

The Development of End of Life Care Standards for People with End Stage Dementia

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Introduction

A myriad of disparate standards have been developed for older people in long stay care both in the Republic of Ireland, Northern Ireland and in the UK including:

- (i) nursing home (DHSSPSNI,2008, DOH,2003, HIQA,2008)
- (ii) residential (DHSSPSNI, 2008)
- (iii) dementia care (NCF, 2007)
- (iv) death and dying (DOH, 2009)
- (v) end of life (EoL) (HFH,2010) and
- (vi) bereavement (DHSSPSNI, 2009)

However a review of these standards demonstrates a notable absence of a specific standard or guideline for the provision of end of life (EoL) care to people with dementia.

Whilst some might argue that generic standards and guidelines are adequate for this group, the unique and complex needs of people with end stage Alzheimer's disease, or the related dementias are often poorly understood, inappropriately addressed and regularly neglected. It is noted that, too little or too much, is often done for them in environments, which hinder rather than support optimal care (Downs et al, 2006). The needs of this large group of people with dementia approaching EoL are so particularly challenging that they clearly warrant independent dementia-specific guidelines.

The aim of this study was to contribute to improving quality of life for people with end stage dementia living in residential care settings by investigating the experiences of elderly spouses whose relatives had recently died with end-stage dementia in nursing homes in both Northern Ireland (NI) and the Republic of Ireland (RoI). In addition, from the data collected, guidelines will be drafted for delivery of quality care in end stage dementia in long stay residential institutions. The drafted guidelines will then be circulated to a multi-disciplinary group of health service professionals across Ireland (four health service professionals in NI and four in RoI) and their views on the guidelines sought.

Literature Review

A short literature review was carried out using the online search engine PUB MED and the search terms, 'Dementia', 'End of Life', 'Palliative Care', 'Residential Care', and 'Alzheimers'. In addition articles were located through bibliographical searches from these papers as well as from key reports produced in the UK and Ireland. This review summarises the key findings from this search.

People dying from and with a dementia are an especially vulnerable group. Their EoL care needs may be further complicated by cognitive impairment; the prolonged illness trajectory, pain and communication difficulties, challenging behaviours and often the absence of staff specifically trained to manage both EoL and dementia care issues. It has been argued that good EoL care is dependent on sound clinical leadership, education for care staff and a more collaborative approach with families (Ryan et al, 2009). In this way a coherent, relationship-centred approach can be achieved (Ryan et al, 2009). Tilley and colleagues writing from the US, recommend the importance of consistency in individualized or person-centred care approaches, the development of relationships between staff and residents and increasing staff knowledge of individual resident needs abilities and preferences (Tilley & Fok, 2008). Volicer, who has produced scales to evaluate end of life care needs of people dying from dementia, (Volicer et al, 2001) advocates for appropriate management of symptoms such as pain and behaviours for those with advanced dementia, the involvement in programs such as hospice, and decisions regarding various medical interventions. A crucial component of end of life care, he and his colleagues argue, is transmission of information to the resident's surrogate decision maker. The benefits and burdens of interventions and the development of a care plan that considers previous wishes of the resident, if any, is vital to ensure the residents' best interests as interpreted by the decision maker.

Several experts (Bayer, 2006, Tilley & Fok, 2008) writing about death and dementia have called for care to extend beyond symptom control and encompass patient's psychological and spiritual needs as well as a consideration of the needs of their families who have often borne the burden of care for many years. Hughes and his colleagues, in a powerful editorial in the BMJ, make a case for specialist hospices for people with advanced dementia and call for the use of palliative care approaches which

foster holistic care.(Hughes et al, 2005). They argue that by encouraging an empathic approach, reflected in a social environment rich with meaningful activities, the judicious use of medicine and specialist teams, quality of life for people with dementia can be nurtured and enhanced.

