NETWORK RECORDING DECLARATION

During this ECHO session discussions will be recorded so that people who cannot attend will be able to benefit at another time. Filming is regarded as ‘personal data’ under the General Data Protection Regulations (GDPR) under that law we need you to be aware that this Data will be stored with password protection on the internet.

This Data will be available for as long as your network continues to meet and will then be taken down from the internet and either stored securely at the Superhub or deleted.

Your ongoing participation in this ECHO session is assumed to imply your agreement to the use of your data in this way.

If you are NOT willing for your data to be used in this way, please LEAVE the session at this point.

www.hospiceuk.org
February 9, 2022

How do we continue to do this with compassion?

RESPONDING
- Evidence Update Max Watson
- Palliative Care Research Kate Flemming

RECOVERY – Partnerships & Research
- Lancet Commission Libby Sallnow
- Inequalities of access review Madeleine French
- Care after death guidance Theresa Mann

RENEWAL –

Breakout discussion & Chatbox

How are we managing the transition from Pandemic to Endemic for Patients, Staff and Services?

Chat Box
- Your Questions
- Resources
- Information /innovations
- Email clinical@hospiceuk.org

Please share resources, powerpoint, links etc. with those who would benefit
The terminally ill fear the unknown more than the known, professional disinterest more than professional ineptitude, the process of dying more than death itself.

-Derek Doyle
CHATBOX & BREAKOUT

How will we manage the transition from Pandemic to Endemic for Patients, Staff and Services?

High rates of PTSD across NHS Staff

Safety in uncertainty

“Don’t want to be the first or the last to ease up restrictions”

Compassionate Leadership?

Visiting?

What will we stop doing and when?

PPE & Testing?
Update
6th February 2022

2 Billion more vaccinations administered

87 million infected in last month
(15 million in November)
Wanting it to be over ≠ being over

Covid-19 in the UK

- Daily cases: 60,578 (-15,491 vs last week)
- Daily deaths: 259
- Total deaths: 158,243

Vaccination rollout

- Received 1st dose: 78.1%
- Received 2nd dose: 72.4%
- Received 3rd dose: 55.9%

UK: which areas are hardest hit?

Click to show data for each area, double click or pinch to zoom in

Vaccinations: Rate per 100k last week

Cases and deaths as published 5 Feb 2022. Vaccinations as % of total population (including under 18s) published 4 Feb 2022. Weekly change shows difference from 7 days ago. Source: data.gov.uk.

Trisha Greenhalgh @trishgree 1d
Two years ago, could you have imagined a pandemic causing 379 deaths in a single day (UK), with politicians insisting the disease was “mild” and nobody in the media reporting it?
Situation by WHO Region

- **Europe** - 151,505,696 confirmed
- **Americas** - 138,060,024 confirmed
- **South-East Asia** - 53,006,544 confirmed
- **Eastern Mediterranean** - 19,374,914 confirmed
- **Western Pacific** - 16,468,434 confirmed
- **Africa** - 8,132,586 confirmed

Source: World Health Organization

Data may be incomplete for the current day or week.
Virus
Incubation period
5 days original
4 days delta
3 days omicron

Viral load
3 days peak
6 days alpha and delta
Infected period 1 day shorter and lower peak for Omicron but?
Due to vaccination/previous infection
Omicron variant longer

Pathology
Upper respiratory tract rather than lungs

Consequently less severe, less hospitalisations less ICU
But
Is that due to previous vaccination/infection
Unvaccinated and immunosuppressed still getting very sick and hospitalised
Long COVID unknown

Infectious usually 1-2 days before symptoms and 2-3 days after
Omicron BA.2: What we know about the Covid sub-variant

The latest data from the UK Health Security Agency (UKHSA) suggest that the BA.2 strain of Omicron may be even more transmissible than the original variant. But the good news is that current vaccines appear to offer the same level of protection against symptomatic disease.

According to the agency’s latest technical briefing on novel SARS-CoV-2 variants, a total of 1072 genomically confirmed cases of BA.2 have been identified in England as of 24 January 2022, with the largest numbers in London (34%) and the South East (26.5%).

Due to the relatively small number of confirmed cases, the UKHSA cautions that any conclusions are provisional. But early analyses do suggest an increased growth rate compared with BA.1.

