Improving evening and weekend care for dying people

The challenges for out of hours (OOH) palliative care and what needs to be done: considerations for research and practice

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1. Aim of this report

- To outline the key challenges in delivering and accessing out of hours (OOH) palliative and end of life care.
- To provide a summary of Marie Curie funded research exploring issues related to delivering palliative care outside of working hours.
- To outline policy and research recommendations for OOH care drawn from a workshop facilitated by Marie Curie involving patients, carers, family members, researchers, clinicians, and service providers.

2. Introduction

2.1 What do we mean by out of hours (OOH) palliative care?

Typically, most services operate between 9am and 5pm, meaning that a large portion of time in the day when a patient needs support is considered 'out of hours'. People at the end of their lives can suffer from symptoms such as extreme pain and agitation at any hour of the day or night. Up to 30% of patients may access OOH palliative care in the last year of their life[1]. For many, this care can quickly relieve unnecessary suffering in their homes, meaning they can avoid going to A&E unnecessarily[2]. High quality OOH care can also increase the likelihood of someone being cared for and dying in their preferred place.

OOH care is part of a complex system which includes 'in hours' generalist palliative provision, urgent care, nursing and social care and specialist care services[3]. Addington-Hall et al[3] found that there were significant variations in the quality of OOH palliative care services within and between primary care organisations in both England and Scotland. This variation was also recognised by Sue Ryder, who found that only 16% of CCGs in England provide full 24/7 support and coordination services for people at end of life[4].

Continuity is important in high quality palliative care[4]. Transitions between services and teams can mean important information about the patient isn't shared, and a lack of consistency in the people providing care. In a review of primary care organisations in England and Scotland, under half of services reported that district nurses were available for patients 24 hours a day. The remaining organisations reported partial provision[5]. Less than half of surveyed ambulance services reported they were able to access information on palliative patients. These systematic challenges provide great barriers to efficient care.

A national retrospective study exploring unscheduled and OOH care in Scotland showed that over 90% of people used NHS unscheduled care in their last year of life. When it came to continuous unscheduled pathways, 64.8% of these started out of hours. Use of unscheduled care increased towards the end of life with 34.2% occurring during last month of life, with a disproportionate number of episodes involving primary OOH care services[5].

A number of policy reports have highlighted how improvements in OOH care are needed to improve end of life experiences for patients and families[6, 7]. In addition, improving access to palliative care beyond working hours was identified as the top priority for research after an extensive, 18-month consultation involving over 1,400 patients, current and former carers, and health and social care professionals[8]. This consultation identified the following top research priority:

'What are the best ways of providing palliative care outside of working hours to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families'. James Lind Alliance[8]

2.2 Challenges of accessing OOH support

> *"Why is it so hard to find a carer through social services? Why is support so complicated? Why do some hospices not accept patients on weekends and holidays? Why is there such limited palliative care available after hours?"*
>
> Bereaved family member

The quote above is from a bereaved family member who participated in the James Lind alliance Priority Setting Partnership exercise to identify the key unanswered questions in palliative and end of life care research[8].

The uncertainty expressed in this quote highlights the need for accessible and coordinated OOH care for people with palliative care needs. This uncertainty has been echoed across research with patients and family members. Within the literature, concerns and difficulties about gaining timely access to effective palliative care and support during the OOH period are common[9-11] and include, but are not limited to:

- limited continuity and communication between services, meaning that patients felt unknown by professionals[10, 12, 13]
- difficulty accessing services, both physically and in terms of knowing who to contact[12]
- delays when waiting for call backs or home visits[14]
- a lack of flexibility within services[11]
- delays in people seeking help due to negative experiences with OOH services[15]
- reluctance to contact OOH services due to concerns about being a burden and legitimacy of needs[9, 13].

In 2004, the National Institute for Clinical Excellence (NICE) guidance for supportive and palliative care in cancer recommended the extension of the palliative care clinical nurse specialists (CNSs) model. Previously, this had functioned from 9am to 5pm during week days. NICE recommended it should be extended to a seven day service[16], in recognition of the likely need for ongoing face-to-face patient reviews across weekends.

However, a literature review[17] exploring palliative care CNS provision revealed key difference between weekday and weekend working and the types of support offered. Over the weekend, predominantly urgent cases were seen, and often by CNSs that were not known to the patient or family. In addition, over the weekend there appeared to be less focus on emotional or holistic needs and greatly reduced staffing levels. The review also highlighted a paucity of robust research into this area, drawing mainly from service evaluations.

2.3 Research addressing the challenges of OOH care provision

While it's widely accepted that integrated, 24-hour care and support for people with palliative care needs is essential for high quality care, there remains little academic evidence or policy documentation on how to organise, provide, or evaluate this[18].

A review commissioned by NICE in 2019 reviewed the evidence around different OOH services, models and policies. All of these aimed to support people with progressive, life-limiting conditions thought to be entering their last year of life to stay in their preferred place of care[19]. The review identified evaluations of four services which offered various levels of support in different formats outside of working hours. The quality of evidence from all four models was rated as low or very low. However, improvements on outcomes such as achieving preferred place of death and reductions in attendance to accident and emergency services were noted. This highlights the need for more robust evidence, including economic evaluations, to be conducted.

A Marie Curie funded grant-mapping exercise revealed that, in 2014, despite being rated as the top priority for research, OOH care was the second lowest funded of the priorities identified in the James Lind Alliance Priority Setting Partnership exercise[20]. Research exploring OOH palliative care received just 0.03% of health research funding, based on data from the UK Clinical Research Collaboration's (UKCRC) Health Research Classification System (HRCS 2014) dataset.

Subsequently, research to improve OOH care was selected as a theme in Marie Curie's open calls for research in 2016/17 and 2017/18. The National Institute for Health Research (NIHR) also funded research in this area in 2018. Marie Curie has since funded five research projects exploring the challenges and opportunities for OOH palliative care. Please see the appendices for an outline of these projects.

