quality of life" "relationship" "everyday life" "home" and related concepts. Databases: PubMed, Cinahl, Scopus, Web of Science and PsycInfo.

## Phase 2. Interviews with people with dementia and partners

Participants were a convenience sample of five Swedish couples (n=10) recruited from a memory clinic. Staff at the memory clinic approached the couples and mediated the contact between researchers and participants. Inclusion criteria were: couples of any gender, living in their own home and a diagnosis of dementia for one partner. Participant characteristics are displayed in table 2.

Table 2. Participant characteristics

	Couple 1	Couple 2	Couple 3	Couple 4	Couple 5
Gender person with dementia/partner	F/M	M/F	M/F	F/M	M/F
Age person with dementia/Partner	74/77	71/67	74/72	74/74	77/73
Diagnosis of dementia	Alzheimer	Alzheimer	Alzheimer	Alzheimer	Alzheimer

## Data collection

Data consisted of ten semi-structured interviews (one initial and one follow-up for each couple), and written comments from the couples. The framework of themes, constructed in phase 1 (table 1), guided the interviews. The primary objectives of the interviews were to confirm the relevance of themes, represent subjective meaning of the themes, and to add new themes of relevance from the interview data. Participants were asked to assess the relevance of the themes and to give examples from their own lives related to the themes. Each theme in the draft framework was presented to couples with a “trigger” in shape of a quote, which was followed by a question (see example in table 3). In order to allow new perspectives outside the draft framework, the main interviewer (first author) was responsive to new topics during the interviews. The first author, who is a specialist nurse in the care of older people, and has several years’ experience of communication with people with dementia and their family members, conducted all the interviews. The couples decided when and where the interviews would be held. All couples chose to be interviewed in their home and were interviewed together as a unit (Sohier, 1995).

Written informed consent was collected from all participants before the first interview started. Each couple kept the draft framework with the added triggers and questions to reflect upon in between interviews. This created conditions for couples to participate in different types of ways and when it best suited them both. Couples also received material to write comments of the themes in the draft framework, and could also choose to record their reflections/discussions of the themes by using a voice recorder, also with the intention to offer various opportunities to participate (Bartlett, 2012). Three

couples chose to write comments about the themes between the interviews and two couples discussed all of the themes with the interviewer during interviews and choose not to write any comments between the interviews. No couple chose to use the voice recorder. The second interview was a follow-up interview including collection of written comments and was conducted approximately two weeks after the first interview. The interviews length varied between 40-90 minutes. Interviews were audio recorded and transcribed verbatim and all written comments were gathered in documents.

Table 3. Example from the draft framework, as presented for couples

**Theme: Meeting other couples with dementia**

*"When we meet in the group, it is nice to know that you are not alone and that there are others like us. You can relax, share experiences and get great tips from each other "*

What are your thoughts of meeting other couples living with dementia?

\* Trigger

## Data analysis

### The hybrid approach of thematic analysis

Thematic analysis can be used for both deductive and inductive analysis, which means that themes can be brought *to* the data set, and/or brought *from* the dataset, in order to interpret data. The analysis followed the hybrid approach of thematic analysis by Fereday and Muir (2006), which combines deductive and inductive processes.

### Development of a template of themes

The first step involved the development of a template of themes. We used the themes of the draft framework (table 1) for this purpose. The template consisted of the names of the themes, definitions of what the themes concerns, and a description of how to know when

the themes occurred in the interview data. An example of the template is displayed in table 4.

Table 4. Example from the template of themes

Theme 1	
Name of theme:	The meaning of home
Definition:	Physical and emotional space of home
Description:	Description of home or feelings of being at home and in familiar surroundings.
Theme 2	
Name of theme:	Comfort/safety inside home
Definition:	Physical safety, adaptations facilitating everyday life.
Description:	Descriptions of comfort, safety and function of home related to everyday living

### Applying themes from the template to the interview data (deductive analysis)

The transcribed interviews, and couples' written comments, were read multiple times and text of potential interest highlighted. Testing of themes applicability to the data was undertaken using the first transcribed interview as a test piece. First and last author of this article discussed the applicability of the themes on the basis of the test piece. No modifications of the template were required. Themes from the template were matched with segments of data that was representative of the themes (table 5).

