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IDENTIFYING THE CAUSES, PREVENTION AND MANAGEMENT OF CRISES IN DEMENTIA. AN ONLINE SURVEY OF STAKEHOLDERS

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Key points:

1. Stakeholders, including professionals and consumers, were surveyed to rank the perceived importance of potential causes of, and interventions for crises in dementia
2. Compared to staff views, carers seemed less concerned about aggression and more concerned about level of impairment.
3. Education and support for family carers and home care staff was highly valued for preventing crises.

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Abstract

Background - Crisis situations in dementia can lead to hospital admission or institutionalisation. Offering immediate interventions may help avoid admission whilst stabilising measures can help prevent future crises

Objective – To identify the main causes of crisis and interventions to treat or prevent crisis in persons with dementia based on different stakeholder perspectives.

Methods – An online questionnaire was developed to identify the causes of crisis and appropriate interventions in a crisis. Participants included people with dementia, family carers, staff working in health and social care, including emergency and voluntary sectors, and academia.

Results – The results ranked the main causes of crisis, interventions that can prevent a crisis and interventions that can be useful in a crisis. Wandering, falls, and infection were highly rated as risk factors for crises across all stakeholder groups. Consumers rated aggression as less important but severity of memory impairment as much more important than the other groups did. Education and support for family carers and home care staff was highly valued for preventing crises. Well trained home care staff, communication equipment, emergency contacts and access to respite were highly valued for managing crises.

Conclusions – We identified triggers and interventions that different stakeholders see as important for crisis in dementia. Recognition of these may be critical to planning effective and accepted support and care for people with dementia.

INTRODUCTION:

Crisis situations in dementia are common, often multifactorial and frequently result in hospital and care home admissions. Factors such as living alone, increased dependency and severity of dementia, high levels of carer burden and poor social support networks contribute to the risk of people with dementia being institutionalised (Smith et al., 2001; Spitznagel et al., 2006; Yaffe et al., 2002). The English National Dementia Strategy emphasises care at home and the avoidance of hospital admissions, which can be detrimental for people with dementia (DH, 2009). Interventions directed at avoiding or delaying institutionalisation, such as reducing difficult behaviours and carer burden, may result in improved quality of life for people with dementia and their family carers, greater independence and economic benefits (Yaffe et al., 2002, Banerjee & Wittenberg, 2009).

A crisis in dementia was defined as “a process where there is a stressor(s) that causes an imbalance requiring an immediate decision which leads to a desired outcome and therefore crisis resolution. If the crisis is not resolved, the cycle continues” (Macneil-Vroomen et al., 2013). Whilst immediate interventions may be necessary, stabilising measures can also help prevent future crises. These home treatment interventions should be shaped by preferences and choice to ensure their acceptability to people with dementia and family carers. A qualitative study (Toot et al., 2013) showed that staff often emphasised more costly and intensive interventions for crises, such as extended hours services and multidisciplinary work, but people with dementia and their carers valued practical help, such as home care, home adaptations, and support from family and friends.

Whilst many stakeholders are involved in the management of dementia, particularly health and social care professionals, family carers and people with dementia themselves, there is little published research that compares their views on crisis. This study aimed to identify the main causes of crisis and interventions to treat or prevent crisis in persons with dementia, based on different stakeholder perspectives.

METHODS:

Design

An online survey was designed based upon a literature review of crisis interventions in dementia and analysis of focus groups that explored the causes of crisis in dementia and identified appropriate interventions (Toot et al., 2013 – see Table 1). The survey was developed to identify the primary causes of crisis, and distinguish interventions useful for managing or preventing a crisis for people with dementia and was part of a modified Delphi Process (Murphy et al., 1998; Fink et al., 1984) used to develop a model of home treatment for the Support at Home: Interventions to Enhance Life in Dementia (SHIELD) research programme.

Participants

We aimed to generate at least 200 responses through an open survey and approached a network of key stakeholders that included academic experts in dementia care, health and social care staff, emergency services, representatives of professional bodies such as the Royal College of Nursing and College of Occupational Therapists, voluntary sector staff, home care agency staff, people with dementia and family carers. Participants were asked to indicate if they had experience of a crisis situation whilst supporting someone with dementia.