Professor Jonathan Ball, professor of molecular virology at the University of Nottingham, said: "It’s still early days, but the evidence so far suggests that BA.2 may be more transmissible than its close relative Omicron. However, the key issues are whether this variant is associated with more severe disease and if it can escape immunity delivered by vaccines."

“Early indicators suggest that the vaccines will provide similar levels of protection as we have seen for Omicron, so this is good news. Whether or not it causes more severe disease will become apparent as more data is collected.”
Coronavirus waves compared

Cases

Hospitalisations

Deaths

Data: data.gov.uk, updated 26 January, 2022 Each line shows the seven-day average. Alpha wave taken as starting on 12 Dec 2020, Delta wave 15 May 2021 and Omicron wave 11 December 2021. These are the weeks before that particular variant comprised 50% of sequenced cases, as per covid19.sanger.ac.uk.
ADJUSTED SEVERITY of Omicron vs Delta—Need to discuss *intrinsic severity* versus *observed severity* of #Omicron, which reinfects & evasive against 2-vaccine shots. New 🇬🇧 study found that after adjusting for factors, Omicron is only slightly intrinsically milder—2%-12% (red) 👇
Pediatric Patients Currently Hospitalized with Confirmed COVID-19
United States 01-Jan-2021 to 06-Jan-2022
www.covkidproject.org  @covkidproject

Eric Feigl-Ding
@DrEricDing

I hate how leaders are ignoring RECORD HIGH PEDIATRIC #COVID19 HOSPITALIZATIONS. This is not just happening in England but also in France, Spain, US and more. Yet some dismissive soulless ghouls still try to claim kids are “practically immune” or kids overblown!
7-day average of Covid hospital admissions in England since July 2020 for children

- 0-5 yr olds
- 6-17 yr olds

Graph showing the trend of hospital admissions for children in England from July 2020 to January 2022.
Daily Covid hospital admissions in England for all children (0-18 yrs) since the start of the pandemic

More children have been admitted in the last 3 weeks (1,598) than over the whole of the first wave (March – August 2020: 1,333)

Data from https://coronavirus.data.gov.uk/
Pre School Children take longer to recover from COVID-19 Alpha and Delta

OBJECTIVES: To explore whether and for how long use of healthcare services is increased among children and adolescents after covid-19.

DESIGN: Before and after register based study.

SETTING: General population of Norway.

PARTICIPANTS: Norwegians aged 1-19 years (n=706 885) who were tested for SARS-CoV-2 from 1 August 2020 to 1 February 2021 (n=10 279 positive, n=275 859 negative) or not tested (n=420 747) and were not admitted to hospital, by age groups 1-5, 6-15, and 16-19 years.

MAIN OUTCOME MEASURES: Monthly percentages of all cause and cause specific healthcare use in primary care (general practitioner, emergency ward) and specialist care (outpatient, Inpatient) from six months before to about six months after the week of being tested for SARS-CoV-2, using a difference-in-differences approach.

RESULTS: A substantial short term relative increase in primary care use was observed for participants during the first month after a positive SARS-CoV-2 test result compared with those who tested negative (age 1-5 years: 339%, 95% confidence interval 308% to 369%; 6-15 years: 471%, 450% to 491%; 16-19 years: 401%, 380% to 422%). Use of primary care for the younger age groups was still increased at two months (1-5 years: 22%, 4% to 40%; 6-15 years: 14%, 2% to 26%; and three months (1-5 years: 26%, 7% to 46%; 6-15 years: 15%, 3% to 28%), but not for the oldest group (16-19 years: 11%, -2% to 24% and 8%, -7% to 19%, respectively). Children aged 1-5 years who tested positive also showed a minor long term (≥6 months) relative increase in primary care use (13%, -0% to 26%) that was not observed for the older age groups, compared with same aged children who tested negative. Results were similar yet the age differences less pronounced compared with untested controls. For all age groups, the increase in primary care visits was due to respiratory and general or unspecified conditions. No increased use of specialist care was observed.

