# Dyadic construction of dementia: Meta-ethnography and behaviour-process synthesis.

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## Abstract

**Objectives** Positive identity in people with dementia is maintained when there is good interaction with family caregivers. However, research on the experiences of dyadic interaction in dementia care is still limited. For this reason, we aimed to systematically review the dyadic experience of dementia caring.

**Method** Studies were identified through searching five databases: MedLine, EMBASE, PsycInfo, ASSIA, and CINAHL. Eligible studies employed qualitative or mixed method design, reported the experience of dyads of dementia with no comorbid organic or psychiatric disorders. No restrictions were made on language or year of publication, nor on sex or age of participants.The quality appraisal of studies was conducted by two researchers independently.We used meta-ethnography to synthesise data and developed a behavioural model to explain dyadic interaction.

**Results** A total of 17 studies were included in the review.The meta-ethnography generated two third-order constructs: Personal orientation and noises.When both people with dementia and their carers opt for dyadic oriented goals, their behavioural responses are likely to promote positive interaction. When only one partner opts for dyadic goals, the stress posed by the context may affect the interaction because of no perceived shared understanding of the situation.

**Conclusion** Our findings suggest that unequal power distribution within dementia dyads, can cause significant stress especially when coping strategies are impaired. Implications are found for family carers, people with dementia, and health professionals as the model we derived enhances the understanding of dyadic dynamics to care.

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**Keywords:** Dementia, family carers, self, identity, dyadic interaction.

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# Introduction

An estimated 670,000 informal carers provide care to people with dementia in the UK, the majority of whom comprises middle-aged female family members (i.e. spouses, daughter) (Dementia Research Group, 2004). Family carers are often defined as the ‘invisible patients’ and as the ‘first port of call’ (Brodaty & Donkin, 2009), owing to their crucial role for the maintenance of quality of life and decreased hospitalisation in the person with dementia. Carers’ responsibilities are plenty: They offer practical support, providing hands-on care, managing finances and general day-to-day activities; they act as care managers, arranging for other people to support the person with dementia, and they offer key emotional support (Archbold, 1981). The identity of the carers becomes threatened when the person with dementia is perceived as being particularly difficult to manage as the carers attempt to manage the emotional and behavioural difficulties of the person with dementia, yet failing to do so, they absorb the overwhelming experience of caring (Harris & Keady, 2009). In order to overcome such negative experience, Harris and Keady (2009) point at the safeguarding of the identities of both the carer and the person with dementia by virtue of the fact that the management of their identities is intimately interconnected. Such interconnection places the continuity of the self at the core of the caring process (Åberg, Sidenvall, Hepworth, O'Reilly, & Lithell, 2004).

The study of dyadic interactions may represent an opportunity for the carers to understand/challenge their own views and to position themselves with respect to the experience of dementia care. Although there is extensive literature on the experience of carers of dementia, research is still far from robust on the dyadic interaction in dementia care. We aimed to explore the experience of social interaction between people with dementia and their family carers. Specifically, our review responds to the question: What is the experience of dyadic interaction in dementia care?

As part of our analysis we developed a behavioural model, defined here as ‘behaviour-process synthesis’ to explain the behavioural process of dyadic interaction in the context of dementia care.

# Methods

This review complied with the PRISMA checklist (Moher, Liberati, Tetzlaff, & Altman, 2009). Two Initial meetings were held between the qualitative researcher (AB), one professional with expertise in old age psychiatry (MO), one expert in social care in dementia (JS), and one with expertise in neuropsychology of dementia (DMCS) to define the scope of the review and to agree on the subsequent development of the review protocol.

## Theoretical framework

We used social constructivism to interpret the qualitative findings of the studies, as we believe that the reality is shaped by cultural and social forces, and people’s values, beliefs and attitudes. As such, we understand dementia as a social construction which denotes different meanings and ways of acting towards the person with dementia. For this reason, we prioritise the familial bond and dyadic relationship as function of increased perceived quality of life and wellbeing in carers and people with dementia.

We applied two main elements of social constructivism, the concept of ‘subject position’ informed by the notion of interpellation as theorised by Althusser (1971), and the concept of inferential communication (Hutchby & Woofﬁtt, 1998; Potter, 1996).

The subjective positioning in interaction, that we define here as ‘personal orientation’, contends that interactional practices entail that individuals take up social roles, and that these roles are characterised by certain rights and duties (Harre’ & van Langenhove, 1999). Applied to the context of our review on dyadic interaction, the agents in care, the person with dementia and their carer, offer each other different subject positions (i.e. personal orientation in regard to the situation) which lead to inferences on their own identity and on that of the other agent involved in the interaction.

