

## Generalist Palliative Care Delivered by Community Nurses

Deirdre Carroll<sup>1</sup>, Deirdre Shanagher<sup>2\*</sup> and Marie Lynch<sup>3</sup>

<sup>1</sup>Community Intervention Team, Anam Cara Health Centre, St Canice's Road, Glasnevin, Dublin 11, Ireland

<sup>2</sup>Irish Hospice Foundation, Morrison Chambers, 32 Nassau Street, Dublin 2, Ireland

<sup>3</sup>Irish Hospice Foundation, 32 Nassau Street, Dublin 2, Ireland

\*Corresponding author: Deirdre Shanagher, Development Officer, Irish Hospice Foundation, Morrison Chambers, 32 Nassau Street, Dublin 2, Ireland, Tel: 0035316793188; Fax: 0035316730040; E-mail: [Deirdre.Shanagher@hospicefoundation.ie](mailto:Deirdre.Shanagher@hospicefoundation.ie)

Received date: May 13, 2016; Accepted date: May 20, 2016; Published date: May 27, 2016

Copyright: © 2016 Carroll D, et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

### Abstract

**Background:** Little is known about general nurses providing palliative care in the community. This case outlines the care delivered to a gentleman living at home with COPD by a Community Intervention Team (CIT) working in collaboration with allied health professionals.

**Case presentation:** The care of a gentleman who has expressed a wish to be cared for at home is outlined. His care is managed by a range of professionals to include the GP, public health nurse (PHN), pharmacist and CIT.

**Outcome and follow up:** The CIT deliver physical and psychological care, both of which are indicative of palliative care. The service supports GPs and PHNs and is demonstrated as being a key service that supports the delivery of palliative care in the community. The CIT work as a service to ensure that the gentleman and his family access both primary and specialist services in a co-ordinated and efficient manner.

**Conclusion:** General community nurses provide a palliative approach to care. This case displays that communication and collaboration among team members working in the community are key to the delivery of palliative care. More research is needed to clarify the role of general nurses delivering palliative care in the community.

**Keywords:** Palliative care; Community nursing; Generalist approach

### Introduction

It is widely accepted that palliative care is applicable to all people with a life limiting illness and not just those with a diagnosis of cancer. We also know that two thirds of people in Ireland wish to die at home [1]. This co-occurs with the fact that people are living longer with more illnesses [2] such as COPD which has an uncertain trajectory [3] and will ultimately lead to an increase in the demand placed on palliative care services [2]. This also indicates the necessity for palliative care to be fully integrated into healthcare delivery within every setting to include primary care settings and was advocated for by the World Health Assembly in 2014 [4]. In addition, the Prague Charter for palliative care as a human right presses for worldwide development of policies, and the integration of palliative care into health care systems [5].

At European level the European Association of Palliative Care Taskforce on Primary Palliative Care was formed to scope the extent of and learn about what facilitates and hinders the development of palliative care in the community across Europe [6]. It specifically highlighted that primary care has significant potential to access and deliver palliative care [4]. Within the United Kingdom the End of Life Care strategy sets out a vision for end of life care for people being cared for across all care settings to include the community and residential care settings [7]. This strategy offers guidance for primary care

healthcare workers on the provision of palliative care in the community.

In Ireland the department of health and children describes palliative care as being delivered at three levels of specialisation:

Level one: Palliative care approach. Palliative principles should be appropriately applied by all healthcare professionals.

Level two: General Palliative Care. At an intermediate level, a proportion of patients and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have some additional training and experience in palliative care.

Level three: Specialist Palliative Care. Those services whose core activity is limited to the provision of palliative care [8].

Irish policy acknowledges the provision of palliative care by primary care healthcare workers at levels one and two above noting that GPs and community nurses are the main providers of palliative care that often do not require specialist palliative care input [8]. This is not surprising, given that 90% of care in the last year of a persons life is provided by the primary care team [9]. More recently the palliative care competence framework acknowledges the role of generalist healthcare professionals in providing palliative care at levels one and two above. This framework outlines core competencies that are applicable regardless of setting and acknowledges the role of education when working towards these competencies [10].

