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Title

Crisis management for a person with dementia living at home: mixed-methods case study research to investigate critical factors for successful home treatment

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Title

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Abstract

Best practice in dementia care is support in the home. Yet, crisis is common and can often result in hospital admission with adverse consequences. The objective of this mixed-methods case study research was to identify critical factors for resolving crisis for a person with dementia living at home.

The research was an in depth investigation of what happens during crisis for people with dementia and how it is managed by a Home Treatment Crisis Team to resolution and outcome at six weeks and six months. The methods were; observation of crisis management for 15 patients with dementia (max 3 observations per patient, total 41), interviews with patients with dementia (n=5), carers (n=13), and professionals (n= 14, range 1 to 6 interviews per person, total 29), focus group (nine professionals), and extraction of demographics and medical history from medical records. Analysis focused on the identification of factors important for crisis resolution and avoidance of hospital admission.

Critical factors for the Home Treatment Crisis Team to enable successful crisis resolution were: immediate action to reduce risk of harm, expertise in dementia care and carer education, communication skills to establish trust and promote benefits of home treatment, shared decision making, medication management, addressing the needs of carers independently of the person with dementia and, local availability of respite and other community services.

The Home Treatment Crisis Team integrated the seven factors to deploy a biopsychosocial systems approach with embedded respect for personhood. This approach enabled crisis resolution for a person with dementia by creating a system of services, treatments, resources and relationships, 'Safe Dementia Space,' in the community with avoidance of hospital admission in more than 80% of referrals.

The identified critical factors for crisis resolution are important considerations in the design and delivery of home treatment services for people with dementia.

Key words

Dementia care, Community care, Crisis resolution, Multidisciplinary working, Research, Case study

What is known about this topic

- Crisis is common for people with dementia living at home and often results in hospital admission
- Hospital admission can have adverse consequences for a person with dementia
- Factors that are critical to a home treatment crisis service for successful crisis resolution are unknown.

What this paper adds

- The identification of seven critical success factors that affect a home treatment crisis service's ability to facilitate crisis resolution for people with dementia living at home
- A model of the process of crisis resolution for people with dementia living in the community
- Evidence that at biopsychosocial systems approach to home treatment of crisis for people with dementia can enable successful crisis resolution

Background

Dementia is a public health priority, as globally 50 million people have a dementia diagnosis (WHO, 2017). Worldwide, there is commitment to develop community services to enable people with dementia to live well at home (WHO, 2018).

In the UK, everyone over age 65 years lives at home or in a care home (Social Care Institute of Excellence, 2020). Best practice guidance is to support people with dementia at home, whenever possible, because this is their preference and because institutional care can have adverse outcomes (NICE, 2018). However, crisis is a common problem and reason for hospital admission (Backhouse, 2018; Streater, Coleston-Shields, Yates, Stanyon, & Orrell, 2017). Crisis occurs when a person with dementia or others are at risk of harm, for example, when the person goes missing (Bowen et al. 2011) or their carer becomes unwell and unable to continue in the carer role (Sadak et al. 2017).

Home treatment of crisis can reduce hospital admission rates for people with dementia (Toot, Devine, & Orrell, 2011) but, crisis service provision is variable, with different hours of service provision and service models, and no provision in some geographical locations (Lloyd-Evans et al., 2018; Streater et al., 2017). There is limited empirically based knowledge of the process and management of crisis in the home (Hopkinson et al. 2020).

This research sought to identify characteristics of service delivery that are so frequently necessary for crisis resolution and avoidance of hospital admission for people with dementia, that they can be considered to be critical factors for the successful deployment of a Home Treatment Crisis Team.

Question

What factors are critical to a Home Treatment Crisis Team's ability to facilitate crisis resolution for people with dementia living at home?

Methods

The research was a mixed-methods case study design (Johnson, Onwuegbuzie, & Turner, 2007) for in-depth investigation of what happens leading up to a crisis for a person with dementia and its management to resolution. Case studies capture information about the how and why of a complex situation (Yin, 2009). Crisis was assumed to be complex and case study a way of tracing events, decisions and changes across time whilst minimising burden on study participants.

The case was a Home Treatment Crisis Team established in 2011 and offering a service to older people with mental health issues including people with dementia of any age. It comprised an old age psychiatrist, a speciality doctor, eight community psychiatric nurses, six healthcare assistants, a carer support worker and a psychologist. The team served a population of 1.5 million people, of whom 3,000 were known to have a diagnosis of dementia, across urban and rural communities, Wales, UK.

