Executive Summary

August 2019
Acknowledgements

Thank you

Thank you to the staff who so generously shared their time, experiences and perspectives for the purpose of this evaluation. As a result of your participation, we now have an in-depth understanding of the service triumphs, challenges and improvement opportunities.

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Authors

Alisha Newman
Research Associate, Marie Curie Palliative Care Research Centre and Wales Cancer Research Centre, Cardiff.

Dr Mirella Longo
Research Associate, Marie Curie Palliative Care Research Centre, Cardiff.

Howell Edwards
Research Partner, Marie Curie Palliative Care Research Centre and Wales Cancer Research Centre, Cardiff.

Prof. Annmarie Nelson
Scientific Director, Marie Curie Palliative Care Research Centre, Cardiff.

Prof. Anthony Byrne
Clinical Director, Marie Curie Palliative Care Research Centre, Cardiff.

Mel Lewis
Lead Nurse, Palliative Care Service, Cardiff and Vale University Health Board, Cardiff.

Coordinating Centre

Marie Curie Palliative Care Research Centre
Division of Population Medicine
Cardiff University School of Medicine
8th Floor, Neuadd Meirionnydd
Heath Park, Cardiff.

Telephone: 029206 87175
Email: mariecuriecentre@cardiff.ac.uk
Website: https://www.cardiff.ac.uk/marie-curie-palliative-care-research-centre

Commissioned by

Specialist Palliative Care Service, Cardiff and Vale University Health Board, Cardiff.

Further information

Contact Alisha Newman, Research Associate on newmana3@cardiff.ac.uk or 029206 87948.
1. Introduction

The Cardiff and Vale University Health Board (CVUHB) Specialist Palliative Care (SPC) service offers specialist advice, support and symptom management to people with progressive non-curable illnesses, their families and allied professionals throughout the hospital inpatient and community areas. The service is delivered through collaboration and integration with City Hospice and Marie Curie.

Many non-emergency health services are provided 9-5pm and during Monday to Friday, leaving core and emergency services to provide care at weekends; traditionally SPC services developed in this way. However, CVUHB, in line with the rest of Wales, have provided a SPC Clinical Nurse Specialist (CNS) service at weekends and bank holidays since 2010.

The weekend/bank holiday SPC CNS service model has evolved over time in response to clinical demand, internal service reviews and service improvements. Staff delivering the service voiced the opinion that there is growing service demand and workload at weekends across the community and hospital areas for Palliative Care; coupled with the projected population growth and aging expected for the local area, this reinforced the need for an independent service review to ensure that going forward, the service is fit for purpose, service users receive timely and appropriate care, and staff feel well supported to deliver the service.

In 2018, the Marie Curie Palliative Care Research Centre was commissioned by the CVUHB Specialist Palliative Care Service to review the weekend and bank holiday SPC CNS service. A mixed method approach was taken to fulfil the evaluation objectives, including a rapid review of existing literature, a survey of CNS staff (n=18), interviews with CNS staff and service managers (n=12), and analysis of routinely collected service activity data.

The full 108 page report provides a detailed description of the review findings. This executive summary gives readers a concise content overview, including recommendations to support the future sustainability and development of the service.

2. Results

The review has identified aspects of the service that work well, service challenges and improvement opportunities. Recorded service activity has been measured and described and key differences between the weekday and weekend/bank holiday service have been identified.

Staffs’ commitment to the provision of high-quality care became evident through the review, and the wellbeing of service users emerged as paramount. Staff were genuinely interested in helping to improve the service and there was a high level of consensus among CNSs and managers on the service challenges and improvement opportunities. Their perspectives are clearly communicated throughout the report under thematic headings (See graphic). Many of the identified themes are interconnected. Accordingly, improvements in one area have the potential to impact positively on others.
a. Service design

The values, resources, systems and processes of three organisations have been brought together to deliver a single weekend and bank holiday service that supports those who are most sick, and most in need, at home and in hospital. The tri-organisational collaboration required to develop and maintain it should be celebrated.

Whilst a clear written core service offer was absent, the service foci were said to be (1) support for known and new patients with urgent specialist palliative support needs, and (2) the review of those who had adjustments to medications late in the week. (3) CNS support to other health professionals was an important feature in the hospital setting. The type and intensity of patients seen at weekends was said to be a key difference when compared to the week, with CNSs often supporting patients/families unknown to them.

The majority of staff said they had all or almost all the clinical skills, knowledge and experience required for weekend and bank holiday working. Staff induction was thought to be ample by most, although some staff still felt daunted, despite having worked several weekend shifts.

The impact of lone working at weekends was a recurring theme throughout the review. Informal support networks had been developed within teams which enabled on-duty CNSs to discuss complex patients with SPC colleagues. The on-call SPC Registrars and Consultants offered CNSs essential weekend and bank holiday clinical support.

