

Couplehood as a compass: Spousal perspectives on the diminished everyday competence of partners

Dementia

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Abstract

Research on spousal relations and caregiving, when one of the persons in the dyad has a dementia diagnosis, has recognized that the degree of diminished everyday competence (DEC) the person with dementia is experiencing has implications for these relations and for how spousal caregiving is ultimately experienced. The present exploratory study uses an inductive approach to analyze data from 22 qualitative interviews with and observation notes on couples living with dementia to shed light on the ways in which the person *without* dementia views the DEC his/her partner is experiencing. The findings show that spouses can choose to disregard their partners' DEC or to acknowledge it in either an egocentric or a couple-centered way; they also show that spouses' choice of approach does not seem to be dictated by how cognitively impaired their partners have become. This suggests that spouses' approach to partners' DEC deserves more of our attention as it could have implications not only for transitions into spousal caregiving but also for caregiving experiences as such.

Keywords

couplehood, dementia, diminished everyday competence, spousal caregiving

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Introduction

Research has shown that our psychological well-being, life satisfaction, and self-esteem are all related to how we perceive our everyday competence (Diehl, 1998; Pinquart & Sörensen, 2000). This suggests that the way in which the debilitating changes characterizing the dementia trajectory are viewed could have an effect on how spousal relations develop once a person is diagnosed with this condition (e.g., Ablitt et al., 2009; Shim et al., 2012). This is the case because maintaining a sense of personal control—which facilitates implementation of cognitive adjustment strategies that can help us handle prolonged stress—is crucial to our ability to cope with adversity (Ågren, 1992, 1998; Carlsson et al., 1991; Pitcher & Hong, 1986).

In the present article, we draw attention to everyday competence, a term seldom used by dementia scholars that refers to “a person’s ability to perform, when necessary, a broad array of activities considered essential for independent living, even though in daily life the individual may not perform these tasks on a regular basis or may only perform a subset of these activities” (Diehl, 1998, p. 422). The term encompasses a person’s physical, psychological, and social functioning, even though most research on everyday competence has concentrated almost exclusively on instrumental activities of daily living, which are mainly domains of competence that concern physical and/or functional health (cf. Willis, 1991). To this end, it is important to stress that everyday competence “refers to the ability to solve problems associated with everyday life” (Schaie et al., 2005, p. 216). Inspired by the lines of reasoning that open up when we regard diminished everyday competence (DEC) as reduced ability to solve problems and explore the subjectivity with which competence can be approached, the present article focuses specifically on the ways in which the spouses of people diagnosed with dementia view their partners’ DEC.

This line of reasoning is important because research has shown that persons living with dementia consider themselves more capable and agentic than their spousal caregivers do (Hedman et al., 2017). The present article focuses on spouses’ approach to their partners’ DEC. Note, however, that neither the persons with dementia nor their spouses need to be aware that differentiating between actual DEC and the ways in which one approaches DEC can have implications for how both parties make sense of dementia. This is why we suggest that at the very core of this differentiation lies our ability to understand that when one defines something as real, it becomes real in its consequences. We take for granted that spouses’ approaches to their partners’ DEC vary, but wonder whether the ways in which the spouses of people diagnosed with dementia construe the challenges their partners’ face, and the tasks spouses have taken on (or are bound to take on) as their partners’ dementia trajectories progress, have any bearing on these variations.

One of the reasons why we deem this angle to be worthy of exploration is that the research on spousal caregiving in relation to dementia has suggested that variations in caregiving experiences are partly determined by the degree of DEC the person with dementia is experiencing (e.g., O’Shaughnessy et al., 2010). Although we have no reason to doubt that this is the case, we suspect that variations in spousal approaches to the DEC of persons with dementia may also have some bearing not only on how they transition into the caregiving role they will most likely assume in the future but also on how their caregiving experiences are shaped. Because the experience of spousal caregiving is multifaceted, we assume that an array of aspects [e.g., the nature of the pre-dementia relationship, how spouses find meaning in their caregiving (Shim et al. 2012), and to what extent spouses’ needs for support are met (Marmstål Hammar et al., 2019)] affect this form of caregiving. Thus, our inquiry concerns one potential perspective on this multifaceted experience, that is, *spouses’ approach to their partners’ DEC*. The assumption in the literature tends to be that the degree of DEC the person with dementia is experiencing affects the spousal caregiving experience

(e.g., O'Shaughnessy et al., 2010), but what if the dementia-free spouses' approach to their partners' DEC also matters? This is the question that set in motion the analysis presented here. Thus, the aim of the present study is to shed light on the ways in which the person *without* dementia in the dyad views the DEC his/her partner is experiencing.

