





The impact of the Covid-19 pandemic on specialist palliative care services and how they have responded

Prof Katherine Sleeman

Laing Galazka Chair in Palliative Care King's College London Cicely Saunders Institute

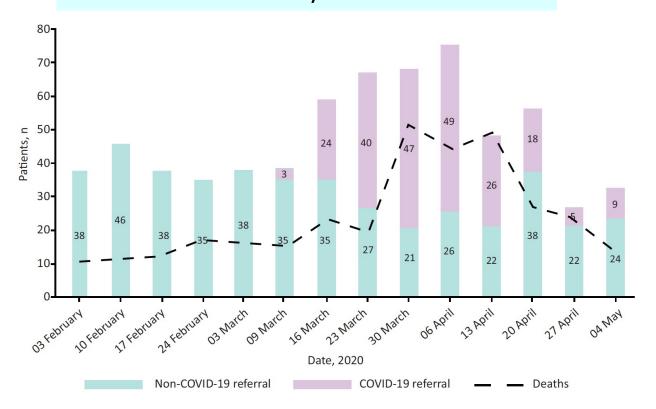
Honorary Consultant in Palliative Medicine King's College Hospital NHS Trust

www.csi.kcl.ac.uk

Palliative care services have an essential front-line role... but early on this was not recognised



Locally: Sudden increase in palliative care team clinical activity from March 2020



Nationally: Essential front-line role of palliative care not recognised; palliative care community came together to raise awareness of needs and search for solutions





Urgent need for **research** to guide care and services

Edmonds PM, Sleeman KE, Lovell N, et al. The impact of and response to the COVID-19 pandemic on a hospital palliative care team. Future Healthc J. 2021 Mar;8(1):62-64.

March 2020: Rapid systematic review identified priorities for palliative care pandemic response



SYSTEMS

Policies

- **Maintain** flexibility and the ability to rapidly modify or implement new policies, such as changes to admission criteria.
- If visiting hours are limited, consider providing daily telephone support to families.

Training and protocols

- Provide protocols for non-specialists on symptom management and provide basic palliative care training including communication
- Consider separate guidelines for specific populations such as those in care homes

Communication and coordination

- **Identify** a key decision maker to improve communication, particularly if multiple professionals are involved outside of their usual practice
- Involvement in triage systems to assess likelihood of response to treatment and risk of dying
- Share protocols and advice within organisations

Data

Standardise information collection & monitoring to inform operational changes
(for example number of patients seen, main symptoms and concerns, treatments, effectiveness of treatment,
and outcomes)

SPACE

Maintain ability to move resources between settings

- Consider moving resources from inpatient to community setting according to need
- **Ensure** palliative care services are integrated into new systems for care, including community care centres and temporary hospitals

Technology

- Use virtual technology to enable communication when visiting is restricted

STAFF

Deployment

- Deploy staff flexibly between palliative care settings according to need
- Prioritise sufficient staff numbers
- If patient contact with volunteer services needs to be restricted, consider alternative roles for example psychological support, bereavement support

Skill mix

Involve chaplains and psychologists with specialist palliative care expertise

Resilience

- Facilitate camaraderie, promote connectedness, develop systems for reducing stress, and support non-specialist staff
- Provide training in communication and bereavement

Rapid systematic review of role and response of hospice and palliative care services in epidemics

STUFF

Medicines and equipment

- Include relevant symptom medications in formularies (to treat breathlessness, cough, fever, delirium, anxiety, agitation and pain)
- Ensure supplies of medications, IV and subcutaneous delivery systems and lines

Personal protective equipment

Ensure sufficient supplies of PPE

Etkind et al. 2020. The Role and Response of Palliative Care and Hospice Services in Epidemics and Pandemics: A Rapid Review to Inform Practice During the COVID-19 Pandemic. JPSM, 60 (1).