3. Workshop – exploring the unanswered questions for OOH palliative care

3.1 Aims of the workshop

This workshop was convened to bring together patients, researchers, clinicians, and policy makers to promote future research that meets the needs of all stakeholders and could inform future research, policy and practice.

To meet these goals, the aims of the workshop were:

• to foster collaboration between researchers, Marie Curie services and policy makers
• to explore how Marie Curie can maximise the impact of existing and future research on improving OOH care
• to identify unanswered research questions in relation to OOH palliative care.

3.2 Structure of the workshop

The workshop was attended by 42 delegates. These included:

• 20 Marie Curie funded researchers
• nine health and social care professionals from Marie Curie and other organisations
• two representatives from the Marie Curie policy team
• four service user representatives from the Research Voices Group
• seven funder representatives from all four nations and funders of the original Priority Setting Partnership.

Marie Curie funded researchers presented their ongoing work into OOH palliative care (Table 1) and members of the Marie Curie Research Voices group shared their experiences of accessing OOH palliative care for their loved ones.

The presentations were followed by small group discussions (between delegates with a range of professional and personal experiences of OOH palliative care) to answer the following questions:

1. **How** can research findings be taken forward into policy and practice to improve the end of life experience for everyone affected by dying, death and bereavement?

2. What **gaps in the evidence base** for OOH palliative care remain?

3. As the evidence base develops, how will we know that the palliative end of life care experience is **improving**?

3.3 Summary of group discussions

Delegates discussed the mismatch between the amount of time that is 'out of hours' (weekends, evenings, and nights – around 75% of a normal week) and the resources allocated to OOH care. Delegates described how issues that could have been responded to in the daytime often roll over into the OOH period, when it is often much harder for resolution of issues to be reached.

It was also highlighted how different audiences may use different language to describe OOH services. Some providers may talk about 'scheduled' or 'unscheduled' care, 'rapid response' or 'out of hours' care.

3.3.1 Question 1: How can research findings be taken forward into policy and practice to improve the end of life experience for everyone affected by dying, death and bereavement?

Recommendations for taking research findings forward into policy and practice

1. Build knowledge transfer and exchange into the design of research

2. Raise the profile and importance of palliative and end of life care among the public, politicians/policy makers and commissioners

3. Advocate for improved OOH care for all services, not just palliative care

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The following section of the report expands on these recommendations and provides some tips, examples, and resources to help you implement them with your own research or practice.

Recommendation 1: Build knowledge transfer and exchange into the design of research

What is knowledge translation?

Knowledge translation is quite a new term used to describe an old problem: the underuse of evidence-based research in systems of care. Knowledge translation activities aim to bridge the gap between what's known, and what's currently done. These activities can take a range of forms, but often involve tailoring messages for specific audiences, presenting these in an appropriate format and evaluating their impact.

There are many models for knowledge transfer and exchange available. A model for knowledge transfer and exchange (KTE) developed specifically with palliative care research in mind is the EMTReK (an Evidence-based Model for the Transfer and Exchange of Research Knowledge[24]. The key considerations for knowledge translation that should be considered in the development of future research into OOH palliative care are presented in Figure 1[23]:

- What's the message?
- To whom should the message be transferred?
- By whom should the message be transferred?
- How could this be done?
- What would the expected impact of sharing this message be?

Figure 1 Key considerations for knowledge transfer

What are knowledge transfer activities?

Knowledge transfer activities range widely. They could include, but are not limited to the following:

- writing briefs for policy makers
- developing clinical guidelines for health care professionals
- creating decision aids or infographics for patients
- holding events, webinars, or conferences to share information with different audiences
- building relationships and creating channels of communication between researchers and policy makers (see case study 1)
- making outputs accessible to different audiences (Figure 2).

Tips for making outputs accessible to different audiences
- Identify the audience for research outputs and tailor messages accordingly.
- Use creative and engaging dissemination methods. Go beyond publications and conferences and tailor messaging to different audiences.
- Work with patients and the public as well as professionals to share knowledge in a digestible format
- Make research open access where possible.
- Use case studies as well as numbers.

Figure 2 How to make outputs accessible to different audiences

Useful resources to help in the planning of your own knowledge transfer activities can be found here.

Research to Practice: A Knowledge Transfer Planning Guide (2006) –
developed by the Institute for Work and Health

The Dissemination and Implementation Models in Health Research and Practice webtool –
developed by the University of Colorado, the Washington University Institute for Clinical and Translational Science and at UC San Diego

Four-step knowledge exchange process –
developed and implemented by Marie Curie Research and Policy in Scotland

Recommendation 2: Raise the profile and importance of palliative and end of life care among the public, politicians, policy makers and commissioners

In order to advocate for improvements to OOH services for people with palliative or end of life care needs, delegates at the workshop described a need for a clear campaigning strategy to build public and political support to move palliative and end of life care up the political and health agenda.

In order to reach the audiences necessary to do this, different messages and approaches will be needed. The following are recommendations from delegates about the types of messages that may be useful for different audiences to raise the profile of palliative and end of life care in universal discussions about health care.

Positioning the issue for policy makers, politicians, and commissioners

Delegates at the workshop felt that it would be useful to use different types of evidence to highlight the importance of palliative and end of life care and the impact that poor or limited OOH services may have.

The importance of qualitative data

To do this, delegates suggested using case studies to share patient, carer, and family member experiences of trying to access care out of hours, and the challenges and distress that poor access to services can have.

"Access to information, support and help 24/7 is essential, so why isn't this the case? Amazingly enough, people don't just feel sicker between 9am and 5pm Monday to Friday. Even if it was just a telephone support network, to let the patient know they have someone to speak to and that help is close to hand."

Bereaved family member[21]

Case study one demonstrates the implications for families and individuals of poor access to care outside of working hours for people towards the end of their lives.

