How do activating interventions fit the personal needs, characteristics and preferences of people with dementia living in the community and their informal caregivers?

Netta Van’t Leven and Jacomine de Lange
Centre of Expertise Innovations in Care, Rotterdam University of Applied Sciences, Rotterdam, the Netherlands

Anna-Eva Prick and Anne Margriet Pot
Department of Clinical Psychology, Vrije Universiteit Amsterdam; EMGO+Institute: Institute for Health and Care Research, Amsterdam, the Netherlands

Abstract
Psychosocial interventions aim to mitigate the serious consequences of dementia for the daily life of people with dementia and their informal caregivers. To deliver a person-centred approach, it is crucial to take needs, characteristics and preferences of people with dementia and their informal caregivers into account. However, these factors are generally not systematically checked in order to determine which intervention will be most appropriate. Additionally, little is known about which intervention suits which needs, characteristics and preferences. Therefore, this study examined how three multiple-component, activating dyadic interventions fitted needs, characteristics, and preferences of both the people with dementia and their informal caregivers: the Pleasant Events Program, the Exercise and Support Intervention for People with Dementia and Their Caregivers, and Occupational Therapy. Semi-structured interviews were held with participants in either one of the interventions, 34 dyads and 19 professionals. The constant comparative method was used for the analysis. Five factors influenced the dyad’s ‘fit’: timing, need for activity, lifestyle, apart-or-together and meaning of (lost) activity. The factors ‘timing’ and a ‘need for activity’ were conditional for these activating interventions. Dyads in an early stage of dementia, who were aware of the effects on daily life, were open to a change in routine, and had a need to maintain activities profited from these interventions. Three distinctive factors were
important for the fit of one of the three interventions in particular: ‘lifestyle’, ‘apart or together’ and ‘meaning of (lost) activity’. The Pleasant Events Programme and the Exercise and Support intervention properly addressed the need for activities that afforded daily pastimes or structure. The Exercise and Support Intervention addressed the need for physical activity and emphasized shared activity. Occupational Therapy properly addressed the need for self-sufficiency, maintaining activities and adjustment to physical limitations. These factors can contribute to a more person-centred application of the interventions.

Keywords
caregivers, intervention, dementia, person-centred care, qualitative research

Introduction
Dementia reduces the quality of life of people with dementia and their informal caregivers (CGs) (Pinquart & Sorensen, 2006; von Kutzleben, Schmid, Halek, Holle, & Bartholomeyczik, 2012; Zwaanswijk, Peeters, van Beek, Meerveld, & Francke, 2013). Psychosocial interventions aim to mitigate the results of this process. The importance of a person-centred approach of these interventions has been increasingly recognised. Person-centred care was introduced almost two decades ago by Kitwood (1997) who emphasized the importance of addressing the psychological needs of people with dementia and the maintenance of their personhood. Understanding the history and individual needs, characteristics and preferences of people with dementia is crucial for a person-centred approach (Brooker & Latham, 2016). Unfortunately, when interventions are offered to people with dementia in clinical practice or research trials, their needs, characteristics and preferences are generally not systematically checked to determine which intervention will be the most appropriate one. Insight into the applicability, or ‘fit’, of an intervention with the needs, characteristics, and preferences may help to apply interventions in a more person-centred manner. Fit indicates the extent to which an intervention fulfils individual needs and is attuned to characteristics and preferences.

In recent years, psychosocial interventions have increasingly focused on ‘dyads’, consisting of both the person with dementia (PwD) and the primary informal CG, often a spouse or child. This was the result of an increasing awareness that the functioning of people with dementia was related to the functioning of their primary informal CGs (Ablitt, Jones, & Muers, 2009; De Vugt et al., 2004). Dyadic interventions take this mutual influence between the PwD and the informal CG into account. The effects of dyadic psychosocial intervention programmes have been studied in previous reviews (Smits et al., 2007; Van ‘t Leven et al., 2013). Results indicate the beneficial potential of these interventions for maintaining independency in activities of daily living for people with dementia and competence for CGs, contributing to a better quality of life.

This study is focused on three dyadic, multi-component interventions, to support the dyad in recognizing which activities are still possible to engage in, despite the challenges posed by dementia. Those were: the Pleasant Events Program (Verkaik, Francke, Lahr, & Zuidervaart, 2005), the Exercise and Support Intervention for People with Dementia Living at Home and Their Caregivers (Prick, de Lange, Scherder, & Pot, 2011) and Occupational Therapy According to the ‘Community Occupational Therapy in Dementia
These interventions make use of various activities, offer psycho-education, and provide emotional care that help
the dyad adapt to the effects of dementia in their daily lives. The PwD and the informal CG
practice these activities together. The interventions have a basic structure to start with and
are adjusted to the dyad’s wishes and needs. All three are short-term interventions consisting
of six to ten home visits. They differ in the nature of their activities. In the next paragraph we
describe each of the three interventions in more detail. For additional details of the
interventions, see Table 1.

