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Causes of crises and appropriate interventions: the views of people with dementia,
carers and healthcare professionals

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Abstract

The aims of this study were to identify which factors may lead to crisis for people with dementia and their carers and identify interventions these individuals believe could help in crisis. Qualitative study using focus groups to compare the perspectives of people with dementia, family carers and healthcare professionals on causes of crises and crisis interventions. To help in a crisis, people with dementia were favourable towards support from family and friends, access to mobile phones and home adaptations to reduce risks. Carers were keen on assistive technology and home adaptation. Both carers and staff valued carer training and education, care plans and well-coordinated care. Staff were the only group emphasizing more intensive interventions such as emergency home respite and extended hours services. In terms of causes of crises, people with dementia focused on risks and hazards in their home, whereas family carers emphasized carer stress and their own mental health problems. Staff, in contrast were concerned about problems with service organization and coordination leading to crises. Physical problems were less commonly identified as causes of crises but when they did occur they had a major impact. Practical interventions such as home adaptations, assistive technology, education and training for family carers, and flexible home care services were highly valued by service users and their families during times of crisis and may help prevent hospital admissions. Specialist home care was highly valued by all groups.

Declaration of interest: None.

Keywords: dementia; crisis; risks; interventions; hospitalization

Background

Crises are common in people with dementia and can lead to care home and hospital admissions (Andrieu et al., 2002; Banerjee et al., 2003). A recent systematic review on crisis intervention teams for older people with mental health problems concluded that they were likely to reduce the number of acute admissions (Toot, Devine, & Orrell, 2011).

Crises in dementia may be precipitated by a number of interacting factors that lead to a point where the individual and their carer cannot cope, or may arise from a single traumatic event. Contributing factors include carer burden, behavioural and psychological characteristics, physical health problems, social factors related to the person with dementia, or their environment (Yaffe et al. 2002; Gaugler et al. 2007; Smith et al. 2001; Spitznagel et al. 2006; Kim et al. 2002; Banerjee et al. 2003; Luppá et al. 2008; Pasquini et al. 2007; Carter & Porell 2005). This study aims to identify factors which could precipitate crises and identify interventions to help manage crises for people with dementia living at home and their carers.

Method

Design

Focus groups were selected to allow the in-depth exploration of topics including exploring people's own meaning and understanding of a health-related problem (Bowling, 1997; Wilkinson 1998).

Participants

Focus groups were conducted with the following stakeholder groups: people with dementia (3 groups); family carers (3 groups); and staff from Home Treatment Teams (HTTs) and Older People's Community Mental Health Teams (3 groups).

This ensured that the views of relevant stakeholders were included. There were between 4-8 participants in each focus group.

Clinical staff from two day hospitals and one day centre was asked to refer appropriate people with mild/moderate dementia who would be willing and able to consent to participate in our focus groups. Valid informed consent was obtained by two researchers (ST & RL). Eighteen people with mild/moderate dementia (females n=10, 56%; males n=8, 44%) living in the community were recruited into this study, characteristics of the sample are found in Table 1.

Fifteen family carers (females n=9, 60%; males n=6, 40%) who lived locally were recruited via voluntary sector organisations such as Dementia UK and local carer support groups. We included both current carers and former carers, from a range of ethnicities and age groups. In addition, the carers we approached had different types of relationships with their relatives including spouses, children, and nieces/nephews. The family carers were providing or had previously provided care for a minimum of 4 hours per week for a relative with dementia. Nineteen healthcare professionals (females n=11, 58%; males n=8, 42%) who work with people with dementia at times of crisis including Occupational Therapists, Admiral Nurses, Day Hospital Managers, Home Treatment Team Managers, Psychologists and Psychiatric Nurses were recruited into the groups. The groups had a mixed gender wherever possible.