We drew on inferential communication to describe how dyads construct meaning through interaction. Various inferences about meaning are made available during interaction and through inferential communication their social practices (e.g. talk) become means of *‘constructing understandings, identities, relationships and even dementia itself’* (Forbat, 2003).

## Eligibility criteria

1. The study is qualitative or contains an element of qualitative analysis, with reported quotes in the analysis/result section.
2. The study reports on the experience of dyads of the dementia caring process.
3. No restriction is made on the stage of dementia caring because:
4. Participants’ experience of early diagnosis or late stage dementia are consequential and they are both essential for the understanding of the dynamics of caring.
5. Articles need to be on dementia with no comorbid diagnosis with other organic or mental health conditions.
6. No restriction based on age or sex is made.
7. No restriction on language or year of publication.

Studies were excluded when their analysis mainly reported the interpretation of the authors with no reference to the direct experience (quotes) of participants, and when they reported on the experience of people with dementia and their carers with respect to life domains different from dementia caring (e.g. interaction with primary health care providers, experience of therapeutic interventions for behavioural psychological symptoms of dementia). In addition, studies were excluded when they clearly reported on the qualitative methods for data collection but not on the method employed for the analysis of data.

## Information sources

Our search strategy was informed by the PICO format (Sackett, Richardson, Rosenburg, & Haynes, 1997) only to define the population and outcomes of the systematic review. We run our search on five databases: MedLine, EMBASE, PsycInfo, ASSIA, and CINAHL. Different domains of investigation have been defined to retrieve articles:

1. Dementia domain: dement\*, alzheimer\*.
2. Participant domain: caregiver\*, relative\*, spouse\*, dyad\*, carer\*, partner\*.
3. Relational domain: communicat\* or relation\* or interaction\*.
4. Experience domain: experienc\*, social\* constru\*.

Table 1 contains the terms used to run EMBASE.

The above terms have been adapted for the other databases. In order to include relevant grey literature and campaigning literature from charities, we also considered the first 100 hits on google scholar and cross reference the studies retrieved. We had the search strategy checked for accuracy by an independent librarian based at the University of Nottingham. Two rounds of search strategy were necessary to refine our searching method.

## Study records

In regard to the selection process of articles, we used three-levels screening (Figure 2 for study flowchart). The first level consisted in two reviewers (AB and LS) independently screening titles and abstracts of the articles retrieved through the electronic database against the inclusion/exclusion criteria, the second level, consisted in the critical appraisal of the full text of each of the studies which passed the first screening, the third screening consisted in the use of the quality appraisal checklist for a final assessment of the studies.

In regard to the second screening the two researchers assessed whether the studies met preliminary criteria around research question (i.e. do the authors clearly address the research question), methods for data collection and analysis (do the authors employed valid method pertinent with their research question), and around whether their findings were relevant to the aims and objectives of this review. Only those studies that did not meet any of the criteria did not reach the final third level of screening.

With respect to the third level of screening this was made independently by two raters (AB and LS) by employing the Spencer et al.’s framework (Spencer, Ritchie, Lewis, & Dillon, 2003) for quality assessment in qualitative research. This framework analyses the articles against four guiding principles of good practice in qualitative research: contributory to knowledge, defensibility in design, rigorousness in conduct and credibility in claim. The robustness of the findings (i.e. the quality of the studies) and their relevance will be graded as low, medium or high. The agreement of rating between the two reviewers were assessed by means of inter-rater agreement and in the presence of discrepancies between raters, these were resolved through consensus or through consultation with a third external assessor. Inter-rater agreement was measured through Kappa coefficient (Cohen’s Kappa) (Cohen, 1960) and the parameters were based on the ranges by Landis and Koch (Landis & Koch, 1977):

0.81–1.00 = almost perfect;

0.61–0.80 = substantial;

0.41–0.60 = moderate;

0.21–0.40 = fair;

0.00–0.20 = slight;

< 0.00 = poor.

We extracted the data of the studies included in the review, onto NVivo 11 (QSR International, 2012). Data were extracted for study design, qualitative methods of data collection and analysis, theoretical framework, participants’ demographics, and areas of appraisal (e.g. experience of caring, quality of relationship, style of dyadic interaction).

In case of duplicates of study findings, we selected the publication containing the most complete and updated information as the primary source of reference. The remaining papers were considered as secondary sources.

## Data Synthesis

We used meta-ethnography as proposed by Noblit & Hare (1988) and applied Schultz’s (Schütz, 1962) definition of third order constructs (i.e. our interpretation), first and second order interpretations (i.e. the first order construct representing the participants’ reported life experiences, the second order construct representing the authors’ interpretation of the first order constructs). The analytical process was iterative and required the monitoring of an external researcher (LS) for the accuracy and quality of the synthesis of the data and to reach the third order interpretations.