Survey Design

Causes of crisis:

The thematic analysis from the earlier focus groups study and the literature review identified five categories for causes of crisis: behavioural/psychological, physical health, vulnerability, family carer and environment (Toot et al., 2013). Each category included a list of factors that could precipitate a crisis for people with dementia and their carers (Table 1). To prioritise and rank the factors most likely to cause a crisis, participants were asked to choose the fifty percent of these items that they thought were the most important contributors to a crisis. The questionnaire also allowed for comments about causes that might not have been included.

(Table 1 here)

Interventions in a crisis:

Four categories of interventions: professional healthcare, social home care, family carer and home living environment were identified through the thematic analysis of the focus group transcripts and the literature review (Toot et al 2013). Each category included a list of interventions and respondents were asked to indicate those interventions which were important in managing and/or preventing a crisis. Respondents were able to comment on interventions that had not been included and on the importance and frequency of the interventions for effectiveness and usefulness.

Dissemination of the survey

The questionnaire was made available in both online and paper versions for completion between November 2010 and January 2011. The online survey was created through SurveyMonkey (SurveyMonkey 2010). Dissemination was via: professional organisations, Dementia and Neurodegenerative Diseases Research Network (DeNDRoN) and NHS Trusts (health care professionals); direct/personal email correspondence to published academics; Dementia UK (carers); participants in the focus groups (carers and health care professionals); and day centres/hospitals (including 1:1 meetings with people with dementia following consultation with service managers).

Ethical considerations

Ethical approval was obtained as part of the SHIELD home treatment programme study (REC Reference Number: 10/H0701/20). Prior to starting the questionnaire, respondents were asked to tick a box consenting to their participation in the research. The survey was anonymous; however participants had the option to enter contact details on a separate questionnaire if they wished to enter a prize draw for a £150 shopping voucher.

Statistical Analysis

Frequency distributions were used to determine the top five choices of causes and interventions for crisis. Chi-square tests were used to examine whether there were differences in responses between the four groups and p-values were calculated. For groups which had cells with frequency counts less than five, Fisher's Exact Test was used.

RESULTS:

Responses

Overall 719 respondents completed the questionnaire, comprising: 20 academics (2.8%), 562 health sector staff (78.2%), 54 family carers (7.5%), 23 social care sector staff (3.2%), 16 emergency services staff (2.2%), 12 voluntary sector staff (1.7%), 4 people with dementia (0.5%) and 28 others (3.9%). In all, 711 (99%) questionnaires were completed online, 4 (0.5%) were completed by hand and returned by post, and 4 (0.5%) were completed by hand by the researcher through interviewing people with dementia.

Of these, 627 (87%) respondents were female and 620 (86%) reported having experienced at least one crisis involving people with dementia and their carers.

The participants were grouped into the following four categories for the purpose of analysis: 395 (54.9%) physical health staff, 227 (31.6%) mental health staff, 72 (10%) consumers (people with dementia, family carers and voluntary sector) and 25 (3.5%) academics.

Causes of Crisis

The top five causes of crisis, ranked by each of the four groups are listed in Table 2. The 5 most commonly cited risks were ranked in order from 1 to 5.

(Table 2 here)

Behavioural and Psychological Factors

Wandering, physical and verbal aggression, sleep disturbance and suspicious/paranoid ideas were consistently deemed important across the four groups and were nearly always ranked in the top five causes of crisis for behavioural and psychological problems. However, consumers rated physical aggression as much less important ($p<.001$) and severity of memory impairment as much more important ($p<.001$) than the other three groups. Mental health staff were more concerned about suspicious/paranoid ideas ($p<.004$) than the other three groups.

Physical Health Factors

Falls, infection, delirium, immobility and incontinence were rated consistently as key risk factors precipitating crisis indeed falls, infection and delirium were rated much more highly than all other causes. Mental health staff had a greater concern over delirium as a risk factor compared to the other three groups ($p< .001$), whereas consumers felt incontinence was a bigger problem ($p<.006$).

Vulnerability

Inability to identify potential risks, poor nutrition, abuse of the person with dementia, lack of support services and safety outdoors were identified consistently as risk factors for crisis. Mental health staff were more concerned at the risk of abuse ($p<.001$). Neglect of personal hygiene was also considered highly important.

Family carer

The family carers' physical and mental health, carer burden, and the sudden absence or death of the family carer were rated very highly important across the groups.