The Pleasant Events Program provided support in adapting and planning pleasant
activities, e.g. learning to use Skype with children and grandchildren with a stepwise
manual, occasionally taking public transport to a historic city part when going shopping
instead of the usual shops, watching national geographic on television or having a walk in
the neighbourhood. The Exercise and Support Intervention contained exercises for
flexibility, balance, strength and/or endurance exercises using a ball, weights and elastic
bands and combined this physical exercise with support for planning pleasant activities, as
well as psycho-education and communication skill-training. Occupational Therapy consisted
of the improvement of self-care in a broad spectrum, such as learning to use the remote
control for the television with orientation marks, making a bicycle-tour that is worry-free for
the informal CG at home by taking a well-known route and using a mobile phone, helping to
keep a daily structure and schedule with an individually adapted agenda.

The three dyadic, multi-component interventions described above have been proven
effective in scientific research (Gitlin et al., 2008; Graff, Vernooij-Dassen, Thijssen, et al.,
2006, Graff et al., 2007; Teri et al., 2003; Teri, Logsdon, Uomoto, & McCurry, 1997).
However, recent studies could not confirm the original results (Dopp et al., 2014; Prick,
This might be due to the adaptation or implementation of the interventions or to the
different characteristics of the settings in which they were re-tested (Dopp, Graff, Rikkert,
Nijhuis van der Sanden, & Vernooij-Dassen, 2013; Prick, de Lange, van ’t Leven, & Pot,
2014; Vernooij-Dassen & Moniz-Cook, 2014; Voigt-Radloff, Graff, Leonhart, Hull, et al.,
2011). Process evaluations of these trials showed positive experiences of participants with
these interventions (Dopp et al., 2013; Prick et al., 2014; Voigt-Radloff, Graff, Leonhart,
Hull, et al., 2011). Finding no significant results of interventions might also be a result of not
fitting the needs, characteristics and preferences of people with dementia. When choosing an
intervention, ‘Which intervention works?’ is not the only question, but also ‘What works, for
whom, and at what times?’ (Brodaty & Arasaratnam, 2012; Gitlin, 2012; Van’t Leven et al.,
2013; Van Mierlo, Van der Roest, Meiland, & Droes, 2010). Therefore our research question
for this study was: which factors explain the appropriateness or fit of the three interventions
with the needs, characteristics, and preferences of the participating dyads?

Method

We used a qualitative design with semi-structured interviews to gather in-depth information
about the fit of these interventions in relation to the needs, characteristics and preferences of
the dyads (Hsieh & Shannon, 2005; Hunter, Murphy, Grealish, Casey, & Keady, 2011;
Kvale & Brinkmann, 2009; Maso & Smaling, 1998). We wanted to integrate the
perspectives of people with dementia, their informal CGs, and the professionals who
guided them through the intervention, and we included and studied them as cases.
<table>
<thead>
<tr>
<th>Pleasant Events Program</th>
<th>Exercise and support intervention for people with dementia and their caregivers</th>
<th>Community Occupational Therapy in Dementia (COTID)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Original interventions</strong></td>
<td>This programme is based on Teri et al. (1997). The Dutch manual for the programme was published by Nivel (Dutch Institute for Primary Healthcare) (Verkaik et al., 2005), and is supplemented by examples from Gitlin et al.’s (2008) programme.</td>
<td>This therapy is described in Graff, Vernooij-Dassen, Thijssen, et al. (2006) Graff, Vernooij-Dassen, Zajec, et al. (2006) Graff et al. (2010-in Dutch).</td>
</tr>
<tr>
<td><strong>Primary goal</strong></td>
<td>Maintaining activity, having pleasant activities, and preventing depression of people with dementia and the informal caregiver.</td>
<td>Preventing depression of people with dementia and the informal caregiver.</td>
</tr>
<tr>
<td><strong>Components</strong></td>
<td>- Choosing and planning pleasant activities for the person with dementia, the informal caregiver or both, - Practicing these activities, - Adjusting activities to the capabilities of the person with dementia, - Psycho-education, - Homework: pleasant activities.</td>
<td>- Exercises for flexibility, balance, power, and stamina of the person with dementia and the informal caregiver, supervised by a coach at home. - Identifying pleasant activities for both, - Psycho-education and communication training to manage behavioral problems, - Homework: repeating mobility exercises and pleasant activities (preferred at least 3 times a week).</td>
</tr>
<tr>
<td><strong>Duration</strong></td>
<td>A maximum of 6 home visits of 1.5 h each.</td>
<td>A maximum of 8 home visits of 1 h each.</td>
</tr>
</tbody>
</table>

