

COVID-19 reflection on the impact of the pandemic on a community specialist palliative care nurse team

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Abstract

Background: A global COVID-19 pandemic was declared by the World Health Organisation in March 2020. **Aim:** To explore COVID-19's impact on one specialist community palliative care nurse (SCPCN) team 8 months after the first COVID-19 wave in the UK. **Method:** The Gibbs Reflective Cycle was used. **Findings:** This SCPCN team described the COVID-19 pandemic as the most difficult and challenging time they have ever had at work, due to the increased workload and having to provide unsustainable levels of support for patients and their families. **Conclusion:** Despite COVID-19's significant demands on community palliative care, the SCPCN team was able to adapt accordingly. This resulted in an increasingly collaborative, reflexive, responsive, skilled, and resilient team, proud of the personalised support offered to patients, their families and to other services.

Key words: ● community palliative care nurse team ● COVID-19 ● specialist palliative care ● workload ● capacity

A global COVID-19 pandemic was declared on 11 March 2020 by the World Health Organization (Ghebreyesus, 2020). The declaration stated:

‘This is not just a public health crisis; it is a crisis that will touch every sector—so every sector and every individual must be involved in the fight.’ (Ghebreyesus, 2020)

The UK Government followed the measures taken by many countries by enforcing a restrictive lockdown in England on 23 March 2020, requesting that people stay at home in order to protect its National Health Service (NHS) and save lives (Government UK, 2020a). These restrictions were not lifted until the end of June 2020, with many caveats left in place including the need for continued social distancing and public health and infection control measures for the NHS, and other public services.

As the UK prepared for the unprecedented demands of COVID-19 and its implications, NHS England equipped itself for mass infection and a huge demand on acute inpatient hospital services (Government UK, 2020b). The specialist community palliative care nurse (SCPCN) team at Forest Holme Hospice (Dorset, UK) was only

too aware of this acute care preparation as it included a significant and speedy shift of patient care into the community.

The SCPCN team's remit is to support palliative care patients at home who require complex symptom control and psychological support (NHS England, 2016). As a team of seven full-time employees, they supported on average 170–180 community patients at any one time covering a wide geographical region of East Dorset covering urban, rural and coastal areas (*Figure 1*). This team is part of a wider multi-professional specialist palliative care (SPC) service which incorporated in-patient hospice and hospital palliative care and end-of-life care, teams and other services. This enabled a SPC out-of-hours advice service to operate, manned by community and hospital SPC nurse teams providing cover for patients in the community as well as the hospital.

The Gibbs Reflective Cycle (Gibbs, 1988) was chosen for this paper due to its framework for examining experiences that develop iteratively. This seemed entirely applicable to this pandemic with its ever-developing nature and impact. Gibbs reflective model covers six stages (*Figure 2*) and each stage has been employed to present this reflection.

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Reflection on the impact of the COVID-19 pandemic on the community specialist palliative care nurse team

Description

Rapid changes were made to all NHS services when the COVID-19 pandemic was first declared (NHS England, 2020a; NHS England, 2020b); outpatient appointments were cancelled, as many in-patients as possible were discharged, all planned and routine surgery was suspended, general medical practitioners (GPs) stopped all but essential face-to-face visits, oncological treatments were re-appraised, reduced or stopped and staff were readied for relocation to in-patient areas likely to be most in need.

At this time, specialist palliative care locally and nationally played a crucial role in the preparation, education and planning for the management of symptoms relating to COVID-19. Demand arose to provide symptom control guidelines quickly and succinctly (Jenkins, 2020; National Institute for Health and Care Excellence, 2020). Locally, GPs and other healthcare professionals requested urgent teaching and advice on how to undertake difficult conversations about advance care planning, including ethical decision making in relation to treatment escalation plans for those most seriously ill.

Swift changes were implemented within the specialist palliative care service; online platforms for virtual meetings and the sharing of resources were quickly enabled to allow for easier collaborative working across hospital, community and in-patient palliative care teams with additional linking to the oncology directorate. This enabled guidance to be quickly produced and shared and pathways around management of patient care to be discussed. Daily hospice 'briefing huddles' took place to maximise communication of updates around COVID-19 and to offer peer support. The 24-hour SPC advice service was also extensively promoted to ensure both in-patient and community services were aware of how to access palliative care advice. The SCPCN team moved to remote working where possible and adopted virtual clinic software and Wi-Fi calling to cater for poor rural mobile coverage while at home.

