

Supporting Persons with Intellectual Disability & Advanced Dementia

Fusing the Horizons of Intellectual Disability, Palliative & Person-Centred Dementia Care

FINAL REPORT

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School of Nursing & Midwifery
Trinity College Dublin
Supporting Persons with Intellectual Disabilities & Advanced Dementia



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Introduction

Dementia is an irreversible, progressive, organic disease that has multiple causes. The most common type of dementia is Alzheimer's disease. The increasing survival of people with intellectual disabilities into old age, also means that greater numbers of individuals are surviving into the age of risk where they are developing Alzheimer's dementia. This is particularly true for older people with Down syndrome (DS) who are uniquely at risk of developing Alzheimer's dementia (AD) at earlier ages. Current estimates are that 15-40% of persons with DS over the age of 35 years, present with symptoms of dementia and consequently, their related declines are precipitous (Prasher, 1995; Prasher et al., 1998). Onset is also earlier with the mean age of dementia in persons with Down syndrome being estimated at 51.3 years.

It is evident from reports on the National Intellectual Disability Database in Ireland that we are witnessing a change in the demography of people with intellectual disability. There are increasing ageing trends in the prevalence rates. In 1974, 28.5% of persons registered on the data base were over 35; in 1996 this had risen to 38% and in 2007, the figure was 48% (Kelly et al., 2007). The biggest proportional increase in persons with intellectual disability in the next 5-10 years will be among persons aged 50 years and over and they are at risk of developing age-related diseases such as dementia. There is a lack of preparedness and understanding among staff in the intellectual disability services into the course of dementia, advanced dementia and end-of-life issues (McCarron & Lawlor, 2003; McCallion & McCarron 2004).

Many developments and a core philosophy have shaped current intellectual disability services that now address services for persons in older age. These present competing challenges to service providers. A citizenship model of care emphasises that a person with an intellectual disability be recognised by other people as an individual who is a full member of society (Duffy 2003). As a citizen, the person with intellectual disability should have choice about where to be cared for and where to die and staff are challenged by how then to respond to the additional care needs of the person on a journey with a terminal illness (Blackman & Todd 2005) such as advanced dementia. The training and skill sets of staff in intellectual disabilities services need to be revisited in order to understand and address additional education and training needs.

Palliative care services will also be challenged to provide support for this population. Palliative care has traditionally been provided predominantly to persons with malignant disease and to a lesser extent to persons with some non-malignant diseases (DOH&C 2001). It remains to be demonstrated whether the knowledge gained in other fields such as cancer care will transfer easily to populations

with terminal diseases such as dementia. There are also additional challenges such as (1) the lack of recognition and acceptance that dementia is a terminal illness, (2) the difficulty in prognostication and in the defining of the terminal stage of dementia. The latter is often further confounded in persons with intellectual disability by the level of pre-existing intellectual impairment and sometimes to pre-existing high dependency levels.

Despite the fact that it is generally accepted that palliative care principles should be extended to other groups with terminal illnesses such as dementia, much work remains to be done from a policy, resource and educational perspective to operationalize this intent (Luddington et al., 2001; Lloyd-Williams & Payne, 2002). Many intellectual disability services are poorly prepared to meet and respond to these increasing care needs at end-stage dementia in terms of the suitability of the environments, the skill mix and the knowledge base of staff. Education, training and support for staff are central to utilising principles and practice of palliative care in patients with non-malignancy (Parker et al., 2005). Palliative care specialists may lack the knowledge and skills necessary to communicate effectively with persons with intellectual disability and often have limited experience in working with persons with dementia.

Rationale and Study Objectives

This study began with an effort to understand staff experiences in supporting persons with intellectual disability and advanced dementia. A cross section of intellectual disability service providers and a specialist palliative care provider in the Republic of Ireland were involved in the study. Their experiences were interpreted to gain an understanding of their education and training needs and this information was then the basis for an educational intervention which was designed, delivered and evaluated as a pilot effort with these services. A partnership approach which involved the Trinity College School of Nursing and Midwifery research team, intellectual disability service providers and a specialist palliative care service was crucial to the success of this study.

Study Aims:

- To explore the experiences of staff in intellectual disability and specialist palliative care services in supporting persons with intellectual disability and advanced dementia.
- To develop and deliver an educational intervention which is responsive to the experiences and the related educational needs of intellectual disability staff and specialist palliative care staff in the care of persons with intellectual disabilities and advanced dementia.

The objectives of the study were:

- To explore the experiences of staff from the multidisciplinary teams in intellectual disability services.
- To explore the experiences of staff from the multidisciplinary team in a specialist palliative care service.
- To identify the educational and training needs of staff supporting persons with intellectual disability and advanced dementia in both service systems.
- To develop, deliver and evaluate a responsive educational intervention for paid caregivers in both services systems.

Study Populations

- There were a total of fifty-seven participants in the focus groups. Fifty participants were drawn from six intellectual disability service providers in the greater Dublin area of Ireland. Seven research participants were drawn from one specialist palliative care service in the same catchment area.
- The educational intervention was delivered to sixteen staff drawn from the six intellectually disability services settings.

Data Collection

A total of fourteen focus group interviews were conducted. The data collected captured the experiences of the staff who were currently delivering or had delivered care to persons with intellectual disability and advanced dementia across a variety of care type settings. When the initial recordings and transcripts were listened to and read, they revealed the importance of cultural issues and of concerns among staff in relation to approaches to end-of-life care. Four of the Intellectual disability sites, where there was staff from different cultural groups, were revisited to gather additional data in regard to this. In order to contextualize the data, demographic information was collected on all research participants.

Further data was collected from the participants who undertook the educational intervention. This data included their daily evaluations of the intervention and the findings from pre and post-training questionnaires, which they completed on key end-of-life care concerns.

Data Analysis

Initially, analysis of the focus group data was undertaken manually, followed by the use of a computer-assisted qualitative data analysis software (QAQDAS), NVivo 7 (QSR International 2006). This combined approach was used to maximise thorough analysis. Qualitative content analysis was used as it is the choice most suitable for descriptive qualitative research and it is naturally oriented to the presentation of a summary of the informational contents of the data (Sandelowski 2000). Codes were generated from the data and systematically applied throughout the analysis. During the course of the interviews, the interviewer incorporated

constant comparative analysis which validated and confirmed the participants' descriptions and meanings against concepts which had emerged from previous interviews. Further validation involved exhaustive discussion and verification with other members of the research team. Questionnaire data was entered into SPSS Version 12, descriptive statistics were generated and pre to post questionnaire comparisons were completed.

Ethical Conduct

All research activity associated with the study was in accordance with the regulations of the University of Dublin, Trinity College Guidelines for the conduct of Research Studies (2002). Ethical approval was received from the Faculty of Health Sciences Ethics Committee and from the Ethics Committees of all the participating service providers. Written consent was obtained from all the participants. The anonymity of all the participants was assured through the use of identification numbers rather than the use of names or other identifying information.

The Focus Group Findings

Two core themes emerged from the focus group data:

(1) Building Upon Services' History and Personal Caring: Offering Quality and Sensitive Care.

This core theme speaks to staff perceptions of the essential prerequisites fundamental to good care at end-of-life for persons with dementia. Participants believed that in good care the person is at the centre, quality care, comfort and spiritual support are paramount, and services are delivered in an environment which is capable, peaceful and supportive. For many, small community settings where people had always lived seemed the optimal setting. Good care also includes support for peers, family and staff. The commitment of many participants to sustaining the person where they have also lived was challenged by their concerns for the potential of negative impacts on peers in that setting. Participants recognised that coordination of care across service systems was also needed. While there was great diversity in perceptions regarding the ideal care settings for persons with advanced dementia, there was also a consensus that persons were best cared for in a familiar environment, with familiar staff and a person-centred, coordinated and multidisciplinary approach. Participants further recognised that when dementia is advanced, care needs become more significant and this requires serious attention to appropriate environments, staff skills, supports and resources.

(2) Supporting Comfort and Optimal Death in Persons with Intellectual Disability and Advanced Dementia.

This core theme spoke to a number of critical care concerns, all associated with death and dying. These concerns included symptom control and life sustaining treatment, pain assessment and management, adequate nutrition and hydration, resuscitation,

cultural issues, loss, grief and bereavement, management of the symptoms of dying and the need to acquire the skills to respond effectively. Several interesting issues were highlighted:

1. The absolute desire and commitment of the staff to continue to support persons throughout their journey with dementia and their endeavour to keep them in their usual home.
2. The central tenets of intellectual disability care mirrored those of palliative care; yet, staff in intellectual disability services did not necessarily identify the care they offered as palliative care.
3. Staff would benefit from training to help them appreciate and recognize the quality in what they were doing, and the consistency of their efforts with the principles of palliative care.
4. There were also additional training needs to be met particularly in the area of pain and symptom management and the maintenance of nutrition and hydration.
5. Loss, grief and bereavement and the associated support needs were critical concerns for intellectual disability services staff.
6. Cultural issues were of great influence for staff, particularly on their understanding of end-of-life and their comfort levels with palliative approaches. A disconnect was highlighted for many staff not born in Ireland between personal beliefs about both the need for curative care and rituals around death and the accepted practices they work with in Ireland.
7. Specialist Palliative Care staff identified communication difficulties with persons with intellectual disability, difficulties in understanding needs, lack of a general understanding of dementia, and poor understanding both of current services structures in intellectual disability and where palliative care fits and best addresses the gaps in current service provision
8. Specialist Palliative Care staff recognized that in order to work effectively with intellectual disability services, they needed support in understanding how care was planned, organized and delivered in these services. They valued collaboration with staff who knew the person well and saw themselves primarily in a consultative and educational role.
9. Specialist Palliative Care staff perceived that their major contribution was to support staff in optimal symptom management in the terminal stages of the disease and in helping to address grief and bereavement concerns.

Design and Delivery of the Intervention

A multi-component 20 session educational intervention was developed and implemented by a multi-disciplinary team of trainers drawn from intellectual disability and specialist palliative care services. The intervention was designed to respond to the training needs identified within the two core themes, and recommendations from the literature. The curriculum developed celebrated the individual service systems and their common strengths and addressed disconnects, building synergy to address

care needs through the fusing of perspectives. A continuous quality improvement approach was taken as to its refinement where feedback from the participants and the trainers was used to improve specific content, relevance to staff and overall delivery. The components of the educational intervention included:

- Introduction to the History and Philosophy of Intellectual Disability Care.
- Alzheimer's Dementia in Persons with an Intellectual Disability
- Health Co-morbidities in the person with Intellectual Disability/Advanced Dementia.
- Understanding Person-Centred Care in Persons who are Deeply Forgetful.
- Introduction, History and Philosophy of Palliative Care
- Fusing the Horizons of Care.
- Ethics, Decision-Making and the Person with Intellectual Disability and Dementia.
- Influences of Culture in Approaching Illness, Dementia and Healthcare.
- Death and Dying: Exploring Our Own Values and Beliefs.
- Loss, Grief and Bereavement Theory.
- Loss, Grief and Bereavement in Intellectual Disability Care.
- Breaking Bad News – Some Important Principles.
- Communicating about Loss, Dementia, Death and Dying with Persons with Intellectual Disability.
- End-of-Life Care – the last 24 to 48 hours,
- Teamwork and Collaboration.
- Syringe Drivers.

Formal feedback from staff indicated that the educational intervention was highly valued and addressed key training concerns. They agreed that the training supported 'ageing in place', and the preparation for a good death including support for staff, peers and family in their grief and bereavement. The data collected from the pre and post intervention questionnaires further supported these reports.

Conclusions

The research team, drawing upon the perspectives of the staff within intellectual disability services and specialist palliative care developed a curriculum that celebrated individual service systems and common strengths, brought about a synergy to address care needs through the fusing of service system perspectives and responded to the cultural challenges inherent in a multi-cultural workforce within Ireland.

However, education and training alone will not address all challenges. The narratives of the staff suggested that the emotional costs, distress and exhaustion for intellectual disability services staff were fuelled more often by lack of resources and of appropriate environments than by a lack of understanding of 'good care at end-of-life'. Therefore recommendations for future work and research emerging from this study and the associated training addressed a number of areas:

1. Sustainable services with the ability to develop care for older persons with intellectual disability and dementia are needed.
2. Integrated packages of care are needed, i.e., intellectual disability, dementia and specialist palliative care, responsive to the person's changing needs across the continuum of dementia and including terminal and end-stage dementia.
3. To better address dementia issues, memory clinics are needed within intellectual disability services with collaboration and specialist support from main-stream dementia services.
4. Greater effort is needed in involving the person in planning and in including their views and wishes in end-of-life care.
5. More work is required in understanding the terminal stage of dementia, the duration of this phase, and the timing of modification of aggressive treatment in persons with dementia.
6. Given that cultural differences were identified in beliefs about active vs. versus palliative treatment of people with terminal dementia, rituals at the time of death, and talking to a person about dying, there is a need for further research and training to better understand cultural differences among staff and its implications for care.
7. Specialist palliative support for staff in intellectual disability services is needed to help develop and operationalize emerging end-of-life care guidelines.
8. As is also true for palliative care for the general population, a different relationship is needed with acute care settings to ensure that care planning for end of life is supported when persons with advanced dementia are transferred to these settings; this includes improving understanding by hospital staff of the unique role of intellectual disability services staff in the care and support of persons with intellectual disabilities.

9. Ethics committees are needed in intellectual disabilities services equipped to advise on planning for end-of-life care and on addressing nutrition and hydration and other concerns for families, staff and persons with advanced dementia
10. Additional research and education will be needed to further build capacity to respond effectively to advanced dementia needs.
11. Developments like clinical nurse specialist and nurse practitioner posts in dementia and intellectual disability should be pursued to help services better respond to changing needs and support staff working in these settings.
12. Further research is needed on care needs at different stages of dementia, improved understanding of the range of grief and bereavement experienced by persons with intellectual disability and best practice models for collaboration between intellectual disability and specialist palliative care services.
13. Relationships among the person with advanced dementia, the staff, peers and families appeared critical in supporting a person across the continuum of dementia. Relationship centred care may prove a more fruitful concept in understanding care in advanced dementia and is worthy of future systematic consideration.

This project benefited from the honest expression of caring concerns by staff. There was a desire to offer better care, openness to new ideas and yet a questioning of the alternative specialist palliative care approaches being offered when they appeared to conflict with the philosophies of care in which participants were trained. In the end the researchers were in awe of the thoughtfulness and care offered by staff to the persons with dementia, their peers and their families. This work offers a picture of their experiences and a respectful intervention to respond to their concerns.

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BACKGROUND TO THE STUDY

This work originates from the World Health Organisation (WHO) recommendations that the needs of older people with intellectual disability ought to be included in policies and approaches designed for the betterment of all older people; that access to the full range of health services be assured and that developed countries take a lead in such provision to guide progress in developing countries (Hogg et al., 2000). On a national level, the Irish National Disability Authority (NDA) goes further and recommends that additional services for people with intellectual disability need to be developed in order to address the existing gaps in services (NDA, 2001). Equity of access to healthcare is a key concern for the island of Ireland as highlighted in the Quality and Fairness Health Strategy Report (DHC, 2001). In the pursuit of such improvements, the NDA further recommends that evidence from the national intellectual disability database (Kelly et al., 2007) be incorporated into service delivery and resource allocations. Influenced by all of these documents, this study was designed to improve the care of older persons with intellectual disability by responding to the documented current and predicted increase in numbers of ageing persons noted in the national disability database. It was furthermore designed to encourage an expansion of palliative care health services to this population, and to respond to the NDA concerns about gaps in the services. Finally, it was designed to address the needs of persons with end-stage dementia in ways encouraged by the WHO and which will be exemplary for other nations.

There is a change in the demography of persons with intellectual disability. The recent report from the national disability database suggests that the biggest proportional increase in people with intellectual disability over the next 5-10 years will be in persons aged 50 years and over (Kelly et al., 2007). As well as the benefits that accrue from a longer life, there is also an increased risk of age-associated chronic illnesses including Alzheimer's dementia (McCarron 2003; Tyrrell et al., 2003). This is particularly evident in persons with Down syndrome and there is now general agreement that up to 15-45% of persons with Down syndrome over the age of 40 have dementia; this risk also increases significantly with age (Prasher & Krishnan, 1993). Given pre-existing disabilities, the lack of established memory clinics and appropriately trained personnel, a unique challenge in intellectual disability is the difficulty in the assessing for and in the establishing of the diagnosis of dementia. This is further complicated by the difficulty of defining the terminal stage. This is not unique to persons with intellectual disability as this is also a challenge in the generic population. This situation is further confounded by a lack of preparedness and understanding within intellectual

disability services into the course of advanced dementia and of end-of-life concerns (McCallion & McCarron, 2004).

The growing numbers of ageing persons with intellectual disability and persons with the dual diagnosis of intellectual disability with Alzheimer's dementia are challenging the intellectual disability services system. Without new approaches to meet the needs of this emerging population, there is a danger that the benefits from health and community participation to date for persons with intellectual disability will be reversed in old age. Traditionally, the intellectual disability service system has been underpinned by a philosophy where the major emphasis has been on the empowerment of individuals, on the promotion of skills acquisition, and the building of individual independence; the realisation of the highest level of community presence possible is also of paramount importance. These concepts will always remain an important component of the intellectual disability care agenda; however this approach may be less helpful when supporting persons with intellectual disability to cope with increasing disability and the inherent decline evident in dementia. The lack of experience of service providers with issues in relation to an ageing population means that aggressive approaches to care may be prolonged or futile. Furthermore, the transfer of the person to more restrictive settings may be considered rather than the service continuing to support him/her with 'ageing in place' (McCallion & McCarron, 2004).

This study responded to the above challenges by:

- The engaging of experienced practitioners in the intellectual disability field to elicit their experiences and concerns in supporting persons with advanced dementia.
- The engaging of experienced practitioners in the palliative care field to explore care improvements for persons with intellectual disability and advanced dementia.
- The inclusion of the needs of carers, families and peers in end-of-life care planning.

There are challenges also for palliative care providers. The inclusion of specialist palliative care staff in this project was designed to provide information and tools to increase knowledge for both services and to facilitate greater equity and access to specialist palliative care services. The Report of the National Advisory Committee on Palliative Care (DoH&C, 2001) acknowledges that there is an existing emphasis of palliative care delivery to persons with cancer (95% of recipients). Palliative care approaches developed from cancer and AIDS models, may not easily translate into useful information for care planning for broader groups of frail elderly persons (Abbey, 2003; Lynn & Adamson, 2003). If the extending of palliative

care to generic populations with chronic conditions such as dementia is complex, then the extending of such approaches to persons with the dual disability of intellectual disability and dementia is potentially even more difficult. Not enough has been done to understand the unique issues in the care of persons with intellectual disability and advanced dementia. Neither has enough been done to share the resources and perspectives available in palliative care provision nor to consider how the prevalent palliative care approaches may be modified to better meet the needs of persons with intellectual disability and dementia (McCallion & McCarron, 2004). In response to these concerns, this study makes it possible to better address issues such as equity, access and service delivery which are concerns of the NDA and of the DoH&C (Quality and Fairness Health Strategy). This study also makes it possible to address the recommendations of the DoH&C that palliative care should be extended to persons with intellectual disability (2001:11), be integrated into community settings, involve community based practitioners (2001:88), and be more influenced by the perspectives of patients and families (2001:52).

This study engaged experienced staff from both intellectual disability services and specialist palliative care services to address these challenges. The research sought to expand the existing definitions and related training in palliative care to include persons with intellectual disability and Alzheimer's dementia, with potential relevance to the care of all persons with advanced dementia. The engagement of the specialist palliative care staff with the intellectual disability staff was also designed to broaden the experience of both services and gain a deeper understanding of the challenges for both specialty areas. Indeed, the modelling of a collaborative working relationship between a specialist palliative care provider and intellectual disability providers, which could be replicated throughout the Island of Ireland and internationally, was a key goal.

End-of-life care models exist in the hospice and palliative care fields but primarily address chronic illnesses such as cancers and are only recently being applied to Alzheimer's dementia. The Report of the National Advisory Committee on Palliative Care (DoH&C, 2001) recommends the extension of specialist palliative care services to patients with progressive and advanced disease of non-cancer aetiology and the inclusion of at-risk groups such as persons with intellectual disability. The extension of palliative care services to persons with intellectual disability is challenging; a recent review reports a lack of empirical data on the palliative care needs of this vulnerable and at-risk population (Tuffrey-Wijne, 2003). The range of levels of intellectual disability may mean that there are different needs and different abilities of persons to participate in care decisions.

The ability to make such care decisions by the person himself/herself is a key component of current palliative care models. The meeting of the palliative needs of the person with an intellectual disability will likely require close collaboration and interdisciplinary working between the intellectual disability and palliative care services. Such collaborative working has been recommended to create a greater understanding of the unique needs of persons with intellectual disability (DoH&C, 2001; Keenan & McIntosh, 2000; McCallion & McCarron, 2004).

Given these intentions for the study, it is important to understand firstly the changing trends in ageing within the intellectual disability services, and how this and the dual diagnosis of intellectual disability and dementia impacts on services and care. It is also important to understand the evolution of palliative care responses including the efforts being made to respond to the challenges posed by persons with both dementia and intellectual disability.

Key Demographic Influences

Ageing with intellectual disability represents the success of many factors. These include the resilience of people with intellectual disabilities, advances in medical care and treatment, advocacy and self-advocacy, and the development by providers of quality living environments and opportunities for enriching the lives of the persons served. Equally, the dedication of family carers, principally of parents and increasingly of siblings, has supported the ageing of many more people with intellectual disability.

There has been a distinctive changing age-profile in intellectual disability over the past 25 years with increased longevity and an ageing trend in the prevalence rates (Kelly et al., 2007). This trend appears all the more dramatic in Ireland. A drop-off in the incidence of intellectual disabilities at earlier ages, which is largely attributable to declining birth rates and improved prenatal care, has combined with the current ageing of a substantial baby boom generation to create this population of older persons with intellectual disabilities. A steady increase in persons with intellectual disabilities over the age of 35 years has been observed in the National Intellectual Disability Database (Kelly et al., 2007). In 1974, 28.5% of persons registered on the data base were over 35; in 1996 this had risen to 38% and in 2007, the figure was 48%. This is consistent with trends in other developed countries. Over the next 5- 10 years, the biggest proportional increase in people with intellectual disability is likely to be in the 50 and older age group, the age group at increased risk of dementia. In spite of these demographic trends, policy and service provision for this population is lacking.

Ageing, Intellectual Disability and Dementia

The dramatic shift in the age profile of persons with intellectual disability in Ireland and indeed elsewhere from a younger to an older population has also resulted in a growing awareness of new and emerging challenges. As stated previously, people with intellectual disability are living longer and greater numbers of individuals are surviving into the age of risk where they are developing dementia. An Irish study involving 285 subjects with Down syndrome reported an age specific prevalence of dementia at 5.7% in persons aged 40-50 years, 30.4% in persons aged 50-60 years, 41.7% in persons aged 60-70 years, and 50% in persons over the age of 70 years (Tyrrell et al., 2001). There is also evidence that people with Down syndrome experience an early and more abrupt decline in memory, behaviour, work skills and in day-to-day functioning. It is also critical that intellectual disability services are aware that regardless of Down syndrome, ageing itself is a known risk for dementia (O'Shea 2007). Given the changing ageing demographics of persons with intellectual disability, their changing care needs must be anticipated and planned for. The prevalence of dementia in adults with intellectual disability other than Down syndrome has been reported to be from 15.6% in persons aged 65-75 years, 23.5% in persons aged 65-84 years, and 70% in persons aged 85-94 years (Cooper, 1997). This reflects a higher incidence than that of the general population. However, others (e.g., Janicki & Dalton, 2000) report rates of prevalence similar to that of the general population.

The increase in the numbers of people with intellectual disability and dementia is posing new challenges for those caring for and developing services for people with intellectual disability. However, as stated, policy and service provision for this population is lacking. Many services are poorly prepared to meet and respond to the diagnostic and care needs of people with intellectual disability who are at risk of dementia or have dementia. Even more challenging is the response to the care of the person with end-stage dementia. Medical complications associated with dementia are inevitable as the disease progresses. Alterations in feeding, mobility and continence, combined with the development of seizures and marked personality and mood changes, result in the dementia becoming a complex physical, emotional and social condition which requires specialist nursing and terminal care (Prasher, 1995; McCarron et al., 2005). A terminal stage which presents with a clinical picture of severe intellectual deterioration, marked personality and mood changes, loss of sphincter control, seizure activity, immobility with hypertonia and complete loss of self-care skills has been confirmed (McCarron et al., 2005; Prasher 1995b; Visser et al., 1997; Cosgrave et al., 2000). Ongoing longitudinal work and statistics drawn from one Irish

service provider identifies some of the critical implications of the increasing care challenges associated with Alzheimer's dementia. In 1993, at the Daughters of Charity Service in preparation for a longitudinal study, 80 women with Down syndrome were identified who, at that time, were aged over 35 years. They were then periodically assessed and followed up over a 12-year period. In 1993, 9% (7) of the women were assessed as having symptoms of dementia. In 2006 (notwithstanding that some deaths from the sample population had occurred over this time), 80% (64) were diagnosed with dementia. Currently within the Dublin region of the Daughters of Charity Service there are 48 women with Down syndrome and Alzheimer's dementia, and 13 out of the 31 community group homes of this service are currently supporting at least one person with dementia; five of these homes support two to three people with dementia. Given the increasing ageing demographics of the population served by the Daughters of Charity Service and the use of age specific prevalence rates for dementia in persons with Down syndrome, it appears that in 5 years there will be 30 more persons with this diagnosis and in 10 years this will have increased to 51. Out of the current 31 community group homes are likely to be 23 of them supporting persons with dementia (McCarron, 2005).