The case study had nested patient cases. A recruitment target of 15 was estimated to be feasible, based on historical data on referrals to the service over a 12 month period and recruitment rates into other studies about sensitive topics led by the team. Participants with dementia were a purposive sample of new referrals to the Home Treatment Crisis Team admitted as patients to the service and selected to be as diverse a group of people with dementia as possible. Those eligible to take part were:

- Diagnosed with dementia and identified on referral to be in crisis.
- Adult (18 years or older).
- Living in the community i.e. private dwelling or nursing/care home.
- With or without capacity to consent.
- Willing to participate.

Data sources were:

- Observation of crisis management during initial assessment at home and up to two subsequent crisis-related clinical consultations per patient.

- Interviews with patients at home post dementia crisis (one per patient) with a carer present at the patient request or, if advised, by a Consultee.

- Interviews with carers post dementia crisis (one per carer).

- Interviews with clinicians during the period of dementia crisis management (1-5 per patient) to explore decision-making and to identify factors considered important for crisis resolution.

- Home Treatment Crisis Team focus group to explore contextual issues important to the management of crisis

- Demographics and medical history extracted from clinical records of observed patients and outcomes six weeks and 6 months after study recruitment.

Interviews and focus group topic guides were devised drawing on existing literature and reviewed by the research Advisory Group and people affected by dementia prior to data collection. Interviews were semi-structured, audio-recorded and transcribed verbatim. Field notes were taken during observations, including verbatim statements, and were entered into a coding frame on the same or following day.

Standard practice was for a senior clinician to screen referrals to the Home Treatment Crisis Team using the following criteria:

'A dementia crisis is when a person with dementia presents to a health or public service in a state where they, or a family member, are at risk of serious harm or death.'

Accepted referrals were classified as being in need of urgent assessment (within 4 hours) or non-urgent (within 48 hours). Assessments were by either one or two members of the Home Treatment Crisis Team in the home of the patient with dementia. During crisis, the

researcher (FE or JH) accompanied clinicians on assessment visits and gained verbal consent from patient, carer and healthcare professionals for data collection. After crisis resolution, written consent was taken from the patient with dementia or from a Nominated or Professional Consultee if the patient lacked capacity to consent (UK Government, 2005). If no written consent was obtained, data was destroyed. This enabled the collection of data for analysis relating to 15 crises (ten urgent and five non-urgent). The researcher (FE) received training in dementia care, data collection methods and assessment of mental capacity, did not have a clinical background and was unknown to participants prior to their participation in the study. She was supported by a nurse researcher (JH) with 20 years of experience conducting research about sensitive topics, who collected data from the first five participants (to test the feasibility of the methods and who can be contacted for further details) and co-facilitated the focus group. The researchers were introduced to participants as researchers seeking to find out how best to help people experiencing crisis.

Computer software, NVIVO, assisted management of the qualitative data and supported an initial framework analysis (FE)(Gale, Heath, Cameron, Rashid & Redwood, 2013) based on the causes of crisis previously reported; behavioural/psychological, physical health, vulnerability, family carer and environment, and management categories; professional healthcare support, home living environment, social home care support and family carer (Ledgerd et al., 2016; Toot et al., 2013). Data summaries that captured all coding of field notes and each of the participant groups (JE, JH) formed the basis of the interpretive process (JH). Maps of relationships between categories and overarching themes were devised (Miles & Huberman, 1994), which were then checked and refined through a search for disconfirming evidence by returning to the original transcripts and field notes (JH) (van Manen, 2016). A decision trail was maintained (Koch, 1994) and rigour strengthened by testing emergent understanding and hypotheses in discussion with clinicians and experts beyond the participating clinical team and the research team (van Manen, 2016). (See Figure 1. Process of data analysis)

Wales Research Ethics Committee 3 (reference 17/WA/00) approved the study.

Findings

During the study period, March 2017 to January 2018, a total 88 patients with dementia received the home treatment service during a time of crisis. Seventeen people with dementia, their carer and social care professionals gave verbal agreement for data collection during a treatment episode. Reasons for referral were suicide risk, physical and verbal aggression/self harm, vulnerability, carer stress and future crisis prevention, reflecting the diverse presentation of crisis (see Table 1.). Patients are denoted by P followed by their participant number, carers C followed by the related patient number and staff S with numbers unrelated to a specific patient.