Case study one: a carer perspective from the Better End of Life 2021 Report[22]

*"My mother has terminal heart and kidney failure conditions. She now lives at home with us. Before lockdown, my mother received daily community nurse visits, and a professional personal care visit three times a day. This all changed abruptly in March 2020, when the community nurse and professional care visits suddenly stopped without any communication. My wife and I had no other option but to step up to manage all my mother's personal care needs. **We also experienced great difficulties accessing our GP surgery, including 'out of hours' support. This was very stressful and challenging for us.** We were very lucky as we have two nieces who are doctors and they were able to help and guide us on what to do and how to manage her medications."*

Ivan Pantic

Using quantitative data to drive changes in practice

Delegates also recognised the importance of quantitative and economic data when making a case for improved palliative care, both within and outside of working hours. Data gathered from patient safety incidents in the OOH period were identified as being particularly useful for demonstrating the importance of high-quality palliative care support during this time.

Case study two below explores how Marie Curie funded researchers developed a toolkit for reducing patient safety incidents in palliative care delivered out of hours.

Case study two: learning from patient safety incidents to identify changes for end of life care

The analysis of quantitative data is an important part of identifying the nature and causes of unsafe care being delivered to patients who are receiving palliative care from primary-care services outside normal working hours. Researchers from Cardiff University undertook a cross-sectional analysis of patient safety incident reports from the National Reporting and Learning System [23]. The researchers analysed data over a five-year period and identified four main issues that required improvement in the delivery of this kind of care:

Errors in medication provision

Securing access to timely care

Inefficient transfer of information between healthcare teams

Problems with non-medication based treatments like urinary catheters and nasogastric tubes (feeding tubes).

In the study, almost two-thirds of the patient safety incidents reviewed described 'actual harm' to patients, including emotional and psychological distress to them and those close to them. Serious harm (moderate harm or worse) was reported in 129 (12%) of the cases studied while the majority of incidents reported were medication related [23].

Building on this analysis, a 'how to guide' has been produced which aims to help OOH GP practices use easily accessible data, such as patient safety incident reports, to help them form an improvement agenda in relation to OOH palliative and end of life care. When used alongside stakeholder engagement, the analysis of patient safety incidents can form a key role in the diagnostic arm of a quality improvement programme.

Economic data to highlight the impact of poor OOH services

Data outlining the potential implications of poor OOH support for people with palliative or end of life care needs could be useful. Data about groups on other already stretched services, such as accident and emergency departments, could help to build a case for commissioners to raise the profile of palliative care, especially in the OOH period.

Marie Curie estimates that the total cost of emergency admissions for people in the last 12 months of life exceeded £1.2 billion in 2018-19. A 2021 Marie Curie analysis of emergency admissions in the UK found that men, those with less common cancers, and those aged 65-84, can all expect to experience more emergency admissions in the last year of their life. They're also more likely to experience multiple visits to an A&E department. While those with dementia experience fewer admissions, the fact that they spend significantly longer in hospital once admitted than those with other conditions is a further cause for concern. While some of these admissions will have occurred within working hours, a large proportion are likely to have occurred in the OOH period[24].

Shaping the public's knowledge and attitudes towards palliative care

Delegates also emphasised the importance of promoting palliative care, and normalising conversations around death and dying to the general public.

The findings of a study exploring public attitudes towards death and dying in Wales in 2018 (led by Annmarie Nelson at the Marie Curie Centre, Cardiff University), illustrated that people were ready to speak about death and dying. Of the delegates, 72% advocated for normalising talking about death and dying, as well as demystifying death with a positive approach[25]. In 2021, a further study included people from across the four UK nations and showed that 84% of people were comfortable to talk about death and dying. However, only 14% have done so, displaying a huge gap between the proportion of people who say that they are happy to talk about death and dying, and those who do.

Marie Curie's *Talkabout campaign* aims to encourage more conversation about dying, death, bereavement and palliative care. The importance of such campaigns was recognised and delegates suggested a similar campaign targeted at professionals could also be another avenue for shaping public opinion about palliative and end of life care.

Case study three: "Whatever you call it, we should talk about it"

Marie Curie's Talkabout campaign aims to support people in preparing and planning for better end of life. Resources and tools have been developed to encourage people to start having meaningful conversations about death and dying that included a TV and digital advertising campaign, a thought-provoking card game, a planning checklist and information booklet. The campaign also includes the podcasts, blogs, articles, and stories in which people share their experiences in talking about and planning for a better end of life, and dealing with grief and loss..

"Death doesn't only happen to old people. We need to plan for the end of our lives."

Alex Delaney, guest Talkabout blogger

You can read more about the Talkabout campaign including Alex's blog here
https://www.mariecurie.org.uk/talkabout

Sharing information about OOH services

Delegates also felt there was a need to increase the sharing of information, on both national and local levels about existing OOH services, and how people could access them. This was highlighted as important in shaping the public's knowledge and attitudes towards existing OOH services.

Recommendation 3: advocate for improved OOH care for all services, not just palliative and end of life care

While delegates recognised the need to raise the profile of palliative and end of life care services generally, it was also felt that to improve palliative care support OOH, services needed to be improved across the board.

Delegates highlighted how improving general OOH care may positively influence the care received by patients at the end of their lives in that period.

With that in mind, in order to effectively advocate for improvements for OOH services, partnerships with other organisations were suggested. Such partnerships could bring different aspects of health and social care together to put out a united call for improvements in OOH services. Through these partnerships, palliative and end of life care could become part of universal discussions about the future of health and social care services.

3.3.2 **Question 2:** What **gaps in the evidence base** for OOH palliative care remain?

