

# **Narrative inquiry on case studies of crisis in dementia.**

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## Abstract

**Purpose:** This study explored the coping styles that can be inferred from the discourse of dyads with dementia, and how these appear to impact on care management.

**Design:** This was a case study approach. Participants were recruited from two teams managing crisis in dementia in the UK. We employed multiple qualitative interviews with people with dementia and their family carers over the course of one month. The analysis was first performed through thematic analysis. Data were further analysed through narrative inquiry to create a story line, or play in our case, for our findings.

**Findings:** Five dyads were interviewed and a total of 16 interviews were conducted. Three dyads were husband-wife and two were daughter-mother relationships. The mean age was 67.4 for carers and 79.8 for people with dementia. In these cases, the carer assumed responsibility for managing the episode and was more likely to seek formal help if a pre-existing plan was in place. Otherwise, when a crisis arose, dyads preferred to avoid involving professionals.

**Originality:** This is the first study using qualitative interviews of dyads to inquire into their experience of mental health crisis.

**Practical implications:** Psychosocial interventions should aim to identify and replace unhelpful strategies used by dyads to manage crisis episodes.

**Keywords:** Dementia, mental health crisis, dyadic interviews, narrative inquiry, coping skills, help seeking behaviour.

Words: 219/250

## Introduction

Symptoms of dementia can be experienced as a crisis by the person with dementia and the carer (Pink *et al.*, 2018). Examples of behaviours associated with crisis are agitation/aggression, delusions, wandering, dysphoria, resistance to care (Backhouse, 2018). Crises can further lead to increased hospital admissions and decreased quality of life (Ledgerd *et al.*, 2016). A crisis is ‘a process where there is a stressor(s) that causes an imbalance requiring an immediate decision which leads to a desired outcome, and therefore crisis resolution. If the crisis is not resolved, the cycle continues’ (MacNeil *et al.*, 2013).

In the UK, professional support for dementia crisis is provided by a range of secondary care teams managing crisis in dementia (TMCDs). TMCDs provide multidisciplinary assessment and a range of short-term care services (telephone consultation, at home or care home visits), that are usually provided for up to 6 weeks. They may then refer the person with dementia to appropriate longer-term mental health teams or other care providers if necessary. Despite this potential to effectively manage critical episodes in people with dementia, few such teams currently exist (Streater *et al.*, 2017).

***Crisis episodes altering the equilibrium of the family.*** As the primary providers of care for people with dementia, family carers may experience a sense of burden and decreased mental health. Crises, in turn, may destabilise the support systems of the dyad (Toot *et al.*, 2013). When the demands of care made by the person with dementia do not adequately match with the resources available to the carers (personal resources such as self-efficacy or external support from friends or peers), the carers may experience a series of deleterious consequences for their wellbeing (Au *et al.*, 2010).

Fingerman and Bermann (2000) frame this in terms of disruption to the familial system; individuals expect the family system to maintain a certain tone, which is based on a series of expected behaviours. This can be seen as systemic homeostasis within the family. Research on dementia caring reveals that family members tend to favour homeostasis when facing critical changes engendered by dementia rather than challenging each respective role with respect to the situation (Vroomen *et al.*, 2013). Therefore disruption to the family system has ill effects on carers’ mental health.

***Dyadic coping with dementia.*** Bosco *et al.* (2018) described how relational processes influence the coping strategies that each member of the care dyad enacts when dealing with adverse events. For example, when the dyad is confronted with a situation (be it challenging or of everyday concerns) the members of the dyad engage in an inter-dependant process, depending on their respective role in the relationship, to appraise and manage the situation. This process of joint coping requires a certain degree of shared responsibility towards the situation (Lyons *et al.*, 1998). It follows that when both the carer and the person with dementia assume co-ownership and responsibility for managing it (dyadic coping style), there is more equal distribution of power and the event is less likely to negatively affect the person with dementia or the carer. Conversely, when only one member or neither engages in coping (individual coping style), and both the person with dementia and the carer maintain differing views on how to manage the situation, it is more likely that the stress posed by the event will have a major impact on them. Research on dyadic coping has pointed to a positive association between perceived quality of the relationship and wellbeing in the person with dementia and the carer; poor relationship quality being associated with increased carer strain and feelings of being unable to cope (Litwin *et al.*, 2014).