The fifteen participants with dementia (see Table 2.) included eight women and seven men, age range 58-95 (median 80). Three had vascular dementia, ten Alzheimer's disease and two a combination of both. Thirteen were living in a private dwelling and two in a care home. Of those living in a private dwelling, three people were living alone, seven had a family carer, two had both family and paid carer and one had a paid carer only. The total 47 interviews included five people with dementia, 13 of their carers and 14 crisis team members (29 interviews). A focus group was also held with 9 crisis team members and observational data was collected during 41 care contacts (typically 30 to 60 minutes duration) during the 15 episodes of crisis studied.

At six weeks from referral, 2/15 people had been admitted to hospital and 13/15 (87%) remained in the community, of whom three were admitted to a nursing or care home and ten remained in the same place of residence. At six months 3/15 had died, 2/12 remained hospitalised, and 10/12 (83%) remained in the community, six in their original place of residence.

The following analysis is presented as a description of each participant group's perspective of crisis, ending with the dominant themes identified for the group. The cross-group analysis is then captured in a model of crisis resolution in the home (see Figure 1.) along with the identification of seven critical factors for crisis resolution in the community (Table 3.)

Patient perspective

Five of the fifteen people with dementia agreed to interview following a crisis episode (interview duration median 62 minutes, range 17 to 66 minutes) with agreement from a Consultee, if they lacked capacity. Three of these people evidenced vulnerability through their lack of awareness of their dementia diagnosis and associated difficulties. Two people had some insight. One talked about going out at night in pyjamas to catch a bus and being in 'a horrible place (P11).' The second, when asked about health said, 'I've got Alzheimer's, I suppose I have (P4)' but then goes on to talk about a cardiac problem experienced more than a decade previously and, when asked about memory, responds 'As far as I'm concerned my memory is alright (P4).'

The patients interviewed were therefore unable to talk about the nature and cause of the crisis that had led to their referral to the home treatment team. They talked about 'everything being fine (P5)' and being 'fit and healthy, thank God (P9).' P5 had intermittent difficulty concentrating, as she was distracted by thoughts about 'people taking things from me.' Only P11 recalled referral to the home treatment team and the reason for this, explaining suicidal thoughts had precipitated referral, 'I was crying all the time and I didn't want to be here (P11).'

The patient participants remembered professionals coming to the house to talk to them. Four spoke about this as a positive experience. Comments included, 'They are all nice people (P15),' and 'it would be nice to have more of that (P5). The fifth patient was ambivalent, 'I

didn't take a lot of notice of what he had to say... he just got a job to do and I goes along with him (P4).' Only one was clearly able to discriminate between the home treatment team and other services received. This patient recognised interventions offered and valued the approach taken, 'Dr didn't talk to me like a doctor. She talked to me as, me and you. Person to person (P11).' Others claimed not to need help, for example explaining help would be unwelcome 'because I won't have nothing to do (P9).'

Themes revealed by patient interviews

People with dementia liked the home treatment team because they were experienced as 'nice people' thus winning trust (see Table 3. Critical factor 3.), probably because they respect personhood, talking 'person to person' (see Table 3. Critical factor 4.) The patient interviews also reveal team members needed expertise in managing mental health problems, including suicidal ideation (see Table 3. Critical factor 2.) and could not rely on the patient's account alone to assess risk of harm (see Table 3. Critical factor 1.).

Carer perspective

Family carers of thirteen of the fifteen people with dementia agreed to take part in the study (interview duration 8 to 64 minutes, median 39 minutes). All of the carers spoke about behavioural and psychological symptoms of dementia contributing to referral to the home treatment team. They gave examples of threatening behaviour, agitation, restlessness at night, trying to exit to go home to parents, wandering and hallucinations.

Seven of the carers spoke about the vulnerability of the patient with dementia. Their stories included comments such as 'a danger to herself (P8)' and fear of the person coming to harm, for example whilst wandering the streets (P4) in nightclothes at night (P8 & P9). In the time leading up to referral to the crisis team they were 'at the point whereby I can't cope'

(C15), fearful for their own safety, 'I felt vulnerable (C3), 'just waiting for him to do something he shouldn't (C7), and feeling 'closed in' and 'suicidal (C4).' They were also faced with other family members and neighbours who suggested the person with dementia should be in a care home or hospital (C6, C9) or themselves thought the person with dementia should be in an institution (C1, C4).