During the workshop, there was much discussion about the evidence gaps that surround how best to provide OOH care for people with palliative and end of life care needs.
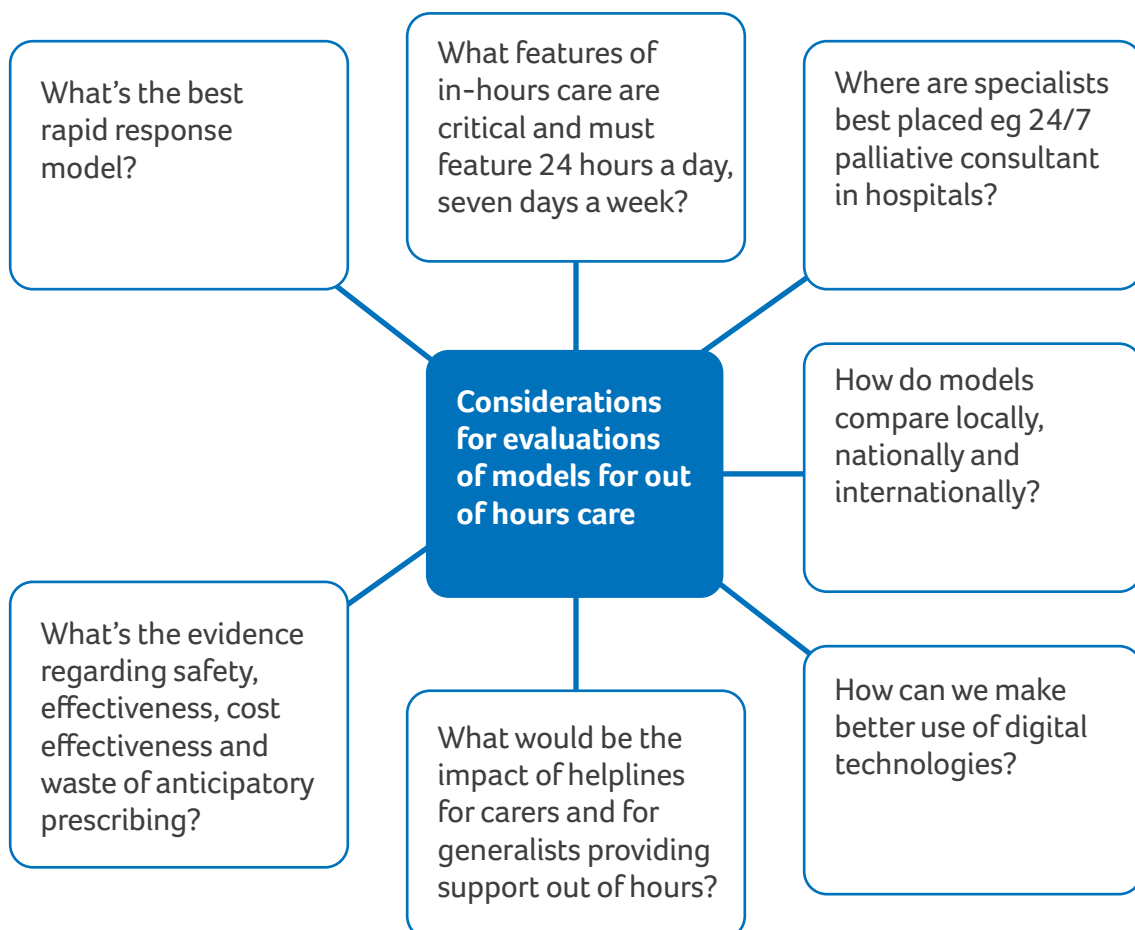
This section provides a summary of the discussions that were held and the gaps in the evidence base around OOH care that were identified.

What are the gaps in the evidence base for palliative care out of hours?

1. Identifying and evaluating models of care

2. Generating data to evidence the need for improved OOH care for people with palliative and end of life care support needs

3. Highlighting other research areas to explore

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1. Identifying and evaluating models of OOH care

Delegates identified the need for robust evaluations of multiple models of OOH care to establish which may have the greatest potential. Within these evaluations, the following were identified as important for consideration:

What's the best rapid response model?

What features of in-hours care are critical and must feature 24 hours a day, seven days a week?

Where are specialists best placed eg 24/7 palliative consultant in hospitals?

Considerations for evaluations of models for out of hours care

How do models compare locally, nationally and internationally?

What's the evidence regarding safety, effectiveness, cost effectiveness and waste of anticipatory prescribing?

What would be the impact of helplines for carers and for generalists providing support out of hours?

How can we make better use of digital technologies?

2. Generating data to evidence the need for improved OOH care for people with palliative and end of life care support needs

Using data to evidence the best ways of addressing known needs

Workshop delegates felt there was work to be done regarding the use of existing data to evidence needs relating to support for people with palliative and end of life care needs in the OOH period. Two types of data were identified by delegate which they felt had the potential to highlight needs and gaps in services: routine data and big data.

Improving routine data and its use

The following recommendations relate to improving data and its use to evidence and support the need for OOH palliative and end of life support services. Further work is needed to ascertain who should be collecting this data, and the methods and standards they should be using to achieve this. However the following recommendations are a useful starting point:

- **National unscheduled care datasets should all include routinely collected palliative care indicators.**

As highlighted in a recent retrospective cohort analysis of unscheduled and out-of-hours care for people in their last year of life, very few national datasets contain information that could indicate whether a person was identified for palliative care[5]. This needs to be addressed to ensure we are able to fully understand access and challenges for OOH care for people with palliative and end of life care needs.

- Routine collection of when people are identified as palliative – how long before death?

Given that palliative indicators seem not to be currently included in national datasets, this presents an opportunity for exploration of which indicators should be routinely collected and included in future analyses.

- Standardised data around hospital admissions, re-admissions, reasons for re-admissions, and pathways

In addition, there's a need for standardisation between settings regarding contacts such as admissions, re-admissions, and care pathways for a full picture to be ascertained.

- **Need for complete and consistent data collection to support work on inequalities**

Research suggests that primary OOH services were used less by people living in the more deprived areas[26]. Gaining a full picture of inequalities and inequities in OOH palliative and end of life care will require ongoing research using population-level data, encompassing all settings, including the community both within and outside of working hours. Workshop delegates emphasised how data around protected characteristics should be routinely and consistently collected to ensure that work on inequalities can be undertaken with the best possible data. Consistency will also be required in the methods and timings of the collection of such data.