CONCLUSION: Covid-19 among children and adolescents was found to have limited impact on healthcare services in Norway. Preschool aged children might take longer to recover (3-6 months) than primary or secondary school students (1-3 months), usually because of respiratory conditions.
REACT study

Fall in coronavirus infections in England may have stalled at high level - REACT
by Justine Alford
20 January 2022

More than 2 million people tested
Latest findings first 2 weeks of Jan 2022
100 000 PCRs

1:23infected (1:70 in Dec)

Peak 5th Jan

School aged 5-11yo highest rate 1:13 +ve
Aged 75+ lowest rate 1:41
(12x Dec rates)
Researchers at University hospital Zurich

175 people Covid +ve
40 healthy volunteers control group

followed 134 of the Covid patients for up to a year after their initial infection.

IgM antibodies ramp up rapidly, while IgG antibodies rise later and provide longer-term protection.

Those who developed long Covid – also known as post-acute Covid-19 syndrome (Pacs) – tended to have low levels of IgM and the antibody IgG3.
Xenon gas behaves like oxygen but can be seen by scans. People with breathlessness in Post Covid Syndrome had less transfer of gas.

Case report in Lancet showing micro emboli post COVID in 14 year old girl.
This study used the anonymised medical records of 6,910,695 people (aged 20-99) who attended 1,500 GP practices across England. The data were linked to positive test results for COVID-19, and information on admission into hospital, intensive care or death.

In the three months to April 2020, 13,503 people were admitted to hospital, 1,601 to intensive care, and 5,479 died after a positive test.

The study found that people with a BMI of 23 had the lowest risk of admission to hospital, intensive care or death. As BMI increased, so did the risk of poorer COVID-19 outcomes.

Every unit increase in BMI:
- increased risk of hospital admission by 5% (above BMI of 23, in the healthy range)
- increased risk of death by 4% (above BMI of 28, in the overweight range)
- increased risk of intensive care by 10% (for any BMI).

Being underweight also came with risks. Rates of hospital admission and death increased progressively as the BMI dropped below 20.

The researchers found that other factors influenced how much impact BMI had on outcomes from COVID-19.
- **Age:** In people over 80, a higher BMI did not increase the risk of poorer outcomes. The risk of hospitalisation with higher BMI was greatest among the under-40s. But this group generally has a low risk of complications. The extra risk with increased BMI was most apparent for people in their 40s and 50s.
- **Ethnicity:** People of Afro-Caribbean or Black African ethnicity faced higher risks of poor outcomes with increasing BMI. The risk among people of Asian or Chinese ethnicity was similar to the risk among the White population.

Previous research has suggested that being male increases the risk of poorer COVID-19 outcomes. However, this study found that sex had no effect on the association between BMI and severe COVID-19 outcomes. Similarly, having another health condition such as type 2 diabetes, high blood pressure or cardiovascular disease, did not add to the risks with increasing BMI.
Covid-19: Pandemic waste threatens human and environmental health, says WHO

BMJ 2022; 376 doi: https://doi.org/10.1136/bmj.o266

The World Health Organization has called for urgent improvements in waste management systems in light of the tens of thousands of tonnes of extra medical waste produced in response to the covid-19 pandemic. It has warned in a report that the massive amount of covid-19 related healthcare waste has put tremendous strain on waste management systems around the world, threatening human and environmental health.

The report estimates that one and a half billion units of personal protective equipment (PPE), weighing 87 000 tonnes, were procured between March 2020 and November 2021 and shipped to countries around the world through a joint UN emergency initiative. Most of this equipment is expected to end up as waste. This only represents a small fraction of the total global waste problem, however, as it does not include PPE bought outside the initiative or waste generated by the public, such as disposable face masks.
Vaccine
Vaccine Efficacy

Critical care admissions by vaccination status – May-December 2021

- Unvaccinated
- Double-vaccinated
- Boosted

Source: ICNARC COVID-19 report 7 January 2021; vaccinated rates from NMS service; unvaccinated calculated with ONS mid-2020 population estimates.
Vaccines & Transmission

1. Several studies have provided evidence that vaccines are effective at preventing infection,” it states, “Uninfected people cannot transmit; therefore, the vaccines are also effective at preventing transmission.”

2. Even a single dose of a Covid-19 vaccine reduced the likelihood of household transmission by 40-50%.

3. Vaccines aren’t preventing onward transmission by reducing the viral load in your body.

4. People who have completed the primary series of vaccination experienced secondary attack rates (SARS) of 32% in households with omicron and 19% in households with delta. With a booster, omicron SAR 25%, delta 11%.

