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| Title                       | Specialist palliative care professionals' views on access to their services for people with dementia                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| Authors                     | Cronin, Lisa;O'Shea, Emma;Fox, Siobhán                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
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Ms Lisa Cronin\*, Centre for Gerontology and Rehabilitation, School of Medicine, University College Cork, Ireland.

Dr Emma O'Shea, Centre for Gerontology and Rehabilitation, School of Medicine, University College Cork, Ireland.

Dr Siobhán Fox, Centre for Gerontology and Rehabilitation, School of Medicine, University College Cork, Ireland.

\*Corresponding author, address: 2, The Avenue, Priory Court, Watergrasshill, Cork T56 YX61,

[email99020882@umail.ucc.ie](mailto:email99020882@umail.ucc.ie)

**Title:** Specialist Palliative Care Professionals' views on access to their services for people with dementia

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### **Abstract**

**Background:** In Ireland and around the world populations are ageing, contributing to an increase in the number of people living with dementia. Dementia is a life-limiting condition and evidence suggests that people with dementia would benefit from specialist palliative care (SPC) input. There is ongoing investigation into how people with dementia access the services they need at the right time.

**Aim:** The aim of this study was to explore how people with dementia access SPC services in a region in the Mid-West of Ireland, from the perspectives of key healthcare workers linked to the service.

**Methods:** Semi-structured qualitative interviews (n=10) were conducted with healthcare professionals involved in the referral process of accessing SPC input, including consultants, specialist registrars, clinical nurse managers and an assistant director of nursing. The data was analysed using thematic analysis.

**Results:** Overall four main themes were identified from the data: Capacity for providing SPC services to people with dementia; Appropriate Referrals and Recognising Need; Inadequate volume and inequitable geographical distribution of dementia services; Service integration and inter-professional collaboration. The underlying premise was the disease trajectory of dementia and a changing model of care.

**Conclusion:** A needs assessment rather than a diagnosis is the referral process that underpins access to SPC for people with dementia. However, there is little consensus on 'grey' areas within this process and some SPC professionals may be less comfortable with treating patients with dementia. A different model of care is needed.

Keywords: Specialist palliative care, dementia, needs assessment, referral

## Introduction

Dementia is an umbrella term for a range of conditions that affect memory, thinking, language, and the ability to carry out activities of daily living. In Ireland, over 64,000 people are living with dementia with 11,000 new cases every year<sup>1</sup>. This is forecasted to be more than double in the next 25 years to over 150,000 in Ireland<sup>2</sup> and over 14,298,671 in Europe by 2050.

Palliative care is the active, total care of patients whose disease is not responsive to curative treatment<sup>3</sup>. Dementia is not a normal part of ageing; it is an incurable, life-limiting illness. It is now widely accepted that a palliative care approach is applicable for people with dementia, and results in better outcomes for this vulnerable population and their families<sup>4</sup>. However, despite mounting empirical evidence and numerous policy reports highlighting the need, only a minority of European countries currently have sufficiently available palliative care to their citizens with dementia<sup>5</sup>. This is especially concerning considering that the need for palliative care is expected to increase further from 25-47% by 2040, and dementia is the main driver of this increasing need<sup>6</sup>. One reason for inadequate access to specialist palliative care (SPC) services for people with dementia is that the disease

trajectory of dementia is different to other conditions requiring SPC. Dementia can have a gradual decline over many years<sup>7</sup>. Although the course can be long and protracted for some people, for others it can be cut short due to an acute event such as a pneumonia or a fall<sup>7</sup>. An assessment of SPC needs can be carried out at diagnosis, episodes of exacerbation or progression, a significant change in family and/or support systems, a significant change in functional status, at request of patient and/or family and, of course, at end-of-life<sup>8</sup>.

The National Clinical Programme for Palliative Care in Ireland has the aim that “every person with a life-limiting condition can easily access a level of palliative care appropriate to their needs regardless of care setting or diagnosis in order to optimise quality-of-life”<sup>9</sup>. To ensure an equitable provision of limited SPC service capacity, it is helpful to understand the processes around referrals to SPC of people with dementia, including the drivers and the appropriateness of referrals. The research question driving this study was, what are SPC professional’s views on access to their services for people with dementia?