One of the largest prospective studies which looked at 438 people who developed dementia in England and Wales has highlighted that people with dementia need a wide range of coordinated care and support from a variety of services to meet their particular needs. (Xie et al, 2008). In another interesting article, reported in the literature in 2005, a call for the development of practice guidelines for EoL care and dementia was made and an argument marshalled that compared with cancer care, there was little practical guidance on the provision of EoL care in dementia (Robinson et al, 2005). The recently completed National Audit of End of Life Care in Hospitals undertaken by the Hospice Friendly Hospitals (McKeown et al, 2010) assessed quality of care provided by Irish hospitals in the last week of life and concluded that quality of care and quality of life for those dying in Irish hospitals was good. It was noted in this study that experiences are influenced by patient's symptoms and the type of care provided and that the latter in turn determine relatives' views of death.

Methods

This study had two phases. Phase one involved conducting in-depth qualitative interviews according to a piloted protocol with 16 elderly spouse caregivers (8 from NI and 8 from RoI) whose relatives had died from dementia in long stay care environments. The purpose of these interviews was to collect information on family caregivers' experiences of their spouses' end of life care.

Phase two entailed incorporating the information gathered into draft guidelines and disseminating these to a multi-disciplinary group of health service professionals for their views. The draft guidelines were then amended.

Phase 1

Sampling

The sample was recruited through statutory and independent Nursing Homes, Carers' Organisations, (Caring for Carers Rol, and Alzheimer's Society NI) the Northern Ireland Hospice, and organisations such as Nursing Homes Ireland and the Independent Health and Care Providers. After contact with 170 Nursing Homes and 4 organisations, 33 information packs were sent out in NI, detailing the study, its aims and enclosing consent forms. Out of this group, a total of 8 subjects consented to participate in this study and agreed to be interviewed. These 8 bereaved spouses were recruited from 5 independent nursing homes and 1 supported housing scheme. The original protocol stipulated that to be eligible for the study, death of the spouse needed to have occurred within the last 6 to 24 months. However with recruitment so difficult, the restriction regarding time since death was removed. Ethical approval in NI through ORECNI required that Nursing Homes needed to make direct contact with potential subjects and contact details for potential participants could only be accessed by the research team after completed consent forms were returned.

Ethical approval in the Rol was less proscriptive. Accordingly in Rol, contact was made with senior staff in twenty-two Nursing Homes known to professionals working in the area of dementia and end of life care. These staff identified relevant family members, and obtained their verbal consent to participate. Their names and details were then given to the researcher for a follow up phone call about the study. Eight family caregivers were recruited in the Rol, three through Caring for the Carers, two from a Dementia Unit in a private nursing home, two from a Health Service Executive Nursing Home and one from a general private nursing home.

Data Collection Instrument

Drawing extensively on Volicer's original work where three scales along with sub-scales were developed to evaluate end of life care and dementia (Volicer et al, 2001), an interview schedule was designed to examine older spouses' experiences of the time period leading up to and surrounding their relatives' death. The interview schedule was divided into 7 sections:

Section 1 and 2, collected socio-demographic data and explored the profiles of the deceased and the bereaved spouses.

Section 3, collected general information about the time spent by the deceased in the nursing home.

Section 4, explored quality of care issues in the last 90 days prior to death.

Section 5, explored symptom and pain control.

Section 6, investigated comfort control approaching death.

Section 7, the final part of the interview schedule (not reported on here) examined post-bereavement experiences.

The instrument was piloted on two bereaved spouses and subsequently revised and confirmed.

Data Analysis

The methodological approach used to analyse the data collected was qualitative thematic analysis (Seale et al, 2007). Interviews were recorded using a digital recorder and all recordings were transcribed. One researcher initially read and re-read the transcripts to ensure familiarity with the interviews (Denscombe, 2007) and to ensure no subtleties had been missed. Responses pertaining to individual questions from each interviewee were summarized on a structured table and key quotes noted. This information was then scrutinised and themes emerging from the data identified. The research team discussed the initial findings and then verified the interpretations through examination of the transcribed interviews. Minor adjustments were made and findings discussed and agreed.