5. The amount of viral RNA in patients with omicron was highest three to six days after diagnosis or symptom onset. This appears to be two or three days later than other variants.
Vaccines Globally

**Sep-Dec 2021***

**Vaccine**

*Pfizer*

0.9bn doses

*High†*

**AstraZeneca**

1.3bn doses

*Upper middle*

*Lower middle*

*To Dec 8th† Includes Romania
Sources: Airfinity; World Bank

**Destination countries**

*By income group/organisation*

**COVAX**
Novavax expected to be become fourth Covid vaccine available in UK

Trials show the protein-based jab causes fewer side-effects - and hundreds of British jobs depend on it

- Coronavirus - latest updates
- See all our coronavirus coverage

Less side effects. Protein based. Might help Vaccine hesitant Britain Not only do we expect a strong durable response but also good stability at fridge temperature, so it can be rolled out with the flu vaccine next winter as part of the winter campaign. "This should replace the need to buy more Pfizer and Moderna vaccine and save the UK Government a considerable amount of money."
CLINICAL
Post-traumatic stress disorder and major depression among frontline healthcare staff working during the COVID-19 pandemic

Abstract

Objectives

High rates of probable post-traumatic stress disorder (PTSD) and major depressive disorder (MDD) have been reported for frontline healthcare staff during the COVID-19 pandemic. However, rates determined by diagnostic assessment are unknown, as are the onset of symptoms and associated index events.

Methods

We assessed frontline healthcare staff with the Structured Clinical Interview for DSM-5.

Results

Forty-four percent met criteria for PTSD and 39% met criteria for MDD. Twenty-four percent reported COVID-19 trauma as their index event, with the majority of staff reporting trauma that pre-dated the pandemic. While PTSD was likely to be pre-existing, MDD was more likely to develop during pandemic working.

Conclusion

These findings indicate the propensity of healthcare staff to experience a range of occupational and personal trauma associated with PTSD and the need to assess index trauma when diagnosing psychopathology in order to best understand the needs of this workforce.

- Healthcare workers appear to have high rates of PTSD related to occupational and personal trauma, which warrants specific focus in service planning.
**Direction**: Agreement on what the collective is trying to achieve together.

**Alignment**: Effective coordination and integration of the different aspects of the work so that it fits together in service of the shared direction.

**Commitment**: People who are making the success of the collective (not just their individual success) a personal priority.
The data shows the number of overall reinfections is small. They only make up 4% of the 14.8 million positive tests recorded so far - but since the start of the Omicron wave in December, they've been rising sharply. From representing around one in 100 daily cases up to November, reinfections now make up one in 10.
A modelling study published in *PLOS Computational Biology* suggests that care homes significantly dependent on agency staff have more than twice the likelihood of COVID-19 transmission among their residents.

Care homes in several countries, including the UK, strongly rely on temporary bank or agency staff due to persistent staff shortages, which have been further worsened during the COVID-19 pandemic.

An average of 10% bank/agency staff had a relative risk (RR) of infection of 2.65 (95% CI 2.57 to 2.72) for residents compared with care homes not using bank/agency staff. The RR rose to 5.17 (95% CI 5.03 to 5.30) when the average level of bank/agency staff was increased to 20%. A similar trend was seen for RRs of outbreaks in care homes.

In the presence of high compliance to weekly testing (80%), the infection risk for residents in care homes using bank/agency staff declined, but remained significant (10% and 20% agency staff: RRs 1.28 and 1.64, respectively).
TESTING at the moment??

Asymptomatic  Lat Flow
Symptomatic  PCR
LAMP???
“Excess deaths” is the best metric for tracking the pandemic

It’s more informative and accurate than covid-19 deaths or cases

Nasir Ullah epidemiologist

The term “excess deaths” is currently used mainly to track the pandemic’s direct effects on human lives, but the term is not just about the direct and deaths caused by SARS-CoV-2. It is far reaching in its effects—direct and indirect—with short and long term consequences for both individuals and populations.

Deaths from covid-19 account for only a fraction of the short term direct effects of SARS-CoV-2. Other critical outcomes include hospital admission, mechanical ventilation, and need for intensive care. Medium to long term direct effects include loss of small earnings, mental health, boredom, chest pain, and respiratory problems.

