The provision of community nursing support for persons with an intellectual disability and palliative care needs: a descriptive survey

By

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The support needs of community nurses caring for persons with an intellectual disability and palliative/end of life care needs. (23)

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Acknowledgements
Glossary / Abbreviation of terms

ADPHN – Assistant Director of Public Health Nursing

CNM – Clinical Nurse Manager

CNS – Clinical Nurse Specialist

DoHC – Department of Health and Children

GP – General Practitioner

HSE – Health Service Executive

IHF – Irish Hospice Foundation

NHS – National Health Service

NICE - National Institute for Clinical Excellence

PHN – Public Health Nurse

RNID – Registered Nurse Intellectual Disability

UK – United Kingdom

WHO – World Health Organisation
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Forward

On behalf of the research team, I am pleased to introduce this report which presents the findings of a regional evaluation entitled: The provision of community nursing support for persons with an intellectual disability and palliative care needs.

The broadening of the World Health Organisation (2002) position on palliative care, developed to include the provision of palliative care for all persons with a life threatening illness regardless of diagnosis, has resulted in increased numbers of patients and families accessing palliative/end of life care services. It is known that people with an intellectual disability have a disproportionate health burden when compared with the general population and accessing health service can be difficult. In today’s society people with an intellectual disability have largely moved away from a long term residential model of care, and are accessing wider health services. They are entitled to receive equitable care and support from a workforce that recognises all as equal citizens. However, internationally it is acknowledged that there is an inequity of experience for people with an intellectual disability within mainstream health services, and this is not satisfactory. This report provides a snapshot of community nursing practice in an Irish setting of palliative/end of life care for people with an intellectual disability in a health region. The report is a welcome addition to the existing international literature which includes a small number of Irish studies.

I would like to take this opportunity to sincerely thank the respondents for giving of their time to complete the questionnaire and the Irish Hospice Foundation and the University of Limerick for their continued interest and support.

Signature:

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Executive Summary

People with an intellectual disability are known to have a higher prevalence of certain medical conditions and poorer access to health screening than those in the general population. In addition people with an intellectual disability are experiencing increased longevity with changing patterns of morbidity and mortality. As life expectancy increases it follows that more people with an intellectual disability experience prolonged periods of living with a life limiting illness that may or may not be the result of a malignancy. Health care literature recognises that for those with severe intellectual disability there continues to be a high risk of death in childhood. However, with advancing medical knowledge, neonatal technology and care interventions, increasing numbers of this population group are living longer with a life limiting illness. As this phenomenon has gained momentum in more recent years, there is a dearth of knowledge regarding palliative/end of life care needs of people with an intellectual disability. In addition it has been identified that there is limited access to palliative/end of life care services for people with an intellectual disability and consequently fewer referrals are received. With a high proportion of persons with an intellectual disability living in the community there is an increased responsibility for community health services to address the needs of this patient/client group.

The aim of this study was to describe the provision of community nursing support for persons with an intellectual disability and palliative/end of life care needs in one HSE region. This descriptive survey of community based nurses utilised a 26 item self reporting questionnaire comprising of open and closed questions. The questions related to respondents demographic details, referral patterns and demographic details of the patient/client group with an intellectual disability, the support provided to the patient/client group with an intellectual disability and professional support issues.

The broad findings of the study are in keeping with national and international research literature and are as follows:

- Respondents had infrequently cared for persons with an intellectual disability with palliative/end of life care needs.
- Mainly those living at home and who had a mild intellectual disability were referred for palliative/end of life care.
• A collaborative approach between both service providers and family carers was described as essential for effective provision of care.
• Collaborative in-service education utilising workshops/lectures was described by respondents as their preferred method for professional development.

While the findings mirror the published literature in the field, the report reveals the present regional issues pertaining to intellectual disability and palliative/end of life care. In this context, a number of recommendations are made in order to support local service provision and these recommendations may have broader national and international impact.

• Further investigation of referral practices to palliative/end of life care service for individuals with an intellectual disability.
• The development of collaborative/partnership working across traditional boundaries is to be encouraged to become the main mechanism for the way we deliver effective care into the future.
• Recognition of expertise must go beyond the professional practitioner/s and extend to the key family cares who have known the individual patient/client over a sustained period of time.
• Early referral is essential to support advanced care planning thus enabling increased access to services and choices for the individual and family cares.
• Further research in all aspects of care provision and access should continue in order to improve the quality of life and death for persons with an intellectual disability.
Chapter One - Introduction

The modern palliative care movement developed primarily for patients with cancer (Saunders and Baines, 1983). However in the last decade international palliative care policy has developed to include the provision of palliative care for all persons with a life threatening illness regardless of diagnosis. The World Health Organisation (WHO, 2002) defines palliative care as:

"An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment, and treatment of pain and other symptoms – physical, psychosocial and spiritual."

The broadening of the WHO position on palliative care, coupled with major developments in the last decade in the treatment of cancer and non malignant diseases such as cardiovascular, respiratory and neurological conditions, heralds an increase in the numbers of patients accessing palliative care services. In Ireland the Report of the National Advisory Committee on Palliative Care (DoHC, 2001a), outlined the Irish situation in responding to persons with palliative care needs. The committee recommended that palliative care should be structured into three levels (Table 1.1) with the vision that patients would receive palliative care according to their level of need regardless of diagnosis.

<table>
<thead>
<tr>
<th>Table 1.1: Three levels of ascending specialisation of Palliative Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Level 1 – Palliative Care Approach</td>
</tr>
<tr>
<td>• Level 2 – General Palliative Care</td>
</tr>
<tr>
<td>• Level 3 – Specialist Palliative Care</td>
</tr>
</tbody>
</table>

All patients should be able to engage easily with the level of expertise most appropriate to their needs

It has been argued that the word ‘palliative’ is used in a death denying society (Praill, 2000). However Buckley, (2008) suggests that it is more an indication of the evolution of palliative care services that has led to changes in terminology. These changes in terminology have resulted in words such as ‘terminal and terminal care’ that were formally used to indicate the patients last days or weeks of life, removed in
favour of the term ‘end of life care.’ Terminology changes have gained considerable momentum in recent years and in particular since the introduction of End of Life Care Pathways (Ellershaw and Wilkinson, 2003).