Most carers were very satisfied by the home treatment service. The service was described as, 'Wonderful (C12),' 'Five star. Gold star (C8),' 'Reassuring (C12)' and 'Caring and competent (C15).' The exception was C16 who thought that a GP would admit to hospital, whereas the home treatment team 'just come here but don't do anything.'

All carers knew that the home treatment team were conducting repeat assessments of medications (C1, C3, C6, C7, C8, C17), behavioural and psychological symptoms (C1, C3, C9, C12, C16), mental capacity (C4), pain (C1), distress and suicide risk (C6), or their own mood and behaviour (C11, C13, C15). They all identified ways that the home treatment team were supporting the patient with dementia. However, the attention they had received themselves dominated their talk. C1 explains 'They have helped me and I feel I'm not on my own.' They felt listened to 'She was concerned for me. Nice, because nobody else seems to worry about the carer (C4).' They appreciated education and skills training, for example, on breaking tasks down into 'bite sized chunks (C15), and use of distraction (C3). They also felt encouraged by assurance of help to 'get you over it (C11).'

A number of carers spoke about the approach of the home treatment team. They had received a clear explanation of 'what they were able to provide (C6)' and 'what they wanted from us (C6).' They 'get on well with everyone….don't push it….don't impose themselves (C9), which C9 explains is important because his mother is independent and if she thinks people are trying to take over is 'resistant.' They do what they say they will do (C15, C8), which 'builds confidence (C8).' They make 'No hasty decisions (C17).'

Three carers gave both positive and negative feedback on the crisis service. All three believed the person with dementia in their care should be in hospital or a care home.

Themes revealed by carer interviews

Carers of people with dementia valued consideration of their own support, education and training needs. This reduced their feelings of isolation (see Table 3. Critical factor 6). Carers also needed advice and information, for example, to understand the benefits of treatment and care in the home (see Table 3. Critical factor 3.)

Home Treatment Crisis Team staff perspective

Fourteen home treatment nurses, support workers and doctors took part in 29 interviews (duration 5 to 25 minutes, median 12 minutes) to explore aspects of the fifteen crises observed. The staff interviews demonstrated respect for personhood, perhaps explaining why people with dementia described them as kind. Like carers, they spoke about behavioural and psychological symptoms of dementia and vulnerability, such as lack of insight into cognitive impairment (P9, P5, P16, P13), contributing to referral to the Home Treatment Crisis Team. Unlike carers, they identified other contributory factors that included non-compliance with medication, change in living environment (P1 & P17), environmental triggers (P17 & P14), lack of dementia care expertise in other services, and family carers suggesting residential care. They also spoke about indicators of patients' mental ill health; suspicious behaviour, delusions, accusing family members, low mood, disengaging with services, excessive purchases, and suicidal ideation.

Visits to the people with dementia ranged in number from twice weekly to multiple in the same day. In three cases, suicide risk was assessed over a period of time (P11, P3, P5).

Other on-going assessments were of mood (P11, P8, P12, P3, P16), aggression (P4, P7, P12), agitation (P3, P7, P8, P13), sleep (P11, P7, P8, P5), other behavioural and psychological symptoms of dementia and triggers of these symptoms (P3, P6, P7, P8, P9, P12, P14, P13, P17, P5, P16), perspectives of patient and carer (P6, P7, P11, P8, P9, P12, P16), and relationship between patient and carer (P6, P7, P12, P16, P13, P14, P11) or neighbours (P9). To conduct repeat assessments the team spoke about the importance of building rapport with the patient with dementia and their family members (P3, P6, P7, P11, P15, P16). Their approach included being clear about what the service could offer and direct in 'what we are doing right now….Filtering everything that's said to identify what's important now (S3).' Review and monitoring was 'An holistic approach' to 'look at the whole thing. Activities of daily living, care package, functioning, what she does daily (S16).' Evaluation of intervention was in partnership with people with dementia and their carers, and also professional staff in other services. In every crisis studied, the team considered care of the carer to be a core component, necessary for reducing crisis escalation risk and the avoidance of hospital admission.

A second core component of the home treatment package was medication review and monitoring of the effect of medication over time. An aspect of medication management for the patient with dementia was described in 21 of the interviews covering 13/15 of the people with dementia leaving only two of the fifteen crises where medication review, monitoring or medication change played no part in management.