Table 5. Applying a theme from the template

Theme from the manual:	The meaning of home
Segment from transcribed interviews	<i>"I feel peace and harmony in my home. We like to go out as well, but there's nothing better than coming home when you've been out, closing the door behind us and just relax"</i>

### Additional theming of the interview data (inductive analysis) and connection of themes

The “theming” process also included the inductive approach where data-driven themes were applied to segments of data that described new themes not included in the template (table 6). Themes associated to each other (from the template and data-driven), were then clustered and connected in order to form main themes.

Table 6. Example of a data-driven theme

Data-driven theme:	State of mind/living as usual
Explanation of theme:	Coping strategies and description of how to adapt to changes
Data from interviews:	<i>“It’s a matter of living as usual. Doing as much as possible in the way we usually do”.</i>

### Phase 3. Authentication of themes through expert groups of people with dementia and carers

Consultation meetings with people with dementia and carers took place after analysis of data and after themes had been confirmed, revised or added in accordance to the findings from the interviews. In order to increase transferability to a UK context, consultation meetings were held both in Norrköping, Sweden and Manchester, UK (see the feasibility trial of the “Living Life and Doing things Together” study, outlined earlier). In Sweden, consultation meetings were held with a total of 40 people recruited from an Alzheimer café for people with dementia and carers, a center for carers and at a book café for couples where one partner has a diagnosis of dementia. In Manchester, consultation meetings were held with a group consisting of six couples where one partner has a diagnosis of dementia. The objectives of the meetings were to use the themes as sensitizing concepts that were tested for empirical validity, and with potential to discover

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3 additional themes of importance for people with dementia and partners.  
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## 6 Ethical considerations

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9 Participants in the study received relevant oral and written information about the study  
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11 and that they could withdraw from the study without declaring any reason. Written and  
12  
13 verbal consent was collected from people with dementia and partners and all data were  
14  
15 kept confidential (World Medical Association, 2016). Despite the information of  
16  
17 voluntary participation, underlying power structure within the relationship may influence  
18  
19 choice (Braybrook, Mróz, Robertson, White & Milnes, 2017). It is therefore important  
20  
21 that the researcher is responsive and applies a “process consent” method (Hellström,  
22  
23 Nolan, Nordenfeldt & Lundh, 2007), whereby the researcher enables participants to make  
24  
25 informed decision from the point of initial contact to completion of the study (Dewing,  
26  
27 2008). The study was given ethical approval by the Regional Ethical Review Board in  
28  
29 Linköping and assigned the following code: 2014/419-31. Interviews with participants  
30  
31 and meetings with members of the consultation groups were guided by the core principles  
32  
33 for involving people with dementia in research (Scottish Dementia Working Group,  
34  
35 2014). The benefits of collaborative research have shown to contribute to participants’  
36  
37 sense of purpose, satisfaction and to increased knowledge and self-confidence  
38  
39 (Littlechild, Tanner & Hall, 2015). After the interviews, participants received information  
40  
41 about the progress of the study by letter and telephone calls in order to ensure that they  
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43 were being involved and valued throughout the process.  
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## 51 Findings

### 52 Confirmed themes of the framework



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3 The deductive analysis, in which the template of themes was applied to the interview  
4 data, confirmed the relevance of the pre-determined themes of the draft framework.  
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## 8 Home and neighborhood 9

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11 Couples described their home as an important place where they wished to stay as long as  
12 possible. Home was perceived as a place of peace, safety and relaxation. Safety was both  
13 physical and psychological. Safety inside home was described in concrete physical safety  
14 rather than psychological, as actions undertaken to increase security, comfort and  
15 independence inside the home. The psychological meaning of home was referred to as a  
16 place representing peace, wellbeing and familiarity:  
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26 *“I feel peace and harmony in my home. We like to go out as well, but there’s nothing*  
27 *better than coming home when you’ve been out, closing the door behind us and just*  
28 *relax”*  
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34 It was not just the home (e.g. house, apartment) that participants described of importance.  
35 Relationships with neighbors in the neighborhood, and the sense of having support of  
36 each other in everyday life played an important role and contributed to sense of security.  
37 Getting out and about in the neighborhood was important to couples and they described  
38 the importance of a familiar environment:  
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46 *“We have lived here so long. Here, I can move about freely. We know the people who live*  
47 *in the area, so you know how you stand, you could say.”*  
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52 For two couples it was no problem for the partner with dementia to take walks relative far  
53 away from home, provided that there was a route they had walked many times before.  
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3 One partner with dementia took three hour-long walks around town and one partner with  
4 dementia walked to their allotment everyday.  
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## 8 9 **Meaningful activities and relationships**