There has not been any adequate planning to respond to the changing needs of persons with dementia particularly in terms of the challenges for new needs for 24 hour staffing, increased medical costs, and the need for capital support for environmental modifications. In addition, staffing numbers, patterns of staffing and the training of staff have traditionally been focused upon caring for young and middle aged adults who are working, participating in community living and are supported to live as independently as possible. Therefore, the different issues associated with caring for a population with Alzheimer's dementia are challenging these patterns of staffing and philosophies of care. A comparative study by McCarron (2002) reported significant differences in average time spent in care-giving over a 24-hour period for persons with Down syndrome, with and without dementia, to be 7.71 hours versus 2.66 hours respectively. There was no significant difference reported in the time spent care-giving for subjects at mid-dementia vs end-stage dementia; however, the nature and tasks of care-giving changed as the dementia progressed. The biggest proportional amount of time spent in care-giving being at the end-stage dementia. This increased time was spent in addressing nursing and end-of-life care needs.

Impact for Care and Service Provision

Despite these pressing concerns, responses to dementia issues to date have tended to be reactive rather than proactive and

the intellectual disability services system is just beginning to address these concerns. The impact on family carers is at an even earlier stage of response (McCallion et al., 2005). For service providers, staff and families, these are new care situations and there is a need for an evidence-based model for services if a resolution is to be realised, if institutionalisation and re-institutionalisation is to be avoided, the quality of life maintained and costs contained. Help is also needed with day-to-day care issues when dementia is present.

The intellectual disability services system has traditionally been focused upon the serving and the maintaining of persons with intellectual disability in the community for as long as possible and has been driven by a services philosophy which emphasises positive approaches, skill acquisition and increasing independence. The inevitable decline associated with Alzheimer's dementia challenges this programming philosophy and there has been a danger within intellectual disability services that with the changing needs of persons with dementia, providers will seek a transfer of the person to other, often more expensive, institutional alternatives. This does not need to happen. Instead there are also opportunities and efforts to support 'ageing in place' and a growing interest in understanding the role of specialised units for people with intellectual disability and Alzheimer's dementia (Janicki et al., 2002; McCarron et al., 2005). There have been some important developments in Ireland: the development of the first special residential unit for persons with Down syndrome and Alzheimer's dementia at St. Michael's House services; the first post graduate diploma to prepare clinical nurse specialists in intellectual disability and Alzheimer's dementia at Trinity College Dublin, and the organisation of an intellectual disability and Alzheimer's dementia Memory Clinic at the Daughters of Charity Services. There is also research underway that is looking at the characteristics of models of service to maintain persons with intellectual disability and Alzheimer's dementia in the community (see for example Janicki et al., 2002; McCallion, et al., 2005; McCarron et al., 2005). One particular concern remaining is how best to address end-of-life care issues for persons with intellectual disability and advanced dementia and this will necessitate intellectual disability services and specialist palliative care services working and learning together.

Palliative Care

There are many definitions of palliative care in the literature, all of which integrate psycho-social, physical and spiritual care of the person and his/her family (DoH&C 2001, Abu-Saad 2001). The World Health Organisation (2002) defines palliative care as an approach that improves the quality of life of patients and their families who face the problems associated with

life-threatening illness through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems, physical, psychological and spiritual. Principles of palliative care include:

- The relief of pain and other distressing symptoms.
- The affirmation of life and the acceptance of dying as a normal process.
- The intention to neither hasten nor postpone death.
- The integration of psychological and spiritual care of the person.
- The support of patients to enable them to live as actively as possible until death.
- The support of family to help them to cope with the illness and the bereavement.
- A team approach to meet patient and family needs.
- The enhancing of the quality of life for persons by the positive influencing of their experience of illness.
- The application of palliative care early in the course of illness in conjunction with other therapeutic interventions.

The philosophy of palliative care embraces two broad goals: effective symptom control and maintaining quality of life (Abu-Saad, 2001). The practice of palliative care developed from the modern hospice movement of the 1960s; the terms hospice care and palliative care are sometimes used synonymously (Abu-Saad 2001). The original hospice or care offered to the dying in Europe was initiated by Mme. Jeanne Garnier in France at the end of the nineteenth century. Hospice care offered to dying persons in Ireland began at the end of the nineteenth century led by the Irish Sisters of Charity (Council of Europe 2003, O'Brien & Clark 2005). However, management of the physiological aspects of pain and symptoms at end-of-life were hampered by a lack of knowledge and a lack of appropriate medications (Council of Europe 2003). Development of drug therapies, along with greater understanding of the psycho-social and spiritual needs of persons who were dying paved the way for the development of palliative care services as we know them today (Council of Europe 2003). The evolution of the new hospice and palliative care movement is attributed to Dame Cecily Saunders who opened St Christopher's Hospice in London in the middle of the twentieth Century (Council of Europe 2003). The important objectives of care stressed by Dr Saunders were: "care of the patient and family as a unit, an interdisciplinary team approach, the use of volunteers, a continuum of care that included the home setting and follow up of family members after the patient's death" (Abu-Saad 2001:5).

Palliative care can be applied in all care settings and there is no one model of palliative care provision which is applicable

in all care situations (Council of Europe 2003:21). Palliative care is viewed more as a continuum; comfort and supportive measures are available throughout the trajectory of illness and increase as active interventions (disease specific therapy) decrease. It also gives importance to bereavement care post demise (Doyle et al., 1998). Doyle (2003:151) states that persons working in specialist palliative care have no monopoly on 'caring and concern', as many doctors and nurses in other areas of practice are as eager to give the terminally ill the best possible care. Therefore, he concludes that the principles of palliative care which he identifies as 'attention to detail, patient centred holistic care, team caring, honesty in all dealings with patients and superb communications' ought to be taught to all medical students and be integral to all areas of care delivered to patients (Doyle 2003:151). He sees the universal education of medical and nursing students as the future of good palliative care. He cautions against losing some of the uniqueness of 'care' within palliative care especially if it becomes just another speciality and if students regard it as nothing more than good pain and symptom management. The uniqueness of care that he refers to is that death is anticipated and not viewed as a medical failure, that staff accept uncertainty and communicate honestly, that it is ethically challenging, non-judgemental care which values a dignified death and equality of access to individualised care for all. Doyle (2003) states that the claim by palliative care to be unique, based on their holistic approach to care, is unjustified as many other specialties could claim equally to be sensitive to such an holistic approach. However, he questions whether other specialities are as sensitive to the spiritual care of patients.

Palliative Care in Ireland

The National Health Strategy of Ireland (1994) recognised the importance of developing structured palliative care services in order to improve the quality of life for persons with a terminal illness. National policy recommendations for palliative care in Ireland were published in the Report of the National Advisory Committee on Palliative Care (DoH&C 2001). "The goal of Palliative Care is the highest possible quality of life for both patient and family" (DoH&C 2001:20). The family is defined as "any person who is significant to the patient" (DoH&C 2001:21). Palliative care is recognised as a core component of the role of all health care personnel, (DoH&C 2001; O'Connor & Aranda 2003) and a vital component of all health care (Council of Europe 2003). Palliative care can be delivered at three levels (DoH&C 2001). The first level is using a 'palliative care approach' where all staff in a general setting have core knowledge and skills of palliative care which they use when caring for a person with a life threatening illness or a person who is dying. They consult with specialist palliative care experts on issues where they do not have specialist knowledge (DoH&C 2001). The second

level is using specialists when palliative care interventions are required for symptom management, such as radiotherapy. This is referred to as general palliative care (DoH&C 2001), Council of Europe (2003). The third level is when specialist palliative care is delivered by staff qualified in palliative care operating from a palliative care specialist practice setting, (DoH&C 2001; O'Connor & Aranda 2003).

Access to Specialist Palliative Care

Specialist palliative care is accessed by patients with cancer (95%) more commonly than any non-malignant condition (DoH&C 2001). A key recommendation of the national report is that specialist palliative care should be considered for people with intellectual, physical and sensory disabilities (DoH&C 2001:48). Despite this recommendation, minimal reference is given to persons with disabilities in the report but it states that further research is required to identify the needs of these persons; furthermore links should be formed between disability service providers and specialist palliative care services in order to promote a quality service for all (DoH&C 2002:48).

Palliative Care and Dementia

Lynn and Adamson (2003) identified that in America the health care and community services were not organised to meet the needs of persons with a progressive illness and disability such as dementia. They recognised that such patients had to navigate a fragmented and uncoordinated health-care system. This was also identified by Nolan et al., (2006) in an exploratory study undertaken in Ireland. Lynn and Adamson (2003) suggested models of hospice care developed in America in the 1970s did not apply well to persons with chronic illness such as dementia because of the traditional distinction of palliative care being seen as the turning away from conventional (active) care. It is their belief that persons with dementia will require a mix of both kinds of care particularly in the early stages of the disease.

Others report that people with dementia still receive sub-optimal end-of-life care (Sachs et al., 2004) citing barriers such as the unpredictable nature of the illness, issues with assessment and management and the fact that dementia is not viewed as a terminal illness. Professionals and family have difficulty in viewing dementia as a terminal condition and identification of the terminal phase of this illness remains a challenge (Sachs et al., 2004:1058). Solomon and Jennings (1998:137) conclude that palliative care is medically, ethically and legally better for the person with dementia when the benefit-to-burden ratio is better with palliative care rather than with life prolonging treatment. A view of dementia as a neuro-psychiatric condition has hindered special consideration of end-of-life care issues and further isolated the person from accessing services such as

specialist palliative care (Downs et al., 2006). Yet the person-centred approaches used in dementia care concerned with maintaining a quality of life for the person, supporting the persons in living until they die and ensuring that family/carers or persons close to him/her are included in their care (Downs et al., 2006) marries well with the palliative philosophy. One theme which is now emerging in the development or provision of hospice care for patients with advanced Alzheimer's disease in the USA is the avoidance of transferring the person to hospital when an acute medical problem presents (Solomon & Jennings 1998). This, the authors state, is a key burden to the persons and challenges staff of the care setting to develop the ability to care for dying patients on site.

Palliative Care and Intellectual Disability

The need to consider palliative care for persons with an intellectual disability is now receiving some attention (Blackman & Todd, 2005; Ryan & Mc Quillan, 2005). Palliative care seeks to "respect individuals for whom they are" (O'Brien, 2001:4; DoH&C 2001). This philosophy of care is equally important in the care of persons with dementia (Kitwood, 1997) and in the care of persons with intellectual disability (Gates, 2006). Ireland recognises that the principles of palliative care apply to all patients with advanced progressive disease regardless of aetiology and in all care settings, (DoH&C 2001). However, a University of Sydney review (DADHC 2004) reports on the difficulty which still exists in relation to the initiation of palliative care for persons with intellectual disability and also on the fact that staff in intellectual disability services do not normally hold palliative care skills. In a study by Ng and Li (2003), a lack of knowledge of effective communication with the dying person and a lack of knowledge about bereavement support were important issues identified among carers of persons with intellectual disability. Ryan and McQuillan (2005) acknowledge that the needs of persons with intellectual disability are not being met by current palliative care services. Many of the intellectual disability services in Ireland are dependent on General Practitioners to deliver medical care to the people they care for. Therefore, the General Practitioner is often a member of the multi-disciplinary care team. If the person with intellectual disability and dementia is being cared for at home, this will also be the case.

The integration into palliative care of Primary Care services in Ireland is sub-optimal according to the International Expert Advisory Group Report on Palliative Care in Ireland; furthermore they have stated that General Practitioners have very little experience or training in palliative care (IEAGRPC 2006). There are similar challenges for other team members and carers (Ng & Li, 2003).

Person-Centred Care

Person-centred approaches to care are central to palliative care; the challenge for palliative care lies in finding agreement amongst the individual, the physician(s), the primary caregiver, and the hospice team. The expected outcomes are the relief from distressing symptoms, the easing of pain and/or the enhancement of the quality of life; then to pursue a plan for the realisation of this outcome that in particular respects the wishes of the individual patient. Such ideas are not new to intellectual disability services or to dementia care. In intellectual disability services, there are well established systematic processes to the discovery of an individual's gifts, capacities, experiences, core beliefs and dreams. The collaborative development of plans by service providers to realise those dreams is enhanced by the commitment to the individual by valued persons who help to realise the plan (Abery & McBride, 1998).

Dementia care has drawn upon the person-centred approaches pioneered in intellectual disability services. Kitwood (1997) argued that as well as meeting the physical needs of the person with dementia, the enabling of the exercise of choice for the person, the use of the person's abilities, the fostering of the expression of his/his feelings and enabling him/her to live in the context of relationship, were also critical to his/her care. Kitwood (1997) identified five core care issues: Comfort, Attachment, Inclusion, Occupation and Identity. He believed that a person needs comfort in times of distress and loss. Even in dementia, people require to be attached and in a relationship with someone. Being included means being part of a group and if this need is not met the person can go into decline or retreat. Occupation is to be involved, and if this need is not met, the person's abilities can deteriorate. Identity provides esteem, consistency and respect. Kitwood (1997) saw these five elements as critical to good care. Such good care could be limited by the inadequate preparation of staff, a lack of opportunities and a lack of ability among staff to interact on care concerns and solutions with each other and with the person with dementia.

Relationship-Centred Care

Critiques of person-centred care are beginning to emerge (Adams & Grieder, 2005). Nolan, Keady and Aveyard (2001) acknowledge that person-centred care has had a far reaching impact on care in dementia but it is not enough to consider the individual without considering his/her relationships as they are crucial to determining a person's quality of life. Relationship-centred care is proposed for situations where relationships have developed over long periods of time such as in care homes (Nolan et al. 2006) and this has relevance for intellectual disability care settings. Dementia care triads are models of relationship-centred care and recognise that there are at least

three people in these relationships: the person with dementia, the informal carer and one or more health and social care professionals (Adams & Grieder 2005). Relationships may also extend beyond three people to include other people involved in the care of the person. Relationship-centred care was first described by Tresoloni and Pew-Fetzer (1994). This approach to care embraces relationships as a central factor in health care where health care becomes a human activity given meaning by people within relationships (Tresoloni & Pew-Fetzer 1994).

TRAINING NEEDS

Knowledge and Skills of Caring for a Person with Intellectual Disability

A lack of knowledge of the needs of persons with intellectual disability by staff in general acute medical settings has been identified as leading to diagnostic overshadowing and unexpected and unexplained deaths (MENCAP 2007). Tuffrey-Wijne (1998) and Lindop and Read (2000) have identified (1) a need to be able to interpret non-verbal and alternative communication strategies and (2) the assessment and management of pain as two major educational needs for nurses in general practice to care efficiently for this population. For staff in intellectual disability settings there is an additional need for training and education about the ageing of persons with intellectual disability and the implications of care for a person presenting with symptoms of dementia (McCarron & Lawlor 2003). As persons with intellectual disability experience terminal illness and approach their end of life, this poses further challenges for the staff in intellectual disability settings. Hospice and other palliative care staff must also be equipped to understand the care of persons with intellectual disability (McCallion & McCarron, 2004).

Knowledge and Skills of Caring for a person with Dementia

Regarding care for the general population with dementia, McCallion et al., (1999) reported that care assistants in nursing homes themselves identified a need for education on communicating with the person with dementia and on managing behavioural issues. Despite such requests, there has been minimal training for staff or carers. Kitwood (1997) argues that this may result from society's fear of ageing, illness, mental illness and death as well as the lack of understanding of dementia. He argues that good quality and sensitive interactions between carers and individuals with dementia are essential for good care (Kitwood 1997). Similar needs have been identified for staff in intellectual disability settings including their need to know how to recognise and manage dementia-associated changes in the person (McCarron & Lawlor, 2003). Sachs et al., (2004) go further, observing that staff should understand the need for early planning of care for the person with dementia,

and ensuring continuity of care throughout the trajectory of the illness at early, mid and late stages. The diagnosis of dementia in persons with intellectual disability is complex and the up-skilling of staff in intellectual disability services in the assessment and support of the person with dementia will be crucial, as will on-going education of staff and family on the needs and care issues for the person (McCarron & Lawlor, 2003). Nutrition and hydration also cause concern for family and staff because often "the act of providing sustenance symbolises love and caring" (Solomon & Jennings, 1998:138).

Another issue in the care of a person with dementia is team-work: "Caring involves the actions of people who are resourceful and aware, who can trust each other and work easily as a team." (Kitwood, 1997:103). This view encourages in-service training, ensuring shared goals and moving the content of training beyond the theoretical (Kitwood, 1997). A new culture of care emerges that does not pathologise dementia. Instead it focuses on the uniqueness of each person and respects what s/he has accomplished and allows what s/he has endured to be understood compassionately. With such a view interactions are a truly healing component of care (Kitwood, 1997). In the longer term, fostering changes in the culture of care requires both resourcing and training of staff:

"essential to have a properly trained work-force at all levels, and care assistants need to be equipped not only for essential physical aspects of their work but also for psychological tasks, in particular, developing those skills of interaction." (Kitwood, 1997: 142).

"Education is the key to setting and maintaining standards of care and best practice" (O'Sioran and Ling (2005:209) and such education is important for the future direction of intellectual disability care, dementia care and palliative care in Ireland.

Knowledge and Skills of Culturally Competent Caring

In a multicultural healthcare context as Ireland now is, there is a need to deliver culturally competent care (Tuffrey-Wijne, 1998). Culture affects every aspect of a person's being (Tracey & Ling, 2005). In Ireland, the term 'non national' is used to describe persons from other countries and cultures (Tracey & Ling 2005). In considering the development of an educational intervention, the needs of such a multicultural workforce encourage culture specific content without reducing the topic of cultural care to a 'recipe approach' (Tracey & Ling, 2005:172) or reducing persons from one culture to a stereotype, i.e. that they have identical beliefs and values (McCallion, Grant-Griffin & Janicki, 1997). Therefore, remembering the individuality of persons is important when addressing such educational needs.

Broad culture-specific issues have previously been identified

in relation to terminal illness disclosure, breaking bad news, advance planning and locus of decision-making (Searight & Gafford, 2005). In the last 40 years "The North American culture advocates explicit disclosure of cancer diagnosis and frank planning for end-of-life care" (Candib, 2002:213). This approach may not be acceptable to other cultural groups i.e. cultures that place higher value on family connectedness than on individual autonomy and may value life at all costs over an easy death. Explicit examples quoted by Candib (2002) are that some cultural groups would not tell a person that s/he is dying but would offer encouragement about treatments and give them hope. Another example is that some cultural groups do not discuss a terminal diagnosis with the older person who is experiencing symptoms but would discuss it with the family. The family then helps with decision-making. However, it is important to acknowledge that within ethnic groups there are also considerable variations (Searight & Gafford, 2005) and that immigrants may assimilate and adopt the values and beliefs of the host country (McCallion et al., 2007). Educational interventions must therefore take cognisance of the potential range of ways in which culture may influence beliefs and behaviours of carers who are caring for persons with terminal illness and who are faced with the processes of decision-making and end-of-life decision-making for the person with a terminal illness.

In the intellectual disability setting, McConkey (2004:35) identified that new staff members rely heavily on verbal communication; yet asking too many questions may actually make situations more complex. This may be particularly true for carers whose own first language is not English and where English is the first language of those people in their care. McCallion et al., (1997) identified that professional staff in intellectual disability services may also not be sufficiently sensitive to cultural differences and influences and, in particular, fail to recognise the strengths in other cultures. Culturally appropriate care then respects and recognises the contributions of everyone involved. "Education is the key to the provision of culturally appropriate care" as noted by DoH&C (2001:45).

Knowledge and Skills of Palliative Care

Staff in intellectual disability services are not generally prepared in palliative care skills (DADHC 2004). This is compounded by a clear lack of literature about the palliative care needs of persons with intellectual disability (Tuffrey-Wijne, 1997). Tuffrey-Wijne (1997) reports that while staff supported offering death and dying care in principle, they did not feel they had the expertise in practice. Furthermore, staff may be unprepared for the family dynamics around caring for someone with a terminal illness and the emotions involved. Tuffrey-Wijne (2002) suggests that a more collaborative working relationship

between intellectual disability staff and palliative care staff may improve care. Collaboration with specialist palliative care would also encourage greater exchange of expertise. Tuffrey-Wijne (2002) and Todd (2004) agree that carers in intellectual disability services would benefit from education on what to report to the palliative care team. Some important issues would be, for example, what to expect in the progression of the disease/illness and how to interpret important changes which could indicate pain.

Findings elsewhere suggest that nursing staff who acquired knowledge about the use of drugs commonly used in the symptomatic and palliative management of patients, developed new confidence and found ways to make their assessments of the end-of life care needs of the patients more explicit to other practitioners, thus improving care (Watson et al., 2006). Whittaker et al., (2007) argue that frontline staff and their skills determine the quality of care delivered to people. In their study, they identified that the education and training needs of carers included more training in psycho-social care, spiritual care and meeting cultural needs. Solomon and Jennings (1998) also report that medical and nursing staff would benefit from training in the pharmacological and non-pharmacological management of pain and other symptoms to improve palliation. These findings for care of the general population clearly have implications for care staff, nursing staff and medical staff within the intellectual disability services.

Knowledge of and Skills in Addressing Nutrition, Hydration and Pain Concerns

Feeding difficulties and challenges experienced as part of end-stage dementia care by persons with intellectual disability mirror those difficulties described in the generic care literature in persons with Alzheimer's dementia (Biernacki & Barratt 2001; McCarron & McCallion, 2007; Norberg et al., 1994). Lack of ability to self-feed, the difficulty of holding food in one's own mouth, chewing and swallowing concerns, agitation and distress, spitting, and food inhalation/aspiration all culminate in stress for the person, the family and staff (McCarron et al., 2003). For example, staff report that watching someone they know and care for who is now unable to eat/drink is difficult and they describe feelings of guilt and remorse when faced with this concern (Service, 2002). The assessment of pain in persons with cognitive impairment or intellectual disability is problematic (Regnard et al., 2003; 2006). The assessment of pain in patients with Alzheimer's dementia appears to be even more complex again (Regnard et al., 2006). Specialist palliative care services must then recognize that the assessment instruments used for the general population for both pain and nutrition needs are rarely helpful (McCallion & McCarron, 2004; McCarron &

McCallion, 2007). Staff in intellectual disability services therefore would benefit from additional guidance from generic palliative care services on such issues as pain management.

Similarly, within the generic care literature there is little evidence to support the use of tube feeding in persons with advanced dementia (Mitchell et al., 1998; Finucane et al., 1999; Volicer, 2005). Perceived benefits of tube feeding in persons with advanced dementia such as preventing malnutrition and reducing risk of pressure sores, preventing pneumonia, promoting comfort and improving functional status have not been upheld in the reported research (see Finucane & Bynum, 1996; Finucane et al., 1999; Volicer, 2005).

Knowledge and Skills of Facilitating Grief and Loss

Loss can be broadly divided into the two categories of physical loss and psycho-social loss (Rando, 1993). The ensuing state of one's having experienced a loss is bereavement (Rando, 1993). When someone experiences the death of any loved one, there will be the potential for the loss to manifest in bereavement (Rando, 1993:22). Grief is the process of experiencing the psychological, behavioural, and social reactions to the experience of the loss (Rando, 1993:22). Mourning is the cultural and/or public display of grief which acts as a vehicle for social communication (Rando, 1993). Many authors have explored bereavement and grief in order to define normal or uncomplicated grief versus complicated or unresolved grief in efforts to increase understanding and generate theories of grieving. Rando (1993) states that long term illnesses can give rise to complicated grieving due in part to the unpredictable nature of the illness and to the difficult decision-making that may be required along the course of the illness.

Disenfranchised Grief

Bereavement issues are reported to be different in dementia compared to other terminal conditions (Sachs et al., 2004). Solomon and Jennings (1998) highlighted the complexity of bereavement and grief issues for relatives of persons with dementia who experience mourning along the trajectory of the illness and long before the person actually dies. Despite the findings of Moss and Moss (2002:202) that staff in hospitals and nursing homes are "not kin" and have "no lifelong ties with the resident" others argue that staff form relationships with the person with dementia and have their own grief issues (Whittaker et al., 2007). A services framework that emphasises physical and medical care and sees psycho-social needs in relation to death as secondary (Moss & Moss 2002) fosters staff ideologies such as 'professional distance' that are linked to disenfranchised grief. In intellectual disability services many staff have lifelong ties with the person with dementia.

Furthermore, staff caring for persons with intellectual disability have been found to be heavily involved in the rituals around the death of a person in their care (Dodd et al., 2005). Yet palliative care staff and some intellectual disability services administrators may still respond to staff in intellectual disability services as if the Moss and Moss model applies, making this group particularly prone to disenfranchised grief.

Disenfranchised grief as a concept was first put forward by Doka (1989:4) as "the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned or socially supported". This concept validates grief which had not previously been acknowledged (Corr, 2002). Health care professionals "rarely grieve the death of patients", and "usually do not participate in funerals or mourning rituals for deceased patients" according to Lamers (2002:183). "Disenfranchised grief occurs when staff members perceive that their loss is not legitimised and that their relationship with the deceased does not entitle them to feel or express grief" (Moss & Moss, 2002:205). Care-giving staff may also experience vicarious grief (Kastenbaum, 1989) where they identify with a surviving resident who was a long-term friend or room mate. In intellectual disability services such grief challenges staff in their supporting of surviving peers. Many staff in intellectual disability services want the people they care for to die in their own home and actively attempt to keep other services at a distance in the belief that they are more knowledgeable and sympathetic to this group (Todd, 2004). However, staff are often unprepared educationally to care for the dying and they struggle to give end-of-life care to the best of their abilities, providing lots of love and personal care (Todd, 2004). Institutional policies and procedures compound disenfranchised grief of staff when they do not support an overt grieving process (Landers, 2002).