The SCPCN team triaged clinical care, reprioritising face-to-face visits with risk assessments undertaken prior to every home visit including basic screening for COVID-19 within the whole household. Transmission risk was reduced with a move from traditional non uniform back to uniforms/scrubs to allow for

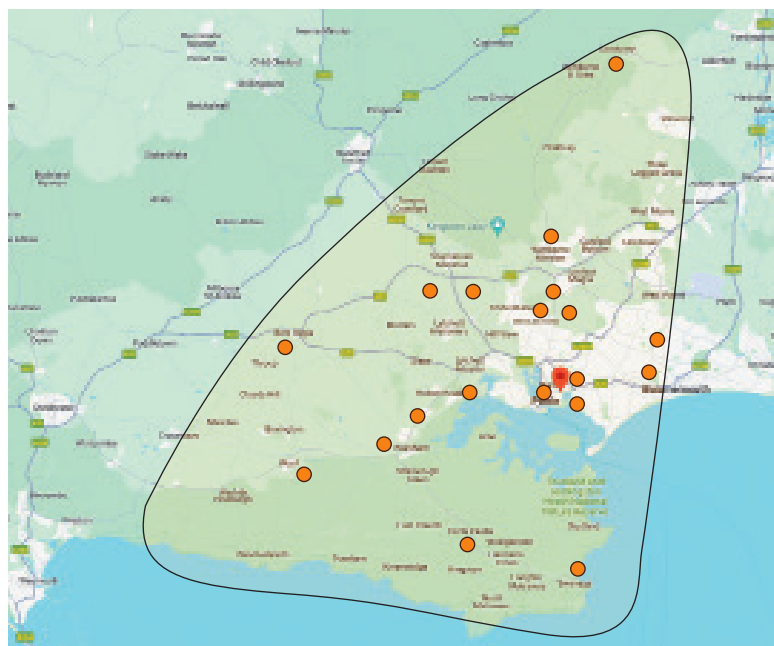


Figure 1. Geographical provision of care from Forest Holme hospice community specialist palliative care service (October, 2020)

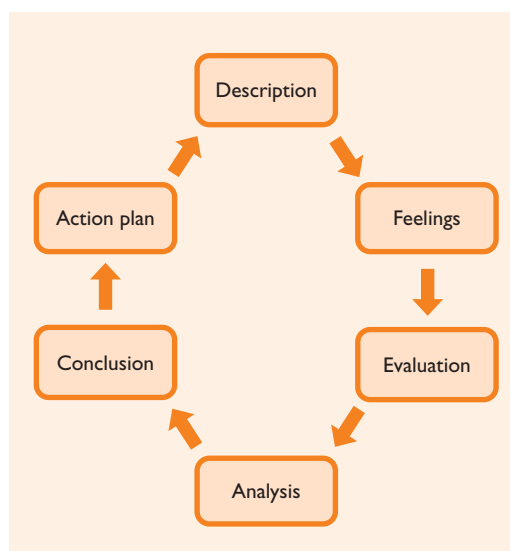


Figure 2. Gibbs reflective model (Gibbs, 1988)

appropriate washing, and appropriate personal protective equipment (PPE) was adorned at every home visit.

Increased referral rates

Many referrals to the service during the lockdown (Figure 3) originated from hospital clinicians, unable to hold face-to-face outpatient appointments, yet concerned about patients with palliative care needs through telephone or video consultations. The SCPCN service was identified as an appropriate service to follow up these patients and undertake home visits. After rising

at the start of the lockdown, referral rates dipped in April 2020, perhaps in part due to initial video out-patient consultations having already taken place. Rates then increased again, likely as a result of disease progression and an urgent need for SPC input. Referrals to the SCPCN service then stabilised, but at higher than previous averages, with some appearing to be due to delayed diagnoses as a result of late presentation and others whose disease has progressed perhaps due to treatment being halted.