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11 Keeping involved in everyday activities and social activities were confirmed to be of  
12 great importance. Physical activity, most commonly by taking walks, was an activity that  
13 most couples enjoyed to do together. Couples had routines of taking walks together and  
14 sometimes individually and they described various benefits from being active, such as  
15 improved sleep, mood and cognition:  
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24 *“Yesterday, my partner came home from a long walk with some lovely coffee bread and a*  
25 *bouquet of flowers for me. It was the first time in a long time. I think maybe the*  
26 *endorphins that get activated influence the brain and make my partner less ill. The*  
27 *exercise makes my partner feel better, instead of lying about at home and becoming*  
28 *weary and forgetful”.*  
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36  
37 Couples described various ways of mental exercise, but not very often with the aim of  
38 improve cognition. They described it in terms of leisure on an everyday basis that was  
39 integrated in their interaction *“We talk to each other a lot...and we read weekly*  
40 *magazines, and daily newspapers...long and well”*. One partner with dementia used to  
41 play the piano to keep the brain active *“Of course I notice I’m not as good at playing, but*  
42 *it is important for me to maintain the ability”*.  
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51  
52 Couples confirmed the importance of meeting peers but none of the couples has had the  
53 opportunity to do so. They described such an opportunity in terms of feelings of  
54 belonging and being understood. The couple in which the partner with dementia attended  
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3 a day centre described that it had become a very important social world with new  
4  
5 relationships where the partner with dementia could be herself:  
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10 *“We would love to meet other couples, but we haven’t had the opportunity. I see how*  
11 *good the day center is for my partner. A similar environment, where both can participate,*  
12 *would be good”.*  
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14  
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### 16 17 18 **Approach and empowerment** 19

20 Informing others about having dementia was natural and empowering for couples.

21 Informing others contributed to reduced stress due to not having to cover up symptoms  
22 and contributed to conditions for other people to be supportive and understanding. One  
23 reason for informing others was to fight the stigma related to dementia:  
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30 *“We have been very open about it, always. It is nothing to be ashamed of. I can’t help it.*  
31 *It has become much more accepted”.*  
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36 On the other hand, meeting with people, in particular new people could create stress due  
37 to insecurity, *“I get stressed by being so unsure of myself. I can’t find the right word and*  
38 *forget things”.*  
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43  
44 In order to reduce stress and feelings of insecurity couples adapted to their situation by  
45 choosing which people to socialize with, by adapting activity to capability, and helping  
46 each other out in order to keep partaking in valuable activities:  
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52 *“We plan activities that allow my partner to participate without feeling responsible,*  
53 *because pressure just causes a loss of initiative”.*  
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3 The theme “future and planning” were changed in terms of the significance and the  
4 subjective meaning for the couples. As described in the rationale (table 1), the theme was  
5 initially directed towards planning ahead for future impact of the condition, such as  
6 learning more about dementia, talking things through about the person with dementia's  
7 preferences and desires in the event that he or she would not be able to express it in the  
8 future. The meaning of “future and planning” for the couples in this study did not mean  
9 the same; for instance, all couples described that they avoided thinking about the future  
10 by living day by day and by making the most of the situation:  
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22 *“It’s difficult to plan for an uncertain future. We believe it will become obvious as the*  
23 *disease develops. It is probably a conscious strategy to live from day to day. There is no*  
24 *point in wallowing in misery, because it will come on its own, if it comes”.*  
25  
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29

30 It became obvious that the couples strived to live in the present, they saw no point in  
31 wasting their valuable time together worrying about the future. However, sometimes they  
32 couldn’t help thinking about how it will be in the future *“but of course there are some*  
33 *things that worry me, when I cannot sleep you know...”*.  
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## 41 Couplehood

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43 Couples spent a lot of time together, sharing chores and activities. It did not mean that  
44 they necessarily did the same thing but they were near each other. For example, one  
45 couple described that one of them used to cut the grass while the other raked. Couples  
46 also tried new things and took actions when they felt under stimulated:  
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52  
53 *“When things get dull at home, we usually think of something to do. We might go out and*  
54 *eat on an outing. We dress up and eat out. Hanging out at home with nothing to do has a*  
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3 *negative effect on the brain. We see that clearly after a few days”.*  
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6  
7 Couples described the balance between being as active and independent as possible but  
8  
9 still needing support to some extent. It could be a challenge for both partners as  
10  
11 articulated by one partner with dementia *“I need to feel we are on the same level. I don’t*  
12  
13 *want a pat on the head and a compliment on how obedient I’ve been”*. Support could also  
14  
15 be in terms of reassurance, not just actions:  
16  
17

