Thinking ahead about medical treatments in advanced illness: a qualitative study of barriers and enablers in end-of-life care planning with patients and families from ethnically diverse backgrounds

Zoebia Islam,[1*] Kristian Pollock,[2] Anne Patterson,[1]
Matilda Hanjari,[1] Louise Wallace,[3] Irfhan Mururajani,[1]
Simon Conroy[4] and Christina Faull[1,5]

[1]Leicestershire and Rutland Organisation for the Relief of Suffering (LOROS) Hospice, Leicester, UK
[2]School of Health Sciences, University of Nottingham, Nottingham, UK
[3]Faculty of Wellbeing, Education and Language Studies, The Open University, Milton Keynes, UK
[4]Department of Health Sciences, University of Leicester, Leicester, UK
[5]University Hospitals of Leicester NHS Trust, Leicester

[*]Corresponding author ZoebiaIslam@loros.co.uk

Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/JVFW4781.

Primary conflicts of interest: Louise Wallace was member of the DH Service Delivery and Organization Evaluations Panel (2009-11), the DH NIHR Health Services & Research Development Panel (2012-13), the HS&DR Researcher Lead Panel (2013-16) and the DHSC Health and Social Care Delivery Panel- (Seacole) (2019-22).

Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

Published June 2023
DOI: 10.3310/JVFW4781

Plain language summary

Thinking ahead about medical treatments in advanced illness: a qualitative study of barriers and enablers in end-of-life care planning with patients and families from ethnically diverse backgrounds

Health and Social Care Delivery Research 2023; Vol. 11: No. 7
DOI: 10.3310/JVFW4781

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Plain language summary

This study explored the experiences of terminally ill patients and their families from different ethnic backgrounds and whether or not, and how, they think ahead about their health getting worse and about dying. It included 93 interviews from 18 patient case studies, 19 interviews with bereaved family caregivers and workshops with 50 public and professional stakeholders.

Most patients and their family caregivers lived with hope, considering the future only in terms of practical matters of wills and funerals, rather than thinking about becoming less well and dying, which, for some, was counter to their beliefs. Family duty and community expectations stopped some participants from seeking additional support. However, when the family did not know how gravely ill the patient was, the patient's unexpected decline and death could be a devastating experience, with regret that they had been denied the chance to prepare and to make the best use of the time. Health-care professionals appear to feature little in people's lives. Some participants indicated a lack of trust and a poor experience of health care, but others talked of good experiences.

People want care that is personal to them and compassionate. This is no different from people from white British backgrounds and supports the use of different physical, social, spiritual and psychological care frameworks used in palliative care to address the individual needs of patients and families. However, health-care professionals need additional skills to navigate complex, sensitive communication and enquire about aspects of people's lives that may be unfamiliar. Personalising care requires health-care professionals to get to 'know' the person and develop confidence and skills to support patients and their families. Training, using stories based on our interviews, was seen as an effective way to support this. Effective communication and information-sharing between trusted individuals was seen by stakeholders as important in providing better care.

Health and Social Care Delivery Research

ISSN 2755-0060 (Print)

ISSN 2755-0079 (Online)

Health and Social Care Delivery Research (HSDR) was launched in 2013 and is indexed by Europe PMC, DOAJ, INAHTA, Ulrichsweb (ProQuest LLC, Ann Arbor, MI, USA) and NCBI Bookshelf.

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

This journal was previously published as Health Services and Delivery Research (Volumes 1–9); ISSN 2050-4349 (print), ISSN 2050-4357 (online)

The full HSDR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hsdr.

Criteria for inclusion in the *Health and Social Care Delivery Research* journal

Reports are published in *Health and Social Care Delivery Research* (HSDR) if (1) they have resulted from work for the HSDR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HSDR programme

The HSDR programme funds research to produce evidence to impact on the quality, accessibility and organisation of health and social care services. This includes evaluations of how the NHS and social care might improve delivery of services.

For more information about the HSDR programme please visit the website at https://www.nihr.ac.uk/explore-nihr/funding-programmes/ health-and-social-care-delivery-research.htm.

This report

The research reported in this issue of the journal was funded by the HSDR programme or one of its preceding programmes as project number 17/05/30. The contractual start date was in November 2018. The final report began editorial review in December 2021. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HSDR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health and Care Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the HSDR programme or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, the HSDR programme or the Department of Health and Social Care.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Newgen Digitalworks Pvt Ltd, Chennai, India (www.newgen.co).

NIHR Journals Library Editor-in-Chief

Dr Cat Chatfield Director of Health Services Research UK

NIHR Journals Library Editors

Professor John Powell Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK, and Professor of Digital Health Care, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

Professor Andrée Le May Chair of NIHR Journals Library Editorial Group (HSDR, PGfAR, PHR journals) and Editor-in-Chief of HSDR, PGfAR, PHR journals

Professor Matthias Beck Professor of Management, Cork University Business School, Department of Management and Marketing, University College Cork, Ireland

Dr Tessa Crilly Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin Consultant in Public Health, Delta Public Health Consulting Ltd, UK

Dr Peter Davidson Interim Chair of HTA and EME Editorial Board. Consultant Advisor, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Ms Tara Lamont Senior Adviser, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Dr Catriona McDaid Reader in Trials, Department of Health Sciences, University of York, UK

Professor William McGuire Professor of Child Health, Hull York Medical School, University of York, UK

Professor Geoffrey Meads Emeritus Professor of Wellbeing Research, University of Winchester, UK

Professor James Raftery Professor of Health Technology Assessment, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Dr Rob Riemsma Consultant Advisor, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Professor Helen Roberts Professor of Child Health Research, Child and Adolescent Mental Health, Palliative Care and Paediatrics Unit, Population Policy and Practice Programme, UCL Great Ormond Street Institute of Child Health, London, UK

Professor Jonathan Ross Professor of Sexual Health and HIV, University Hospital Birmingham, UK

Professor Helen Snooks Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

Professor Ken Stein Professor of Public Health, University of Exeter Medical School, UK

Professor Jim Thornton Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

Please visit the website for a list of editors: www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: journals.library@nihr.ac.uk