

Palliative Care- shifting the focus from equality to equity

Dr Sabrina Bajwah

Clinical Senior Lecturer King's College London

Consultant Palliative Care King's Health Partners



OPEN ACCESS

Specialist palliative care services response to ethnic minority groups with COVID-19: equal but inequitable—an observational study

Sabrina Bajwah ,^{1,2} Jonathan Koffman ,¹ Jamilla Hussain,³ Andy Bradshaw ,³ Mevhibe B Hocaoglu,¹ Lorna K Fraser ,⁴ Adejoke Oluyase ,¹ Caitlin Allwin,¹ Lesley Dunleavy,⁵ Nancy Preston,⁵ Rachel Cripps,¹ Matthew Maddocks,¹ Katherine E Sleeman ,^{1,2} Irene J Higginson ,^{1,2} Catherine Walshe ,⁵ Fliss E M Murtagh ,^{1,3} on behalf of the CovPall study team

ABSTRACT

Objectives To develop insights into response of palliative care services caring for people from ethnic minority groups during COVID-19.

Methods Cross-sectional online survey of UK palliative care services response to COVID-19. Quantitative data were summarised descriptively and χ^2 tests used to explore relationships between categorical variables. Free text comments were analysed using reflexive thematic analysis.

Results 277 UK services responded. 168 included hospice teams (76% of all UK hospice teams). Services supporting those from ethnic minority groups were more likely to include hospital ($p<0.001$) and less likely to include hospice ($p<0.001$) or home care teams ($p=0.008$). 34% (93/277) of services had

Key messages

What was already known?

- ▶ COVID-19 has disproportionately affected ethnic minority groups.

What are the new findings?

- ▶ Policies may have disproportionately impacted ethnic minorities at end of life.
- ▶ Palliative care response may have been equal but inequitable.

What is their significance?

- ▶ Systemic steps, including equality impact assessments, are urgently needed to address inequity.
- ▶ Focus on individualised care may be insufficient to provide equitable care.

Aim

To map and develop insights into the response of specialist palliative care services caring for patients and families from ethnic minority groups during the first wave of the COVID-19 pandemic.

Methods

- Cross-sectional on-line survey of UK palliative care services' response to COVID-19.
- Quantitative data were summarised descriptively and chi-square tests used to explore relationships between categorical variables.
- Free-text comments were analysed using reflexive thematic analysis.

¹Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College London, London, UK

²Department of Palliative Care, King's College Hospital NHS Foundation Trust, London, UK

³Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, Hull, UK

⁴Health Sciences, University of York, York, UK

⁵International Observatory on End of Life Care, Division of Health Research, Lancaster University, Lancaster, UK

Correspondence to Dr Sabrina Bajwah, Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College London, London WC2R 2LS, UK; email: s.bajwah@kcl.ac.uk

Closed-ended	Have you encountered patient or families with COVID-19 who are from black and minority ethnic groups? Yes / No (if yes, free text box opened)
Open-ended	Are there any differences in how you are supporting or reaching them?
Open-ended	Are there any groups (different religions, cultures) where you have found supporting the individual needs of people affected by COVID-19 particularly challenging?