Using big data to evidence need

Workshop delegates felt that big data was currently the lacking denominator in evidence around OOH care for people with palliative and end of life care needs. In addition, delegates suggested that data regarding the demand for these services is currently greater than that regarding the use of them, or their outcomes.

The following were suggested as opportunities for increasing the use of big data to explore the need for improved OOH palliative care services:

- **There's a need to expand the research around emergency admissions in the last year of life to look at the time of day that these admissions occurred and whether these were deemed to be necessary or unnecessary admissions.**
- **Linked to this, it would be useful to look at all unscheduled care in the last year of life, not just OOH.**
- **The final aspect of big data suggested by delegates concerned the use of real-time data for improvement.**

3. Other research gaps identified

In addition to the need to identify and evaluate models of care for OOH service provision, four key research gaps were also identified:

Carers	Culturally appropriate end of life care	Risk in out of hours care	Culturally appropriate end of life care
• What are carers' experiences of out of hours care? • The contribution of carers should be included and considered in research studies, especially their economic value. • Carers' experiences should also be the starting point for service design.	• How can we ensure that the care we deliver is culturally compentent?	• Is professional fear of consequences justified? What can be done to mitigate risk in out of hours palliative care? • Exploring team cultures around risk • What's needed for staff to feel comfortable making decisions based on the information in front of them?	• What are the different models for advance care planning that are used in the four nations? • What facilitates or blocks the use of advance care plans in different contexts and with different groups?

> **Research gaps relating to the experience of patients and families during the Covid-19 pandemic**
>
> When this workshop was held, access to health care was quite different to how it currently stands, in the midst of the Covid-19 pandemic.
>
> Additional knowledge and research gaps have been brought into sharp relief by the pandemic and the changing situations in which people find themselves. These include but are not limited to:
>
> - Exploring the experiences of patients and carers during the pandemic and the identification of the right lessons from these experiences that can be taken forward to guide future care and support for people with palliative and end of life care needs.
> - The acceptability and effectiveness of different types of remote consultation and communication.

3.3.3 Question 3: As the evidence base develops, how will we know that the palliative end of life care experience is **improving?**

Linked to gaps in data, the need for standardised outcomes and measures for evaluating OOH services was discussed by delegates as a means to explore whether palliative and end of life care experiences are improving. Central to this discussion was consideration of any outcome measures that may be less helpful for identifyng improvements in palliative care experience.

Delegates suggested looking at routine data, monitoring the use of advance care plans and establishing and monitoring quality measures could all be useful for assessing whether palliative and end of life care experiences are improving.

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How will we know that the palliative and end of life care experience is improving?

1. Using routine data

2. Monitoring the use of advance care plans

3. Establishing and monitoring quality and experience measures

1. Using routine data

a. Expanding the use of routine data – unscheduled care use

Delegates agreed that the improvement and assessment of key method routine data, such as the collection of prognostic indicators and the consistent recording of data around emergency admissions, would be essential in helping us to monitor changes and improvements in care accessed out of hours by patients with palliative and end of life care needs.

It was also highlighted that it would be essential to be able to distinguish between 'necessary' and 'avoidable' admissions, from the point of view of both clinicians and patients and those close to them. Furthermore, the use of unscheduled care within working hours, as well as outside of working hours would be needed for assessments of quality of care to be made.

b. Place of death as an outcome measure

There was discussion around the usefulness of place of death as an outcome for measuring the success of palliative and end of life care both within and outside working hours. Place of death may previously have been used as an indicator of high-quality palliative care. However, as outlined in our recent report 'A place for everyone'[26], it's vital to recognise that dying at home is not the simple indicator of a good experience at the end of life that it's often assumed to be. Failing to recognise this will mean people who don't have the option of being cared for and dying at home, or who choose not to, won't get the quality of experience they should expect.

2. Advance care plans

a. Monitoring the use and impact of advance care plans

Workshop delegates felt that monitoring the numbers of advance care plans being completed, exploring whether or not they are followed and also the impact that they may have had could be strong indicators for improvement in palliative and end of life care, especially in the OOH period. There was discussion about the different tools being used in different nations to assist with advance care planning and the possibility of comparing completion and follow rates for each.

b. Increased training and support for a range of professional groups about the different tools available for advance care planning

Workshop delegates felt that in order to promote the use of advance care plans, training for a range of professional groups about the different tools available for advance are planning (eg Coordinate my Care, KISS summaries etc) was required. Paramedics in particular were identified by delegates as a group that may benefit from training in this area, in relation to the OOH period.

3. Establishing and monitoring quality and experience measures

a. The need for both patient, family and staff experience outcome measures as well as process measures

In order to evaluate support during the OOH period for palliative or end of life care patients and their families, workshop delegates described how it would be essential to establish sound and robust benchmark measures against which to monitor progress.

Specific types of outcomes identified by workshop delegates included quality of life for patients and those close to them, as well as patient and family experiences of, and satisfaction with, care, stress and anxiety, exploration of bereavement and complicated grief. The group felt that existing frameworks and tools could be beneficial, as long as they were being used consistently across patient groups and settings.

Workshop delegates also felt it would be important to explore the confidence and competence of health care professionals, from different backgrounds with regards to the delivery of OOH support for this group in a consistent manner. Furthermore, process level outcomes such as patient contact with services and avoidable unscheduled admissions were also thought to be potential indicators of the quality of care received by those with palliative or end of life care needs.

4. Recommendations for practice

In addition to answering the three questions above, several recommendations for practice were identified by workshop delegates that fell outside of our key questions.