This is also disenfranchised grief for the other persons with intellectual disability in the home and for the family. There is both a long-standing belief that persons with intellectual disability do not experience the range of emotions of others including feelings of grief at the loss of family members and close friends/neighbours; conversely, there are concerns that they will not be able to "handle" the associated feelings (Yanok & Beifus, 1993). These beliefs and concerns are often used by family members to justify not informing persons with intellectual disability of the death of parents and for not involving them in funerals and other death and mourning rituals. It is not just a "family" problem. Todd (2002) points out that staff too have difficulties with the issue of death; family desires become a convenient explanation for a lack of advocacy for death experiences and education for persons with

intellectual disability. Yet persons with intellectual disability, as they age, are likely to experience losses through death; the implications of the losses may be greater for the persons with intellectual disability as the loss may also mean they will have to move to a sibling's home or to an out-of-home placement (McHale & Carey, 2002). However, not having experienced death and mourning will mean that many persons with intellectual disability will poorly understand death and not be prepared for their own deaths (Clegg & Lansdall-Welfare, 2003).

While death and bereavement is a poorly researched area (Todd, 2002), there is evidence that persons with intellectual disability do indeed understand the finality of death and have often formed bonds with family members and others and feel personal loss and grief. However, being shielded from funerals, even the announcement of death may mean that people with intellectual do not know how to or have the opportunity to express their grief (Yanok & Beifus, 1993).

Grief does surface. Symptoms of normal grief as defined by ICD-10 occur within one month of the bereavement and do not exceed 6 months duration. For persons with intellectual disability, later onset and longer duration of grief symptoms are more likely. Also, as well as with increased levels of depression, anxiety and distress, grief reactions in persons with intellectual disability are often manifested in behavioural difficulties. These behaviours are more likely to be viewed by family members and professionals as psychosocial concerns rather than as the expression of grief (Hollins & Esterhuyzen, 1997; McHale & Carey, 2002). Reflecting these findings, Dodd et al., (2005) identified a need for staff training to support the grieving process for people with intellectual disability.

CURRICULUM ISSUES

A curriculum should not only comprise the ideas of the curriculum planning group but also reflect the ideas and beliefs of those for whom the training is intended (Oliver & Endersby, 1994). The educational philosophy of course development should be in line with the philosophy of the educational climate and the relationships between students and educators. Lack of consultation will lead to a lack of ownership on the part of those expected to implement and participate in the course. The participants for the curriculum to be developed here are adults and are an experienced group of practitioners. Knowles (1984) indicates that androgogy is the art and science of teaching adults and implies that students are central to their own learning, take an active part in learning, have a more equal relationship with the teacher and accept responsibility for their own learning (Howard 1999). Benner (1984) identified that intuition was a distinguishing feature of the expert practitioner

and subsequently, authors like Schon (1983) identified that reflection and reflective learning allowed access to this tacit knowledge or intuition and is a good approach to teaching communication skills (Oliver & Endersby 1994; Tresoloni & Pew-Fetzer (1994). Team teaching is also seen as critical to teaching effective communication skills (Oliver and Endersby, 1994). All of these issues are central to the curriculum design to be considered for a short course of study like the one required from this research.

Conclusion

This review of the literature on dementia care, intellectual disability care, and palliative care demonstrates that there are similar philosophies underlying each one and, equally, there are overlapping training needs for staff caring for persons in these three specialist areas. A theme very central to all is the respect for the individual and maximising his/her quality of life. Distinctions between delivering a palliative care approach or utilising specialist palliative care in the care of ageing persons, persons with dementia, or persons with intellectual disability are not very explicit in the literature but there is growing consensus that staff in intellectual disability services require an understanding of practice and principles of palliative care and, especially, skills and knowledge in end-of life care (Wilkinson 2005). Similarly, staff from palliative care require skills and knowledge in working with people with intellectual disability especially in relation to communication issues which impact on the process of assessment (Tuffrey-Wijne 1998, 2002). Teamwork is valued in all three settings.

In response to the identified training needs, this study sought to reflect the changing trends in ageing, intellectual disability and dementia and their impact on services and care; to further understanding of the evolution of specialist palliative care responses, including efforts to respond to the challenges of both dementia and intellectual disability; and finally to advance responses to the grief and bereavement of the staff, the carers and the peers of persons with intellectual disabilities and advanced dementia.

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INTRODUCTION

This chapter outlines the research methodology and the methods used to conduct the study. The research design is identified and justification is offered for the approach. The study aims and objectives are outlined and a description of the study population and sampling method is given. Conceptual definitions of key terms used in the study are described. Procedural stages of data collection, data management and issues relating to rigour and data analysis are described. Ethical and consent issues are also discussed.

Aims and Objectives of the study

Study Aims:

- To explore the experiences of staff in intellectual disability and specialist palliative care services in supporting persons with intellectual disability and advanced dementia.
- To develop and deliver an educational intervention which is responsive to the experiences and the related educational needs of intellectual disability staff and specialist palliative care staff in the care of persons with intellectual disabilities and advanced dementia.

The objectives of the study were:

- To explore the experiences of staff from the multidisciplinary teams in intellectual disability services
- To explore the experiences of staff from the multidisciplinary team in a specialist palliative care service
- To identify the educational and training needs of staff supporting persons with intellectual disability and advanced dementia in both service systems
- To develop, deliver and evaluate a responsive educational intervention for paid caregivers in both services systems

Research Approach

A combination of both qualitative and quantitative methodologies was used. However, the primary mode of data collection utilised was a qualitative descriptive design. The major method used was a series of focus group interviews.

Qualitative Descriptive Design

Qualitative descriptive design was considered an appropriate approach for this study as it is particularly suited to understanding the lived experience of participants, the so called emic perspective. It draws on naturalistic enquiry or the study of something in its natural state. Therefore it is of more value to a study where obtaining straight information in relation to people's concerns about a service is sought and to discover what is important to them within that service

(Sandelowski, 2000:337). Since the primary aim of this study was to understand the experience of staff in supporting persons with intellectual disability and advanced dementia it was considered that this approach would enable a comprehensive understanding of this experience. A series of 14 interviews were held. Thirteen were with intellectual disability services staff and 1 was with staff at a specialist palliative care service. The first 13 interviews included focus groups and a mix of individual and group (2-3 people) interviews. These were held with multidisciplinary staff from intellectual disability care settings who were experienced in supporting persons with intellectual disability and advanced dementia in a variety of out of home placements. The fourteenth focus group interview was held with multidisciplinary staff working in a specialist palliative care service. Extensive field notes and a reflective journal were also recorded and were used to assist with the interpretation and to give meaning to key findings. Sandelowski and Barroso (2002) suggest that making it explicit and giving meaning to how the researcher arrived at the decision to report what they did is essential in qualitative enquiry. The combination in the use of these approaches facilitated the identification of the staffs' preparation for the delivery of care to persons with advanced dementia in terms of their education and training needs. Once these needs were explicated, an educational intervention was subsequently designed and delivered to address the key concerns identified.

Goodness in Qualitative Research

There is on-going debate in relation to the measurement of the 'goodness' in qualitative research (Emden & Sandelowski, 1998), and some would suggest that the reaching of a consensus on criteria for assessing the quality in qualitative research remains elusive (Tobin & Begley, 2004:390). Goodness is seen to be an application of rigour (Denzin & Lincoln, 2000) and this goodness should be reflected throughout the study and not just referred to within the methodological discussion of the study (Tobin & Begley, 2004). In this study a mixed manual and computer assisted approach to analysis was undertaken in order to enhance rigour and to provide a clear audit trail of decision-making.

Validity and Reliability

Many proponents of flexible qualitative research avoid the terms validity and reliability (Robson, 2002). Qualitative descriptive research seeks descriptive validity and interpretive validity (Sandelowski & Barroso, 2002). Descriptive validity can be demonstrated by the researcher choosing the facts in the interview and accurately reporting them, sequence is important as observers see what the researcher reports. In this study facts are reported and as coding was built up from one transcript to the next throughout the fourteen interviews the sequence of

how codes and categories developed are also reported. Staying very close to the data is the keystone of qualitative descriptive methodology ensuring accuracy of representation in order to increase the descriptive validity (Sandelowski & Barroso, 2002). This was operationalized in this study by the researcher consistently reviewing the transcripts and writing notes on them. The audio-taped interviews were transferred on to compact discs (CDs) and the researcher listened to them while reading the transcripts which gave a richer opportunity to allow reflections and comments to be added to the texts. Keeping a reflective journal further enabled the researcher to increase descriptive validity. This audit trail was considered important in giving an honest and transparent account on how interpretation and meanings were reached. The discussion on the findings was done in close alignment with the current literature and the theory on the history and philosophy of caring within intellectual disability care, person-centred dementia care, and palliative care.

The use of independent experts to review data and give their expert opinion of emerging themes enhances the validity and reliability of this qualitative research (Cormack, 1996). The principle investigators of this study served this role as independent reviewers given their expert knowledge of intellectual disability care, dementia care and palliative care; they provided consistent and at times challenging and constructive feedback during the analytic process.

Population and Sampling

Well considered sampling is important in qualitative descriptive methodology which ensures that practitioners have experience of the phenomena under investigation (Sandelowski, 2000). Therefore all staff selected to participate in this study had (current or past) experience of caring for persons with intellectual disability and advanced dementia. Furthermore, as the understanding of the palliative care needs of persons with advanced dementia was a central consideration in this study the experience and concerns of specialist palliative care staff in supporting this population was equally important. In order to ascertain how best to approach care which incorporates best practice from both fields, the sample was drawn from staff working in a variety of out of home intellectual disability care settings and staff working in a specialist palliative care setting.

Sample

There were a total of fifty-seven participants in the first phase of this study. Fifty participants were drawn from six intellectual disability service providers within the Dublin North East and Dublin Mid-Leinster areas of the Health Service Executive (HSE 2006). Five of these providers were voluntary organisations

and one was a statutory organisation. Each was a major service provider for persons with an intellectual disability with numbers of individuals served ranging between 400 and 1,400 persons. All six services provide a variety of out of home placements for persons with dementia including community group homes, campus group homes, institutional/residential type settings, and a dementia specific group home. One of the institutional/residential type settings had a specialist facility to support people who were terminally ill and who required intensive nursing support. Within this facility a number of staff had undertaken specific training in palliative care. A number of the staff working in campus group homes described themselves as working in ageing specific units that primarily supported medically frail persons. The remaining seven participants were drawn from one specialist palliative care service in the Dublin area.

DEFINITION OF KEY TERMS

It appears logical from the above discussion that what is to be explored needs to be precisely described. This will not only assist in the interpretation of the results obtained, but will also allow for reliable and meaningful inferences to be made with the results from other studies in the future. For the purpose of this study key terms are defined as follows:

- **Alzheimer's Dementia**

Alzheimer's dementia is a disability, which results from a gradual deterioration in the condition of the nerve cells in the brain, and is characterised by impaired ability and progressive deterioration in memory, intellect, learning, reasoning, language, judgement, perception and ability for self care (Marshall, 1997).

- **Mid-Stage Dementia**

Is characterised by decline from the previous level of function in the area of language and comprehension, orientation and awareness, memory, language, ability to attend to self care needs, such as personal hygiene, continence, eating and drinking etc. There is also a decline in work and leisure related activities, with increased signs of personality and emotional changes; for some this stage also marks the development of new onset seizures. (McCarron, 2002)

- **End-Stage/Advanced Dementia**

During this stage the person with AD experiences substantial dysfunction across all areas. There is marked intellectual deterioration, unawareness of surroundings, inability to communicate verbally, immobility with hypertonia, seizure activity, incontinence, and total assistance is required in all areas of self care such as eating and drinking, personal hygiene etc. Problems associated with swallowing and respiratory difficulties, dehydration and the general complications of immobility, along with issues of death and dying necessitate skilled nursing and terminal care. (Prasher, 1995; McCarron, 2002;)

- **Key Worker**

The named person who has the responsibility for the day-to-day care of the person with dementia.

- **Intellectual Disability**

A condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the development period which contributes to the overall level of intelligence, i.e., cognitive, language, motor and social abilities (World Health Organisation 1992).

- **Down syndrome**

Down syndrome is a disorder in which a characteristic chromosomal aberration is associated with distinctive morphological phenotypic anomalies, clinically recognizable initially at, or soon after birth, and with a mental deficit of variable degree as a persistent feature (Berg et al., 1993).

- **Care Type Settings within the Intellectual Disability Services: Residential/Institutional Type Setting**

A setting that provides 24-hour support, has awake staff covering nights, has additional nurse coverage, has shared central facilities such as day care, church, sports facilities, and on site multidisciplinary staff back up; caters for 15-25 people.

- **Campus Group Home**

A setting (care facility) in which housing for persons with intellectual disability were clustered together on one site. The group home accessed shared central facilities such as day care, church, sports facilities, has on site multidisciplinary staff back up, and caters for no more than 8-10 people.

- **Community Group Home**

A setting in which persons with intellectual disability lived in domestic dispersed housing in the community. They accessed community resources in terms of church, shops, and health care. The community group homes offer varying degrees of support, with houses generally un-staffed during the day (10am-4 pm) and often having sleep over staff at night to respond to emergencies only. Range in number of residents: 5-8.

- **Dementia Specific Unit**

A specifically constructed or renovated unit on or off a campus with specialised staff trained in dementia and a specialised environment designed to best provide for long term care and geared toward care in later stages of Alzheimer's disease (or other dementias). A unit just like any other home but equipped to meet increased needs and deliberately located close to other services. Range in number of residents: 5-12.

- **Specialist Palliative Care Service**

Working as specialist multidisciplinary palliative care teams, a specialist palliative care service offers in-patient facilities (in hospices or hospitals), intensive coordinated home support and day facilities for persons with advanced illness and their families who would benefit from comfort care and continuous support and the expertise of trained specialist palliative care staff

DATA COLLECTION

Qualitative Data Collection: Focus Group Interviews
Focus Groups

Focus group interviews were chosen for this study because of their suitability in bringing people together with a particular expertise (Krueger & Casey 2000). A total of fourteen interviews were facilitated involving fifty seven participants. Thirteen focus group interviews were planned across the six intellectual disability service providers. Focus groups usually have a minimum number of 4 participants in an interview (Krueger and Casey 2000). Due to staffing and logistical issues one interview was with one individual and two other interviews had 2 and 3 persons respectively. One focus group interview was held with multidisciplinary staff working in a specialist palliative care service.

The reading of and the listening to the first three transcripts and the reflecting on the visits helped to identify some potential 'cultural issues' among staff beliefs and attitudes in relation to end-of-life care. Therefore, four of the Intellectual disability sites, where there were persons on staff from different cultural groups, were revisited and second interviews were held. This fulfilled two purposes, the first was to verify findings from the first visit interview and the second purpose was to collect additional data from non-Irish staff in relation to any additional training needs (if any) of this group.

The Interview Process

The interviews were held in a place and at a time convenient to the various members of the team. The interviews were conducted in a systematic yet flexible manner using non-directive interview guides. The interview guide was developed to address the broad aims and objectives of the study and contained topic areas designed to facilitate exploration of staff experiences in supporting persons with intellectual disability and advanced dementia. (See appendices 1 and 2). A core set of questions was used but a flexible approach was employed by the interviewer and the direction of the interview was guided and influenced by the nature of the participants responses and later interviews were also informed and developed by emergent categories. The interview times varied between forty and eighty minutes. All interviews were digitally recorded with the participants' permission and then they were professionally transcribed.

The collaborative nature of the focus group interviews enabled the researcher and the participants to come to a collective understanding of their experiences and their concerns in the supporting of persons with advanced dementia. It provided

the opportunity for participants to discuss experiences from their own perspectives while at the same time enabling multidisciplinary team members to gain new insight into each other's perspectives during the interview and to come to new understandings. The key characteristic of the information/data gathered was the insight/data produced as a result of the interaction between the participants in the focus group (Gibbs 1997; Krueger & Casey 2000).

The interviewer had significant experience and expertise in conducting groups, and in the managing of issues of sensitivity in counselling and educational settings. Such skills were needed and tested by the groups. At some sites there were individuals who often dominated the conversations both because of their understanding and experience of the phenomenon; however, at times, a power differential between manager and sub-ordinate was apparent and the managing of group dynamics was stressful. The interviewer took a proactive approach to the management of these situations by the building of rapport and the expression of genuine interest in the experience of each participant in the group as advised by Gibbs (1997), and Polit et al., (2001). Probing and clarification by the interviewer was guided by sensitivity to the issues emerging and this facilitated greater in-depth exploration without undue influence or direction.

Study Population

As stated a range of staff from different settings participated in the focus groups. In setting up the interviews at each setting it was explicit in all communications that any member of the multi-disciplinary team was welcome to participate. However in the first focus group interviews held at the six intellectual disability sites, nursing and social or care staff only attended. To capture data from the wider multidisciplinary team, two further groups were organized involving doctors, a clinical nurse specialist in dementia care and a social worker from intellectual disability services. An additional focus group meeting with community intellectual disability staff was organized to reflect that a community voice needed to be heard in relation to the care needs of the population under study. The final focus group consisted of members of the multidisciplinary team at the Specialist Palliative Care provider.

Second visits were made to four randomly selected sites from the six intellectual disability service providers in order to (1) further validate ideas emerging from the first focus group interviews and (2) collect additional data from non-Irish staff as cultural issues and their implications for training were identified as an area to explore further.

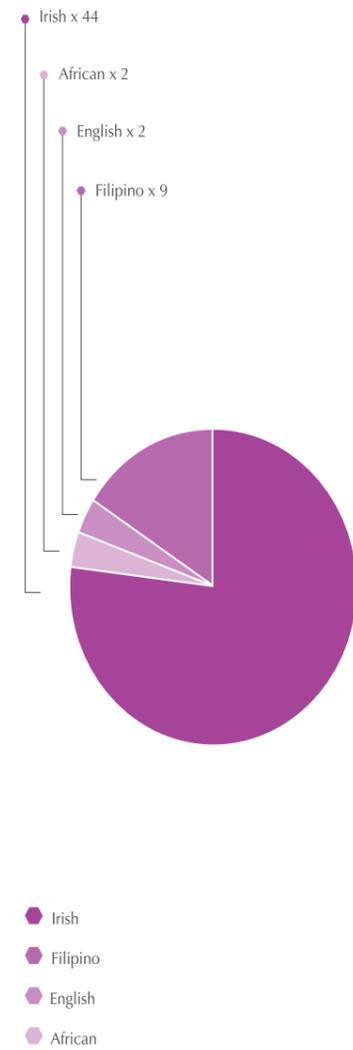
Demographic Profile

Of the total of fifty-seven participants, fifty participants were from intellectual disability services and seven from a specialist palliative care service.

Nationality of Participants

Forty four of the study participants documented themselves as Irish. Two documented themselves as English, two as African and nine documented themselves as Filipino.

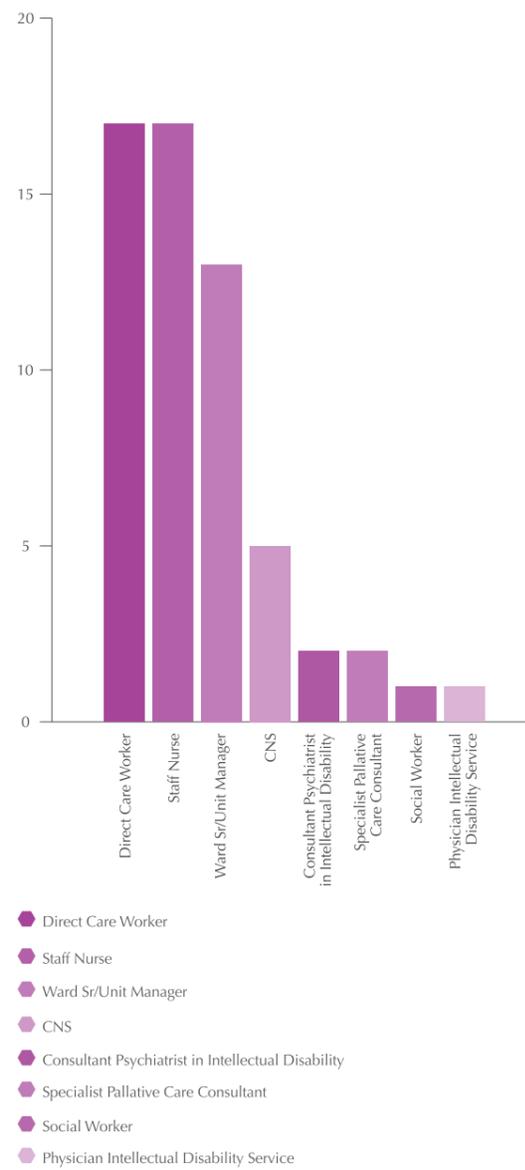
Nationality of Respondant/Participant (Total 57)



Participant Professions

There were thirty four nursing participants, seventeen care workers, five doctors and one social worker. The gender breakdown was four males (two nurses and two care workers) and fifty three females.

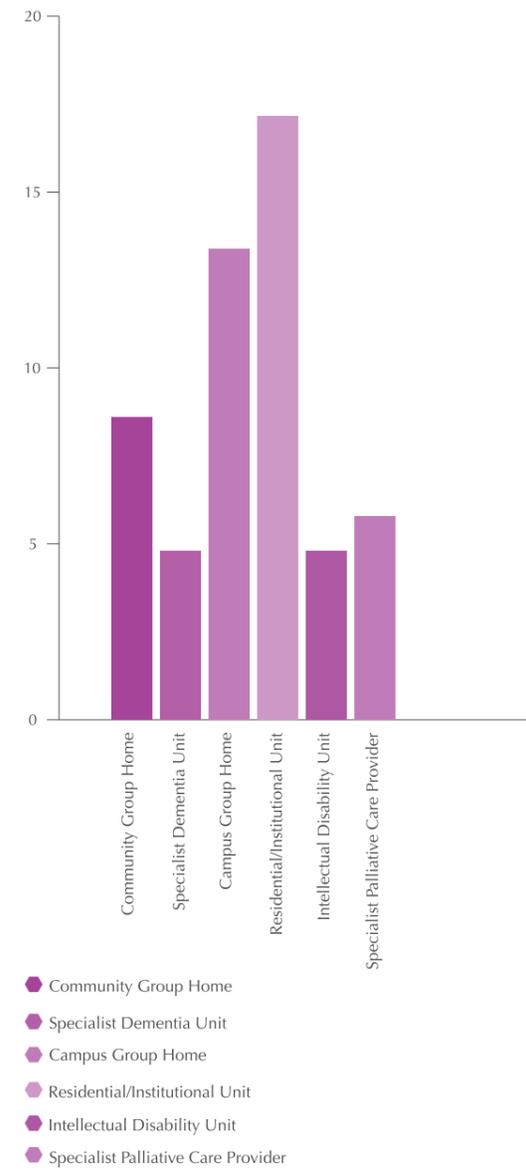
Participant Professions



Care Setting

The study was concerned to understand the experiences of staff supporting persons with dementia across a range of settings in order to get a fuller understanding of their experiences. Participants represented community group homes, institutional settings, campus group homes, specialist dementia facility, specialist ageing type units and specialist palliative care settings.

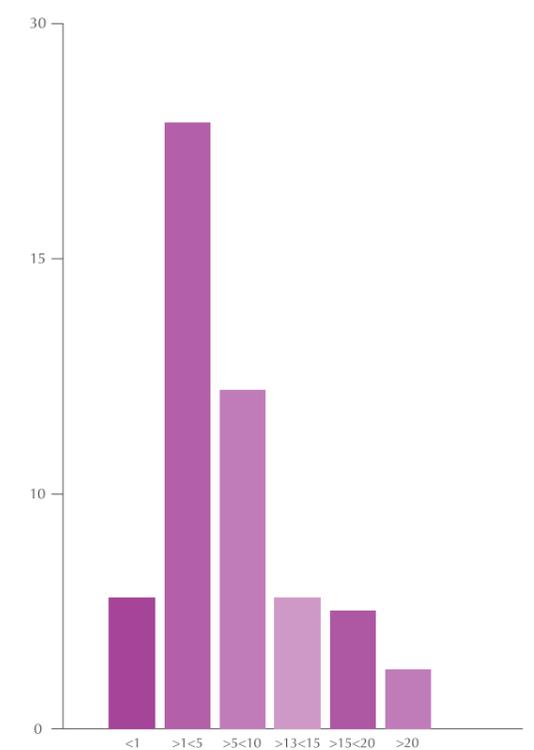
Type of Care Setting



Experience in Current Specialty and Dementia Care

Participant experience in their current care setting (Intellectual disability or Palliative Care) ranged from one to thirty years; 60% had less than 5 years experience, 23% between 5 and 10 years and approximately 17% between 10 and 30 years of experience. Participants' experience of working with persons with Dementia also ranged from one year to over thirty years.

Years Working in Current Care Setting

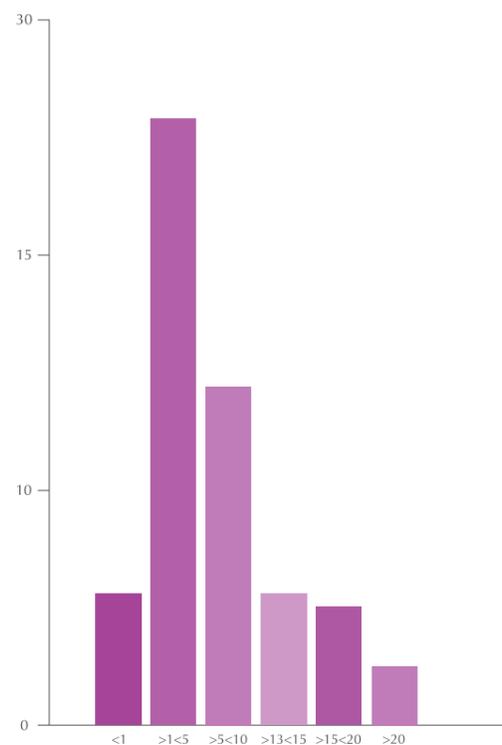


Education and Training in Dementia and in Palliative Care

All participants had experience of caring for someone with dementia as this was one of the inclusion criteria for participating in the focus groups. Thirty seven participants recorded no formal training in dementia care. The remaining twenty participants reported having formal training as part of on-going education or as part of undergraduate and postgraduate medical and nursing training. Eight participants reported attending training from one hour to four hours.