Non-face-to-face contacts

The numbers of telephone calls received and made overall by the SCPCN team increased significantly (Figure 4) averaging 55% between April and June (2020) compared to the same period in 2019. At their peak, they increased by over 120% with an additional 384 calls

in 1 week (Figure 5) and a rise also seen with the weekend service (Figure 6). There was also an increase in numbers of calls regarding community patients compared to in-patients. This was not surprising, but was made exceptional by call duration—the team anecdotally reported that telephone consults with family members took up to 20 minutes longer than typical. Additionally, an increased numbers of calls were received from community nurses requesting prescribing advice and reassurance on decision making within their own increased workload.

Video consultations were few and far between, as although this technology was now available to the team there was little initial opportunity for the SCPCN’s to become practiced in its use while working remotely and with limited availability of appropriately distanced clinic room space.

Feelings—what were you thinking and feeling?

The SCPCN team has throughout this pandemic felt proud of its ability to adapt to the changes in clinical practice and of the NHS nationally and locally. While the NHS dealt with this change in a remarkable way, the shift of many aspects of hospital care into the community during this first wave had consequences that challenged the team significantly. The scale of this impact was not foreseen, but quickly unfolded as a massive challenge in providing what felt like hospital and hospice care but in the community setting.

Non-face-to-face contacts

The demand on the SCPCN’s telephone support was unsustainable with the team making and receiving over 2600 calls with extended durations in a 4-month period. Numerous intense conversations took place with little reprieve from calls (principally with patients, relatives, community nurses and GPs). The sheer number of calls was exhausting and frequently emotionally draining. Many related to heightened anxieties, fears and concerns around being a source of virus transmission as a relative, or because of increased vulnerability (patients recognising the potential for a catastrophic outcome if catching COVID-19). Patients were also increasingly terrified of hospital or hospice admission due to this risk and were afraid of being alone in hospital due to visiting restrictions.

As well as offering extended emotional support, telephone calls involved lengthy extensive and comprehensive assessments of patients to ensure the correct management of symptoms and delivery of plans of care. It was

