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Conceptualizing Dementia Crisis and Preferences for Resolution: A Public Perspective

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Abstract

Background: Crisis intervention services for people with dementia in the United Kingdom are poorly defined with no standardized model of working. This may be due to the lack of a clear conceptualization of dementia crisis, resulting in variation in national service delivery. **Methods:** This study employed a novel public engagement questionnaire data collection technique with 57 participants to gain an updated perspective on the concept of health-related crisis from the point of view of the public. **Results:** Analysis revealed crisis as a transformational moment that may arrive unexpectedly but could also be the culmination of a sequence of events. Crisis resolution requires external and expert help, and associated feelings of panic and despair can engender the task of resolution by oneself insurmountable. **Conclusions:** Participants had clear expectations of crisis intervention services, with initial practical and emotional support to reduce risks, and a person-centered approach with family involvement.

Keywords

crisis, dementia, health services, public engagement

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Background

There is not currently a clear definition of what constitutes a personal crisis for older people with dementia, and this may be contributing to the absence of national guidance for services designed to assist with crisis resolution in this population. Crises in people with dementia arise for many reasons and may require a longer period of intensive support to resolve when compared to crises occurring in working age adults.[1]

Crisis theory defines crisis as a short-term period of distress caused by the perception of a particular situation that individuals can no longer manage by using their usual, or novel means of coping.[2-4] Crises can occur in any aspect of life, and may encompass physical health issues, mental health or psychiatric issues, changes in behavior, social problems, or economic issues. Crisis intervention is where a crisis is deliberately used to bring about change as a person is more open to the influence of others and is willing to make adaptive resolutions, which could help them cope with future hazardous events.[5]

Remaining independent is a key concern for many people living with dementia and their caregivers, and is associated with both an increased quality of life for people with dementia[6] and a reduction in costs for healthcare providers and informal caregivers.[7,8] Admissions to inpatient settings are associated with a further loss of independence through a decline in mobility and ability to complete activities of daily living[9,10] with significant increase in costs compared to the person with dementia who has been able to remain at home.[11] In order to increase the quality of the health care experience while simultaneously reducing costs of providing care, many local health care providers and commissioning organizations have implemented crisis intervention services to support older people,[12] and especially those with dementia.[13] These teams have often been set up as a pragmatic response to the need to prevent hospital admissions and their theoretical underpinnings of crisis and crisis intervention are not explicit.[14] In addition to the United Kingdom

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similar services are also being introduced in other nations such as Australia, the United States, Norway, and Flanders (Belgium),[14,15] and therefore research into their suitability has international connotations.

Crisis intervention services for people with dementia typically offer a short intervention of approximately 6 weeks to reduce risk and stabilize changes in behavior. This often involves providing home visits up to twice daily, assessments, practical help, medication reviews, and the arranging of longer-term support provided by other services. Although specialist crisis intervention services are mentioned in the Guidance for Commissioners of Older Peoples' Mental Health Services[1] and the 2009 Living Well with Dementia: A National Dementia Strategy,[16] there is no detail provided about how these services should be designed or implemented. Also, their purpose or theoretical approach is not specified in the way that other services, such as memory assessment services, are. This lack of guidance is a potential contributor to the large variation seen across the United Kingdom in crisis services for older people, specifically for those living with dementia.[14]

It is not currently known what the general public understands about the crisis management or what they might expect from services that provide crisis management interventions. We therefore pose the question: could an understanding of how the public conceptualize crisis, and their expectations of crisis intervention services, identify a useful approach for services that respond to the crises of older people and people with dementia? We sought to address this question by using a unique, public engagement approach to gather views of members of the public, who we encouraged to take the perspective of a person with dementia when considering crisis and the support required.

Methods

The present study was conducted during a public engagement initiative held at a university in the East Midlands, UK. A qualitative questionnaire design was used to collect data about the public perspective on the concept of crisis and how crisis intervention services could operate. Using a qualitative questionnaire allowed for the voice of the individual to still be heard while being practical to administer, less labor intensive than interviews and retaining the privacy that would not be possible in a focus group setting. Ethical approval was obtained from the School of Psychology Ethics Committee within the university.

Members of the public were invited to the event through posters, social media advertising and invitations issued by the organizers of the event. Opportunistic sampling was used as members of the public who approached the researchers for information about the project were invited to participate.

The questionnaire was developed by the research team to explore public conceptions of crisis and preferences for how crisis intervention services should operate (Figure 1). Demographic information was captured through closed questions at the start of the questionnaire, and open-ended questions were used to investigate 2 areas of interest: the definition of crisis and the expectations of services that manage crisis. No personal identifiable information was collected. The use of a questionnaire allowed for a balance between breadth and depth through the use of structured, open questions, making it possible to pose questions that revealed people's experiences, understandings, and interpretations of real or hypothetical circumstances, as well as their reactions to them. While the focus of this investigation is on crisis services for people with dementia, the questionnaire did not explicitly ask about participants' experience with dementia as we did not wish to exclude people without experience of dementia.