(continued)
<table>
<thead>
<tr>
<th>Table 1. Continued.</th>
<th>Pleasant Events Program</th>
<th>Exercise and support intervention for people with dementia and their caregivers</th>
<th>Community Occupational Therapy in Dementia (COTiD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evidence</td>
<td>Positive effects on depression for people with dementia and informal caregivers (Teri et al., 1997) and on occupational engagement and agitated behaviour (Gitlin et al., 2008).</td>
<td>Positive effects on depression and general health of people with dementia (Teri et al., 2003). An RCT with the adjusted programme found only a quantitative effect on cognition (Prick, de Lange, Twisk &amp; Pot, 2015).</td>
<td>Positive effects on daily functioning of people with dementia and competence of informal caregivers, as well as on depression, general health and quality of life of both (Graff, Vernooij-Dassen, Thijssen, et al., 2006, Graff et al., 2007). These effects were not demonstrated in studies by (Voigt-Radloff, Graff, Leonhart, Schornstein,. et al., 2011) and Döpp et al. (2014).</td>
</tr>
<tr>
<td>Provision</td>
<td>The programme was offered as part of the University Collaborative Centre for Dementia, which entails the collaboration of Rotterdam University, the Home Care Organization ‘De Zellingen’ and the Van Kleeif Institute (for generating and disseminating knowledge for home care professionals). The coaches were students graduating in healthcare studies and home-care workers from De Zellingen. They were supervised during the intervention. The project leader and case manager in the region recruited participants.</td>
<td>The programme was offered within an RCT from the Department of Clinical Psychology, VU University, Amsterdam (Prick et al., 2011; Teri et al., 2003). The coaches were Master students from the Department of Clinical Psychology, VU University, who completed a special training programme for geropsychology. They were supervised during the project. The project leader recruited participants for the programme with the help of caregiver organizations, local Alzheimer cafes (public meetings for people with dementia, their caregivers, and others) and case managers throughout the Netherlands.</td>
<td></td>
</tr>
</tbody>
</table>

RCT: randomized controlled trial.
The Pleasant Events Program and the Exercise and Support Intervention were both evaluated in a larger study (see Table 1). Ethical approval for the interviews in our study was already included in the study designs (Pleasant Events Program: Medical Ethics Review Committee of the Erasmus Medical Center, number 2009-117; Exercise and Support Intervention: Medical Ethics Review Committee of the VU University Medical Center, number 2008/320). For the interviews about the Occupational Therapy Intervention ethical approval was attained separately (Medical-Ethical Review Committee for Mental Health Care, number 11.123).

Participants

We recruited participants who had either taken part in the Pleasant Events project, the trial for the Exercise and Support Intervention, both already research participants, or had Occupational Therapy according to the COTiD-guideline as a clinical service. The participants had been recruited for or referred to that particular intervention (they were not offered a choice of which intervention they thought would best suit them). Participants for the Pleasant Events Program and the Exercise and Support Intervention were recruited via the project managers, coordinating those studies. Participants for occupational therapy (OT) were recruited via occupational therapists. The project managers asked participants in both studies, after the intervention had ended, if they were open for an interview with an independent researcher. The occupational therapists asked their clients after the intervention if they were open for an interview too. They had leaflets with information about the study and the interviewer available for a dyad. When participants were positive to an interview they asked permission to share their name and telephone number with the interviewer. The researcher contacted the dyad per telephone, explaining again the goal of the interview and the study. If the dyad was still open for an interview, an appointment was made. This appointment was confirmed by post with an informative letter and a form for informed consent for the interview and audio-recording was already sent. Four dyads still cancelled their interviews, because of illness or being otherwise engaged. At the time of the interview at home the information was repeated and the informed consent was signed. We used one form with both names of the dyad. The people with dementia signed if they wanted and it did not confuse them. The informal CG also signed. If the people with dementia could not sign, the informal CG signed for both of them as a couple.

Our intention was to obtain a variety in cases to include a broad spectrum of experiences, needs and characteristics in the data. So we asked them for both successful and less successful cases and also those that had not finished the programme. In this way convenient samples were composed for each intervention.

Data collection

We aimed to interview both members of the dyad, either together or separately, depending on their preference, so that they would feel at ease. Seven informal CGs indicated that their partner or parent with dementia could no longer reflect on their experiences and a joint interview would be too burdensome for them. These informal CGs agreed to an interview on a day that the PwD was in day care. The interviews with people with dementia and informal CGs took place in the participants’ homes. An interview with a couple started with an open
question about the interviewees’ experiences with the intervention. Follow-up questions addressed initial expectations, continuation of exercises and activities, usefulness of the advice, what the couple had gained from the intervention, and what was still missing. Especially in the interviews with people with dementia, the interviewers used short sentences and prompts, and tried to follow their reasoning through, repeated parts of their answers to stick to their story, and sometimes presented a photo of the professional. They spent sufficient time with small talk between questions to let the PwD rest and followed their track of thought (Beuscher & Grando, 2009; van Baalen, Vingerhoets, Sixma, & de Lange, 2011). We did not mention the term dementia or Alzheimer unless the PwD or CG had first used this term. Some CGs added their perspective afterwards. The interviews lasted 50 to 120 minutes. The first and third authors (NL, AEP) conducted the interviews. In case the need for information or a helpful conversation emerged, we had leaflets for the dyads for telephone support, a service of the national Alzheimer’s Association, where they could talk with peers.

The interview with the professional took place after the interviews with the dyad, at their workplace or at a public space. Some professionals were interviewed about their experiences with several dyads during one appointment, but each dyad was discussed separately. This interview started with an open question about the professional’s experience of the intervention related to the dyad. Follow-up questions addressed what results were achieved, how the professional tailored the intervention to the needs and preferences of the dyad, and what was not achieved. These interviews lasted 20 to 30 minutes. The recordings of the interviews were transcribed verbatim and imported into Atlas-ti-6/7.1 for qualitative analysis (Friese, 2012).