Procedure

The focus groups lasted 60 to 90 minutes and the sessions commenced with a brief presentation about the project overall and explanation of the focus group 'ground rules'. Each focus group was presented with the following definition: 'A crisis is

defined as an urgent demand for immediate psychiatric intervention for a patient living in the community' (Ratna 1982). This definition was used as a focal point for discussion to help develop the definition for future research work in the area. The participants were asked their opinions on the definition and the feedback from the focus groups were taken to a consensus conference. The facilitator then asked the participants to focus on all types of causes of crisis involving people with dementia and their carers including psychiatric, physical health and carer-related factors as well as helpful crisis interventions and support. A framework was used to construct and develop the focus group discussions. The participants were asked to express their opinions and discuss issues through using a series of open questions. The questions included in the framework were;

- a) What sort of issues do you think could lead to a crisis situation? What about in the context of people who are having memory problems? [Prompts from the evidence base provided if necessary]
- b) What kind of support do you think would be helpful in a crisis?
- c) Do you think any of the following would be helpful in a crisis? [Interventions from the evidence base]

Analyses

Two researchers conducted the focus groups (ST/RL), one of whom acted as the moderator by facilitating the group, keeping the discussion going and encouraging all group members to participate fully. The second researcher actively listened, sought clarification and ensured accuracy of content as needed during the interview (Morgan, 1993), as well as recording field-notes during and immediately after the focus groups (Burgess 1984). Participants gave permission for the focus groups to be audio tape-recorded and these were transcribed verbatim. The data were qualitatively analysed to identify broad similarities and differences, using a data

driven inductive thematic analysis (Boyatzis 1998; Braun & Clarke 2006) and 'long table' approach to code and analyse information. The focus group transcripts were analysed independently by two researchers (ST, RL) as a method of quality control and validation. In addition, the focus group transcripts were read twice by both researchers to familiarise themselves with the data. Initial codes were generated by coding interesting features within the transcripts in a systematic and rigorous way across the entire data set, collating data relevant to each code. The codes were then collated into potential themes, gathering all data relevant to each theme. The themes were then applied to all the transcripts again to assess the applicability, and were reviewed and refined as necessary, generating a 'thematic' map of analysis. Themes were continually reviewed through the ongoing analysis and clear definitions and names were finally applied to the agreed themes. A codebook was produced which highlighted the views of the three stakeholder groups, allowing us to assess the similarities and differences between them.

Results

Tables 2 and 3 present the themes derived from this study according to category and stakeholder group for causes of crisis and interventions which could help prevent or manage a crisis. The numbers of counts illustrate the number of times the theme was discussed by participants in each stakeholder group. There were five categories relating to themes for causes of crisis: (i) carer related (ii) environmental (iii) vulnerability (iv) behavioural/ psychological (v) physical health (Table 2), and there were four categories relating to themes for interventions: (i) home environment interventions; (ii) carer interventions; (iii) professional healthcare support; (iv) social and home care support (Table 3).

Causes of Crisis

Risks and hazards in the home

People with dementia felt that risks and hazards were the key factors precipitating crises including hazards in daily living tasks in the home such as leaving the gas on or taps running, cooking and fire hazards, “I thought I had forgotten to turn the fire off and you wouldn’t see how quickly I ran to get home”.

Falls and physical hazards around the home were of serious concern to people with dementia and carers, “maybe living alone is a crisis and I end up dead...I fall everywhere! Bathroom, kitchen, sitting room”. Outdoor safety was frequently mentioned, including road safety, forgetting keys, and accidents in the garden: “Being involved in an accident....on the roads....accident in the garden...At work!”. Inability to identify potential risks was a concern for people with dementia such as opening the door at night without knowing who it was, and letting strangers or burglars into the home: “I shouldn’t have opened it (*the front door*). You know it was about 11 o’clock...Without knowing who is on the other side”. This was similarly a concern for family carers also, ‘My Dad will bring in anyone from the street . . . to our house, which is a bit of a worry’.