In brief, we undertook the following stages of analysis: First the researcher (AB) read the articles in-depth and determined how studies were related, which required an iterative process. For this purpose, the second and first order constructs were divided into text units (i.e. paragraphs) and coded by paragraphs. Then we used constant comparative method to generate theme categories from first and second order constructs. Constant comparative method is key in the process of finding concepts across studies that could explain social reality (Charmaz, 2006).

The studies included in the review were found to have a similar focus around the effects of dementia on dyadic communication, and on quality of interaction. We found through constant comparative analysis themes around participants’ behaviours, the consequences of these behaviours on the quality of interaction and the response of participants to the behaviours. The initial themes we found were: dyadic communication, mutual engagement, role sharing, shared commitment, ambivalent relationship, inability to engage in communication, sense of duty, loss of affection, increased tension in dyadic relationship, loss of mutual understanding).

The research team discussed on the accuracy of these preliminary themes and decided that a quality improvement theory based on the Betari model as a framework (Appendix A), could be effectively used to organise themes according to the cyclical patterns of behaviours, the interconnection of attitudes, beliefs and behaviours of carers and people living with dementia. The Betari box (also defined as attitude and behavioural cycle) entailed for example, that when the carers’ attitude or emotions are friendly and inclusive, this will be exhibited in their behaviour. This, will then have an impact on the attitude or emotions of the person with dementia and in turn it will impact on their behaviour and so on. By organising themes according to the interconnection of attitudes and behaviours of people with dementia and their carers during interaction, we reached our third order interpretations by translating the negative factors impacting on the dyadic interaction into ‘noises buffering the quality of interaction’, and the way they orientated themselves with respect to the situation and in reference to each other’s attitudes and behaviours into ‘personal orientation in presence of a stressor’.

We expressed the synthesis through the development of a linear model that could facilitate the understanding of the translation process. The model has been informed by the concepts of orientation and responsibility described by Afifi, Hutchinson, and Krouse (2006) (Figure 1). In brief, the model suggests that the context dictates whether in presence of a stressor, this is owned and dealt with by each single individual in the interaction or collaboratively. The inter-relational dynamics between the agents determine whether there is shared ownership and responsibility to manage the stressor (Afifi. Hutchinson, & Krouse, 2006).

# Result

Our systematic search yielded a total of 4,647 studies (11 studies were retrieved from addition sources). After screening for title and abstract, 4,508 studies were excluded and the remaining 139 were screened for eligibility against our inclusion/exclusion criteria (Figure 2 for the flow chart of the selection process). We further excluded 122 studies with reason and included in the review 17 studies.

## Studies characteristics

The 17 studies we included, were published on peer reviewed journals from 1999 to 2016 (Appendix B for single study characteristics).

Most studies were from the UK (n=6), Canada (n=4), Sweden (n=3) and the USA (n=2). Only one study was from France and one from Singapore. We found five most frequently reported themes across studies, these were: Experience of dementia caregiving (N=10), dyadic experience of dementia (N=4), carers’ strategies in dementia caregiving (N=1), conversational interaction between dyads (N=1), dyadic coping with dementia (N=1).

## Quality appraisal of included studies

All the studies were found of medium/high quality, with some reporting medium scores only for the clarity in the description of the sample and data analysis. The inter-rater agreement ranged from moderate (k= 0.48) to almost perfect (k= 0.88). We found difficult to rate studies on ethical issues as this information was not clearly stated by the authors.

## Meta-ethnography

From the meta-ethnography, two third-order constructs emerged: Personal orientation and noises. Each third-order construct has a number of associated theme categories (Table 2 for a description of third order constructs and theme categories). The expressed synthesis is illustrated in Figure 3. Our expressed synthesis is informed by a previous model on communal coping with a focus on the appraisal of the event and the actions made by each interacting agent. However, in our behaviour-process model, we highlight (i) how different care scenarios in dementia can elicit different appraisals of the situation, (ii) how these appraisals lead to various behavioural responses, (iii) the different levels of responsibility and personal orientation that each agent holds with respect to stressors posed by dementia (i.e. they either self-orient or consider the stressor as a shared responsibility, a dyad-oriented response to the event).

***Personal orientation in presence of a stressor.*** This theme refers to the ways the agents involved in the social interaction orientate themselves with respect to the situation. In other words, this theme describes the appraisal and behavioural responses of each interacting agent and whether these are individual-oriented or dyad-oriented. This theme comprises three subthemes: The first describes the way people with dementia appraise and respond to the stressful event and how this response is experienced by the carer; the second describes the carer’s appraisal and response to stressful events and how their response is experienced by the person with dementia; the third describes how the stressful experience is shared by the dyad collaboratively and dealt with through co-ownership and responsibility of their response.