**Analysis**

Data collection and analysis was an iterative and reflexive process, based on the constant comparative method (Boeije, 2010; Bogdan & Biklen, 1997; Maso & Smaling, 1998). An interview with a PwD and a CG was linked to the interview with the professional (PROF), and was included as a case (Figure 1).

Transcripts were read to capture an overall impression and a preliminary summary was made with the perspectives of the PwD, CG and PROF, similarities and differences. The transcripts were unravelled with open codes, to describe all aspects of the content (Hsieh & Shannon, 2005).

The analysis consisted of three phases in a back and forth process. In the first phase, 11 cases were analysed exhaustively with open coding. Some codes referring to the same phenomenon were already grouped together to include convergence and divergence. We summarized the degree of fit for each case. In the second phase, we grouped the codes into categories under the themes: needs, personal characteristics, contributing elements, perceived results and fit. NL coded 10 new cases and recoded the 11 earlier cases. We extracted within these themes what kind of needs and which characteristics were important for the fit of the intervention. This led to an analytical framework with preliminary factors that affected the fit. In the third phase, we used the remaining 13 cases to test this analytical framework and to search for new perspectives. No new codes were needed, which showed that saturation had been reached. The preliminary factors were condensed to five factors that were important for the fit of the interventions for the participants.
Methods to enhance credibility in the analysis

Three researchers (NL, JL, AEP) independently coded the interviews of four cases. They discussed any coding differences. NL analysed all data in detail. NL and JL frequently discussed results during all phases for plausibility and consistency. Several independent researchers conducted peer reviews on preliminary results. We offered every respondent at the end of the interview the possibility to read the transcript or receive a copy of the article at the time of publishing. All authors discussed methods, summaries, analyses and results in the study process. Table 2 shows details of the participating couples and professionals to conclude on the degree of transferability.

Figure 1. Cases and analysis process. PE: Pleasant Events Program, EP: Exercise Program, OT: Occupational theory Program, PwD: person with dementia, CG: caregiver.
Findings

Characteristics of the participants

We included a total of 34 cases, although some cases missed the interview of the PwD, and some the interview of the coach (Table 2).

The interviewees indicated that the onset of the dementia’s symptoms had begun between one and five years ago at the time of the intervention, although the syndrome was often formally diagnosed later. The Pleasant Events Program included comparatively more participants with advanced dementia and poor communication ability, who needed assistance for personal care and attended day-care for several days. The Occupational Therapy intervention included more people with physical limitations, such as poor eyesight or difficulty with walking, than the other interventions. Sometimes physical limitations were the reason for the referral rather than cognitive limitations. The overall professional support for the participating dyads ranged from supervision by a geriatrician and case manager only, to day-care and personal care several times a week. Most of the participating dyads were partners, others parent–child. The majority of the people with dementia were men in all three interventions.

Five factors for fit of the interventions

The analysis of the interviews led to five client-related factors that affected the fit of the interventions to needs, characteristics, and preferences of a dyad: two conditional factors, ‘timing’ and ‘need for activity’, and three distinctive factors, ‘lifestyle’, ‘apart or together’, and ‘meaning of (lost) activities’ (Table 3).

Timing

Most interviewees who took part in the intervention when the dementia was in an early stage claimed that it had helped them continue their activities. The professionals confirmed this in their interviews. Those who could accept change in order to cope with the consequences of the dementia process and were willing to put suggestions into practice benefitted considerably from the intervention. Some people with dementia said they wanted to slow down the dementia process as much as possible. They felt responsible for their health. The intervention offered them the opportunity to help combat the onset of the dementia disease. One man with dementia explained:

It’s simply a nasty disease. We have to face many problems. But my wife gets the most of it. And I simply can’t help all the time... The good news is that there are some small stepping stones (such as this intervention, the Exercise and Support Intervention), where I can make an effort ‘to slow the dementia down’. I do hope so.

We concluded that participating in the intervention and performing the exercises were meaningful for him. It supports him in coping with his illness.

Many informal caregivers stated that they had already actively sought information or other help. One informal caregiver said:

I believe that the more tips and help and guidelines you can obtain for dementia, the better it is for everybody. I have often seen informal caregivers in my network who have the notion that
Table 2. Participants.