Family carer

People with dementia rarely mentioned that carer related factors could lead to crisis but they were aware that the absence of a family carer, could potentially lead to a crisis. Carers and staff, however, acknowledged that carer-related factors particularly the carer’s mental ill health could lead to crisis.

For carers, family carer burden due to excessive caring commitments and carer’s mental health were the key factors thought to cause crises, “I live a little way away and I’ve got four children; and that’s hard in itself. I have to look after her as well. Some days, I might be having a crisis before I have even seen her.”

Some carers reported feeling very depressed. One carer whose wife became very emotional and cried for long periods of time when her memory was rapidly deteriorating reported, "You say to yourself, I wish I was dead".

Male carers felt distressed and uncomfortable taking on intimate tasks which they were not accustomed to, such as their wife's personal hygiene, as illustrated by this discussion between two male carers, ".....the crisis I had was with incontinence and being a man, I didn't like the idea", "even with your wife this is a personal thing, especially to a woman it's very important, even to my wife, married all those years".

Person with dementia's memory and behaviour

People with dementia, carers and staff often felt that the severity of the person's memory impairment led to a crisis situation as one person with dementia stated, "saying the wrong things at the wrong time...putting your foot right in it!" One carer described how their relative's memory impairment led to significant problems, "...asking them (neighbours) to call the police to get this woman (*person with dementia's wife*) out of his house".

Behaviour problems including wandering behaviour and physical aggression were often a great cause of concern to carers. One carer described their concerns about wandering behaviour, "morning or night.....she was missing and I woke up at six and she was right down the front at the water's edge".

Community services

Poor and inadequate community services including poor continuity of care were leading causes of crisis according to staff and carers. Staff reported that a crisis could often arise as a result of physical problems not being fully investigated or

healthcare professionals not acting quickly enough or calling in support services. Staff reported that, "...a lot of the time GPs don't act quickly enough on call, or in support servicesSocial Services are quite slow to see people".

Carers reported that it was difficult to often approach community services. One carer described NHS continuing care services as, "a hospital ward with no staff. That's what it feels like! You are on your own. There is nobody there!".

Staff felt introducing new home care staff to people with dementia could be confusing and upsetting for people with dementia: One member of staff reported a recent example and added, "there was an incident today. Home care staff changed and everything was chaotic". Additionally, staff felt that unsuitably trained home care staff working with people with dementia could also result in people with dementia and their families becoming unnecessarily distressed.

Physical health factors

Physical health related factors were mentioned less often within all groups but incontinence, falls and infections were discussed at length and very often the ensuing crisis was quite intense and traumatic for both the carer and the person with dementia. Staff reported that people with dementia with poor eating/drinking patterns could find themselves in a crisis resulting in hospital admissions, ' . . . get admitted to hospital because it's weight loss because they are refusing food . . . '.

Social/environmental changes

Staff mentioned that home environment changes (e.g. adaptations) could cause confusion for people with dementia. Staff were concerned about changes in the family (e.g. relatives getting married or having children), and the family carer having limited awareness about dementia could lead to arguments between carers and people with dementia and subsequent crises.

Interventions in a Crisis

Home adaptations (including specialist assistive technology)

People with dementia felt that prompts/cues/reminders around the home, such as lists and notes could be very useful to help avoid various crisis situations. Communication equipment (people with dementia) such as having a telephone, and equipment/adaptations (people with dementia and carers) were thought to help prevent crises. People with dementia said, “You could use your phone if you had a bad fall. If you had a mobile you could take around with you” and “I have a gas fire..... so now I have had it disconnected. I've got my central heating, so I'll be warmso I'm safer!”. Family carers and staff highlighted the value of assistive technology such as gas detectors, personal safety alarm, and alerts/pagers and movement detectors. One carer said, “If you are worried about somebody getting out of bed, or getting out of a chair, like I was, they are absolutely brilliant. It actually gave me a bit more freedom as well....”.