*PWD appraisal and response (I think I do).* The way people with dementia experience the situation and the social interaction with their carers is highly influenced by the extent to which their primary appraisal is dyad- or individual- oriented.Establishing an open communication with the carers, enables the person with dementia to appreciate the carers’ views of the situation and to give an empathic and altruistic response that attend to the needs of both agents:

*‘I’m drawn closer because of his condition and the frequent contact with him and everything. Pain, he ask me to massage, I massage. Very close contact now, so learn to love him better.’* (Netto, Gyn, & Philip, 2009).

Considering the carer’s perspective on the situation, leads the person with dementia to compromise at times in order not to send a negative message to the carer:

*‘I have a greater autonomy margin than she thinks, but there again, I do not want to upset her, so I often give in.’* (Person with dementia) (Wawrziczny, Antoine, Ducharme, Kergoat, & Pasquier, 2016).

Another author reported how some people with dementia avoid also showing problems they have because of dementia to maintain a positive appraisal of the situation in the carer:

*‘I’m well aware that there are some things that are not working at all anymore, that I no longer react as I used to. I realize it but I avoid talking about it, I avoid showing it too much and [talking to his wife] it’s for you, I know you’re going to worry about it.’* (Person with dementia) (Wawrziczny et al., 2016).

The sense of reassuring that people with dementia experience as a result of the carers’ support, buffer the quality of appraisal of the situation and better the experience of caring: *‘She looks out for me... If I’m feeling a bit funny she’ll come and give me a cuddle ...’* (Merrick, Camic, & O’Shaughnessy, 2016).

Whereas dyad-oriented goals positively influence the dyadic interaction, an individualistic orientation focussed entirely on own needs, will lead to an individualistic behavioural response to the situation, which will in turn affect the appraisal and behavioural response of the other agent involved in the social interaction.

In the next excerpt, an author reported on a conversation between a wife with dementia and a carer in which the negative experience of dementia has led the dyad to feel a sense of disconnection. In fact, the fear and distress caused by the new identity of the partner (now the carer) creates a sense of inadequacy in the person with dementia who used to equally support each other before the diagnosis:

‘I think Jim’s more of a carer than I am.’ (Person with dementia) (Molyneaux, Butchard, Simpson, & Murray, 2011).

Despite the effort of the carer to re-orientate the goal of the appraisal from the individual to the dyad, the person with dementia holds a meaning of the new role of the husband as that of a carer, feeling this way disconnected from the very nature of their relationship. The behavioural response becomes entrenched with a feeling of detachment and a socially constructed role of recipient of care emerges from the interaction: *‘Well what about what a wife does?’* (Person with dementia) (Molyneaux et al., 2011).

The constructed role of care recipient, is triggered by the condition of dementia, and reinforced by the lack of intimacy and closeness emerging from daily interactions: *‘There’s no way I want to be gaga with somebody looking after me all the time, not by anybody.* (Person with dementia) (Clare & Shakespeare, 2004). This leads to an increased sense of inadequacy in the carer who impulsively reply in an attempt to manage the fear and anxiety posed by the situation: *‘Well, don’t worry about it.’* (Carer) (Clare & Shakespeare, 2004).

*Carers’ appraisal and response (I think I do).* Similarly to what occurs for people with dementia, carers’ appraisal of the situation and behavioural response is influenced by their orientation with respect to the interaction/event. For example, the use of scaffoldings by the carers help the person with dementia engage in a conversation with decreased risks that their memory loss could negatively impact on their social interaction and on the functioning of the relationship. This dyad-oriented strategy promotes positive communication between the agents:

*‘I’ll say things more like, “It . . . wasn’t it fun when we, when we took a trip to Colorado?” and she’ll think about it and say, “Yeah, I remember that. It was fun.” And, uh, rather than saying, “Remember when we were in Colorado, we did such-and-such?’* (Carer)(Phinney, 2006).

Maintaining conversation with the person with dementia is key in determining the quality of interaction between partners. One way to keep the flow of conversation is to stimulate engagement in the person with dementia. This is a behavioural technique that carers act out in response to the lack of participation of the person with dementia in every-day life activities:

*‘I suppose I’ve got into a routine now…. If we sit to have a meal, I’ll make sure there is conversation, or if he’s watching television I will comment on it. Even if it’s commenting on the adverts [advertisements] to see what he will say about them. For example, there’s a silly car advert . . . and I do it every time.’* (Carer) (Kindell, Sage, Wilkinson, & Keady, 2014).

In order to avoid the person with dementia feel a burden, carers make their caring tasks less explicit:

*‘We always hope to be together. That is what we say every night, ‘I can’t manage without you’, he tells me. He is incredibly thankful for whatever I do. I don’t want him to feel like a burden for me. Instead I always try to cover up [some of my caring].* (Carer) (Hellstrom, Nolan, & Lundh, 2007).