18  
19 *“It’s a relief to have in the background, someone who knows how things usually are, and*  
20  
21 *how they used to be. But that’s what it’s all about: supporting and encouraging each*  
22  
23 *other. So, it’s not so strange”*.  
24  
25

26  
27 Communication and interaction was an additional theme that was confirmed but changed  
28  
29 in terms of the significance. The pre-determined theme “communication” was initially  
30  
31 directed towards support strategies to facilitate communication between spouses, e.g. by  
32  
33 using reminiscence strategies. Couples in this study described that they did not use these  
34  
35 strategies “yet”, which indicated that they might not need to use them yet. One couple  
36  
37 thus said that they sometimes look at photos in their album but not more than other  
38  
39 people do. The same couple said, *“We are not spending our time trying to remember*  
40  
41 *things, because that is the problem, to remember...”*. The meaning of the theme  
42  
43 “communication” was instead described as spending time together and to interact in  
44  
45 various ways. For one couple, the significance of their communication had changed, as  
46  
47 described by the partner *“What we say is not as important as how we say it”*, indicating  
48  
49 that it is of great importance with a friendly atmosphere.  
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## 55 Additional themes

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3 The inductive analysis of interview data resulted in three additional themes “socializing  
4 with family and friends” “state of mind and living as usual” and “being a comfort and a  
5 friend”.  
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10 Couples described wellbeing in meeting their friends and family. Meeting with  
11 familiar people instead of new people could reduce the stress of socializing, which in turn  
12 also contributed to less noticeable dementia symptoms. One couple described that it was  
13 very important for the partner with dementia to continue attending the monthly senior-  
14 center meetings. She had always been in charge of buying and serving the refreshments  
15 and for her to keep seeing her friends, and also to continue her role in the refreshments,  
16 her partner helped her by driving to the location and supported her making the coffee and  
17 setting the table. Socializing with friends and family was also described challenging due  
18 to some friends and family being overly helpful. One couple had chosen to stop seeing  
19 friends that did not contribute to their wellbeing:  
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34 *“We’ve chosen to stop seeing a couple of friends. One was so overly helpful and wanted*  
35 *to “take care of” so much it became offensive. It’s sad, but we have to socialize with*  
36 *people who make us feel good”.*  
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42 The added theme “State of mind/living as usual” emerged as a result of the changed  
43 significance of the theme “future and planning” as it was evident that couples strived to  
44 live as normal lives as possible, take one day at a time and to sustain positivity in their  
45 lives, as these two quotations illustrate:  
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52 *“I don’t feel sick. Of course, there are some difficulties, but we are living as we always*  
53 *have”.*  
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3 *“I feel it is important to try to behave as usual and not be thinking, “I can’t do this, and I*  
4 *can’t do that... not just sit at home and withdraw into oneself and think about how old*  
5 *and sick one is. I think that is dangerous”.*

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11 Sustaining positivity, and a positive state of mind was also described as something  
12  
13 couples could chose to some extent, by seeing the good before the bad and not worry  
14  
15 about trivial things that used to worry them. Keeping a positive spirit was something  
16  
17 couples worked on continually:  
18

19  
20  
21 *“We decided to not be that kind of discontented people but instead would take*  
22 *responsibility for finding fun things. We believe it is possible for us to choose the mood to*  
23 *some extent. It is not worthwhile to get angry over a bit of dust here and there. There are*  
24 *more important things”.*

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31 The theme “being a comfort and a friend” represented partners giving each other comfort  
32  
33 and support when they felt sad. The most important component in comforting was  
34  
35 closeness, hugs and touch:  
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37

38  
39 *“Sometimes I need some extra comfort, when I am sad, and I wonder how things will be.*  
40 *I get angry at everything, but then my partner comes and holds me, and then it usually*  
41 *gets better. Sometimes just a little bit of strength is needed like that”.*

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47 Both partners comforted each other, even in really difficult moments. One partner was  
48  
49 worried about if he should die before his wife with dementia and said *“Who is going to*  
50 *care for you then”?* His partner with dementia comforted him by saying that he should  
51  
52 not think of that *“we will handle that then, if it turns out like that”.*  
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## Subtheme added through consultation groups