Neighbours and friends

People with dementia primarily felt that a network of supportive friends/ neighbours in the local area and having a family carer were most useful to help prevent a crisis and during a time of crisis, “My neighbour, she watches my lights go on and off, so she knows when I go to bed when it's dark”.

Specialist home care services

People with dementia, carers and staff thought that homecare services were a very useful intervention during a time of crisis. As one carer said, “It's been a great help to me, because my wife goes to the cinema and goes out walking. The home care worker cooks, cleans and she is a real bubbly person...I know that I can go out and feel secure that she is in good hands.”. Carers also highlighted the importance of

providing homecare staff with specialist training in order to work with people with dementia and their relatives. Staff also advocated emergency access to respite in the home, “Instant home based respite. Somebody sitting in the day and somebody overnight.”

Family carer education and training

Staff and carers stressed the importance of providing family carers with education and training in dementia. Carers wanted general courses on first aid, moving and handling, and information on coping strategies to help prevent a crisis, ‘a first aid course . . . would teach me the basics what to do with a scald, what to do with a fire burn, because they are the household things I am going to be dealing with’. Staff, on the other hand, stressed the importance of a more tailored approach: ‘every client is different. Information that you give to that person, like individual care for the client or carer, you need to gear it to the right level and their understanding’.

Carers also valued having access to and attending family carer support groups to prevent crises.

Professional healthcare support

People with dementia highlighted some professional healthcare support interventions which could help them in a crisis, but their focus was around having easier access to A&E services in hospital and the emergency services. One carer described an out of hours doctors service, “I found that actually every time I rang them about myself or my wife, I got a response and they came out to see me.” Staff also stated there was a need for healthcare professionals to be available for extended hours.

Staff also suggested regular physical health checks stating that many crises were unrelated to a mental health condition whereas carers valued medication reviews. Staff felt multidisciplinary team assessments were valuable to prevent and manage a

crisis. Carers particularly valued having an Admiral Nurse “Thank God for the Admiral Nurses. They are the ones to tell you everything.”. There was a general consensus amongst staff and carers that healthcare professionals should be more reassuring and express more empathy towards people with dementia and their families.

Carers and staff thought the implementation of a care plan and having one main point of contact (known to the person with dementia and carer) were helpful interventions in a crisis, “someone you can rely on that you trust you can get hold of. I know not everybody is available 24 hours a day”. Staff said, “With people with dementia it's important to have some kind of continuity” and stressed the value of “familiarity and to know what that person needs”.

Discussion

This is the first paper to explore the views of a diverse range of stakeholders involved in crises with people with dementia. People with dementia worried about the risks and their increased vulnerability associated with their declining cognition but wanted support to allow them to remain at home safely. However, rather than expecting a lot of input from professionals, they valued informal support such as local support from family, friends and neighbours, notes and reminders, mobile phones, and aids and adaptations around the home to help manage risks related to gas, electric, cooking, and fire hazards. Family carers also had concerns about vulnerability and safety and valued home adaptations and specialist assistive technology as being especially useful to them and their relative with dementia during times of crisis. Staff also mentioned that specialist assistive technology should be more widely available for families in crisis.

Family carers had a broad understanding of the range of factors precipitating crises but their main concerns related to increased carer burden, poor carer mental health

and lack of support from other family members or other services. Carers valued education and training as being useful to help prevent, and to help them cope during times of crisis.