Excess deaths are more informative because they reflect morbidity and mortality due to covid-19 and other causes, both short and long term. Both all-cause mortality and excess deaths are affected by these inaccuracies and capture both direct deaths from covid-19 and deaths caused indirectly by the pandemic. Data on all-cause mortality allow us to estimate excess deaths in 2020 to be lower than in most previous years, with a reference year of 2018, while others used an average of the past few years. The scenario above could indicate that country A had relatively poorer healthcare resilience, and perhaps deliberately under-reported deaths from covid-19 for political reasons, and the quantification of excess deaths reveals that they were indeed failing to protect their citizens.

Although restrictions on human mobility reduced air pollution and deaths from road traffic incidents, hospitals and healthcare services have been widely disrupted, with critical shortages of medical supplies and reduced access to emergency and non-emergency care. Excess deaths are a powerful metric even when causes of death are perfectly related. For example, if two countries have identical healthcare structures and perfect data on causes of death report rates and excess covid-19 deaths, respectively, we might conclude that country A had achieved better pandemic control than country B. However, estimated excess deaths in two countries of rasy and yzy, respectively, would mean that despite fewer deaths from covid-19, country A failed to prevent deaths from other causes directly or indirectly related to the pandemic.

The two metrics give opposing perspectives on the relative effectiveness of countries’ pandemic control measures. The scenario above could indicate that country A had relatively poorer healthcare resilience, and perhaps deliberately under-reported deaths from covid-19 for political reasons, and the quantification of excess deaths reveals that they were indeed failing to protect their citizens. Excess deaths are a powerful metric even when causes of death are perfectly related. For example, if two countries have identical healthcare structures and perfect data on causes of death report rates and excess covid-19 deaths, respectively, we might conclude that country A had achieved better pandemic control than country B. However, estimated excess deaths in two countries of rasy and yzy, respectively, would mean that despite fewer deaths from covid-19, country A failed to prevent deaths from other causes directly or indirectly related to the pandemic.

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Background: Globally, the prison population is growing and ageing, as is the need for palliative care but little is known about how people in prison perceive palliative care provision in this setting.

Aim: to identify the
- perceptions of palliative care provision and dying in custody by people in prison
- perceived barriers and facilitators of person-centred palliative care provision in prison

Methods: Qualitative evidence synthesis of 12 international research papers
What they found

Expectation of equitable palliative and supportive care
Access to routine and acute palliative care in prison was limited by internal procedures

Challenges of building a connection between patient and clinicians in prison
Limited by the environment, with mistrust, administrative barriers and physical environment all playing a part. There was a wish for clear and respectful communication with their clinicians to adequately convey complex medical information

Differentiation between just and unjust punishment
The experience of illness, palliative care and dying in prison became a ‘double burden’; an unjustified and unfair additional punishment that denied the essential humanity of people in prison. Separation from family at the end of life exacerbated this
Capacity to make choices is severely limited
- Opportunities for self-determination are rare, some patients chose to proactively make choices.
- Advance Care Planning was undertaken.
- Making choices about death was an opportunity for self-determination

Physical environment complicates access to care
- Managing complex palliative care symptom needs was perceived to be challenging in the prison setting, especially in relation to pain.
- Inability to access parts of the prison due to poor mobility
- Environmental conditions such as poor temperature control, cleanliness and noise were common issues

Dying in prison adds complexity to mortality
- People in prison face additional complicating factors when facing their own mortality.
- Universal concerns such as fear of death and dying were omnipresent.
- Prison is a restrictive and punitive correctional environment that prohibits many supports available to people in the community with palliative care needs.
In conclusion

• There is a perception that having a life-limiting illness and death in prison is a further loss of liberty and punishment

• People in prison believed that there is limited capacity to provide respectful and dignified care at the end-of-life in custody

• Strategies should be designed and implemented to ensure that people in prison receive adequate psychological, social, emotional and physical support during the end-of-life

• Capacity needs to be provided for people to make choices about their own care.
Palliative and End of Life Care Network

Welcome to the Palliative and End of Life Care Network

This workspace is for colleagues working to improve palliative and end of life care (PEoLC) for people, patients, families and carers.

You can share best practice, upcoming events, and start a discussion to learn from each other. All national updates and key publications are shared on this workspace to support you.