Whilst CNSs said their skills were most effectively used when working within the boundaries of their specialist role, one in four said they regularly performed duties outside it, primarily to ensure the timely fulfillment of patients’ needs.

Staff described having an extended role at weekends/bank holidays. This included increased decision-making responsibilities in relation to complex patients who might ordinarily receive consultant support during the week. The added responsibility and time implications of answering and triaging all incoming calls at weekends was highlighted by community staff. The wider geographic and hospital site remit was thought to be a disadvantage.

Despite the assertion that the CNS role is extended at weekends, many suggested further increasing their remit to include prescribing in order to reduce delays in symptom management for patients. The ability to undertake chest and abdomen examinations and neurological assessment was suggested as another way to enhance patient care.
The ability of CNSs to complete their workload in contracted hours varied, with two in three CNSs stating this was always or was frequently achieved. Some thought service quality and equity were sustained through working additional hours. The distances between home visits, traffic conditions, and late calls that result in home visits were all cited as reasons community staff worked late. Finishing work on time was thought to be more achievable in the hospital setting on days when two nurses were on shift. The manageability of the weekday caseload was thought to impact on the weekend workload due to overspill.

A marked difference in CNS numbers at weekends/bank holidays when compared to weekdays was observed. Whilst the caseload and referral criteria were said to be more focused at weekends, this did not appear to adequately compensate for the staff reduction and extended remit they described. Some CNSs said that the weekend/bank holiday workload had become unmanageable due to the number and complexity of patients needing support. The future sustainability of the weekend/bank holiday service with existing resource was questioned.

Additional staffing was frequently proposed as a way to improve the service and CNSs experiences of delivering it. Proposals were cautious. The anticipated advantages of having two staff members available in each setting on each shift included less travel between hospital sites and patients’ homes, improved efficiency of call handling and patient triage, more time available to spend with patients and families, easier access to peer support, confidence in shared decision-making, improved staff safety and reduced feelings of isolation, pressure and stress. Opportunity costs to the weekday service were a consideration.

b. Service delivery

Most staff felt the demands on the CNS role had changed over time. Demand was said to fluctuate with quiet shifts being rare. Greater awareness and acceptance of the service was thought to have influenced an increase in calls and referrals, including for those with a non-cancer diagnosis; yet the need for greater awareness of the service among ward staff was proposed, which suggests the possibility of untapped demand.

CNSs described the unpredictable nature of weekend/bank holiday shifts and the challenge of simultaneously managing planned and unplanned referrals. Triaging and prioritising patients was seen as a vital, yet complex part of the role.

The need for a cross-organisationally agreed written referral criteria, and education on appropriate referrals for CNSs and allied professionals were proposed as ways to prevent referral of routine work and to make the CNSs caseload more manageable. The amount and quality of information written on handover sheets was said to affect the assessment and prioritisation of patients. Use of a single standardised referral form was suggested. Completion of advice sheets that document all CNS telephone and face to face contacts with patients/families was said to be time consuming. Some CNSs completed paperwork after their contracted hours at home.
A number of factors were said to affect service efficiency. Community staff described feeling under pressure because of the need to answer the phone whilst carrying out other tasks, and taking incoming calls was said to interrupt and delay planned face to face visits. CNSs from both settings said time was wasted travelling. In particular, the time spent travelling between patient homes was thought to be excessive due to the vast geographical area CNSs must cover. Peripatetic working across settings was proposed.

Despite the Canisc record system being described as clunky and time consuming, the routine digital recording of all patient contacts by all providers was proposed as a way to improve efficiency and information sharing on known patients. It was thought access to digital records could be improved through provision of extra computers for hospital-based CNSs and the use of portable devices such as tablets and laptops for those in the community.

Inter-professional relationships with, access to, and support from allied professionals, were said to affect service delivery and patient wellbeing. The demands on and availability of other health and care services during weekends and bank holidays were cited as factors that influenced the need for CNSs to absorb non-specialist work. Tasks such as taking drug charts to ward doctors and out of hours GPs aimed to hasten support to patients by plugging gaps left by limited seven day working in other areas. The failing of some dedicated pharmacies to hold adequate stock of palliative care drugs was cited as another drain on time that could impact on patients’ quality of life. Limitations to the SPC clinical telephone support available to CNSs were highlighted, including call back delays and the unavailability of face to face patient review.

c. Service outcomes and impact

Weekend and bank holiday access to specialist, rather than generalist palliative support, was believed to have helped maintain the wellbeing of patients and families. Continuity of care and better symptom management to known patients, timely support for urgent new referrals, and the ability to make safe changes to medications on a Friday were cited as key benefits. Seven day access was thought to help patients, family members, and the allied staff who work with them, to feel reassured, more confident, and well supported. Some community CNSs believed acute hospital admissions were avoided due to their intervention.