The accuracy of the confirmed themes and the added themes were discussed in the consultation groups of people with dementia and carers in Sweden and in UK. Field notes were taken during the consultation meetings that confirmed all the themes accuracy, and also resulted in a new theme “intimacy”. The discussion about intimacy occurred in relation to couplehood. Several members described, in particular the partners, that physical closeness and sexual intimacy had become problematic in their relationship. One carer, whose partner with dementia recently had moved to a special accommodation, described a dramatic change in her relationship with her husband, from the couple being physical and cuddly, to her husband laying at the edge of the bed, risking to fall down on the floor, just to avoid being close to her. Another aspect of sexuality came from a man who was highlighting the issue of consent; how could he be sure that his wife with dementia gave her consent to their sexual activities?

## Summary - revision of the framework

Findings of the interviews and from the consultation meetings required modifications of the draft framework. The confirmed themes and added themes were connected into the four main themes; “Home and Neighborhood”, “Meaningful Activities and Relationships”, “Approach and Empowerment” and “Couplehood” with corresponding sub themes. The revised framework with confirmed themes and added themes is displayed in figure 1.



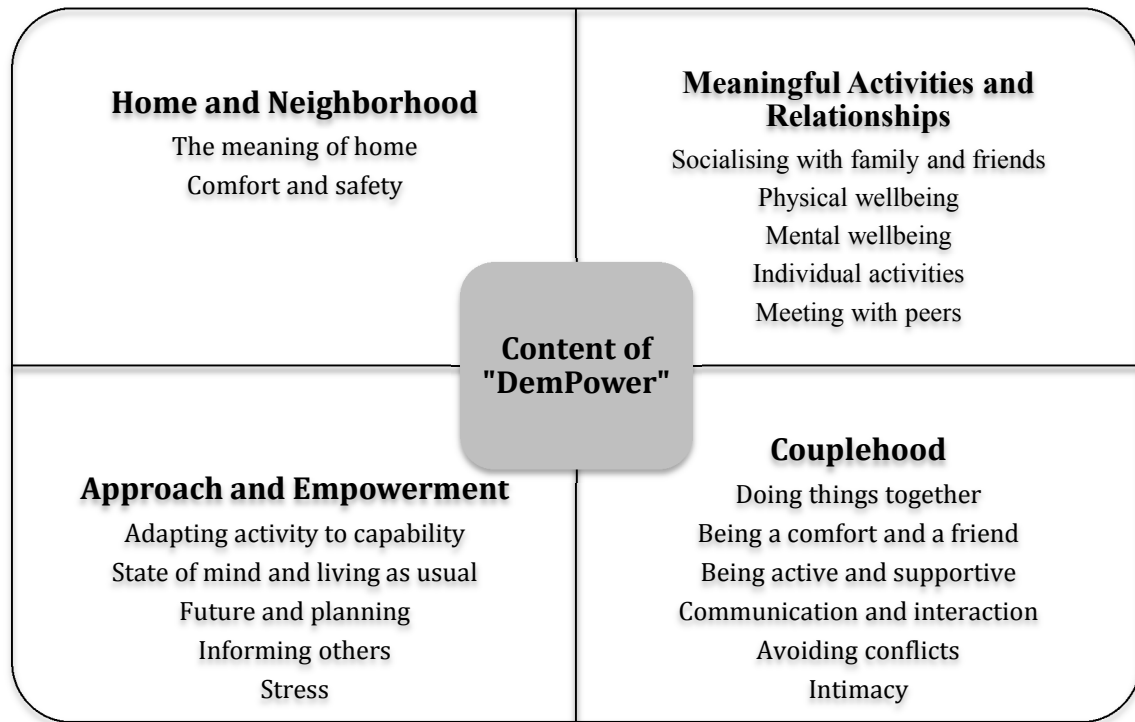


Figure 1. Revised framework of the self-management guide

## Discussion

The aim of this study was to identify relevant content for a self-management guide aimed at couples where one partner has a diagnosis of dementia. To the best of our knowledge, no previous self-management support has been developed that targets the couple as a unit, for couples to engage in as a dyad without professionals present, and which addresses the couples' relationship in the context of everyday life. The people with dementia who participated in this study received their dementia diagnosis between three to eight years ago. However, we do not consider that the time for diagnosis is a good measure of how long a person has lived with dementia. The person who was diagnosed three years ago may have lived with the condition longer, and at the time for the interviews, with a more severe dementia than the person diagnosed eight years ago. We