Environment

There were more differences in relation to environmental risks between the four groups. Physical health staff rated hazards around the home as the top risk factor ($p<.005$) and mental health staff rated hazards associated with daily living tasks likewise ($p<.04$). In contrast, consumers felt that the person with dementia living alone ($p<.004$) was the most important risk factor, but felt that changes in the home environment were also key. Being unable to access essential amenities was regarded as important across the groups. Consumers particularly noted problems leading to crisis for people who are unable to access services ($p<.0005$) and all rated inadequate community services as important. Lack of suitably trained care staff was highlighted by all groups and lack of coordination between health and social care services was strongly rated by physical health staff, consumers and academics, but less so by mental health staff.

Crisis interventions

Participant rankings of the interventions in each of the four categories: professional healthcare support; social home care support; family carer support; and home living environment; that respondents thought most likely to be useful in *managing* a crisis are shown in Table 3. Again, they are ranked with the top five items shown in order. Participant rankings of the interventions in each of the four categories that respondents thought most likely to be useful in *preventing* a crisis are shown in ranked order in Table 4.

(Tables 3 and 4 here)

Interventions used to manage and prevent a crisis

Professional Healthcare Support

Managing a crisis: 24 hour availability of professionals, accident and emergency services, health staff working longer hours, and access to a safeguarding adults team, a telephone helpline and a single point of contact were all considered highly important in managing a crisis.

Preventing a crisis: In contrast, key factors in preventing a crisis included early referrals to support services, a coordinated care plan, specialist training for health staff, multidisciplinary assessments and provision of purposeful activities. However, consumers (mostly carers) rated involving the person with dementia in care planning as less important than did health staff ($p \leq .001$). Physical health checks and medication reviews were also rated as important by academics and health staff, but consumers rated medication reviews as less important ($p \leq .005$).

Social Home Care

Managing a crisis: Emergency care provision and other emergency services related to social care were seen as cornerstones of helping to manage a crisis, assisted by a centralised database of people and their needs. Flexible services, specialised training for home care staff and other home care services were also of importance. Physical health staff placed less value on home care staff training than did mental health staff and consumers ($p<.02$).

Preventing a crisis: Presence and training of home care staff were seen as the most important factors in preventing a crisis. Day care services, flexible services and a centrally held database of needs and preferences of people with dementia were also seen across the groups as central to helping to prevent a crisis.

Family Carer

Managing a crisis: Respite at home, respite in a care home or respite at a day centre/day hospital were considered by all groups the best ways of supporting the family carer in the midst of a crisis. Other factors, such as counselling and family carer education, were considered important but much less so.

Preventing a Crisis: Family carer education was considered the key factor in helping to prevent a crisis, followed by planning care with the family carer and access to carer support groups. Counselling and advice about financial matters were also considered highly important across the four groups.

Home Living Environment

Managing a crisis: Communication equipment was highly valued as a means of helping to manage a crisis. People also felt that having a family carer and supportive friends and neighbours were very important. Specialist assistive technology ($p< .004$) and assistance with medication ($p< .008$) were valued particularly by mental health staff.

Preventing a crisis: There was a general view that having a daily routine at home could help prevent a crisis. This included having support for administering and monitoring medication. Having a family carer and the support of friends and neighbours were also important. Home adaptations and equipment were also highly regarded, along with prompts and cues around the home (though these were less valued by consumers $p<.001$). Lastly, specialist assistive technology and purposeful activities, although not usually ranked in the top five, were consistently valued across the four groups.

Finally, participants were asked to rank the categories in order of likelihood of causing a crisis in dementia. ‘Behavioural/psychological factors’ was ranked as the most likely category to cause a crisis, while the ‘environment’ was ranked lowest by all participant groups. The mental health group ranked the categories in the same order as the overall ranking: behavioural/psychological, physical, vulnerability, family carer and environment, whereas the physical health group ranked physical health factors third and had equal rankings for family carer factors in second and fourth place.

DISCUSSION:

This is the first large scale study to compare the views of different stakeholders And identify their top ranked causes of crisis and interventions for managing or preventing crisis for people with dementia and their carers. The results are surprisingly consistent between the four stakeholder groups, providing a clear indication of the likely precipitating causes and favoured interventions for crisis prevention and management. However, there were some clear differences of opinion.