In tandem with these developments the Irish population has grown in number and diversity (Drumm, 2006). The Annual Report of The National Intellectual Disability Database (Kelly et al. 2010) highlights, in particular, that people with an intellectual disability are surviving into old age and that they require services appropriate to their age group (Kelly et al. 2010). Ireland is further witness to a change in the demography of persons with an intellectual disability. As a consequence of government policy and legislation, there has been a shift from hospital/institutional care to community care (Doody, 2011), resulting in the traditional institutional model becoming outdated with more persons with an intellectual disability living in the community. In 2009 a total of 26,066 people with an intellectual disability were registered on the National Intellectual Disability Database (NIDD). Of these, 25,556 (98%) were registered as receiving services; 16,742 (64%) were living at home with family/carer and 8,252 (32.3%) were living within full time residential services. These residential services mainly included community group homes and residential centres (Kelly et al. 2010) while 992 individuals (3.8%) lived independently or semi-independently. Descriptions of living arrangements for people with an intellectual disability can cause confusion due to the varying terminologies used locally, nationally and internationally. For the purposes of this research the terminology for living arrangements have been identified as shown in Table 1.2.

<table>
<thead>
<tr>
<th>Accommodation</th>
<th>Supports</th>
</tr>
</thead>
<tbody>
<tr>
<td>Traditional residential setting</td>
<td>Staffed: mainly nursing with access to relevant healthcare professionals</td>
</tr>
<tr>
<td>On campus community residence</td>
<td>Staffed: mainly nursing with access to relevant healthcare professionals</td>
</tr>
<tr>
<td>Living Off campus community group homes</td>
<td>Staffed: mainly social carers with access to relevant healthcare professionals</td>
</tr>
<tr>
<td>Community living (Family)</td>
<td>Family home with access to relevant healthcare professionals</td>
</tr>
<tr>
<td>Community living (Independent)</td>
<td>Independent with access to relevant healthcare professionals</td>
</tr>
</tbody>
</table>
However, while service provision for persons with an intellectual disability has developed over the years moving from a traditional custodial model of care, to a social model that supports independence and community living. There is an apparent trend towards returning persons with an intellectual disability to institutional care settings for palliative/end of life care. This approach is contrary to the principles of normalisation and the social role valorisation outlined by Wolfensberger, (1983). These principles are closely allied to the philosophies of palliative care (Sinclair, 2007) and further identified in the Health Service Executive (HSE) and Irish Hospice Foundation (IHF) joint report ‘Palliative Care for All’ (HSE and IHF, 2008). While this document outlines a model of palliative support for persons with dementia there is minimal reference to the particular challenges confronting persons with an intellectual disability and their carers requiring palliative care. However anecdotal evidence locally suggests that when persons with an intellectual disability have palliative/end of life care needs, such needs are not being met in the community in which the person has settled. In the United Kingdom (UK), Read, (2005) noted that despite emphasis on reducing inequalities in palliative care (National Institute for Clinical Excellence - NICE, 2004) there persists personal, professional and practical misunderstandings which create barriers to palliative care services particularly for marginalised groups such as those individuals with an intellectual disability.

In Ireland the HSE, (2009) palliative care services five year/medium term development plan, identified that current home help and public health nursing capacity is often insufficient to meet the needs of palliative care patients in the community. Given these resource implications within the community nursing system coupled with the knowledge that many palliative care patients/clients with an intellectual disability may be non-cancer patients, such patients/clients may therefore be denied the same or equal access to services/community resources. In addition the HSE Transformation Programme (HSE, 2007) challenges service providers to improve community management of common and disabling illnesses of later life. However with only speculative evidence and minimal research literature further inquiry is required in order to ascertain the current picture. This research into the incidence and experiences of community nurses caring for persons with an intellectual disability and palliative/end of life care needs will add to the growing body of knowledge and serve to inform future research and education strategies in this area.
This chapter introduced the concept of palliative/end of life care and its application to intellectual disability service and service users. With growing numbers of ageing people with an intellectual disability and individuals born with life limiting or severe disabilities living longer due to nursing/medical advances, there is a greater recognition of an increasing demand being placed on both intellectual disability and palliative/end of life care services for this population group. While both palliative/end of life care and intellectual disability services have grown and developed over the years to support patients/clients there is anecdotal evidence locally which suggests that the needs of people with an intellectual disability requiring palliative/end or life care are not being met in the community. Chapter 2 will address the research design, chapter 3 addresses the findings of the survey highlighting the referring patterns, reasons for referral and supports identified by respondents required to facilitate care provision. Chapter 4 provides a discussion of the findings of this study. Chapter 5 highlights the conclusions drawn from the study and chapter 6 outlines recommendations based on the study findings for service provision and education.
Chapter Two - Methodology

Introduction
Chapter two commences with a presentation of the aim and objectives of the study to describe the provision of community nursing support for persons with an intellectual disability and palliative/end of life care needs. The sample group including inclusion/exclusion criteria and access is identified. An account of the research design utilising a descriptive survey (26 item questionnaire) and ethical approval is provided. Reliability and validity is outlined and data analysis explained with limitations identified.

Aim of the Study
The aim of the study was to describe the provision of community nursing support for persons with an intellectual disability and palliative/end of life care needs in one HSE region.

Objectives of the Study
The aim of the research will be achieved through the following research objectives within the study area:

1. To identify the numbers of people with an intellectual disability and palliative/end of life care needs accessing community nursing services during the previous 3 years.
2. To identify the referral patterns for palliative/end of life care for patients/clients with intellectual disability.
3. To identify and describe the reasons for referral to palliative/end of life care services.
4. To identify and describe the factors that facilitate/hinder provision of care for persons with an intellectual disability and palliative/end of life care needs.
5. To identify and describe the support needs of community nurses caring for persons with an intellectual disability and palliative/end of life care needs.

Sample
The sample consisted of Public Health Nurses (PHN), Community Nurses (HSE), Practice Nurses, and Hospice at Home Palliative Care Nurses, currently working in
the HSE West region (Ireland). To assist in identifying the potential respondents’ inclusion/exclusion criteria were developed as follows:

**Inclusion criteria**
- Currently working in the HSE West region.
- Currently practicing in one of the following services: Public Health Nursing; Practice Nursing; Hospice Home Care/Community Palliative Care Nursing; Hospice at Home Nursing.

**Exclusion criteria**
- Non nursing grades working in a community setting.
- Registered nurses working in the community on long term leave.

A sample of n=290 nurses in the HSE West region was identified, of which 94 (32%) respondents returned the completed questionnaire.

**Access**
On receipt of ethical approval from the University of Limerick Research Ethics Committee, access to the sample was gained through the relevant Directors of Nursing/Public Health Nursing and Services. A research pack containing an invitation letter, information sheet, questionnaire and a stamped addressed envelope was distributed to each potential respondent. Consent was implied by respondents returning a completed questionnaire.