CovPall study: Rapid evaluation of the Covid-19 pandemic response in PEoLC





Survey of hospice and palliative care services (Apr-Jul 2020); followed by study of symptoms & outcomes; and in depth case studies

458 responses: 277 UK, 85 Rest of Europe, 95 Rest of World

81% had cared for patients with suspected / confirmed COVID-19

Palliative care and hospice services were overwhelmed during the early pandemic but felt overlooked and lacked equipment, PPE, medicines and staff









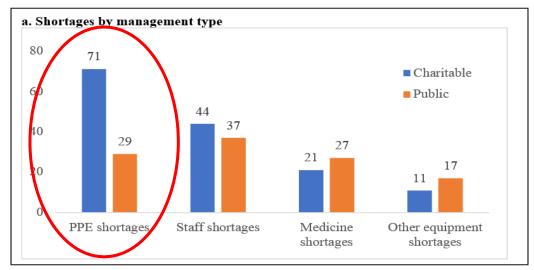


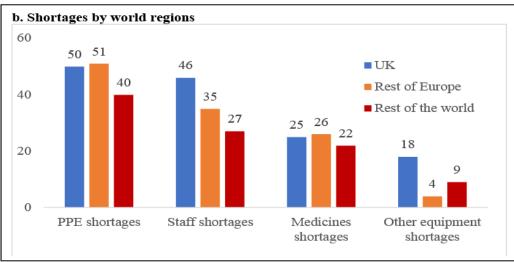






Medical Research Council



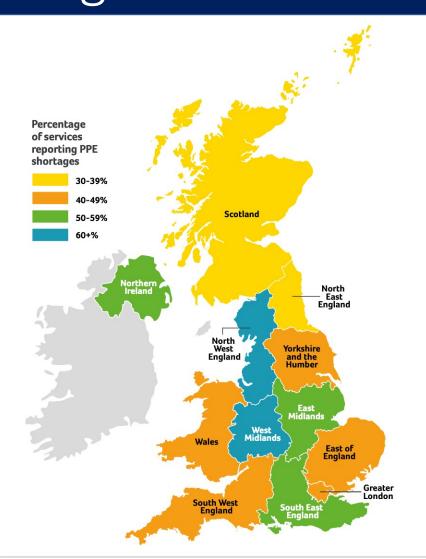




Services felt overlooked, and not recognised as front line NHS







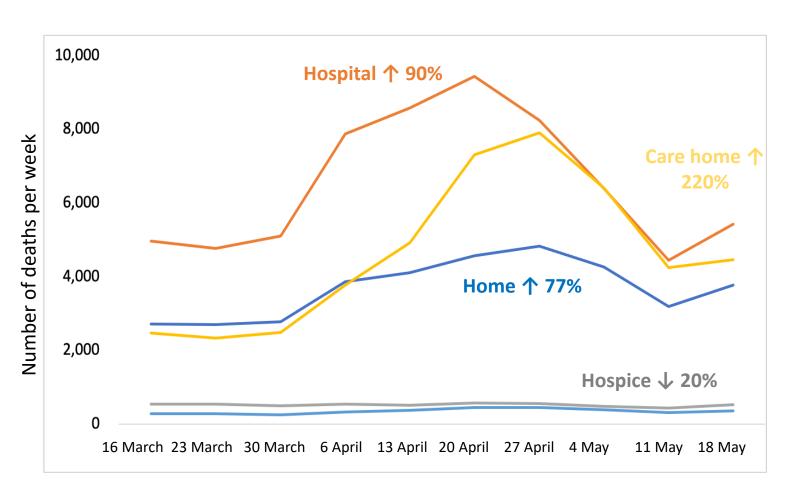
PPE shortages were common, often because services were not recognised as front line

"Masks and gowns – as we are not classed as 'frontline NHS' we were unable to access from our local NHS board. this was less than satisfactory for 7 weeks, however this has now been resolved." (Scotland)

"Tried to liaise with procurements services, NHS suppliers/CCG's/local hospitals, appealing to local community through social media liaising with community groups and other organisations. Drawing on local networks available to us e.g. GP surgeries, schools, dentists, vets, local hardware companies, beauticians." (South East)

Deaths shifted from hospice inpatient units into the community





Population data for England and Wales

Number of deaths per week in care homes, hospitals and at home increased

Hospice deaths fell by 20% during first wave of Covid-19

Bone AE et al. 2020. Changing patterns of mortality during the COVID-19 pandemic: Population-based modelling to understand palliative care implications. Pall Med.

Hospice and palliative care services reported being more busy than before the pandemic

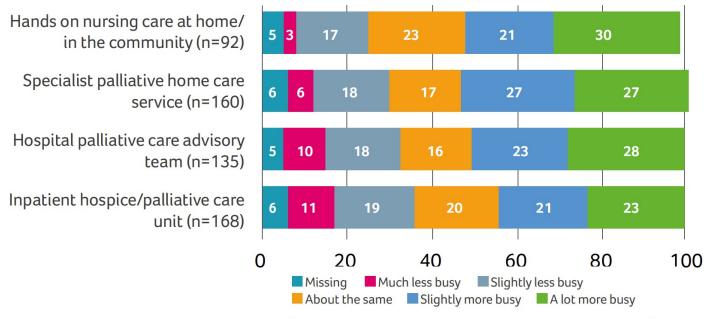


CovPall data for UK services

48% (133) reported being more busy

Busyness was consequence of:

- Shifting resources in response to needs
- Telephone and remote working
- Educating, upskilling and supporting



Due to rounding, percentages may not total 100%.