The top ranked factors such as wandering, aggression, falls, infection, carer burden and environment match the most commonly cited causes of crisis and institutionalisation (Sörensen et al., 2006; Knapp et al., 2007; George, 2011; Mukaetova-Ladinska and McKeith, 2004 Philip et al., 2010; Toot et al., 2013; Johnson et al., 2013; Pinquart, 2003; George, 2010; Pimouguet et al., 2010; Wolfs et al., 2012). Similarly, a systematic review undertaken by Macneil-Vroomen et al., 2013 identified a range of stressors that could lead to crisis from the perspectives of family carers, people with dementia and healthcare providers. Participants in this study listed the top ranked factors of crisis as the inability to live independently, intense behavioural and psychological symptoms and emotional toll on informal care givers. Our study includes the perspectives of different groups of healthcare professionals and academics as well as family carers and people with dementia.

Consumers' rankings of the causes of crisis diverged most from the other three groups. These variations are important to recognise, particularly in the development of policy and strategies aimed at avoiding and managing crisis effectively. Consumers' views differed from others in three of the five domains of causes of crisis, which suggests that they may interpret crisis situations differently to healthcare professionals and that this may impact on their acceptance of services offered. In particular, they were more concerned about factors potentially less amenable to interventions, such as severity of dementia and living alone. This divergence of opinion reflects previous findings that people with dementia and family carers do not always concur with providers on the desired content of care services (Denson 2013).

Despite the increased emphasis on involving people with dementia and family carers in planning the care they get, nearly half report little or no involvement in the decisions and choices made about the support services they receive (SfC/DUK, 2012). This study highlights the importance of taking into account the views of people with dementia and their families about their needs and choices when planning care interventions, particularly at times of crisis, as these may not concur with the priorities perceived by healthcare professionals. Despite this, the consumers in our study (mostly carers) placed less emphasis on involving people with dementia in their own care planning. The findings also highlight the need to ensure that government policy and practice standards about client centred care reflect the needs and preferences of people with dementia (DH, 2009).

With regard to the different professional groups, government policies and guidelines highlight the need for health and social care staff to work more collaboratively in understanding and supporting people with dementia (DH, 2009). This study suggests few significant differences between mental and physical health practitioners' views on the causes of crisis, which provides a positive platform for interprofessional collaboration in this area.

However, consumers may not always weight certain factors associated with crisis in the same way, given their relatively lower ranking of abuse, neglect and alcohol consumption, raising implications for safety. Staff may need to explore these issues with carers and include them in educational packages, whilst recognising the inherent sensitivities of topics.

The findings underline the importance of family carer related factors as contributors to crisis and breakdown of community tenure (Cassie & Sanders, 2008). The provision of timely and immediate interventions is critical in resolving crises in dementia, which are often complicated by comorbidity and safety issues. However, the provision of preventative interventions is also important, since the degenerative and complex nature of dementia, with its impact on families, requires that support and care provided should both offer stability and be responsive and sustainable in the longer term.

The results of this study demonstrate that interventions selected as being useful in *managing* a crisis were, in most cases, less frequently selected as being useful in *preventing* a crisis, as illustrated by the differences in how the interventions were ranked.

Overall, there was greater consensus between groups ranking the top five interventions that could be useful in managing a crisis. This reflects the evidence that people with dementia and their carers view being able to access accident and emergency services in a crisis as important (Toot et al., 2013). Unfortunately, people with dementia are more likely to experience negative outcomes following a hospital admission, such as longer stays, increased confusion, infection and disorientation (Challis et al., 2014). Given that the number of avoidable hospital admissions appears to be rising (CQC 2013), healthcare practitioners could have a valuable role in promoting alternative community-based care responses.

Mental health professionals considered referral for a specialist assessment to be important in managing a crisis, whereas physical health practitioners ranked this as a more preventative intervention. This may indicate the different context for such assessments (one a crisis response, the other more oriented to identifying undetected morbidity). However, it suggests that consideration should be given to ensuring that all practitioners are aware of the range of potential services and timely assessments that could promote wellbeing and support for people with dementia and their carers.

The use of assistive technology in the management of dementia is widely reported in the literature. However, different opinions regarding its efficacy in managing a crisis were observed in the results. The disparity between mental health practitioners' and academics' views suggests differences in the perceived clinical use of assistive technology, even though the published evidence supports its use as an acute or preventative intervention (Damant et al., 2013)

The findings also challenge the use of prompts and cues as an effective preventative intervention for people with dementia, with consumers ranking these lower than the other three groups. This is of particular interest when comparing advice published by charities and carer support groups on the importance of this type of intervention. Equally, understanding the different views of people with dementia and family carers about the use of prompts/cues could be important, especially if valued by people with dementia and not by family carers.