All three stakeholder groups felt that regular and flexible homecare services during or leading up to a crisis were very useful for both the carer and the person with dementia. It was noted however, that homecare staff needed to be adequately trained in order to work well with people who have dementia, and that poorly trained homecare staff offered little benefit, especially if the family decided to decline homecare services as a result. Staff and family carers both felt that poor and inadequate community services, including primary care and social services, were key factors leading to crises but people with dementia did not mention this. Staff and family carers felt that many services did not offer person-centred care and that there was a lack of age appropriate services for crises. They agreed that health and social care professionals should be more reassuring and empathetic and have a more understanding approach towards families, as these factors may determine whether interventions are accepted and work in practice. In addition, there was a strong view that families should have a single familiar point of contact when they are faced with crisis. Carers stressed the importance of having continuity when dealing with health and social care staff because it can very often impact on whether or not the crisis is effectively resolved. Poor knowledge and understanding of dementia amongst primary care, social services and homecare agencies, was a cause for concern. Family carers also felt that some community services were very difficult to approach and could often deter families from contacting them. In contrast to the views of health care professionals, people with dementia and carers did not consider having access to staff during extended working hours or 24 hours a day a very useful intervention. Many stated they would not contact staff in the evening or late at night, primarily because they did not feel comfortable allowing staff into their homes at these times.

Physical illnesses play a key role in many crises in older people (Magaziner et al. 2005; Carter & Porrell 2005), and though few examples were mentioned there was clear agreement that physical problems such as falls and infections lead to major crises and often hospitalisation for people with dementia, and a number of health care professionals advised that regular physical health checks might help prevent acute general hospital admissions.

Strengths and weaknesses of study

All groups found it easier to discuss causes of crisis than to identify interventions to help. The three key stakeholder groups from a range of backgrounds, settings, and disciplines allowed us to achieve theoretical validity and theoretical saturation as well as a comprehensive and rich dataset. However some professional groups were absent from our study, particularly those from outside mental health services such as GPs and Social Services. People with dementia required more frequent prompts from the group facilitator than the other stakeholder groups and despite encouragement some participants contributed little to the discussion. Hearing impairment led to some difficulties but the research team had anticipated this and ensured that there was additional staff support available when needed.

Clinical and policy implications

Crises faced by people with dementia and their families are complicated and distressing for them (Michon 2006), and the challenges in providing solutions or support for the crises are profound. Interventions need to be flexible and tailored to both the individual person's needs and their crisis situation (Parker & Bradley 2003). The findings from this study support the case for involving services users and carers in service planning. Research evidence also indicates that education and training can help to preserve family carer wellbeing and avoid crises (Vickrey 2006; Chien & Lee

2008). This suggests that specific carer training to help avoid crises should be more widespread.

Conclusion

People with dementia and family carers have much to offer in their understanding of the most important causes and the most useful interventions in times of crisis. Whereas healthcare professionals often emphasised more costly and intensive interventions (such as extended hours services and multidisciplinary interventions), people with dementia often preferred support from family and friends, notes and reminders and home adaptations to reduce risks. Specialist home care was highly valued by all groups. Health and social care professionals aiming to support people at home during crises should understand that the needs and preferences of people with dementia and carers may be different from what they might expect, and be aware of the potential value of less resource intensive interventions such as assistive technology and education. Future research is needed to understand how carers make decisions when dealing with crises and how these findings can be incorporated into providing appropriate and acceptable crisis interventions.

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Authors' Contributions

S Toot, J Hoe, R Ledgerd, K Burnell, M Devine, M Orrell contributed to the design of this study. ST wrote the paper under the supervision of JH and MO. ST and RL identified all the participants, facilitated all the focus groups, analysed the data for themes and interpreted the study results. All authors contributed substantially to the conception and design or analysis and interpretations, and to drafting the article or revising it critically for important intellectual content. All authors had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis. M Orrell is the guarantor.

