

# A Community Specialist Palliative Care Service Evaluation: What Input Do Care Homes Need from Specialist Palliative Care?

Dr. Susan Rees<sup>1\*</sup>, Dr. Fiona Rawlinson<sup>2</sup> and Terri Gazi<sup>2</sup>

<sup>1</sup>Department of Community Palliative Care, Whitchurch Hospital, Park Road, Cardiff, United Kingdom

<sup>2</sup>Department of Community Palliative Care, City Hospice, Cardiff, Wales, United Kingdom

## Abstract

**Objectives:** City Hospice is a community specialist palliative care (SPC) team caring for the population of Cardiff. A service evaluation was undertaken to review the scope of SPC input required for residents referred from care homes (residential and nursing homes).

**Methods:** A mixed method evaluation was undertaken for all patients from care homes referred between 1st January 2019 and 31st December 2020. Key themes of the required input from the SPC team were captured, and statistical analysis performed on the dataset.

**Results:** 272 referrals (12% of total referrals) were from care homes during the specified time period, the majority with a non-malignant diagnosis. 81% of residents were deemed to have SPC needs on first assessment. The main SPC needs fell into the following categories: recognition of a deterioration, symptom control, future care planning (FCP), symptom control, and facilitation of communication and supporting care home staff.

**Conclusions:** Community SPC teams have an important role in supporting residents, care home and primary care in delivering high quality palliative care. This role has been amplified in the current constraints placed on health and social care due to the COVID-19 pandemic.

**Keywords:** Nursing home care; Residential home care; Care homes; End of life care; Terminal care; COVID-19; Specialist palliative care; Supportive care

## Introduction

A service evaluation was undertaken to evaluate what input the City Hospice (CH) community SPC team has with care home residents. The aim of the service evaluation was firstly to answer the important question of whether care home residents have true SPC needs and hence require SPC input, or whether their care including end of life care could be managed exclusively by primary care. Secondly, the results of the service evaluation would help target resources depending on the specific (if any) SPC needs. The time period for the evaluation (2019-2020) spanned both pre and post COVID-19 pandemic periods. Ethical approval was not required.

Cardiff is the capital city of Wales, with a population of 372 000 with population demographics atypical of the rest of Wales. 14.2% of the population in Cardiff is over age of 65, which is a smaller proportion of the overall population in comparison with all other local authorities in Wales [1]. 20% of the population of Cardiff consider their ethnicity from a Black Asian or Minority Ethnic group which compares with only 5.6% of people in Wales [2]. Within Cardiff there are 55 registered residential homes, 10 nursing homes, and 13 with dual registration of both residential and nursing facilities. Throughout the article, 'care homes' encompasses both residential and nursing facilities.

CH provides community specialist palliative care (SPC) to the city of Cardiff. City Hospice does not directly have any SPC inpatient beds, but has access to beds provided by another charity. Members of the SPC multidisciplinary team undertake domiciliary visits to care homes, patients' own homes, supported living accommodation and Her Majesty's Prison Cardiff. Staffs work with health care professionals in the wider primary care team, including local District Nursing (DN) services and General Practitioners (GPs) to provide palliative care support to any person with a life limiting illness aged 16 or over. SPC

advice is available to all healthcare professionals (HCP) 24 hours a day across Cardiff. Clinical Nurse Specialists (CNS) work a 7/7 rota, providing specialist advice and face to face review 7 days per week, with 2 CNS working within the Out of Hours service at weekends. City Hospice has continued face to face assessment throughout the COVID-19 pandemic following up to date infection prevention and control measures, including for care home residents.

Referrals for care home residents are received either from the residents GP or the care home directly (permission from the GP with whom the resident is registered is sought before review). A first assessment by a SPC doctor and CNS, the resident, care home staff and any persons who are important to the resident is undertaken. Ongoing clinical review of the resident and support for the care home is provided by a named CNS, either until the resident dies or is discharged from the care of the SPC team.