<table>
<thead>
<tr>
<th>Programme</th>
<th>Pleasant Events Program</th>
<th>Exercise and Support Program</th>
<th>Community Occupational Therapy</th>
<th>Dyads per professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with dementia</td>
<td>Mean age (years)</td>
<td>78.1</td>
<td>75</td>
<td>80</td>
</tr>
<tr>
<td></td>
<td>Sex</td>
<td>7 M/2 W</td>
<td>6 M/5 W</td>
<td>9 M/5 W</td>
</tr>
<tr>
<td></td>
<td>Onset of dementia: Range (Mean)</td>
<td>1–4 years (2.4)</td>
<td>1–5 years (2.9)</td>
<td>1–4 years (2.4)</td>
</tr>
<tr>
<td></td>
<td>Interview</td>
<td>10 PwD</td>
<td>Partners: 72.6</td>
<td>Partners: 77.3</td>
</tr>
<tr>
<td>Caregivers</td>
<td>Mean age (years)</td>
<td>Partners: 76</td>
<td>Child: 53</td>
<td>Children: 53</td>
</tr>
<tr>
<td></td>
<td>Sex</td>
<td>Partners: 76</td>
<td>4 M/7 W</td>
<td>3 M/10W</td>
</tr>
<tr>
<td></td>
<td>Relation</td>
<td>10 partners</td>
<td>1 parent/child</td>
<td>9 partners</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9 x partners</td>
<td>2 master students</td>
<td>5 parent/child</td>
</tr>
<tr>
<td>Coaches/Professionals</td>
<td>Background</td>
<td>3 pairs of 4-year students; 2 master students clinical psychology,</td>
<td>9 occupational therapists,</td>
<td>19 coaches/ professionals, involved in 28 cases</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 homecare workers; 9 cases</td>
<td>5 cases</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dyads per professional</td>
<td>1 or 2 dyads per pair; 2 or 3 dyads per pair;</td>
<td>2 or 3 dyads per coach</td>
<td>1, 2 or 5 dyads per OT</td>
</tr>
</tbody>
</table>

PwD, person with dementia; CG, primary informal caregiver; M, men; W, women.
<table>
<thead>
<tr>
<th>Fit-factors</th>
<th>Pleasant Events Program</th>
<th>Exercise and support intervention for people with dementia living at home and their caregivers</th>
<th>Occupational therapy according to the COTID Guideline</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Conditional factors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Timing</td>
<td>Early phase of dementia&lt;br&gt;Openness to change&lt;br&gt;Accepts change to cope with consequences of dementia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need for activity</td>
<td>Maintain activity&lt;br&gt;Training of lost activities&lt;br&gt;Support for caregiver to instruct the PwD to carry out activities.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Distinctive factors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lifestyle, For both or for one of them</td>
<td>Active&lt;br&gt;Link to: all kinds of activity at home or outside; conviviality</td>
<td>Active&lt;br&gt;Link to: exercise, sports, walking, etc.; physically active</td>
<td>Active&lt;br&gt;Link to: all kinds of daily activities at home or outside; “do what you can yourself”</td>
</tr>
<tr>
<td>Apart or together</td>
<td>Apart or together&lt;br&gt;Need for maintaining activity, daily pastimes, structure</td>
<td>Together&lt;br&gt;Need for training and physical activity, daily pastimes, structure</td>
<td>Apart or together&lt;br&gt;Need for doing things oneself and self-sufficiency, adjustment to physical limitations, daily pastimes, structure</td>
</tr>
<tr>
<td>Meaning of (lost) activities</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
they have to be able to do it all on their own, because accepting help is a sign of weakness. I’ve never seen it that way myself.

Some participants in the Pleasant Events Program and the Exercise and Support Intervention did not want to emphasize ‘problems’ they needed help with, but were very positive about the intervention. They perceived it as a course in staying active and learning about living with dementia. For them, the intervention had been offered well on time.

Many professionals mentioned that openness towards the intervention was related to addressing the real needs of a dyad. It was quite a challenge for them because a question often illustrated a deeper need. When they managed to make this deeper need explicit, most dyads were open and willingly to get involved in the intervention. Most of the professionals stated that the intervention should have been available for their clients at an earlier stage. An occupational therapist explained:

Ideally, we would like to get involved when people with dementia can still learn a bit and we can anticipate future problems. For example, it can be worthwhile to install a telephone with photo buttons in a fixed location when they can still make a telephone call themselves. This makes it easier for them to operate. The same is true for the timely installation of a date clock. We’re often brought in too late. My colleagues and I consider cases where the family needed to ‘turn off the gas for safety’ the most difficult. This means you are a little too late. Perhaps in an earlier phase we could have helped the person find a way to compensate.

The intervention was deemed too late if a PwD could no longer absorb new information or could no longer retain focus. The intervention was also too late if the informal CG was overburdened and lacked the energy to attempt new behaviour, which was particularly important for these activating interventions. These informal CGs did feel the professional supported them, but they had benefitted little from the intervention.

In contrast, the intervention came too early for some dyads. One dyad needed more time to acknowledge the diagnosis and primarily needed information at that point in time. Another dyad wished to retain their normal way of life for as long as possible, and was not yet open to the advice. Dyads that were less able to change had fewer results. These interventions, that mobilised them to adapt to the effects of dementia in their daily lives, called for the adjustment of their existing habits. Some found that the activities and advice did not apply to their situation, despite the professional’s attempts to motivate them. An informal CG reported that the advice was not very useful for her because she just wanted her husband to do the activities the way he always did them:

   I was advised to ask him directly for activity because of his lack of initiative. I did try this. He helps dry the dishes, but puts everything on the counter, right, rather than where it’s supposed to go… That makes me think, “Well, I’ll just do it myself”.