The implementation of policy is being delivered by a number of organisations. In 2011 the Irish Hospice Foundation Primary Palliative Care Programme published a report outlining initiatives and recommendations required to support primary care teams in their delivery of palliative care in the community. That report outlined the level of awareness, professional competencies and existing practices within primary care in Ireland [11]. Community based healthcare staff took part in consultation meetings (n=123) and a survey (n=182). Healthcare professionals acknowledged wanting enhanced communication skills, stronger information transfer systems, improved services and role clarity. In particular the nurses expressed needing skills to care for the imminently dying and those with non-cancer diagnoses [11]. Currently the Dignity Care Intervention Pilot Project is underway in Ireland. This project involves implementing a tool that is used by public health nurses to preserve dignity at the end of life and highlights the delivery of palliative care by nurses in the community [12].

Other literature about this topic indicates knowledge, competence and confidence deficits in delivering palliative care [13–15]. However, there is evidence to indicate that palliative care is a core component of the work carried out by the generalist community nurse that is often perceived to be unrecognised by other healthcare professionals [16]. Central to the delivery and quality of palliative care by community nurses is knowledge of patients [17]. It is pointed out that community nurses achieve this by developing strong nurse-patient-carer relationships [18,19]. Small caseloads of people approaching the end of life and unclear models of care for the delivery of palliative care often impact on the delivery of palliative care by community nurses [20]. However, it is highlighted that providing palliative care can be rewarding [21,22]. Crucially what is evident from the literature is that ambiguity exists around the specific input of generalist nurses when delivering palliative care which results in both healthcare professionals and service users being unaware of what supports are available in the community [18]. This is a relatively new area of research and subsequently there is little known about the role of community nurses providing palliative care [13,23]. This instrumental case aims to address this by outlining the role of the CIT in delivering palliative care as an element of community nursing.

The CIT is a nurse led service which provides short term episodes of nursing care for people in their home. The service operates from 8.00 to 22.00 seven days a week [24,25]. The role of the CIT service includes facilitating early discharge of patients from hospital by carrying out activities such as administering home I.V antibiotics and providing episodes of enhanced nursing care working with primary care services such as GPs, Community Care of the Elderly services and Public Health Nurses, thus enabling hospital avoidance where appropriate and in doing so reduce costs to the health service [26]. The CIT nurses have additional skills and training that enable them to provide acute nursing care in the community such as phlebotomy, cannulation, central venous access care and management, administration of I.V and subcutaneous medication including use of syringe drivers. The Health service Executive have committed to extend the coverage of CITs in 2015 [27].

## Case Presentation

A 70 year old gentleman was referred to the CIT with a ten year history of Chronic Obstructive Pulmonary Disease (COPD). He lives at home with his partner and son. The COPD illness had progressed to end stage disease. In that time his mobility and independence had

decreased significantly and he was experiencing exacerbations of his COPD that required administration of intravenous antibiotics from the CIT. When this gentleman was initially visited by the CIT he spoke openly and at length about his diagnosis. He also expressed a preference to be cared for as much as possible at home as he wants to make the most of his limited time with his family.

The initial CIT nursing assessment signalled that this gentleman was at the end stage of his COPD and required support in the form of medical treatment (intravenous antibiotics) for an acute infective exacerbation of his illness. He also required support with his anxiety and information about coping techniques. His partner and son required support in the form of information about the illness, use of equipment and there was a requirement for a source of support outside of normal/office working hours. Upon discussion with the gentleman, his family, the medical team, consultant and CIT with the GP and public health nurse a care plan was put in place by the CIT nurse. It was decided that should there be an acute exacerbation of his COPD this man would need to attend the accident and emergency department to confirm the diagnosis and stabilise his condition. After which he could be discharged home and to the care of the CIT for administration of intravenous antibiotics.

## Treatment

Four exacerbations of COPD were experienced with CIT involvement. As agreed with the medical team and as per the care plan, when this man presented at the accident and emergency department family members contacted the CIT who liaised with on call teams in the hospital. Once the exacerbation was stabilised the gentleman was discharged home. The CIT then sent a letter to the GP, public health nurse and respiratory team informing them of the plan of care.

On each of the four accident and emergency presentations the gentleman was seen by the CIT within 24 hours. Outside of these four occasions the GP and public health nurse also referred to the CIT for extra support that was required outside of normal/office hours and during periods of increasing deterioration in his condition. The gentleman also self-referred on three occasions and these occurred at the weekend. On one weekend occasion he contacted the CIT as his nebuliser was broken and he required an urgent replacement. On the two other occasions he self-referred due to feeling anxious about his condition and feeling unsure about contacting the on-call GP or emergency services.