Phase 2

Based on findings emerging from Phase 1 of this study, guidelines to assist Nursing Homes to develop policies and practices on end of life care for residents with dementia were developed.

Sampling

These guidelines were then circulated to a selected sample of eight professionals known to the three researchers who were invited to read the guidelines and provide feedback. The sample of professionals included a Geriatrician, Old Age Psychiatrist, two Palliative Care Physicians, three specialist Nurses, and a Dementia Expert.

Results

Table 1 reports findings on the socio-demographic profile of the sample of bereaved family caregivers. It shows that all but four of the sample were elderly wives whose mean age was 77 (range was 62 to 88 years). Most had been in long-term marriages, with the mean duration of marriage 46 years (range was 18-60 years).

Table 2 reports findings on key characteristics of the sample of deceased men and women. It shows that the majority of the deceased were men whose mean age at death was 81 years. Most (13 out of 16) had a formal diagnosis of dementia but only one had been told of his diagnosis. Diagnoses tended to be made by either Psychiatrists or GPs and other health service professionals. The mean length of stay in nursing homes was almost three years (33 months). In all but two of the death certificates, dementia was not mentioned as the primary cause of death. In seven cases dementia was referred to as being a secondary cause of death. All but three of these deaths occurred in Nursing Homes. The remaining deaths occurred in hospitals.

Satisfaction with Care

Quality of Care at End of Life (last 90 days)

In response to a series of questions asked about how the Nursing Home cared for the deceased person during the last 90 days of life, 13 out of 16 respondents reported that their relative received good care². The same 13 respondents stated that their relative was kept comfortable during the last 90 days of life. All but two respondents claimed their spouses received the nursing care needed and 12 out of the 16 respondents interviewed (75%) described the care received from Nursing Home staff in very positive terms.

When asked to identify what staff actions were taken to ensure their relative's comfort during this period, good personal care emerged as the greatest contributor to resident comfort. Caregivers' narratives revealed how this support was provided practically and honed in on issues such as personal hygiene, body temperature, and maintaining the dignity of their dying spouse.

"They changed his position, they turned him around, they changed the bed linen on the bed." Ro14

"Just changing him regularly, keeping him dry and they turned him in and out, they made sure he wasn't lying on one side and he got turned over. I wouldn't say there was any one thing it was just the general care, it was just good all round care...He never had any skin breakdown, he was well nourished, they took time to feed him if I wasn't there. He always looked nice, his clothes were clean." NI6

"I think all those little things that he was made really comfortable physically. They were very understanding just down to how warm he was, how cold he was you know, what he needed on top of him, his pillows you know just very small details like giving him his face and hands a wee wipe because they felt a bit clammy or you know changing quilts, changing sheets. It was excellent care." NI2

² For detailed findings on the three dissatisfied family caregiver, please see Appendix 1.

Person-Centred Care

The perceived caring attitudes of nursing home staff, their professionalism, and the person/relationship-centred way in which end of life care was delivered to dying spouses emerged as the most valued aspects of care for fourteen out of the sixteen respondents (88%). Most bereaved spouses also commented on the way in which Nursing Home staff monitored and spent time physically in the company of their relatives when they themselves were unable to be present. Knowing that staff were physically present with their dying relatives inspired trust and relieved anxiety. Many were also pleased that staff continued to verbally communicate with their dying relatives, even in circumstances when the latter could no longer understand verbal communication. Bereaved spouses reported they appreciated their dying relative being treated with dignity and empathy, being listened to, being treated as normal people and on occasion, being joked with:

“And the nurses would laugh with him and he thought this was just wonderful and they would tease him and he just thought he was the cat’s pajamas.” NI6

“You know they were talking to him, they were laughing with him, they were joking. I don’t know how much he understood and they would have come in you know when they wouldn’t have had to come in. They were sort of with him constantly you know so it was sort of very very good.” NI2