Method

The data on which the present article is based were collected in a larger project that aimed to explore how persons with dementia, their next of kin, and their formal caregivers make sense of and experience this condition. A total of 67 people—including 24 couples—were interviewed for the “parent project” (28 persons with dementia, 30 next of kin, and nine formal caregivers).

Sample recruitment and characteristics

The recruitment of informants for the parent project took place through staff at two memory clinics, as we had three sampling criteria for the project that we felt could best be met by enlisting their help. The criteria were the following: informants with a diagnosis of dementia, informants who also lived in ordinary housing, and informants who were at different stages of disease progression. This recruitment method allowed us to safeguard that the person with dementia who participated in the project was informed about his/her diagnosis. If the person with dementia and his/her next of kin were interested in taking part in the parent project, they received an information letter, which was followed up by a phone call (made by the first author), to ask whether they wanted to participate in the project. If they agreed, a date was set for the interview(s) and observations that constitute the project data.

In the present article, we use the interviews with—and observation notes on—22 couples as two of the interviews did not include lengthy discussions about the DEC of the person diagnosed with dementia. Table 1 summarizes the characteristics of the informants. The most common diagnosis was Alzheimer's disease. The stage of dementia disease was established by the first author, who is a nurse with long experience of working with persons with dementia, using the Functional Assessment Staging Test (FAST) (Reisberg, 1988). This test uses a scale from 1 to 7 (including the substages 6a–e and 7a–f), where higher scores denote lower functional capacity and can therefore be considered a proxy for substantial DEC.

Table 2 shows that the FAST scores of the persons with dementia varied from 2 to 7a (FAST 2 = n7, FAST 3 = n3, FAST 4 = n4, FAST 5 = n2, FAST 6a = n2, FAST 6c = n3, and FAST 7a = 1). This is important, considering what we claimed earlier with regard to the inadvertent suggestion the research on dementia often makes, that is, that the variations in DEC that couples living with dementia experience are determined by the degree of DEC the person with dementia is experiencing (e.g., O'Shaughnessy et al., 2010).

Data collection and analysis

Except for one couple, the first author visited all of our informants in their home to get a sense of how they lived and to witness firsthand how they interacted with one another in their own surroundings (see Table 1). For each of the couples, the first author took notes on the interactions observed between them and the overall impression of their relational dynamic as a couple. These notes are part of the data the present analysis relies on.

Table 1. Sample characteristics for the informants.

Informant's pseudonym			Retired (a)	Individual/joint	Formal support (person with dementia)	Interview at home
N = 22	Age ^a (years)	Type of relation	Working (b)	interview	yes/no	yes/no
Bo	75	Husband	a	Joint	No	Yes
Britt	70	Wife	a	Joint	No	Yes
Olle	65	Husband	a	Joint	No	Yes
Jacob	70	Husband	a	Joint	No	Yes
Ulla	70	Wife	a	Individual	Yes (day care and respite care)	Yes
Maria	60	Wife	b	Individual	No	Yes
Anita	60	Wife	b	Individual	No	Yes
Katarina	60	Wife	b	Individual	Yes (day care)	Yes
Bertil	80	Husband	a	Individual	No	Yes
Siv	80	Wife	a	Individual	Yes (day care)	Yes
Barbro	60	Wife	b	Individual	Yes (day care)	No
Hans	75	Husband	a	Individual	No	Yes
Margita	60	Wife	b	Joint	No	Yes
Mona	70	Wife	a	Individual	No	Yes
Nils	65	Husband	a	Individual	No	Yes
Lars	80	Husband	a	Individual	Yes (day care)	Yes
Johan	65	Husband	a	Joint	No	Yes
Sixten	70	Husband	a	Individual	Yes (day care and care home during the week)	Yes
Lisbeth	60	Wife	b	Individual	Yes (day care)	Yes
Helena	60	Wife	b (paid carer)	Joint	Yes (day care and respite care)	Yes
Margareta	80	Wife	a	Joint	No	Yes
Erik	70	Husband	a	Individual	No	Yes

^aEstimated age.