## Methods

This was a mixed methods evaluation. All referrals for residents in care homes received by CH between 1<sup>st</sup> January 2019 - 31<sup>st</sup> December 2020 were included in the evaluation. The case notes of all residents were reviewed: key themes were generated through the review of all

**\*Corresponding author:** Susan Rees, Department of Community Palliative Care, Whitchurch Hospital, Park Road, Cardiff, Wales, United Kingdom, Tel: 02920 524150, E-mail: Margred.m.capel@wales.nhs.uk

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case notes by 2 Palliative Medicine Consultants. A proforma was designed to capture the key themes outlined in the initial referral or identified during first assessment of all residents of care homes referred to CH during the specified time period. The actions undertaken by the SPC team resulting from the first assessment were also categorised using a separate proforma, including any documentation of future care planning (FCP), including preferred place of care (PPC) and preferred place of death (PPD).

The data was entered into a spreadsheet, including demographic data of residents, and statistical analysis performed.

## Results

12% of all referrals during 2019-2020 came from care homes (n=272); of these 87% (n=236) were from nursing homes and 13% (n=36) from residential homes. 67% of residents had a non-malignant diagnosis, predominantly dementia and/or frailty (Figure 1).

Care home residents represented 18% of all patient deaths known to CH during 2019-2020; 288 nursing home and 30 residential home residents died during this time period (these figures included those care home residents referred to the SPC team prior to 2019 but who died in 2019/2020).

The overall number of referrals to City Hospice increased during the start of the COVID-19 pandemic [3], however referrals from care homes decreased from March 2020 onwards [Figure 1], presumably reflecting care home interpretation of the national guidance to 'limit footfall' and shield the residents of care homes [4], coupled with a reduction in face to face GP reviews of care home residents which would usually instigate a referral. This raises the concern of potentially unmet needs of residents who may have benefited from SPC intervention but were not referred during this period. Evaluation of this impact is outside of the scope of this paper, but is likely to form part of national inquiries into the COVID-19 pandemic.

The average length of time that nursing home residents had SPC involvement was 146 days (median 57 days), with the average length of time for residential home residents being shorter at 49 days (median 23 days). During the timeframe analysed, 36 patients already under SPC were admitted to a care home environment from their own home, and were included in the data analysis.

42 care home residents (15% of those referred: 40 nursing, 2 residential) referred during the time period were not assessed by CH, either dying due to an acute deterioration in the care home before initial assessment or the resident having been admitted to secondary care and dying in hospital. These residents were included in the analysis as telephone advice was provided to the care home or GP to support the care of the resident in 47% of these referrals.

60% of the total referrals were marked 'urgent' by the referrer, necessitating contact by the SPC team with the care home within 48 hours as determined by CH clinical standards. The standard for routine referrals is contact within 5 days.

13% of patients referred from care homes died prior to the initial assessment. CH continued adherence to its clinical standards determined by the local University Health Board for review of urgent (contact within 2 days) and routine referrals (contact within 5 days), including throughout the COVID-19 pandemic.

Analysis of the data found that 81% of residents had SPC needs on first assessment. Figure 2 outlines the key themes determined from referral and first assessment (Figure 2).

The actions undertaken by the SPC team following first assessment were also categorised (Figure 3).

### FCP discussions and decisions:

89% of residents had a decision regarding CPR in place prior to first assessment (recorded in the form of a completed All Wales DNACPR form [5]). Further FCP discussions was undertaken with the resident and/or family, resulting in:

- Preferred place of death (PPD) was established in 94% of residents. For the vast majority of nursing home residents this was the nursing home. For residential home residents, PPD was either the residential home or inpatient hospice.
- Completion of a formal ACP document occurred in 58% of patients, of which 46% were in the form of a treatment escalation guide for those patients who lacked mental capacity for such decisions.

**Organise medication to support symptom control:** In 69% of residents, medication was arranged via the GP to aid current symptom control, or to support an expected further deterioration in the