> **Recommendations for taking research findings forward into policy and practice**
>
> 1. Build knowledge transfer and exchange into the design of research
>
> 2. Raise the profile and importance of palliative care among the public, politicians/ policy makers and commissioners
>
> 3. Advocate for improved OOH care for all services, not just palliative care

Recognising and supporting the role of carers

Delegates felt strongly that carers need to be recognised as members of the caring team due to the invaluable role they play in the experience of the patient. During the OOH period, delegates felt this role played even greater significance, with carers often playing the role of 'co-ordinator' for their loved ones when continuity between the people and services caring for them, and the information they have, are missing.

In recognition of the role of carers, delegates felt they could be offered training or information about various aspects of navigating care during (and beyond) the OOH period. They also felt that carers should have easy access to a 24-hour telephone helpline, specifically related to supporting someone with palliative and end of life care needs. Delegates felt that capturing and evaluating the experiences of carers could be a useful indicator of the quality of palliative or end of life care.

From specialist to generalist in community teams

Other recommendations from workshop delegates included focusing on the development of OOH community services (community teams, care and nursing homes and staff in sheltered accommodation). Embedding palliative care nurses in generalist community OOH teams was one suggestion for how to better share expertise across services.

A related suggestion was to provide training and support to upskill all generalists in the community team on the basics of palliative care, to build skills and confidence in supporting people with those care needs. This might include providing telephone access to palliative care specialists in the OOH period, to generalists can specialist support when they need it. An example was given of Healthcare Assistant visiting a patient with palliative care needs in the OOH period, who had telephone support from a palliative care specialist.

Brian Morrison/Marie Curie

Utilising technology

Over the course of the Covid-19 pandemic, we've seen how technology can be utilised to reach people in challenging situations. Workshop delegates felt that the potential of digital consultations to reach a wider range of people and filling workforce gaps could be explored to improve support during the OOH period. Delegates also highlighted how electronic data-sharing systems such as Key Information Summary (KIS) and Coordinate my Care are available and in place in some locations.

The role of volunteers

The final recommendation included a greater potential role for volunteers. Suggestions included acting as care navigators. Delegates felt that this was an area that required further investigation and consideration.

5. The impact of the Covid-19 pandemic

Since this workshop was held, the COVID-19 pandemic has changed many aspects of how support is accessed and delivered for those with palliative and end of life care needs, both within and outside of working hours. Progress has been made regarding many of the recommendations for practice identified in the workshop, simply because there has been no other choice. Multi-professional teams have been forced to integrate and innovate in ways that we haven't seen before.

The use of technology in particular has been greatly accelerated by the pandemic, both in terms of communication within palliative care teams[27] and between health care providers and patients and families[28]. The number of virtual consultations for people with palliative and end of life care needs has increased dramatically, and many palliative and end of life care services reported an increase in activity during the pandemic[22].

However, it's clear that work remains to ensure that people with palliative and end of life care needs, and their families and loved ones, are able to access support when and how they need it.

6. Conclusions

This report outlines the themes and discussions from a workshop held in January 2020. That workshop explored recommendations for research, policy and practice on how best to evidence the need for OOH support for people with palliative and end of life care needs, their families, carers and loved ones. It also explored how to improve and then evaluate this care.

As outlined in our Better End of Life Report 2021, improving OOH support for people at the end of life will require a whole system approach to palliative and end of life care that includes the whole health and social care system, not just the palliative and end of life care sector. As part of this approach, arrangements for Integrated Care Systems set out in the Health and Care Bill should be used to ensure that local systems place the needs of people at the end of life at the centre of their governance, staffing and commissioning arrangements.

7. Next steps

Research

This report outlines key areas and questions to be considered in future research exploring palliative care access and delivery in the OOH period. In particular, Marie Curie are interested in exploring the challenges of receiving care OOH for those that live alone, or in rural areas. We're also interested in exploring and evaluating models for rapid response services, the use of real-time data for improvement and the support provided to health professionals to mitigate risk in OOH services.

Three further grants have been awarded by Marie Curie in 2019 which, due to the Covid pandemic, could only start in 2021. Their details are included in the appendix.'

Policy

Addressing the issues experienced and described by workshop delegates around OOH palliative care will require improved OOH services across the board. This includes making sure palliative care services – both within and outside of the NHS – are resourced appropriately, recognising the important role that family members and care givers provide in palliative and end of life care. It also includes ensuring that data systems include information on dying, death and bereavement outcomes.

References

1. Brettell R, Fisher R, Hunt H, Garland S, Lasserson D, Hayward G. What proportion of patients at the end of life contact out-of-hours primary care? A data linkage study in Oxfordshire. BMJ open. 2018;8(4).

2. Green E, Ward S, Brierley W, Riley B, Sattar H, Harris T. "They shouldn't be coming to the ED, should they?": a descriptive service evaluation of why patients with palliative care needs present to the emergency department. American Journal of Hospice and Palliative Medicine®. 2017;34(10):984-90.

3. Addington-Hall J, Gerard K, Brien S, Brailsford S, Salisbury C, Heaney D, et al. Variations in out of hours end of life care provision across primary care organisations in England and Scotland. Final Report. NIHR Service Delivery and Organisation Programme. 2013.

4. D L, F W. Dying still doesn't work 9-5. What's changed since 2014. Sue Ryder; 2016.

5. Mason B, Kerssens JJ, Stoddart A, Murray SA, Moine S, Finucane AM, et al. Unscheduled and out-of-hours care for people in their last year of life: a retrospective cohort analysis of national datasets. BMJ Open. 2020;10(11):e041888.

6. National Palliative and End of Life Care Partnership (2015) Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020. https:// endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for- Palliative-and-End-of-Life-Care.pdf.

7. In and out of hospital: Understanding disparities in emergency admissions in the final year of life. Marie Curie; 2018

8. PeolcPSP. Priority Setting Partnership with the James Lind Alliance. Palliative and end of life care Priority Setting Partnership (PeolcPSP) [version 1; not peer reviewed]. AMRC Open Res 2020, 2:14 (document); 2015.