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2  
3 believe that the themes of the self-management guide and the self-management approach  
4 can be used from mild dementia to later stages, even though the partner may need to take  
5 more responsibility and initiative for the activities to be carried out and adjusted to suit  
6 the current situation and the couple. Being a couple - and sense of couplehood - is not  
7 dependent on gender and can therefore be applied to any dyad who are partners and live  
8 in a couple-based relationship.  
9

10  
11 The findings of this study highlight four main themes of importance for people  
12 with dementia and partners: “Home and Neighborhood”, “Meaningful Activities and  
13 Relationships”, “Approach and Empowerment” and ‘Couplehood’. Not surprisingly,  
14 these four main themes cover most aspects of well being for people in general; most  
15 people wish to feel safe and loved, be able to live in their own home, to be included in  
16 social life, to live as independent as possible, to have a meaningful everyday life with  
17 their family and friends, and to live as ‘normal’ a life as possible (WHO, 2018).  
18

19  
20 According to the findings of our study, areas of potential challenge for couples with  
21 dementia were related to these universal aspects of wellbeing and where therefore present  
22 in the context of everyday life.  
23

24  
25 The findings of this study suggest that “living as usual” and to “normalize” was  
26 an important aspect of wellbeing, and also an important coping strategy used by the  
27 couples. These findings are in line with previous research (McRae, 2011; van Nes,  
28 Jonsson, Abma & Deeg, 2013; Genoe & Dupuis, 2014; Torrington, 2009) and further  
29 imply that couples, where one partner has a diagnosis of dementia, need to be supported  
30 in the context of an everyday normal life. Self-management support targeting the  
31 everyday, therefore, may be an important aspect in such a care approach. Furthermore, as  
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3 highlighted above, what contributes to wellbeing for couples where one partner has a  
4 diagnosis of dementia should be the same for couples in general. Normalizing the needs  
5 of people with dementia and partners may therefore be of particular importance in order  
6 to spread greater understanding among the general population and for communities to pay  
7 attention to, and act upon the needs of people with dementia (and partners) to a higher  
8 extent.  
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### 18 **Targets and topics of self-management in dementia**

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20 A review of self-management for people with dementia indicated that self-management  
21 in dementia often involve carers and/or partners but are carried out as group support  
22 (Quinn, Toms, Anderson & Clare, 2016), thus contributing to limits for a couplehood  
23 approach. However, the main findings of our study are in line with previous research of  
24 self-management in dementia, several of our identified topics can be found in recent  
25 studies, for example; relationships, coping, communication, physical and psychological  
26 wellbeing, meaningful activities and planning for the future (Sprange, Mountain,  
27 Shortland, Craig, Blackburn & Bowie et al. 2015; Mountain & Craig, 2012; Martin,  
28 Turner, Wallace, Stanley, Jesuthasan & Bradbury, 2015; Quinn, Toms, Jones, Brand,  
29 Edwards & Sanders et al. 2016). The latter, “planning for the future”, seems to be a  
30 recurring topic within self-management for people with dementia and often involves  
31 learning about dementia and planning for future impacts (Quinn et al. 2016a). However,  
32 there are significant differences in how couples with dementia choses to cope with  
33 thoughts about the future. In Hellström and Torres’ (2013) study, most participants  
34 wanted to know and learn about the condition in order to be prepared for the future,  
35 whilst other studies, including the present one, revealed that couples where one partner  
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3 has a diagnosis of dementia often handle their situation by living in the present and taking  
4 one day at a time (McRae, 2010; Hellström et al. 2007; Hellström & Torres, 2016). In the  
5 literature, learning about dementia seems to be perceived as either helpful, or depressing  
6 and limiting, by couples where one partner has a diagnosis of dementia (Robinson et al.  
7 2015; Grand et al. 2011; Hellström & Torres, 2016 McRae, 2010; Hellström et al. 2007).