Results

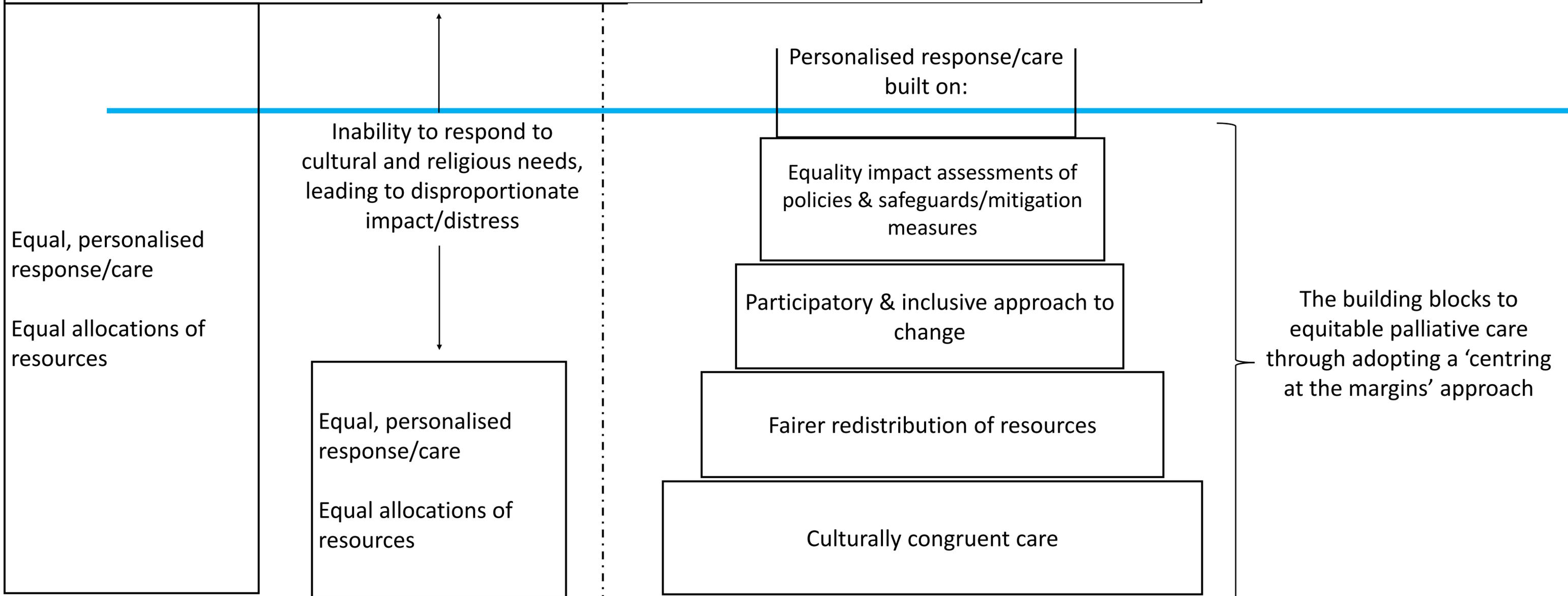
Quantitative

- 93/277 services had cared for ED patients
 - 23% inpatient hospice teams
 - 30% home teams
 - 49% hospital teams
- Services who had supported those from ED groups
 - more likely to have hospital palliative care teams ($\chi^2 = 15.21, p < 0.001$)
 - less likely to have inpatient hospice ($\chi^2 = 30.11, p < 0.001$)
 - or home palliative care teams ($\chi^2 = 7.05, p = 0.008$)

Qualitative

1. disproportionate adverse impact of restricted visiting
2. compounded communication challenges
3. unmet religious and faith needs
4. mistrust of services
5. focus on equal and personalised care

The bar for high quality palliative care and outcomes



Served groups

Underserved groups

All groups

An **equal** response

An **equitable** response

The building blocks to equitable palliative care through adopting a 'centring at the margins' approach

Bajwah et al 2021

Dissemination and impact

Qualitative & mixed methods



Specialist palliative care services response to ethnic minority groups with COVID-19: equal but inequitable—an observational study

Sabrina Bajwah ^{1,2}, Jonathan Koffman ¹, Jamilla Hussain ³,
Andy Bradshaw ³, Mevhibe B Hocaoglu ¹, Lorna K Fraser ⁴,
Adejoke Oluyase ¹, Caitlin Allwin ¹, Lesley Dunleavy ⁵, Nancy Preston ⁵,
Rachel Cripps ¹, Matthew Maddocks ¹, Katherine E Sleeman ^{1,2},
Irene J Higginson ^{1,2}, Catherine Walshe ⁵, Fliss E M Murtagh ^{1,3}
on behalf of the CovPall study team

¹Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College London, London, UK
²Department of Palliative Care, King's College Hospital NHS Foundation Trust, London, UK
³Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, Hull, UK
⁴Health Sciences, University of York, York, UK
⁵International Observatory on End of Life Care, Division of Health Research, Lancaster University, Lancaster, UK
Correspondence to
Dr Sabrina Bajwah, Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College London, London

ABSTRACT

Objectives To develop insights into response of palliative care services caring for people from ethnic minority groups during COVID-19.
Methods Cross-sectional online survey of UK palliative care services response to COVID-19. Quantitative data were summarised descriptively and χ^2 tests used to explore relationships between categorical variables. Free text comments were analysed using reflexive thematic analysis.
Results 277 UK services responded. 168 included hospice teams (76% of all UK hospice teams). Services supporting those from ethnic minority groups were more likely to include hospital ($p<0.001$) and less likely to include hospice ($p<0.001$) or home care teams ($p=0.008$). 34% (93/277) of services had

Key messages

- What was already known?**
- ▶ COVID-19 has disproportionately affected ethnic minority groups.
- What are the new findings?**
- ▶ Policies may have disproportionately impacted ethnic minorities at end of life.
 - ▶ Palliative care response may have been equal but inequitable.
- What is their significance?**
- ▶ Systemic steps, including equality impact assessments, are urgently needed to address inequity.
 - ▶ Focus on individualised care may be insufficient to provide equitable care.