Our user guide shows how to upload a document or start a discussion. Please use the search function to find existing documents and discussions. If you have any queries contact england.palliativeandendoflife@nhs.net.
Getting to Outstanding *New information pages now live*

Primary Care End of Life Register and ReSPECT

EoL "Comfort" Discharge boxes

Collection of bereavement feedback

Identifying and supporting patients with Heart Failure the last year of life

numbers of CNS palliative care required in Acute trusts

ICD deactivation in dementia / advance decisions

https://future.nhs.uk/
Executive Summary
The story of dying in the 21st century is a story of paradox. COVID-19 has meant people have died outside medicalised deaths, often alone in hospitals with little communication with their families. But in other settings, including in some lower income countries, many people remain undertreated, dying of preventable conditions and without access to basic pain relief. The unbalanced and contradictory picture of death and dying is the basis for the Lancet Commission on the Value of Death. Drawing on multidisciplinary perspectives from around the globe, the Commissioners argue that death and life are bound together: without death there would be no life. The Commission proposes a new vision for death and dying, with greater community involvement alongside health and social care services, and increased bereavement support.
The *Lancet* Value of Death Commission: bringing death back into life

*Dr Libby Sallnow*

*Lead author, Lancet Commission*

*Palliative Medicine Consultant (CNWL)*

*Senior Honorary Clinical Lecturer, St Christopher’s Hospice and UCL*
The impetus for a commission on death

Death, dying and grief are core, universal human concerns

How people die has changed significantly over recent generations

Some changes have been for the better – people die later in life and many have access to pain and symptom relief as they die

Some changes have been for the worse – dying is prolonged, people increasingly die in hospital, families and communities feel unprepared
The approach of the Commission

• Global in perspective
• Commissioners across disciplines and countries
• Uses a systems approach to understand challenges
• Looks beyond palliative care and healthcare services
• Structural issues such as gender, race and power considered alongside healthcare services, philosophy, consumerism and economics
Key messages from the report

1. Dying in the 21st century is a paradox – overtreated and undertreated.
2. Death, dying, and grieving today have become unbalanced.
3. Delusion that we are in control of, not part of, nature.
4. Rebalancing death and dying depends on changes across “death systems.”
5. Disadvantaged and powerless suffer most from the imbalance.
6. Five principles of “realistic utopia” – a new vision of how death and dying could be.
7. Communities reclaiming death, dying and grief as social concerns are more needed.
8. Radical changes across all death systems are a collective responsibility.
“The future is already here, just not very evenly distributed”.

William Gibson

Scenario planning

- Five scenarios described imagining different futures for death and dying
  - Death overwhelms health systems
  - Immortality and inequity
  - Climate change and greater equity
  - Rebalancing
  - Assisted dying spreads
A realistic utopia

• A radically different vision of future society

• Whilst radical, it is also achievable

• Profound rather than incremental change

[A realistic utopia] "joins reasonableness and justice with conditions enabling citizens to realize their fundamental interests.”

John Rawls (1993)
The realistic utopia of the Commission

1. The social determinants of death, dying, and grieving are tackled
The realistic utopia of the Commission

2. Dying is understood to be a relational and spiritual process rather than simply a physiological event.
The realistic utopia of the Commission

3. Networks of care lead support for people dying, caring, and grieving
The realistic utopia of the Commission

4. Conversations and stories about everyday death, dying, and grief become common
The realistic utopia of the Commission

5. Death is recognized as having value
**Examples of our recommendations**

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<td>Relationships are central</td>
<td>Community action</td>
<td>Healthcare profs competence</td>
<td>Focus on systems change outside healthcare</td>
<td>End the silence on death in policies</td>
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<td>Death literacy built for all</td>
<td>Stories of ‘ordinary dying’ shared</td>
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The Lancet Commission on the Value of Death: bringing death back into life

The best science for better lives
Thank you

For more information:
@VoDCommission #ValueOfDeath
Exploring socioeconomic inequities in access to palliative and end-of-life care in the UK: a narrative synthesis

9th February 2022

Dr Maddy French
Systematic literature review

First stage of my PhD: what UK research has been carried out into socioeconomic position and access to palliative care

Two review aims:

1. To explore UK research evidence on **socioeconomic differences in use** of palliative / EoL care

2. To explore the **usefulness of the candidacy model** for understanding **how socioeconomic position influences access** to palliative/ EoL care in the UK
The Candidacy model of access

*(Dixon-Woods et al., 2006)*

Access is continuously generated through negotiation and interactions (rather than someone having/not having access)