Lack of open communication and shared understanding of the situation leads the carers to greater responsibilities, disappointment and to an appraisal of the situation made in terms of individual-oriented goals (i.e. I think I do and I feel I need):

*‘I’ve got to keep, well, going through the act of making love once a week for him, because I know it will upset him if we hit that on the head [give it up] completely . . but I can’t wait for it to be over as quickly as possible, because I get no enjoyment out of it at all. And also I’m a carer, a mother, a nurse. I’m treating him like a child three quarters of the time, and then I’ve got to reverse my roles to be wife again, and a lover, and one thing and another.’* (Oyebode, Bradley, & Allen, 2013).

This negative scenario leads the way to a mechanical interaction between agents, with the carers disengaging from a genuine display of emotions:

*‘I am mentally so filled with sorrow. In practical situations I go on like a* *machine. And emotionally, I also go on like a machine. You just go on, and on, and on. My frustration increases, and my husband is victimized by it.’* (Vikstrom, Josephsson, Stigsdotter-Neely, & Nygard, 2008).

*Dyad-specific behavioural response (We think we do).* Dyad-oriented goals represent the instances in which interacting agents take co-ownership and responsibility of their actions in order to maintain a positive relationship. Communal efforts are made and the agents socially construct a unifying entity, that of the ‘dyad’ through the use of the pronoun ‘We’: *‘It is WE that is going through this. It isn’t him-me.’* (Carer) (Merrick et al., 2016). This clearly defines a shift from a ‘self-centred’ appraisal to an ‘altruistic’ appraisal of the situation. In other words, a shift from a behavioural response aiming at individual-oriented goals to a behavioural response aiming at communal/dyad-oriented goals. Also, through balancing roles, each agent acknowledges the autonomy, views, and preferences of the other. It follows that a sense of belongingness to the dyad is felt through reciprocity:

*‘I mean it works very well. She does the laundry and ironing, we clean together.* *I hoover and she dusts, so it works well, and then we go shopping together as much as we can…’* (Hellstrom et al., 2007).

***Noises buffering the quality of interaction.*** These represent the variables that negatively impact on the quality of interaction of the dyad. The variables are the dementia symptoms and the negative past experiences that are carried on in the interaction. When these are present, the ability of the agents to aim at dyad- oriented goals becomes altered. It follows that the appraisal of the situation is made according to each individual sets of goals, thus, an individualistic behavioural response is favoured.

*Dementia symptoms.* The cognitive decline of the person with dementia may prove difficult to manage for the carer and when this leads to increased burden, the carer elicits a behavioural response denoting frustration: *‘Her mind is sort of blank and it is frustrating for the caregiver ‘cause you sort of get mad.’* (Carer)(Siriopoulos, Brown, & Wright, 1999).

*Past experiences.* Negative past experiences with the person with dementiabuffer the ability of the carer to appraise and orientate the aims of the response in terms of communal goal: *‘He always puts me down and I haven’t felt like I was capable of doing anything. He still wants to be the head. He insults me. [. . .] I’ve never had any sympathy from* *him so to speak.’’* (Carer) (Shim, Barroso, & Davis, 2012).

# Discussion

This review aimed at the exploration of dyadic interaction in dementia care, between people with dementia and their carers. We were interested in how these agents construct their experience of care through conversation. What we found is that in the context of dementia care, and in presence of stressors posed by the condition, the interaction between agents is mediated by the degree to which they pursue either individual or dyad-oriented goals.

## Line of argument. The personal orientation of the agents involved in interaction during dementia care proves key in influencing their appraisal and decoding of the verbal/non-verbal messages and in determining their behavioural responses. It follows that when both agents set dyad-oriented goals, their decoding of the messages and their behavioural responses are more likely to promote an equal distribution of power. When only one partner opts for shared goals, there may still be positive outcomes, however the burden and stress posed by the context is likely to affect the dyadic interaction because of no perceived shared understanding of the situation over time.

***Dyadic construction of the event/situation.*** In line with previous findings on communal coping (Hobfoll, Schroder, & Malek, 2002; Kowal, Johnson, & Lee, 2003), our review confirmed the existence of the inter-dependant process of appraisal of an event between interacting agents of the dyad. This interpretation of coping in terms of dyadic effort, points at the role of different individuals in confronting the adverse event or situation. It follows that during interaction, the agents construct the event and the response to the event as a shared problem and having co-ownership of the experience. From this point of view, we are close to Lyon, Mickelson, Sullivan, and Coyne’s (1998) description of communal coping as involving both a shared appraisal and understanding of the situation and the *‘the pooling of resources of several individuals’* to manage the situation. Contrary to the line of argument proposed by the literature on collective coping (Hobfoll et al., 2002), in which members of a group respond to the stressor with no shared responsibility and co-ownership of the experience, our review was based on concepts of shared meaning and responsibility of the event -A collaborative effort to aim at communal oriented goals.