Equality and Human Rights Monitor

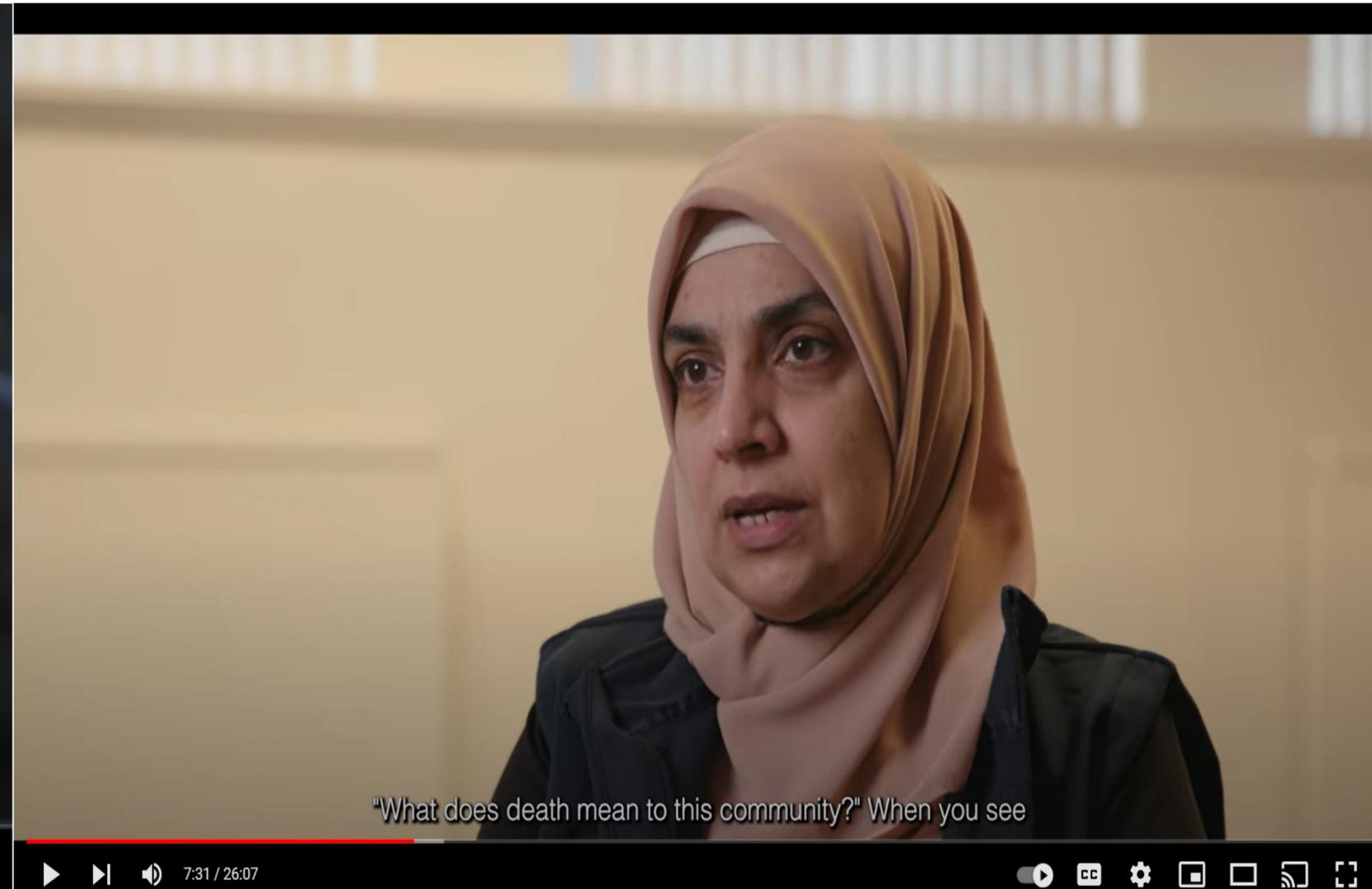
November 2023

equalityhumanrights.com

Transforming the health and social equity landscape

Promoting socially just and inclusive growth to improve resilience, solidarity and peace





Toby Porter, Chief Executive of Hospice UK:

"This film is so important, and beautifully made. It should be compulsory viewing for everyone currently working or thinking about working in palliative care."

CoyPall
Palliative care in COVID-19



Palliative care: shifting the focus of care from equality to equity

Sign in

Session information

Title:

Palliative care: shifting the focus of care from equality to equity

Description:

This session aims to provide all those working in palliative and end-of-life care with a greater understanding and confidence when caring for ethnically diverse patients.

The content of this session is based on research conducted by the CovPall study team (read a full definition of this term).

Hierarchy:

End of Life Care (e-ELCA) > e-ELCA 05: Integrating learning in end-of-life care > 05_05 Best practice > Palliative care: shifting the focus of care from equality to equity

Author(s):

Sabrina Bajwah
Derek Willis

Created:

9 Jun 2023

Last Major Update:

9 Jun 2023

Keywords:

215-0529 ,end of life, palliative, care, equality, equity, Applied Research Collaboration South London at King's College Hospital NHS Foundation Trust



Acknowledgments

This film was funded by a grant from the Medical Research Foundation-
MRF-145-0015-DG-BAJW-C0926

Chief Investigator: S Bajwah

Co-investigators: I J Higginson,
J Koffman, M Watson, K Flemming,
J Hussain, R Kumar

Collaborator: Hospice UK

The CovPall Project was funded by a grant from the Medical Research Council-
MR/V012908/1

Chief Investigator: I J Higginson

Co-investigators: F Murtagh,
N Preston, K Sleeman, M Maddocks,
S Bajwah, L Fraser, M Hocaglu ,
A Oluyase, C Walshe



This project is supported by the NIHR Applied Research Collaboration South London at King's College Hospital NHS Foundation Trust. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care

Thank you



sabrina.bajwah@kcl.ac.uk

 [@SBajwah](https://twitter.com/SBajwah)