The interviews lasted between 18 minutes and two hours and were recorded and transcribed verbatim. They focused on the following themes: the dementia disease; the family and social network; the home and surroundings; a typical day; their health; and current as well as perceived future support. The interview guide was, however, semi-structured and offered sufficient flexibility to adjust to individual informants' trains of thought.

The analysis we present here did not follow any specific data analysis approach as it was inductive in nature and driven by the need to identify not only themes but also patterns in the data (see [Luborsky, 1994](#) for the difference between these two levels of analysis). The latter is, namely, what we ought to aim for when conducting exploratory inquiries intended to inform future research. Thus, qualitative analyses aiming to move beyond the mere identification of themes tend to follow an array of steps, which are inductively determined and require movement from one step to another, and back

again, until all angles of exploration worth pursuing have been systematically addressed. In the present study, we have followed the steps described below:

1. The transcribed interviews—and the notes and summaries of the interviews and home visits—were read several times to get an overall impression of what they suggested about the DEC the person with dementia was experiencing, their own approach to it, and their spouses' view of it.
2. The parts of the interviews that specifically concerned DEC were identified and moved to a separate document to facilitate the analytical movements necessary between not only different types of data but also data excerpts that could be used to illustrate patterns (i.e., the interview excerpts that are used as quotes in the present article) and that seem to inform them (i.e., the data as a whole in relation to each couple).
3. Given the previous research suggesting that degree of DEC is important, we also identified the parts of the interviews that concerned the everyday tasks the person with dementia had performed, still performed, and were assumed to be able to manage in the future. These tasks were sorted into those that were still being performed, those that were deemed to be plausible in the foreseeable future, and those that were deemed to become difficult to perform in the not-so-distant future, allowing us to juxtapose these categories with the findings from different analytical steps.
4. The observational notes on the participating couples' dynamics (e.g., how they talked to/about each other) were then juxtaposed with the results from Step 2–3.
5. Once analytical notes had been taken in relation to the above, we proceeded to explore whether couples' orientations toward the words "I" or "we" had any bearing on what was noted from Step 3–4 as previous research has suggested that these differences ought to be taken into account (see, e.g., [Kaplan et al., 1995](#)).
6. The types of everyday challenges that the person with dementia in the dyad faces (as well as the challenges they face as a couple) were then listed per dyad.
7. The results of Step 6 were sorted into three types: physical, psychological, and social everyday challenges as we wanted to explore whether these types had any bearing on the results of Steps 3–5 and the patterns we envisioned being able to discern.
8. We then explored whether or not commonalities in the informants' characteristics (or the characteristics of their partners with dementia) could be discerned in relation to the results of each of the steps described above (and because such commonalities seemed to exist, we devised [Table 2](#) to expose the patterns revealed).
9. The final step thus involved constructing [Table 2](#), which provides an example of what [Miles et al. \(2013\)](#) called data displays, the goal being to facilitate visualization of the results. The results of Steps 3 and 7 are not included in this table because they did not reveal any patterns worth mentioning.

The array of steps performed were inspired by [Silverman's \(2015\)](#) suggestion that identifying interrelated topics is crucial to shedding light on the kind of unexpected relationships between phenomena that exploratory research should focus on. One of the features of qualitative research intended to go beyond merely identifying themes (which is what research guided by "what questions" is about) is that it aims to propose how one could go about asking "why questions" (i.e., the potential explanation for the variation found). Although the data utilized in this analysis are too limited in quantity to address "why questions," we have in fact found that—at least in this material—neither degree of DEC (as the FAST scores suggest), types of tasks still being carried out by the person with dementia and/or that they foresee not being able to complete in the future (Step 3), nor the types of everyday challenges that partners' DEC poses (Step 6 and 7) can explain *how* spouses

Table 2. Patterns of spousal approaches to their partners' DEC found in data.