**Need for activity**

The interventions addressed the dyads’ need to maintain activities. People with dementia often mentioned activity in general, such as ‘doing what I was used to doing’, or ‘keeping a hold of things’. Some CGs explained that the people they cared for had difficulty with various activities: hobbies, daily tasks or getting out. CGs also had general questions about ‘how to support the PwD best to perform activities’. One informal CG spoke about the problems she encountered:
Recently I asked you “Could you make a cup of tea?” Then you did your utmost best and came back with two plates of strawberries. And then I repeated, “You need to make a cup of tea, dear.” And then, you came back with...another bowl of strawberries. The third one! And usually, you’ve never had a problem doing something, and now, when I ask you for something, you just can’t figure it out.

This CG required help in helping her husband complete activities by himself, as many informal CGs did. The informal CGs needed advice for their new role of supporting the PwD in carrying out activities. The problems included ‘Which instructions are required?’ and ‘Should I take charge or let him/her figure it out and do it alone?’ Many informal CGs also mentioned their difficulty with the apathy of the PwD: ‘He just sits on the couch’. They needed advice about how to motivate the PwD and how to adapt activities to their limitations.

All professionals mentioned efforts to explore the latent needs of a dyad for activities. There were also a few dyads who did not experience a need for activities, and for them, the intervention had less impact. An informal CG reflected:

Yes, we are very busy. We have a pretty large family. We are both married for the second time. So we’ve got four families... And the kids, of course. Plenty of work to go around... She (the partner with dementia) is still pretty present. We go everywhere. So we said to each other: “Actually, we do not think this (the intervention) is for us.” We are not far enough along yet.

Lifestyle

Lifestyle was shown to be a factor for the fit of the interventions. In this context, lifestyle means activities and habits. Some dyads explained how they usually spent their time, both in the past and in the present. This gave us insight into their interests and what was important to them. Expressions such as ‘Well, you know, staying active, that’s important...’ or ‘we like to make an outing regularly, visit a museum for example’ or ‘My wife and I have always taken part in sports’ or: ‘He’s a real outdoor man’ show their activity preferences. Many dyads shared values such as ‘keeping active’, ‘staying mobile’, or ‘getting out of the house every day’. Some dyads shared interests, whereas others had differing interests. Either way, the professional could adapt the intervention to address different needs. At least one of them should have an active lifestyle for the fit of these interventions. It appeared that the CG not only tried to facilitate the PwD in continuing his or her usual activities, but also tried to activate the PwD with activities the CG liked to do him- or herself.

Apart or together

The interventions seemed to satisfy the need to do something together very well. Many of the people with dementia enjoyed spending time with their informal CGs; they felt at ease. The informal CGs expressed this need another way. They often spent a lot of time caring for the PwD, but missed the contact and mutuality they had before. Particularly, informal CGs of dyads who were used to doing a lot together were still looking for moments to share their experiences. The intervention helped them to do things together and to get a feeling of togetherness again. Some informal CGs had no need for additional joined activities. The time spent on providing care was enough. For them, it was especially important to keep the
PwD busy for a while or do the exercises on their own so they could attend to their own activities. The professionals adjusted the intervention to these needs of a dyad.

All three interventions required input from both the PwD and the informal CG, and they required some togetherness and cooperative action. If there was a limited need to do things together the Occupational Therapy and the Pleasant Events Program was more applicable than the Exercise and Support Intervention. The Exercise and Support Intervention requires participants to do the exercises together three times a week and to plan pleasant activities. Some of the dyads particularly appreciated having an additional shared activity. For them, the intervention fulfilled the need to do something together. One professional said: ‘They were keen on doing something together, being active, so the exercise program was a good offer for them’. For other dyads, practicing three times a week was a burden on the informal CG and did not fit their needs for togetherness and independence. The Pleasant Events Program is oriented on fun pastimes and Occupational Therapy on the ability of people with dementia to do activities more independently. Depending on their needs and abilities, a dyad can choose to do more or less together, and the therapist can choose to be more or less oriented on joint activities.

**Meaning of (lost) activity**

The result of the activity itself, such as making a cup of coffee, or going outside for a walk was important for a dyad, of course. However, the corresponding meaning of these activities for a PwD or the informal CG determined the degree of feeling a loss of activities. Making a cup of coffee could mean independency but could also mean caring for the partner, while going for a walk could mean just passing time but could also mean being physically active or having social contact. The activity could mean a pastime, maintaining structure, being physically active, having social contact, being self-sufficient, or may add to satisfaction and self-appreciation. For example, for one lady with dementia who lived by herself, the lack of activities meant a lack of structure in the day. She was facilitated in performing some activities again through memory-aids and a telephone call from her daughter. The rhythm and structure in the day was enough for her to also pick up other activities like making coffee and making bread, so she could maintain living on her own. If the lost activities primarily were related to the meaning of the activity, couples often did not specifically call it loss of an activity. For example, the dementia patients said they had nothing to do anymore, or CGs explained they felt powerless to handle the situation. For others the result of the activity itself was important. In those cases, people tended to name specific activities during which they experienced a lack of self-sufficiency: hobbies, household activities, getting dressed, or operating devices in the house. One woman with dementia said:

> I like watching television. I tend to turn it on for a bit in the morning, and then at the end of the afternoon. Well, that didn’t go well any more.