	Question	Response required
1	Gender	Closed categorical
2	Age group	Closed categorical
3	Postcode	Open
4	Have you had a health-related crisis?	Closed categorical
5	How would you define a crisis?	Open
6	What does crisis mean to you?	Open
7	What would you expect a team that manages crisis in people with dementia to do?	Open
8	How would you access a team like this?	Open
9	Have you accessed support from Social Services?	Open
10	How are the services provided to you by the NHS and by social services coordinated?	Open

Figure 1. Questionnaire used to elicit understandings of crisis, preferences for how a crisis intervention team should operate and coordinate with other services.

Members of the public approached the research team at a public engagement event and were asked if they wished to fill in a questionnaire about their understanding of crisis. Participants provided fully informed written consent and received a questionnaire to complete. If participants preferred, they were able to dictate their answers to a member of the research team who completed the questionnaire on the participant's behalf. On completion of the questionnaire, participants received a debrief form that provided more information about the study and further contact details for the research team. All questionnaire and consent forms were stored in accordance with the university's data protection policies.

Braun and Clarke stages	Our methodology
Familiarising yourself with your data	Data were transcribed from the initial responses in the questionnaire into a framework where each participant had a row, and each question an individual column. The two researchers (JY and MS) independently read each column of responses and noted similarities, contrasting accounts, common patterns, and insights.
Generating initial codes	JY and MS discussed these notes to develop initial codes. Interesting features, and features that helped to answer each question, were coded within each question column. Links between the question columns were then explored and JY and MS identified that the first two open questions could utilise the same coding system, and remaining open questions could utilise another coding system. Data relevant to each code were collated within the Nvivo program.
Searching for themes	JY and MS discussed the codes and collated similar codes into potential themes, again using Nvivo to manage and facilitate this process.
Reviewing themes	Themes were mapped back on to the spreadsheet containing the original dataset and checked against specific quotes to ensure that the themes fit the data.
Defining and naming themes	Themes were refined and renamed in discussion with a third researcher MR. The definitions of each theme were challenged and confirmed through this process.
Producing the report	Examples that provided the best and most representative evidence for each theme were selected to base the interpretive accounts around. Extracts that were considered 'deviant' in that they highlighted opposing or challenging views in comparison to other participants' views were detailed as such and used as contrasting perspectives.

Figure 2. Stages of thematic analysis.

Responses from the questionnaire were entered into NVivo 11 and thematically analyzed using the method proposed by Braun and Clarke[17] (Figure 2) along the 2 areas of interest: the definition and conceptualization of crisis, and the desired characteristics of crisis intervention services. Responses were transcribed from the original questionnaires into a database and read to become familiar with the data. Two researchers independently coded the data into initial codes, the codes were then collated by the 2 researchers into overarching themes. A third researcher was involved in examining codes and themes through discussion, challenging ideas, and agreement.

Responses from the first 2 open questions were analyzed to explore how people conceptualize crisis. Responses from the remaining open questions were analyzed to understand public preferences and expectations of crisis intervention services.

Results

Table 1 displays the demographic details of the 57 participants. The sample were mostly female with the majority living in urban areas. Older and younger age groups were well represented.

Table 1. Demographic Information.

Demographic	n (%)
Sex	
Female	40 (70)
Male	17 (30)
Age (in years)	
<40	20 (35)
41-50	2 (4)
51-60	1 (2)
61-70	19 (30)
71-80	10 (18)
81-90	5 (9)
>90	0 (0)
Had a health crisis	
Yes	22 (39)
No	35 (61)
Rurality	
Rural	14 (25)
Urban	41 (72)
Not specified	2 (3)

Conceptualizing Crisis

When exploring how the public conceptualized crisis, 3 themes were common across the participants and are summarized in the following 3 paragraphs. Participants described both crises that had actually occurred and hypothetical crises. Participants distinguished between crises that tested abilities to cope emotionally, for example, coping with a new identity as a caregiver and coping practically, for example, the need for external assistance to complete important tasks.

Participants described the occurrence of crisis as a moment in time that threatened the continuation of their lives as they currently know them: *an event that suddenly changes the status quo*, potentially affecting several aspects of life such as health, finances, or loved ones. For some participants, crisis was conceptualized as a potentially fatal situation, but typically crisis was understood as a disruption to daily life, where normality was held in *suspension* until the crisis could be resolved. Contrasting views suggest that there are potentially 2 crisis trajectories, one where a crisis is sudden, and *often a catalyst or unexpected*, with no identifiable precursors. Or, a crisis may take the path of a culmination of smaller issues that have built up over time and created a tipping point, or *pinnacle*, where an individual can no longer manage. Although most participants felt that once in a crisis it would be difficult, if not impossible, to see beyond the crisis, some acknowledged that crisis may represent a catalyst for change.