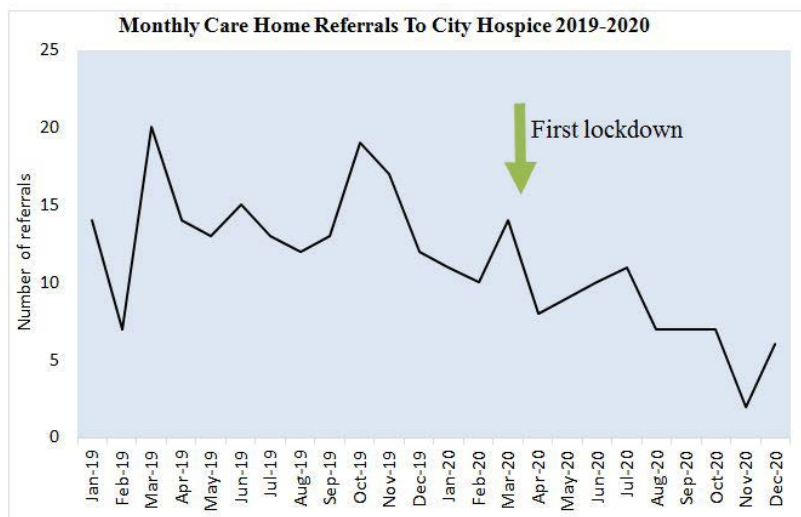


Figure 1: Monthly care home referrals to city hospice 2019-2020.



Figure 2: Key themes identified from referral and first assessment of resident of care home.

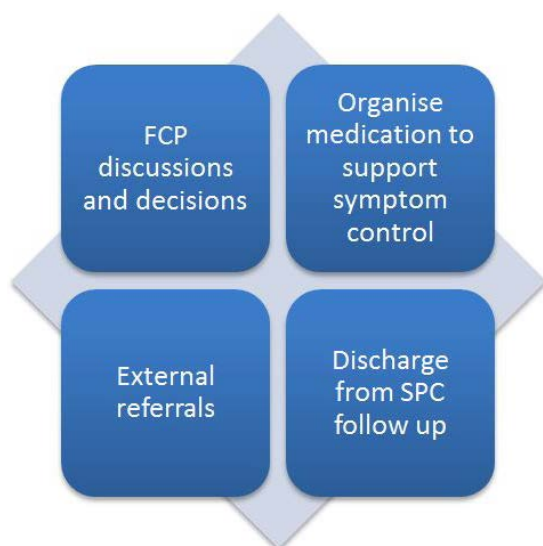


Figure 3: Summary of key actions undertaken following first assessment of care home resident.

individual's health. This included subcutaneous injectable 'anticipatory medications' for managing potential pain, distress, nausea and vomiting and secretions at the end of life.

**External referrals:** In a small proportion (16%) of residents, referrals were made to other HCP e.g. DN's, Speech and Language therapists, dieticians. These referrals were in addition to ongoing SPC support. The most common referral was to the DN service.

**Discharge from SPC follow up:** 5% of residents were discharged from SPC follow up following the initial assessment, as no SPC needs were identified. A further 5% of residents were discharged at subsequent follow up visits as all actions from the initial assessment had been completed, symptoms were well controlled and the residents' health was considered stable at time of discharge.

What happened to residents' after the first assessment?

96% of residents of nursing homes achieved their PPD; this was the care home for the vast majority of residents. 98% of residents had anticipatory medication in place to support their EOLC at the time of death; 42% of residents received medication using a syringe driver. For those residents who did not achieve their PPD, the residents were admitted to secondary care due to acute precipitants including infection

(including suspected COVID-19), haemorrhage and exacerbation of heart failure, where they subsequently died.

88% of residents of residential homes achieved their PPD. All of these individuals had anticipatory medication prescribed; 78% of residents received medications via a syringe driver, with DN support setting up and maintain the syringe driver. For those not achieving PPD, all were admitted to secondary care for management of acute infections, where they subsequently died.

## Discussion

During 2019-2020, referrals to CH from care homes consisted 12% of total referrals, but constituted 18% of overall patient deaths. The proportionally higher death rate amongst the care home residents reflects the increased frailty of this cohort [6]. National statistics concerning life expectancy for residents in nursing care (12 months) and residential care (24 months) highlights that many care home residents (especially nursing home residents) are approaching the end of life, necessitating both generalist and SPC support in the final stages of a resident's life [7-9]. Overall, the majority of patients referred to City Hospice (70%) have a malignant diagnosis, whereas the majority of referrals of residents in care homes have multiple comorbidities and underlying non-cancer diagnosis (67%). These individuals have an ongoing variable physical and/or cognitive decline; statistics suggest that they are more likely to be die and more likely to be admitted to hospital [7, 10, 11].