Informant's pseudonym	Disregard DEC	Egocentric approaches to DEC	Couple-centered approaches to DEC	Talks about caregiving tasks	Functional Assessment Staging Test score (person with dementia)
				Yes (a)—in future Yes (b)—in present No	
N = 22					
Bo	X			No	2
Britt	X			No	2
Olle	X			No	3
Jacob	X			No	3
Ulla		X		Yes (b)	4
Maria		X		Yes (a)	2
Anita		X		Yes (a)	2
Katarina		X		Yes (b)	6c
Bertil		X		Yes	4
Siv		X		Yes (a and b)	6a
Barbro		X		Yes (a and b)	6a
Hans			X	No	2
Margita			X	No	3
Mona			X	Yes (a and b)	4
Nils			X	Yes (a)	2
Lars			X	Yes (b)	5
Johan			X	Yes (a and b)	6c
Sixten			X	Yes (b)	6
Lisbeth			X	Yes (a and b)	5
Helena			X	Yes (a and b)	7a
Margareta			X	Yes (b)	4
Erik			X	Yes (a)	2

DEC: diminished everyday competence.

approach their partners' DEC (Step 1–2) or *how they orient themselves* (Step 5) when describing what this means in their everyday lives.

To guarantee the trustworthiness of the findings, we used peer-debriefing sessions in which the second author acted as a peer debriefer for the first author, who was the primary coder (cf. [Creswell, 2012](#)). In addition, we also looked for disconfirming evidence (cf. [Silverman, 2015](#)) to ensure that the findings presented here do justice to the perspectives of the people in these dyads whose approaches to DEC, tasks, and challenges we now turn our attention.

Ethical considerations

The Regional Ethical Review Board at Linköping University in Sweden approved the project (Dnr: 104-09). As already stated, the informants received written and oral information about the aim of the

project and the procedures to be employed. They were also informed that participation was voluntary and that they were entitled to withdraw from the project without stating a reason. Persons living with dementia were selected for inclusion by staff working at memory clinics. Thus, it was this clinical staff who made the initial judgment as to the person's likely ability to participate and the potential benefits and stresses that participation could entail. The team at the memory clinic was also a resource for the participants if any stress or questions about their condition were raised by the questions posed during the interviews. Considerable attention was paid to the ways in which the interviews were to be conducted, and great care was taken to put the persons with dementia at ease. This is why we offered the possibility to choose between individual and dyadic interviews and between being interviewed at home and at a location of their choice (see Table 1). Last but not least, it is important to note that the first author is a clinical expert on dementia; she ensured that the pace and length of the interviews were appropriate.

Findings

The analyses revealed three patterns in spousal approaches to their partners' DEC that seems to have bearing on how the informants viewed the challenges their partners and they themselves were facing, as well as the tasks they now perform owing to their partners' DEC.

Disregard diminished everyday competence

Table 2 shows that Bo, Britt, Olle, and Jacob seem to disregard that DEC is a given for their spouses with dementia. They also do not talk about the caregiving tasks one would assume they perform. Interesting to note here is that the FAST scores of the persons with dementia they live with were low when the interviews were conducted (ranging from 2–3), which may explain why these people seem to disregard this.

Jacob, for example, describes the debilitating changes that his wife—whose FAST score is 3—is experiencing by alluding to the fact that she is no longer able to write her name, solve crossword puzzles, remember passwords, operate the remote control, remember where things in their home ought to be stored, and take care of their grandchildren alone. Although Jacob acknowledges all of this, he gives the impression of wanting to disregard his wife's DEC during the entire interview, and he does so by downplaying the importance of these abilities and/or the effects they have on the couple's everyday life. Thus, by pointing out that she did far more household work earlier in their marriage, he indicates that it makes sense for him to step up now. By claiming that he also forgets (memory changes are something everyone experiences), and by joining her when she visits their grandchildren (which he seldom did before) because she can no longer manage the logistics of transport on her own, Jacob indicates that DEC is a given in his wife's case but not something that troubles him too much.

Olle, in turn, talks about the fact that the DEC his wife is experiencing (she has a FAST score of 3) is part of the reason why they decided to move into a more manageable place. In spite of this, when he describes how stressful the move itself was, he does not allude to his wife's dementia or the fact that she is experiencing DEC but talks instead about the fact that she is quite stubborn and how the move itself caused her a great deal of stress because of her stubbornness:

"I noted that (i.e., that she was experiencing stress during the move) but then again she is a bit melodramatic, but yeah, I mean, I saw that she was tired then /.../ but it worked quite well, I think /.../ and yes, I guess you could say that I really saw the face of Alzheimer's then since she was so tired, and pretty

much lost it....and yes, I saw that it was confusing for you (speaking to his wife), but I think you just needed to rest...she's so stubborn you know" (Olle, spouse of a person with dementia).