‘I feel that my weekend / bank holiday time is mostly spent on travel, documentation and general paperwork. Much of this time could be spend clinically with patients in the community setting. Clinical time is often interrupted by the pressure to answer in-coming calls, re-evaluate and triage your day to respond to patients in an appropriate fashion…’

(Community-based survey respondent)

‘...I think there may be times when patients probably could have had more of our time where we could have listened a bit longer... where you’re not being rushed off to drive to the edges of the city to see the next person. Erm, but that’s just a sacrifice we have to make, and... you use your clinical judgement to make that decision when it’s safe to do and when it’s not...’

(Community-based interviewee)

‘... the patient[s] have access to specialist palliative care nurses, advice and experience on the weekend which is great, and if we weren’t there, they wouldn’t have that, and they’d suffer for it. I think we add to the out of hours, it’s important that we’re there... unfortunately people deteriorate and die out of hours, they don’t all die Monday to Friday 9 to 5. It’s life isn’t it.’

(Community-based interviewee)
The majority of staff felt weekend working had an impact on the weekday service. Positive influences included relieving pressure on staff during the week and continuity of advice and symptom management for patients and families. Some thought that staff rota planning limited any adverse effects on the weekday service. Others said taking time back for weekend hours worked, disrupted weekday service continuity and added to colleagues’ workloads. Accommodating other absences, including staff sickness and annual leave were said to make it more difficult to balance resources across seven days. Small teams were thought to be most affected.

Whilst it was proposed that increased staffing at weekends/bank holidays would reap many benefits, the potential sacrifice this might impose on weekday provision was discussed. For smaller teams, the proposition was said to be untenable with their existing resources, as it could potentially threaten service sustainability as a whole.

Staff commented on the rewarding yet demanding nature of the work. The role was often described as emotionally and physically draining. A range of factors were thought to contribute to this including the type and complexity of patients, the level of decision-making in relation to them, and shift patterns across seven days. Some felt isolated due to lone working. Procedures for lone working and risk assessment were said to be different in the community on weekends/bank holidays. It was proposed that this may have repercussions for staff safety.

CNSs said they strived to achieve equity of support during the weekend/bank holiday and some believed it was accomplished. Staff from both settings said that patients received the same support for symptom control at weekends as they did during the week. Some said clinical work was prioritised over support for emotional distress. Community-based CNSs said that in principal, all known patients have equal access to the service as they are given the number to call. Conversely, ward staff act as gatekeepers to the service for those in hospital. There was a suggestion that there may be access inequity for inpatients in hospitals other than the primary district general hospital.

Some CNSs said the extended remit and reduced staffing levels at weekends limited their ability to carry out face to face visits, potentially introducing difference in the way support is delivered to weekend/bank holiday service users. Some thought that weekend time constraints reduced how long they could spend with patients. Several staff acknowledged that the service had to be different at weekends due to reduced resources.

‘... it is very isolating ... although there are other ... teams around you you’re essentially working on your own ... so definitely works better on the Saturday with the two people, ... if it’s a complex person then often, erm, they can discuss that person ... and develop a plan together.’

(Hospital-based interviewee)

‘... you know, it is a challenging job, stressful, because when it’s busy, it’s really hard to prioritise ... Still learning all the time ... because there’s just so many different diseases and treatments ... but I like it as well ... you know, it is rewarding, oh yeah, that’s important.’

(Community-based interviewee)
d. Key differences

Six key differences between the week day and weekend/bank holiday service were identified:

- **Type and intensity of patients:** Predominantly urgent cases at weekends, as opposed to a mix of non-urgent and urgent need in the week. Patients/families often unknown to the CNS at weekends.
- **Patient care focus:** Primarily clinical support at weekends, less focus on emotional/holistic care as is provided during the week.
- **Staffing levels:** Greatly reduced staffing at weekends, with just one community CNS and one or two hospital-based CNSs on duty.
- **Lone working:** Reduced peer support, different risk assessment and safety procedures at weekends.
- **Task and geographic deviation:** Managing all incoming calls/pagers, and covering the entire community geographic remit/all hospital sites at weekends.
- **External infrastructure:** Reduced availability of SPC colleagues and allied health and care professionals at weekends. Also, different and/or extended processes to access their advice and patient support.

e. Service activity

The available data showed established service activity, analysis of which suggests an increase of activity across the service as a whole (see graph).

The service primarily supported patients residing in their own homes and district general hospitals. Despite the comments of some CNSs that support to people with non-cancer diagnoses was increasing, those with cancer accounted for 80 and 90 percent of patient referrals to the hospital and community teams respectively.

Symptom control was most commonly recorded as the reason for referral, which indicates that the majority of referrals aimed to elicit clinical support. The yearly average of 255 new referrals and unplanned reviews shows the responsive nature of the service, as ensuing action could have reduced the time patients and families waited to receive urgently needed support, and averted hospitalisation of patients residing in the community. Either of which could have positive implications for the health and well-being of service users, the latter facilitating savings in inpatient care costs.