**Research Design**
A descriptive survey utilising a self reporting questionnaire was utilised to achieve the research objectives. The 26 item questionnaire which comprised of open and closed questions was developed by the researcher specifically for this survey and validated by an expert panel. This method of data collection was chosen as it is user friendly for respondents and has the advantage of being coded quickly for usage with computer analysis packages (Bryman, 2004; Parahoo, 2006). In order to enhance reliability and
validity the researchers consulted with the local statistical consultancy unit within the researchers’ university.

The questionnaire comprised of four sections. Section one related to demographic details, such as age category, practice area, position held and years experience. Section two identified the referral pattern and demographic details of the patient/client group with an intellectual disability. Section three identified the support provided to the patient/client group with an intellectual disability and section four identified professional support issues.

**Reliability/validity**
Reliability and validity of the instrument was addressed by a pilot study and statistical testing of the instrument itself. Internal validity was tested by two individuals with experience of designing questionnaires and quantitative research. A sufficient degree of face validity was indicated as there was agreement that the items focused on the constructs under investigation. The instrument was piloted with nurses not associated with this inquiry to determine if the instrument was clear and unambiguous (Coughlan et al. 2007). Following this, only minor changes to the wording of some of the questions were necessary.

**Data analysis**
Data was coded and inputted into SPSS (statistical analysis software) version 18. The data set was checked and cleaned against the original data so that missing values or errors in inputting were identified and rectified. Descriptive analysis was conducted to describe frequencies and to identify patterns of the respondents which are reported as statistical summaries. In addition thematic analysis was used to identify the main themes emerging from the responses to the open ended questions.

**Limitations**
Generalisations of findings are limited due to the small sample size, and that the sample was selected from one geographical HSE region. However little research has been conducted on palliative/end of life care provision for persons with an intellectual
disability within Ireland and this study adds to a growing picture of knowledge that is emerging across HSE regions.

**Conclusion**
This chapter provided an overview of the research approach taken by the researchers to achieve the aim and objectives of this study. The sample was identified with reliability/validity and limitations of the study addressed. Data analyses were conducted through SPSS statistical software and are presented in chapter three.
Chapter Three - Findings

Introduction
The findings of this study identify the number of people with an intellectual disability and palliative/end of life care needs reported as accessing community nursing services during the previous 3 years. Within the findings the referring patterns and reasons for referral were identified together with the supports required by the respondents to facilitate palliative/end of life care provision. Findings presented are based on the responses to the questions and missing data was omitted for the presentation of the findings.

Demographic Details
Of the respondents (n=94), 32.1% (n=27) were Staff Nurses; 16.7% (n=14) Clinical Nurse Specialists (CNS’s); 6% (n=5) Clinical Nurse Managers (CNM); 26.2% (n=22) Public Health Nurses (PHN’s); 19% (n=16) Assistant Director of Public Health Nursing (ADPHN). Table 3.1 identifies the range and numbers of clinical grades and position held.

<table>
<thead>
<tr>
<th>Current Position</th>
<th>Staff Nurse</th>
<th>Nurse Specialist</th>
<th>Nurse Managers</th>
<th>Public Health Nurse</th>
<th>Assistant Director of Public Health Nursing</th>
<th>Did not Respond</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public Health Nurse</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>21</td>
<td>12</td>
<td>0</td>
<td>36</td>
</tr>
<tr>
<td>Community Registered Nurse</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Practice Nurse</td>
<td>19</td>
<td>6</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>30</td>
</tr>
<tr>
<td>Hospice at Home Nurse</td>
<td>0</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Hospice Home Care/Community Palliative Care Nurse</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Assistant Director of Public Health Nursing</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Did not Respond</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>27</td>
<td>14</td>
<td>5</td>
<td>22</td>
<td>16</td>
<td>10</td>
<td>94</td>
</tr>
</tbody>
</table>

Across all nursing disciplines there was evidence of considerable nursing experience. Those nurses with 1-5 years experience were the largest group at 35.5% (n=33)
followed by nurses with 6-10 years 26.9% (n=25), 16-20 years 14% (n=13) and 11-15 years and 20+ years both 11.8% (n=11).

Respondents were evenly distributed between rural and urban centres with 43.5% in rural and 41.3% in urban areas with the remaining 15.2% covering both rural and urban areas. From the total respondents surveyed only one respondent held a Registered Nurse Intellectual Disability (RNID) qualification however 80.9% of the sample had undertaken additional education in relevant or specialist areas. 25% held a nursing degree, 45.7% post graduate diploma and 6.5% MSc.

**Referral patterns of patients/clients.**

Of the respondents only 35.1% (n=33) had cared for a person with intellectual disability and palliative care/end of life care needs in the last three years. Of the 61 respondents who had not cared for a person with intellectual disability several explanations were given for this outlined in Table 3.2.

<table>
<thead>
<tr>
<th>Reason (more than one reason was permitted)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No such referral has been made to your team</td>
<td>70.5% (n=43)</td>
</tr>
<tr>
<td>There is a nurse in the team with specific skills and experience in palliative care and caring for persons with an intellectual disability and the patients/clients are referred to him/her</td>
<td>1.6% (n=1)</td>
</tr>
<tr>
<td>You do not consider that you possess the necessary skills and experience to support a person with an intellectual disability and palliative/end of life care needs</td>
<td>13.1% (n=8)</td>
</tr>
<tr>
<td>Other (The person was living in a care home n=1, the GP did house calls n=1, Manager role and no direct care/caseload n=5, person went back to intellectual disability service n=3, don’t take intellectual disability referrals n=2)</td>
<td>19.7% (n=12)</td>
</tr>
</tbody>
</table>

In the past three years, a total of 85 referrals were received by the 33 nurses, 72.7% (n=24) of which reported having up to two cases, 18.2% (n=6) having three to five cases and 9.1% (n=3) having over nine cases. The majority of patients/clients were living at home with their family 61.2% (n=52). A further 23.5% (n=20) were living in community group homes, 8.2% (n=7) living within intellectual disability services and 7.1% (n=6) either living alone (n=2), in a high support unit (n=1) or a nursing home (n=2).

Referrals were received from General Practitioners (GP) 37.7% (n=32), 23.5% (n=20) from intellectual disability services (residential and community services), 15.3%
(n=13) from hospital consultants and 23.5% (n=20) from a range of services such as (hospital referral, combined palliative care team and general practice, mental health – high support unit, children’s hospital, family member, Jack and Jill agency). Within the GP referral pattern a ratio of 2:1 occurred between rural versus urban referrals. The reasons for referral varied and respondents reported a wide range of reasons which were collated and are presented in Table 3.3.