## **Methods**

### **Design**

The study adopted a qualitative approach. Semi-structured interviews with open-ended questions were used due to their ability to explore participant thoughts, feelings and beliefs about a particular topic and to delve deeply into issues of interest<sup>10</sup>.

### **Setting**

This study was conducted in a medium-sized hospice and co-located residential care facility, in the Mid-West of Ireland. The service is a voluntary, not-for-profit organisation, specialising in SPC and older person services. The hospice and the residential care facility share resources but have different management structures. All prospective study participants were employees of this service.

### **Participants**

The target population was healthcare professionals involved in the coordination and/or provision of dementia and palliative care, including those who refer and accept referrals to the hospice inpatient unit. This included SPC healthcare professionals working in the community, the inpatient unit, clinical management, and managers from the residential care facility for older people.

Inclusion criteria were those professionals who refer to the SPC inpatient unit, those who accept the referrals as part of a multi-disciplinary team discussion and healthcare professionals involved in delivering SPC, care of the older person and triaging referrals. General palliative care nurses, healthcare assistants and allied health professionals were excluded due to their lack of involvement in the referral process.

### Recruitment

Participants were recruited using a mixture of purposive sampling and convenience sampling. An invite was sent to recruit all professionals involved in the referral acceptance process and this included consultants, doctors, charge nurses and clinical management.

An invitation e-mail, including details of the study and contact details for the researcher, was sent to all prospective participants meeting the inclusion criteria via their work email addresses. Prospective participants then opted-in to the study by approaching the researcher either in person or contacting them via e-mail.

### Researcher's relationship to participants

The researcher who conducted the interviews worked at the service where this study was conducted, and had a professional relationship with the participants. To maintain rigour and transparency, interviews were standardised; all participants were asked the same questions in the interview in the same format. The researcher was critically self-reflective about their own preconceptions and relationship dynamics<sup>11</sup> and two supervisors experienced in qualitative methodology oversaw this process.

### Data Collection

Data was collected over a three-month period, between March-May 2021. Interviews were conducted either in-person in a private room or via teleconferencing in private office spaces. This was due to Covid-19 restrictions and poor availability of appropriately sized and ventilated rooms. All interviews were audio-recorded. Participants were all informed that the interview was being recorded and how the resulting data would be used.

A total of ten interviews took place (see Table 1 for participant characteristics). The range of the interviews was 13- 40 minutes and the average was 20 minutes 30 seconds.

| <b>Roles</b>                      | <b>N</b> |
|-----------------------------------|----------|
| Clinical Nurse Manager in Hospice | 3        |
| Consultants                       | 2        |
| Specialist Registrars             | 2        |
| Specialist community Nurses       | 1        |
| CNM of residential care facility  | 1        |
| Assistant Director of Nursing     | 1        |

### Data Analysis

Thematic analysis was employed. Thematic analysis 'is a method for identifying, analysing and reporting patterns (themes) within data. It minimally organises and describes your dataset in (rich) detail'<sup>12</sup>. Braun and Clarke's<sup>13</sup> seven stage framework of thematic analysis was followed: 1. Transcription, 2. Reading and familiarisation, 3. Coding, 4. Searching for themes, 5. Reviewing themes, 6. Defining and naming themes, 7. Writing– final analysis.<sup>13</sup> The transcribed data was read and re-read prior to coding, for familiarity. It was then colour-coded into specific themes that were relevant to the research question and organised with memos and brief summaries of what was being said and the potential meaning(s) behind this.

### Ethics

Ethical approval was granted via the Social Research Ethics Committee at University College Cork. The study was also approved locally at the hospice by the head of education and the consultant with remit for research studies. GDPR approval was obtained from the local GDPR commissioner.

## **Results**

Overall four main themes were identified in the dataset: Capacity for providing SPC services to people with dementia; Appropriate Referrals and Recognising Need; Inadequate volume and inequitable geographical distribution of dementia services; Service integration and inter-professional collaboration.