***Narrative studies on dementia caring.*** Narrative approaches have been used in dementia caring to explore how individuals make sense of their life and the way they negotiate their roles when managing complex situations. These approaches facilitate the structuring of individuals’ experiences according to past events and in view of future events (Clark, 2001). In participants with dementia, narrative methodology has been associated with positive experience in terms of reminiscing about

past and future events. This approach may also aid the quality of communication within dyads and their sense of identity as a couple (Scherrer *et al.*, 2014).

Despite the research cited here into familial roles and identities, little is known about how people with dementia and their carers cope with mental health crises. This project therefore aimed to explore the ways in which the family carer and the person with dementia coped with episodes of mental health crisis across time. We also set out to identify barriers that could influence the likelihood of seeking professional help from TMCD.

## **Methods**

### ***Study design***

This study employed a case study design to undertake interviews with the person with dementia and their carer at the same time (dyadic interviews) over the course of one month. We complied with the COREQ checklist for qualitative studies to comprehensively report on study methods for data collection and analysis used, context of the study, and findings (Tong *et al.*, 2007). The study was granted ethical approval from the East Midlands – Derby Research Committee (reference 18/EM/0023).

### ***Participatory research as meta-method.***

The study utilised a community-based participatory approach informed by the tenets of co-operative inquiry into health care practice (Borg *et al.*, 2012). It employed two co-researchers with lived experience of dementia in the delivery of interviews.

### ***Study participants***

The person with dementia was eligible to join the study if s/he:

- Was on a caseload of TMCD.
- Was 50 years old or above.
- Received support from an informal carer.
- Had a formal diagnosis of dementia.
- Was identified by staff as being cognitively able to participate in the interview.
- Was aware of their diagnosis of dementia and willing to talk about dementia.

The carer was eligible if s/he:

- Was a family carer of a person with dementia (either spouse or child) who met the above inclusion criteria
- Was willing to discuss dementia and their experiences of mental health crisis.

### ***Patient and Public Involvement (PPI).***

Two meetings were held with a local PPI group; one to explore the relevance of the aims and objectives, a second meeting after 8 months during the development of study material. We based this process on the National Institute for Health and Clinical Excellence (NICE) (NICE, 2014) guidelines on conducting health and social care research.

### ***Recruitment and training of co-researchers.***

The co-researchers with dementia were identified during PPI meetings and asked if they were willing to participate in the research study. They were recruited if they were 50 years old or above, had a formal diagnosis of dementia, and were cognitively able to conduct the interview in English. The carer co-researcher was a family carer of a person with a formal diagnosis of dementia. No restrictions on age or sex were applied. A total of six co-researchers were identified (two carers and four people with dementia) as eligible to participate. Four agreed to take part in the initial briefing about the study (i.e. to explain the study and the implications of acting as co-researcher) but did not continue because they

were unable to commit to it regularly. Hence, only two co-researchers received training in delivering qualitative interviews and helped to analyse data (CB helped with the organisation of themes for the thematic analysis, and one carer DC helped deliver the interviews by prompting participants with further questions around managing crisis care). DC could help deliver interviews for only one dyad as the other dyads preferred not to have more than one interviewer in the room to avoid confusion in the person with dementia. Thus, AB delivered the remaining interviews alone.

Training of co-researchers was informed by the literature (Di Lorito *et al.*, 2017) and consisted of two pre-interview and one post-interview sessions. The pre-interview sessions were held on consecutive days, lasted for two hours each, and consisted of role play scenarios of dyadic interviews. In addition, a 20-minute briefing was held on the day before the interview to discuss the process in detail. The follow up session was held post-interview and consisted of a 10-minute de-briefing around what was the purpose of the study and participants' right to withdraw to take part in follow-up interviews.