9. Worth A, Boyd K, Kendall M, Heaney D, Macleod U, Cormie P, et al. Out-of-hours palliative care: a qualitative study of cancer patients, carers and professionals. British Journal of General Practice. 2006;56(522):6-13.

10. Hudson BF, Best S, Stone P, Noble T. Impact of informational and relational continuity for people with palliative care needs: a mixed methods rapid review. BMJ Open. 2019;9(5):e027323.

11. King N, Bell D, Thomas K. Family carers' experiences of out-of-hours community palliative care: a qualitative study. International journal of palliative nursing. 2004;10(2):76-83.

12. Van Godwin J, Sivell S, Byrne A, Nelson A. PeolcPCP Out of hours emergency and support sub-theme (internal report). Marie Curie Palliative Care Research Centre, Cardiff University School of Medicine; 2015.

13. Richards SH, Winder R, Seamark C, Seamark D, Avery S, Gilbert J, et al. The experiences and needs of people seeking palliative health care out-of-hours: a qualitative study. Primary health care research & development. 2011;12(2):165-78.

14. Richards S, Pound P, Dickens A, Greco M, Campbell J. Exploring users' experiences of accessing out-of-hours primary medical care services. BMJ Quality & Safety. 2007;16(6):469-77.

15. Seamark D, Blake S, Brearley SG, Milligan C, Thomas C, Turner M, et al. Dying at home: a qualitative study of family carers' views of support provided by GPs community staff. Br J Gen Pract. 2014;64(629):e796-e803.

16. NICE. Improving supportive and palliative care for adults with cancer. CSG4. https://www.nice.org.uk/guidance/csg42004.

17. Palliative Care Evidence Review Service. A rapid review: What is the impact and effectiveness of the 7 Day CNS services have on palliative care patients and their families? Cardiff: Palliative Care Evidence Review Service (PaCERS); 2018 May. http://palliativecare.walescancerresearchcentre.com/uploads/Rapid_Review/CNSS_7_day_Report_FINAL.pdf.

18. Johnston B, May P, McCauley R, McQuillan R, Rabbitte M, Honohan C, et al. Out-of-hours specialist and generalist palliative care service provision. An evidence review. Dublin Health Research Board 2019.

19. NICE. End of life care for adults: service delivery. Evidence review: Out of hours services. 2019.

20. Todd Fordham F CB, McMillan S et al. Does current palliative and end of life care research match the priorities of patients, carers and clinicians? A grant mapping analysis of the UK Clinical Research Collaboration's Health Research Classification System) dataset 2014 [version 1; not peer reviewed] AMRC Open Res 2020, 2:17 (document) (https://doiorg/1021955/amrcopenres11149151. 2020.

21. Nelson A. Beyond the questions Shared experiences of palliative and end of life care. Marie Curie; 2016.

22. Sleeman KE, Murtagh, F.E.M., Kumar, R., O'Donnell, S., Cripps, R.L., Bone, A., McAleese, J., Lovick, R., Barclay, S., Higginson, I.J. (King's College London, Cicely Saunders Institute; Hull York Medical School, University of Hull; and University of Cambridge, UK). Better End of Life 2021. Dying, death and bereavement during Covid-19. Research report. London (UK): Marie Curie; 2021 April.

23. Yardley I, Yardley S, Williams H, Carson-Stevens A, Donaldson LJ. Patient safety in palliative care: A mixed-methods study of reports to a national database of serious incidents. Palliative Medicine. 2018;32(8):1353-62.

24. Payne, C., Brown, M. J., Guerin, S., & Kernohan, W. G. (2019). EMTReK: An Evidence-based Model for the Transfer & Exchange of Research Knowledge - Five Case Studies in Palliative Care. SAGE open nursing, 5, 2377960819861854.

25. Islam I, Nelson A, Longo M, Byrne A. Before the 2020 Pandemic: an observational study exploring public knowledge, attitudes, plans, and preferences towards death and end of life care in Wales. BMC Palliative Care. 2021;20(1):116.

26. Stone V. A Place for Everyone - What stops people from choosing where they die? A review of the barriers to good end of life care facing diverse groups in the UK. Marie Curie; 2020.

27. Crosby B, Hanchanale S, Stanley S, Nwosu A. Evaluating the use of video communication technology in a hospital specialist palliative care team during the COVID-19 pandemic [version 1; peer review: 1 approved, 1 approved with reservations]. AMRC Open Research. 2021;3(5).

28. Hawkins JP, Gannon C, Palfrey J. Virtual visits in palliative care: about time or against the grain? BMJ Supportive; Palliative Care. 2020;10(3):331-6.

29. Williams H, Donaldson SL, Noble S, Hibbert P, Watson R, Kenkre J, et al. Quality improvement priorities for safer out-of-hours palliative care: Lessons from a mixed-methods analysis of a national incident-reporting database. Palliative medicine. 2019;33(3):346-56.

30. Hasson F, McIlfatrick S, Payne S, Slater P, Finlay D-A, McConnell T, et al. Protocol for a mixed methods exploratory investigation into the role and contribution of the healthcare assistant in out-of-hours palliative care. BMC Nursing. 2021;20(1):55.

31. Fee A, Muldrew D, Slater P, Payne S, McIlfatrick S, McConnell T, et al. The roles, responsibilities and practices of healthcare assistants in out-of-hours community palliative care: A systematic scoping review. Palliative Medicine. 2020;34(8):976-88.

32. Felicity H, Paul S, Anne F, Tracey M, Sheila P, Dori-Anne F, et al. BMC Palliative Care. 2021.

33. Papavasiliou E, Hoare S, Bowers B, Kelly MP, Barclay S. Out-of-hours services and end-of-life hospital admissions: a complex intervention systematic review and narrative synthesis. British Journal of General Practice. 2021:BJGP.2021.0194.