<table>
<thead>
<tr>
<th>Table 3.3: Reasons for referrals</th>
<th>Examples provided</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Reason for referral</strong></td>
<td><strong>Examples provided</strong></td>
</tr>
</tbody>
</table>
| Support | To provide information and support to the family  
To support and advise staff  
To establish and coordinate services  
To assist in setting up a twilight nursing service in the home |
| Nursing | Care provision and symptom management  
Consulting and referrals within the team  
Nursing advice – pressure relief and skin care  
Assessment of client  
Diet and nutrition management |
| End of life care | Providing nursing care in the home and supporting patient/client/family choice  
Providing palliative care  
Hospital /hospice referral  
General management of care at end of life |

**Demographic profile of patient/client group**
The age profile of the patient/clients referred is identified in Figure 3.1; with the 40-79 age grouping reported the highest frequency. In addition 68.2% (n=58) of clients referred were in the mild to moderate ranges of disability, while 28.2% (n=24) were within the severe range and 3.6% (n=3) had a profound disability.
Support provided identified by respondents
Respondents reported a range of services provided to support the patient/client. Included in the range of supports was the liaison aspect of their role with multiple team members and agencies e.g. dietician, physiotherapists, general practitioners, pharmacists, day services, speech and language therapist, palliative care team, disability services, Enable Ireland, Jack and Jill, home help service, social welfare, acute hospital, private nursing agency and early intervention services. Figure 3.2 identifies the range of supports provided by respondents.

**FIGURE 3.2: TYPE OF SUPPORT PROVIDED**

Of the referrals received 71.8% (n=61) of patients/clients remained within their home and received support until death. 10.6% (n=9) were admitted for inpatient care in hospice, 10.6% (n=9) were referred back to a residential services for people with intellectual disability service for care provision and 7% (n=6) were admitted to a nursing home. Respondents reported a number of factors that they considered facilitated the care giving process such as; family support, teamwork, professional attributes and skills, previous experience of intellectual disability, knowing the patient/client and supportive professional carers within the intellectual disability services. In addition respondents noted factors that hindered the care giving process such as; lack of education, lack of understanding, lack of confidence, communication skills and lack of resources. Table 3.4 identifies the range of factors identified as
facilitating or hindering the nurse in the care giving process for people with an intellectual disability requiring palliative care/end of life care.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Facilitating care giving</th>
<th>Hinders care giving</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family involvement and support</td>
<td>Family cooperation and understanding. Recognition that the family know the person best. The openness of the family to develop a working relationship with healthcare professional.</td>
<td>Lack of cooperation from the family member/s. Uncertainty causing over protective family member/s.</td>
</tr>
<tr>
<td>Previous experience of intellectual disability</td>
<td>Past experience and care episodes of working with people with intellectual disability and their family/s. Development of understanding and skills (non-verbal, observational).</td>
<td>Limited education. Lack of understanding and lack knowledge of intellectual disability (specific conditions).</td>
</tr>
<tr>
<td>Teamwork and collaboration</td>
<td>Support for team members and colleagues. Collaboration, co-ordination and co-operation between all care providers. Shared responsibility.</td>
<td>Absence of critical team members. Decision making processes within organisations and family/s.</td>
</tr>
<tr>
<td>Supportive professional carers in intellectual disability services</td>
<td>Recognition and acceptance of the need for palliative care support within the intellectual disability service. Willingness of intellectual disability staff to share their knowledge and skill to support palliative care service.</td>
<td>Delay in recognition of transition to end of life. Delay in referral to palliative services for end of life care.</td>
</tr>
<tr>
<td>Personal attributes</td>
<td>Knowledge of services available and access that service. Humanistic approach - listening, communicating, advising, kindness, awareness, honesty, caring, understanding, sincerity.</td>
<td>Fear due to lack of knowledge, education and experience. Lack of confidence in communicating with a person with intellectual disability.</td>
</tr>
<tr>
<td>Knowing the person</td>
<td>Recognising resources - long term carers of the patient/client. Building a relationship and sharing the journey. Building trust of the client and the family. Early referral and advance planning.</td>
<td>Poor referral information. Delayed referral and lack of advanced planning. Interpreting communication differences of people with intellectual disability.</td>
</tr>
</tbody>
</table>

**Professional Support**

In relation to the educational support required to facilitate caring for people with an intellectual disability and palliative/end of life care needs. 2.1% (n=2) of respondents reported not having any educational need at present however 87.2% (n=82) of respondents reported requiring educational support in developing understanding and communicating skills for working with persons with an intellectual disability. Additionally 64.9% (n=61) of respondents requested palliative care education and 76.6% (n=72) of respondents required education regarding the specific health needs of persons with an intellectual disability. The use of sign language was specifically identified by 3.2% (n=3) as a tool that would effectively support nurses in caring for the person with an intellectual disability and palliative care/end of life care needs.
Respondents identified their preferred educational delivery format and mode of educational delivery as in-service education with lectures/workshops scoring highest as outlined in Table 3.5.

<table>
<thead>
<tr>
<th>Educational delivery format</th>
<th>Mode of delivery</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-service education</td>
<td>74.5%, n=70</td>
</tr>
<tr>
<td>Workshops</td>
<td>64.9%, n=61</td>
</tr>
<tr>
<td>University module</td>
<td>47.9%, n=45</td>
</tr>
<tr>
<td>Conference/seminar</td>
<td>17%, n=16</td>
</tr>
<tr>
<td>Distance learning</td>
<td>3.2%, n=3</td>
</tr>
<tr>
<td>University programmes</td>
<td>2.1%, n=2</td>
</tr>
<tr>
<td>Lecturer</td>
<td>70.2%, n=66</td>
</tr>
<tr>
<td>Workshops</td>
<td>70.2%, n=66</td>
</tr>
<tr>
<td>Distance learning</td>
<td>11.7%, n=11</td>
</tr>
<tr>
<td>Blended learning</td>
<td>9.6%, n=9</td>
</tr>
<tr>
<td>Online learning</td>
<td>8.5%, n=8</td>
</tr>
<tr>
<td>Journal club</td>
<td>5.3%, n=5</td>
</tr>
</tbody>
</table>

**Supports for role development**

Respondents were invited to suggest how they could develop their role to support persons living in the community with an intellectual disability and palliative care/end of life care needs. Qualitative responses offered numerous suggestions as to how an individual’s role may be developed to support persons with an intellectual disability and palliative care/end of life care needs in the community. Through content analysis responses were grouped and condensed to formulate themes, the three themes identified comprised of Education; Communication and Collaboration; Access and availability of resources. While the questionnaire surveyed the supports that would facilitate and hinder the nurse in caring for a patient/client with an intellectual disability with palliative/end of life care needs, the open ended questions captured respondents’ opinions which may have been overlooked or unknown to the researchers in the construction of the questionnaire. While similarities to questionnaire responses were noted new information was gathered and the following sections present the qualitative data under the three themes identified.