In line with the frail nature of residential home patients, 81% of care home residents referred to SPC were deemed to have SPC needs on first assessment. Only 5% of residents were discharged following initial assessment, strongly suggesting a role for ongoing SPC support with this cohort of patients. The main input from the CH MDT are supporting FCP and symptom control, facilitating planning for a deterioration and subsequent EOLC for the resident. These themes are in line with the Department of Health and Social Care 'End of Life Care Strategy' [12].

A high proportion (89%) of residents had a DNACPR decision (in the form of a completed All Wales DNACPR form) made prior to referral to SPC. However, DNACPR decisions are only one facet of holistic FCP discussions [13]. The majority of residents didn't have any record of other components of FCP in place e.g. clarifying PPD or completion of an ACP document. Facilitation of FCP decisions was a key component of the CH input, with PPD being established in 94% of residents and completion of an ACP document in 58%. Such discussions

often take more than 1 visit or phone call in order to adequately allow patients and family member's time to consider the relevant issues before formalising FCP, which can be resource intensive. However, FCP decisions are shown to reduce the time spent in hospital and death in hospital, as well as improve the perceived quality of EOLC [14-16]. Involvement of SPC teams has been recognised to reduce admissions to hospital and correlate with patients achieving their preference for location of death [14, 15]. This is reflected in this service evaluation, with a high proportion achieving their PPD (96% of nursing home residents and 88% if residential home residents).

As discussed, a significant proportion (69%) of patients required medication on the advice of the SPC team at the time of first assessment. This suggests a benefit from SPC input not only in FCP but in a fundamental goal of palliative care: the management of physical symptoms [17]. At the time of death, the vast majority of care home residents had anticipatory medications in place (98% of nursing home and 100% of residential residents). These medications were delivered via a syringe driver in 42% of nursing home and 78% of residential home residents. This suggests that pre-emptively providing these medications for use at the end of life was appropriate, and aided in good symptom control for these residents. A proportion of the residents who required medication prescriptions facilitated by the SPC at first assessment had been discharged to care homes from hospital for EOLC, highlighting the importance in not assuming that all required symptom control medications has been put in place at the time of discharge, and to undertake a holistic assessment of needs [18].

13% of patients referred from care homes died prior to the initial assessment. Despite adherence to clinical standards in terms of speed of review, a cohort of residents in whom a rapid deterioration in health, coupled with a possible lack of recognition by care home staff or other HCP that a resident is approaching EOL resulted in a lack of face to face SPC review prior to death. Where a rapid decline was identified at the time of referral, verbal advice regarding FCP and symptom control was provided to the HCP whilst awaiting face to face initial assessment. Interestingly, none of the individuals in this 'never met' cohort were admitted to hospital for EOLC, suggesting this advice may aid in preventing inappropriate admissions at the end of life.

## Conclusions

This service evaluation has highlighted the important role that community SPC teams have in supporting residents in care homes who are approaching the end of life. The main interventions required for these residents is furthering FCP and symptom control. The interventions outlined in the paper result in an improvement in 'hard outcomes' such as achievement of PPD. 'Softer' outcomes around improvements in quality of life are more difficult to quantitatively measure, but it is likely that community SPC teams add significant benefit in these areas through achieving symptom control and avoiding unwanted admissions.

Palliative care is not solely the remit of the SPC team. Up-skilling of the wider health and social care staff to support and engage in FCP discussions, as well as ensuring primary care teams and care home staff have 'core competencies' to both recognise and appropriately respond to the needs of residents approaching EOL can only enhance the quality of EOLC for all current and future residents in the care home sector. There is an ongoing education programme provided by CH to care home staff in Cardiff, aimed at recognising a deteriorating

resident along with symptom management, with the aim of ensuring all residents receive quality generalist palliative care and a timely and appropriate SPC referral. On a national level there is a drive to use the All Wales Care Decisions for the Last Days of Life [19] to support HCP's in providing EOLC in all settings, including care homes. The hope is that increased use of this decision aid tool will help non SPC professionals feel empowered to regularly review an individual under their care and to recognise and appropriately respond to the common symptoms of a patient approaching the end of life.

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## Conflict of Interest:

The authors declare no conflict of interest.

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