Appendix

Topic	Aims	Authors	Year	Methods	Stage	Key results	Outputs
Patient safety incidents in OOH care	To explore the nature and causes of unsafe care delivered to patients receiving palliative care from primary-care services outside normal working hours.	Dr Huw Williams	January 2107 – April 2019	A mixed-methods cross-sectional analysis of patient safety incident reports from the National Reporting and Learning System	Complete	Incidents included issues with: • medications; • access to timely care; • information transfer, • and/or non-medication-related treatment Almost two-thirds of reports described harm with outcomes such as increased pain, emotional, and psychological distress featuring highly. Commonly identified contributory factors to these incidents were a failure to follow protocol, lack of skills/confidence of staff, and patients requiring medication delivered via a syringe driver.	Peer reviewed papers[23, 29] Quality improvement toolkit developed for OOH services

Topic	Aims	Authors	Year	Methods	Stage	Key results	Outputs
The role of health care assistants in OOH community palliative care	To examine the role, contribution, and impact of healthcare assistants within out-of-hours palliative care, based in the community.	Dr Felicity Hasson	January 2019 – July 2021	Literature review, survey of health care assistants, development of case studies and a workshop	Ongoing	Scoping review themes: • Lack of recognition of the role and contribution of healthcare assistants. • Healthcare assistants continually monitored and responded to patient's and family's physical and emotional needs; • Self-reported evidence indicating patient and family benefit, such as maintaining a sense of normality and support to remain at home. Covid-19 impact on out-of-hours community-based palliative care: • Hospices reconjured services; redeployed staff; and introduced new policies and procedures to minimize virus transmission. • Lack of integration between charitably and state funded palliative care providers. The interconnected issues of the use and availability of Personal Protective Equipment (n=21) and infection control screening (n=12) resulted in changes in nursing practices due to fear of contagion for patients, carers and staff.	Publications to date: Protocol for a mixed methods exploratory investigation into the role and contribution[30] The roles, responsibilities and practices of healthcare assistants in out-of-hours community palliative care: A systematic scoping review[31] The Impact Of Covid-19 On Out-Of-Hours Adult Hospice Care: An Online Survey[32].

Topic	Aims	Authors	Year	Methods	Stage	Key results	Outputs
OOH service development in Scotland *	To examine the Scottish OOH service as it currently operates before proposed changes are implemented and explore how OOH services are understood and used by service users with PEoLC needs to inform redesign of health and social care delivery OOH.	Professor Scott Murray	April 2017 – May 2019	Quantitative analyses of Scottish OOH service use in the last year of life and qualitative study involving patients and carers	Complete	**Use and costs of unscheduled care services** Over 95% of people who died in Scotland in 2016 needed unscheduled care during their last year of life. Over 400,000 episodes of unscheduled care were delivered (Eight per person); a third in the last month of life. People with lung, heart or liver problems and their carers tended to phone for an ambulance and went to A&E, while people with frailty or dementia living at home or in care homes tended to use NHS24 and be treated by the Primary Care OOH service (PCOOH). People with cancer sometimes had direct access to hospital during their treatment, so they used NHS24 less. People from poorer areas used unscheduled care nearly twice as much as those from richer areas. Total unscheduled care costs in the last year of life were nearly £176 million; with only 6% for primary care services: NHS24 and PCOOH. *continued on next page*	Unscheduled and out of hours care for people in their last year of life: a retrospective cohort analysis of national datasets[5].

Topic	Aims	Authors	Year	Methods	Stage	Key results
						Experiences of services
						Most people reported positive experiences of care. Some were frustrated at delays, waiting for calls back and repeating medical details. Several carers had difficulties with call-handlers insisting on speaking with ill people.
						Primary care workload sometimes affected availability of electronic care plans for unscheduled services, although professionals considered these important. PCOOH and NHS24 services wanted to provide quicker advice and better care but lacked resources.
						Understanding the system
						Most delegates lacked understanding of how unscheduled care works. Several delegates spoke about not wanting to go to hospital but needed reassurance and care quickly if situations changed unexpectedly. This sometimes meant they called an ambulance, or rushed the patient to A&E. The carer often made the decision to call.
						The service they chose greatly affected outcomes. Better access to assessment and treatment in the community would benefit patients/ carers and prevent some admissions, potentially saving millions of pounds.

Topic	Aims	Authors	Year	Methods	Stage	Key results	Outputs
Community based palliative care	To understand different models of 'out-of-hours' community-based specialist palliative care (SPC), develop a typology for these models, and compare the experience of patients and families from differing models of 'out-of-hours' care.	Professor Richard Harding and Dr Fliss Murtagh	February 2019 – January 2022	A systematic review, qualitative interviews, and a Delphi study	Ongoing		

Topic	Aims	Authors	Year	Methods	Stage	Key results	Outputs
Hospital admissions for end of life patients	To identify and draw together what is currently known about out-of-hours end-of-life admissions and discover knowledge gaps	Dr Sarah Hoare	April 2019 – March 2020	Systematic review	Complete	Admissions were instigated primarily to address: • Clinical needs • Caregiver and/or patient distress • Discontinuity or unavailability of care provision and were arranged by a range of out-of-hours providers. Further research is therefore necessary to understand the complexities of out-of-hours services-initiated end-of-life care hospital admissions and how the challenges underpinning such admissions might best be addressed	Out-of-hours services and end-of-life hospital admissions: a complex intervention systematic review and narrative synthesis[33].

New awards

Professor Amanda Clarke and Mrs Joanne Atkinson, Northumbria University
Rapid response service models in end of life care: what works for whom and in which circumstances?

Dr Sarah Yardley, UCL
Getting prescription medications right at home, in hospital and hospice: an activity theory analysis to improve patient safety and confidence in palliative care

Dr Kirsty Boyd, University of Edinburgh
Implementation of an integrated care planning and electronic care coordination intervention in primary care for people living at home or in a care home at risk of deteriorating or dying: mixed-method study across Scotland (4-ACP)

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