### **Data collection**

The recruitment of participants took place with the support of TMCDs. The qualitative interviews with dyads were conducted by AB and DC. As the therapeutic input of TMCD lasts up to 6 weeks, up to four interviews were conducted with each dyad. This was to ensure that each dyad was receiving support for crisis from the team at the time the interviews took place. In concert with Legard *et al.* (2003), we used an individual-oriented perspective for saturation and stopped conducting new interviews with each dyad when no new information was being generated during the interviews. We consulted the TMCD about recruiting new participants. Interviews lasted around 90 minutes for each of the four interview sessions.

Findings from a previously published systematic review (Bosco *et al.*, 2018), guided the topics for the interviews. For example, questions around dyadic coping were used during the interviews (e.g. 'how do you manage the crisis as a couple?'). We used multiple, semi-structured interviews, as they allowed us to explore how each member of the dyad negotiated their respective role and the role of teams in supporting them over time (e.g. 'compared to last time we met, has any new difficult situation or crisis arisen?', and if so 'how did you manage it?' and 'how did you both feel about that situation?').

This line of inquiry enabled a first exploration of the type of coping mechanisms used by each dyad. For example, the response was deemed a dyadic coping style when both members of the dyad showed a shared understanding of the crisis and agreed on how to manage the event. Individual coping style was characterised when there was disagreement within the dyad about what constituted a crisis and how best to manage it. Further questions looked at how dyads constructed the experience of crisis, and what led them to call for professional help. Questions also explored the process of contacting the crisis teams and the quality of care received. At the end of the series of interviews, each dyad was asked to reflect back on the resolution of the crisis, and whether they thought they would be able to manage future crises. For this task, the researcher (AB) employed a what-if strategy to explore what occurred in the dyad and what did not occur during crises (Clandinin and Connelly 2000).

### **Data analysis**

The interviews were audio-recorded, transcribed and transferred onto NVivo® 11 for categorisation (QSR International, 2012). The analysis was performed within cases (i.e. the interpretation of the transcripts for each dyad was treated as a single case) and across cases (i.e. a thematic interpretation of the transcripts was made across cases to find common themes). Thematic analysis by Braun and Clarke (2006) was used to identify, analyse and report themes or patterns across cases. We used constant comparison (Strauss & Corbin, 1990) to explore participants' responses both within and between cases. Hence, the first coding of the interview transcripts was performed by paragraph, and memos (or short comments) were recorded for each code, to clarify the relationship between the code and the relevant piece of text. Memos proved key to the analytic process, enabling more abstract

categorisation of the data. The thematic analysis lent the interview data definite structure around themes. Themes were then organised in a diagram to explore how they linked to one another to form a coherent flow for the argument around managing crisis in dementia. This flow helped create a storyline or play through narrative inquiry.

Explanatory narrative methods by Kleinman (1980) and Williams (1984) were used to describe how dementia dyads retrospectively constructed crisis events. These were recent memories of crisis occurring during the month the dyad was receiving support from TMCDs. Three features of narrative inquiry: temporality, social aspect and place, constituted the analysis of complex relational dynamics of individuals' stories.

We adopted the two-stage narrative analysis advocated by Burnell *et al.* (2009) by looking at both the content and the form of the narrative. We explored the individual and dyadic coping mechanisms identified by Bodenmann (1995).

## Results

Five dyads were interviewed over one month, a total of 16 interviews. The mean age for carers was 67.4 and for people with dementia was 79.8 (Table 1). The interviews lasted on average 46.3 minutes. All the married dyads were living together (married for more than 20 years) but in a different household from their adult children. The daughter-mother dyads lived separately but in the same neighbourhood.

*Table 1 here.*

From the analysis of power relations, we found that participants fell into two categories: a dyadic coping style (N=2) or an individual coping style (N=3). The narrative approach led us to structure findings into three 'acts': the setup, confrontation and resolution of crises (Table 2). As the crisis unfolded, narratives differed according to whether couples used dyadic or individual coping styles.

*Table 2 here.*

### *First act – Setup and antecedent of crises (Past narrative pre-crises)*

The first act concerns the life-story or 'play' of each dyad, their characteristic roles and relationships. The first act also reports how dyads typically negotiate everyday life in the absence of a crisis. The events that led to the crisis under examination represent the end of the first act.