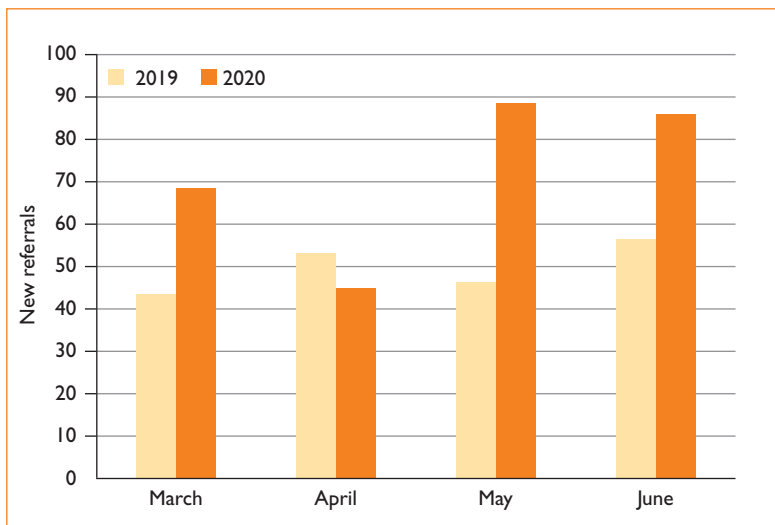


Figure 3. Comparison of number of referrals to the SCPCN team 2019 versus 2020

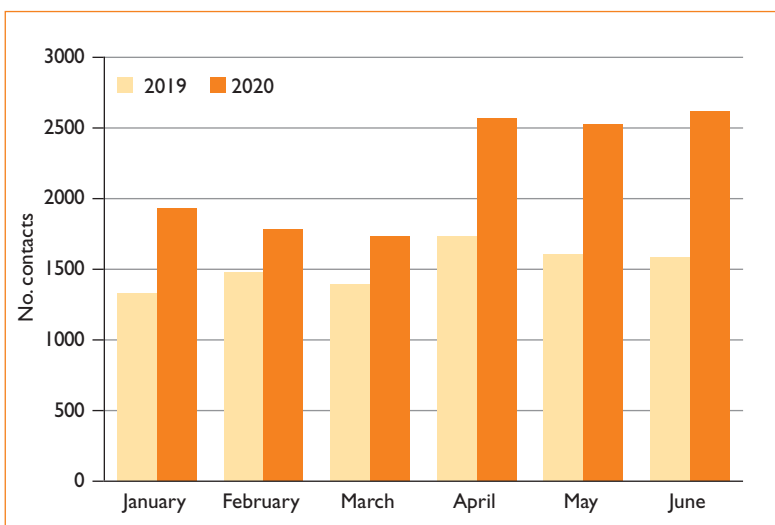


Figure 4. Comparison of WEEKDAY non face-to-face contacts 2019 versus 2020

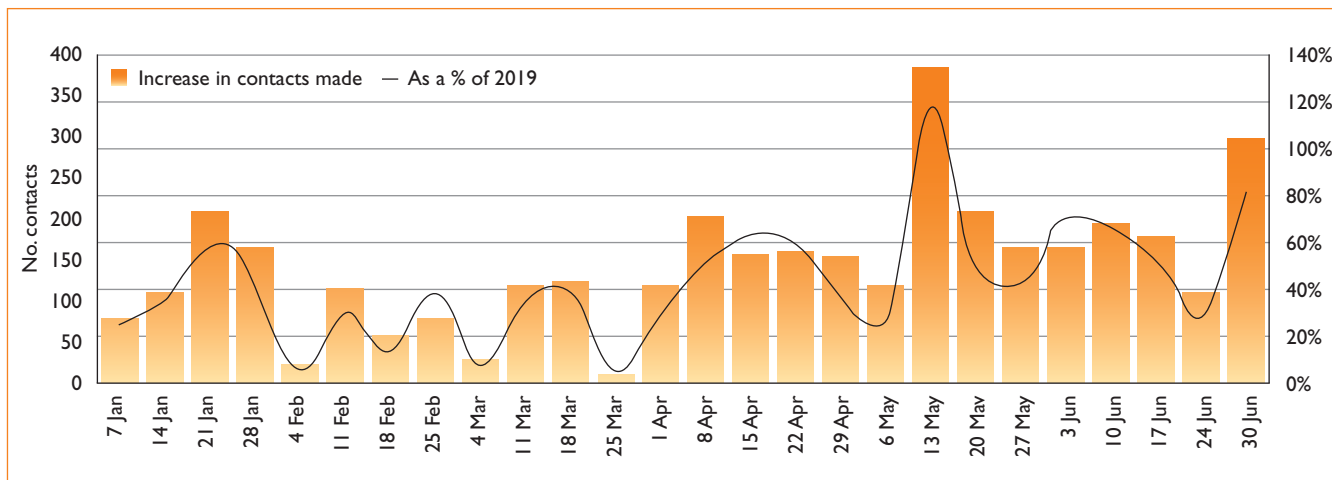


Figure 5. Week by week increase in non face-to-face contacts 2019 versus 2020

difficult to gauge symptoms from telephone consultations that challenged subsequent management decisions, and this created some professional anxiety. Prior to COVID-19, such calls would have been followed by a visit, but this was now difficult for the reasons above.

Face-to-face visits

Face-to-face visits that were undertaken by the SCPCN became increasingly lengthy, not least because each required adorning PPE. PPE made sensitive conversations painfully impersonal with advanced communication skills obfuscated by the use of face masks, gloves, aprons and social distancing making it harder to display empathy with facial expression and touch. While much of the population identified similar challenges, the emotional content of SCPCN conversations made this harder, exacerbated by reduced privacy when children were present due to schools being closed.

The importance of technology in supporting these conversations was invaluable for distanced relatives, but introduced further challenges as some families used online platforms to listen in on conversations. The desperation of families unable to meet but trying to enjoy what remaining time there was left in their loved one’s life, was clear and added to the personal strain on the team supporting distressed families.

The intense psychological support required tended to align to the complexity of physical symptoms. Families who were adhering to strict shielding measures and initially declining visits conceded to the SCPCN visiting once the patient was experiencing considerable discomfort and too difficult for the families to deal with. Many of the symptoms that patients were experiencing as a result of a lack of SCPCN visitation could have been anticipated with earlier intervention, but were now multiple in number. This caused

the team feelings of inadequacy in what they could realistically achieve in a timely way.