Inequities in access arise from a misalignment between patient circumstances/experiences and service assessment/offer of care

The work needed to happen to become a candidate for care is harder in the context of socioeconomic disadvantage
The Candidacy model

Identification of candidacy
*E.g. Social patterning of perceptions of health*

Adjudications
*E.g. ability to benefit, social deservedness*

Local operating conditions
*E.g. inequities in resources allocation*

Offers / Resistance

Navigation of services

Permeability of services (ease of access)
*E.g. stringent referral criteria, transport costs*

Appearances
*E.g. power dynamics, articulating need*
Literature searching

Six different databases (up until July 2020) + grey literature reports

Looked through the full articles of 69 papers.

I included 29 articles that matched search criteria (UK based, looking at socioeconomic position and palliative/end of life care/hospices).

Narrative synthesis approach
What did I find?

*Aim: socioeconomic differences in use of palliative / EoL care*

Not clear or consistent narrative about socioeconomic inequities in use of care in UK literature.

Uncertainty added to by difficulties accounting for potentially **higher need** for palliative care among people in socioeconomically disadvantaged circumstances.
Aim: how socioeconomic position influences access / usefulness of the candidacy model

Identification of candidacy
Lack of evidence of socioeconomic differences in identifying need for/attitude towards palliative care

Adjudications
Seen as having less time to talk
Normalising of symptoms/death?
Perception of ‘socioeconomic needs’ in pall care

Local operating conditions
Regional differences
Socio-political structures/attitudes?
Financing/resource decisions?

Offers / Resistance?

Navigation of services
Potential socioeconomic differences in informational resources

Permeability of services (ease of access)
Types of service models?
Different pathways?
Untrustworthy?

Appearances
Relying on ‘forceful’ family members
Requests made, but unheard
Candidacy implies that equitable access is:

Not just about providing more information and same services to different groups of people -> *Are there varied and flexible pathways into care? Different ways of providing support?*

Not just knowing who is getting into a service but something *continuously generated* in interactions, including after referral

About *implicit and explicit expectations* services have of patients -> *how do services respond when expectations aren’t met e.g. support network, articulating needs, adaptable home environments?*
Thank you

m.french4@lancaster.ac.uk
@mddyfrnch

4th Edition Registered Nurse Verification of expected Death Adult Guidance 2022

• Fully updated guideline with amended title which will continued to be reviewed and updated by Hospice UK

• Significant to all nursing staff who are responsible for performing verification

• Supports the care of the deceased adult during the time of COVID-19

• Includes an updated practical guide and competency assessment
Updates in 4th edition-RNVoEAD

Education and Training

Personal Care after Death

Reference list
Page 3- This guidance may be used to inform training for other registered healthcare professionals who are regulated by a professional body who, under statutory regulation, is recognised by the Professional Standards Authority Professional Standards Authority (2021)

Page 3-Notifiable Diseases- now includes sentence: For other notifiable diseases refer to Managing Infection Risks HSE
P.7-Equipment: surgical face mask ** Where Covid-19 is suspected of confirmed, an additional face mask is required to place over the deceased’s mouth when moving them.

P.7 Risk Assessment: Where there is risk of contamination from respiratory droplets, when moving the patient, a barrier such as a cloth or face mask is required to place over the deceased’s mouth when moving them to prevent the potential release of respiratory tract droplets on movement.

P.15 Assessment of competence: Knows that if the patient has COVID-19 or is suspected of COVID-19 that a face mask is placed over the patient’s mouth prior to any movement / positioning.

CHATBOX & BREAKOUT

How will we manage the transition from Pandemic to Endemic for Patients, Staff and Services?

High rates of PTSD across NHS Staff

Safety in uncertainty

“Don’t want to be the first or the last to ease up restrictions”

Compassionate Leadership?

Visiting?

What will we stop doing and when?

PPE & Testing?
Breakout Rooms Together
How will we manage the transition from Pandemic to Endemic for Patients, Staff and Services?

1. Patients
2. Staff
3. Services
CHATBOX
Eighth WHO living Guideline on Drugs for COVID-19
How will you AFFIRM what your team have done?
WHAT MATTERS MOST:
IMPORTANT CONVERSATIONS FOR LIVING AND DYING WELL

A collaborative conference celebrating best practice on planning ahead, wellbeing and compassionate community-led care.