> Her daughter added: My mother had another device with a remote control, and she had a remote control for the television. She couldn’t keep them apart.

Some of the participants also suffered from physical limitations, apart from the cognitive or behavioural problems caused by the dementia. This made it difficult for them to maintain the same level of activity. They needed to adjust their standard activities to both their physical and cognitive limitations.
Discussion

Main findings and reflections

This study presented five factors that reflect the fit of the three studied interventions to the dyads’ needs, characteristics and preferences. Timing and a need for activities are both conditional factors for the fit of any of these activating multiple-component interventions with dyads’ needs and characteristics. The factors lifestyle, the need to do something together or apart, and the individual meaning of activities are indications of the fit of one of the three interventions in particular. The Pleasant Events Program was well suited to dyads that enjoyed various activities at home or outside, together, but also apart, for pleasure and daily pastimes. The Exercise and Support Intervention was appropriate for dyads of whom one of the two preferred exercise or sports, were open to exercise together a few times a week, and had a need for daily pastimes and keeping active. Occupational Therapy was well suited to dyads for which self-sufficiency of the PwD was the primary goal, in shared as well as individual activities. Occupational Therapy also took into account the need of advice about activities for dyads with physical limitations.

In clinical practice and in inclusion for trials these factors are often not taken into account. Characteristics such as age, level of education, social economic status and social network may be collected, but it is not common to discuss preferences, habits and values systematically with a dyad. In this study we also collected data about socio-economic status, level of education, (former) job and religion of the participating dyads, but these data did not reveal factors for the fit of the interventions. The five factors found in this study are all related to preferences (although lifestyle is related to educational level and socio-economic status too).

Clinicians need to take a person-centred approach by carefully considering a dyad’s needs, characteristics, and preferences to determine the intervention that is likely to be the best fit. Based on the results of this study, a two-step process may be advised. The first step, for professionals like physicians and case managers who would like to refer people with dementia and their CGs to an activating intervention, is about assessing the needs of a dyad before referral to a specific intervention. Clinicians need to be alert on the dyad’s openness or readiness for change and ask what their need for activities is. The ‘timing’ requires careful monitoring of a dyad, because their needs for support are not static and change due to the progress of dementia. In a second step, a specific activating, multi-component intervention needs to be selected. Clinicians need to ask both the PwD and the CG whether they prefer to do things together or apart, what their life-style has been (active, physically active, doing sports, outings) and the meaning of activity for them conviviality, pastime, self-sufficiency). This might be a challenge for clinicians, because although some dyads ask for advice or support in a direct way, often help is needed to make their latent needs explicit (van der Roest et al., 2007).

The three interventions aim at maintaining the functional abilities of people with dementia, supporting the CG, and helping both to cope with dementia progression. The preventive character of these programmes, which are limited in both duration and cost, makes them suitable for all dyads who recognize difficulty with activities. Emphasising possibilities despite apparent limitations may strengthen a dyad, as well as attention to maintaining activity; but this has not been made a part of standard care yet. Some dyads who participated in the Exercise and Support Intervention did not want to talk about ‘problems’. They stated that the intervention trained them to cope with their situation by improving their capacities instead.
of emphasising problems. In line with Haberstroh, Neumeyer, Krause, Franzmann, and Pantel (2011), the term ‘support’ was associated with helplessness, whereas the term ‘training’ was associated with maintaining capacities and empowering. This finding suggests offering these interventions to dyads as training to improve their skills in dealing with the effects of dementia, as to distinguish this type of support from other support such as respite care. Such an approach may stimulate openness to an intervention.

**Strengths and limitations of the study**

The dyads involved in this study may not be representative for the total group of people with dementia and their informal CGs who participated in the three interventions, although the respondents did represent a group of people of diverse age, education, work and dementia duration. Both the dyads and the professionals in this study were willing to be interviewed because they wanted to contribute to good care for people with dementia. Furthermore, only a few of them dropped out during the intervention. In recruitment of dyads for this study we asked specifically for dyads and professionals with positive and negative experiences. We included five dyads (3 Pleasant Events Programme, 2 Occupational Therapy) who ended the intervention after one or two home visits. The caregiver was overburdened, there was no need for activity (not yet or not anymore) or there were personal problems. So most dyads found enough benefit of the intervention to continue to apply it to at least some degree. We recommend that future studies interview more dyads who chose not to take part or dropped out early, because they can afford more insight into the fit of interventions.

One particular strength of the study is the involvement of people with dementia. A significant number of interviewees with dementia related their intervention experiences in the interview. Some were no longer able to reflect on the intervention, but they could still indicate what activities were important to them and why. The period between the completion of the intervention and the interview varied from 1 to 10 months. Many people with dementia who were able to participate in an interview could still talk about the intervention or the professional, even after six or nine months, which enabled us to include experiences over a longer time.