On one self-referral occasion the gentleman required hospitalisation and on the other two occasions the on-call GP service was contacted and oral medications were prescribed. Daily CIT nurse visits occurred at this time until his condition stabilised. During those visits reassurance was provided to family members and anxiety about the illness addressed. A close relationship was established with this man and the CIT whereby nurses grew to know the man and he grew to know the nurses. His family also became familiar with the CIT members. He expressed that knowing there are nurses a phone call away seven days a week was a comfort and that he felt better able to cope with that support.

On one CIT nurse visit a needs assessment (The Needs Assessment Tool: Progressive Disease [28]) was carried out that identified unaddressed psychological symptoms that were contributing to increased levels of anxiety and breathlessness. At this point the gentleman's mobility and independence had significantly reduced. Upon discussion of the CIT assessment outcome with the GP, a

community palliative care team referral was sent. The CIT also liaised with the public health nurse about applying for a homecare package and a home hospital bed. The community palliative care team reviewed this man and suggested some changes to medication that were implemented by his GP. After this change, the palliative care team advised the GP to contact them again if further specialist palliative care input was required.

## Outcome and Follow Up

Although at present this gentleman's condition continues to deteriorate and challenges remain in determining the trajectory of his end stage non-malignant illness his care needs continue to be met at home by a collaboration of services to include the accident and emergency staff, the hospital consultant and medical team, the GP, GP on-call service, public health nurse and CIT. Generalist palliative care as an element of community nursing has been shown here to include providing relief from suffering through assessment, treatment of physical and psychological problems, respecting choice and responding appropriately to include helping family members to cope and deal with practical issues.

The general nurse working in the community has been displayed as being a key team member that contributes to continuity of care through the delivery of holistic co-ordinated care as part of a team of professionals working across acute and community care settings. The accessibility of the CIT seven days a week is evidently a key factor in the delivery of holistic, person centred palliative care in the community. In this way the primary care service, with support from the CIT and where a CIT is in place, is responsive, co-ordinated and easily accessible by the people that need it.

## Discussion

Generalist palliative care is not clearly defined within the literature or within clinical practice to date. The literature does point out that the delivery of palliative care in the community requires knowledge of patients and strong relationships [17–19]. This case presentation outlines the skills of the CIT along with the communication requirements with the other healthcare team members that enabled the completion of an advance care plan. Also outlined is the acknowledgement to access specialist services when required and the necessity of services being available outside of normal/office working hours.

The delivery of palliative care in the community requires a co-ordinated response across settings and healthcare specific disciplines with the CIT made up of general nurses being only one cog in the wheel of palliative care delivery in the community. The contribution of generalist healthcare workers is acknowledged as having the potential to enhance therapeutic relationships and support a more integrated care delivery system [22]. It is certain that as people live longer with illnesses that have an uncertain trajectory that the demand for generalist palliative care delivered in the community will continue to increase. It is therefore imperative that the role of community nursing to include the CIT in providing this care is acknowledged and emphasised. This case study can contribute to highlighting the role of community nurses in providing generalist palliative care and to the growing body of literature that indicates a positive link between palliative care and an increase in quality of life by those in receipt of it [29]. However, more research is required to fully understand palliative care as an element of community nursing.

## Learning Points

CITs provide generalist palliative care but are one team among others working in primary care that provide generalist palliative care.

The delivery of generalist palliative care requires collaboration and effective communication among healthcare team members both in the acute and primary care setting.

More emphasis about the role of the CIT within community nursing delivering generalist palliative care is required.

More research is required to fully understand the role of community nurses in delivering palliative care.

## Acknowledgements

We would like to acknowledge this gentleman and his family for allowing us to tell his story and to Mary Flanagan who supported this work.

## Conflicts of Interest

The authors declare that there is no conflict of interest regarding the publication of this paper.