A third core component was arranging activities outside the home, including day care one or more times per week (P4, P7, P8, P9, P16) , arranging social activity (P5, P7, P9, P11, P12, P13), information about services provided by Third Sector organisations (P3, P6, P12, P13) and NHS services (P8) and arranging on-going support, for example from a Community Mental Health Team (P8, P12, P13, P5), or admission (P6). A social worker was key to crisis resolution in three cases (P4, P9, P1) and an increase in social care package following

discharge from the crisis service in two cases (P16, P5). Time taken to liaise with other health, social care and charity services enabled advice, education and interventions consistent with earlier reviews and treatments by staff from these other services.

Themes revealed by Home Treatment Crisis Team staff interviews

The crisis team members were aware of many more characteristics of their service important for successful resolution of crisis than either people with dementia or their carers. They drew attention to the importance of building rapport with the patient with dementia and their carer (see Table 3. Critical factor 3.), to enable negotiation of shared decisions about treatment (see Table 3. Critical factor 4.) and to address carer need for support, education and training (see Table 3. Critical factor 6.) Other activities reported as being necessary for crisis resolution in the majority of cases were medicines review (see Table 3. Critical factor 5.), management of behavioural and psychological symptoms (see Table 3. Critical factor 2.) and an available and networked system of respite and support services beyond the home (see Table 3. Critical factor 7.).

Home Treatment Crisis Team staff perspective captured via focus group

The focus group discussion (64 minutes duration) exposed a shared and strongly held view concerning importance of educating the public and peers in other services about the benefits of treating crisis in someone with dementia at home.

> They (family) have a view, when unwell with dementia, they should be in hospital or a care home. We have to fight against that. …. But equally we also have, within the staff, like with the Community Mental Health Team…some social workers…. So just to have that educating element for the patient, carers and for some of the staff who won't really understand that we can do things safely in the community (S2).

The focus group also emphasised the importance of being able to offer flexible and intensive visiting and the availability of respite and social care services for crisis resolution. Any crisis

might require adjustments within a wide network of people, relationships, voluntary and statutory services around the person with dementia;

> It's a network isn't it? (S3) Yeah, whoever is, whoever touches that person's life really, is crucial really in helping them to maintain the environment they're living in (S1)….Neighbours…dogs, cats…(S3).

In the first instance, adjustments are immediate and temporary. The initial task was ' looking at what is the most difficult thing and working on that first of all (S7),' which might be ' to give medication for the crisis to be averted. ….when the medication is kicking in, we then see (what other support is needed)(S22). The team held the person with dementia in a safe place;

> …. there's already enough disruption, so adding in the disruption of moving environments for someone just makes, just compounds matters. So the great thing about being able to cope, to look after someone where they are, is that it sort of contains it in a way (S5).

Themes revealed by Home Treatment Crisis Team staff focus group

The focus group revealed the importance of the context beyond the home of the person with dementia for successful crisis resolution and avoidance of hospital admission. It was necessary for there to be a network of respite and other services with good channels of communication for sharing information (see Table 3. Critical factor 7.) This network must have a shared understanding of the benefits and thus commitment to care and treat people in their home whenever possible. A major task for the crisis team was to disseminate knowledge of the possibility and potential benefits of treatment at home (see Table 3. Critical factor 3.).

Observational data findings

Observations were conducted during forty-one assessment and treatment visits to a patient's home. The researcher accompanied Home Treatment Crisis Team members (typically two

15

per visit) during these meetings with a patient and/or carer, family members, friends or neighbours.

The primary concern at first contact was assessment of the risk of harm and taking any necessary immediate action to mitigate this risk, for example, removing medications from the home. In parallel, the life of the person with dementia was mapped. This involved understanding their daily activities, relationships with people, home and local environment and services available to them. Their mental health was assessed and sometimes physical health, such as nutritional status. Visits by different members of the team were used to gather a range of expert views, continuing both the mapping process and the evaluation of any intervention, such as change to medication or education and training for the carer. Building rapport and trust, using kindness with non-confrontational probing and validation, was essential to the success of this process. Without seemingly being aware, the team used an enablement model of care (Hudon, St-Cyr Tribble, Bravo, Poitras, 2011) and supported others to use the same approach. For example, they supported care home staff to gather information to inform their decision of how best to manage a resident's aggressive and resistive behaviour.