***Strength and limitations.*** To our knowledge our review is the first to explore dyadic interaction in dementia care through the lens of social constructivism and to develop a behaviour-process model to express the synthesis of our findings. We engaged in a systematic search with pre-defined search criteria, whose strategy was checked for accuracy by an experienced librarian, the selection of studies was undertaken by two researchers independently and the synthesis process of meta-ethnography was checked by three experts in dementia care. As our studies were all of high quality, to decrease bias in the interpretation of our third order constructs, we further checked our interpretations against those studies that we excluded with reasons (e.g. because not clearly reporting qualitative methods, comorbid with other conditions). This strategy allowed to find new themes, however, we found that these were reflected in the data that we analysed to reach third order interpretations. Limitations may reside in the concept of dyadic coping, as it implies continuous negotiations between agents, rather than a static meaning-making process of coping between agents. In concert with system theorists (Minuchin, 1974; vonBertalanffy, 1968), the behavioural response of the members of the dyad (be it a family, or social network), is mediated by their interaction with one another and by the level and quality of communication they establish. This means that our findings may not adequately reflect the fluid interactional dynamics that occur between multiple interacting agents in dementia care.

***Implications of the behaviour-process synthesis.*** The model we derived has important implication for family carers and people with dementia as it provides a conceptual illustration of how interactional dynamics are influenced by the social construction of communal coping aiming at dyad-oriented goals. Our relational model further emphasises the transactional process of coping in dementia care which is influenced by the constant exchange of messages and experiences during social interaction. However, further research is needed to explore the extent to which and how the interacting members of the dyad negotiate the strategies to cope with the stress posed by the situation, and to what extent for example, people with dementia feel the need to conform to family carers’ request.

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Table 1. Search strategy run for EMBASE (1980 to 2017 Week 05).

|  |  |  |
| --- | --- | --- |
|  | **Defining Terms** |  |
| **1** | exp dementia/ |  |
| **2** | exp alzheimer's disease/ |  |
| **3** | (dement\* or alzheimer\*).ti,ab. |  |
| **4** | exp family relation/ or exp human relation/ or exp sibling relation/ |  |
| **5** | exp social interaction/ or exp family interaction/ |  |
| **6** | exp interpersonal communication/ |  |
| **7** | exp experience/ or exp personal experience/ |  |
| **8** | experienc\*.ti,ab. |  |
| **9** | "social\* constru\*".ti,ab. |  |
| **10** | (caregiver\* or relative\* or spouse\* or dyad\* or carer\* or partner\*).ti,ab. |  |
| **11** | (communicat\* or relation\* or “social interaction\*” or “famil\* interaction\*” or “dyad\* interaction”).ti,ab. |  |
| **12** | 1 or 2 or 3 |  |
| **13** | exp caregiver support/ |  |
| **14** | exp caregiver/ |  |
| **15** | 4 or 5 or 6 or 11 |  |
| **16** | 10 or 13 or 14 |  |
| **17** | 7 or 8 or 9 |  |
| **18** | 12 and 15 and 16 and 17 |  |

Figure 1. Dimension of communal coping by Afifi, Hutchinson, and Krouse (2006).

**Orientation**

Individualistic

**Group norms**

**Practices, behaviours**

**Power**

**Shared understanding**

**Context/**

**Type of stressor**

Choosing appropriate level

of ownership and

responsibility for stressor

Communal

Figure 2. Flow chart for selection of papers.

Additional records identified through other sources (n = 30)

Records identified through database searching (n = 4,617)

Records excluded

(n = 4,508)

Records screened

(n = 4,647)

Full-text articles excluded with reasons

(n = 122)

n= 93 not clearly reporting first or second order constructs.

n= 18 comorbid with other conditions

n= 10 not reporting qualitative methods

n= 1 book

Full-text articles assessed for eligibility (n = 139)

Studies included in thematic analysis

(n =17)

Table 2. Meta-ethnography: Third order constructs.