## References

1. Murray E (2013) Access to Specialist Palliative Care Services and Place of Death in Ireland. Irish Hospice Foundation.
2. Kane P, Daveson B, Ryan K, McQuillan R, Higginson I, et al. (2015) The need for palliative care in Ireland: a population-based estimate of palliative care using routine mortality data, inclusive of nonmalignant conditions. *J Pain Symptom Manage* 49: 726–733.
3. The Irish Hospice Foundation H (2008) Palliative Care for All Integrating Palliative Care into Disease Management Frameworks. Joint HSE and IHF Report.
4. Murray S, Firth A, Schneider N, Van den Eynden B, Gomez-Batiste X, et al. (2015) Promoting palliative care in the community: Production of the primary palliative care toolkit by the European Association of Palliative Care Taskforce in primary palliative care. *Palliat Med* 29: 101–111.
5. Radburch L, DeLima L, Lohmann D, Gwyther E, Payne S (2013) The Prague Charter: Urging governments to relieve suffering and ensure the right to palliative care. *Palliat Med* 27: 101–102.
6. European Association of Palliative Care (EAPC) (2014) EAPC Taskforce in Primary Palliative Care. EAPC.
7. Germain A, Doyle R, Nolan K, Gambles M, Roberts A, et al. (2015) PA3 Using the lived experience of volunteers to enhance the care of dying patients and their families. *BMJ Support Palliat Care* 5 Suppl 1: A20.
8. Department of Health and Children (2001) Report of the National Advisory Committee on Palliative Care.
9. Tiernan E, O'Connor M, O'Siorain L, Kearney M (2002) A prospective study of preferred versus actual place of death among patients referred to a palliative care home-care service. *Ir Med J* 95: 232–235.
10. Palliative Care Competence Framework Steering Group (2014) Palliative Care Competence Framework. Health Service Executive.
11. Primary Palliative Care in Ireland Identifying improvements in primary care to support the care of those in their last year of life (2011) Irish Hospice Foundation, Health Service Executive and Irish College of General Practitioners.
12. Sonja McIlfratrick, Michael Connolly, Philip Larkin, Bridget Johnston (2015) Implementing a Dignity Care Intervention for individuals with life limiting illness in a community setting in Ireland. EAPC 2015 14th World Congress of the European Association of Palliative Care Building Bridges.

13. Hughes PM, Parker C, Payne S, Ingleton MC, Noble B (2006) Evaluating an education programme in general palliative care for community nurses. *Int J Palliat Nurs* 12: 123-131.
14. Brumley D, Fisher J, Robinson H, Ashby M (2006) Improving access to clinical information in after hours community palliative care. *Aust J Adv Nurs* 24: 27-32.
15. Cruickshank S, Adamson E, Logan J, Brackenridge K (2010) Using syringe drivers in palliative care within a rural, community setting: capturing the whole experience. *Int J Palliat Nurs* 16: 126-132.
16. Burt J, Shipman C, Addington-Hall J, White P (2008) Nursing the dying within a generalist caseload: a focus group study of district nurses. *Int J Nurs Stud* 45: 1470-1478.
17. Walshe C, Caress A, Chew-Graham C, Todd C (2011) Equity, choice or chance? *Community Palliative Care. J Community Nurs* 25: 16-18.
18. O'Brien M, Jack B (2010) Barriers to dying at home: the impact of poor co-ordination of community service provision for patients with cancer. *Health Soc Care Community* 18: 337-345.
19. Tomison G, McDowell JR (2011) Nurses' needs in delivering palliative care for long-term conditions. *Br J Community Nurs* 16: 274-276, 278-81.
20. Shipman C, Gysels M, White P, Worth A, Murray S, et al. (2008) Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups. *Br Med J* 337: a1720.
21. Dunne K, Sullivan K, Kernohan G (2005) Palliative care for patients with cancer: district nurses' experiences. *J Adv Nurs* 50: 372-380.
22. Quill TE, Abernethy AP (2013) Generalist plus specialist palliative care--creating a more sustainable model. *N Engl J Med* 368: 1173-1175.
23. Rose J, Glass N (2006) Nurses and palliation in the community: the current discourse. *Int J Palliat Nurs* 12: 588-594.
24. Cork Community Intervention Team (2006) *EMed Handbook Emergency Medicine Cork Community Intervention Team (CIT). Cork Emergency Medicine.*
25. Health Service Executive (HSE) (2013) *National Rapid Discharge Guidance For Patients Who Wish To Die At Home. Health Service Executive.*
26. Brian Murphy (2014) *Primary Care - Priorities for Future.*
27. Health Service Executive (2015) *Health Service Executive National Service Plan 2015. Health Service Executive (HSE).*
28. Centre for Health Research and Psycho-oncology (2010) *Needs Assessment Tool: Progressive Disease (NAT: PD) User Guide. Centre for Health Research and Psycho-oncology.*
29. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, et al. (2010) Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 363: 733-742.