Limitations

Online surveys may introduce bias due to the non-representative nature of the internet population (Eysenk & Wyatt, 2002). However, the large number of responses received indicates that an increasing number of people now have access to the internet, including family carers. The option of completing paper versions of the survey with assistance from a researcher was used by a small number of people with dementia. There were significantly more responses from physical health practitioners than mental health practitioners and this reflects the increasing contribution of the physical health sector in caring for people with dementia, which has been previously acknowledged (DH, 2009). Future work could usefully explore further the perspectives of the relatively under-represented groups in the present study, for example people with dementia, thereby complementing the present findings.

CONCLUSION:

The results provide a useful insight into the perspectives of staff and consumers and could contribute to further development of assessment processes, for example, robust risk assessments that also capture individuals’ unmet needs. Risk and unmet needs assessments should explore carers’ perceptions about what they feel they could or could not cope with which, in turn, could shape carer education and support strategies as part of a preventative care plan.

Healthcare professionals may also benefit from insight into consumer perspectives that could affect the causes and management of crises. These include perceptions about incontinence and low awareness of types of abuse, which could form part of a risk management strategy.

Reconfiguring services to provide support in the home, including alternatives to the use of accident and emergency facilities in a crisis, may also have quality of life benefits for the person with dementia. Equally, commissioners will need to consider consumers' views about accessing services in a crisis when designing alternative strategies to crisis management.

On the basis of this research, we have developed a manual of interventions, linked to risk factors, to help manage crises in dementia. Further research is required about the delivery of interventions at home during a time of crisis and potential challenges to their successful implementation. The use of care management as a method of preventing and managing crisis situations through a coordinated and planned response could be explored further to assist in the development of best practice treatment models.

Ethical Approval

Outer London Research Ethics Committee 3 approved the study in 2010, reference number: 10/H0701/20.

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Table 1 List of the five domains of crisis and their associated factors

Behavioural and Psychological
Anxiety symptoms (e.g. constant worrying, irritability, agitation)
Delusions (false beliefs)
Depressive symptoms (e.g. suicidal thoughts, low mood)
Disinhibition (e.g. over familiarity, inappropriate comments)
Hallucinations (e.g. seeing and/or hearing things that are not there)
Physical aggression (e.g. hitting out, throwing things)
Poor ability to communicate effectively
Repetitive speech and actions
Severity of memory impairment (disorientation, forgetfulness)
Sleep disturbance/ excessive night time activity
Sudden and unexplained changes in mood (e.g. crying)
Suspicious/paranoid ideas (persecutory beliefs/accusatory thoughts)
Verbal aggression (e.g. shouting, threatening and abusive comments)
Wandering (e.g. wandering excessively around the home/outdoors, night time walking)
Physical Health
Alcohol problems
Chronic Diseases (e.g. heart conditions, chest problems, diabetes)
Constipation
Delirium (confusional state – sudden onset)
Falls
Immobility/ Difficulty in Walking
Incontinence
Infections (e.g. UTI, chest infection)
Medication Side Effects
Pain
Vulnerability
Declining support services (e.g. Care package)
Inability to identify potential risks (e.g. leaving the front door open, bogus callers)
Inability to manage finance/bills
Non adherence to medication routine
Outdoor safety (road awareness, getting lost)
Person with dementia/memory problems is being abused (e.g. physically, verbally, emotionally, sexually, financially)
Reluctance/Refusing to call for help or assistance
Severe neglect of personal hygiene/personal care
Social isolation
Very poor eating/drinking
Family Carer
Death of the family carer
Family Carer burden (e.g. stress, workload)
Family carer is abusing the person with dementia/ memory problems
Family Carer is being abused
Family carer is experiencing financial difficulties
Family carer is not actively involved in the care planning process
Family Carer is unable to access support services (e.g. home care services, respite)
Family Carer mental health (depression, anxiety)
Family carer refusing help or assistance
Family Carer's physical health
Limited family carer awareness and understanding of dementia/memory problems
Sudden absence of family carer (e.g. hospitalisation)

Environment
Changes in family and relationships
Changes in the home environment
Hazards related to daily living tasks in the home
Lack of activities in the home for the person with dementia/ memory problems
Lack of coordination between health and social support services
Lack of supportive neighbours/friends
Living Alone
Physical hazards around the home
Poor/Inadequate community services
Reduced driving ability
Too much activity/ stimulus in the home
Unable to access essential amenities
Unsuitably trained paid care staff
Unplanned absence of paid care staff