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15 The reason for feeling depressed and limited may due to couples being  
16 “convinced” that the progression of the dementia will be in line with the “bleak  
17 prognosis” as described in literature rather than embracing the fact that symptoms, and  
18 manifestations, of dementia differ widely (Mountain, 2006; Pearlin, Harrington, Lawton,  
19 Montgomery & Zarit, 2001). This does not only raise questions about how information  
20 about dementia and its content is delivered, could it also be that researchers and health  
21 care professionals have taken precedence in the interpretation of what people with  
22 dementia and partners need in order to manage their future? The key may be to identify  
23 couples coping strategies prior to an intervention(s) in order to support their way of  
24 handling their situation and to not impose "lessons" which could lead to negative  
25 outcomes.  
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40 The sexual aspect of intimacy was not included within the predetermined  
41 framework of themes in this study, which in retrospect may seem as a limitation. The  
42 reason why the topic “sexuality” was not recurring in the literature search prior to this  
43 study may due to the salutogenic approach that our study is based upon, while most of the  
44 research conducted within the topic is problem-based (e.g. hyper sexuality) (Bauer, Nay,  
45 Tarzia, Fetherstonhaugh, Wellman & Beattie, 2014; Youell, Callaghan, Buchanan, 2016).  
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54 Additionally, when the subject occurred during consultation meetings, it was in relation  
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3 to problems, which indicates that the subject may be unsuitable to include in a self-  
4 management guide that couples engage in without the presence of a professional. An  
5 additional reason for sexuality being overlooked may due to the sparse research regarding  
6 lived experiences of sex and intimacy in dementia (Youell et al. 2016). However, the  
7 theme "Being a comfort and a friend" in this study, included intimacy like touch,  
8 closeness and togetherness which are important aspects of relationships in dementia, as it  
9 becomes a source of extended communication in the context of everyday life, described  
10 by (Youell et al. 2016, p. 954) as "embodied day-to-day-ness of living together, of shared  
11 relational spaces". Nevertheless, the discussions in the consultation groups in this study  
12 indicated that sexuality could be a problem, and that it should be addressed to a greater  
13 extent in research.  
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### 30 Challenging the traditional views and approaches of self- 31 management 32

33 Self-management aimed at people with dementia is controversial. Martin, Turner,  
34 Wallace, Choudhry and Bradbury (2013) found that barriers to self-management lie on  
35 multiple levels; among people with dementia, carers, health care professionals and the  
36 general public. The most prominent barriers seem to be a deficit focus, lack of services  
37 with a positive and enabling approach, and the view of people with dementia as passive  
38 recipients of care. Martin et al. (2013a), found that skepticism towards the benefits of  
39 self-management was evident among carers and health care professionals, but not among  
40 people with dementia. In addition, perceived barriers to self-management among people  
41 with dementia included worries, fears and lack of confidence, which may be a reflection  
42 of the overall negative view of self-management for people with dementia. Thus, there is  
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3 an imminent risk of a negative spiral of disempowerment; how should people with  
4 dementia believe in their own abilities when no one else does?  
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8 On the other hand, there is a growing interest for self-management in dementia,  
9  
10 and the views of people with dementia being unable to learn new skills are being  
11 challenged (Mountain, 2006). The small number of studies being conducted in the area  
12 has shown promising results for participant's general wellbeing and sense of self-efficacy  
13 (see for example Quinn et al. 2016b; Sprange et al. 2015; Hickman, Wiersma & Harvey,  
14 2015; Laakkonen, Kautiainen, Hölttä, Saivikko, Tilvis & Strandberg et al. 2016).  
15  
16 Furthermore, the traditional approach of self-management may also need to be challenged  
17 in order for self-management to be successfully applied for people with dementia. For  
18 example, self-management is often highly related to the management of symptoms of the  
19 condition, and based on people's perceived problems (Lorig & Holmen, 2003). Our  
20 findings of this study suggest that, in line with Martin et al. (2013), self-management for  
21 people with dementia should promote positive and meaningful experiences and  
22 emphasize managing everyday life rather than managing the dementia itself. We  
23 therefore consider that a self-management guide can help couples to make "value-  
24 orientations" which can support them in finding and utilizing their positive resources and  
25 strengths, which in turn may contribute to higher sense of meaningfulness.  
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44 Hickman et al. (2015) found that the three core skills for self-management in  
45 dementia should focus on "adapting to change", "finding meaning and purpose" and  
46 "communication". These core skills can be found in several of our themes, for example in  
47 "adapting activity to capability", "meaningful activities and relationships" and  
48 "communication and interaction", and seem to be suitable goals for self-management in  
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3 dementia, when problem based and disease specific issues may not be applicable.  
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5 Another important aspect of self-management for people with dementia would be easy  
6  
7 access. According to the review conducted by Quinn et al. (2016a) and the review of  
8  
9 Bielsten & Hellström (2017b), self-management interventions for people with dementia  
10  
11 are dependent on the delivery of professionals and on particular locations, which leads to  
12  
13 various limits such as limited access and wider dissemination. Given that the number of  
14  
15 couples where one partner has a diagnosis of dementia will increase in the coming years,  
16  
17 there is a need for support that are not solely dependent on resources in health care. Easy  
18  
19 accessible self-management tools thus have the potential of positive impact for couples  
20  
21 where one partner has a diagnosis of dementia, and could also contribute to less strain on  
22  
23 community resources.  
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### 30 Trustworthiness