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References

1. Knapp, M., Prince, M., Albanese, E. et al. *Dementia UK. The full report.* Alzheimer's Society, London; 2007
2. Goldsmith M. *Hearing the voice of people with dementia: Opportunities and obstacles.* Jessica Kingsley Publishers; 1996.
3. Banerjee S, Murray J, Foley B, Arkins L, Schneider J, Mann A. Predictors of institutionalisation in people with dementia. *J Neurol Neurosurg Psychiatry.* 2003; **74**: 1315-6.
4. Luppá M, Luck T, Brähler E, König HH, Riedel-Heller SG. Prediction of Institutionalisation in Dementia: A Systematic Review. *Dement Geriatr Cogn Disord* 2008; **26**: 65–78.
5. Department of Health. *National Service Framework for Mental Health: Modern standards and service models.* Crown copyright; 1999.
6. Department of Health. *National Service Framework for Older People.* Crown copyright; 2001.
7. Toot S, Devine M, Orrell M. The effectiveness of crisis resolution/ home treatment teams for older people with mental health problems: a systematic review and scoping exercise. *Int J Geriatr Psychiatry* 2011 Feb 23. DOI: 10.1002/gps.2686.
8. Yaffe K, Fox P, Newcomer R, Sands L, Lindquist K, Dane K et al. Patient and caregiver characteristics and nursing home placement in patients with dementia. *JAMA* 2002; **287**(16): 2090-7.
9. Gaugler J, Kane R, Newcomer R. Resilience and transitions from dementia caregiving. *J Gerontol B Psychol Sci Soc Sci* 2007; **62**(1): 38-44.
10. Smith GE, O'Brien PC, Ivnik RJ, Kokmen E, Tangalos EG. Prospective analysis of risk factors for nursing home placement of dementia patients. *Neurology* 2001; **57**: 1467-73.

11. Spitznagel MB, Tremont G, Duncan Davis J, Foster SM. Psychosocial predictors of dementia caregiver desire to institutionalise: caregiver, care recipient, and family relationship factors. *J Geriatr Psychiatry Neurol* 2006; **19**(1): 16-20.
12. Kim JM, Shin IS, Jeong SJ, Gormley N, Yoon JS. Predictors of institutionalization in patients with dementia in Korea. *Int J Geriatr Psychiatry* 2002; **17**(2): 101–6.
13. Pasquini M, Leys D, Rousseaux M, Pasquier F, Henon H. Influence of cognitive impairment on the institutionalisation rate 3 years after a stroke. *J Neurol Neurosurg Psychiatry* 2007; **78**: 56-59.
14. Carter M, Porell F. Vulnerable populations at risk of potentially avoidable hospitalizations: The case of nursing home residents with Alzheimer's disease. *Am J Alzheimers Dis Other Demen* 2005; **20**(6): 349-58.
15. Wilkinson S, Focus Groups in Health Research: Exploring the Meanings of Health and Illness. *J Health Psychol* 1998; **3**(3): 329-48.
16. Marks DF, Yardley L. *Research Methods for Clinical and Health Psychology*. Sage Publications; 2004.
17. Sofaer S. Qualitative methods: what are they and why use them? *Health Serv Res* 1999; **34**: 1101-18.
18. Bowling A. *Research methods in health, investigating health and health services*. Buckingham: Open University Press; 1997.
19. Morgan DL. *Focus Groups as Qualitative Research*. Sage Publications; 1997.
20. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32 item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; **9**: 349-57.

21. Ratna L. Crisis intervention in psychogeriatrics. *Br J Psychiatry* 1982; **141**: 296-301.
22. Burgess R. *In the Field: an introduction to field research*. Allen and Unwin: London; 1984.
23. Boyatzis RE. *Transforming qualitative information: thematic analysis and code development*. London: Sage Publications; 1998.
24. Braun V, Clarke V. Using thematic analysis in Psychology. *Qualitative Research in Psychology* 2006; **3**: 77-101.
25. Fereday J, Muir-Cochrane E. Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development. *International Journal of Qualitative Methods* 2006; **5** (1): 1-11.
26. Parker J, Bradley, G. *Transforming Social Work Practice in Assessment, Planning Intervention and Review*. Exeter: Learning Matters; 2003.
27. Vickrey BG, Mittman BS, Connor KI, Pearson ML, Della Penna RD, Ganiats TG et al. The Effect of a Disease Management Intervention on Quality and Outcomes of Dementia Care: A Randomized Controlled Trial. *Ann Intern Med* 2006; **145** (10): 713-25.
28. Chien WT, Lee YM. A Disease Management Program for Families of Persons in Hong Kong with Dementia. *Psychiatr Serv* 2008; **59**: 433-6.
29. Magaziner J, Zimmerman S, Gruber-Baldini AL, Van Doorn C, Hebel JR, German P, Burton L et al. Mortality and Adverse Health Events in Newly Admitted Nursing Home Residents with and without Dementia. *J Am Geriatr Soc* 2005; **53**(11): 1858-66.
30. Michon A. Crisis intervention in dementia. *Psychol Neuropsychiatr Vieil* 2006; **42**: 121-5..