Shielding guidelines applied to all individuals on the caseload (Government UK, 2020b). The conflict for families around this, versus the absolute need for face-to-face visits in complex cases, added an emotional complexity to the home situation and nurses were often made aware of the risk they posed by entering. Management of this fear became an integral part of the support required but added to the pressures on the SCPCN.

Although the team has recognised its important contribution during this pandemic and continued to work hard to fulfil this, the initial lockdown was broadly a lonely and isolating time in where members of the team worked with reduced peer contact and emotional support. Staff were unable to relax at home due to the increased pressure at work, and felt that

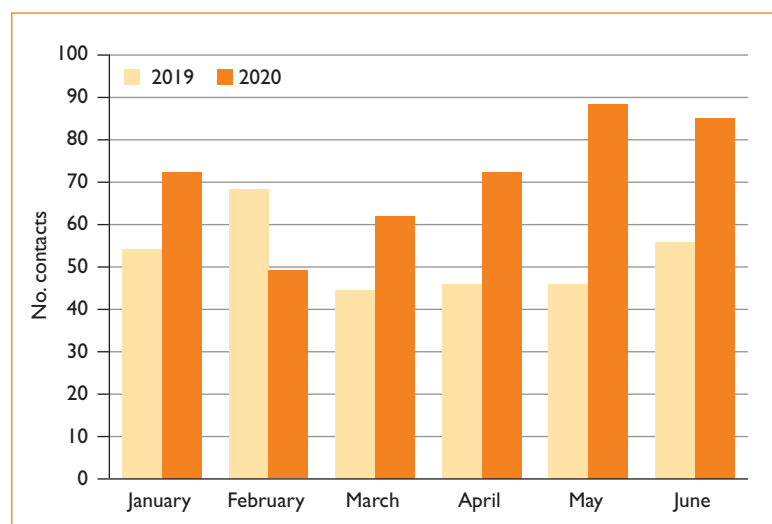


Figure 6. Comparison of WEEKEND non face-to-face contacts 2019 versus 2020

they could not share these increased fears and anxieties with their family which led to them feeling further isolated. Alongside this, staff felt that they had to shower and immediately wash their clothes when coming home in order to keep their family safe. This fear of contamination intensified among the team when two of the team's members fell ill with COVID-19.

Evaluation—what was good and bad about the experience?

The traditional model of SCPCN care with its combination of phone support and face-to-face visits for patients was significantly challenged shortly after the first lockdown began. Expectations of the latter changed as both patients and nurses needed to re-think their requirement for and acceptance of a visit. With increasing demands on staff time and the risk of COVID-19 transmission prevalent, face-to-face visits were prioritised to those most in need and the practice of routine visiting became obsolete. Telephone support continued and its demand rose significantly as evidenced earlier. The rapid adoption of technology, such as video consultations, enabled a new 'middle ground' between telephone support and face-to-face visits and with increasing familiarity, has become an integral additional support the SPC service can offer.

The rapid implementation of technology and Dorset's accelerated ratification of policy change that enabled family carers to administer subcutaneous medication for symptom control at the end of life has demonstrated that change can be instantiated quickly and effectively when required. This was not only encouraging, but shows that the status quo within clinical practice can be challenged.

Analysis—what else can you make of the situation?

UK media focussed on the impact of COVID-19 on hospital care during the first wave of the COVID-19 pandemic. However, the needs of patients in the community were rarely highlighted due to the focus on critical inpatient care. Few would have foreseen the resulting impact on the SCPCN teams. Media attention may also have contributed to misguided perceptions that non-acute services were closed—a myth that NHS advertisements later tried to dispel.

Locally, SCPC services were viewed as being 'open' for business and therefore in demand, even more so by patients and their relatives under their care. Additional pressure was put on the

weekend service with some relatives phoning for advice about COVID-19 when unable to get through to the increasingly burdened NHS out of hours service.

The sheer complexity and extended durations around all aspects of patient care became incredibly burdensome, from risk assessments and anxieties around COVID-19 transmission to difficulties in working meaningfully with patients, all of whom were shielding. The massive increase of non face-to-face visits coupled with the above complexity pushed the service to breaking point.

With patients who would normally consider hospital or hospice admission now refusing, SCPCN's were left ill-equipped to manage such complexities in a patient's house but still needing to palliate symptoms and manage heightened anxieties. This was additionally challenged by increased difficulties in accessing medication and equipment in a timely manner which threatened the quality of care provided.