### ***Capacity for providing SPC services to people with dementia.***

Unanimously, participants felt there is an increasingly high demand for non-malignant conditions, accessing this SPC service:

*“Absolutely, we get much more admissions of patients with non-malignant conditions. So, we’re seeing a lot more MND [Motor Neurone Disease]. We’re seeing a lot more Parkinson’s dementia. So, like, we’re definitely seeing a lot more of those conditions. But I think people are becoming more aware that actually palliative care isn’t just about cancer patients, that it’s about patients that have a terminal illness, whether it’s malignant or not.” (Participant 2)*

Participants questioned the current capacity of SPC services. A common premise, was that SPC services typically do not provide the same quality of dementia care as a dementia specific unit. Participants noted that while SPC services do, and should, have a role in caring for people with dementia, those with dementia tend to have complex needs, are often older and have multiple comorbidities.

*“...in our society now, everyone’s got a diagnosis of something. And if you have someone with cognitive impairment, people with dementia [you’re] less able to manage those as actively as you would like.” (Participant 5)*

Some focused on capacity in terms of the infrastructure and resources needed to provide SPC to people with dementia. The interviewees noted that the building, including the

facilities and physical environment are not optimized according to the needs of people with dementia:

*“It’s not a dementia unit only built for patients with dementia. The ward is one long corridor, it’s not what you would look for in a dementia unit.” (Participant 4)*

### ***Appropriate Referrals and Recognising Need***

In the context of greatly increased demand, participants stressed that providing SPC must be appropriate for every referral accepted. Some participants spoke of an approach for “the right care at the right time for the right person”, and that admission is based on a person’s overall needs as opposed to their diagnosis:

*“I think any patient including patients with dementia, if they meet the criteria for admission, we’ll present them to the multi-disciplinary team in addition to community services.”*  
*(Participant 7)*

Participants acknowledge that there are many people with dementia who do require SPC input at a certain point in their life. SPC can assist not only in managing physical symptoms, but can also facilitate important discussions and decisions relating to the patient’s current and future care preferences:

*“...Sometimes with dementia, I suppose our role might be in terms of planning for the future, like for example, ceilings of care, the appropriateness of future hospital admissions, and it might be that specialist palliative care services are part of the discussion of the multi-disciplinary team with the GP, geriatrician, with the patient, if they are able...and with the patient’s families and there can be a role in communicating with regards to realistic prognosis, what could be achieved, what will be the benefit versus burden...” (Participant 6)*

Interviewees expressed that SPC input for dementia patients may be at multiple points in time along the person’s illness trajectory, in response to their changing needs, rather than at one specific point in time. This is different to the traditional model of SPC where involvement was for a defined time, namely for end-of-life care:

*“...So, it might be a dip in and dip out...but it might be that everything that’s needed to be done is done at that visit, and the specialist palliative care team may or may not be involved again, say, if that person deteriorates and starts to die and is having particularly complex symptoms. So, I suppose, it’s not so much an access issue, its more that the model of care might be a little different to best meet these people’s needs.” (Participant 6)*

### ***Inadequate volume and inequitable geographical distribution of dementia services***

Participants recognized one of the reasons for the volume of referrals and some of the inappropriate referrals, may be the limited options available to people with dementia within services in the community. Even if the information is available in the person’s locality, there may not be enough services available and/or available services are not easily accessible to people:

*“...but even community-based services aren’t enough (dementia specific care), and that’s just a reflection of the health service and the community services that we live in. I think they have gotten better, but we do have a long way to go, you know.” (1)*

One participant with previous professional experience outside of Ireland was able to compare and contrast services, adding to the argument of limited dementia specific community services:

*“Yeah, I think there’s a very big geographic variation and it often depends on the strength of the local geriatric service and psychiatry service...And having worked in the UK previously, I would see that our community services are not as well developed, not as well coordinated as the services I would have been familiar with in the NHS. And so, I think particularly the respite side of things is very ad hoc.” (Participant 10)*

On the other hand, if SPC services are not available for people with dementia and their families, it may not have a direct impact on SPC services but can directly impact on people with dementia, adding to the inequality in service provision:

*“If patients don’t ask, they don’t get...If a consultant doesn’t have a lot of knowledge or experience about, or in palliative medicine, then they’re less likely to refer...And it’s down to either a patient’s family member or GP to suggest because we don’t know these patients exist until they are referred.” (Participant 5)*

### ***Service Integration and inter-professional collaboration***

These participants saw the solution to effective palliative care for people with dementia to be service integration and inter-professional collaboration. This was seen to be best for the patient as participants acknowledged one professional or one team cannot be the expert in everything:

*“...The behavioural and psychological symptoms of dementia, I think, there is kind of ongoing discussion, but it may well be that medicine for the elderly doctors or geriatricians are better placed to meet those needs and are more expert in that area rather than specialist palliative care doctors.” (Participant 6)*

Participants maintained that there is always a role for education and upskilling through inter-professional collaboration. Healthcare professionals outside of SPC can have increased confidence and enjoy a level of trust in themselves that they are providing high quality [palliative] care. An interviewee summed this up in a recent positive experience:

*“For the specialist palliative care teams to provide training in nursing homes. With regard to end-of-life care, absolutely, and I think a lot of this is actually being done in the last few years...And I think it is kind of empowering people for the people who are dying without complex symptoms...I do think there is an ongoing role for education and collaborative working there.” (Participant 6)*

### **Discussion**

There is a growing amount of literature to suggest that palliative approaches at end-of-life for people with dementia are effective, yet there are insufficient levels of palliative care services available to people with dementia<sup>14</sup>. Within a changing landscape of SPC service provision, including the upcoming model of palliative care for dementia in Ireland<sup>15,16</sup>; it is important to understand the views of SPC professionals on the increasing volume of referrals for people with dementia to their services<sup>7</sup>.

This study has provided some understanding of the process involved in the facilitation or the barriers that people with dementia can face when referred for SPC input. The disease

trajectory of dementia is long and progressive, with a gradual decline. It is often not well defined and individual patients will die at various stages along their predicted trajectory<sup>7</sup>. SPC professionals in this study identified that there needs to be a changing model of care to meet the needs of different people on different disease trajectories. The typical model of cancer palliative care might not suit people who have a gradual, progressive decline with unpredictable exacerbations<sup>7</sup>. This changing model of care may come in the form of a more intermittent involvement, providing assistance when needs are exacerbated and anticipatory care planning<sup>16</sup>. The importance of working with families and advance decision making was also highlighted<sup>17</sup>. The findings of this study suggest that this has already been in motion for some time given the changing nature of referrals and input from SPC.

SPC professionals agree that there needs to be collaborative working and education to effectively implement this changing model of care. Combining knowledge and expertise from SPC and dementia care can have positive outcomes<sup>4,16,17</sup>. SPC does not need to be involved with every person with a life-limiting illness, it is more of a health care system revision that needs to adapt to integrated working when needed<sup>18</sup>. The findings of this study propose that this integrated working is already happening due to the different disease trajectories and presentations. Perhaps it needs to be better resourced within the wider health care system in Ireland. This also incorporates inequitable services for people with dementia throughout the country. A national population-based study concluded that a larger number of people with advanced dementia can benefit from access to supportive services including skilled palliative care staff<sup>19</sup>. There is a need to develop a dementia specific palliative care pathway or referral guidelines to promote a needs-based palliative care models<sup>19</sup>. This is sharply underlined by the finding of this study that SPC staff feel they are lacking the expertise to effectively treat and manage patients with dementia.

This study concurs with other sources demonstrating the variability in healthcare access and how national standardised formats continue to have 'grey' areas<sup>9,16</sup>. There is no clear distinction to which stages of dementia that SPC applies<sup>16</sup>; although there is a higher tendency to agree it was more applicable in severe dementia<sup>16</sup> and this concurs with the findings of this study. As the disease trajectory is so protracted in dementia, there can be many times that SPC is needed, however these may all not be in one period. Although, there is more focus on the latter stages,<sup>16</sup> it is important to note that a palliative care approach

might be beneficial prior to the advanced stages in life limiting illness other than cancer<sup>18</sup> and a multidisciplinary palliative approach is ideally suited to all people and not confined to those actively dying<sup>18</sup>. This is in agreement with this study with regards to anticipatory care planning and working in partnership with families and colleagues in different areas of expertise.

### **Limitations**

This was a single-centre qualitative study, and the results are therefore not generalisable to the population. However, the study provided insight on the experiences of an SPC team on referrals for people with dementia. Some interviews were conducted online, owing to Covid-19 restrictions, however, efforts were made to increase rapport with participants through small talk preceding the interviews, and a good quality teleconferencing software . The researcher worked with the participants, but a critically reflective approach was adopted to maintain transparency and rigour in data collection and analysis.