Table 1. Demographic information on carers and people with dementia.

Carers		N (%)
Relationship to person with dementia	Spouse	9 (60%)
	Child	5 (33%)
	Friend/neighbour	1 (7%)
	Other	0 (0%)
Gender	Male	6 (40%)
	Female	9 (60%)
Current/former carer	Current	12 (80%)
	Former	3 (20%)
Age group	<65 years	6 (40%)
	>65 years	9 (60%)
People with dementia		N (%)
Gender	Male	8 (44%)
	Female	10 (56%)
Age group	<65 years	1 (6%)
	>65 years	17 (94%)

Table 2: Categories and themes for causes of crisis (number of times topic was discussed in each group)

Stakeholder Group	Carer related factors	Environmental Factors	Vulnerability Factors	Behavioural/ Psychological Factors	Physical Health Factors
People with Dementia	Family carer absent (5) Family carer death (1)	Hazards relating to daily living tasks in the home (16) Physical hazards around the home (5) Too much activity/ stimulus in the home (2) Outdoor safety (1)	Outdoor safety (6) Inability to identify potential risks (5) Changes in environment (3) Social isolation (2) Reluctance/ refusing to call for help/ assistance (2) PWD is being abused (1) Inability to manage finances/bills (1) Non adherence to medication routine (1)	Severity of memory impairment (9) Anxiety symptoms (2) Depressive symptoms (1) Poor ability to communicate effectively (1)	Falls (5)
Carers	Family carer burden (16) Family carer's mental health (14) Limited family carer awareness and understanding of dementia (6) Family carer is unable to access support services (4) Family carer absent (4) Family carer's physical health (2) Family carer is abusing PWD (2) Carer refusing help or assistance (1) Family carer is not actively involved in the care planning process (1)	Poor inadequate community services (8) Hazards relating to daily living tasks in the home (5) Physical hazards around the home (4) Lack of co-coordinated health and social support services (4) Unable to access essential amenities (2) Outdoor safety (1) Unplanned absence of care staff (1)	Inability to identify potential risks (7) Reluctance or refusing to access help (3) Refusing/ forgetting to take medication or taking too many medicines (1) Non adherence to medication routine (1) Declining support services (1)	Severity of memory impairment (8) Wandering (8) Physical aggression (5) Verbal aggressions (2) Poor inability to communicate effectively (2) Sleep disturbances (2) Hallucinations (1) Depressive symptoms (1) Repetitive speech (1)	Incontinence (4) Infections (4) Falls (3) Immobility/ difficulty in walking (3) Pain (1)
Healthcare Professionals	Family carer's mental health (9) Limited family carer awareness (5) Family carer burden (3) Family carer absence (3) Carers refusing help (1) Family carer is abusing the PWD (1) Family carer's physical health (1)	Poor/inadequate community services (17) Changes in the home environment (6) Lack of co-coordinated health and social support services (6) Unsuitably trained paid care staff (5) Changes in Family & Relationships (4) Hazards relating to daily living tasks (3) Lack of supportive neighbours/ friends in the local area (3) Unplanned absence of paid care staff (3) Lack of activities in the home for PWD (2) Different types of weather/ seasons (1) Living alone (1) Reduced driving ability (1) Physical hazards around the home (1) Unable to access essential amenities (1)	Very poor eating/ drinking (6) Declining support services (4) Reluctance or refusing to access help (3) Inability to identify potential risks (3) PWD is being abused (3) Social isolation for PWD (2) Non adherence to medication routine (2) Inability to manage finances/ bills (2) Severe neglect of personal hygiene/ personal care (1) Outdoor safety (1)	Severity of memory impairment (6) Wandering (4) Verbal aggression (3) Hallucinations (2) Sleep disturbance/ Excessive night time activity (2) Depressive symptoms (2) Paranoia/ suspicious symptoms (1) Poor ability to communicate (1) Disinhibition (1) Physical aggression (1)	Immobility/ difficulty in walking (3) Incontinence (3) Infections (3) Falls (2) Chronic diseases (2) Delirium (1) Constipation (1) Medication side effects (1)