The lack of community COVID-19 screening and coronavirus understanding at the time, undoubtedly also made it difficult to determine whether patients' increasingly complex symptoms were a result of COVID-19 or a progression of disease, straining professional intuition to the maximum.

Conclusion—what else could you have done?

Like most NHS Hospitals, Poole Hospital prepared for a significant influx of inpatient admissions for patients with COVID-19 as requested (Government UK, 2020b). While entirely understandable, an equivalent preparation for an influx of patients in the community and its subsequent impact on primary care was largely underestimated (The Health Foundation, 2020; Mitchell, 2020). The SCPCN team adapted as best it could, and the prompt availability of improved collaboration tools proved to be enormously helpful. Although the SCPCN team lacked the initial capacity to cope with the unprecedented demands faced, they adapted quickly and the Pan-Dorset palliative care stakeholder steering group (created during the first COVID-19 wave) has continued, enabling ongoing collaboration and strengthening of the relationships between all supporting services and has ensured resilience for any unprecedented events in the future.

This first wave of the COVID-19 pandemic demonstrated the value that SPC brings across professional disciplines in all its patient settings, and an understanding of the personal impact

that such an unprecedented event can have on its staff. The team can now look back, proud of its resilience and adaptability.

Action plan—if it arose again, what would you do?

When the second wave of the COVID-19 pandemic occurred, the team was better prepared. The team's telephone assessment skills had increased, there was more cross working, so SCPCN's could cross cover with in-patient and out-patient work/services. Nominated nurses from the hospice in-patient unit learned how to triage community calls, a number of hospital SPC nurses cross-worked to familiarise themselves with community working and medical cover became more aligned with community requirements. With enhanced collaborative working, meeting daily to identify 'tipping points' and the provision of clinical cover where the need is greatest, the service became more sustainable. Clinical and peer supervision continues to be prioritised as an integral aspect of staff support and services previously working in isolation have partnered and strengthened working relationships.

This SPC service and the hospital it worked under (Poole Hospital) has now merged with another local hospital (Royal Bournemouth Hospital) to become University Hospitals Dorset. This also brings another SPC service (Macmillan Unit) under the same NHS Trust combining two SPC services with a shared common experience.

Both SCPCN teams similarly reflect on the COVID-19 pandemic, and there is a sense of having been through it together, and now an identity of being 'stronger together' in a service that is collaborative, reflexive, responsive, highly skilled, resilient and proud of the personalised support it offers patients, their families and to other services. This is of crucial importance given the predicted increased numbers of patients with palliative care needs and the demand these services will experience (Etkind, 2020; Rosa, 2020; Hospice UK, 2020).

Summary

This pandemic is now over, but its impact and repercussions are reported daily as COVID-19 enquiries take place in the UK and its direct and in-direct effects are publicised. Many health, social and public services, as well as the general population, will have their own stories to tell, many are harrowing, impactful and deeply personal. This reflection highlighted the experience of one SCPCN team in an area of relatively low COVID-19 infection rate, and yet

CPD reflective questions

- What was your personal and professional experience of the COVID-19 pandemic?
- How did you look after yourself during the COVID-19 pandemic?
- How would you describe resilience in yourself and your colleagues?
- What lessons have you learned from the COVID-19 pandemic?

Key points

- Comprehensive telephone assessments can be an acceptable, appropriate alternative to face-to-face visits for some aspects of palliative care
- Collaboration, cross-working and partnership working has strengthened the specialist palliative care service and better prepared it for any future pandemic
- Prioritising clinical and peer supervision as an integral aspect of staff support has helped to build the ongoing resilience of the specialist palliative care nursing team
- The creation of a Pan-Dorset Palliative Care Steering group during COVID-19 remains successful in enhancing collaboration and partnership working between specialist palliative care nursing teams

even within this context, demonstrates the significant impact that COVID-19 pandemic has had. Across the country, the experiences of other SPC services may be vastly different depending on the prevalence of COVID-19. Professionally, it seems likely that this team's experience will resonate with others. Publishing this experience, provides an opportunity to reflect on the positive and productive consequences of COVID-19 and the important contribution of specialist palliative care. *IJPN*

Statement of interest: None

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