“I think the fact that the staff tried to listen to him even if he wasn’t making a lot of sense, they would stand there and listen to him.” NI6

“If you came and slipped quietly down to his room before you went in you could hear somebody talking to him and calling his name and that kind of thing so it wasn’t a pretence to us, it was what happened.” Ro14

“What I loved most was that they would get down if he was sitting in his reclining chair. They got down on their hunkers so that they were at eye level with him to try to figure out what he was trying to get across.” NI6

Pain and Symptom Control at End of Life

Twelve (75%) of the sample acknowledged that their spouse did not appear to be in pain during the end of life period. Only two bereaved spouses claimed they were unsure about their relatives' pain control and two were unable to answer the question.

"If he needed pain relief he got it oh he got it." NI6

"This was one of the things that I felt very content about...they were looking after that (pain)." NI3

"I don't know whether he had pain or what." RoI1

Findings also showed that bereaved spouses had a high level of confidence in the medical care administered during the last 90 days of life. The level of confidence in the medical care received was marginally higher in NI (87%) compared with RoI (75%). Medical care at end of life was interpreted by most as care provided by GPs. Interestingly where confidence was low, three (19%), this was related to the absence of regular GP visits to the nursing home. One person referred to the need for GP training in dementia and another believed that there should be doctors available with a specialist remit in dementia. None of the 16 respondents claimed their relative was under-treated at end of life and only one person stated that her spouse was over-treated. In this case the gentleman, according to his wife, was admitted too often and unnecessarily to hospital, *"It was too often and not doing him any good."* NI7

According to bereaved spouses, the most important aspect of medical care was the individualized attention given by GPs. Only one respondent experienced a community palliative care team approach, where the GP, Nurses and Palliative Care Specialists worked collaboratively in delivering care. In two other cases the dying person experienced end of life care in a facility where nurses were specially trained in Palliative Care. In general these spouses' experiences of Palliative Care Teams (N=1) and palliative care approaches (N=2) were very positive:

“The palliative care team came in a lot. Matron suggested they call in palliative care. When the lady from palliative care came in we had music on in the corner of the room but it was like running water. We were all sitting around and she just said, “this is lovely and peaceful and xxx is so lucky.” It was lovely having her there...” Ro14

“The doctors were very good, if they had to come they were here immediately...there was a charge nurse from the dementia unit and I just felt she was really tuned into x.....it was just a whole team really and I felt very much part of that team.” NI2

Hospital Care

Hospital experiences were reported mostly in negative terms. Six spouses reported very unpleasant experiences relating to the impact of hospitalization on the wellbeing of the person with dementia. They referred to hospital environments being inappropriate and that staff lacked the knowledge and skills necessary to care for people with dementia-

“I don’t think general hospitals provide for people with dementia...they just don’t have the facilities.” NI2

“They weren’t able to cope with the dementia side of things and they’d have been ringing me up at all hours of the night to say X wants to speak to me you know and sometimes she would be pacified but when I would go in she was usually in a terrible state wandering about. That was a very difficult time.” NI3

“He used to be terribly disturbed by going into hospital.” Ro12

Staff Training

Whilst no specific questions were asked about staff training on specialist end of life and dementia care, six respondents volunteered information on this topic. Three people referred specifically to the importance of and need for general dementia staff training:

“Every nursing home should have people who understand dementia.” NI3

“There has to be a lot more training and a lot more in-depth training - not just about the symptoms of dementia.” NI2

Three other respondents made particular reference to the need for specialist training in palliative care and specialist dementia care.