Different stimuli acted as triggers for a mental health crisis in people with dementia. Such stimuli may be caused by the symptoms of dementia or be external to the individual. What seems to be a common factor is the disequilibrium in the person with dementia associated with such stimuli. People with dementia in three dyads reported triggers for crises that were associated with hallucinations. These were described as '*alterations of reality*' by one participant. The same person spoke of 'seeing' his wife cheating on him with other men from his past when in fact she was sleeping in the bed next to him. This couple exemplified a dyadic-focused coping style, illustrated by the wife's account of how she felt before the situation escalated to a crisis:

*'He was very threatening but in my heart I knew he was not going to do any harm. He thinks that I am cheating on him. It is just an hallucination...'* (D3S1).

When hallucinations are coupled with memory problems, the person may feel disoriented and unable to experience the environment clearly. This was the case for a woman with dementia who reported 'seeing' her husband in the room at night when in fact he had died some time ago. As her daughter explained:

258 *'My mum would call you at night if she thinks she has seen my dad next to her, she would get scared*  
259 *because he was not an easy man but she is not able to remember that my dad is now gone' (D2S1).*

260 An individual-specific coping style characterised this (mother-daughter) dyad, with the mother  
261 maintaining her firm belief that that situation, as described by the daughter, was not related to crisis:

262 *'That was not a crisis for me, and was not going to be one, you say it was, but again for me it was*  
263 *normal' (D2S1).*

264 Triggers may also come from the social environment, such as when the person feels s/he is not being  
265 acknowledged. A wife explained that the feeling of 'being ignored by her' upset her husband so much  
266 that he would cry in his chair (D1S2).

267 Constant anxiety was a feature of the situations studied. This affected even distant family members  
268 who were apprehensive about receiving phone calls concerning a crisis. Anxiety could prove  
269 overwhelming for those providing more direct care. This feeling was common to dyads with either  
270 coping style. One carer reported:

271 *'...my brother lives away, my sister panics because she does not drive and it would take ages for*  
272 *her..., so everything is on me really...' (D2S1).*

273 Although many symptoms associated with dementia were deemed difficult to manage (e.g. getting  
274 lost, continual crying), dyads reported that what constituted a crisis was not necessarily the severity of  
275 the behaviour but rather their inability to deal with the situation. As a carer pointed out, a crisis means  
276 being left with no clue about how to help the person:

277 *'...He looks very angry but I really believe I am safe, but how can I help him? I am old and tired, I*  
278 *never had to deal with this before...' (D3S1).*

279 Having described how crises come about and what features they seem to share, as well as identifying  
280 different coping styles, the analysis next developed accounts of how the crises unfold.

281 ***Second act – Confrontation - Being in crisis (Present narrative at the time of appraisal and***  
282 ***response)***

283 The second act featured the 'rising action' of the play, a narrative around the way dyads made sense  
284 of the crisis and how they attempted to cope with the difficult situation. Sometimes they failed,  
285 sometimes they learned new skills to manage the situation. Through confronting the crisis, some  
286 dyads developed a sense of awareness of the critical situation and reached a point that may be seen as  
287 transformational. This phase of development seemed to be promoted by external support, be it close  
288 friends or TMCD.

289 Appraisal. Dyads displayed either a shared appraisal or an individual appraisal of the crisis. Open  
290 communication was usually fostered for both appraisals of the event. Dyads with shared  
291 understanding of the situation tended to first acknowledge the existence of the crisis and to evaluate  
292 together whether or not they had enough resources to cope with the situation through a perspective-  
293 taking process. In one case, warning signs included clenching teeth and prolonged eye contact  
294 (D3S1), or irritability (D1S2). While these signs were not always acknowledged by the person with  
295 dementia, he knew that something was not right with his behaviour because the carer would sit next to  
296 him to calm him down:

297 *'Yes the armchair is the safe place we sit together and then I calm down...I now know when*  
298 *something is wrong because I usually sit with her on here' (D3S1).*

299 This illustrates shared appraisal and dyadic coping. Conversely, dyads with individual approaches  
300 sometimes differed in their appraisal of whether a given episode was a crisis. In one case, the memory

of the participant with dementia was not at issue, rather, that person firmly held to their own experience of the event, *'It was OK for me, full stop. No crisis'* (D2S1). This was in direct contrast to the carer's appraisal.