Change across time was subtle and consistent with the claims made by staff during their interviews; 'assess in detail (S1)' take 'an holistic approach. 'Look at the whole thing (S16),' 'aim not to make too many drastic changes (S24)' and try 'the least restrictive options (S2).' Crisis team members shared information at twice-daily meetings when solutions were generated that were later discussed with people with dementia and/or their carer and family members to reach a shared decision. For example, a patient living alone was assessed over a week, following referral because they were wandering the streets day and night carrying large sums of money. Repeat assessments found them to have no awareness of their dementia diagnosis and symptoms, but typically to be in good spirits and thinking it was an earlier time in their life when they did the daily family shopping. It became apparent they

were eating and drinking erratically. Medications were reviewed and interventions put in place, to administer medication, support nutrition and hydration and to disrupt the problematic routine wandering by offering and supporting attendance at a day centre. There was no rush to fix problems at the first assessment. There was an initial assessment of risk of harm, a shared process of gathering information, followed by the introduction of interventions in agreement with a family carer and the patient. Crisis was resolved within two weeks.

Themes revealed by researchers' observations

The observational data revealed a pattern of treatment, care and role modelling which was consistent with a holistic enablement model (see Table 3. Critical factor 4.). The focus was on building trust and rapport (see Table 3. Critical factor 3.) using validation and non-confrontational probing (see Table 3. Critical factor 2.), in the first instance to assess risk of harm (see Table 3. Critical factor 1.) then to offer pharmacological and other supportive care (see Table 3. Critical factor 5,6&7.). A process of multidisciplinary mapping behaviours and decision-making followed (see Table 3. Critical factor 4.). This always had the purpose of creating a geographical, practical, relational, social and emotional space that was agreed by the Home Treatment Crisis Team, person with dementia and significant others to be acceptable and sustainable - a safe dementia space.

Synthesis: Critical factors for home treatment of crisis

Achieving crisis resolution in the person's home was a process (see Figure 2.) that began with assessment of risk of harm and identification of the most difficult and immediate problem. Immediate short-term action was taken to reduce risk of harm and enabled on-going assessment and monitoring with decisions taken by the Home Treatment Crisis Team in partnership with the patient, carer and other health, social care and community staff. Over

time, agreement was reached that the crisis had resolved, for example with P17, following education of care home staff, or was unmanageable in the community, for example, the crisis escalated for P1 who was then abandoned by their carer.

The primary aim of this project was to identify and understand critical factors for successful home treatment of a dementia crisis. The analysis reveals seven aspects of home treatment to be so frequently necessary for crisis resolution that they can be considered critical to the Home Treatment Crisis Team's success (see Table 3). Critical factors 1, 2, 3, 4 and 6 all involve team interaction with carers, revealing it is key to address carer need to resolve crisis in the home of a person with dementia. Critical factor 3 evidences the importance of embedding respect for personhood in the model of practice. Critical factor 5 is a reminder that the biomedical management of disease using medicines has a part to play in crisis resolution. Factor 7 draws attention to the criticality of partnership working across a wide range of health, social and community services. The team attends not only to adaptations within the home and management of disease, but to relationships and the broad social context of care, to create 'Safe Dementia Spaces' for people living with dementia. Thus, the Home Treatment Crisis Team was found to use a biopsychosocial approach to achieve crisis resolution for a person with dementia living in the community.

Discussion

This study found that a Home Treatment Crisis Team restored Safe Dementia Space in the community to resolve crisis. Attention to disease, behaviours, relationships and social networks were all important for creating a Safe Dementia Space that extends beyond the boundary of the home to achieve crisis resolution. Thus, achieving crisis resolution in the home is consistent with and requires implementation of the NHS England policy on dementia care, which includes the 'Well Pathway for Dementia' (NHS England, 2017).

The Home Treatment Crisis Team used their knowledge of adverse outcomes from hospitalisation of a person with dementia, to justify their aim of crisis resolution in the community. Thus, the analysis revealed education and training of staff, carers and the wider community in the potential benefits of home treatment, critical to successful crisis resolution in the home. The benefit of education during crisis for carers has been reported previously (Jacobsohn et al., 2019; Toot et al., 2013), with evidence of alleviation of anxiety, depression and burden (Morris, Horne, McEvoy & Williamson, 2018; Laver, Milte, Dyer & Crotty, 2017), enhanced ability to identify risk of harm early (Sloane et al. 2017) and reduced use of emergency departments (Tremont et al. 2017). The public education role of staff working in dementia care is recognised in recent practice guidelines and policy, for example, as a requirement for creating dementia friendly communities (Department of Health, 2016; Department of Health, 2015). It has not previously been a finding of empirical research about crisis for people with dementia. However, other empirical studies have revealed the importance of complex intervention for crisis resolution. Johnson et al. (2012) conducted an observational study of PREVENT for people with dementia, a standardised protocol coordinated by a care manager, for prevention and management of psychiatric crisis, which concluded outcomes depend on non-pharmacological interventions and reducing family distress during crisis, in addition to medical interventions. In the UK, 'The vision for the nurse's role in dementia is primarily an interpersonal and social model of care' applied in practice 'with the medical aspects of care using a person-centred approach' (Department of Health, 2016).' This research has found a multidisciplinary Home Treatment Crisis Team can successfully practise the approach, demonstrating it is a vision that can be realised beyond nursing.