“I think staff both medical and nursing should have more training in treating dementia patients...I think Medical care should be provided by a specialist in dementia and not a GP who as far as I know only sees a patient when called in due to illness... there were no specialist nurses or others to provide Palliative Care.” Rol6

Decision-Making, Relationships and Trust

When asked to identify who was in charge of their spouses' end of life care, two respondents identified the Nurse Manager, two referred to an individual nurse staff member and one reported that the Proprietor of the Nursing Home was in charge home. Another five claimed that a combination of staff, including the Nursing Home Proprietor and Manager, were in charge and two others, nominated the nursing home staff in collaboration with the GP. One person did not identify any one person. Two stated that they felt that a team of which they were also a member was in charge. Interestingly, one elderly husband stated that he was in charge of his wife with dementia. This situation was unusual in that both he and his wife lived in supported housing, with the husband primarily supporting and caring for his wife, while the staff supported him in the delivery of that care.

Eight out of the sixteen spouses (50%) reported they had major decisions to make during the last three months of care and six of these men and women felt fully informed about and involved in the decision-making process. Important decisions centred around (i) Admissions to hospital 4 (25%); (ii) Removal of PEG feeding 1 (6%); (iii) Treatment decisions including treatment for other illnesses/not dementia 2 (13%); and (iv) Medication withdrawal 1 (6%). Being kept informed and working in partnership with staff was deemed important particularly when decisions had to be taken in the best interests of the person with dementia. A few interviewees emphasized the importance of taking time, if available, to ensure the right decision was being taken.

“I took my time and figured out whether it was the right thing or what was the best thing to do rather than just running into it without thinking about it and afterward then realising it was a mistake.” NI8

“The person who is not affected is left with all the decisions. These decisions were so tough. ...the 3 GPs in the practice and they had spent a lot of time with me and explained that this is what’s going to happen if we keep this in you know so I was well enough informed about that.” NI2

Only two respondents reported not being well prepared for decision-making at their relatives’ end of life. Both these spouses had been advised about the need for hospitalisation (in one case by the GP, and in the other by Nursing Home staff) and asked if they wished their relative’s hospital admissions to proceed. Their responses reflected that they were unprepared to make such decisions and had difficulty understanding the responsibility involved. These bereaved spouses claimed they ultimately based their decisions on the best interests of the person with dementia. Although only one dying person had made an Advanced Directive, other bereaved spouses involved in decision-making, claimed that knowing what they considered to be appropriate and “right” for their relative made decision-making easier.

Relationships

In reporting their experiences of good quality care, bereaved spouses frequently referred to their evolving relationships with nursing home staff and with other residents and their family members. Relationships were fostered and developed through regular and often daily visiting, to the extent that several bereaved spouses expressed feelings of being part of a family within the Nursing Home. The comment of one bereaved spouse echoed the views of several others. She reported:

“Well I felt like part of a family. And somehow or other they treated him like a member of the family you know. ...I think the dementia unit is like a family you know all the residents are like part of one big family. ...I think they were feeling what I was feeling to a degree, what my family were feeling, because he was like part of their family.” NI2

Over time, regular visits and liaison with staff engendered trust:

“Complete and total trust in the decisions that were made here. I had total confidence in the decisions here.” Ro14

“Extremely understanding they just...they knew exactly how to deal with things as they arose.” NI4

“I knew that he was getting the best possible care. I wouldn’t have been happy if he was being neglected.” NI1

Not everyone could visit on a daily or frequent basis, because of transport, health or debility and the three people who were generally dissatisfied with care were the same three spouses who had been unable to visit on a daily basis.

Time of Death

No interviewee referred to anything in the nursing home that was deemed unsupportive at the time of death. In response to another question asked about grief, nobody stated that their grief had been affected negatively by the actions of the nursing home staff.

The support and understanding of staff was especially valued by bereaved spouses at the time of death. All those who experienced good care thought staff were very understanding of the needs of the person with dementia at end of life and also mentioned to how they trusted the Nursing Home staff. Interestingly two of the three people who had concerns about care in general claimed they were content about the care provided during the last week of the life of the person with dementia.