All participants working in the specialist palliative care service had undertaken palliative care training either during undergraduate/postgraduate medical training or in a nursing diploma or a degree programme in palliative care. There was one member of staff from the participating intellectual disability services with palliative care specialist training and six participants had undertaken formal 3-5 day training courses in palliative care for the older person. Forty four of the fifty participants from Intellectual disability had no formal training in Palliative Care.

Years Working in Current Care Setting



Five participants (doctors) reported that it was difficult to calculate but that they had undergone significant training throughout their careers as both undergraduates and postgraduates. Six participants (nurses and care staff) from one service reported that they had participated in a three/ four day dementia course offered as an in-house educational intervention. One participant (clinical nurse specialist) had completed a Postgraduate Diploma in the care of persons with intellectual disability and dementia.

Qualitative Data Analysis

Introduction

Collection and analysis of data proceeded concurrently with qualitative research (Horsburgh, 2003). The interviewer became very familiar with the data as a result of engaging with the audio tapes and the written transcripts over a period of many weeks, a process of immersion. This immersion is seen to be of great advantage when one is analysing the data because the interviewer knows the content so well (Krueger & Casey, 2000). The interviews sites were numbered chronologically from interview to interview. This number was followed by the number of the visit (visit 1 or 2) and finally a number was allocated to each participant as he/she spoke in the interview. Therefore when extrapolating information or quotes from the data, for example, 1.1.4 represents site one; visit one; participant four and 4.2.3 represents site four; visit two; participant three.

Approach to Data Analysis

Data analysis was initially done manually and subsequently by using a computer-assisted qualitative data analysis software (QAQDAS), NVivo 7 (QSR International 2006). This combined approach was used to maximise a thorough analysis which Gibbs (2002) considers enhances the analytic process in terms of transparency, reliability and accuracy. Computer assisted qualitative data analysis software however cannot interpret the meaning of the data; the researcher must know the data very well in order to be able to operate an effective analytical process. In this study the interviewer completed the data collection and transcription and was immersed in the data for many weeks, listening and reading/re-reading the interviews and transcripts. Reflective thoughts were recorded in field notes immediately after each interview and at other times during the analysis of the data. Such reflections were about the interviews, the research participants, the persons living in the settings (whom the interviewer observed), the sites and the context of the interviews. This enabled the interviewer to plan from one interview to the next and to develop questioning techniques. This assisted the analysis of the data in the transcripts when revisited to reflect on the meaning in relation to contextual issues.

Content and Thematic Analysis

Qualitative content analysis is the choice most suitable for descriptive qualitative research because it is naturally oriented to presenting a summary of the informational contents of the data (Sandelowski, 2000). Data analysis of qualitative research is reflexive as the researcher is collecting data and analysing at the same time and has to continue to consider all of the information and facts as they are being collected (Miles & Huberman, 1994). The outcome of a qualitative descriptive study

is “a straight descriptive summary of the informational contents of data organised in a way that best fits the data” (Sandelowski, 2000:339). For this study the following phases of analysis were carried out:

Phase 1 - Analysis

The interviewer/analyst on reading the transcripts while simultaneously listening to them on tape, wrote topics as they arose in the margins of the transcripts. These topics became the codes in the transcripts (nodes in the computer assisted analysis). These initial topics or nodes identified at this first stage of analysis are known as ‘free nodes’ in the computer assisted programme. The coding of the emergent themes arose from analysing these topics ‘free nodes’ for relevancy using four main criteria:

1. How often a topic was raised in the 14 transcripts
 2. How much time the topic took up in the 14 transcripts
 3. How many individual people raised the topic
 4. How much time individual people spoke on the topic
- Not all words or ideas were heavily coded at this phase.

Topics considered by the interviewer to be relevant to the focus of enquiry in relation to training needs or palliative care were of most interest but other information was not ignored and was also carried forward to Phase Two analysis.

Phase 2 - Analysis

In this phase of analysis free nodes were grouped into headings using the four criteria stated above and their relevancy as defined in phase one with respect to the focus of the research inquiry.

Coding involves grouping the nodes together and making link between nodes. This process yielded five themes (known as Tree nodes in the computer assisted package). These were:

1. Perceptions of Desirable Care
2. Loss and Grief,
3. Cultural Diversity
4. Communication
5. Education and Training needs.

These Themes were further broken down into sub-themes or categories and placed in hierarchical order. Some categories were grouped under multiple Themes. For example ‘telling’ was coded under ‘Communications’, ‘Cultural Diversity’ and ‘Perceptions of Desirable Care’. Other categories were eliminated if they were not central to the focus of enquiry of the research question or re-categorised if deemed too broad or refined if deemed too vague.

Phase 3 - Analysis

Phase three analysis involved the exploration of the relationships between themes identified in Phase two relevant to the focus of enquiry. These themes were analysed under the two major elements of the focus of enquiry which were the Education and Training deficits and the perceptions of Palliative Care. Database query tools enabled the researcher to draw text references across and between themes from phase two. Data brought from Phase two was further distilled by:

- The merging and collapsing of nodes. This involved one's merging nodes with similar content together and un-coding any content which did not reflect the newly defined properties of the node.
- The ignoring of nodes. Some nodes were ignored if they did not identify a training need and/or the content of it was already represented in another Theme.
- The reducing of nodes. The number of nodes was reduced after the above processes were complete.

Quantitative Data Collection

In addition to the focus group interviews, demographic information was collected to contextualize the qualitative analysis. The numbers interviewed in each group was too small to allow any conclusive inferences to be drawn from this data. However, it does provide important background information on the context of the care settings and on the study participants.

As a test of the effectiveness of the training intervention, a questionnaire was administered to the participants before (pre test) and after (post test) the educational intervention. Data was collected on staff knowledge in relation to dementia care and end-of-life care and their understanding and perceptions of palliative care. The data gathered and scales used were as follows:

- Demographic information was collected in relation to the background of the study participants, their educational and professional qualifications, their gender, and nationality, their experience and education in dementia care and their experience and education in palliative care.
- No suitable scale to measure perceptions and attitudes toward palliative care for persons with intellectual disability and dementia were found. However, one of the investigators had been involved in the development of an extensive scale which measured the perceptions and attitudes of staff towards palliative care for persons with advanced dementia who were living in nursing homes in the U.S.A. These scales and the testing of their properties were the basis for the development of a successfully defended doctoral

thesis (Lacey, 2002). With the author's permission, the two project lead investigators reviewed the scales for face and content validity for the population of interest, (persons with intellectual disability and advanced dementia) and added some items testing specific knowledge of end of life needs. Approximately 56 items consisting of scale components and knowledge questions were selected as potentially relevant. Of these small wording changes were necessary in approximately 15 scale items to reflect the change in population (persons with intellectual disability and dementia) and the change in location (Ireland as opposed to the U.S.A.). Items were scaled using a five point scale reflecting the respondents' level of agreement with the statement made.

It was not anticipated that all 56 items would be useful. The strategy was to examine the item responses for variability and to select those where there was initial variation among respondents of at least one standard deviation and then to examine the level of additional variation in each item selected from the pre-to the post test questionnaire in the belief that such variation is likely attributable to the experience of participating in the training intervention.

Quantitative Data Analysis

Demographic data was coded and entered onto SPSS version 12 for the purposes of analysis. Items Descriptive statistics were generated for the original 56 items and the items with at least one standard deviation at baseline selected. Mean scores on those selected items were compared pre-to post test and the differences interpreted. This measured whether the participants' knowledge and attitudes changed between filling in the questionnaire before the educational intervention and after the educational intervention was completed.

ETHICAL CONDUCT**Introduction**

The ethical conduct of research is an important issue for the researcher because "the conduct of research itself has to be subject to the practice of the intellectual and moral habits intrinsic to the conduct of research" (Gregory, 2003:15). All participants were afforded care in line with best ethical practice reflecting the ethical principles of Beneficence, Nonmaleficence, Autonomy and Justice as outlined by (Beauchamp & Childress, 2001) and in line with the Declaration of Helsinki research on Human participants (1989). Some of the key components which demonstrate good ethical conduct in this study are now presented.

The research team were aware that participants in the study were likely to have had both positive and negative experiences in supporting persons with dementia across the various settings and that recalling this experience could be an emotionally challenging experience. A multi-stage approach to address important ethical concerns was consequently adopted.

Phase 1 - Ethical Approval

- Ethical approval for the study was obtained from the Ethics Committee at the Faculty of Health Sciences, Trinity College Dublin.

Phase 2 - Access to Sites and Ethical Approval

- Ethical approval was obtained from the Ethics Committee and or the Board of Management of each of the seven participating sites.
- Gatekeepers were used at the various sites to distributed initial letters of invitation and information sheets about the study to the appropriate personnel at the various sites.

Phase 3 - Consent Anonymity and Confidentiality of Participants

- All participants were given the research study information, interview guide and consent form at least two weeks before taking part in the study and were clearly informed that they were participating voluntarily and could withdraw at any time if they wished, without any penalty.
- Written consent for participation in the study was gained from all participants at each interview and the researcher was available to answer any questions about the research at the beginning and end of each interview.
- All participants were assured of anonymity by stating that each individual participant would be given an identification number which would be known only to the researcher.
- Since this was a focus group interview ground rules were laid down regarding the confidentiality of information discussed during the interview.

- Each participant was assured of confidentiality in respect of his/her own name and the name of this/her Organisation in any presentation of the findings from the study. They were informed that the names of any individual/s i.e., persons/service users discussed at the interviews would be changed in the transcriptions in order to protect person/service user anonymity. An initial would only be used which would not reflect the first letter of the person/services user's real first name.

Phase 4 - Storage of Raw Data

- All data was stored and destroyed in keeping with the Data Protection (Amended 2003) Act (GOI 2003).
- All tapes and transcripts were available to the researcher only and to her supervisors on occasion, (for expert review), and were kept safely and securely with computer password protection.
- All tapes and transcripts that had any participant or person/service user identifying features were replaced with case numbers/initials and site and visit codes.

Conclusion

Within this chapter the research methodology, research methods used, the approach taken to analysis, and the ethical conduct of the study were all outlined. The research methodology was both qualitative/descriptive and quantitative. The research methods in the development of the intervention were a combination of focus groups interviews, interviews and reflection. The analysis was a thematic analysis and was completed using a combination of manual and computer assisted analysis methods. SPSS software supported the quantitative analysis of outcomes of the intervention.

BUILDING UPON SERVICES' HISTORY AND PERSONAL CARING: OFFERING QUALITY AND SENSITIVE CARE

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Introduction

A broader consideration of some aspects of the data collected during the focus group interviews with staff in the two service systems will be found in the (as yet) unpublished thesis of Fahey–McCarthy. The presentation here is of two core themes identified in the analyses: (1) Building Upon Services' History and Personal Caring: Offering Quality and Sensitive Care, and, (2) Supporting Comfort and Optimal Death in Persons with Intellectual Disability and Advanced Dementia. Consideration of the components and categories of these two themes led to the identification of a series of training needs which informed the development of a training manual (Fahey-McCarthy et al., 2008) to guide the project intervention.

This chapter presents the core theme of Building Upon Services History and Personal Caring: Offering Quality and Sensitive Care. It speaks to participants' perceptions of the essential pre-requisites which should underpin 'good care' at end-of-life for persons with dementia. This 'good care' implies that the person is at the centre, that there is a choice of place where care is provided, the environment is capable, supportive and peaceful; it also implies the provision of supports for peers, together with quality care and comfort. There should also be attention to spiritual care and planning care where families are involved and where there is a co-ordination of care across service systems. The next section of the report will present the second core theme of Supporting Comfort and Optimal Death in Persons with Intellectual Disability and Advanced Dementia.

The Person at the Centre

To keep the person at the centre of care proved, not simply to be a philosophical statement, but a critical guide for staff in the delivery of care. Two key issues were identified: knowing the person and maintaining relationships.

To Know the Person.

To know the person appeared to be a central pre-requisite in upholding the person's dignity and identity. While participants did not explicitly use this language, the person's likes and dislikes appeared to be guiding the guiding concerns underpinning care. Participants across all sites consistently spoke about the individuality of each person; some individuals liked and disliked different things in the area of physical or psychological care, psychosocial or occupational needs or of the minutiae of their grooming likes and dislikes. They did not see every person with an intellectual disability as the same nor did they see everyone with dementia as the same. When asked what they thought the end-of-life care needs of someone with dementia might be, they inevitably anchored their response in the individuality of the person with whom they worked.

For Example:

.. well that would depend wouldn't it on the resident, everybody is so different.. (1.1.2)

One participant spoke about a person who was transferred out of their care and how when he was transferred to an outside service, the new staff appeared not to understand or value the importance of personal grooming for this person:

...his care wasn't... ideal like .. it wasn't .. his hygiene .. wasn't.. he was a man who loved.... he would spend hours washing his face and had the comb in his back pocket and would be constantly you know fixing himself and... and to see him in a nursing home was just dreadful. I'd say a lot of staff are still very, very angry about it. (2.1.2)

Interestingly, participants did not explicitly use the term 'person-centred care'. On many occasions at non interview times, the researcher witnessed across all sites what would be considered person-centred care being delivered as routine. Staff knew the intimate details of what made 'Mary happy' or 'John sad', what made them 'glad or mad' (pseudonyms used). Participants used scrapbooks, photo albums, favourite music of the past, and entertained the person with hobbies they used to like before they had dementia. They still saw persons as they were, irrespective of their changing cognitive and psychomotor deterioration. This was captured eloquently in a quote from one participant from the specialist palliative care service:

.. another thing I think intellectual disability services have got right is that they have a very strong philosophy of person centred care .. they see the person still the same at the end .. even though cognitively they're dis-improved because of the Alzheimer's .. they still see the person .. the spirit or whatever of the person .. even though they're not the person they were ..(9.1.2)

The Maintaining of Relationships (Holding on and staying close to the person)

The maintaining of relationships refers to the importance which participants placed on keeping links between family and staff who were/are familiar with the person throughout the continuum of dementia. The participants believed that it was important to maintain a close and familiar relationship with the person throughout his/her journey with dementia to the end-of-life. Despite the apparent burden at times, it was evident from the narratives that staff went to great lengths to keep persons in their current home. A participant (manager) described that she knew that when staff said they could no longer cope with caring for a person with dementia in their current care setting either because of a lack of resources or

Place of Care

'In Home vs Out of Home'

Across all sites, the participants stated that the preferred place of care for the person with dementia was the person's own home:

.. if we've looked after them all those years and ..sort of grown with them like you know it's very hard when they're at the end stage of their life to.. to send them off to another unit ..and it would be our last option .. we/it would really need .. we'd have to be in a position whereby we could do no more ..you know .. (6.1.2)

Generally, the participants across all intellectual disability sites appeared to support an ageing in place model but they also acknowledged that this was often difficult to sustain. Many of the care settings were not designed to support people with mid-late stage dementia and staffing levels and skill mix did not often reflect the increased care demands. One participant, working in a service which had minimal experience of supporting persons with late stage dementia, recalled their experience of having to transfer a person with advanced dementia to a generic care service and the impact that this had on all staff concerned. Participants described how they felt angry; they felt they had let down the person, and felt disempowered as is evident in the following quote:

.. my ideal situation was that we would have looked after him in his own home and that was the ideal for his family as well .. he was an elderly man as well ..and that would have been the ideal situation.. but equally ..when you know you don't have the support that you need .. you know the frustration level that.. (2.1.2)

Another participant commented on additional adaptations that were made by the organisation to support the person and from the narrative it appeared that they were more pleased for the person because they had better accommodation now, rather than for themselves that they had a better working environment.

.. he was in a double room .. but there was plenty space in it .. you know that we were able to manage the hoist .. he had a nice room now .. (6.1.1)

The participants also recognised that as the person's overall care needs increased they were often challenged to deliver the care they desired in the person's home where the environment was often unsuitable:

.. if you have a person up there with dementia ..it's going to be bad for everybody.. The person that is suffering and everybody around them.. (1.2.2)

health and safety issues, that it should have been said six months previously. This participant felt that very often staff would continue to struggle day to day and would almost be at breaking point before they would admit they could no longer cope.

These excerpts provide some insight into this resistance to letting go and the difficulty for staff was strongly palpable:

.. my experience is that if you said to the nurse would you like us to take Mary and bring her somewhere else, you know, for the end stage they would probably say no .. even though they are very overworked and over-stretched providing care to everybody else who doesn't have dementia on the unit.. (7.1.1)

Participants also described efforts to maintain these relationships even when the person was transferred and they also considered it important to bring old friends along in order to keep the peer-relationship alive.

..a good few years now. .. About 2½, nearly 3 years and they still visit on a regular basis.. (10.1.3)

The participants also spoke about the importance of this bond and relationship in the supporting of persons through death, and of the importance of ensuring that the person did not die alone. This was said with a sense of satisfaction:

.. it was just a gradual thing so staff were with her every day and there was none no problem .. no problem .. she still died .. but like staff were there.. (3.1.7)

In three sites the participants spoke explicitly about the compassion of their organisation if the person had to be transferred to an outside hospital or care setting:

..if em the hospital indicate to us that time is getting close that .. that they see that there is a real time limit .. the time that this person has left with us em .. the service does eh .. it's just that somebody regular would be with the resident.. can spend time with the resident if they do pass away ..that somebody that was familiar to them is there.. (4.1.1)

Other participants working in community services had significant experience in supporting persons across of the continuum of dementia and felt that they could manage up to a certain point along the trajectory of the illness:

We can manage them early, mid stage.. (10.1.1)

They identified that at the late/mid stage, the person's care needs complicate living in community for both staff and other residents (peers). The challenges which the participants spoke about centred on resources, time, impact on peers and skills required for care-giving. From their experience, they knew that they could not provide desirable care once the person had to be chaperoned; this was due more to staff ratio concerns and the reality that the provision of a safe environment for the one person may severely curtail the freedom of others in the home. In addition, the emergence of new behaviours combined with agitation or aggression sometimes evidenced at mid stage dementia was distressing for other peers in the home. The participants also spoke about the challenges in community settings in supporting persons with advanced dementia and related health care issues which often required twenty- four hour nursing care. The giving of care with comfort and with safety was often seen as a challenge:

....The environment is wrong, the supports are wrong, there's an awful lot wrong.. (10.1.1)

....Community houses shouldn't be lock ups, they should not be prisons, we should be there supporting the persons in their environment, living in a community environment and allowing them to make decisions affecting their lives and make their own decisions with support obviously, its not living, I mean I don't go home and I haven't to lock the door between the kitchen and the sitting room, there's nobody going to turn around the corner and attack me in my own home, its not a home like environment.. (10.1.4)

.. at the very end stages where their environment absolutely you know is unsuitable for aging because of physical restraints such as you know hoists, transfers, bathing, and all the rest .it becomes completely impractical.. (7.1.2)

Yet, other participants argued that a community house was a better environment for the person because of the smaller numbers of persons living there and the consequent environmental familiarity.

.. coming from the community setting and it may not be ideal you know .. but it's a warmer closer, you see more staff out there .. (2.1.1)

The participants in community settings commented on the lack of knowing whether the person with dementia would be staying or that there would be a transfer of location. This added to the day to day difficulties. They wanted a plan:

Yeah, its whether this, well how long more have we to keep going like this, its getting worse every day, you don't have, there's no vision .. (10.1.5)

Some participants (experienced intellectual disability nurses) envisaged that the care of persons with advanced dementia dying at home in the community could be possible and was preferable if community houses were adequately resourced with specialist nursing and palliative advice and supports.

.. it has a huge impact unless you have.. staff that are actually qualified .. em the last few days em are very intense and I don't know whether the community houses would actually be able to physically and emotionally manage .with .the service users that they have .. obviously it's a huge impact on them .. now in saying that .. in years to come if the proper supports were put in place ..maybe if they had a team that were mobile that you could put working within a unit that .. the ideal thing would be if you had facilities there yes! Cause ideally it would be nice for people to die at home.. (5.1.1)

Participants also spoke about the need for different type environments which would be responsive to the needs of persons across the continuum of dementia recognizing the fact that the needs of the person at mid- stage dementia and end stage dementia were often different as evidenced in the following quotes:

.. they moved her into Y (end-of-life care unit) which was a disaster because she screamed the house down morning, noon and night. She was disorientated with time and there were ladies there who needed palliative care, and it was an awful move actually. So what we actually do need is a step down unit.. You know, say the likes of here or X (residential unit of the service) where the behaviour becomes such they cannot be managed in the community house anymore or at home living with their parents. They could be moved into this step down unit .. but it's not palliative care either.. (8.1.1)

... at agitated stage .. we can't you know provide what they need at that stage in Y (unit for end of life care), because you've other people who might be dying or have other difficulties and it's supposed to be the quiet unit where you know .. (3.1.5)

A Peaceful Environment at End of Life

There was a general consensus across all interviews that persons with intellectual disability and dementia were best supported within the intellectual disability service system; but successfully supporting people across the continuum of dementia required certain standards of environment. In particular participants spoke about having a peaceful, beautiful environment for the person at the time of death.

The likes of A was down there dying, gradually she was just drifting away, and they were all going about their business, and d'you know I thought I would have liked you know a beautiful quiet setting, now not a kind of a morbid setting, a bit of music maybe or something nice, but you had those coming in and out..but they were her family her friends here, I understand, but there was hustle and bustle and I think it should have been a more. A more peaceful and dignified way to... (1.1.1)

The participants from the services where there was a specialist dementia/palliative care type settings described in very positive terms their experiences of persons dying. Staff there had undertaken specialist training and education in end-of-life care. In addition, the unit offered individual rooms and personal space and families were usually involved. In such settings, the participants reiterated that death was, in general, dignified and peaceful.

.. Well it's been generally very peaceful, its generally them slipping away, its been generally done in privacy. People would have their own bedrooms in which they would die.. (7.1.1)

The absence of a quiet place would even encourage some participants to consider moving persons out of their usual home /community setting:

..... there is a certain stage where you can say sorry ..there is still too much noise here, you know ..let the person stay with us as long as possible, for as long as they're comfortable . But it gets to the stage all right where you have to say no, the noise levels wouldn't be conducive to someone that was unwell, you know... (3.2.2)

Most participants across the intellectual disability service sites had some experience of people dying, with nursing and care staff more intensely involved in the day to day care of the dying person. Such experienced nursing and care staff appeared to have developed their own intuitive coping strategies and felt competent to deliver the basic nursing care required to look after someone who was dying and who did not require specialized pain or symptom management:

.. at the end it was literally .. just basic nursing care at the end ... (3.2.2)

Despite their feeling confident about delivering basic nursing care to the person who was dying, participants did express a need for specialist support particularly around pain and symptom management received from others in a supportive and consultative manner:

.. I definitely would want input .. you know .. while we would be able to do the basics .. I would like a visit to see how ..just encouragement to make sure we were doing it right and everything and.. just to monitor it .. (6.1.2)

Some participants also favoured having a specialist unit within the intellectual disability service where the person could be transferred when they required more intensive nursing and palliative type care as evidenced in the following quote:

.. I think there is no doubt that it comes a stage that people need full time nursing care. And that is expensive and again you need your, your experienced staff and their right mindset to provide that. From my experience its better later on to have a specialist unit for that end stage ..but within the organisation .. (8.1.1)

But other participants disagreed:

.. rather than making one area for palliative care because then you're isolating them again.. then we're back to where X is where you go to die ...and now we're going to a palliative care unit to die like you know, if we wheel her up to that area whatever it is oh well sure .. she's finished now .. you know what I mean.. so if we could train on the ground that we deal with it in our own situation rather than taking them to a specialised area for it you know.. (2.1.1)

In some sites it appeared to be common practice that the person would transfer to an acute hospital for terminal care and die in the hospital. Participants stated that this generally happened because staff did not have the clinical skills or medical support to provide optimal end-of- life care. Participants expressed that this was difficult and frustrating for staff and families and their sense of sadness of not being able to provide care was almost palpable:

.. it's kind of common knowledge at the end that they would be in and out of hospital .. say they'd be in for a week ..with dehydration or a chest infection or whatever ..they'd have IV antibiotics and then they'd be out again for a while and back in .. that could happen a few times before the end comes .. now they sometimes have been here at the very end but ..I'd say the majority probably do end up in X (hospital) .. we would definitely prefer to have them here their families I think the majority of them would prefer to have them here as well .. and it's a pity that we can't provide to their needs ..you know at the very end .. (4.1.2)

In the service which has a purpose-built unit to care for persons with dementia, participants stated that a person could be admitted at any stage of dementia but would ideally come to that unit when they were at late stage disease.

.. ideally they would only come here in the late stages but .. depending on their social circumstances .. whether they're in a unit that is a community house ..it appears that they might not be able to cope with .. that they're moved in here early .. or that the social circumstances at home mean that they're unable to be cared for there .. (5.1.1)

Supporting Peers

The participants recognized that peers at times often had established and long term relationships with the person with dementia. They also recognised the importance of these continuing bonds and relationships speaking about the peers of the person being their family just as much as the staff and their own family if they had one.

.. well it's like as if they were dying at home like .. you'd be around them (6.1.3)

The participants across sites also commented on the need to balance the well-being of the person with dementia with the well-being of the other peers in the setting. They also recognised that care for the person with dementia significantly impacted at times on the quality of life for peers in the home and that the level of activity for others was often defined by the person with the greatest level of need:

.. it's the every day, day to day living because your may plan to go out or whatever and then that person doesn't want to go or is confused, looks out the front door, doesn't really want to go and one can go.. (10.1.5)

....Suddenly the doors had to be locked because they couldn't get out, their freedom of movement within a house had to, was restricted necessarily unfortunately and they just saw it as somebody just disrupting their whole lifestyle .. (10.1.2)

The participants in one service reflected on the burden expressed by one peer resident of the home:

..... told the staff that they could get away from it but she couldn't. This upset the staff that she could understand and felt trapped living in her own home.....

The participants stated that people outside of the setting have limited understanding of the difficulties of living in such a setting and even wondered whether they themselves really understood the situation from a peer's perspective:

....They are there all the time and it's just, I don't think you can even comprehend how difficult it is for them no matter how long we're there.