**Education**

Respondents described several formats through which they might access additional education to support their practice, including in-service and further education in both the areas of intellectual disability and palliative care. Respondents reported lectures, workshops, university modules and distance learning programmes as a means of accessing these educational supports. Respondents further identified that the
education provided should be appropriate to the patient/client needs and practical aspects should be considered in-order to achieve this appropriateness.

“Appropriate education is needed that is tailored to the person with intellectual disability and palliative care, but we need to be supported to develop our own approach to the clients and develop our understanding of their condition and fears and of existing intellectual disability services”

In addition to this education and practice need, respondents identified exposure and experience of caring for a person with an intellectual disability as an important component of role development.

“More exposure to clients with intellectual disability would give a greater understanding of needs and their family’s needs and help use understanding their disability more”

Respondent acknowledged the untapped resource of the local intellectual disability service where they could gain some practical and appropriate skills through exposure and experience.

“We have a wealth of resource here in that there is an intellectual disability sector which we should be tapping into and utilising more”

Respondents also noted a need for education in developing their ability to communicate with persons with an intellectual disability.

“Workshops are needed to develop an understanding of communication methods and interpreting their needs, sign language is a measure that could facilitate caring for a person with an intellectual disability”

Respondents reported they required more frequent in-service education in the area of intellectual disability and palliative/end of life care and to engage in other opportunities in accessing information such as on-line learning.

“We need to use electronic learning; there are internet journals, online advice forums and networks that are updated regularly and easily interpreted providing advice on care”

Respondents who were not from a specialist palliative care background expressed a wish for additional learning opportunities and palliative/end of life care education.
“Staff need training in this field it is a specialist area and can be quite complex, without the education staff can feel incompetent in this area creating concern and fear around medication and end of life care”

**Communication and collaboration**

Effective communication skills were described by respondents as a key factor in supporting patients/clients with an intellectual disability and palliative care/end of life care needs. In addition some respondents also indicated that they considered closer collaboration between both service providers as a strategy to overcome some of the knowledge deficits and education needs they had previously described. Respondents recognised the need to liaise closely with their intellectual disability colleagues in order to facilitate the delivery of care.

“If we develop closer working relationships and good communication processes with those specializing in care of patients/clients with an intellectual disability this would help and support us in our role.”

There was recognition of the need to know the patient/client with intellectual disability or have in depth knowledge of him/her. This was highlighted by several respondents as a significant factor in enabling effective communication in order to understand individual communication pattern, responses and behaviours. Such knowledge could be gained either through direct contact with the patient/client and family/carer or through communication and collaboration with intellectual disability care providers.

“Input and support from intellectual disability carers who know the person with intellectual disability offer increased opportunities to develop our understanding and we should be able to liaise with the intellectual disability CNS.”

For the patient/client with palliative/end of life care needs and an intellectual disability, respondents noted the need for effective team working between the RNID and Palliative Care Services.

“We need a direct link with RNID who know the client well together with the support of palliative care nurses.”
Other respondents suggested that where services were fragmented a more collaborative working pattern could be developed.

“The working together as a team would strengthen the services that sometimes can be fragmented, more communication between all would lead to greater awareness of what is happening to patient/client and be of greater support to all rather than waiting till things go wrong.”

In order to achieve closer collaboration and improved communication, shared documentation was identified as a means of developing interagency communication and supporting the patient/client and family through continuity and consistency of care.

“It would be helpful if client records were available to be utilised in home communications with the family and patient/client and insure they are always at the centre.”

**Access and availability of resources**

Awareness, availability and accessibility to services in the community for persons with an intellectual disability and palliative/end of life care needs were a concern for several respondents. The provision of palliative care to persons with an intellectual disability in the community is reliant on ease of access and availability of resources as and when they are required. Respondents were invited to suggest any additional resources they considered would enhance their role in supporting this client group. Responses largely fell into five categories, physical aids; services including specialised services time; advanced planning and funding (Table 3.6).

Respondents emphasised the importance of a whole family approach and while this can be challenging it can also be a source of support for the nurse.

“Communication is often difficult with the patient/client therefore you involve the family during the visit as they can help you as they know the person well, but you need to consider their needs also be they a parent, sibling or other close family members and while you want to support then you have to know is it there need or the patients/clients need they are identifying.”
Table 3.6: Resources required

<table>
<thead>
<tr>
<th>Resource required</th>
<th>Respondents specified examples</th>
</tr>
</thead>
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| Physical aids          | • Greater availability of physical aids  
                          • Greater availability of equipment  
                          • Wheelchair access to surgery  
                          • Wheelchair aids |
| Services/Specialised services | • Development of home care support  
                          • Access to healthcare professionals  
                          • Early intervention  
                          • Easy access to acute hospital and reduced waiting times  
                          • Geographical location of respite services that are accessible  
                          • GP being more informed of services  
                          • 24hour services to provide quality home nursing  
                          • Extend community care services to all family members  
                          • Access to specialist/expert palliative care services  
                          • Community nursing services with nursing resources to support people who need end of life care  
                          • Additional allocation of palliative care beds locally  
                          • Availability of night nurses with experience in intellectual disability nursing for patients/clients at home  
                          • CNS for intellectual disability / palliative care /end of life care.  |
| Time                   | • More time allocated for visits  
                          • More time for implement care planning  
                          • Time for evaluation |
| Advanced care planning | • Discharge planning  
                          • Early referral {to palliative care service}  
                          • More information on patients/clients treatment/prognosis  
                          • Knowledge about social history of family  
                          • PHN to visit the patient/client in hospital prior to discharge |
| Funding                | • Additional funding for nursing care at home in the end stage of life  
                          • Information of family entitlements  
                          • Respite |

Woven into this tapestry of support is the need to be sensitive to all family member’s needs and wishes. The need for advanced planning through early referral was particularly highlighted to allow more time to build trust and provide effective care for all.