"One hospice unit has closed and the other has had to reduce beds [as they are] too close together. This has led to increase in community workload with more complex and unwell people at home requiring assessment, care coordination, clinical decision making and support." (Scotland)

"We are supporting patients to remain in their usual place of care, home or care home. Patients/carer have been more psychologically distressed, and this is requiring more prolonged non face-to-face consultations." (North East)

"We have also been engaging in much more education to healthcare professionals across all settings, including the care homes." (Wales)

Hospice and palliative care services made rapid changes and 'frugal innovations'





Services made rapid changes within a context of *crisis*

Services have been flexible, highly adaptive and have adopted a 'frugal innovation' model

Hospices used, adjusted and recombined existing resources, structures and processes to deliver care.

'The crisis context'

Barriers to change

- Fear and anxiety
- Duplication of effort
- Information overload
- IT infrastructure issues
- Funding issues

Changes involved

- Streamlining access
- Extending services
- Increasing outreach
- Using communication technology
- Implementing innovations for staff wellbeing

Enablers to change

- Pooling of staffing resources
- Staff flexibility
- Pre-existing IT infrastructure
- Collaborative teamwork
- Strong leadership

Dunleavy et al. 2021. 'Necessity is the mother of invention': Specialist palliative care service innovation and practice change in response to COVID-19. Results from a multinational survey (CovPall). Pall Med, 35 (5)

Palliative care and hospice services experiences of advance care planning





277 UK hospice and palliative care services; 38% did more direct advance care planning; 59% provided more support to others

Specialist palliative care teams/personnel with experience in advance care planning

Within teams and services

Training, education and support

- Anticipatory prescribing
- Approaching difficult conversations
- Webinars
- Signposting to already existing resources
- Treatment escalation planning
- Role play discussions
- General advance care planning support and advice

Care Homes

- · Hands-on support
- Teaching and education on:
 - Having remote conversations
 - Treatment escalation planning
 - Communication skills
 - Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) forms
 - Role modelling

Between teams and services

- Hands-on support
- Teaching and education on:

Hospitals

- Managing patient distress
- Treatment escalation planning

General Practitioners

- Advisory support
- Teaching and education on:
 - Adopting an individualised approach
 - · Communication skills
 - Electronic documentation

Community staff

General education and support

collaborative approach...' [Mixed setting Palliative Care Team, Adult Service, Wales]

'...on the ground

care homes. This

support in the

has been a

Clinical Commissioning Groups

- Strategic advice
- Development of guidance

Paediatricians

- Support on beginning conversations
- Ethical decision making for parents

Mental health units

 General support and education

End of life care teams

 General support of advance care planning

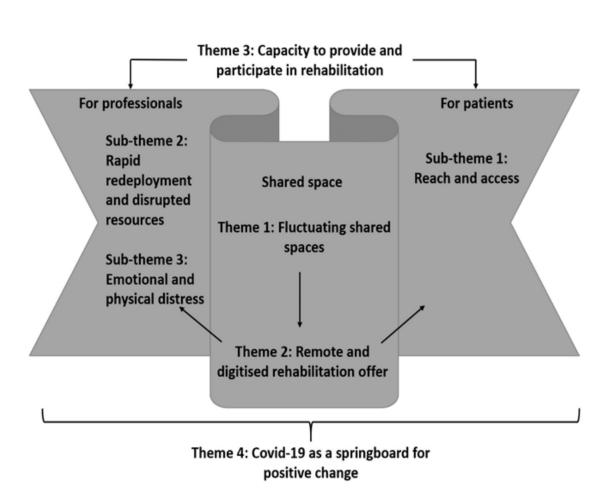
General support between services

- Sharing resources online
- Developing and reviewing advance care planning guidance
- General teaching and support

Bradshaw et al. 2021. Understanding and addressing challenges for advance care planning in the COVID-19 pandemic: An analysis of the UK CovPall survey data from specialist palliative care services. Palliative Medicine 35(7) 1225 –1237.