You'd want to sit I think in our house actually at the moment for, if you could manage for 2 hours and just see that the actual dynamics of it, I mean it would be intolerable I think for an awful lot of people, it really would, the dynamics in the house at the moment is just.. terrible (10.1.3)

The participants also indicated that often it was not until the person with dementia had actually transferred that they themselves had time to reflect on the impact their care had on other people living in the group home: this perhaps should also be in the conclusion

.. when you remove that person its just like .. oh my God this is how the house used to be.. and they have actually realised that they have forgotten to spend time with the other service users that have been in that unit .. and it's an opportunity for them to spend time .. (5.1.1)

The provision of peer education and support was reported to improve the situation at one site:

We also run peer training as well were we go into ..say a house in the community where somebody is presenting with dementia and taking up a lot of staff time and the peers are getting angry because they are not getting the attention that they need.. So we would go in and do peer training as well and that has worked out very well. You know explaining very simply, just maybe one hour a week for a number of weeks, its worked out very well.. (8.1.2)

Quality Care and Comfort

The participants across all sites made reference to the importance of endeavouring to give the best care and comfort to the person with dementia. This was supported by the researcher's observations of their attention to comfort; a reflection on one such visit is presented in Appendix 3.

The participants spoke with pride about the quality of care and comfort which they delivered in their service and several mentioned experiences where a person with intellectual disability was transferred from their care into an acute hospital setting:

.. we've all had the experience of where they've gone into hospital for an overnight or a few we.. few days and where they come back withwe'd would do anything rather than let them off.. they come back with broken skin and everything that we wouldn't .. that we'd be so careful of.. (2.1.1)

The "Ordinariness" of care in providing comfort was recognised to be important:

yeh it could be even changing their position ..even putting them into their bed for a little while .. turn off the television and turn on some music.. little things like that even.. (4.1.2)

To spend time with the person e.g. a staff member sitting with someone regularly, long before she was actively dying, was seen as valuable:

She died very, very peacefully and she hadn't become emaciated or anything, chest infection in the end would have been what would have caused it..... but I think it's the time.. ... time is the thing ..time with the person (9.1.4)

The ultimate level of comfort that participants expressed they wished for the person was that they would be pain free and in a state of comfort in their final hours. One participant (non Irish nurse) stated that initially when she began working in intellectual disability services she struggled in adjusting to caring for someone where a palliative approach was being used. She had worked for over one year and saw people being kept comfortable rather than their receiving active medical interventions which she had been more accustomed to; she now had reflected and thought that the palliative care approach was more appropriate. This participant described how she understood from the persons face that they were comfortable at the end at the time of death:

.. and I can see here that the, you can see in their face its just comfort. During the last stage.. (5.2.1)

Involvement in Previously-Valued Life Experiences

The participants stated that it was their experience that persons were living longer with dementia and therefore they were making every effort to involve people in previously-valued life activities:

.. and at the minute we'd have a lot of socialisation and activation therapies ..there are a couple of people still going to their day services.. to try to keep them involved with the people they used to be at services with .. (5.1.1)

At one of the purpose-built sites (built to support intensive nursing-related needs), the interviewer observed staff taking persons with quite an advanced stage of dementia out shopping or for coffee and encouraging family to take them out or home as regularly as possible. The participants believed that the maintaining of normality like this supported an individual's quality of life as evidenced in the following quotes:

.. last week and there was just only myself and a service user here .. everybody else was out .. so I mean you can look at it as a unit yes where they do die but people at home die people anywhere die ..but yes it's a specialised centre .. but we still are going out .. we still do daily things .. (5.1.1)

.....and when the weather is fine we take him out for a walk around the grounds .. you know and we have his own programme then we have it worked out for him here.. (6.1.2)

.....we have a multi-sensory room which he quite enjoys .. we also do hand massage and stuff .. it helps his mood (6.1.3)

.. Yeah we would have, this lady now would have loved art and crafts and stuff like that so even though she's sort of regressed in a lot of ways, she's doing colouring books and stuff which is actually giving her entertainment for an hour or she has an Andy Stewart video who she's obsessed with, so that goes on every day, to maintain, that reminds her of great times at home with the family. Like that we'd have the nice story book, that comes out for half an hour in the day time .. (10.1.4)

Spiritual Care

The participants identified that the person with dementia needed spiritual care well before and at the end of life. Some intellectual disability services were supported by a chaplaincy service while others were not. Participants also identified the need for additional training in spiritual care; the desire for additional skills and supports was evident from the narratives:

.. they need the time for both medical and spiritual cause like you say the fear that they go through .. you can see it in their eyes.. at the very end you can see that fear .. petrified .. d'you know and it's just they need a lot more time maybe than the next person who might be just sick and needs attention too .. but that fear is a huge thing I think for nursing .. for anyone nursing or caring for someone with dementia.. and then spiritual needs .. I think a lot of training needs to be in that .. that as well reminiscence definitely because the fear is huge.. (3.1.5)

.....And spiritual needs of a resident and knowing exactly what to do.. (1.2.1)

Planning Care – Involving Families

The participants realised that planning the care of the person from the earliest possible time following a diagnosis was important. Interestingly, while the participants spoke about the ideal of early planning for end-of-life care, no participant explicitly spoke about including the person in this planning. It was not clear whether this was because the participants were not normally accustomed

to involving people with intellectual disability in health related decision-making or whether they thought that one's ability to participate was impaired by dementia.

The participants also recalled some bad experiences when they did not have a plan in place to address end of life care issues:

.. we've learnt the hard way that but we've learnt none the less to have a plan in place .. and we would discuss it at our team meetings.. I mean it would be coming up anyway but as I say .. as 5.1.1 said it's more nurse led now .. (5.1.2)

It was evident from the narratives that the participants respected that not all families wanted to plan ahead but some were working in services more actively trying to start this planning process with families as early after the diagnosis as possible:

.. some families don't want to buy-into that early plan that we have .. certainly families that hasn't been an option for them .. but the majority of cases that we have, we had that forward planning from the start.. (7.1.1)

The participants across all sites recognised that the person's family were the legal decision-makers so they actively encouraged family involvement:

.....I think the only eh .. I think we have on-going contact with family and our ethos here in X (ID service).. is to involve family as much as possible in the care that's given to their relative .. and particularly when you look at dementia and palliative care needs.. their contact as E pointed out becomes more .. depending on the family .. they're a bit more involved and we encourage their involvement .. so they're part of the process .. they're seen as an integral part of the process ..like I mean to be fully consulted .. and if anything new happens that they know about it .. if they have any concerns that they can speak to the staff here ... or if they need to speak to the managers here or a GP .. that would be facilitated as well .. we do involve them .. as best we can .. (4.1.1)

Similarly,I think certainly having the meeting with the family early on and discussing you know, the possibilities, they are very forthright and up front basically and getting the families feedback, at least then if the nurse does go to a general hospital they are going with an agenda,.. they are bringing it on behalf of the family. Because certainly a few years ago we had problems with someone going out with pneumonia to the general hospital and they came out with peg, I mean like that was a big issue basically which I think don't know how, because the family expressed wishes and because the nurses, I'm not aware that would happen now for quite a while in our organisation certainly .. (7.1.1)

The participants also expressed concern that sometimes family members had limited relationship with the person and therefore did not necessarily know the wishes of the person; because of legal implications (as next of kin), they could be asked for consent to a procedure and this often caused huge distress as evidenced in the following quotes.

One lady in particular this year in the last year who had end stage Alzheimer's Disease and Downs Syndrome who the family decided to put a peg in I think it's a year or so.. within the year and the poor little woman has just ballooned up and she has no..her quality of life has just been..in my opinion affected because of what was done to her it's horrendous you know (3.1.5)

I suppose you feel you know them better than their families, you know, its heart breaking for someone that doesn't know them, that comes every Christmas and suddenly they have this decision to make (3.2.2)

The participants from the specialist palliative care service agreed that the involving of key people such as families in planning is important for good palliative care:

Sitting with the persons who are significant to the persons care ..meeting with the people who are in contact with the person is important for good care .. (9.1.1)

Co-ordination of Care: (Who takes Responsibility?)

The participants across sites expressed a range of experiences of end-of-life planning.

.. planning would be I think.. at an early stage even along the route of em ...what's going to happen rather than waiting until God we're here now and what are we going to do about a PEG and all the discussion this is what we do .. put one in .. rather than .. look we've time now, family have time .. I suppose planning is major.. (2.1.2)

.. there wouldn't be formal meeting sure there wouldn't .. of whole team.. (4.1.2)

Staff recognised that a team approach was necessary. If team meetings were deemed necessary, it was the nurses who usually initiated them but not always:

.. Now as I said the physician will meet later on, on the campuses that she covers she will be very actively part of that meeting with the families as will the dementia team plus a member of the unit. in other parts of the service where they have GP cover.. the GP.. a dementia person usually a nurse or care staff from the unit would also attend that meeting with the family and they would talk through

the various issues about transfer to hospital, aggressive treatment and peg feeding, all these.. at quite an early stage.. (7.1.2)

The participants from the specialist palliative care service, having worked with three of the six intellectual disability services involved in this study, noted how advanced were planning and team processes in those services and indicated that such practices are in line with good palliative care practice.

The other things in palliative care we do is like communication or forward planning and a lot of that has already been done by the ID services and I think that's something that definitely I've noticed has got much more focus in recent times, people who are part of ID services are less likely if they have ID to end up in hospital having a peg tube on a bank holiday week-end you know .. they're less likely to have that now, there's more forward planning, you know this is a progressive fatal illness so we're thinking ahead what we might do rather than something happening acutely.. (9.1.1)

General Practitioner Roles

Given that many persons with intellectual disability and dementia live in the community, general practitioners (GPs) were key health care professionals. The participants from the specialist palliative care service identified that GPs have limited experience of dealing with dying in the community, and therefore caring for someone with the dual diagnosis of intellectual disability and dementia will be a challenge for them in future care:

.. GP's experience with end of life care in the general population and you estimate that a GP will only have 5 cases every year, so GP's by and large feel very under skilled in caring for people at the end of life, let alone add in the complexity of dementia, intellectual disability and end of life care. So I think that's a really interesting point as to whether people are going to have their individual GP's or whether you have a GP developing a special interest able to pick up .. in terms of GP's and their level of knowledge around palliative care because you link in with them a lot.. (9.1.2)

The additional complication of intellectual disability services using contract medical staff led one participant, herself a senior medical staff person, to argue that future planning ought to include the intellectual disability nurses in a lead role:

.. Because one of the problems with learning disability is there are very few dedicated physicians in learning disability.. The majority of cases will just have GPs popping in and out. And then you are calling contractors or bureau doctors. So for continuity of care to a degree it has to be nurse led or nurse driven and that is why we need really good experienced people, that can ring up and say look you know I can't get the medication in, she is fitting, I think I

need to go ahead and give subcutaneous medazolam or something, somebody at that level, that is very important. So that is where I think we have to train up nurses to do that. Because if you are relying on doctors or GPs or whatever ..that is not going to work. And that will be a big hiatus in the service.. (8.1.1)

Working with Hospitals

The participants expressed their frustration many times when persons were transferred to outside health care (acute hospitals); in those hospitals decisions were made about the person without any communication with staff from the intellectual disability service despite the fact that acute hospital staff were poorly equipped to make such decisions:

.. people that they are seeing don't have any learning disabilities and dementia. They may have certain ethical differences with regard to feeding and different things and aspiration. Usuallyyou go to a different doctor each time, you don't build up a relationship, you are usually with a very junior member of staff who isn't going to make.. to have that experience to make those difficult decisions. .. (7.1.1)

The participants felt strongly that often they knew the person so well that they would know whether the person would or would not like a particular intervention, for example a PEG (Percutaneous entero gastrostomy) and often felt frustrated when they were not involved in end-of-life decisions. The participants also reported examples of the family of the person being contacted when the person was in hospital and decisions were rushed about siting a percutaneous endoscopic gastrostomy tube (PEG).

Collaboration

The participants from the specialist palliative care service suggested that collaboration is important in order to capitalise on each other's expertise; to have specialists from palliative care services and intellectual disability services working together would be an important future direction of collaborative working:

.. the idea of collaborative working, so that it would be dementia services intellectual disability services and palliative care with .. (9.1.1)

The participants identified a lack of clear boundaries about who co-ordinates care for the person internally within the intellectual disability service and externally when the person was being cared for in a hospital. The participants, even on a site where there were regular multi-disciplinary team meetings, reported that there was no particular lead person to bring the care of the person together, because reporting mechanisms were different for the various members of the team:

.. the difficulty with the place I work is that no one person takes responsibility for everything.. So you have a manager, then you have the independent clinicians and so therefore who we report to is very different. . (7.1.1)

In another site, the participants said that while internally the working of the multi-disciplinary team was usually efficient, the continuity of care of the person with advanced dementia was fragmented once they were transferred to an outside hospital because of a lack of clarity regarding accountability:

.. we have a lot of problems with some general practitioner teams. ..you know hospital practitioners .. not our own .. no one seems to be accountable.. no one seems to know what everyone else is doing. They leave here on a list of past medical history and medication .. you go down and she's not getting this and that and they have nothing written down.. and when you ask .. Oh I don't know, I'll ask, oh no I don't know, we'll ask the doctor, where is all these notes. No one is accountable for anything .. (3.2.2)

The participants from one service recalled their experience of having a liaison nurse who co-ordinated care between the service and the hospital and lamented the fact that it was no longer available:

.. And especially if the clients are hospitalised .. she went to that and she follow up everything about the client and its really the first hand information... So at the moment we do not have one person that talks to the family. That co-ordinates .. (4.2.4)

The participants from the specialist palliative care service equally had difficulties with this lack of a co-ordinated approach to the management of the person with dementia; their experience was that there was a lack of clarity as to whom had on-going responsibility:

.. but there was also then issues with the medic about, the medics of the organisation but then who provides the GP services, so there were issues there because although the organisation had a medic .. people who lived in this house had GPs, there was also issues about prescribing... who had ongoing responsibility.. (9.1.1)

An intellectual disability services participant also highlighted the need for a person or persons to co-ordinate care:

.. be nice is if you had somebody that was assigned just, a med ..you know, that somebody had a specific slot just on the medical care of dementia and learning disability. That would be lovely if you had a medical post. I would see that as far in the future though.. or that you would have somebody who had palliative care experience(medic) coming into the organisation to work within the organisation.. (7.1.1)

The participants also wished for a team approach to care:

.....there's other people that need to be so much involved like .. there's your Dr., even your psychiatrist, like your psychologist as well like .. if you're going to be meeting their real needs .. all these people .. they all have a niche I think .. and a role. (all others nodding).. (2.1.2)

Five of the six intellectual disability services had access to multidisciplinary teams that extended beyond core disciplines. This team approach was particularly supportive when it came to end-of-life care and took the isolation out of one's having to make decisions alone:

.. went through all our residents and all the people who were coming up for consensus agreement for diagnosis. That was very helpful. I also felt it was very helpful too for myself and the clinical nurse specialist who was also the head of that unit because when you are probably the head of a team and you are giving palliative care and you have a lot of people at different stages of dying ..you really need that backup.. (8.1.1)

One service had nursing, care and medical staff only. The participants from this site were frustrated that persons with intellectual disability were not receiving what they considered desirable care because that would need access to other multi-disciplinary team members:

Like some of them need physiotherapy and need to be .. we don't have a physiotherapist ... like it's all very well to have someone like A,B and C down there that are demented but like .. we can only look after their physical and emotional wellbeing and sort of get the spiritual needs looked after or whatever. . but what do you call it like therapies or whatever .. aromatherapy and all the different teams that could be coming in .. (1.1.1)

The participants also recognised that the multidisciplinary team in intellectual disability services, if they did not have the expertise themselves, could benefit from support from someone from a specialist palliative care service if they did not have the expertise themselves. They suggested that a liaison post between the Palliative care service and the intellectual disability care service might provide such assistance:

.. somebody like a liaison person from the hospice to provide you know back up to the nurses, about if they need to put up a syringe driver, to have that, that is just fantastic.. (7.1.2)

Conclusion

This chapter focused on the participant's perceptions of desirable care for persons with intellectual disability and dementia. It was evident that the addressing of the needs of persons with intellectual disability and dementia across various settings is complex. While there was great diversity in perceptions regarding the ideal care settings for persons with advanced dementia, there was a consensus that persons were best cared for in a familiar environment with familiar staff, that a person-centred, coordinated and multidisciplinary approach is best, that families should be involved and peers supported; that when dementia is advanced, the more significant care-needs require attention to environments, staff skills, supports and resources. At a first level, this core theme and the related values expressed by staff, influenced the design of the intervention.

The next chapter will address the second core theme: **Supporting Comfort and Optimal Death in Persons with Intellectual Disability and Advanced Dementia**

SUPPORTING COMFORT AND OPTIMAL DEATH IN PERSONS WITH INTELLECTUAL DISABILITY AND ADVANCED DEMENTIA

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Introduction

This chapter explores the interests, needs and practical concerns of staff in intellectual disability services and specialist palliative care services supporting persons with advanced dementia. A number of categories emerged from the data, all associated with death and dying: symptom control and life-sustaining treatment, pain assessment and management, supporting the person through death, maintaining adequate nutrition and hydration, resuscitation, fusing the horizons of care, the impact of cultural differences, coping with loss, grief and bereavement, the managing of the symptoms of dying and the acquiring of the skills to respond effectively.

The Acquiring of the skills needed for symptom control and Life-Sustaining Treatment.

Understanding Dementia

Across all sites participants stated that staff needed training and education on dementia. Some participants stated that they had no previous knowledge of dementia and were working by instinct. This is evident from the following participant's comment:

...us care staff come in with nothing like you know and we're more hands on ..I don't mean that in a bad way but we're more hands on at times and we don't what we're meant to be doing... like you know you can't come up with a good way of working ... if you've no knowledge of it like.. (2.1.5)

Participants who had a nursing background also acknowledged that they needed additional knowledge because dementia was not included in their professional training:

...well even as a nurse I'd say you can still need trainingyou have your experience but you don't have specific training on dealing with people with dementia or caring for someone with dementia.. (2.1.4)

Another participant stated:

...we are going to have more people with dementia and dying so it would be important to have more knowledge and skills to deal with it .. (4.1.1)

Some participants remained uncertain as to whether they were managing the person with dementia well and struggled to change their focus of care. One participant spoke of the guilt which she experienced:

...there's certain struggles I suppose every day with it as well and like I said everyone has their own opinion on it so you're kind of

caught between, sometimes your feeling guilty, are you doing the right thing, are you doing the wrong thing, are we pushing her too hard, sure I'll leave her be. (10.1.4)

It was evident from some participants that there was a lack of knowledge of the presentation of dementia in persons with intellectual disability, and this was further confounded by co-morbid health conditions as evidenced in the following quotes:

...there don't.. I have never seen a measurement tool or anything for diagnosing .. (1.1.2)

...there's a lot of medical issues are sorted first and then they're referred for that.. so eyesight, hearing, the regular screening for dementia it's not necessarily Alzheimer's .. (3.1.7)

The participants from one site where there was limited experience of caring for people with dementia stated that they would benefit from consulting and working with other services who had more experience particularly in relation to assessment and care approaches;

It would be nice to have a kind of a consultation with other eh ageing ..areas that have you know a proper model like or whatever like that eh that they have assessments and then to have different things that we can implement.. (1.1.1)

Pain assessment and Management

It was evident from the participants that pain recognition and pain management were required skills, yet many lacked the needed theoretical and the practical knowledge as evidenced by the comments:

.. how to make them comfortable and all that when they are dying and all like.. (1.2.2)

...trying to pick up on those kind of signals at that stage of Are they in pain, are they distressed you know because it is very difficult .. (3.1.1)

....we don't know how much pain he was in .. (6.1.1)

Difficulties in pain management were not unique or confined to participants from the intellectual disability services; it also posed challenges to respondents from the specialist palliative care services. They also identified difficulties in communication and challenges in interpreting the person's communication cues. One participant from the specialist palliative care services commented:

... my involvement with some people who have AD and ID was .. in many ways your trying to basically assess distress and trying and

figure out why someone is distressed, rather than being able to say they have pain because the person themselves are not able to say I've a pain .. (9.1.1)

This was supported by the participants working in intellectual disability services:

...but we also come into difficulties in trying to determine .. like that when we did the pain scale that time when N (name of staff member who gave training in pain assessment) .. trying to pick up on those kind of signals at that stage of Are they in pain, are they distressed you know because it is very difficult .. I suppose even in the general population even to those kind of things ... (3.1.1)

These concerns have implications for the earlier discussion of whether end-of-life care was best delivered in the person's own home. In order for this to happen participants felt that staff should have knowledge and skills to provide the needed care:

.....people should be trained up in syringe pumps.. trained up in something to do with pain assessment or pain symptom control ... definitely (3.1.5)

In some sites participants described how nursing staff had expanded roles and were trained in administering sub-cutaneous fluids and managing the delivery of medication via syringe drivers.

...so it's more the practical .. I suppose the nursing skills that we need to update .. anything along the lines of you know venepuncture, sub-cutaneous, things we generally do the last few days .. the syringe drivers making sure that we're up to date on those that we have the proper guidelines and procedures in place and that kind of thing... (5.1.1)

In contrast, other participants did not possess these skills and stated that they needed additional training to maintain the person's comfort at end-of-life and thereby continue to support the person in their home:

...if we could start doing more clinical things as well such as the sub-cutaneous fluids.. (4.1.2)

Supporting the person through death

The focus on the caring for the person across the continuum of dementia, including supporting the person who was dying featured regularly as issues for participants. It was not unusual for some participants to experience anxiety and uncertainty if a person died while in their care. There appeared to be a lack of knowledge around the process of dying, in addition to the nurse's role as death approached and occurred. The anxiety that resulted for some

participants was almost palpable as evidenced in the following quote:

...I thought my God she can't die now when I'm here because I won't know what to do .. and even that experience alone of thinking what if she dies what will I do or if she's dying what am I going to do .. I've no experience so what do I do? .. (2.1.4)

In some services participants had limited experience of death and spoke of the fact that they were often working in isolation and appeared to have limited knowledge in relation to the care of the body at the time of death:

...when em L (client) was dying there was people saying to.. eh pack the body because she was dying, she was going to die within the week or something and there was a big debate whether you pack someone or whether you don't .. (1.2.1)

Maintaining Adequate Nutrition and Hydration

To maintain adequate nutrition and hydration was often complex in advanced dementia; issues around hand-feeding and the use and experience of PEG tube feeding were highlighted by almost all participants. There appeared to be different experiences and practices across services. Some participants recalled their frustrations regarding the lack of end-of-life planning and regarding the lack of decisions being made on how to support adequate nutrition and hydration at end-of-life. These problems were further confounded when the person was transferred to general hospital for acute care, particularly to accident and emergency departments:

...being sent to casualty...into the acute hospital and then ending up with a peg tube ..a few days before they die,..it's a big problem ...its probably happening more. (9.1.5)

Handfeeding

Participants expressed a desire to give good care and had a general understanding of its prerequisites including meeting nutritional needs. However, delivering such care was often challenging and difficult due to poor staffing levels and the need to support and care for other peers in the home who very often also required significant support:

.. staff .. I mean it's a staff situation .. it boils down to staff .. even the physical thing of sitting down to feed a person .. before it gets to the stage you're talking about .. but it time .. the pace.. the rush that's going on and yet know you have to do this ... (2.1.1)

Maintaining adequate nutrition and hydration and handling the complexities in hand feeding became more difficult as dementia

progressed. Co-morbid health conditions, swallowing difficulties and the risk of aspiration were often a constant source of anxiety for participants and this was further confounded by limited time and resources. All of these concerns were evident in the following quotes:

even the physical thing of sitting down to feed a person .. before it gets to the stage you're talking about .. but it's time .. (2.1.1)

we had to have the thickener as well but then what happened was she would take minor seizures as she was eating, that was scary, kind of she'd be going to eat and then she'd go into this and that really was very frightening and then she'd get a fright with whatever was there and wouldn't eat it at all, you know that kind of way.. (10.1.5)

so she's left sitting and waiting and then she's brought to her room .. what is equitable? but I don't think we can sit down and give hr the ½ hour or whatever it takes ..but prior to that and then you know there's a lot of people anxious about feeding them because of the aspiration and all that like you know.. that you need to sit down with people and .. (2.1.1)

we continued feeding with liquidised meals and so forth and that individual got a lot of chest infections ..and you know it was difficult to feed that person .. (4.1.1)

so then that made it very challenging for the nursing staff to feed her because of the risk, high risk of aspirating .. (1.1.1)

Other participants had very different experiences and expressed confidence and comfort with respect to hand feeding. Knowing the person, understanding the pathology of dementia, having experience and education in caring for persons with dementia appeared to reduce the stress and anxiety associated with eating and drinking:

....I think if they have a good knowledge from the start because ..I have found that with the dementia, you know the way they are feeding themselves today but not tomorrow, and you have staff saying – ‘come on you did it yesterday’. And you are trying to say she just can't remember if she did it yesterday. But you picked up all that from your dementia in-service. (3.1.7)

....What to expect.. to feed themselves and stuff ..can't feed themselves, explain it to people so it doesn't look like you are force feeding them.. If people understand there is a reason. (1.2.3)

Participants perceived eating and drinking as a pleasurable experience for the person and were not anxious to go down the route of PEG feeding:

....but if I couldn't have put something in her mouth arah I wouldn't be able to nurse there .. you know cause food was .. she didn't care about anything else .. just feed her .. you know whether it was her finger in or .. with the bit of jelly or ice cream towards the end that's what we did.. (3.1.7)

Another participant recalled their experience of supporting a person with dementia who had died some years ago before PEGs were in common use and that a team effort was very effective in the maintaining of the person's nutritional state.

and we would go to that person, there was no peg tubes, hadn't become an issue at the time and we went in to her every quarter of an hour to try and give her a spoonful of whatever and that was, and everybody did, anyone who was passing down by the bed, if there was no one with her, you'd go, you'd spent 10 minutes trying to give her 2 or 3 spoonfuls and that was the way that person was minded and she lived for 3 years like that.. and was very well minded.. (7.1.4)

The participants from specialist palliative care services emphasized the complexity in this kind of decision-making:

... it's almost around the polar decisions of kind of.. no peg or peg .., whereas palliative care is a little bit more, I think specialist palliative has moved, say the comparator for us would be hydration at the end of life, that used to be kind of ..hydration, no hydration, polar opposites .. but it is a bit more case by case, individual basis, people are more proficient ethically debating out the issues because we do it in a very organised setting and I just think that's where again we're just perhaps a little bit taking a different approach. Because I just don't see that, its kind of like are you for pegs or are you against pegs, it can't be that you might say that pegs might be good for some people some of the time or whatever .. (9.1.2)

It is evident from the above discussion that the feeding of persons with advanced dementia who are dysphasic is complex, and the participants expressed both positive and negative experiences. While there was no explicit acknowledgement that staff needed additional training in hand-feeding techniques, the experiences described by the participants suggested that further investigation as well as education and training are imperative.