“It is difficult to get to know a family if you are only introduced at the end stage of life and you have to remember the patient/client is your focus so if it is very late you may be into pain management and have very little time to engage, support and build a relationship with the family.”

Conclusion
This chapter presented the findings of the survey identifying both the statistical responses and analysis of the qualitative comments provided by respondents. These
findings highlight service provision and the possibility of future education and training needs identified by respondents. The following chapter discusses the findings and provides a relevant data set of the existing usage, referral patterns and support needs of nurses providing care to this population group.
Chapter Four - Discussion

Introduction

This chapter presents the findings of this study which are discussed in line with the research objectives and in light of relevant literature. Ryan et al. (2010) stress that there is an urgent need to develop a better understanding of the palliative/end of life care needs of people with an intellectual disabilities and their carers in light of the changing demographics of this population. The findings of this study will add to the limited knowledge base available and will highlight the numbers of people with an intellectual disability and palliative/end of life care needs accessing community nursing services during the previous 3 years. The referral patterns for palliative/end of life care for patients/clients with an intellectual disability and the reasons for referral to palliative/end of life care services will be discussed. The factors that facilitate/hinder provision of care for persons with an intellectual disability and palliative/end of life care needs will be identified. Finally, the support needs of community nurses caring for persons with an intellectual disability and palliative/end of life care needs will be outlined.

The numbers of people with an intellectual disability and palliative/end of life care needs accessing community nursing services during the previous 3 years.

Within this study a total of 85 persons with an intellectual disability and palliative/end of life care needs accessed community nursing services within the last three years. This figure seems relatively low given that the current population of people with intellectual disability residing in the HSE West region is 6,820 (Kelly et al. 2010). However this figure needs to be considered in the light of dual factors:

- Only 32% (n=94) of the sample population (n=290) responded to the survey.
- Respondents may have provided joint/overlapping care and thus duplication of numbers may have occurred.
Nevertheless the literature recognises that referral rates are often low for this population group (Tuffrey-Wijne et al. 2008). Given there is an acknowledgement that people with an intellectual disability experience poorer health (Cumella and Martin, 2004; Matthews, 2005; Doody et al. 2011) the findings raise issues and concerns regarding access and accessibility of palliative/end of life care services for people with an intellectual disability and may highlight inequalities in service provision which conflict with national strategies/reports (DoHC, 2001b; DoHC and IHF, 2005: HSE, 2007; HSE and IHF, 2008; HSE, 2009, DoHC, 2010).

**Referral patterns for palliative/end of life care for patients/clients with intellectual disability.**

Responses indicate that the majority of patients/clients with an intellectual disability and palliative/end of life care needs were living at home (58.8%) or in a community residence (21.1%). While the classification of living arrangement maybe essential for the purpose of gathering data, statistical comparisons and respondents understanding. The authors would argue that these terms should become redundant as, for the person with an intellectual disability, no matter where that person lives, even if it is in a residential setting; it may become, for them, their home. The authors view takes cognisance of the patient/client’s world view and sit well within the philosophies of care, respect, individuality and inclusion. The argument will be further reinforced if and when recommendations of Report of the Working Group on Congregated Settings (HSE, 2011) are implemented where people with an intellectual disability will move from congregated settings to community service within the coming seven years (HSE, 2011). However, Doody, (2011) cautions that given the current economic downturn and the value for money policy review initiatives 2008-2011, this goal may not be achieved in the near future and a one size fits all approach fails to recognise the differences between groups such as age, type or degree of disability and community living systems (Doody, 2011).

The main sources of referrals identified in the study were from General Practitioners (GPs), intellectual disability services and hospital consultants. Rural GP referrals were reported as much higher than urban referral; the reasons for this were not part of this inquiry and are an area for further research. However overall urban versus rural referrals were similar and comparable to Nicholson and Cooper, (2011) whose study
identifies that living in a rural environment does not create further disadvantage in access as rates were generally similar across urban and rural populations. There was a representation of referrals across all age groupings. Given the range of conditions/associated conditions within intellectual disability coupled with the fact that people with an intellectual disability age earlier (Bittles et al. 2002) it is not surprising that over half of the people with intellectual disability referred for palliative/end of life care were over the age of 40 years. In terms of degree of intellectual disability, the mild to moderate groupings accounted for just over two thirds of the population referred and this would be in line with community living referral patterns. However, given that people with severe to profound disability also have a poorer health trajectory as they age (Krahn et al. 2006; Patja et al. 2001), it is of concern that greater numbers/referrals have not been identified within the severe to profound groupings.

The reasons for referral to palliative/end of life care services.
Respondents indicated several reasons for referral to palliative/end of life care services, mainly highlighting support, nursing interventions and end of life care. Within the supports respondents identifies aspects of providing information to the family, providing advice, coordinating services, and gaining access to services. Such supports are in line with a palliative/end of life approach to care (Faull et al. 2005; Buckley, 2008; Payne et al. 2008) and would be similar to reasons for referral of persons in main stream healthcare. The nursing interventions identified included activities aimed specifically to support persons with an intellectual disability and palliative/end of life care needs covering assessment, on going referral, symptom management, nutritional management and general nursing care. These nursing needs would be in line with care required by palliative care patients/clients who do not have an intellectual disability.

End of life care incorporated providing information and support to enable the patient/client/family to choose the place of care and set up supports to achieve this wish. Lock and Higginson, (2005) observe that achieving the person’s choice relating to their place of death is a useful quality marker of palliative/end of life care outcomes. While it was not the purpose of this study to measure outcomes it is
encouraging that the majority of respondents stressed the importance of patient/client choice in selecting the place for palliative/end of life care.

**The factors that facilitate/hinder provision of care for persons with an intellectual disability and palliative/end of life care needs.**

From the responses received concerning factors that facilitate/hinder provision of care six themes emerged namely family involvement and support, previous experience of intellectual disability, teamwork and collaboration, supportive professional carers in intellectual disability services, personal attributes, and knowing the person. The ability of the healthcare professional to recognise ‘the family know the person best’ and the willingness of both parties to develop a working relationship with the healthcare professional were identified as factors that facilitated the provision of palliative/end of life care. However respondents identified that often family members may be ‘overprotective’ and this factor inhibited/hindered the provision of care for persons with an intellectual disability and palliative/end of life care needs. This finding is in keeping with McCarron et al. (2010) which identified that in order to achieve effective palliative/end of life care it is important to involve families in care planning for their loved one. As healthcare professionals we should be conscious that in palliative/end of life care family members who had a previously ‘limited relationship’ with the person may now be the lead carer and caution may be necessary as such persons may have limited knowledge of the individual (McCarron et al. 2010). This potentially places a greater responsibility on us as healthcare professionals to proactively engage with the family and support them to become part of the care planning process.