### **Conclusion**

There are many factors to consider when managing the referral process for all people with a life limiting condition for access to a SPC service. With new policies and models promoting the access of people with dementia to SPC services, which are often already near capacity, the challenge is to have a standardised format for equity for all. This can be difficult and requires appreciating limitations of, and changing, models of care that are well established, changing work practices, and looking to the health service for a more realistic integrated way of working.

### **References**

1. Dementia in the Media. Alzheimer; no date. [cited 2021 May 23] Available from: [https://alzheimer.ie/creating-change/awareness- raising/dementia-in-the-media/](https://alzheimer.ie/creating-change/awareness-raising/dementia-in-the-media/).
2. Irish National Dementia Strategy 2014. 3276adf5273f4a9aa67e7f3a970d9cb1.pdf; no date. [cited 2021 April 28]. Available from: <https://assets.gov.ie/10870/3276adf5273f4a9aa67e7f3a970d9cb1. pdf>.
3. What We Do – European Association for Palliative Care, EAPC; no date. [cited 2021 June 14] Available from: <https:// www.eapcnet.eu/about-us/what-we-do/>.

4. Ryan T, Gardiner C, Bellamy G, Gott M, Ingleton C. Barriers and facilitators to the receipt of palliative care for people with dementia: The views of medical and nursing staff. *Palliative Medicine* 2012;26(7):879–86. doi:10.1177/0269216311423443.
5. Alzheimer Europe European Dementia Monitor. *Comparing and benchmarking national dementia strategies and policies*. Luxembourg: Rue Dicks; 2020.
6. Etkind SN, Bone AE, Gomes B, Lovell N, Evans CJ, Higginson IJ, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine* 2017;15(1):102.
7. Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. *BMJ* 2005;330(7498):1007–11. doi:10.1136/ bmj.330.7498.1007.
8. Peelo-Kilroe L, Fitzpatrick S. *Palliative care needs assessment guidance*; 2015. p. 13.
9. ncp-palliative-care-model-of-care-24-04-0219.pdf; no date. [cited 2021 June 14] Available from: <https://www.hse.ie/eng/ about/who/cspd/ncps/palliative-care/moc/ncp-palliative-care- model-of-care-24-04-0219.pdf>.
10. De Jonckheere M, Vaughn LM. Semi structured interviewing in primary care research: a balance of relationship and rigour. *Family Medicine and Community Health* 2019;7:e000057. doi: 10.1136/fmch-2018.
11. Polit DF, Beck CT. *Essentials of nursing research: appraising evidence for nursing practice*. Philadelphia (PA): Wolters Kluwer/ Lippincott/Williams & Wilkins Health; 2014.
12. Boyatzis RE. *Transforming qualitative information: thematic analysis and code development*. Sage; 1998.
13. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006;3(2):77–101. doi:10. 1191/1478088706qp063oa.
14. O’Shea ET, O’Shea ES, Irving K. Multiple stakeholders’ perspectives on respite service access for people with dementia and their carers. *The Gerontologist* 2019;59(5):e490–500.
15. Fox S, O’Connor N, Drennan J, Guerin S, Kernohan WG, Murphy A, Timmons S. Components of a community model of dementia palliative care. *Journal of Integrated Care* 2020;28(4):349–64.

16. Hanson E, Hellström A, Sandvide Å, Jackson GA, MacRae R, Waugh A, et al. The extended palliative phase of dementia – An integrative literature review. *Dementia* (basel, Switzerland) 2019;18(1):108–34. doi:10.1177/1471301216659797.
17. Beernaert K, Deliens L, De Vleminck A, Devroey D, Pardon K, Block LVd, et al. Is there a need for early palliative care in patients with life-limiting illnesses? Interview study with patients about experienced care needs from diagnosis onward. *American Journal of Hospice and Palliative Medicine*® 2016;33(5):489–97. doi:10.1177/1049909115577352.
18. Ding J, Cook A, Qin X, Ho SCH, Johnson CE. Palliative care needs and utilization of specialist services for people imminently dying with dementia: a national population-based study. *International Journal of Nursing Studies* 2020;109:103655. doi:10.1016/j.ijnurstu.2020.103655.