|  |  |
| --- | --- |
| **Third order constructs** | **Theme Categories** |
| **Personal orientation in presence of a stressor** | **PWD appraisal and response** (I think I do)   1. *Dyadic oriented goals*(Hellström, Nolan, & Lundh, 2007; Netto, Jenny, & Philip, 2009; Phinney, Dahlke, &Purves, 2013; Wawrziczny,   Ducharme, Kergoat, & Pasquier, 2016; Phinney, 2006; Merrick, Camic, & O’Shaughnessy, 2016)   1. *Individual oriented goals* (Molyneaux, Butchard, & Murray, 2011; Clare & Shakespeare, 2004) |
| **Carers’ appraisal and response** (I think I do)   1. *Dyadic oriented goals*(Phynney, 2006; Wawrziczny, Ducharme, Kergoat, & Pasquier, 2016; Harris, Adams, Zubatsky, & White, 2011;   Kindell, Sage, Wilkinson, & Keady, 2014; Oyebode, Bradley, & Allen, 2013; Hellström, Nolan, & Lundh, 2007)   1. *Individual oriented goals* (Oyebode, Bradley, & Allen, 2013; Perry, 2002; Shim, Barroso, & Davis, 2011;Harris, Adams, Zubatsky, &   White, 2011; Molyneaux, Butchard, & Murray, 2011; O’Shaughnessy, Lee, & Lintern, 2010; Vikstrom,  Josephsson, Stigsdotter-Neely, & Nygard, 2008; Kindell, Sage, Wilkinson, & Keady, 2014) |
| **Dyad-specific behavioural response** (We think we do)   1. *Shared commitment* (Merrick, Camic, & O’Shaughnessy, 2016; Molyneaux, Butchard, & Murray, 2011; Clare & Shakespeare, 2004) 2. *Balancing roles* (Hellström, Nolan, & Lundh, 2007; Merrick, Camic, & O’Shaughnessy, 2016) 3. *Reciprocity* (Molyneaux, Butchard, & Murray, 2011) |
| **Noises buffering the quality of interaction** | **Dementia symptoms**   1. *Cognitive decline* (Siriopoulos, Brown, & Wright, 1999; Harris, Adams, Zubatsky, & White, 2011) 2. *Behaviour problems* (Svanstrom & Dahlberg, 2004) |
| **Past-experiences**   1. *Bad relationship carried on with dementia* (Shim, Barroso, & Davis, 2011) |

Figure 3. Expressed Synthesis: Behaviour-process synthesis of dyadic interactions in dementia care.

Noises buffering the decoding/appraisal of the messages between participants:

* The cognitive decline of dementia.
* Negative past relationship before diagnosis.

Individual-specific behavioural response

Both members of the dyad choose individual-oriented goals

Personal orientation in regard to the situation: Either ‘I think – I do’ or ‘We think – We do’

Context

Reception of the message

Both members of the dyad (or just one of them) \* choose dyadic-oriented goals

Dyad-specific behavioural response

\*When both agents opt for dyadic oriented goals, the decoding of the messages and the behavioural responses are more likely to be appropriate and to promote an equal distribution of power between partners. When only one partner opts for dyadic oriented goals, there may still be positive outcomes, however the burden and stress posed by the context is likely to affect the dyadic interaction because of no perceived shared understanding of the situation over time.

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Appendix A. Betari Box.