Offering person-centred care to protect personhood has been dominant in best practice and policy guidelines for two decades, since the publication of Kitwood and Bredin's seminal research (1997), which drew on the experiences of people with dementia to recognise the applicability of the concepts to dementia care. Placing value on personhood has been

important for encouraging on-going interaction with the person who has dementia helping to protect them from isolation as the disease progresses. However, the focus on respecting the individual's unique inner existence may have drawn attention away from the wider social system and network of relationships that can enable a person with dementia to remain in their own home. The model of treatment in the home to achieve crisis resolution examined in this study was of respect for personhood embedded within a systems approach to treatment and care. This facilitated consideration of adjustments beyond the immediate problem as understood by the person with dementia and their carer. A focus on personhood may also obscure the importance of medical management of the disease. Medicines management in the home was found necessary for resolving crisis in the home. The biopsychosocial model of home treatment reported here, enabled more than 80% of study participants with dementia to experience resolution of crisis without admission to hospital.

Limitations

This research was a single centre study in the UK. It was about a sensitive, thus under researched topic and included the perspective of people with dementia, which is typically underrepresented. The approach to crisis resolution in the home of people with dementia was dependent on the availability of other health, social care and community services available locally. The transferability of the model emergent from the analysis may be limited to other geographical locations where a similar infrastructure of community services is available. The model should now be tested in comparison with other models used in current practice, paying particular attention to relationships with social care and community services. Economic evaluation is also needed, as there may be cost benefits from avoidance of hospital admission.

Earlier research has based analysis primarily on carer accounts where samples underrepresent older and depressed carers. A limitation of this study is data capture limited

by available resources not data saturation, however, data was captured using multiple methods during the crisis process, giving a new and more robust insight into the process compared to analysis of earlier retrospective and single perspective accounts.

Conclusion

Policy makers and practitioners should consider the identified seven critical factors for the creation of Safe Dementia Space and successful crisis resolution, in the design and delivery of home treatment services for people with dementia. The factors identified were: immediate action to reduce risk of harm, expertise in dementia care and carer education, communication skills to establish trust and promote benefits of home treatment, shared decision making, medication management, addressing the needs of carers independently of the person with dementia and, local availability of respite and other community services.

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Table 1. Primary reason for admission

Reason for referral	Patient participant
Suicide risk	P11
Physical and verbal aggression and self-harm	P17
Vulnerability – no insight and night walking	P16, P9
Carer stress	P1 (new care location and carer)
	P3, P12 (because of patient aggression)
	P4 (with threat of abandonment)
	P7 (and patient neglect)
	P15 (sleep deprived, alone)
Prevention of crisis	P6, P13 (carer stress because of restless at night)
	P5, P8 (delusions, hallucinations)
	P14 (care home staff stress because of patient aggression)

Note: written consent was not obtained for inclusion of data collected with verbal consent from P2 and P10

Participant	Age	Gender	Dementia	Carer
P1	80	Female	Vascular dementia	Daughter
P2	No written informed consent			
P3	74	Male	Vascular dementia	Wife with support from daughter
P4	78	Male	Mixed dementia	Wife
P5	70	Female	Mixed dementia	Lives alone with support from daughter
P6	80	Male	Alzheimer's disease	Paid live-in carer with support from son and daughter
P7	72	Male	Alzheimer's disease	Wife
P8	94	Female	Alzheimer's disease	Lives alone with support from daughter and son
P9	80	Female	Alzheimer's disease	Son
P10	No written informed consent			
P11	62	Female	Young onset Alzheimer's disease	Husband
P12	84	Male	Alzheimer's disease	Wife
P13	88	Male	Vascular dementia	Wife with support from daughter
P14	79	Male	Alzheimer's disease	Care home staff
P15	58	Female	Young onset Alzheimer's disease	Husband
P16	Patient withdrew consent post interview, carer did not			Friend
P17	90	Female	Alzheimer's disease	Care home staff with support from daughter