Here, we see one of the many ways in which the informants whose interviews we have interpreted as belonging to the "disregard DEC pattern" allude to the challenges that their partners face due to the DEC their dementia has brought about while playing down their partners' DEC and even their dementia. Thus, by alluding to other explanations for the challenges they are now facing, these informants seem to be trying to disregard the DEC their partners are experiencing, thus indicating that they are not too unnerved by such things. The fact that these people have partners with relatively low FAST scores may, of course, explain why disregarding DEC is possible in their case, but it is interesting to note that some of our informants seem extremely keen on playing down the challenges posed by their spouses' DEC.

Egocentric approaches to diminished everyday competence

Ulla, Maria, Anita, Katarina, Bertil, Siv, and Barbro are the spouses of persons with dementia in our data that acknowledge the DEC their partners are experiencing, can account for the array of challenges they now face, but tend to do so mostly based on what these challenges mean for them, rather than taking the perspective of the partner with dementia whose caregiving needs they now meet. In addition, the spouses whose interviews we have interpreted as belonging to this "egocentric DEC pattern" are people who volunteer information about everything they do for their partners and do so while referring to these caregiving tasks as a burden. Characteristic of this pattern is also that the person without dementia mostly speaks from an "I" or "me" perspective, even when referring to what "he or she (i.e., their partner)" is suffering from. Their egocentric descriptions of their situation as partners of a person with dementia—with regard to both referrals to DEC and caregiving tasks—are what differentiates them from the pattern presented in the previous section, as well as the one we will present next.

The interview with Ulla—whose husband has a FAST score of 4—is illustrative of this pattern. At the beginning of the interview, she alludes to needing to lure her husband into doing things because his dementia-based DEC means that he no longer grasps what needs to be done (in their household or in other spheres), how it ought to be done, and/or what he could do to alleviate her caregiving burden. With respect to what he is able or unable to do, she says, for example, "I can't let him....when he dries the dishes, for example, he leaves them on the counter....that's OK, I guess, but he knows where things should be placed and how." In addition, when she talks about the tasks he used to perform, before his dementia caused DEC, she is quick to point out that nowadays he can only perform these tasks with her supervision (i.e., "I'm the one who has to push for everything....now we need to do this and that /.../ If we're going to drink a glass of wine, it's mostly me who does that too...yes, everything"). The impression one gets from statements such as this—given that they are part of interviews that on the whole allude to an egocentric way of handling the challenges they face—is that, in these dyads, the person with dementia is seen as burdensome irrespective of what he/she does. If the person with dementia tries to help, he/she is blamed for not doing things properly, and abstaining from helping is perceived as unhelpful.

It is fair to wonder whether the egocentric approach to DEC alluded to here was found among people who were interviewed separately from their partners. We wondered this ourselves and therefore checked to see whether the interview type (i.e., individual vs. joint interview) had any bearing on this pattern. It seemed reasonable to assume that the constant use of "I" and "me" in these interviews could have been related to the interview type. Our analysis shows that this assumption does not necessarily hold. People belonging to the next pattern—who were also interviewed separately from their partners—did not use the "I" and "me" pronouns as often as people in the

egocentric pattern did. This is one of the reasons why we refer to this pattern as the “egocentric approach to DEC.” The fact that these spouses’ approaches to their partners’ DEC seem to be unrelated to the FAST scores of the person with dementia with whom they share their lives is interesting as well (the persons with dementia they are married to have FAST scores ranging from 2 to 6) as it suggests that dementia trajectory may not be what determines how these informants describe their situations.

Couple-centered approaches to diminished everyday competence

In complete contrast to the pattern described above, the informants who have been categorized as belonging to this final pattern (i.e., Hans, Margita, Mona, Nils, Lars, Johan, Sixten, Lisbeth, Helena, Margareta, and Erik) acknowledge their partners’ DEC, but do so in terms of not only what it means for their spouses but also what it means for them as a couple. Similar to the informants in the previous category, these people were married to persons with dementia who had FAST scores ranging from 2 to 7.

