



Supporting Persons with Intellectual Disability & Advanced Dementia



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

EXECUTIVE SUMMARY

School of Nursing & Midwifery
Trinity College Dublin

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ACKNOWLEDGEMENTS

Sincere thanks are extended to the Irish Hospice Foundation and the Health Research Board who so generously funded this two year project.

Sincere thanks are further extended to the six intellectual disability service providers and the specialist palliative service provider who participated in this research project and to all those who generously contributed to the delivery of the pilot course of the training and to the content within the Trainer's manual.

Finally thanks are extended to Ms Anita Muldowney, Ms Caroline Slyne and Mr Thomas McCarthy for their assistance with the final formatting and proof-reading of all of the material presented in relation to this education and training course.

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Citation: McCarron, M. Fahey-McCarthy, E. Connaire, K. McCallion, P. (2008) Supporting Persons with Intellectual Disability and Advanced Dementia: Fusing the Horizons of Intellectual Disability, Dementia and Palliative Care. Report. Dublin: School of Nursing and Midwifery, Trinity College Dublin.

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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 2001a). 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 Research Ethics Committee and from the Research 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,

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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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