Thursday 10 February 2022
12.30 PM - 17.00 PM GMT

FREE + ONLINE Live on RCGP Conference platform

Register now at: www.rcgp.org.uk/events

SPEAKERS INCLUDE
MORE TO BE ANNOUNCED......

Kathryn Mannix
Broadcasting and Medical writer

Maureen Bisognano
Founder of What Matters,
President of Institute of Healthcare, Harvard University

Chris Lubbe
Former photoguard to Nelson Mandela, NHS IPC South West

Karen Turner
Senior Improvement Advisor
Royal Free Hospital

Julie Pearce
Chief Nurse, Executive Director
Quality and Caring Services
Marie Curie

Martin Marshall
Chair, Royal College of GPs

What Matters Most
Tomorrow
12.30 – 17.00

Free Registration
THANK YOU
Next session: April 13 2022

15:30 – 17:00
We are thankful for Clair’s life and for all the happiness we have enjoyed together.

A Service of Thanksgiving

The Thanksgiving Service will be held at Brighton Road Baptist Church, Horsham, on Thursday 17th February 2022 at 2pm.
1. No one tells you you’re dying.

I’ve been told I have stage 4 cancer. I’ve ticked the box for ‘palliative care’. I’ve been referred to a hospice. But no one has ever actually told me that I’m dying, or used the words ‘terminal illness’ to me. You might think it’s obvious, but mostly I’ve had to join the dots for myself.

2. You can be well, but still dying

How ‘well’ I seem has more to do with how much chemo or which surgery I’ve had recently than how close I am to actually dying. I’ve tried hard to prioritise my own wellbeing: diet, exercise, green space, prayer, family connection. My body might not be in a great place anymore, but my mind can be.

3. People find it really uncomfortable to talk about dying

Even when I talk about my own death, which I’m reconciled to and comfortable with, I’ve been told to be more positive, to ‘not talk like that’, to have more faith or worse directed to a range of ‘cures’ that apparently my medical team have overlooked. I’ve been amazed how many people seem to think that we are immortal and that everything can be cured if we try hard enough. But talking about dying and making plans really does help.

4. Cancer is a team sport

It matters to me to talk honestly to those close to me about what’s coming and to include them in my plans because they will be the ones left behind. From a medical point of view there is also a large team involved in my treatment. And although it’s necessary and helpful to have all these people involved, sometimes being a patient can feel a bit like being a project manager.
Clair Fisher 1979 – 2022

My eldest daughter started saying “Goodnight, I love you, Goodbye” to me every day about 2 years into my illness. It’s good to get the goodbyes in ahead of time.

But if you’re reading this now then the time for my final goodbye has come. This last blog post has sat in my drafts folder, a bullet point on my death admin file, to be posted after my death, probably by my husband or my son.

Please know that I haven’t lost a fight and that I didn’t feel let down or failed by anyone. I lived a happy life, and mostly I lived it well. I only ever had modest life goals, and am pleased to have achieved pretty much all of them. By God’s grace I’ve managed to create a space filled with books and fairy lights, a garden full of flowers, and a family secured by faith and love.

I’ve asked that this Dying Well site stays up for a while as part of my legacy. I’ve been amazed at how much this project has resonated with people - both those living with terminal illness and those supporting them. We’ve also had some success nudging a few professionals in the direction of thinking more about wellbeing in end of life care. I hope that some of the content might continue to inspire, to provoke and to challenge. And that wellbeing evidence might start to be more routinely included in consideration about how to improve the lives of people living with terminal illness and the services that are provided for them.

The Dying Well project’s wings have grown thanks to the love and care of Nancy Hey and her amazing team at the What Works Centre for Wellbeing. It has been an absolute joy to have had something so purposeful, interesting and enjoyable to work on as my retirement project. Special thanks to Joanne Smithson who has led so much of this in recent months. I’m delighted to to know that the work we’ve begun together will continue and you can follow it over on their website.

Thank you to all of you who have encouraged and supported me on this journey. The email address associated with this account will no longer be monitored, but you can make contact with my husband on his email address: jon@pashleyfisher.co.uk

Details of my funeral and tributes will be posted at Dandelion Farewells.

…and here’s one final plug for the marvelous work of the team at St. Catherine’s Hospice. Until Hospice care is consistently funded in an integrated way as part of core NHS provision, they rely on donations - you can give here.