Table 2 – Top five causes of crisis in dementia

	Mental Health Practitioners (n=227)	**Physical Health Practitioners (n=395)**	**Consumers (n=72)**	**Academics (n = 25)**	**Total (n = 719)**	**p value**
Behavioural/Psychological	**n (%)**	**n (%)**	**n (%)**	**n (%)**	**n (%)**	
Wandering	198 (87)^{2}	331 (84)^{1}	51 (71)^{1}	21 (84)^{3}	601 (84)^{1}	0.02
Physical Aggression	206 (91)^{1}	304 (77)^{2}	46 (64)^{4}	23 (92)^{1}	579 (81)^{2}	< 0.001
Sleep disturbance	182 (80)^{3}	281 (71)^{3}	51 (71)^{1}	20 (80)^{4}	534 (74)^{3}	0.07
Verbal Aggression	170 (75)^{4}	273 (69)^{4}	45 (63)^{5}	22 (88)^{2}	510 (71)^{4}	0.04
Suspicious/paranoid ideas	164 (72)^{5}	234 (59)^{5}	39 (54)	16 (64)^{5}	453 (63)^{5}	0.004
Anxiety symptoms	117 (52)	232 (59)	41 (57)	16 (64)^{5}	406 (57)	0.3
Severity of memory impairment	68 (30)	181 (46)	47 (65)^{3}	7 (28)	303 (42)	< 0.001
Physical Health						
Falls	205 (90)^{2}	345 (87)^{1}	62 (86)^{1}	23 (92)^{1}	635 (88)^{1}	0.6
Infection	208 (92)^{1}	321 (81)^{2}	61 (85)^{2}	21 (84)^{2}	611 (85)^{2}	0.004
Delirium	195 (86)^{3}	281 (71)^{3}	49 (68)^{3}	18 (72)^{3}	543 (76)^{3}	< 0.0001
Immobility	102 (45)^{4}	202 (51)^{4}	30 (42)^{5}	11 (44)^{5}	345 (48)^{4}	0.3
Incontinence	88 (39)	190 (48)^{5}	44 (61)^{4}	16 (64)^{4}	335 (47)^{5}	0.006
Medication Side Effects	93 (41)^{5}	169 (43)	28 (39)	6 (24)	296 (41)	0.3
Alcohol Problems	52 (23)	73 (18)	11 (15)	11 (44)^{5}	147 (20)	0.02
Vulnerability						
Inability to identify potential risks	173 (76)^{1}	298 (75)^{1}	55 (76)^{1}	20 (80)^{1}	546 (76)^{1}	1.0
Very poor eating and drinking	170 (75)^{3}	267 (68)^{2}	43 (60)^{3}	18 (60)^{3}	495 (69)^{2}	0.04
Person with dementia is being abused	173 (76)^{1}	245 (62)^{3}	44 (61)^{2}	14 (56)^{4}	476 (66)^{3}	0.001
Declining support services	140 (61)^{4}	220 (56)^{4}	41 (57)^{4}	13 (52)^{5}	414 (58)^{4}	0.5
Outdoor Safety	129 (57)^{5}	188 (48)	35 (49)^{5}	13 (52)^{5}	365 (51)^{5}	0.2
Severe neglect of personal hygiene	120 (53)	194 (49)^{5}	29 (40)	17 (68)^{2}	360 (50)	0.1
Family Carer						
Family Carer burden	182 (80)^{2}	314 (80)^{1}	62 (86)^{1}	19 (76)^{2}	577 (80)^{1}	0.6
Sudden absence of family carer	184 (81)^{1}	296 (75)^{3}	53 (74)^{2}	20 (80)^{1}	553 (77)^{2}	0.3
Family Carer's physical health	165 (73)^{3}	301 (76)^{2}	49 (68)^{3}	18 (72)^{4}	533 (74)^{3}	0.4
Death of the family carer	160 (71)^{4}	268 (68)^{4}	43 (60)	17 (68)^{5}	488 (68)^{4}	0.4
Family Carer mental health	146 (64)^{5}	235 (60)^{5}	46 (64)^{4}	19 (76)^{2}	446 (62)^{5}	0.3
Family Carer unable to access services	110 (49)	207 (52)	46 (64)^{4}	12 (48)	375 (52)	0.1
Environment						
Physical hazards around the home	162 (71)^{3}	315 (80)^{1}	46 (64)^{4}	16 (64)	539 (75)^{1}	0.005
Hazards related to daily living tasks	172 (76)^{1}	264 (67)^{3}	44 (61)^{5}	18 (72)^{2}	498 (69)^{2}	0.04
Living Alone	136 (60)	286 (72)^{2}	55 (76)^{1}	15 (60)	492 (68)^{3}	0.004
Unable to access essential amenities	164 (72)^{2}	261 (66)^{4}	43 (60)	18 (72)^{2}	486 (68)^{4}	0.2
Changes in the home environment	161 (71)^{4}	254 (64)^{5}	48 (67)^{2}	19 (76)^{1}	482 (67)^{5}	0.3
Inadequate community services	138 (61)	238 (60)	44 (61)^{5}	15 (60)	435 (61)	1.0
Unsuitably trained care staff	139 (61)^{5}	230 (58)	45 (63)	18 (72)^{2}	432 (60)	0.5
Lack of coordination between health/social services	108 (48)	248 (63)	48 (67)^{2}	18 (72)^{2}	422 (59)	<.001