In sharp contrast to those who talk about DEC and caregiving tasks egocentrically, these interviews are characterized by informants’ use of “we” (even when the interviews were not joint ones), constantly seeking their partners’ point of view during the interviews (irrespective of the FAST scores their partners had), and constantly referring to their partners’ needs (both present and future) as a challenge that they—as a couple—must adapt to. They are, in other words, informants who seem to have thought of the DEC experienced by their partners in relation to not only what it means for their partners’ well-being but also what it entails for the well-being of their couplehood.

It is also worth noting that because they seem to differentiate between dementia (i.e., the disease) and their partners, as opposed to relating to their partners primarily as persons with dementia, these people do not talk about their partners as burdensome per se. Instead, they refer to the condition, and the challenges it entails, as the source of their burden. The debilitating changes their partners are facing, and the repercussions of these changes for their marital unit, are discussed openly by those belonging to this couple-centered pattern. These people do not constantly complain when they describe their situations, do not seem to be grieving what used to be, and do not seem to blame their partners for the fact that their everyday life has changed so drastically over the years—reactions that were so typical of those belonging to the egocentric pattern.

Many expressions provide examples of the type of reasoning that characterizes this couple-centered approach to DEC. They include “it doesn’t matter, we have plenty of time”—which Marita uses when her husband says it takes him five times longer to do the dishes these days; or “if we combine our efforts (meaning hers and her husband’s) we will manage”—as Mona says when she talks about the challenges they face these days; or “this is the sort of thing that comes with the territory” and “I’m not fazed if she asks the same question”—which Hans says while explaining that his wife’s memory is not what it used to be.

One could say that these people saw their marital unit as the starting point for everyday situations (i.e., neither themselves nor their partners seem to be their starting point but rather them as a couple). Thus, while those belonging to the couple-centered pattern tackle the challenges they face as a unit, those who belong to the egocentric pattern seem to assume that their marital unit is no longer relevant because their partners are no longer who they used to be.

Discussion

The starting point of the analysis was the realization that the literature on spousal relations in the context of dementia places great emphasis on the dementia trajectory, suggesting that the transitions

into caregiving that people married to a person with dementia experience can be explained in relation to the debilitating changes the person with dementia is experiencing (O'Shaughnessy et al., 2010). This is understandable considering the research showing that different dementia symptoms, such as irritability and apathy (Tyrrell et al., 2017), and the experiences prompted by these behaviors can augment the sense of identity loss experienced by the person with dementia. There is also evidence in the literature on family caregiving—which focuses on far more than just dementia—to indicate that DEC in the person suffering from a chronic condition that entails a need for care can prompt a sense of relational loss in the person offering that support (Feast et al., 2016). Thus, although these bodies of literature do not use the term DEC particularly often, it is concerns about the degree of DEC that seem to be at the very core of most of this research. This is why we suggested in the introduction that not enough attention had been paid to how spouses approach their partners' DEC when dementia is part of the equation, and why we implicitly argued that there is more to DEC than the actual degree of impairment.

The present findings suggest not only that the spouses of persons with dementia vary in their approach to their partners' DEC but also that this variation seems to have consequences for how they perceive their situation now that their partners' DEC is a given in their everyday lives. Our analyses suggest that *spousal views* on the tasks that their partners can no longer do, and the challenges that their DEC poses to their everyday life, have implications for *how they approach their partners' DEC*, that is, whether they do so by disregarding it or by acknowledging it in an egocentric or couple-oriented manner. These findings resonate well with research showing that different caregiving styles are influenced by social and cultural factors (Corcoran, 2011) as well as management styles (Davis et al., 2014). In a study of spouses caring for a partner with Alzheimer's or Parkinson's disease, Davis et al. (2014) showed, for example, that there are (at least) three management styles: adapters' stories [spouses who focused on solving challenges], strugglers' stories [spouses who focused on describing caregiving problems], and case managers' stories [spouses who described caregiving as "a job to be done"]. These scholars also note that among "adapters," "we" work was more common and that this we/us approach might promote a more positive view on caregiving (Daley et al., 2017). This is in line with the couple-centered approaches to DEC revealed in our analysis. Thus, although we have not studied how caregiving per se is viewed, we can clearly see in our data that spousal approach to DEC could play a role in how the transition to caregiving, and caregiving as such, is experienced, not to mention how the quality of spousal relations is assessed by those who can foresee eventually transitioning into a caregiving role.