* + Affect
  + Affect
  + Affect
  + Affect

Person with dementia Behaviour

Carer's Attitude

Carer's Behaviour

Person with dementia Attitude

*Appendix B. Characteristics of studies (N=17).*

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Author** | **Year** | **Country** | **Study design** | **Published venue** | **Theoretical framework** | **Qualitative methods of data collection** | **Qualitative methods of data analysis** | **Themes** | **Sample demographics** |
| Clare &  Shakespeare [20] | 2004 | UK | Qualitative | Journal | 4Dialectical interactionist | Dyadic observation | Conversational analysis (voice-relational analysis) | Conversational interaction between dyads | N=10 couples (all aged 50+)  PWD= 10 (female=2)  Carers=10 (female=8) |
| Harris, Adams, Zubatsky, & White [33] | 2011 | USA | Qualitative | Journal | 2Descriptive Phenomenology | One-to-one interview with open ended questions | Descriptive phenomenological analysis (meaning unit) **\*** | Experience of dementia caregiving | N=10 carers  (Aged 50+)  (Female=6) |
| Hellström, Nolan, & Lundh [23] | 2007 | Sweden | Mix-method | Journal | 1Grounded theory | Longitudinal interviews (152) | Inductive thematic analysis | Dyadic coping with dementia | N=20 couples (aged 60+)  PWD= 20 (Female= 8)  Carers= 20 (Female= 12) |
| Kindell, Sage, Wilkinson, & Keady [22] | 2014 | UK | Qualitative case study | Journal | 1Narrative | One-to-one semi-structured interviews | Narrative Inquiry (thematic narrative analysis) | Experience of dementia caregiving | N=2 family members (wife and son of PWD) |
| Merrick, Camic, & O’Shaughnessy [18] | 2016 | UK | Qualitative | Journal | 1Phenomenology | Dyadic semi-structured interviews | Interpretive phenomenological analysis (IPA) | Dyadic experience of dementia | N= 7 couples (Aged 60+)  PWD= 7 (Female=2)  Carers =7 (Female=5) |
| Molyneaux, Butchard,  & Murray  [19] | 2011 | UK | Qualitative | Journal | 1Constructivist Grounded theory | Dyadic semi-structured interviews | Thematic analysis | Dyadic experience of dementia | N=5 couples (aged 70+)  PWD=5 (Female=2)  Carers=5 (Female=3) |
| Netto, Jenny, & Philip [16] | 2009 | Singapore | Qualitative | Journal | 1Grounded theory | One-to-one semi-structured interviews | Axial selective coding | Experience of dementia caregiving | N=12 carers  (aged 30+)  (Female= 10) |
| O’Shaughnessy, Lee, & Lintern  [34] | 2010 | UK | Qualitative | Journal | 1Phenomenology | One-to-one semi-structured interviews | Interpretive phenomenological analysis (IPA) (Thematic analysis) | Experience of dementia caregiving | N=7 carers (aged 50+)  (Female=5) |
| Oyebode, Bradley, & Allen [24] | 2013 | UK | Qualitative | Journal | 1Phenomenology | One-to-one semi-structured  in-depth interview | Interpretive phenomenological analysis (IPA) (Thematic analysis) | Experience of dementia caregiving | N=6 carers**\***  (Female=2) |
| Perry [35] | 2002 | Canada | Qualitative | Journal | 1Symbolic interactionism | One-to-one semi-structured  in-depth interview | Grounded theory  (Strauss & Corbin, 1990) | Experience of dementia caregiving | N= 20 carers  (Aged 50+)  (Female=20) |
| Phinney [21] | 2006 | Canada | Mix-method | Journal | 1Phenomenology | Multi method:  - In-depth conversational interviews  - Participant observation | Interpretive phenomenological analysis (IPA) | Carers’ Strategies in dementia | N=8 families  (7 couples + 1 mother and daughter).  PWD= 8 (aged 60+) (female=4)  Carers= 8 (aged 50+) (female=6) |
| Phinney, Dahlke, &  Purves [36] | 2013 | Canada | Qualitative | Journal | 1Phenomenology | Multi-method  In-depth Interview and participant observation | Interpretive phenomenological analysis (IPA) | Experience of dementia caregiving | N=7 (2 aged 60+)  Men (N=2)  All members of one family |
| Shim, Barroso, & Davis [27] | 2011 | USA | Mix-method | Journal | 3Content analysis**†** | Longitudinal interview | Content analysis  (Boyatzis, 1998). | Experience of dementia caregiving | N=21 carers (Aged 50+)  (Female=16) |
| Siriopoulos,  Brown, &  Wright [26] | 1999 | Canada | Qualitative | Journal | 2Descriptive Phenomenology | One to one Semi-structured interviews | Descriptive phenomenological analysis (Giorgi’s approach to meaning unit) | Experience of dementia caregiving | N=8 carers  (Aged 60+)  (all male) |
| Svanstrom & Dahlberg [37] | 2004 | Sweden | Qualitative | Journal | 2Descriptive Phenomenology | Multi methods:  Diary-Based open-ended Interviews with each of the members of the couples | Descriptive phenomenological analysis (Giorgi’s approach to meaning unit) | Experience of dementia caregiving | N=5 couples  PWD= 5  (Aged 70+) (Female=2)  Carers= 5  (Aged 70+)  (Female=3) |
| Vikstrom, Josephsson,  Stigsdotter-Neely,  & Nygard [25] | 2008 | Sweden | Mix-method | Journal | 1,4Grounded theory a | One-to-one interview | Grounded theory (Constant comparative method) (Strauss and Corbin, 1990) | Dyadic experience of dementia | N=26 couples  PWD= 26  (Aged 60+) (Female=12)  Carers= 26  (Aged 50+) (Female=14) |
| Wawrziczny, Ducharme, Kergoat, & Pasquier [17] | 2016 | France | Mix-method | Journal | 1Phenomenology | dyadic semi-structured  interviews. | Interpretive phenomenological analysis (IPA) | Dyadic Experience of dementia | N= 16 couples  PWD= 16  (Age Mean 57.3)  (Female= 9)  Carers= 16  (Age mean 57.4)  (Female= 7) |

Paradigm: 1Constructivist/Interpretive; 2Descriptive/eidetic; 3Positivism; 4Pragmatism. (Definition of paradigm adapted from Mayan, 2016).

**\***Not clearly defined by the author/s. **†**Thematic analysis/Content analysis is used as both theoretical framework and analytical method.

a Although not clearly stated in the study, we interpreted the use of grounded theory as based on both interpretivism and pragmatism paradigms as the article aimed at the understanding of knowledge and the promotion of change (Goldkuhl, 2012).