The 'second appraisal' of the event, the phase in which dyads evaluate whether or not they have enough resources to manage the situation, is when they are most likely to engage in help seeking behaviour. At this point, dyads evaluated their response options to the event, weighing the advantages and disadvantages. Data from the interviews suggested that the advantages were seen in terms of assistance with problems, while disadvantages consisted of having professionals involved.

Calling for help to manage crisis. Although the intensity of the crisis may lead to a more rapid call for help, dyads with either coping style seemed to decide based on when the decision needed to be made. During an episode of crisis, if the call for help needed to be made, dyads balanced the presence of 'too many problems to manage' against the consequences of making such call for help for example, having many professionals in the house, changes to routine and relationships. A carer reported:

*'If I see the crisis is so intense of course I call the ambulance...but usually...the first thing I do is to think "Okay, he is in crisis now." I definitely plan to call the team tomorrow or the day after. There is no way I call for help the same moment he is in crisis, that would make him even more confused'* (D2S2).

During an episode of crisis, if the dyads were presented with the scenario of calling for help 'right now' the members of the dyad (usually the carer) had to weigh up the undesirable consequences against the utility factor (help anticipated). The dyad or the carer were more likely to delay calling for help when episodes were more intense and unmanageable:

*'When I feel agitated, I prefer my wife to help me and not having all 'strangers' (team) here, they would get me more confused than I already am, so if she asks I tell her not to call for help'* (D3S1).

Dyads seemed to reach a threshold for help-seeking behaviour, and this was dependent upon the level of awareness that either member of the dyad (or both members) had of the crisis. It was usually the responsibility of the carer to call for help even when both members reached full awareness. As recounted by one carer, this was mainly the case when the person with dementia had decreased capacity to call for help (in case of dyad-focused coping style). Similarly, this could happen in dyads with individual-specific coping style if, for instance, the person with dementia felt that the crisis was a family matter and not something to share with strangers, yet the carer became unable to manage the situation and decided to contact the crisis team.

Level of support. When the professional support was offered or provided before an episode of crisis arose and information was shared within the couple from the time of diagnosis, dyads seemed to seek help more swiftly when needed. One couple (D1S1) commented on how *'receiving information [support] from a professional right from the beginning takes away so much responsibility'* for action and reduced the risk of disappointment because an outsider was involved. This viewpoint was shared by all dyads irrespective of their individual- or dyad-specific appraisal and responsibility.

Where the dyad's individual coping style was led by the carer, that person tended to delay the search for support because the person with dementia did not necessarily recognise or acknowledge the experience of crisis:

*'Not feeling able to make judgment about the severity of the situation, I am not sure I am the only one thinking it is a crisis'* (D2S1).

Individual appraisal style tended to delay the search of information because of a firm division of roles, typified into that of 'carer' and 'cared for' that was silently accepted and almost unconsciously enacted within the dyad:

346 *'This is a job for my wife, isn't it? I have got dementia, as she puts it, I could get it wrong with the*  
347 *information [support] I'm looking at' (D2S2).*

### 348 ***Third act – Resolution and reappraisal time (future narrative)***

349 A sort of resolution to the crisis was deliberately fostered by the research process. Dyads were asked  
350 to reflect back on their accounts of crisis to explore how their strategies to cope with the crisis  
351 changed over time. Not surprisingly, people with dementia found it relatively difficult to remember  
352 what was discussed in previous interviews and required assistance from their carers to answer the  
353 questions. Differing only according to whether they operated a joint or individual coping style, what  
354 they all said was similar: 'I/we have a problem, I/we call for help'.