Respondents identified that previous experience of caring or working with patients/clients with an intellectual disability as a factor that facilitated care giving for them. This finding concurs with Ryan et al. (2010) when respondents indicated that their experience of working with people with an intellectual disability enhanced their confidence. However in addition the findings of the present study indicate that limited knowledge and experience hindered care giving and/or non provision of care. The
requirement for teamwork and collaboration between all caregivers was identified by respondents as an essential element within the care giving process and is in keeping with the philosophy of palliative/end of life care (Payne et al. 2008). In addition the willingness of intellectual disability staff to share their knowledge and skill with the respondents was significant in supporting respondents deliver appropriate care. Similarly Ryan et al. (2010) highlights that their participants commonly described themselves as being ‘reliant’ or ‘dependant’ on intellectual disability nursing staff. Conversely respondents in the present study also acknowledged the need for palliative/end of life care support within the intellectual disability service and that there needs to be a sharing of responsibility and supports between both services in order to effectively meet the needs of this specific population group. Ryan et al. (2010) noted that the decision making processes within organisations and families together with the absence of critical team members were key areas that hindered the provision of care.

Among a number of personal attributes identified as essential to provide high quality palliative/end of life care for persons with intellectual disability, effective communicational skills, caring, honesty, understanding, sincerity and the ability to advise, identified as essential to the achievement of effective high quality palliative/end of life care for persons with an intellectual disability. On the other hand fear emanating from lack of knowledge, education and experience culminated in a lack of confidence in respondents’ ability to communicate with a person with an intellectual disability. This was a key factor identified by respondents as hindering their willingness and/or ability to deliver palliative/end of life care to a person with an intellectual disability. Within the caring relationship ‘knowing the person’ was expressed by respondents as an essential factor and encapsulates the importance of building the trust of the patient/client and their family. This relationship building is essential in order to facilitate the professional in a ‘sharing of the journey’ (Bailey et al. 2009). It follows therefore that early referral and advanced care planning were also identified as key factors essential to the provision of effective palliative/end of life care for this patient/client population. This is in keeping with Ellershaw et al. (2010) and Quinn and Bailey, (2011) who identify that early referral and advanced care planning facilitate building a relationship, developing trust, anticipating and planning for future needs thus sharing in the patients/clients journey. The absence of early
referral and advanced care planning was described by the study respondents as greatly hindering the delivery of palliative/end of life care.

**The support needs of community nurses caring for persons with an intellectual disability and palliative/end of life care needs.**

Within the findings respondents identified a range of professional supports for their role in supporting people with an intellectual disability and palliative/end of life care needs including education, communication/collaboration and access/availability of resources. Responses reported lectures and workshops as the most preferred format of delivery of information. In-service and/or workshop education were the favoured modes of delivery and this may be reflective of the current constraints on staff with regards to study leave, financial assistance and non replacement of staff for any form of leave. Respondents favoured education tailored specifically to intellectual disability and palliative/end of life care with a cross fertilisation between the specific knowledge base of each professional discipline. Similarly Atkinson et al. (2010) in the UK calls for intellectual disability nurses to break down existing boundaries and recognise the unique role they play and their contribution to health improvements for people with an intellectual disability. This collaborative working situation is necessary given that within each individual practice area there are professionals trained, have specific knowledge and experience, thereby the time has now come for each profession to reflect on and refocus their roles in a manner that supports patients/clients.

Communication and collaboration was identified by respondents as needing to be a two-way-street with information and support flowing in both directions to support the patient/client and their family in a time of need and increased vulnerability. This sharing of information and expertise needs to be integrated at a strategic and practical level between service providers and healthcare professionals working directly with the patient/client and family in sharing care pathways (Ellershaw et al. 2010). The challenge of inclusion and the provision of an inclusive service requires healthcare providers to move towards positive collaborative working within and across services. Utilising a collaborative approach to care would reduce/prevent fragmented service provision and emphasise the importance of a team approach where all are equal.
contributing members of the team. This type of approach may facilitate greater engagement/involvement by the client and their family. Though intellectual disability and palliative/end of life care services differ in a number of ways the challenge of supporting the person with an intellectual disability and their family is a shared goal. A clear starting point for both parties to actively engage in a partnership approach to care provision would be to recognise the unique skills, knowledge and expertise of both disciplines.

In the UK some intellectual disability nurses are now working in hospice care settings (Holmström, 2011), and bring their unique perspective and skill set to influence the care giving skills of nurses positively impacting on people with an intellectual disability with palliative/end of life care. Its time to accept that no one professional group can effectively meet the array of needs for this patient/client group and for this reason collaborative working is an essential requirement (Slevin et al. 2007). Similar to other research, access and availability of resources was highlighted by respondents as an essential support need. Factors included time (Bailey et al. 2009), physical equipment (Ellershaw et al. 2010) and access to specialised services and advanced care planning (Sampson et al. 2011). In order to deliver a seamless quality service care providers must be equipped with the essential tools required for effective delivery of care. Advanced planning offers the opportunity for health care providers to identify future care needs and plan accordingly (NHS, 2010) thereby promoting consistency and continuity of care through a shared understanding of the dynamic and complex needs of this client group.

**Conclusion**

This chapter discusses the finding of the study considering access to palliative/end of life care, referrals patterns and reasons for referral of people with an intellectual disability to palliative/end of life care services in the west region of Ireland. The factors that support and hinder care provision along with the support needs of respondents were identified. Overall this research identified findings consistent with other national and international research literature. Individuals with an intellectual disability and palliative/end of life care needs appear underrepresented in referral patterns described in this study. Individuals with a mild intellectual disability and
living in the family home were most commonly referred for palliative/end of life care services. The main reason for referral was support and nursing intervention. The importance of family involvement, knowledge of the patient/client as an individual and collaborative working were expressed as essential elements of effective care giving for this patient/client population. Among responses relating to education, in-service education provided through lectures and workshops were described as the most favoured strategy for learning.
Chapter Five - Conclusion

The health status of persons with an intellectual disability has been widely reported in the literature (Evenhuis et al. 2001; Mencap, 2004) indicating higher prevalence of certain conditions, poor health screening, unhealthy lifestyles, diagnostic overshadowing and communication problems (Cumella and Martin, 2004; Jenkins, 2005; Matthews, 2005; Doody et al. 2011). Additionally in recent times people with an intellectual disability are experiencing increased longevity and changing patterns of morbidity and mortality (Patja et al. 2000; Tuffrey-Wijne et al. 2007). As life expectancy has increased more people with an intellectual disability now experience prolonged periods of dying not only from cancer but also other life limiting conditions (Tuffrey-Wijne et al. 2007). This is coupled with a high risk of death in childhood particularly for those with severe intellectual disability (Patja et al. 2000). With this increased life expectancy there is a likelihood of prolonged life limiting illnesses similar to the general population. Tuffrey-Wijne, (2003) identified a dearth of knowledge regarding the palliative/end of life care needs of people with an intellectual disability; however since then there has been an increased awareness in the provision of palliative/end of life care for people with an intellectual disability. Nonetheless it has been identified that there is limited access to palliative care services for people with an intellectual disability (Tuffrey-Wijne et al. 2005; McCarron et al. 2011) with fewer referrals to palliative/end of life care services.