Crisis situations were thought to be associated with feeling *out of control* over the management of everyday situations. Help from other people was thought to be necessary to resolve a crisis, some defined it as a situation you *can't sort out yourself*. While the need for assistance from external sources was keenly recognized by participants, they reported that they felt alone and that help was unavailable or difficult to arrange. The type of help required to resolve the crisis was described as expert help, *supported by the right and recognised body/system*, and this is linked to the sense that the inability to cope alone may be driven by a lack of previous experience of that particular situation.

The emotional impact of crisis situations was evident, with many highlighting that a crisis would lead to feelings of, *fear, confusion, anxiety, worry*, and *distress*. The word *panic* was most frequently used by participants, which draws together the ideas of suddenness, and feelings of being overwhelmed, where the crisis *takes one's absolute attention*. Participants spoke of feeling *despair* in a crisis situation, but this emotion manifested itself in different ways, either as a reaction to the actual situation, or as a sense of hopelessness due to not knowing how to get help.

Expectations of Crisis Intervention Services for People With Dementia

Participants expressed several preferences and expectations of a crisis intervention service for people with dementia. Participants did not reveal many specific actions that they wanted crisis intervention services to perform, but focused on the approach of the service.

At the basic level, participants felt that a crisis intervention service should provide practical support to assist the person in crisis *to function on a day to day basis* and *enable life to carry on as near normal as possible*. It was important to participants that the service should have a clear, logical plan, or *route map* to resolve the crisis, which might involve support such as providing help around the house or making changes to the patient's environment. Participants also felt that the service should provide emotional support such as *empathy, comfort, reassurance*, and *kindness* to the person in crisis, acknowledging distress honestly, and *not to make the person contacting them feel guilty* for using the crisis intervention service. The third basic expected function was to ensure that the person in crisis is protected against physical harm, while promoting a culture of emotional safety through a calm, professional approach. These features of the service were felt to underpin more complex functions, and represented the basic foundation of the approach that the service should have.

Beyond being able to make the person in crisis feel safe and supported, participants felt that a crisis intervention service should be staffed by experts. The specialisms of these experts were not specified, but it was agreed that practitioners should possess the appropriate qualifications and experience to assess the crisis and to put in place a plan for resolution. Participants generally reported that the service should be accessible 24 hours per day, 7 days a week, with a clear contact procedure and immediate response. Participants expected coordination within the service where practitioners from different professional disciplines are aligned toward the same care objectives, *so they are all working together with the same goal*, and coordination *with family and other services to ensure . . . the transition to the next steps is smooth and well-informed for all parties*.

Lastly, participants felt that a person-centered ethos should be key to the service. Care should be individualized to the person in crisis and their families, founded on *the person's concerns and needs*. Decisions should be made in accordance with the person in crisis and their caregivers' wishes to create a collaborative ethos. Family involvement, where family members are both informed of decisions and involved in decision making, to *balance the wishes of the patient with those of relatives*, represented an overarching principle of service functioning.

Thirty participants felt that access to the service should be through the National Health Service (NHS) and several responses indicated a referral should be made to the crisis intervention service via the general practitioner (GP). Seven participants suggested social care and 4 participants suggested charitable organizations as potential conduits to receiving crisis care. Twenty participants felt that the telephone was the most appropriate means of accessing a crisis intervention service, and 7 of these expressed a preference for the use of emergency and urgent numbers. Seven participants acknowledged that services should have an internet presence.

Fifteen participants indicated that they had experience of accessing social services, either for themselves or on behalf of someone else. Thirty participants, including those who had accessed social services, were unsure of how NHS and social services coordinated with each other. Participants without experience of using social services expected that the two would coordinate care through referrals received by letter or telephone from the GP, and that specific procedures existed or that the coordination role was undertaken by a specific person employed in one or other service. Some participants felt that social services formed part of the NHS and were unclear who social services were. Many participants responded that they did not know how the two were coordinated. Participants who had experience of social services were generally negative regarding their coordination with NHS services and felt that communication could be better with relatives kept more informed of arrangements.

Discussion

This study aimed to understand how the public conceptualize crisis, and their expectations of crisis intervention services for people with dementia, through gathering the views of members of the public at a public engagement event. The participants' responses showed a marked similarity with the features of crisis listed in the crisis theory literature.[18] Participants were in general agreement that crisis represents a time when ordinary life is suspended, and to get it back on track expert intervention is required. While participants did not specify which experts were favored, our findings clearly show that a multidisciplinary and biopsychosocial approach is advisable. A recent survey of crisis services managing dementia in older people shows similarities to the responses our participants gave,[13] in that crisis intervention services are multidisciplinary and provided support for behavioral and psychological issues.