355 Carers demonstrated some learning about what tactics proved effective in a crisis. A carer reflected  
356 on how a previous crisis made her aware of how to tackle future crises:

357 *'...we help her also with food, cleaning the fridge from food that is no good anymore because my*  
358 *mum has problems checking the dates and she would get agitated and calling everyone saying "I have*  
359 *been poisoned"...' (D1S1).*

360 Another carer reported that contacting the team to help with the crisis made her realise that is best not  
361 to delay the call for help:

362 *'I can manage everyday problems but not crises, I think the earlier they help the better it is...'*  
363 *straight from diagnosis' (D1S2).*

364 There were situations in which different views were held by the team and the carer about the risks and  
365 benefits of certain coping strategies. One carer judged short term coping to warrant the longer-term  
366 risks of diabetes because in her view this avoided a crisis:

367 *'They say I should not give my mum cakes for meals as they give her too much sugar, but I find*  
368 *them to sooth her agitation more than ...meds...and to be honest it is the only thing she wants to eat'*  
369 *(D2S1).*

370 In addition, there are instances when a carer felt the need to contact the team, as in the past they  
371 helped manage the crisis:

372 *'I do not understand why I cannot call the team when I need them, they just said they are for crisis,*  
373 *but who says what I am calling for is not a crisis?'* (D2S1).

374 It appears that in this case the team did not feel that the episode required professional help. It was not  
375 possible to judge the longer-term impact of this response on that carer's help-seeking behaviour.

### 376 **Discussion**

377 A crisis creates an imbalance in the person's ability to adapt to the changes of the situation and can  
378 lead to inappropriate responses by either agent within the dyad (Toot et al, 2013). This study explored  
379 how the primary carer and the person with dementia cope with mental health crises. It further  
380 identified issues that appear to influence the likelihood of seeking help from TMCD.

381 ***Dyadic coping with crises.*** In line with Shim, Barroso and Davis (2012), this study found that, when  
382 the two members of the dyad had no shared understanding of the event, and focused on individual  
383 needs rather than on the needs of the dyad as a system, then it was more likely for the carers to have  
384 negative experiences of caring. Owing to the significant demands of dementia caring, carers often  
385 face reduced mental wellbeing which in turn may affect the extent to which they are able to  
386 effectively provide care for the person with dementia (D'Aoust *et al.*, 2015). Being alone in care  
387 delivery may lead to negative feelings towards the person being cared for, reduced discussion within

dyad about planning for care, reduced opportunity for the person with dementia to engage in decision making about own care (Michon *et al.*, 2005).

In concert with findings by Wadham *et al.* (2016), a strong sense of couplehood was found in pairs who demonstrated dyadic coping based on a strong shared identity. As reported in previous research (O'Shaughnessy *et al.*, 2010), opting for a dyadic coping style was linked with a more open communication between members of the dyad about how to care manage, and could lead to actively seeking professional support in a crisis.

In our study, when a crisis was imminent (e.g. in the next few days), carers engaged in help-seeking behaviour. However, when in the midst of a crisis, they chose to postpone professional support until the crisis was even more intense and severe. As reported in the narratives of our participants, this occurred because the detractors (e.g. having strangers in the home, fear of changes in relationship) 'won' over utility (i.e. receiving help for crisis).

## Conclusions

This is the first qualitative inquiry into the experience of mental health crisis for people with dementia and their carers. We used two qualitative methods for data analysis based on thematic analysis and narrative inquiry and reliability of coding was high. A limitation is the lack of diversity in the participants who were all middle-class white British in heterosexual marriage, or in daughter-mother relationship. Also not included were other family members providing care, or paid carers. These groups might have added new knowledge and insights into coping with crises and accessing professional help.

Our findings suggest that it is timely to develop psychosocial interventions to identify and replace unhelpful coping strategies used by dyads for crisis management. In addition, family carers of people with dementia and health professionals operate in a complex care environment requiring key care decisions to be made in short periods of time, which is immediate for the carer and usually around 6 weeks for the health team. For this reason, it is advisable to provide people with dementia and their carers, as early as possible from the time of diagnosis, with information about what may constitute a crisis and most effective ways to manage such critical situations.

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