CovPall-Rehab study: Impact on delivery of rehabilitation within palliative care services





Online survey, 61 rehabilitation services, 56 in hospices

Rapid adoption of digital and remote care delivery by rehabilitation teams changed capacity to provide and participate in rehabilitation

For some groups this led to enhanced access, teams could expand and reach new people (e.g., in rural areas, younger, unable to travel to the hospice building)

For others, there were concerns about a digital divide (e.g. with communication difficulties, no access to internet)

Hybrid models may expand the equity of access and reach of rehabilitation within specialist palliative care

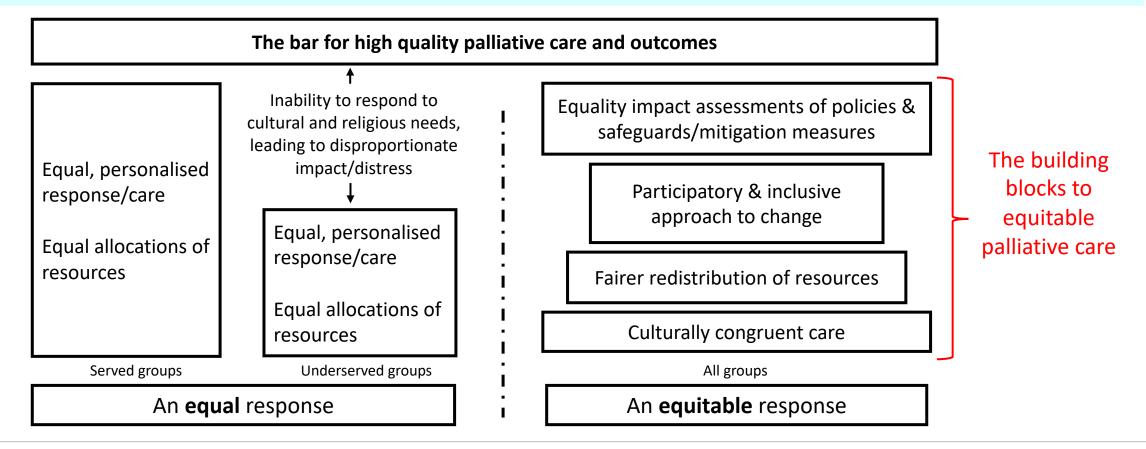
Bayly J, Bradshaw A et al. Understanding the impact of the Covid-19 pandemic on delivery of rehabilitation in specialist palliative care services: An analysis of the CovPall-Rehab survey data. medRxiv doi.org/10.1101/2021.04.13.21255380;

The response of services to people from ethnic minority groups





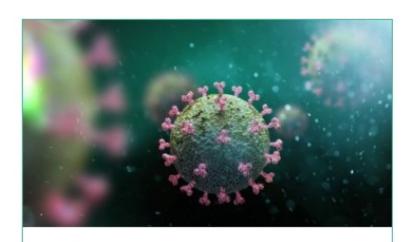
277 UK services; 34% had cared for people with Covid-19 from ethnic minority groups
Restricted visiting and communication challenges impacted disproportionately on ethnic minority groups
Findings identify need for *equitable* (not just equal) palliative care response



Bajwah S, et al. 2021. Equal but inequitable: response of specialist palliative care and hospice services to people from ethnic minority groups with COVID-19. . BMJ SuPaC

CovPall-Connect study: Evaluation of the Covid response, connecting to boost impact and data assets





News

Health Data Research UK selects 12 projects to accelerate use of data for vital COVID-19 research

21 December 2020

12 urgent research projects are to receive new funding following a rapid call for COVID-19 data research initiatives by Health Data Research UK, Office for National Statistics and UK Research and... HDRUK funded project

We will link CovPall data to other sources of nationally collected data (ONS mortality, HES data)

What is the relationship between palliative care responses to Covid-19 and outcomes such as admissions, discharges, place of death?



















Conclusions



- Palliative care and hospice services have had essential, front-line roles during Covid-19...
- ...but they felt overwhelmed during the early pandemic, overlooked, and lacked equipment, PPE, medicines and staff
- Care shifted from inpatient hospice settings into the community
- Hospice and palliative care services made rapid changes, adopting a 'frugal innovation' model
- Services provided direct and indirect care, collaborating across settings
- Disproportionate impact on ethnic minority groups, highlighting need for equitable care
- CovPall study highlights the power of clinical-academic collaborative research

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Contact me:

katherine.sleeman@kcl.ac.uk

@kesleeman