Table 3: Categories and themes for crisis interventions (number of times topic was discussed in each group)

Stakeholder Group	Home environment	Carer related	Professional Healthcare Support	Social and Home Care Support
People with Dementia	Supportive friends/neighbours in local area (11) Communication equipment (11) Equipment/adapted furniture/rails/ramps around the home (9) Prompts/ cues/ reminders around the home (8) Presence of a family carer (8) Maintaining a routine of daily living tasks (4) Administering/ monitoring medication (1) Specialist assistive technology (1)	Family carer education (1)	Easy access to A&E Services in hospital (4) Specialist assessments by a MDT member of staff (2)	Provision of home care services (6) Access to Emergency Services (3) Flexible provision of services (1)
Carers	Specialist assistive technology (9) Equipment/ adapted furniture/ rails/ ramps around the home (7) Engaging in purposeful activities around the home (3) Communications Equipment (2) Administering medication (1) Supportive friends/ neighbours in the local area (1)	Family carer education and training (10) Involvement in family carer support groups (4) Direct payments (3) Emergency access to respite in the home (3) Accessing the internet for advice and support (1) Planning care and support services with the carer (1) Counseling for family carers (1) Advice about financial/ legal matters (1) Emergency access to respite in a residential care home (1)	One main point of contact (5) Admiral Nurse (5) Implementation of a co-coordinated care plan (5) Medication reviews (4) Access to HCPs 24 hours a day (4) Telephone helpline (2) Support/specialist training for HCPs (2) Signposting (2) Daily visits by Home Treatment Team (2) Easy access to a day hospital (1) Easier/ better access to GPs (1) Referrals being made earlier to support services (1)	Provision of home care services (9) Specialist training for home care staff (4) Provision of day care/ centre services (3) Centralised database (1) Flexible provision of services (1) Immediate/ emergency provision of care (1) Access to emergency services (1)
Healthcare Professionals (HCPs)	Specialist assistive technology (4) Equipment/ adapted furniture/ rails/ ramps around the home (1) Communication equipment (1) Engaging in purposeful activities around the home (1)	Emergency access to respite in the home (9) Family carer education and training (7) Planning care and support services with the family carer (3) Accessing internet for advice and support (1) Involvement with carer support groups (1)	HCPs available for longer hours (6) Physical health checks (5) One main point of contact (5) Implementation of a co-coordinated care plan (5) Specialist assessments by MDT Team (5) Support/ specialist training for HCPs (4) Easy access to GP (3) Daily visits by HTT (3) Signposting (3) Telephone helpline (2) Access to Admiral Nurse (2) Referrals being made earlier to support services (2) Access to specialist safeguarding adult teams (2) Involving PWD in planning of their care (1) Medication Review (1) Provision of stimulating activities to PWD (1)	Provision of home care services (4) Easy access to emergency services (1) Specialist training for home care staff (1) Provision of day care/ centre services (1) Immediate/ emergency provision of care (1) Centralised database (1)