Phase 2 Results

Based on these interviews, a draft guideline to assist individual nursing homes to develop policies and practices in relation to end of life care for residents with dementia was developed. These guidelines centred around 5 core areas:

- (i) Person-centred care underpinned by a knowledge of the dying person's life history.
- (ii) Good personal-care based on ongoing assessment and attention to detail.
- (iii) Staff-training in the needs of people with dementia at the end of life.
- (iv) A partnership approach with the nursing home fully integrated into local health care systems.
- (v) A shared approach to care with trusting relationships and involvement in and support with decision-making.

Phase 2 of the study involved distributing a draft version of a proposed guideline to a total of 8 health care professionals who were asked to provide critical feedback. Analysis of these reviews reflected concerns that:

- (i) The guideline read more as a philosophy of care rather than as a template for practical delivery of specific care.
- (ii) There was a need to remove the word "holistic" and consider terms such as "the physical, social psychological and spiritual needs" of those with end stage dementia.
- (iii) There was a need to include reference to specialist gerontological nurse training.
- (iv) The title for the guideline should be amended, as "end of life care" is ambiguous particularly in the dementia context since dementia is a terminal condition.

Other suggestions were more of an editing nature. The guidelines were subsequently reviewed and revised in accordance with the helpful professional feedback received. A revised guideline was then completed.

Discussion

Our findings show that the bereaved spouses who participated in this study were mainly satisfied with the level of care their relatives with dementia received at end of life as residents of nursing homes. Fourteen out of sixteen (87%) of those interviewed reported their spouses received all the care required in the last three months of life and 12 out of 16 (75%) described care in very positive terms using words such as “excellent, superb and second to none”. Some might reflect that elderly spouses would have a vested interest in believing that the care that their partner received was exemplary as to not think so could be a source of self-guilt and recrimination. However the praise for staff and for the kindness and professionalism experienced was so clear and resounding it would be hard to think it was anything other than truly authentic.

None of those interviewed believed their relative was under-treated at his or her end of life and only one respondent claimed that the deceased person was over-treated. A large majority, 75% reported their relative was in no pain during the last 90 days of living.

What was reported as most valued by the sample of bereaved spouses (N=16) at end of life, was good personal care underpinned by a person-centred philosophy that was inclusive of family members, and that enabled them to participate in appropriate decision making at end of life. Bereaved spouses who were satisfied with the care offered, appreciated working in partnership with health service professionals and were kept well informed about issues of relevance to their relatives’ care and comfort.

Overall our findings support the literature and suggest that from the caregivers’ perspective, good end of life care was dependent on clinical leadership, on collaborative approaches on staff education (Ryan et al, 2009) and on individualized person-centred care (Tilley & Fok 2008) which spawned trust in relationships between staff, relatives and residents. Whilst the case for specialist hospice care for those dying with dementia did not emerge in this research, nonetheless it is worth noting that the three families who had the opportunity to experience palliative care approaches were very appreciative of the same. The need for end of life care to extend beyond symptom

control and explicitly encompass patient's psychological and spiritual needs as well as the needs of family caregivers (Bayer, 2006) did not emerge as that salient in this study.

It is worth noting that in relation to the three respondents who were critical of the nursing home care provided, none were in a position to visit the nursing home on a daily basis. Whilst their dissatisfaction with the quality of care provided may be explained by a number of different factors, nonetheless it must be remembered that the absence of frequent visits and probably less involvement and knowledge about the care being administered combined with less opportunity for communication and relationship building may have heightened dissatisfaction. We need to remember that it may not always be easy for elderly relatives including frail spouses to visit nursing homes on a regular basis. Transport, health, other disability issues and indeed fear of what they are about to confront may act as barriers. Our findings suggest that Nursing Homes need to consider the needs of this vulnerable group who may feel disconnected from their loved one during this critical time. Strategies could be developed by Nursing Homes to facilitate more meaningful visits or other methods of maintaining close involvement at this crucial time.