Table 2. Patient participant characteristics

1. Immediate action to reduce risk of harm/death: Information gathering from multiple perspectives to assess the patient and carer's risk of harm (including suicide risk), mental health and physical health; assessment of environmental factors contributing to the crisis; provision of flexible and intensive visiting to manage the crisis; an immediate plan to safeguard the patient, or carer at risk.
2. Expertise in dementia care and carer education: Expertise in managing the behavioural and psychological symptoms of dementia, particularly agitation and aggression; expertise in managing mental health problems, including suicidal ideation; knowledge to educate family carers and care staff in management of the symptoms of dementia particularly resistance and aggression, modelling non-confrontation.
3. Communication skills: Expertise in building rapid rapport and establishing trust with people with dementia, their carers and people in their support network, using an approach that respects personhood, evoking positive emotion and delivering education into the potential benefits of treatment and care in the home.
4. Shared decision making: Negotiating a treatment plan with those at risk; maintaining a trusting relationship; partnership working with other professionals; focusing on patient and carer needs and strengths.
5. Medication management: A medication review to optimise medication regime; support with administering and monitoring medication for symptoms of dementia and physical health problems; and seeking feedback on the effects of medication from formal and informal carers.
6. Addressing the needs of carers independently of the patient with dementia: Listening to carers and encouraging them to express their feelings and needs; reducing carer isolation, for example, by signposting to a carer support group; supporting carers to feel empowered in their caring role; offering education and skills training to help with care.
7. Availability of respite and other services: Social worker and social care; on-going carer support and respite; access to an extended network of support services and emergency respite.

Table 3. Critical factors for successful home treatment

	Patient participants	Carer participants	Home treatment team staff participants	Home treatment team focus group participants	Researcher observations
Figure 1. Process of data analysis					
Categories supported by data	*Causes of crisis*: Behavioural/psychological, Physical health, Vulnerability, Family carer, Environment	*Causes of crisis*: Behavioural/psychological, Physical health, Vulnerability, Family carer, Environment, Other - medication management, Other - issues with social services	*Causes of crisis*: Behavioural/psychological, Physical health, Vulnerability, Family carer, Environment, Other - medication management, Other - issues with social services	*Causes of crisis*: Behavioural/psychological, Physical health, Vulnerability, Family carer, Environment Other – issues with social services Other – training (lack of)	*Causes of crisis*: Behavioural/psychological, Physical health, Vulnerability, Family carer, Environment, Other - medication management, Other - issues with social services
	Management of crisis: Professional healthcare support, Home living environment, Social home care support	*Management of crisis*: Professional healthcare support, Home living environment, Social home care support, Family carer, Other - approach, Other - risk management, Other - shared decisions	*Management of crisis*: Professional healthcare support, Home living environment, Social home care support, Family carer, Other - approach, Other - risk management, Other - shared decisions	*Management of crisis*: Professional healthcare support, Home living environment, Social home care support, Family carer, Other – risk management	*Management of crisis*: Professional healthcare support, Home living environment, Social home care support, Family carer, Other – approach, Other - risk management, Other - safe guarding Other - team working
Themes identified in crisis resolution	Respect for personhood Communication skills to gain trust and acceptance Expertise in managing mental health problems, including suicidal ideation	Meeting carer support, education and training needs Reduced feelings of isolation Education in the benefits of treatment and care in the home	Building rapport with the person with dementia and their family Negotiation of shared decisions about treatment Meeting carer support, education and training needs Medicines review Networked system of respite and support services	Context beyond the home of the person with dementia Network of respite and other services Good channels of communication for sharing information Commitment to care and treat people in their home whenever possible Dissemination of knowledge about the potential benefits of treatment at home	Building trust and rapport Use of validation and non-confrontational probing Assessment of risk of harm Multidisciplinary mapping of behaviours and decision-making Plan agreed by the home treatment team, person with dementia and significant others to be acceptable and sustainable Treatment, care and role modelling consistent with a holistic enablement model
Synthesis	Relationships between themes mapped and modelled (see Figure 2.)				
Hypothesis generation	Proposition of factors (mechanisms in the modelled process) critical to crisis resolution in the community (see Table 3.)				

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Fig.2: Process of crisis resolution