It was also evident that some participants lacked an understanding of what palliative care actually is. Participants at one intellectual disability service associated palliative care with the insertion of a PEG tube. In another site when the participants were asked whether clients received palliative care, they equated the not having a PEG with the non pursuit of the palliative care route:

she didn't have to go down the peg line or anything like that no... (3.2.2)

Peg Tubes

Some participants stated that it was common practice at their service for persons at advanced and terminal dementia to have a PEG tube inserted automatically:

....they would have been in and seen others clients with pegs or whatever and they'd know it was the norm really for a lot of people here .. so it wouldn't be new to them .. (4.1.2)

In contrast other participants reported that PEG feeding was not something with which they were familiar:

....We haven't had as much issues with the peg feeding as other institutions; we have had no one with peg feeding so that kind of 'to feed or not to feed' has not been a question for us. .. (7.1.1)

A participant from one of the intellectual disability services described a person being transferred to an acute hospital with a first chest infection and coming back with a PEG in situ. This participant perceived that this was done because of the sometimes limited respect and understanding that general hospital staff have regarding the needs of the person with intellectual disability and dementia as demonstrated in the following quote:

....The decision really should be made with the family and the people that are actively involved in that persons life.. and it happened to one of our ladies with dementia she never had a chest infection before it was just done like .. yet they don't know the person.. like she's just someone with Down syndrome and dementia (2.1.3)

Other participants recalled the bad memories they had of caring for persons who had a PEG in situ and how in their experience it had resulted in a suboptimal and distressful death as evidenced by the following quotes:

.....well it was awful .. wasn't actually taking out the peg feed ... it was please take it out because the person was just ballooning you know.. it was as if the person was going to burst you know .. but em .. and then it was just sort of .. the time then that the person had left.. (4.1.2)

....it was absolutely horrendous eh and you have like a dietician's point of view where they want you know calories intake to be still maintained .. it's very hard to nurse someone when I know I'm doing that to them .. if I know that I can keep them re-hydrated can that not be enough at that stage when they're actively dying. (3.1.5) The participants were equally distressed when a family member made a decision not to have a PEG tube inserted and they were

left with no support or guidelines other than a medical note in the client's chart :

... to stop all fluids and food.. (1.2.2)

A particular concern for these participants was the issue of their keeping the person comfortable and hydrated in the last days of life. They spoke about the distress and anxiety which this had caused, the lack of support and guidelines, and about how they intuitively felt that this approach also did not lend itself to a good death:

....not giving her a drink and you could see when you were wetting her lips she was so thirsty and .. I just thought this is wrong.. just felt wrong. I kept asking people about it.. (1.2.4)

Many participants identified PEG feeding either explicitly or implicitly as an ethical dilemma.

the family didn't want that eh that person to have a peg feed .. so ..we continued feeding with liquidised meals and so forth and that individual got a lot of chest infections ..and you know it was difficult to feed that person .. it was difficult for staff to have to go through the process feeding the person ..em but it was the family's wishes .. and we respected that .. but it was very .. it was a .. it was an ethical dilemma 4.1.1

Another participant recalled:

....one lady at end stage Alzheimer's dementia the family decided to put a peg in I think it's a year or so the poor little woman has just blown up and she has no quality of life.. it's horrendous you know.. (3.1.1)

Resuscitation

In one site in particular there was an absence of policies, particularly the lack of a 'do not resuscitate (DNR) policy', which made end-of-life care unclear and added stress and anxiety:

...there isn't a policy on DNR in the hospital ..so if you know somebody is at their last and in consultation with their family and doctor you know ..if its decided you know .. well.. keep them comfortable, that's the term for DNR ...its very ambiguous .. (1.1.1)

The participants at two sites commented on the lack of an ethics committee in their services and that their belief decisions would be easier if there were such a committee.

...I think we should have an ethical committee.. I have major issues with that myself.. (3.2.2)

Fusing the Horizons of Care: Timing of Palliative Care

Interestingly, while many participants did not use the term ‘palliative care’, the care approaches and principles which they used on a day-to-day basis mirrored closely those espoused under the broad principles of palliative care. The maximizing of comfort for the person and the maintaining of their quality of life were inherent components of day-to-day care. The participants appeared to associate the words ‘palliative care’ with dying and end-stage disease and they even resisted or questioned the use of the word ‘palliative care’ being used at an earlier stage:

.....are you talking now about palliative .. the very end management or any ..I would imagine that it would be when they are quite unwell .. physically very physically unwell .. chronically sick .. (1.1.2)

.....they are not really, maybe later on.. once they get their diagnosis they are not, no, they are not. They are still being loved and nursed but they are not, you don’t look on them as palliative care ..because you don’t want to look at them as this is a life sentence, you know what I mean..... if anything she has improved since she came here .. so you know, you query, you know, so you can’t just look at someone and say the death sentence.. I suppose we don’t look on it ... (3.2.2)

When they were asked by the researcher at what point did they think that palliative care ought to start, they explored the idea of ‘comfort care’ and whether such care was in fact palliative care. The following combination of quotes demonstrates some of the discussion on this point:

.. That’s a hard one, I suppose we do a certain amount of palliative care unknowingly.. We wouldn’t maybe call it that.. (10.1.3)

.. So it is, I think it is in a different way but we don’t call it palliative.. (10.1.5)

.. And palliative to the extent as well that you’re making so many, you’re trying to bring, as you said the comfort into their lives.. (10.1.4)

.. The comfort I think.. (10.1.5)

The participants from specialist palliative care acknowledged that intellectual disability service staff already had the ability to deliver a palliative care approach:

.. we can’t be all things to all people from the very beginning of an illness, I’m not suggesting that by any manner or means and I’m not suggesting that the ID services don’t have the capabilities

within themselves to do that because I definitely think they do.. but I just wonder whether informing them and .. developing their collaboration at some point is a good thing.. (9.1.2)

Even on the site where there was a purpose-built unit for persons with dementia and where there was an acknowledgement by participants that the care which they delivered could perhaps be coined as ‘palliative care’, it was still described as just good person-centred intellectual disability/dementia care. The emphasis was very much on quality of life and support for the person to continue to live in the face of increasing disability inherent in dementia. Again the words ‘palliative care’ was mostly associated with terminal or end-stage disease:

Yeah, yeah, during this last stage, dealing with the family and this you know ..that is where it comes in.. the palliative care. (5.2.1)

the hospice only come to people with cancer and motor neuron disease .. I suppose we could use them for people with dementia too maybe .. when they’re dying .. (4.1.2)

The participants from specialist palliative care services also appeared to see specialist palliative care support to be more associated with the terminal or end-stage of the disease and they recognised their inherent difficulty in their supporting persons across the continuum of dementia and even questioned its feasibility:

.....we manage dementia very poorly here at the Hospice.. in that we tend not to know.. we can’t .. this is in the regular population, this is not in the eh (ID population!) .. but particular say in the earlier stages, when people aren’t likely to die in weeks or months . I think people who are likely to die in a couple of weeks .. very much on the terminal care side of things .. its very similar for all disease groups. I think the earlier stages its more difficult because the palliative care approach might be about treat a symptom but a lot of the symptoms of dementia, they are sort of agitation, how do you manage that in a way that’s not drug related, how do you manage wandering in ah .. some of those issues we think the dementia service are much better at (9.1.1)

.....well even for the generic dementia patients it’s difficult to know when to introduce palliative care .. I think the dementia services are beginning to be better at applying a palliative approach .. the generic dementia services .. maybe what Intellectual Disability services need is more the terminal care support .. (9.1.1)

The participants from the specialist palliative care service debated what palliative supports intellectual disability services might need to better support persons with dementia:

.. You could actually argue that in a service where people are particularly going to ..be getting dementia why would you need palliative care at all, should part of service development be that part of your development and your service be incorporating the palliative care approach.. (9.1.1)

.. Intellectual Disability services need to recognise and develop dementia services as they are doing and within that then develop a palliative care approach to care for their patients with Alzheimer’s or dementia .. (9.1.1)

The specialist palliative care participants acknowledged that they had a narrow range of experience with intellectual disability services and with working with persons with dementia. Their experience was mainly in end-of-life care and symptom management as evidenced by the following quote:

..Like I would have found that I would have had, like the people I would have been involved with in some ways you’ve a fairly, I would have thought I’ve a fairly minimal piece of involvement into the people with Alzheimer’s, about particular symptoms but like a very narrow range of things, about pain management, management secretions, managing nausea and that’s very basic, very narrow stuff but a lot of the other stuff I think it is about assessing, its about the drug side of it but I think a lot of the ID services are very good at ... (9.1.1)

A statement was made that there can be subtle differences in approaches taken to care: employ a palliative care approach or access a specialist palliative care service to collaborate on care:

.. the collaboration, the important bit because even the advanced planning.. are they coming at it from their own context and I think even just looking at some of the conversations, the advanced directives .. the way they’ve been handled, we might actually have approached them a little bit differently and that’s not to say that that’s right or that’s wrong, but there is definitely a perspective on care that is specialist palliative care if you like, that isn’t palliative care approach or general palliative care knowledge that can maybe inform decision making but its not appropriate.. (9.1.2)

Other useful insights were offered by specialist palliative care participants where it was said that specialist advice and symptom management had potential to improve the quality of life and the quality of death for persons with dementia:

.. ok it could be either around ethical issues or it could be around em .. symptom management. I suppose first of all what strikes me is that the palliative care management that’s delivered by generalists is very much around pain and I find that they’re not

treating secretions, they’re not treating bowel obstruction, they’re not, these are all the slightly more specialist areas, so yes they’re getting the analgesia but are they getting the other medical, the broader spectrum of medications that we would use.. (9.1.2)

The participants from the specialist palliative care service concluded that although staff in intellectual disability care could deliver a palliative care approach, they could also benefit from specialist palliative care input:

.. I suppose its that people aren’t satisfied that a level 2 or general palliative care approach is enough for everything over the time.. that they’re aware that there is more out there as well.. so that they can make the decision that yes this is appropriate for the vast majority of people but we know occasionally some people will need something more and we know where to go to look for that extra rather than in kind of an isolated little pocket of .. we will deliver everything in our service and we won’t look outwards to. I mean that’s the same for us, we need to look outwards as well.. (9.1.2)

.. I think that is the way to go .. collaboration would be important with dementia services also for example ..there is also a place for specialist palliative care where a service can consult with specialist palliative care services on symptom management in the later stages for example .. (9.1.1)

The Impact of Cultural Differences

The participants of the study were drawn from four different nationalities. As stated in the methods chapter, an additional focus group interview was arranged with a group of non-Irish staff to draw out some unique cultural issues that were identified in the initial analysis. Some issues were held in common:

.....because we are all alike, most are Catholic.. we are Catholic as well like .. So the beliefs are the same.. we are similar.. it’s just that you know .. we are new ... (1.2.4)

However, cultural differences were identified and they centred on beliefs about active vs. versus palliative treatment of people with terminal dementia, rituals at the time of death, and talking to a person about dying.

Active vs Palliative Care

Some participants (Filipino nurses) across the sites explicitly commented on the difficulty which they experienced when they were nursing a person who was not receiving active care. Although Filipino nurses had undertaken theoretical training in palliative care in both their earlier and even more recent training they had not experienced palliative care in practice before coming to Ireland as evidenced in this quote:

..... Yes, its different here (in Ireland) ..really different...(3.2.2)

Central to the difficulty which they experienced was the pursuit of patient autonomy; often in their own cultural experience, the wishes of the person being cared for were considered in the wider family context:

.....No, not the doctor, the family will decide. They will ask if they just want palliative care for those dying one .. they will decide, mm, they will talk to each other and the family will still make the final decision .. especially when they're elderly .. invalidated .. they cannot decide on their own .. so the family will be the final decision .. the relatives .. the next of kin.. (3.2.2)

Filipino participants (nurses) on other sites also spoke about their difficulty in coping with the decision sometimes not to treat a person actively. One participant acknowledged that while the person was well cared for and given oral antibiotics, in the Philippines this person would have been transferred to a general hospital for intravenous antibiotics and this participant found the palliative approach particularly distressful as evidenced in the following quote:

.....last time, that was my battle.. why don't you send them and you don't ..do the best you can for them.. Yeah. Send them to hospital.. (5.2.1)

Additionally participants at another site considered it difficult to nurse someone in their care who was given a 'no resuscitation order'. This meant for them that person would not be automatically transferred to a general hospital should they develop medical complications and they could be left to care for the dying person. The distress that this caused was almost palatable as evidenced in the following quote:

...what to do when they are dying especially when there is no further resus.. its very hard, we don't know how to .. how to deal with it...(4.2.2)

In some sites, policies concerning end-of-life care were available to provide guidance to staff; where there were no policies about care of the dying person this clearly added to the distress for participants as evidenced in the following quote:

.....no signed consent, it should have signed consent by the relatives and the doctor who were going to order like no active treatment .. like if there is a dying person we should, we still continue treatment if there is no order.. (1.2.4)

Some participants had worked with persons with advanced dementia where a palliative care approach was used and stated that they had now adapted and could see the benefits of this approach for the person and their families. This resulted in the participants feeling more confident in the care they delivered:

.....from my past experience (Philippines) the family will become panicky do something, do something, do something .. I really want the doctor. But here (Ireland) because from the beginning the family has accepted that this is going to happen at the end so they can prepare ..so when the time comes that they are at their bedside, they understood and have just have accepted and there is not much panicky. That is difference I see here. That is very good, yeah. 5.2.1

This participant also said that they did not feel that their cultural beliefs about care of the dying were compromised in any way, and that their understanding of how palliative care can be delivered has contributed to their own professional development and growth:

.....No, no, we have to adapt. This is your .. your ideas and this is your culture. We came in here we have to adapt and by adapting we learn and by learning we get this understanding .. growth..... (5.2.1)

Some participants stated that while they did communicate with families regarding their family member's having a terminal illness, before coming to nurse in Ireland they felt unprepared and inexperienced to prepare the patient and families for death and dying or to provide aftercare and bereavement support:

where I come from we don't do this bereavement counseling or something ..but here it's very important we have to talk and give the family support .. (5.1.5)

Cultural Rituals at time of Death

There were also differences in relation to rituals at time of death and following death. In the immediate time after the death Filipino participants stated that they had no experience 'of the removing of the person to a funeral home or chapel for a ceremony prior to the burial'. They considered that funerals happened too quickly in Ireland:

.....In the Philippines we don't have this removal .. we just bring the body in the .. the chapel .. and then it would stay there ..it's for how many days the body would stay there and do the prayers, we don't have this thing removal. No..... (3.2.1)

When asked if any of this resembled an Irish wake and rituals at the time of death, it was evident that not even light refreshments would be consumed during this time. Somebody had to remain with the

body at all times and prayers had to be said all the time and it was evident from the narratives that this was distressful:

.....And you won't leave the body .. I saw one of the ladies who died here and they just leave the body in the chapel.. (3.2.1)

African participants shared similar practices as the Filipino participants and described that in their effort to preserve hope, they do not plan funerals in advance of the person's death. They found it strange that, in Ireland, staff would be ringing up relatives about funeral arrangements in advance of the person's actual death:

.. that would be after death. We make the arrangements ..but here if somebody is dying we make the arrangements already here.. but no not home until you confirm that they are dead.. (4.2.2)

Telling the Patient

Some participants (Filipino and African) across sites said that they would not talk directly to the patient about death and dying:

.....We never did .. we never done telling the client .. never done (others join in agreeing)... (4.2.2)

For me with my own religion I would pray .. just say ..no.. you still have a few years to go.. by the grace of God you are not going to die now.. (4.2.5)

Coping with Loss, Grief and Bereavement

The participants identified issues of loss, grief or bereavement for themselves, for the clients, for the peers of clients, for colleagues at work and for the families of clients.

Loss and Grief

Loss and Grief for the Person with Intellectual disability

There were divergent opinions expressed as to whether or not persons with intellectual disability could understand concepts such as death and dying. Some participants thought that it depended on the client's level of intellectual disability:

.. if they were mild ..yeh .. (1.2.1)

In comparison, other participants recalled their experiences of supporting persons with moderate intellectual disability and early dementia, said that many people were very aware of illness, death and dying and were in a position to articulate their anxieties and their wishes that they should not to be moved into residential care:

... and I asked her if she would go into the service just for 24 hour for observation .. that we weren't in a position to bring in night staff and she said "oh God please don't do that .. please don't do that to me .. (2.1.3)

Other participants recalled a change in the person's behaviour and

demeanour as death approached:

... I think what I've seen though ..in terms of the service users themselves ..it gets to the stage where I don't know whether it's a kind of like an acceptance or the fact that they are so much down hill .. but they come to a stage where they are much more relaxed in themselves ..it's like ... (5.1.1)

... they have a peace about them .. (5.1.2)

Another participant believed that the person would not understand death:

... any of the ladies I've had wouldn't have been high ability and wouldn't have understood what you are talking about ..(3.2.2)

A third view was that it was difficult to know:

.. the awareness that they have up until the end .. we don't know .. and people will assume that they're not aware any longer of where they are and what they're doing .. yet they cant vocalise itassume they're content we don't know what.... you look at them at times and .. you wonder how sad they are underneath it all... (2.1.2)

Loss and Grief: Families

Inherent in the dying process are experiences of loss and grief within families. Some participants acknowledged that they found the process of supporting family members a challenging one and that family members at times found it hard to understand and cope with the decline inherent in dementia:

... he (brother of client) found it very hard so we had to deal with him as well.. he was quite upset that she wasn't recognising him and then the next time he'd come in she'd look at him you know and she'd smile you know .. (1.1.1)

It was not uncommon for participants to experience a sense of denial in family members or a reluctance to acknowledge that death was impending. Although it may be argued that this is a regular occurrence in the face of death and dying, it appears more pronounced for these family members - they strive to postpone the inevitability of having to acknowledge the circumstances, not wanting to know that the person has a terminal illness and not wishing to discuss illness and death:

... I know in our situation we have one person now with Alzheimer's and her family does not want to talk about end of life issues. They will deal with things as they arise, they do not want to talk about end of life.. (3.2.2)

It was also evident from the narratives that close relationships had often developed between staff and families and that the maintaining of these relationships was perceived as important; the family, in a sense, had bonded with the intellectual disability service. The participants spoke about the informal visits that the deceased persons relatives would sometimes make, coming back to the home weeks and months after the funeral. While there appeared to be no formal system in place the participants readily welcomed family members back to the home. They regarded this time as an opportunity to talk and listen to the family and give them time:

...there's a huge void that they can't explain .. d' you know they find that really really difficult.. they were such a focus .. (5.1.2)

... families it was the families that had been bereaved that came.. So we are trying to ask them what it is that they want us to do to help them. We do feel we could be more assertive in giving them support ..because they don't fall into the normal category of bereaved people.. (7.1.1)

Supporting the Loss and Grief of Peers

It was evident that the impact of the death of the person extended beyond the family members. The participants stated that death and dying was not hidden from peers, and staff intuitively allowed peers to be part of the experience. Although the participants were not sure about the level of comprehension peers had about dying, they respected a person's desire to be part of the process. Similar to a family context across all sites they facilitated peers' visiting the dying person and been part of the rituals at the time of death:

.....but there is the few that will go into the room and will you know sit .. or sit with the family there in the room and spend time ..I .. I suppose it's not a subject that we hide from anybody .. If somebody's sick and we know they're sick.. (5.1.1)

Another participant commented:

....the majority of them died here like so you were here for the whole process and you got your chance to say goodbye ..and the other men could come in and out like and pray at the bedside .. so you went through the whole process with them and then when the person does die .. the room isn't touched for a certain amount of time and then when the room is being cleared out ..the boys are in and out of the room ..it's automatic for people here .. (6.1.4)

One participant from the intellectual disability palliative care type setting recalled their experience supporting peers with intellectual disability who were waiting for the person to die and who kept asking every time they passed by whether the person was dead yet. It was almost as if the peer wanted 'the death to be over' and this was a challenging and sometimes distressful for staff:

... we often have comments like ..Ah there's no point going in to that room sure they're dead .. or are they dead yet? (6.1.4)

The participants also spoke about the complexities at times in supporting peers. This appeared to be centred on their lack of comprehension, understanding and experience of dealing with issues like death and dying. Participants stated that most people with an intellectual disability would have heard of "heaven" and associated it with death:

.....you say they're up in heaven , and you say to them they're up in heaven with their mammy and daddy.. (5.1.2)

.....a couple of them like N know like..(peer/moderate ID) .. we tell them they have gone to heaven ..(6.1.3)

The participants across the six intellectual disability services had different opinions about whether peers experienced grief and grief reactions. Some participants considered that peers with mild to moderate intellectual disability experienced grief; however, they were unsure if persons with severe/profound disability experienced loss and grief.

.. now the ability of ours .. they don't understand .. they're quite happy to do their own think they seem to be quite independent and they seem to be immune .. (6.1.2)

.. we have only six people in the house and they seem to be ok .. it hasn't been an issue for us .. (4.1.3)

However other participants felt that regardless of the level of intellectual disability peers did have some understanding as evidenced in the following quotes:

.. well it's amazing .. the lads sense it or whatever it is .. whatever it is .. there's a silence around the place .. it's amazing .. honestly .. (6.1.4)

... yeh and it's a grieving process for them as well .. and often they're forgotten about as well in the whole thing .. (2.1.1)

In another site, supporting persons with severe to profound intellectual disability participants acknowledged explicitly that peers were grieving when the person was dying or had died:

... so she was devastated when A.. so we left her into see her when A was kind of .. well maybe not the last few days. But when she died then she sat there for ages and put her head on the bed .. (1.1.1) .. they suffer.... some more than others .. (3.1.5)

Some participants also felt that some people with intellectual disability did understand that dementia led to death because they would be asking the staff who was going to get 'it' next and appeared worried and anxious about this:

... but they're worried too cause after the death you'd be speaking with them and they're all saying "are we next" they're always worrying, who's next going to get this and who's going to ? .. (2.1.2)

The participants were challenged on how best to support peers and felt that there was a risk that more exposure to death and dying did not necessarily mean that peers were dealing well with these issues and that they may need bereavement support:

.....Yes, she can't express it, maybe we've ignored it or not, not ignored it but, not deliberately anyway but.. not dealt with it (10.1.3)

.....But I think there's a bigger need than we acknowledge because we're saying they're so used to it...(10.1.1)

Loss and Grief: Staff

On a number of occasions participants became visibly upset as they reflected and recalled their experiences of supporting persons with intellectual disability and dementia. The participants recalled the efforts the rewards and the pride they had experienced in supporting the person to develop skills and independence. This was now contrasted with watching the person lose those hard-earned skills much more rapidly than they had acquired them and this was difficult. The participants used the word 'sad' over and over to capture the strength of their emotional sorrow:

.....had regressed nearly to the childhood stage really and that's quite difficult to watch.. (10.1.5)

.....yeh ..he was so independent like, he was a free spirit .. you know.. he could come and go ..and all that .. and it was terrible sad to see it .. (6.1.4)

.....at this stage she had Alzheimer's and it was really sad .. really, really sad .. (3.1.5)

Grief is not confined to post death situations as became evident from a number of the participants. It appears that the personal impact of grief and loss was not only associated with the participants knowledge of the person and their family but also with their attunement to the dying process. Some participants recognized that this loss and grief started well before the person actually died:

.....bereavement because it is a bereavement in a way... You have someone who was very high ability, that was joking and laughing.....and suddenly is just sitting there.. its very .. that is heart breaking on staff.. You know if you are any way human at all you are grieving and you are bereaved long before they die ... I think we start to lose some of our ladies long before they actually die.. (3.2.2)

They felt personally bereaved but also perceived that their grieving is disenfranchised both within and outside of the intellectual disability service as evidenced in the following quotes:

.....in a general hospital when someone dies and is gone they don't have anything to do with them .. they don't even know where Mr Mac in bed three has been buried or gone .. where we go to funerals .. we organise funerals .. organise the mass.. we organise everything .. and then you're meant to go back to work and its all over and get on with your day .. (3.1.7)

.....as soon as the person died the bed was nearly warm by the time Joe Bloggs was moved into the bed. It's very, very tough on staff to have to deal with that in this setting, its not an acute setting. So it was very tough for staff to deal with that. sometimes you could nearly be resentful of the person who is being moved into the bed for a short period of time, you know, its human nature.(8.1.2)

The participants recognised that their grief was often similar to that of a family member because they had a long-standing relationship with the person.