*1-5 -Top five rankings for the cause of crisis in dementia, in order of importance

Table 3: Top five Interventions to help manage a crisis in dementia

Ranked list of interventions	Mental Health Practitioners (n=227)	Physical Health Practitioners (n=395)	Consumers (n=72)	Academics (n = 25)	All participants (n = 719)	p value
Professional Healthcare	**n (%)**	**n (%)**	**n (%)**	**n (%)**	**n (%)**	
Professionals available 24 hours a day	158 (70)[1]	301 (76)[1]	48 (67)[1]	15 (60)[1]	522 (73)[1]	0.07
Accident and Emergency services	142 (63)[4]	272 (69)[2]	48 (67)[1]	14 (56)[2]	476 (66)[2]	0.3
Healthcare professionals longer hours	155 (68)[2]	261 (66)[3]	44 (61)[5]	11 (44)	471 (66)[3]	0.1
Safeguarding adults team	143 (63)[3]	236 (60)[5]	44 (61)[5]	14 (56)[2]	437 (61)[4]	0.8
Telephone Helpline	123 (54)[5]	246 (62)[4]	45 (63)[4]	13 (52)[5]	427 (59)[5]	0.2
One point of contact	123 (54)[5]	217 (55)	47 (65)[3]	14 (56)[2]	401 (56)	0.4
Social Home Care						
Emergency provision of care	187 (82)[1]	340 (86)[1]	62 (86)[1]	21 (84)[1]	610 (85)[1]	0.6
Emergency services	186 (82)[2]	335 (85)[2]	61 (85)[2]	21 (84)[1]	603 (84)[2]	0.8
Centralised database of people and their needs	153 (67)[3]	271 (69)[3]	49 (68)[3]	15 (60)[3]	488 (68)[3]	0.8
Flexible provision of services	151 (67)[4]	262 (66)[4]	44 (61)[4]	14 (56)	471 (66)[4]	0.6
Specialist training for home care staff	98 (43)[5]	124 (31)	30 (42)[5]	8 (32)[5]	260 (36)[5]	0.02
Home care services	80 (35)	143 (36)[5]	25 (35)	8 (32)[5]	256 (36)	1.0
Family Carer						
Respite in the home	193 (85)[1]	337 (85)[1]	61 (85)[1]	20 (80)[1]	611 (85)[1]	0.9
Respite in a residential care home	188 (83)[2]	333 (84)[2]	57 (79)[2]	20 (80)[1]	598 (83)[2]	0.6
Respite in a day centre/day hospital	182 (80)[3]	322 (82)[3]	57 (79)[2]	19 (76)[3]	580 (81)[3]	0.8
Counselling	56 (25)[4]	116 (29)[4]	22 (31)[4]	4 (16)[5]	198 (28)[4]	0.3
Family Carers Education	53 (23)[5]	108 (27)[5]	22 (31)[4]	5 (20)[4]	188 (26)[5]	0.5
Home Living Environment						
Communication equipment	173 (76)[1]	296 (75)[1]	50 (69)[1]	11 (44)[3]	530 (74)[1]	0.008
Presence of family carer	161 (71)[2]	244 (62)[2]	44 (61)[3]	16 (64)[1]	465 (65)[2]	0.1
Supportive neighbours/friends	142 (63)[3]	224 (57)[3]	45 (63)[2]	13 (52)[2]	424 (59)[3]	0.4
Specialist Assistive Technology	90 (40)[4]	114 (29)[4]	20 (28)[4]	3 (12)[4]	227 (32)[4]	0.004
Administering/monitoring medication	62 (27)[5]	66 (17)[5]	11 (15)[5]	3 (12)[4]	142 (20)[5]	0.008