It is unclear to what extent a joint interview versus separate interviews affected the study. The informal CGs who were present frequently added to accounts of the people with dementia and helped them express themselves. However, the people with dementia or the informal CGs may have felt difficulty expressing themselves freely in joint interviews. Some informal CGs resolved this by speaking to the interviewer alone after the interview to freely express their opinion. In some of the cases we realized at the time of (re)reading the transcript that the content of what the CG said was not supportive for the PwD’s mood, although the atmosphere and non-verbal signs had been positive. Based on this and other experience (Prick et al., 2014) we would prefer to interview both members of the dyad separately in future situations, perhaps performing three interviews, both separately and jointly.

**Implications for practice**

In clinical practice, programmes with treatment components that are more or less comparable to the studied interventions are becoming increasingly available. The experiences of participants in this study address the importance for researchers and clinicians to take a
person-centred approach and assess the needs, preferences, and characteristics of dyads first, both separately and jointly, to decide through shared decision-making which intervention would best suit these dyads. Referring professionals may use the two conditional factors to discuss with a dyad the appropriateness of any of these activating interventions.

*Timing* concerns questions like:

- is the dyad still overwhelmed by the diagnosis? Then referral to an activating intervention may come too early.
- do both persons have enough energy to participate in an activating intervention? For example, when the CG is overburdened, an activating intervention may be too late.

*Need for activity* may hold questions like:

- does the PwD need to maintain activities or pick them up again? Is he or she able to do more activities?
- does the CG need support in assisting or instructing the PwD to perform activities?
- does the CG need more insight into the capacities of the PwD, what he or she is able to do?

The other factors could help to choose an intervention in particular.

*Lifestyle* holds questions like:

- does the dyad or one of them (PwD or CG) have, or did he have, active lifestyle?
- what kind of activity he or she used to do: physical activity, sports, days out?

*Apart-together* concerns questions like:

- is the PwD accustomed to spending time alone?
- does the PwD depend on the CG?
- does the PwD and/or the CG like to have shared activities?
- does the CG need time for him-/herself?

*Meaning of (lost) activity* concerns questions like:

- is there a need for more daily routine in the activities of the PwD?
- are lost activities related to a lost pastime or self-sufficiency for the PwD?
- is there a need for more safety inside or outside the house in order to be able to continue activities?
- is there a need for adaptations of activities to the physical limitations of the PwD in order to be able to continue these activities?

**Conclusions**

Dyads in an early stage of dementia, who were open to change their habits and routines because of the consequences of the dementia process and had a need to maintain activity,
especially profited of these interventions. The intervention Pleasant Events as well as
the intervention Exercise and Support properly addressed the need for daily pastimes,
structure and fulfilment. The Exercise and Support Intervention addressed the need for
physical activity and emphasised shared activity of the dyad as well. Occupational
Therapy (COTiD) properly addressed the need for additional self-sufficiency, maintaining
activities and adjustment to physical limitations.

Further study of the validity and feasibility of these factors is needed before they can be
used for choosing the appropriate intervention. With the results of this study we are able to
formulate hypothetic indications for these activating interventions directed at maintaining
daily activity and coping with changing roles and diminishing capacities. Consequently,
it would be possible to design a tool for the needs assessment of the activities for a dyad.

Acknowledgements
We thank the participating people living with dementia and their family caregivers, professionals and
students occupational therapy, speech therapy, nursing, master students psychology and project
leaders.

Declaration of Conflicting Interests
The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or
publication of this article.

Funding
The author(s) disclosed receipt of the following financial support for the research, authorship, and or
publication of this article: partly funded for the first author with a grant for a PhD-study of the
Rotterdam University of Applied Sciences, Rotterdam, the Netherlands.

References
Beuscher, L., & Grando, V. T. (2009). Challenges in conducting qualitative research with individuals
with dementia. Research in Gerontological Nursing, 2(1), 6–11.
Bogdan, R. C., & Biklen, S. K. (1997). Qualitative research for education: An introduction to theory and
Brooker, D., & Latham, I. (2016). Person-centred dementia care, making services better with the VIPS
Do caregiver management strategies influences patient behaviour in dementia? International Journal
of Geriatric Psychiatry, 19, 85–92.
Dopp, C. M., Graff, M. J., Rikkert, M. G., Nijhuis van der Sanden, M. W., & Vernooij-Dassen, M. J.
(2013). Determinants for the effectiveness of implementing an occupational therapy intervention in
routine dementia care. Implementation Science, 8, 131.


**Netta Van’t Leven**, MSc, is a PhD student and lecturer at the Centre of Expertise Innovations in Care, Rotterdam University of Applied Sciences, Rotterdam, the Netherlands.

**Jacomine de Lange**, PhD, is a professor at the Centre of Expertise Innovations in Care, Rotterdam University of Applied Sciences, Rotterdam, the Netherlands.
Anna-Eva Prick, MSc, is a PhD student at the Department of Clinical Psychology, VU University of Amsterdam; EMGO+-Institute: Institute for Health and Care Research, Amsterdam, The Netherlands. She is also a clinical psychologist.

Anne Margriet Pot, PhD, is a professor of Clinical Geropsychology, VU University of Amsterdam; EMGO+-Institute: Institute for Health and Care Research, Amsterdam, and Head of the Program on Aging, Netherlands Institute on Mental Health and Addiction, Utrecht, the Netherlands.