31  
32 According to Schutz (1973), second order constructs gain trustworthiness through the  
33  
34 three postulates *logical consistency*, *subjective interpretation* and *adequacy*. Our  
35  
36 literature search of previous research, the anchoring of our findings in research, and our  
37  
38 emphasis on “normality” reflects the *logical consistency* of our findings. The interviews  
39  
40 with couples, where one partner has a diagnosis of dementia, enabled the gathering of  
41  
42 first order information, i.e. from people with lived experience and with *subjective*  
43  
44 *interpretation*. The interview format “dyadic interviewing” also enabled getting closer to  
45  
46 lived experience, as the presence of an additional person living in the situation served as  
47  
48 back up or reliability check. The risk of imposing the researcher’s perspectives or biases  
49  
50 was also reduced when the focus lied on the dialogue between the couple. Moreover,  
51  
52 dyadic interviewing enables partners to support each other and also prompt each other in  
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3 the dialogue, facilitating for the person with dementia to share his/her experiences  
4  
5 (Sohier, 1995). An example of this was when the partner further grounded the theme and  
6  
7 the trigger in the couple's own experiences, for example by saying, "when we do things  
8  
9 like going to the cinema and restaurants". This enabled the person with dementia to share  
10  
11 experiences. On the other hand, there is a risk that dyadic interviewing contributes to  
12  
13 limitations due to the potential of partners not being able to speak freely in front of their  
14  
15 partner. Dyadic interviewing could therefore result in fragmented data, if both partners do  
16  
17 not have an equal voice (Zahrin, 2018).  
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24 Regarding the third postulate, the need for *adequacy*, this was achieved by arriving at  
25  
26 consensus in the consultation groups, in which the subjective meaning of the theme was  
27  
28 verified as being successfully maintained and thereby strengthening credibility. The  
29  
30 hybrid approach of deductive and inductive analysis facilitated the process in following  
31  
32 Schutz (1973) postulates for trustworthiness, and also supported the process of our  
33  
34 collaborative research with and for couples with dementia. Collaborative research has  
35  
36 shown to be an effective method to identify and select themes relevant to the target  
37  
38 group, and has the potential to enhance understanding of data (Littlechild et al. 2015).  
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## 43 Conclusion

44  
45 The findings of this study highlight the importance for couples where one partner has a  
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47 diagnosis of dementia to be enabled to live as normal lives as possible in the context of  
48  
49 everyday life. The needs of couples where one partner has a diagnosis of dementia are no  
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51 different from the needs of couples in general who wish to be recognized and valued by  
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53 each other, as a couple and by the local community. This study also addresses the  
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3 importance of recognizing the strengths and resources of people with dementia and their  
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5 partners in order for them to be empowered instead of disempowered. We have  
6  
7 emphasized and confirmed the normal needs of people with dementia and partners, which  
8  
9 in turn may contribute to reduced stigma and a higher understanding of the needs of  
10  
11 couples where one partner has a diagnosis of dementia. The framework of themes  
12  
13 developed in this study cover the major areas “Home and Neighborhood”, “Meaningful  
14  
15 Activities and Relationships”, “Approach and Empowerment” and “Couplehood” of  
16  
17 wellbeing. Couples need for support is of course not present in all areas. A self-  
18  
19 management tool could therefore serve as a guide for couples in order for them to focus  
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21 on the parts that they consider beneficial for their situation. There is also a potential that a  
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23 framework of themes could serve as a guide for health care professionals in identifying  
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25 areas, in which couples with dementia may need support. Developing and modifying our  
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27 framework into an assessment tool could therefore be of interest for further research.  
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## 34 Conflict of interest

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