There were, however, some areas where the participant's expectations differed from the services currently provided. Some participants expected crisis intervention services to be available 24 hours per day. Currently, the majority of services operate with extended opening hours, for example 07:00 to 22:00 hours,[13] based on research suggesting that a 24-hour service is not necessary or viable.[19] Another area where expectations differ from what is currently provided is the interventions carried out by the crisis service. Participants in our study felt that practical help should be provided by the crisis intervention team with the intervention most often suggested being changes to the home environment. Crisis intervention services who responded to the survey of crisis services[13] ranked addressing environmental needs as one of their lowest used interventions. The differences between expectations and what services actually provide may result in decreased satisfaction with the service if expectations are not set at the beginning of team input.

The participant's suggestion of crisis as an opportunity for growth or positive change shows remarkable similarities to the traditional concept of crisis intervention,[5] however, the pragmatic beginnings of the crisis intervention teams, their lack of theoretical underpinning and current pressures place teams at risk of mistaking emergency management for true crisis intervention. Crisis intervention does not simply seek to avoid hospital admission but would have the goals of deliberate intervention, regaining control, autonomy and creating coping strategies that mitigate against future crises.

This study also showed ways in which the public are uninformed of NHS and social care processes. Many participants were unaware that the NHS and social services are separate organizations that need to coordinate to provide seamless care, and those who were aware typically had poor experiences of the transition between the 2 agencies. Many participants in our study were also unaware of how to get in contact with a crisis service should a crisis occur. This is supported by results from the survey of crisis services which showed that, although most services would accept referrals from a variety of sources, including directly from people in crisis or their relatives, in actuality most referrals come from the GP, suggesting other referral routes are not frequently used.[13]

We acknowledge some methodological considerations with the current study, notably, that some participants had not experienced a crisis and therefore their perspectives may not reflect the true essence of this experience. This was also evident in the way in which some participants struggled to provide detailed answers regarding the coordination between crisis intervention services and social services. While a more targeted approach of recruiting participants who were currently in receipt of both health and social care may have yielded fuller results, the lack of response was an important finding in itself. Nonetheless, themes developed were common across participants regardless of whether they had experienced a crisis or not and the volume and level of detail that participants provided allowed for a thorough and detailed thematic analysis.

This study adds to the literature by being the first of its kind to investigate perceptions of health-related crisis and health services organization preferences at a public engagement event. This approach was innovative, because it led to a more representative sample than if the study had recruited only from people currently in receipt of health and social care services, and removed an element of selection bias inherent in online or postal questionnaire techniques. While the findings may not appear surprising when contextualized with previous literature, this is the first study that clearly states these ideas and preferences from the perspective of the public in a way that captures both breadth and depth of experience.

The findings from our current study, combined with that of prior research, lead us to suggest a number of recommendations for the planning of dementia crisis services. First, crisis intervention services should set expectations at the beginning of their care so that any misconceptions about what a crisis team can offer are rectified and patients are less likely to be dissatisfied with services. Second, the pragmatic beginnings of dementia crisis services should not prevent them from grounding their aims and practice in crisis intervention theory. Service planners should ensure that teams are given the resources and capacity to not only prevent admission to hospital but to engage in adaptive behavior change with patients and to set in place crisis prevention measures. Third, crisis intervention services should be aware that many service users lack insight into the context of the team within the NHS, and how to navigate through services as their crisis either resolves or requires further intervention. Services could assist patients by explaining clearly their role in the process and provide timely advice before the patient is referred to a different team or agency. When designing services for crisis care, service planners should ensure that pathways of care spanning organizational boundaries are simplified and effective, and that staff making referrals have the time and resources to be knowledgeable and coordinated.[20] Fourth, crisis intervention services should be accessible, and the route to referral made clear. Given that crisis is considered a sudden and unexpected event, people in crisis are unlikely to be prepared with contact details. An internet presence for crisis intervention services that explains how someone can access them, and knowledge of the services in GP surgeries, could enable people to seek the help they need.

Future directions for research in this topic area are to explore how this conceptualization of crisis can be developed further into a theoretical framework for crisis working in health, and implemented within the design of crisis services for people with dementia using coproduction and public engagement techniques.

Conclusion

Crisis typically represents a sudden and unexpected event that suspends everyday life, but can be resolved with intervention by accessible, expert services who provide practical and emotional support, coordinate between themselves and other services, and provide a person-centered approach that involves family members. Crisis intervention services for older people and specifically for those living with dementia currently exist, but previous research suggests a picture of variation and a lack of theoretical underpinnings and specification. The findings from this study allow for recommendations for practice such as setting expectations, a grounding in theory, and an awareness of patients' lack of insight into NHS processes, which may help establish an agreed model of working.

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