.....we were all very upset about A, you know.. she was part .. we were part of her family.. (1.1.1)

.....You live with them.. It's not a work relationship, its I know this person this number of years, you can't, I mean you'd want to be ice cold to be able to detach yourself. (10.1.2)

A participant from the specialist palliative care site observed that:

.....staff in Intellectual disability would need that support more because of the nature of their relationship with the person .. they have had years together .. (9.1.2)

Experienced participants who had witnessed many deaths still reported difficulty in coping with the grief and loss they experienced:

....it was the first time, as I was saying it was the first time I was saying it to him .. I was actually realising it was real, you know, because you put on this cap .. put up this block.. it's your job to do this.. I'll never forget that as long as I live.. (3.2.2)

Participants recognised that they needed support in loss, grief and bereavement:

.....bereavement too .. we could always benefit from more training about bereavement .. we are going to have more people with dementia and dying so it would be important to have more knowledge and skills to deal with it ... (4.1.1)

.....think there is a need for staff to deal with loss, be it just the moving on or actual death because we found one of the staff in our house took it very bad when our lady had to be moved and it took a while to kind of talk that out, get to the root of it and she at the end of it all felt a failure.. (10.1.5)

Conclusion

This chapter focused on the needs and practical concerns involved in the support of persons with intellectual disability and advanced dementia. Several interesting issues were highlighted:

1. The recognition that good care is palliative care and yet the staff delivering such care do not label their care as palliative.
2. Specialist palliative care staff appearing to see their support of care as restricted the ending months of life.
3. The depth of grief and bereavement and the range of associated support needs.
4. The impact of cultural differences among staff.
5. The need for training in pain management and other palliative care procedures.
6. The complexities in the maintaining of nutrition and hydration whether through hand feeding or the use of PEG tubes.

The findings reported and the issues which emerged can be considered descriptive in nature and would benefit from a much greater and deeper level of inquiry. Despite this, several important care challenges emerged and the data gleaned offered practical advice to inform the development of an educational intervention. The next chapter will draw together both focus-group findings chapters and the reviewed literature and will outline the educational intervention which they influenced.

THE TRAINING INTERVENTIONS

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Design of the Intervention

The research team considered the training needs, recommendations and cross-training insights identified within the two core focus group categories, and also sought advice on the needed content from academic and practice experts in ageing and intellectual disabilities and in palliative and hospice care; they also considered recommendations from the relevant literatures. In the design of the intervention the research team was also influenced by the needs of adult learners. The educational approach of this course was designed to recognise that many staff members have long and varied life and professional experiences which they bring to the learning situation and which need to be respected. An andragogical approach was used; andragogy is the art and science of teaching adults (Knowles 1980 & 1990). This approach implies that the participants are central to their own learning, take an active part in their own learning, have a more equal relationship with the teacher and accept responsibility for their own learning. The use of reflective learning and case scenario discussion and debate are central to the teaching and learning experiences in this curriculum and complement the scientific content delivered. The research team recognised that there are very experienced people working in intellectual disability and specialist palliative care services. They were also influenced by Benner’s (1984) identification of intuition as a distinguishing feature of the expert nurse in practice, and that reflection and reflective learning allow access to this tacit knowledge or intuition (Schon 1987); therefore the engendering of confidence in using intuitive knowledge was an additional goal of the training.

Training Delivery and Methods

The research team in a series of meetings drew upon the recommendations and the principles of an andragogical approach and developed the aims of the course which included beliefs about the indicative content, a series of learning outcomes to be achieved and an assessment approach. This was necessary if they were to be true to the training challenges identified in the focus groups.

Training Aims

The aims of this course are to: Provide an introductory education and training programme to support persons working in intellectual disability and specialist palliative care services in order to provide optimal end-of-life care for persons with intellectual disability and advanced dementia Enable the course participants to support others within their own services providing care for persons with advanced dementia

Specific Teaching Aims:

To enhance the participant’s knowledge and skills in relation to:

- The various paradigms of care which underpin intellectual disability services.
- The various paradigms of care which underpin person-centred dementia care.
- The nature and course of Alzheimer’s dementia in persons with an intellectual disability.
- The philosophy and principles of palliative care and how these may be integrated in the supporting of the care for the person in intellectual disability services.
- The addressing of the physical, psychological, social, cultural and spiritual aspects of dying.
- The complexities of decision-making and ethical decision-making in persons with advanced dementia.
- The caring for the person, peers, family and staff in relation to quality end-of-life care.
- The co-ordination of care between intellectual disability services and palliative care services.

Broad Indicative Content

- Introduction to intellectual disability services, structures, policies and practices.
- Paradigms of care of persons with an intellectual disability.
- Dementia in persons with an intellectual disability.
- Person-centred dementia care.
- Ethical issues in the caring for persons with advanced dementia
- The addressing of complex care needs in persons with advanced dementia (e.g. feeding, pain and symptom management.)
- Introduction to the history, philosophy and principles of palliative care.
- Physical, spiritual, psycho-social and emotional care.
- End-of-life care and terminal care.
- Loss, grief, bereavement and communication issue.s
- Influences of culture on attitudes and practices in relation to illness, ageing, dementia, death and dying.
- Reflective learning and reflective practice.

Learning Outcomes

The participants will be able to discuss critically and apply new knowledge and skills in relation to:

- The various paradigms of care which underpin intellectual disability services.
- The various paradigms of care which underpin person-centred dementia care.
- The nature and course of Alzheimer’s dementia in persons with intellectual disability.

- The key care needs of the person with intellectual disability and advanced dementia.
- The various strategies for communicating about and assessing these care needs.
- The importance of effective symptom assessment and management of the person regarding end-of-life/terminal care.
- The relevance of decision-making and ethical decision-making for persons with dementia throughout the trajectory of their illness.
- The relevance of advance planning and end-of-life care planning.
- The philosophy and principles which underpin palliative care and how these principles can be incorporated in the care of the person with advanced dementia
- The concepts of loss, grief and bereavement for persons with intellectual disability, family, peers and staff in the context of intellectual disability and dementia.
- The relevance of cultural competence in health and social care.
- The rationale for the use of specialist equipment such as syringe devices in pain and symptom management.
- Reflective practice in relation to the care of a person with intellectual disability and dementia.

Assessment

Assessment was also guided by andragogical and self-direction approaches. The participants were required to keep a reflective diary throughout this course and to present one example of learning from practice from this diary at the end of the course. They were also expected to complete individual learning exercises in practice to demonstrate the achievement of the learning outcomes.

Intervention Content

A team then designed a training manual which was made up of 20 sessions (see Table 1). A group of instructors was selected that included several members of the research team and other experts in ageing and developmental disabilities, in dementia care and in palliative and hospice care. The team was also interdisciplinary with nursing, psychiatry, palliative care consultants and intellectual disability services physicians represented. There was also input from families and from social work. The selected instructors were asked to develop the following components for their module:

- A powerpoint presentation
- Detailed notes on their presentation
- A list of resources and readings
- Interactive exercises to promote learning
- Between session assignments

Instructors were encouraged to develop not just didactic input, but also participant-centred problem-solving, brain storming and case

scenario discussions. A course coordinator, drawn from the research team, managed the training intervention development process with input from other research team members. The course coordinator also designed a participant workbook.

Implementing the Intervention

The complete intervention was delivered twice in two different intellectual disability services locations. Attendance at the course was open to all of the intellectual disability services participating in the project and to the specialist palliative care provider. Delivery was complicated and delayed because of the threat of industrial action but full delivery of the intervention occurred in both sites. Delivery occurred over four days in each case. There were nine participants in the first delivery and seven in the second. They were 14 females and two males with a range of experience from two to thirty-six years of experience with persons with intellectual disability, an average of six years experience with dementia care and four years experience on average with palliative care. Five participants had attended other training on intellectual disability and dementia in the previous twelve months and four had attended other training on palliative care in the previous twelve months. Twelve were registered nurses in intellectual disability (RNIDs), and five were registered general nurses (RGNs). A pre and post test on knowledge of dementia issues in intellectual disabilities and on perceptions of end of life care issues was also administered

Evaluation

The participants completed daily reaction sheets which were then used by the instructors to modify the content they delivered. Not unexpectedly, an example of feedback included concerns about sessions being initially too heavy on theory and that there was not always enough time for the exercises. Instructors were able to make and test modifications in response at the second session. The participant input and data on instructors’ own reaction then informed the development of the final manual. Changes made included:

1. Session content was reworked to offer an introduction and overview of key elements of the subjects covered.
2. More time was allocated to the discussion elements of participant exercises so that deeper exploration of key issues for individual and service developments would be possible
3. Self-directed learning for participants between classroom attendance was further developed to ensure that all teaching aims of the sessions were covered for each session delivered to maximise achievement of the stated learning outcomes for each session.
4. Case scenarios were further refined and developed for sessions in order to give participants the opportunity to explore key practice issues and challenges when they are caring for persons with intellectual disability and dementia, advanced dementia.

In the final consideration of the intervention the participant workbook was further developed and a formal trainer’s manual was designed with expanded notes and resources for sessions, guidelines for delivery, and recommended times for sessions so that other trainers would be able to effectively and completely deliver the training. Completing all of the sessions in the manual comprises a complete programme of study. However, the intervention in its final form is structured so that service providers may decide to run individual sessions from the manual at their own discretion. Feedback from instructors and participants confirmed that the training intervention should be delivered over at most a six to eight week period. It was also recognized and recommended that spreading out days of attendance would enable participants to consolidate their knowledge and skills in practice by using reflective learning and by completing individual learning exercises between class attendances.

Outcomes of the Intervention for the Participants

Evaluation of the pilot course was undertaken to measure pre and post course knowledge and to measure participant satisfaction with the content and delivery of the course. Pre and post course questionnaires were administered to test the existing knowledge of the participants on dementia care, palliative care, attitudes to death and dying and end-of-life care. These questionnaires were adapted from existing measurement tools for these purposes. Day by day evaluation forms were completed and in general were well evaluated in relation to content and delivery. On completion of the course participants were given the opportunity to give an overall general evaluation.

Session 1	Welcome and Overview
Session 2	Reflection, Reflective Practice, Diary-Keeping and Workbook
Session 3	Introduction to the History and Philosophy of Intellectual Disability Care
Session 4	Alzheimer’s Dementia In Persons with an Intellectual Disability
Session 5	Health Co-Morbidities in the Person with Advanced Dementia
Session 6	Understanding Person-Centred Care in persons who are Deeply Forgetful
Session 7	Introduction to the History and Philosophy of Palliative Care
Section 8	Fusing the Horizons of Care
Session 9	Ethics, Decision-Making and the Person with Intellectual Disability and Dementia
Session 10	Influences of Culture in Approaching Illness, Dementia and Duration of Healthcare
Session 11	Death and Dying: Exploring Own Values and Beliefs
Session 12	Loss, Grief and Bereavement
Session 13	Loss, Grief and Bereavement in Intellectual Disability Care
Session 14	Breaking Bad News - Some Important Principles
Session 15	Communicating about Loss, Dementia, Death and Dying with Persons with Intellectual Disability
Session 16	End of Life Care – the last 24 – 48 hours
Session 17	Teamwork & Collaboration
Session 18	Syringe Drivers
Session 19	Feedback from Reflective Diaries/ Workbook
Session 20	Evaluation and Close

Summary

The educational intervention was designed to better prepare staff to care for persons with intellectual disability and advanced dementia. It is an in-service education intervention to be delivered by staff from within their own service setting.

Structure of the Course

The educational intervention has two major elements.

- 1- A Trainer’s manual including a CD with all of the Powerpoint presentations for the course and
- 2- A self-directed student workbook, (in hard copy and on a CD in PDF format).

The trainer’s manual and the powerpoint presentations are for the use of the facilitators within the services.

The self-directed student workbook is for the participants.

Trainer’s Manual

An introduction is given in the trainer’s manual with guidelines on how the course might be run within the services. These guidelines address duration of the course, student effort and content. It is designed to be user friendly so that facilitators can have some flexibility in adapting it within their own work settings. This manual is designed in sessions. There are 20 sessions. Sessions 1-18 give participants theory and background for each session and short student exercises to facilitate learning in the classroom. Session 19 is where each participant presents a reflective piece of work and shares learning with his/her peers. Session 20 is an evaluation session to allow the participants to give feedback on the delivery and content of the course and to record learning achieved. The sessions are stand alone individual sessions that can be delivered at any time.

Self-Directed Workbook

The workbook is intended to support self-directed learning by the participants who undertake the sessions within the course. In the workbook there are additional exercises for the participants to do in their own time after each classroom session is completed. This assists participants to identify their own existing level of knowledge and to begin to reflect on their care practices. The content of some of the sessions challenges individuals to think about their daily work situation and how they currently care for persons with dementia and advanced dementia. The exercises are designed to encourage the participants to think about the theory that they have received in the classroom and to engage in exercises in the classroom and additional reading on their own time to consolidate their learning. The workbooks are used in conjunction with a personal notebook and a reflective diary. The instruction before each exercise indicates whether the exercise is completed in the notebook or in

the reflective diary. The workbook, notebook and reflective diary are personal documents and belong to the individual student. In keeping with an adult educational approach, course participants are expected to take individual responsibility and to make independent decisions as to how and when they undertake these exercises. The participants are asked about their experience of using the workbook in the evaluation of the course on the last day of attendance. They are expected to present (15 minutes), from their reflective diary as they complete the classroom content of the course. The participants choose what material they wish to share with other participants/ facilitator.

Training Materials

Fahey-McCarthy, E., McCallion, P., Connaire, K. McCarron, M. (2008)

Supporting Persons with Intellectual Disability and Advanced Dementia: Fusing the Horizons of Care. An Introductory Education and Training programme.

Trainer Manual. Dublin: Trinity College Dublin.

CONCLUSIONS & RECOMMENDATIONS

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Introduction

This study guided by the literatures on ageing and intellectual disability, dementia care and palliative care, informed by the results of focus groups with staff in intellectual disability services and in specialist palliative care, and responsive to the best principles in education for adult learners resulted in a comprehensive and tested training curriculum which is now available to services throughout Ireland. As such it is an important first step in responding to the challenges posed by advanced dementia in persons with intellectual disabilities.

Ageing and dementia in persons with intellectual disability has profound implications for future policy and service provision. Service providers are currently awakening to the unique needs and care challenges in supporting this population and many are ill prepared. Staffing numbers and patterns and the training of staff have been focused upon young and middle aged adults, and on employment, community participation and independence promotion; consequently the different issues when dementia is present are challenging these staffing approaches and philosophies.

Similarly, it is increasingly accepted that palliative care principles should be applied to the care of persons at end stage dementia (Abbey, 2003; Evens, 2002; Shuster 2000; Mitchell et al 2004; Chang et al. 2005), however despite this intent it is seldom evident in either generic dementia or intellectual disability services supporting persons with dementia. End-of-life care models in the hospice and palliative care fields primarily address chronic illnesses such as cancers and are only recently being applied to dementia care. The Report of the National Advisory Committee on Palliative Care (DoH&C, 2001) recommends the extension of specialist palliative care services to persons with progressive and advanced disease of non-cancer aetiology and the inclusion of at risk groups including persons with intellectual disability. However palliative care has been primarily developed and practised to support people with malignant diseases such as cancer and how it will transfer to other populations is largely untested. In particular, without an understanding of needs of persons with intellectual disability, and the programming philosophies inherent in intellectual disability services, palliative care may flounder when confronted by persons with intellectual disability and advanced dementia

- Dying trajectories are long and often unpredictable, and are often preceded by severe pre-existing intellectual impairment.
- Prognostic models that attempt to estimate survival of less than 6 months in non-cancer patients already difficult in the generic population (Coventry et al., 2005) are likely to be further confounded in persons with intellectual disability and dementia

due to pre-existing impairment, lack of assessment and diagnosis, communication difficulties and the presence of co-morbid conditions.

Indeed one can argue that ‘palliative’ in the context of dementia and intellectual disability is poorly understood and where it fits within the continuum of related care requires greater exploration and discussion.

It was also evident from the narratives in this study that staff working in intellectual disability services supporting persons with advanced dementia operated within a care philosophy which was very consistent with the philosophy and broad principles underpinning palliative care however they did not necessarily ‘coin’ their caring as palliative care. This was equally recognised and acknowledged by staff working in specialist palliative care services. It was further evident that staff in intellectual disability services were highly dedicated and committed to providing optimal care but often lacked knowledge and specific skills particularly in pain and symptom management, and there was often anxiety in supporting the person through death. Equally, specialist palliative care participants spoke about their challenges in terms of communication difficulties with persons with intellectual disability, difficulties in understanding needs, lack of a general understanding of dementia, and poor understanding both of current services structures in intellectual disability and where palliative care fits and bests addresses the gaps in current service provision. The curriculum developed celebrated the individual service systems and common strengths and addressed disconnects, thereby building synergy to address care needs through the fusing of perspectives.

This fusing of perspectives began by raising awareness of the philosophies underpinning care and the expertise inherent in both fields. It also highlighted the challenges, complexities and gaps which needed to be addressed to ensure optimal care for this increasingly at risk and vulnerable population. While participants’ experiences were very personal and varied across and even within the various services, nonetheless they did provide important insights. It is hoped that the data generated and the intervention developed to respond to the needs identified will increase our understanding of these issues and provide a solid foundation on which to build future partnerships between intellectual disability and specialist palliative care services.

There are other important lessons to be noted and areas for additional research that should be highlighted to shape future education and policy directions and particularly the interface between intellectual disability services and specialist palliative care services.

Living Well and Dying Well with Advanced Dementia

The qualitative data in this study suggested that across all of the services and types of care settings participants had witnessed what they termed as ‘good and bad deaths’. Peaceful dying appeared to be as much about living well with advanced dementia as it was about dying well. Broadly participants considered the pre requisites for a good death to include a) a good environment, b) the sustaining of relationships; people significant to the dying person being present, c) the person being as comfortable as possible, d) dying peacefully, and e) having access to professional expertise for help and support should they need it. As noted earlier these concepts then informed the intervention but it is unlikely that this is the last word on these issues. Greater understanding and better services will result from additional research and efforts to further operationalize these concepts. At its most basic level beliefs about what represents ‘good and bad deaths’ will always influence the delivery of care, the satisfaction of staff with the care they deliver and the readiness of individuals, their families and peers for the type of care and the location of care that they receive. A growing cultural diversity was evidenced among staff in intellectual disability services reflected in differences in views on appropriate levels of care in advanced dementia, and rituals at end of life adding to the complexities of this issue. At the very least increasing efforts are needed to understand and consider these differences as well as differences among carers in intellectual disability services and in specialist palliative care services.

Values and beliefs around place of care and death appeared particularly critical. The intellectual disability care settings in this study reflect the typical variation of service provision for persons with intellectual disability in Ireland. These included a purpose built home for persons with intellectual disability and dementia, institutional type care settings, ageing specific settings, campus based group homes, community settings, and a palliative care type setting. There was considerable debate as to whether community living and ageing in place could be maintained. The participants at one site believed that the person should be supported in the community. This echoes authors such as Chaput (2002) and Forbat and Service (2005) who also felt persons with dementia should be supported to remain in their usual home. The participants felt that the moving of the person back into institutional care would isolate them from a life they were used to. Interestingly the service which proposed a community model/ageing in place model of care actually had very little experience of caring for persons with dementia. In contrast, participants from another service where they had had significant experience of caring for persons with dementia offered many reasons for why they felt that community living could not support the person including that many community houses are not equipped to care for someone with ambulatory problems because of building design and structure.

.. at the very end stages where their environment absolutely you know is unsuitable for again because of physical restraints such as you know hoists, transfers, bathing, and all the rest .it becomes completely impractical.. (7.1.2)

Additionally the need for 24 hour care and the lack of nursing staff in many of the community settings was thought to further confound these problems. Historically many of the community care settings were not set up to cater for this level of need and staffing and financial resources reflect this.

Training alone cannot address these challenges. The narratives suggest that emotional costs, distress and exhaustion for carers appeared fuelled more often by lack of resources and appropriate environments than by a lack of understanding of ‘good care at end of life’. While the social model of disability underpinning current intellectual disability services has been hugely influential in improving quality of life for all persons with intellectual disability, it appears that this model is challenged by the demands of effectively supporting people with intellectual disability to age and die in place. Resource allocations in the future will need to reflect the changing needs of this population (McCarron et al., 2005). The Transformation Programme of the HSE (HSE, 2007) already challenges service users and providers to improve community management of common and disabling illnesses of later life. This is particularly relevant to the field of intellectual disability where diseases in later life particularly dementia are more likely to be characterized by complexity and multiple morbidity (McCarron et al., 2005; Prasher, 2005). Sustainable services with the ability to transfer well into aged years are called for, including integrated packages of care responsive to changing needs across the continuum of dementia including terminal and end-stage dementia. Additional research and education will be needed to build capacity to respond more effectively.

Delay in Diagnosis and the Timing of Interventions

The onset of Alzheimer’s disease is insidious, and early symptoms are often not recognised and often attributed to general signs of ageing. It is well established that accurate diagnosis of Alzheimer’s disease in persons with Down syndrome is complex and fraught with difficulties (McCarron & Lawlor, 2003). Many of the difficulties are confounded by pre-existing intellectual impairment, additional physical and mental health co-morbidities, constant staff turnover with poor baseline records to measure decline and many frontline staff unable to recognize and accurately report symptoms. Dementia is often quite progressed before any diagnosis is made. Yet, the key to accessing appropriate dementia care and the basis for many of the therapeutic interventions is early recognition and diagnosis. It also has implications for planning end-of-life care. A decade has passed since consensus recommendations for screening and diagnosis of dementia in persons with intellectual disability were

published (Alyward et al., 1995), however memory clinics, and routine screening are generally not part of the health care landscape for persons with intellectual disability. Many professionals lack the relevant skills or time to perform a comprehensive diagnostic work up for dementia and unlike the generic population there is no equivalent to the Mini-Mental State Examination (MMSE). The narratives from this study confirmed that dementia was often at an advanced stage before any diagnosis is made, and in some instances a formal clinical diagnosis of dementia was not made having a major impact for later life decisions and end of life care.

Consequently, it can be argued that quality end of life care also requires that services supporting ageing persons with intellectual disability should develop appropriate strategies to increase the level and quality of assessment necessary for the diagnosis of dementia. Each service provider should ensure that families, all staff including frontline staff, medical and allied professionals have sufficient educational input on dementia and its presentation in persons with intellectual disability. This was addressed in the intervention developed as part of this project, furthermore there are memory clinics for the general population expanding to serve this population, cd-rom based instructional materials (see for example, McCallion & Janicki, 2000) and a number of specialist training programs e.g., the Post graduate Diploma in Specialist Nursing in Intellectual Disabilities and Dementia at Trinity College and the Dementia Assessment Fellows program developed by the New York State Developmental Disabilities Planning Council, but much more is needed. Again the intervention here makes an important contribution to this effort but the development and dissemination of evidence-based standardized assessment procedures is called for. Accurate diagnosis of dementia has important implications for the planning of future care including end-of-life care, hence it is imperative that memory clinics are established within intellectual disability service with collaboration and specialist support from main stream generic dementia services.

Supportive Environments

It was clearly evident from the narratives that the ‘aesthetic’ environment was another important pre-requisite to living well and dying well with advanced dementia. Similar to the generic population persons with Down syndrome and advanced dementia present with multiple ailments. As alluded to earlier advanced dementia refers to progressive immobility, total dependence in essential activities of daily living such as bathing, washing dressing; nutritional difficulties and severe dysphasia resulting in swallowing difficulties and propensity to aspirate; infections related to immobility and general complications of the disease (McCarron et al., 2005). Many intellectual disability services are poorly prepared to meet and respond to these increasing care needs at end stage dementia in terms of both suitability of the environments and skill mix and knowledge base of staff.

The participants across all of the six intellectual disability sites appeared to generally support an ageing in place model but also acknowledged that this was often difficult to sustain. Despite their best efforts staff graphically described that it was often not possible to continue to give care with comfort or with safety in the person’s own home as evidenced in the following quotes:

.. at the very end stages where their environment absolutely you know is unsuitable for ageing because of physical restraints such as you know hoists, transfers, bathing, and all the rest .it becomes completely impractical.. (7.1.2)

..... there is a certain stage where you can say sorry ..there is still too much noise here, you know ..let the person stay with us as long as possible, for as long as they’re comfortable . But it gets to the stage all right where you have to say no, the noise levels wouldn’t be conducive to someone that was unwell, you know... (3.2.2)

The participants recognised that the living environments in many situations were not conducive to supporting a person with terminal dementia and that personal space and a quiet environment was often difficult to achieve. For example in one setting there were many persons with an intellectual disability and a busy and noisy atmosphere. The logistics of caring for a person with dementia in smaller units and homes were also problematic at times. In the mid stage of dementia there were health and safety issues for staff to consider for the person and their peers. While the person with dementia was mobile it was important to keep them safe and secure in the building but this meant on many occasions that the freedom of other individuals (peers) was curtailed if doors had to be kept locked or kitchen facility access was curtailed. Further research is needed on expanding the use of dementia technology to better address these challenges.

Deaths occurred in settings where they were not formally delivering end-of-life care, as well as in settings which did. Participants reported that ‘good deaths’ occurred when the person had his/her own room/space. They did not necessarily need to have individual rooms as long as the personal space supported the person dying in a dignified manner. This included that there was enough room for any additional equipment such as hoists. The staff generally gave a sense that they were satisfied that they had contributed to the goodness of the dying process by delivering comfort care and making the experience (as much as was possible), like it would have been for anyone dying at home in the general population: One carer said:

.. well it’s like as if they were dying at home like .. you’d be around them (6.1.3).

Some staff wanted a specialist unit for dementia/ end-of-life care, others were very against such units. In one service a specialist dementia unit was reported as supporting and empowering to staff

seeking to provide quality, dignified and sensitive care. In another unit catering for persons at end of life and not dementia specific, staff identified that it was not suitable for persons with earlier stage dementia particularly if they were still ambulant, agitated, or noisy and there were other people dying there who needed a quieter environment and a step down unit was considered preferable.

Equally, while the staff were concerned about giving good care to the person with dementia, they were equally concerned about the peers of the person who were living in the house. It is established that staff are now spending significantly longer periods in direct and indirect care-giving activities for persons with advanced dementia (McCarron et al., 2005). Staff expressed guilt that peers were being neglected either socially or emotionally because the person with dementia required so much time dedicated to his/her care.