In the scholarship on dementia, the notion of personhood is used to refer to whether persons with dementia are able to retain a sense of control over their situation, and whether people in their surroundings orient themselves toward them as a person, as opposed to orienting toward their disease (Kitwood, 1997; O'Connor et al., 2007; Perry & O'Connor, 2002). In contrast, couplehood is a term used to refer to the ways in which couples including a person with dementia orient toward their situation, that is, whether the marital unit continues to be deemed relevant despite the fact that one of them has dementia (Hellström & Torres, 2013; Gallagher & Rickenbach, 2019; Riley et al., 2016). Our analyses suggest that these notions could be used to shed light on how the spouses of persons with dementia view their situation as it is clear that some spouses orient themselves egocentrically toward their partners' DEC (and use "struggler stories"; cf. Davis et al., 2014), while others orient in a couple-centered manner.

In the present exploratory study, we have systematically analyzed whether the orientations in question seem to be dictated by the FAST scores of the persons with dementia, the types of tasks they were struggling to accomplish, the everyday challenges they now face, and/or gender and age-related characteristics (i.e., the spouses' age, their partners' age, and/or the age difference between

them). This is why we propose that spouses' *own approach to their partners' dementia-caused DEC and their orientation when describing their present situation (whether it be egocentric or couple-centered)* are part of a puzzle that deserves more attention. The exploratory analysis we have conducted also suggests—as the title of the article states—that couplehood can be used as a compass when the DEC experienced by persons with dementia is approached, and that this could be of relevance to the ways in which spousal transitions into caregiving play out, how caregiving is experienced, and whether or not providing caregiving for a person with dementia is perceived as burdensome. Thus, easing into the spousal caregiving role may not only be related to the actual dementia trajectory of the person with dementia one is married to but may also be closely related to how the person without dementia in the dyad views the DEC afflicting his/her partner.

Limitations and implications for future research

Although the cross-sectional data the present article is based on do not allow us to specifically study transitions into spousal caregiving when dementia in a partner is at stake, we suggest that spouses' approach to their partners' DEC may have implications for how spousal relationships, and caregiving in the context of dementia, are experienced. In this respect, it is important to stress that we do not claim that the dementia trajectory does not play a role in how DEC is experienced nor do we claim that it is the spouses' approach to DEC that determines whether or not they talk about their caregiving tasks. We do wish to argue, however, that our analyses suggest a number of directions for future research that deserve attention, as they place the person without dementia, as opposed to the person living with this condition, at the very center of future inquiries. Our analyses raise questions about, for example, whether approaches to DEC and orientation are mediated by the quality of spousal relations, the length of these relations, and the coping mechanisms of the person without dementia, to name but a few possible factors. Thus, although our data cannot show causality, and we do not know whether the approach to DEC leads to the approach to caregiving and whether either of these things is mediated by dementia trajectory or FAST scores, we have generated “clues” as to the kind of “why questions” that future research could pose. The fact that the egocentric and the couple-centered approach was exhibited by spouses of persons with dementia with FAST scores from as low as 2 to as high as 7 suggests that the FAST scores of the persons with dementia per se may not determine how spouses approach their partners' DEC. This also suggests that there is more to the degree of DEC than meets the eye.

The fact that most of the interviews categorized as reflecting the egocentric approach to DEC were individual interviews could be considered a limitation. However, because some individual interviews did not display this pattern, we do not believe the egocentric approach to DEC can only be found in individual interviews. In addition, as is typical of most research in this area (Macdonald et al., 2019), the spouses in the present study were drawn from a sample of white, middle-class heterosexual couples. Naturally, this is a limitation, especially considering the evidence indicating that social and cultural factors influence how caregiving is made sense of and/or experienced.

Conclusions

The present study reveals three patterns in spousal approaches to their partners' DEC that could inform further inquiries into the relationship between approaches to DEC, coping mechanisms, caregiving transitions, caregiving experience as well as the ways in which living with dementia can be approached. Although it is too early to say whether these findings should inform interventions and support services, there is evidence here that spousal approach to DEC, and not merely the degree of

DEC their partners exhibit due to dementia, plays a role in how the spouses of people living with dementia view their situation.

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