*1-5 -Top five rankings for the cause of crisis in dementia, in order of importance

Table 4: Top five Interventions to help prevent a crisis in dementia

Ranked list of interventions	Mental Health Practitioners (n=227)	Physical Health Practitioners (n=395)	Consumers (n=72)	Academics (n = 25)	All participants (n = 719)	p value
Professional Healthcare	**n (%)**	**n (%)**	**n (%)**	**n (%)**	**n (%)**	
Referrals made earlier to support services	198 (87)^3	369 (93)^1	62 (86)^1	22 (88)^1	651 (91)^1	0.02
Coordinated care plan	203 (89)^1	353 (89)^2	62 (86)^1	22 (88)^1	640 (89)^2	0.8
Specialist training for healthcare staff	200 (88)^2	351 (89)^4	62 (86)^1	20 (80)^3	633 (88)^3	0.5
Specialist multi-disciplinary assessments	194 (86)^5	353 (89)^2	58 (81)	18 (72)	623 (87)^4	0.02
Provision of purposeful activities	197 (87)^4	337 (85)	59 (82)^4	17 (68)	610 (85)^5	0.1
Person with dementia involved in care planning	188 (83)	340 (86)^5	48 (67)	19 (76)^5	595 (83)	0.001
Physical health checks	184 (81)	329 (83)	56 (78)^5	18 (72)	587 (82)	0.4
Medication Review	162 (71)	323 (82)	49 (68)	20 (80)^3	554 (77)	0.005
Day hospital	154 (68)	289 (73)	42 (58)	19 (76)^5	504 (70)	0.06
Social Home Care						
Specialist training for home care staff	215 (95)^2	376 (95)^1	67 (93)^1	20 (80)^3	678 (94)^1	0.04
Home care services	217 (96)^1	362 (92)^3	65 (90)^2	22 (88)^1	666 (93)^2	0.1
Day care services	203 (89)^3	366 (92)^2	62 (86)^3	22 (88)^1	653 (91)^3	0.2
Flexible provision of services	185 (82)^4	291 (74)^4	56 (78)^4	17 (68)^4	549 (76)^4	0.1
Centralised database of people and their needs	120 (53)^5	242 (61)^5	46 (64)^5	14 (56)^5	422 (59)^5	0.2
Family Carer						
Family Carers Education	216 (95)^1	374 (95)^1	68 (94)^1	20 (80)^3	678 (94)^1	0.05
Planning care with family carer	213 (94)^2	373 (94)^2	67 (93)^2	19 (76)^5	672 (94)^2	0.02
Carer Support Groups	197 (87)^3	355 (90)^3	61 (85)^3	21 (84)^1	634 (88)^3	0.4
Counselling	190 (84)^4	348 (88)^4	60 (83)^4	19 (76)^5	617 (86)^4	0.2
Advice about financial matters	171 (75)^5	346 (88)^5	57 (79)^5	21 (84)^1	595 (83)^5	0.001
Home Living Environment						
Routine of daily living tasks	204 (90)^1	368 (93)^1	67 (93)^2	23 (92)^1	662 (92)^1	0.5
Administering/monitoring medication	204 (90)^1	366 (93)^2	62 (86)^3	21 (84)^3	653 (91)^2	0.1
Presence of family carer	200 (88)^3	354 (90)^5	68 (94)^1	23 (92)^1	645 (90)^3	0.5
Home equipment/adaptations	196 (86)^4	357 (90)^3	62 (86)^3	21 (84)^3	636 (89)^4	0.3
Prompts/cues around the home	186 (82)	357 (90)^3	52 (72)	20 (80)^5	615 (86)^5	<0.001
Supportive neighbours/friends	196 (86)^4	331 (84)	56 (78)^5	19 (76)	602 (84)	0.2
Specialist Assistive Technology	188 (83)	339 (86)	56 (78)^5	18 (72)	601 (84)	0.1
Engaging in purposeful activities	186 (82)	336 (85)	55 (76)	20 (80)^5	597 (83)	0.3

*1-5 -Top five rankings for the cause of crisis in dementia, in order of importance