Regardless of the issues outlined above at all times participants articulated that they wished to care for the person with dementia within the intellectual disability services because they believed that the person would not be understood or his/her needs would not be met in general health settings. Todd (2004) also found this strength of feeling among intellectual disability staff in the United Kingdom. Indeed the report ‘Death by Indifference’ (MENCAP 2007) documented that general health settings manage people with intellectual disabilities inappropriately and with grave consequences. Participants in this study were very distressed by their experiences that when people were moved out to generic services such as nursing homes, that they felt they deteriorated more rapidly and sometimes died unexpectedly, arguing that care was suboptimal:

‘people have been moved out and within three weeks or a month they are dead’ (1.2.3)

and ...his care wasn’t... ideal like .. it wasn’t .. his hygiene .. wasn’t..

.. we’ve all had the experience of where they’ve gone into hospital for an overnight or a few we.. few days and where they come backwith broken skin and everything that we wouldn’t .. that we’d be so careful of.. (2.1.1)

It was clear from the narratives that ageing in place cannot be a trite statement, that although it embodied important values for all involved, a range of environment issues and readiness of staff determined whether it was possible in a particular setting yet there were valid concerns that the difficulties in the particular setting were not the only issue. Transfer in even the most difficult of circumstances was resisted if the alternate setting could not offer the respect, competence, caring and personal attention that staff, peers and family desired. Additional work is clearly needed

on understanding the possibility for ageing in place in intellectual disability service settings and the redesign of alternative settings to better exemplify and incorporate a person-centred approach to care.

Expanding the Ideas of Person-Centred Care

Person-centred care as acknowledged by Kitwood (1997) is at the heart of good intellectual disability care and good dementia care. Kitwood (1997) recognised that comfort care was an important element in the care of someone with advanced dementia. Such care was evident in the visits the researcher made to those settings where every effort was made to ensure that the person had the appropriate equipment, resources and tender loving care to sustain their comfort physically and psychologically. (See Appendix 3). In the intellectual disability care settings in this study the staff continued to identify with the person as s/he was before the dementia and strove to meet the individual’s needs, constantly remembering the person’s likes and dislikes from a time when s/he was able to indicate his/her preferences. Staff from specialist palliative care also explicitly commented on their observations that staff in intellectual disability care were very person-centred in their approach to caring and that psycho-social care was good in these services as evidenced in the following quote:

.. another thing I think Intellectual disability services have got right is that they have a very strong philosophy of person centred care .. they see the person still the same at the end .. even though cognitively they’re disimproved because of the Alzheimer’s .. they still see the person .. the spirit or whatever of the person .. even though they’re not the person they were ..(9.1.2)

However there have been critiques of person-centred care and models of dementia care triads are emerging which acknowledge that there is a minimum of three people in any relationship-centred care model (Adams & Grieder, 2005) - the person with dementia, their carer and a health or social care professional. Tresoloni and Pew-Fetzer (1994) see relationship-centred care as central to giving meaning to health care. In this view a person’s health care needs to be understood within relationships particularly relationships that have developed over long periods of time (Nolan et al 2006), such as in the intellectual disability settings in this study. Oppenheimer, (2006:200) suggests that it is the ‘family of people with dementia who are the most important safe-keepers of their identities, they hold their histories, understand what was important to them in their former lives, and remember preferences and habits of thought’. Many of the intellectual disability participants in this study had known and supported the person for many years often prior to the onset of dementia; they understood the person, their responses, their turn of phrase, their humour, their mannerisms and unique behaviours. It was often through this ‘knowing’ that they could communicate and predict the needs and wants of the person.

Oppenheimer, (2006) would argue that ‘it is part of the joy of being loved to be so predicted’. The participants across all intellectual disability settings expressed that they had formed enduring relationships with the individuals they cared for. Participants spoke about knowing these individuals for up to thirty years. They knew them as children in the child services and then as adults in the various settings and they were now watching them decline and die. They also spoke about the importance of having someone who knew the person very well being with them when they were dying. This meant that when the person had to be transferred to an outside hospital for example they felt that a familiar staff member should be present with them. Dame Cecily Saunders (1993) also emphasized the importance of this personal relationship and its centrality in supporting the person through living with dying. She argued that this relationship built on genuine and personal concern for the patient is necessary to ‘enable the patient to attain a life and death most meaningful to him’ (Randall & Downie, 2006). Many intellectual disability services also respond to hospitalization in this manner but it is imperative that intellectual disability services come to better understand the criticalness of valuing, nurturing and supporting these relationships throughout the experience of advanced dementia.

MacConville (2004) concluded that relationships were central in understanding a good death and these relationships are situated and shaped within a historical and social context. The narratives in this study highlighted the complexities of the relationships; staff supporting persons with intellectual disability and advanced dementia placed great emphasis on the ‘relationship’ they had with the person, offering unconditional positive regard, genuineness and empathy.

Post (2006:231) argues that ‘the reality is that until the very advanced and even terminal stage of dementia, the person with dementia will usually have sporadically articulated memories of deeply meaningful events and relationships ensconced in long term memory’. Consistent with this view, participants also placed great emphasis on people who were significant to the person being present at the time of death and included the peers of the person who was dying. This inclusion of peers did not appear to happen because the staff knew of theoretical encouragements to include peers to facilitate their own grieving but rather because of a sense by staff that peers were family and if you were at home your family would be around and involved. In a study into attitudes to death and disability in Ireland, Dodd et al., (2005) reported that unlike the United Kingdom, intellectual disability services in Ireland were good at including persons with intellectual disabilities in all of the associated rituals around death and dying. He attributed this in part to the historical influence of the religious orders who predominantly founded these intellectual disability institutions in Ireland.

More work is needed to better understand the role of relationships in supporting the journey of a person with intellectual disability and advanced dementia but relationship centred care may prove a more fruitful concept in understanding their care and is worthy of future systematic consideration.

Loss Grief and Bereavement: How can we support staff and peers through the painful process of letting go?

Bereavement care for the families after a death is an integral part of good palliative care. Generally participants identified that families needed support when the person was dying but much depended on the relationship that the family had with the service before their relative died. Remembering the person with intellectual disabilities can be an important element in reinforcing the existence of that individual as some people can think it is a blessing for parents when a child with and intellectual disability dies (Todd, 2005). Some services held a formal religious celebration to remember the deceased and participants believed that this was also good for participants and peers to officially remember the person.

.. it’s very important and we also have mass here once a year for all the ones who have passed on .. it’s good to remember them .. (6.1.2)

Informally relatives of the deceased person came back to the services after the person died and were welcomed by participants who realised that there was a huge void created by the death for these griever. Participants recognised that it was difficult for these persons to adjust to not being involved with the service because they had been so much involved with the service while the person was alive. Todd (2004) identified this phenomenon also in his work with bereaved families of persons with intellectual disabilities in the United Kingdom. Participants in one service reported that they were actively researching the needs of families of those persons who had died because they realised that they needed specific bereavement support.

.. we do feel that we could be more assertive in giving them support .. because they do not fall into the normal category of bereaved people.. (7.1.1)

Some participants explicitly said that peers of the person needed bereavement support, others said they thought that they didn’t understand and so did not need bereavement support. However in services where they were beginning to seriously think about this matter upon reflection they wondered whether changes in people’s behaviours were in fact unresolved grief issues.

.. maybe we’ve ignored it, or not ignored it but, not deliberately anyway.. (10.1.3)

Participants were upset for the peers of the person who died who were lifelong friends or roommates, and identified with the loss the peer was perceived to be experiencing. This identification with the bereavement of another person who is grieving is known as vicarious grief (Kastenbaum, 1989). The participants saw peers as family of the person having shared a lifetime together. They also saw themselves as family to the persons in their care. This issue of who actually is family for the person in intellectual disability care was interesting. In services where individuals with intellectual disability had no family or little contact the participants felt a sense that they were as close as any family.

.. to a lot of them here ..you are all they’ve got. You really are, some of them are blessed to have family and visitors and stuff and others aren’t and its them that you know, you need everything you’ve got .. out of you for them. (1.2.1)

Participants identified many issues related to loss, grief and bereavement in relation to the person with dementia, their peers, their families and to themselves as health and social care staff looking after this person. Participants also reacted to the level of awareness they felt the person with dementia had of their own decline and losses.

.. the awareness that they have up until the end .. we don’t know .. and people will assume that they’re not aware any longer of where they are and what they’re doing .. yet they cant vocalise it or if they can’t give it to us in some way they assume they’re content we don’t know what....I really you look at them at times and .. you wonder how sad they are underneath it all... (2.1.2)

Participants were saddened to watch the person decline and die. They acknowledged the difficulties associated with the long trajectory of the illness and the losses encountered along the way.

... but I think we start to loose some of our ladies long before they die.. (3.2.2)

Participants on some sites believed that the persons they cared for knew they were declining and had some understanding of dying, in one case an individual refused to go into a particular unit because she associated it with the deaths of others. In another site participants reported that individuals became relaxed at a certain point and they believed that the person understood that they were dying. Others acknowledged that they didn’t know whether the individuals they cared for understood the concept and that it remains difficult to generalise for persons with intellectual disability. This issue is well presented in the work of Meeusen-van de Kerkhof (2006) who debates the theoretical understanding of persons from mild to profound intellectual disability and their understandings

of loss and grief. Regardless, many participants got upset when recalling the deaths of people they had known for many years.

There were examples of service management sending staff to support persons in hospital as their lives ended. However there were also participant reports that more senior management did not always fully understand or acknowledge that staff grieve for the person when they die and management’s actions are felt to be insensitive when the decision is made to move another person into the room where the dead person had resided. This is an important area for both future research and for training as not unexpectedly when we encourage staff working in intellectual disability services to fulfil family type roles and create home-like environments for people with intellectual disability; it is very likely that there will be grief and bereavement for staff and peers in the group home/care setting.

In the United Kingdom Todd (2004) identified similar concerns and feelings among staff. Staff there further believed that their long standing relationship with clients and their intense grief about their demise were not acknowledged in any public sense but was hidden within the organisation. Staff compared their feelings of loss and grief and how it was hidden when a person was moved out of an area to another part of the service or to an outside service. Doka (2002) described this grief as disenfranchised grief or grief which is hidden from a societal response.

There were formal bereavement services for peers in some of the intellectual disability services and staff believed that they could access these services for themselves if required. However, staff more often used each other for support, and there were photographs of the deceased person on display within the home/care setting and during the course of visits to many of these sites, staff and peers were observed looking at these photos on occasions and talking about the deceased person. In many ways the staff were facilitating grieving for themselves and peers within the theory of continuing bonds (Klass et al., 1998) thus allowing the surviving household members (staff and peers) to continue to integrate the deceased person in their lives.

Grief and disenfranchised grief from the narratives appeared a critical, complex and multi-faceted issue. Again this was addressed in the intervention designed as part of this study but it is another area worthy of further study and indeed it will be explored further in the thesis being developed by one of the research team members.

Symptom Management and Collaborative Models for Care
In this study some participants expressed concern about a lack of clinical skills necessary for the delivery of optimal care in terminal dementia, specifically, the siting of a sub-cutaneous line, management of nutrition and hydration, assessment of pain/distress and managing syringe drivers. This very often resulted in the person

been transferred out of their usual home to an acute care/ or general hospital setting. In contrast in other services staff had undertaken additional training and had developed knowledge and competence in these specific areas, and consequently felt better prepared to support persons at end-of-life who require more complex care.

At the time of data collection there was few participants from the intellectual disability services with specialist education and training in palliative care. Some participants across services had undertaken short three to five day courses addressing the theory and principles of palliative care and in the purpose built intellectual disability-dementia unit participants had training in siting sub-cutaneous cannulae, fluid replacement and pain and symptom management; however this was not the norm. An approach to addressing this lack of preparation would be to provide more specialized training and certainly this was a feature of the intervention developed as part of this study. However, some participants also had past experience of working collaboratively with specialist palliative care and spoke of how much they had gained from this collaborative working. Such collaborative models have been previously recommended (Parker et al., 2005) and the need for participants in intellectual disability care to be able to report important changes to palliative care staff was identified by Tuffrey-Wijne (2002) and Todd (2004) as critical to good symptom management in terminal care. It was evident from this study that additional education and palliative care intervention guidelines were welcomed by participants and will help to address some of these issues, however it is recommended that future policy and service provision ensure that there is specialist palliative support available to assist staff operationalize these guidelines and approaches if and when necessary. Furthermore it must also be recognised that many staff working particularly in community group homes may not have nursing expertise and there is an need to re evaluate skill mix in some of these settings and developments like clinical nurse specialist and nurse practitioner posts in dementia and intellectual disability to may help services better respond to changing needs and support staff working in these settings.

In units where end of life care was formally delivered or where staff had undertaken additional training, and where they had supported multiple persons along the continuum of dementia, participants reported particularly positive experiences of supporting the person through death as evidenced in this quote:

.. Well it's been generally very peaceful, its generally them slipping away, its been generally done in privacy ... (7.1.1)

However as alluded to earlier for many other participants supporting the person through death was perceived as a terrifying experience in which they felt unprepared for.

Symptom Management

One of the cornerstones of palliative care is symptom management particularly the control of pain, dyspnoea and the management of nutrition and hydration. It was evident from the narratives in this study that participants often struggled around these issues and often equated poor management with 'bad death'. Indeed, lack of experience, understanding and skill in the management of these issues often resulted in the person been transferred from their usual home/care setting. In a similar vein, participants reported bad deaths where they had been unable to keep the person comfortable or to keep the person at home to die because of difficulty in assessing pain and distress in persons with cognitive impairment, areas identified as complex and challenging in this population (Regnard et al., 2006).

Participants from specialist palliative care were very aware of these emerging challenges when supporting persons with intellectual disability and advanced dementia:

"we'd have more concentrated involvement with some people who have Alzheimer's dementia and intellectual disability and it was .. in many ways what you're trying to.. you're basically trying to assess distress ... rather than being able to say they have a pain.. 9.1.1

Specialist palliative care participants also identified their concerns about a lack of policies or committees in place to support decisions about resuscitation, nutrition and hydration at end of life and about the inappropriate versus appropriate use of percutaneous endoscopic gastrostomy (PEG) feeding in a person with advanced dementia. Participants from the intellectual disability services struggled with nutrition and hydration issues especially at the advanced and terminal dementia; PEG feeding was an area of concern across five of the six intellectual disability sites. At sites where nursing staff clearly knew of the benefit to burden debate on the use of PEG feeding in advanced dementia they were visibly upset describing prior experiences where people with end stage terminal dementia were subjected to this process and experienced negative outcomes. Several participants spoke about how disempowered they felt because it was a family decision and they felt that they had to support the family decision. The following quote captures such dilemmas:

...one lady in particular this year.. in the last year who had end stage Alzheimer's dementia .. Downs syndrome who the family decided to put a peg in I think it's a year or so.. within the year and the poor little woman has just blown up .. and she has no .. her quality of life has just been .. in my opinion affected because of what this has done to her.. its horrendous you know.. 3.1.1

Participants on other sites were unsure about the benefits or burdens of PEG feeding. On one site participants stated that relatives knew

that it was the 'norm' in this particular service for persons in late dementia to have a PEG tube inserted as evidenced in the following quote:

....they would have been in and seen others clients with pegs or whatever and they'd know it was the norm really for a lot of people here .. so it wouldn't be new to them .. (4.1.2)

Further concerns were expressed about practices when some people with advanced dementia were admitted to a general hospital:

" that would have happened to one of our lady's now .. she never had a chest infection like and yet when she went over there (a local hospital) ..it was like.. just done like.. that it was the best.. ye they don't know that person they.. she's just a lady who has gone over, she has Down syndrome, she has Alzheimer's .. 2.1.3

Although multidisciplinary teams existed in most services, in some, a co-ordinated approach to the care of the person with advanced dementia was lacking as was collaboration and communication with the local general hospital. In other services there was more collaboration and discussion. Participants also reported that there were often long waiting lists for access to speech and language assessments in the community, with some services having limited or no access, a critical concern which needs to be addressed.

Collaborative Models

A common response was that participants did not know how they would access specialist palliative care support. This was also a finding in Todd's (2004) work in the United Kingdom. Other participants believed that palliative care or hospice care was only for people with malignant disease or motor-neuron disease. Again this is a common finding in the Irish context (IHF 2005; IAPC 2005). The specialist palliative care participants also reported having a very narrow input into supporting a person with intellectual disability and dementia in intellectual disability settings as demonstrated by the following quote:

"I've a fairly minimal piece of involvement into the people with Alzheimer's, about particular symptoms, but like a very narrow range of things, about pain management, management of secretions, managing nausea and that's very basic, very narrow stuff.. I think its about assessing, its about the drug side of it.." 9.1.1

As already stated the specialist palliative care participants felt that the intellectual disability staff were delivering a very person-centred care and delivered good psycho-social care to the person with dementia and wondered whether they might just have a role to play at the terminal stage only. They did not see that they had anything to offer at the early or mid stage of dementia in relation to symptom management as they felt that the generic dementia services would manage these better. Therefore they saw their input mostly being

more likely to be end of life care as they felt that:

.. You could actually argue that in a service where people are particularly going to ..be getting dementia why would you need palliative care at all, should part of service development be that part of your development and your service be incorporating the palliative care approach.. ..the terminal care side of things .. its very similar for all disease groups (9.1.1)

However the specialist palliative care participants felt that what they had to offer over and above symptom management would be some expertise in how to approach decision-making and in particular ethical decision-making issues which potentially arise at the end of life.

"I think specialist palliative care has moved, say the comparator for us would be hydration at the end of life .. that used to be 'hydration.. no hydration, polar opposites'. now its case by case, individual basis and people are more proficient at ethically debating out the issues.." 9.1.2

Participants from specialist palliative were anxious that if staff in intellectual disability services provided a palliative approach to care at level one or a general palliative approach at level two within their own service that they would also know when or how to access the specialist palliative care level three expertise if required.

.. I suppose its that people aren't satisfied that a level 2 or general palliative care approach is enough for everything over the time.. that they're aware that there is more out there as well.. so that they can make the decision that yes this is appropriate for the vast majority of people but we know occasionally some people will need something more and we know where to go to look for that extra rather than in kind of an isolated little pocket of .. we will deliver everything in our service and we won't look outwards to. I mean that's the same for us, we need to look outwards as well.. (9.1.2)

Participants at all of the intellectual disability sites stated that they would welcome support from specialist palliative care services on pain and symptom management in the care of the person with advanced dementia.

The intervention developed as part of this study is intended to help address these concerns by equipping intellectual disability services staff to more appropriately access specialist palliative care services and to encourage staff in palliative care to more effectively offer support for care already being provided but more work is clearly needed to orient providers and staff in both types of settings and to develop models for collaborative care.

Summary Recommendations

A number of end-of-life and palliative care related recommendations emerged as well as more general recommendations for dementia care in intellectual disability services.

1. Sustainable services with the ability to develop care for older persons with intellectual disability and dementia are needed.
2. Integrated packages of care are needed, i.e., intellectual disability, dementia and specialist palliative care, responsive to the person's changing needs across the continuum of dementia and including terminal and end-stage dementia.
3. To better address dementia issues, memory clinics are needed within intellectual disability services with collaboration and specialist support from main-stream dementia services
4. Greater effort is needed in involving the person in planning and in including their views and wishes in end-of-life care
5. More work is required in understanding the terminal stage of dementia, the duration of this phase, and the timing of modification of aggressive treatment in persons with dementia
6. Given that cultural differences were identified in beliefs about active versus palliative treatment of people with terminal dementia, rituals at the time of death, and talking to a person about dying, there is a need for further research and training to better understand cultural differences among staff and its implications for care.
7. Specialist palliative care support for staff in intellectual disability services is needed to help develop and operationalize emerging end-of-life care guidelines
8. As is also true for palliative care for the general population, a different relationship is needed with acute care settings to ensure that care planning for end-of-life is supported when persons with advanced dementia are transferred to these settings; this includes improving understanding by hospital staff of the unique role of intellectual disability services staff in the care and support of persons with intellectual disabilities.
9. Ethics committees are needed in intellectual disabilities services equipped to advise on planning for end-of-life care and on addressing nutrition and hydration and other concerns for families, staff and persons with advanced dementia
10. Additional research and education will be needed to further build capacity to respond effectively to advanced dementia needs.
11. Developments like clinical nurse specialist and nurse practitioner posts in dementia and intellectual disability should be pursued to help services better respond to changing needs and support staff working in these settings.
12. Further research is needed on care needs at different stages of dementia, improved understanding the range of grief and bereavement experienced by persons with intellectual disability and best practice models for collaboration between intellectual disability and specialist palliative care services.
13. Relationships among the person with advanced dementia, the staff, peers and families appeared critical in supporting a person across the continuum of dementia. Relationship centred care may prove a more fruitful concept in understanding care in advanced dementia and is worthy of future systematic consideration.

Final Comments

This project benefited from the honest expression of caring concerns by participants as they considered the needs of persons with intellectual disability and dementia, of families, of peers and of themselves as carers. There was a desire to offer better care, an openness to new ideas and yet a questioning of the alternatives being offered in terms of the philosophies of care in which they were trained and the frustrations they experienced. Opportunities for improved education and collaboration between service systems were identified and an intervention developed and delivered in response. Additional areas for research and training were also identified. In the end the researchers were awed by the thoughtfulness and care offered by staff to persons with dementia their peers and their families. This work offers a picture of their experiences and a respectful intervention to respond to their concerns.

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Appendix 1 Guide Questions for Focus-Group Interviews with Specialist Palliative Care Staff

Welcome
Get written consent
Collect demographic information sheets
Revise project information
Ask if there are any questions

Prompts:

- What have your experiences (past or present) of caring for someone with an intellectual disability and dementia been like?
- Did you find it easy/difficult? Why?
- What were the particular challenges for you as staff?
- When did these challenges occur?
- Are there challenges for others? Who?
- How might the care of persons with intellectual disability and advanced dementia be improved?
- What education and training needs do you believe you have in relation to caring for this population?
- What do you believe are the challenges for you in working with intellectual disability services in caring for someone with advanced dementia?
- Have you any further comments you would like to make before we finish this interview?

Appendix 2 Guide Questions for Focus-Group Interviews with Intellectual Disability Staff

Welcome
Get written consent
Collect demographic information sheets
Revise project information
Ask if there are any questions

Prompts:

- What have your experiences (past or present) of caring for someone with an intellectual disability and dementia been like?
- Did you find it easy/difficult? Why?
- What were the particular challenges for you as staff?
- When did these challenges occur?
- Are there challenges for others? Who?
- How might the care of persons with intellectual disability and advanced dementia be improved?
- What education and training needs do you believe you have in relation to caring for this population?
- Do you (or have you) work/ed with a hospice in the care of persons with Alzheimer's dementia?
- If yes - How does (did) that work? Could it be improved?
- If no – Would you consider working with specialist palliative care for the person with dementia? How would you go about that?
- Have you any further comments you would like to make before we finish this interview?

Appendix 3 Reflection on Practice – Comfort Care

Reflection on a visit to one care setting of an intellectual disability service - Comfort Care.

My first impressions on entering this setting was that it was a very nice environment, quiet, calm and aesthetic. It was spotlessly clean, cosy, very calm environment, very homely with a variety of fresh fruit in a bowl on the centre of the table in the sitting area. The fire was on. There were nice furnishings, paintings, newish equipment e.g. complex wheelchairs, walkers etc in room (sitting room). There was a nice fresh décor overall. I thought about this in the context of the clients in this unit. They had what the staff reported as moderate to severe intellectual disability and there were clients with advanced dementia here also. Does the environment matter to people with cognitive impairment? In order to care for someone in a dignified manner I would think it does.

Staff were welcoming even though they appeared to be busy. They had a number of clients requiring full nursing care and had just finished a round of attending to the nutritional and personal care needs of those clients. The bedbound clients were in their rooms resting.

On general observation the unit was reasonably well resourced with appropriate beds, equipment, and staffing. The clients in the day room on observation appeared physically very well cared for. As I approached one client and held his hand I noticed how moisturised his skin was, no dry areas and I thought that this reflected an excellent level of care as he was unable to move, communicate verbally or take care of his personal hygiene in any way himself. He was sitting in what looked like a very comfortable pose in a very comfortable chair reclined, with a beautifully colourful and soft blanket under him. He appeared at ease. He was meticulously clean, shaved, and his general skincare, oral care, eye care, grooming and clothing were all impeccable. There was a general sense of comfort and no obvious distress on the part of any clients observed during the visit.

This is a unit which the staff reported was dedicated currently to the care of persons with palliative care needs. There was no definite plan to develop it up as such and for this purpose. The unit has developed more in response to the needs of quieter personality type people some of whom had developed illnesses such as dementia. There were a number of regular and mature staff on this unit. They gave the impression that they derived great satisfaction from caring for this population. In the background I could hear the sounds from the other rooms. Sounds of happy, laughing and very busy staff and their clients!

This scene was not unusual. I witnessed such care delivered with love on all of the intellectual disability sites during my visits on this study.

Appendix 4
Day by Day Participant Evaluation Form (Example Day 1)

REFLECTING ON COURSE CONTENT OFFERED TODAY, PLEASE COMPLETE THE FOLLOWING:

	Strongly Agree	Agree a Lot	Tend to Agree	Tend to Disagree	Disagree a Lot	Strongly Disagree
· My expectations of the course were met						
· The topics were delivered at at appropriate depth						
· Presentations were clear and easily understood						
· The volume of the content was right within the time it was delivered.						
· The venue and facilities were to my satisfaction						

THE FOLLOWING SESSIONS MET MY NEEDS:

	Strongly Agree	Agree a Lot	Tend to Agree	Tend to Disagree	Disagree a Lot	Strongly Disagree
· Session 1						
· Session 2						
· Session 3						
· Session 4						
· Session 5						
· Would you like to comment specifically on any of the sessions?						
· How do you think today has benefited you?						