As people with an intellectual disability are among the most vulnerable in society (Gaskell and Nightingale, 2010) and a number of report have been published in the UK raising concern regarding healthcare inequalities experienced by people with an intellectual disability as well as abusive practices and poor care delivery (MENCAP, 2004; Healthcare Commission, 2007; MENCAP, 2007). Evidence still suggests that people with an intellectual disability experience barriers to healthcare resulting in avoidable morbidity and premature death (MENCAP, 2004; Michael, 2008). With practitioners often unaware of best practice and therefore unable to identify poor practice (Disabihty Rights Commission, 2006; MENCAP, 2007; Michael, 2008; Marsham, 2009). As far back as 1986 Julia Cumerledge in the UK recommended that each primary health care team should determine how to facilitate access to primary healthcare services for individuals with an intellectual disability (School of Health and
Social Security, 1986). However across primary care services there is recognition of a lack of confidence, communication difficulties, time, and fear issues in relation to healthcare professionals providing care to people with an intellectual disability (Lindsey, 2002).

With a high proportion of persons with an intellectual disability living in the community there is an increased onus of responsibility for community health services to address the needs of this patient/client group (Tuffrey-Wijne et al. 2007). Additionally those in receipt of specialist intellectual disability services will require access to specialist palliative/end of life care services (Tuffrey-Wijne et al. 2007). Raising the question as to how access and delivery of palliative/end of life care services and be improved given the current emphasis on equal access to palliative/end of life care for all including those vulnerable groups such as persons with an intellectual disability. Which is an essential consideration as early access to services and clinical intervention are recognised to increase life expectancy (Bittles et al. 2007).

As in other studies respondents had infrequently cared for persons with an intellectual disability (Ryan et al. 2010), which may be suggestive that few people with an intellectual disability have access to palliative/end of life care services. However this needs to be considered in light of the fact that referral rates are often low (Tuffrey-Wijne et al. 2008) and intellectual disability services may act as gatekeepers to other services, such practice is in general stemming from welfare concerns for the individual leaving the safety of intellectual disability service (Brown et al. 2002). Insufficient engagement with either the palliative/end of life care providers or the intellectual disability services may cause undue stress with poor pain management and little attention to the spiritual needs (McCarron et al. 2011).

As many healthcare professionals consider themselves as inadequately trained and articulate a knowledge deficit and a lack of confidence concerning their ability to care for people with an intellectual disability (Ryan et al. 2010), a partnership working approach would be regarded as a positive step in providing access for all (NICE, 2004; HSE and IHF, 2008). This would involve palliative/end of life care and intellectual disability services to work effectively together to provide high quality care
to patients/clients. However it has been recognised that while collaborative working creates opportunities for cooperation and service improvement it also raises the potential for significant clashes of professional interest and organisational culture (Holtom, 2001). Therefore there needs to be further education for both staff groups (intellectual disability and palliative/end of life care) and collaborative training initiatives between both service providers in order to improve collaborative working and understanding. The intellectual disability nurses could deliver education, support, advice and consultancy to primary and acute secondary healthcare providers, thereby enhancing their ability to work with people with an intellectual disability and promote more inclusive services (Atkinson et al. 2010). The palliative/end of life care nurses could deliver education, support, advice and consultancy to intellectual disability nurses/services regarding palliative care, pain and symptom management and bereavement support. Figure 5.1 identifies the cross-fertilisation of knowledge, skill, experience and expertise that could occur within a collaborative working and education environment. Utilising the strengths of each profession would enhance the overall care and service received by each patient/client and family and develop a team approach to service provision across service providers.

**Figure 5.1: Transferable knowledge, skill, experience and expertise**

Education and support and are essential to the development of palliative/end of life care for persons with an intellectual disability, and a collaborative working
environment will provide local advice and support. However more formal education and release of staff will also be necessary. This education needs to be accessible and provided in a manner that is appropriate to what practitioners want and in a format that they desire.
Chapter Six - Recommendations

This is a small scale study in one geographical location in Ireland and recommendations are offered based on the data acquired in this study.

Given the concerns regarding equal access to health services for individuals with an intellectual disability, the move away from congregated settings, and the focus in assisting the person to remain within the family home, there is a need for further investigation of referral practices to palliative/end of life care service for individuals with an intellectual disability.

In light of findings which suggest that individuals with mild intellectual disability are disproportional representation within the referrals structure, due cognisance should be afforded to the patients/clients within the other categories of intellectual disability.

Referrals by rural GP were reported as much higher than urban referral; the reasons for this were not part of this inquiry and are an area for further inquiry.

Due to the unique skill set within each discipline of palliative/end of life care and intellectual disability, collaborative/partnership working across traditional boundaries is to be encouraged and developed to become the main mechanism for the way we deliver effective care into the future.

Recognition of expertise must go beyond the professional practitioner and extend to the key family cares who have known the individual patient/client over a sustained period of time.

Through advanced care planning and collaborative working individual care needs can be anticipated thus enabling greater access to services and choices for the patient/client and family cares.

To assist and support collaborative/partnership working, opportunities for joint education and interaction of skill sets should be developed. This may be achieved
through the delivery of joint workshops and in-service education. In this way opportunities to learn from each other can be captured and fostered through collaboration between both practitioners and educational facilitators.

With the move to primary care in Ireland and a focus on the health needs of people with an intellectual disability, it is inevitable that healthcare professionals will have increased contact this patient/client population therefore the necessity for further research in all aspects of care provision and access will continue in order to improve the quality of life and death for persons with an intellectual disability.
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The University of Limerick, Department of Nursing and Midwifery.

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