Conclusions

This study shows that the care delivered to residents living in Nursing Homes with dementia at the end of life was deemed by spouses to be of high quality, contrary to some of the stories highlighted in the media. In particular, person centred, individual, kind and professional care is valued, as is the capacity for Nursing Home care staff to develop close working relationships with both residents and their families. Poor communication, lack of involvement in key decisions, and any sense of the resident not being treated respectfully as a person, or not well symptom controlled, were particular areas of dissatisfaction for a few of these spouses. The subsequent guideline produced was well received by health care professionals with the reservation that in order to be effective such a guideline needs to be practical, and many of these areas relate to an underlying *philosophy* of good quality care. Finally, we hope that the information gained from the research interviews and the resultant guideline developed will contribute to improvements in the care of people with dementia at end of life and should form a basis for the future development of policy, practices and procedures.

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Table 1: The Socio-Demographic characteristics of Bereaved Spouses

N	N=16	%
Gender of Bereaved Spouse		
Female	12	66
Male	4	34
Mean Age of Bereaved Spouse	77	
Range	62-88	
Mean number of Years Married	46 years	
Range	18-60	
Mean time since spouses' death	34 months	
Range	8-100	

Table 2: The Socio-Demographic characteristics of the deceased, their diagnoses and the cause of death

N	N=16	%
Gender of Deceased Spouse		
Female	4	34
Male	12	66
Mean Age of Bereaved Spouse		
Range	67-95	
Formal Prior Diagnosis of Dementia		
Yes	13	
Probably	2	
No formal diagnosis of dementia	1	
Diagnosis made by		
Psychiatrist	5	
GP and or others	4	
Psycho-Geriatrician	2	
Neurologist	2	
Consultant and other	1	
Person with dementia told Diagnosis		
Yes	1	
No	12	
Not sure	3	
Mean Length of time in nursing home		
Range	3-108 months	
Place of Death		

Nursing Home	13	
Hospital	3	
Dementia as primary cause of death		
Yes	2	
No	11	
Unsure	1	
Dementia named as other significant cause of death		
Yes	7	
No	6	
Not sure	3	

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Appendix 1

Dissatisfaction with Care

Quality of Care in Last 90 Days

Only 3 out of the 16 bereaved spouses (19%), expressed overall dissatisfaction in relation to the end of life care their relative received. Two of these three dissatisfied bereaved spouses referred in particular to the lack of personal care provided to their spouse resident in the nursing homes. They stated:

“I think he could have had a change of clothes more often because they left him smelly a few times and he had loads of clothes up there to be changed more often. He needed a little more one to one attention and I think at feeding times in the end they were a bit rough.” Ro15

“I think he should have had a bit more attention.” Ro1

In response to another question asked about what action staff took to ensure comfort needs were met at end of life, two of these three respondents failed to give a clear answer whilst one bereaved husband reported “nothing”. This same elderly man reported how he did not value any particular parts of care, and he “did not know” whether staff were understanding of his wife’s end of life care needs. He said:

“I cannot say the nursing home provided any particular care I would value.” Ro16

Two of these three respondents also referred to poor staffing levels which they argued had a negative impact on the quality of care provided at end of life. Likewise one other bereaved spouse had concerns about staffing levels at night and referred to the overall need to match staffing levels with the needs of the patients

“They could have had more staff.” Ro15

“They didn’t have enough staff. Only for family coming in to look after their loved ones, things could be a lot worse. There could be more incidents and more accidents.” Ro1

“I just wonder you know were there sufficient staff on that night. I don’t know I didn’t ask. ...I think that sufficient qualified carers within the nursing home is really important. ...I think that the relationship to the quality of care that’s needed to each person, that some people need less care, some people are high dependency, there has to be a relationship between the carers and the type of patient or client or person in the nursing home that its quality and numbers.” Rol7

One of these dissatisfied bereaved spouses also complained about the lack of activities available in the nursing home for people with advanced dementia.

“The key thing is a bit of activity. ...They were just sitting all in the room. That’s what I think if she, that’s the only thing I can say if they had got somebody to come in, an activity nurse or something to come in and give them something of interest.” NI5