Follow up data gives an indication of how the service is positioned to support consistency of care to known service users with anticipated needs. The Data showed a growing monthly average of 135 to 159 referrals over two years. It was not possible to track how many of these referrals resulted in the provision of care; however, the work involved in the task of referring should be recognised, particularly as data on the source of referrals showed that the majority of community referrals came from the SPC team.
Face to face contacts with patients and families were shown to be stable across three years, which might reflect staff views that capacity thresholds had been reached. A plateau in demand could be another explanation. An increasing number of non-direct contacts via pager and telephone were recorded. The majority of these were carried out by the community staff. This supports their comments on growing activity in this area and could also reflect the logistics of providing a service across a large geographic area. The increase in the overall number of telephone/pager contacts could reflect an increase of patients, and/or an increase in contacts per patient. The growing number of calls made to other health care professionals could be a proxy for complex cases and indicates the need for cross-functional support for patients at weekends and bank holidays.

Whilst available data on referrals for staff support were limited, it indicates that the hospital-based CNSs received a substantial number of monthly referrals for this purpose.

Through the review it emerged that the data set and descriptors used by the three organisations to record service activity differed slightly, which made data aggregation more complex. Implementation of a tri-organisationally agreed minimum data set would significantly improve ease of whole service reporting.

Currently the activity data captured by the service does not include any that specifically shows the impact of the intervention on service users. Means to evidence service outcomes for patients, family members and professionals should be investigated, so that the benefits of the service can be fully understood and communicated.

3. Conclusion

The extension of the service from five to seven days has facilitated specialist support to those most in need of it seven days a week. Recording and reporting of patient and family outcomes is now required to show the true value of the service through their eyes. Cancer patients do represent the majority of people referred to the service, ensuring accessibility for those with other illnesses is therefore important.

The unification of three service providers has offered a level of flexibility and complexity to service delivery. Analysis of the service activity data clearly suggests whole service growth; however, activity does not automatically translate into increased efficiency and effectiveness. If this growth persists in the absence of system and process improvements and/or staff growth, there may be future implications for the wellbeing of staff and for those the service is intended to support.

The CNSs’ commitment to best care for patients and families shone through during the review. The challenges of the role were also brought into sharp focus. The levels of staff stress and the impact of lone working on CNSs must be recognised and improvement strategies should be explored.

Gaps in seven day working in the wider health and care provision clearly impact on CNS activity. A high level of CNS good will is evident and without it, patients’ quality of life would suffer. Inevitably, time spent on work outside the CNS remit reduces the time available to carry out tasks within it. Accordingly, whilst CNS prescribing was strongly advocated by staff as a means to prevent symptom management delays for patients, a wider health care system solution may be needed.

Staff perspectives on the strengths and limitations of the evolved service and improvement suggestions have been clearly communicated through this report. Actions are now needed to support the next phase of service evolution. Consideration of opportunity costs to the weekday service should be integral to any plans for service change.
4. Recommendations

Implications for practice have been identified through the review. The following recommendations for consideration aim to support future service sustainability and development. An action research approach to some of the recommendations may help to identify the advantages and opportunity costs to the service and its beneficiaries.

Through tri-organisational collaboration:

1. Develop and widely disseminate a clearly defined core offer, which describes the aims and objectives of the service, who can benefit from it, and how to access it, giving consideration to equity of access.

2. Agree the minimum dataset needed for reporting on service activity, giving consideration to the most appropriate outcomes to assess service impact, effectiveness, and cost effectiveness, ensuring the time cost of recording is proportionate to the reason for it.

3. Identify mechanisms for gathering and reporting patient/family and staff service user outcomes for the weekend/bank holiday service. Their views on how to improve the service may also be valuable.

4. Review systems and processes to optimise inter-organisation communication and information sharing including, appraisal of referral/handover documentation, and assessment of the feasibility and resource implications of the routine digital recording of patient contacts by all three SPC providers.

5. Consider ways to reduce the burden of lone working and workload on staff wellbeing and safety, including process/system change and/or increased staffing.

6. Investigate how the burden of call management on staff could be lessened, including increased staffing and/or utilisation of resources outside the CNS team.

7. Consider ways to reduce travel inefficiency, including the potential revision of the geographic remit of community staff and/or peripatetic working across settings.

8. Assess the cost and efficiency benefits of increased computer/remote device access for CNSs at weekends.

9. Review the CNS training portfolio giving consideration to the feasibility and potential risks and benefits of introducing patient assessment training and CNSs prescribing.

10. Instigate discussion with relevant parties regarding the impact of out of hours prescribing delays on patient wellbeing and the need to identify ways to overcome this challenge.