NIHR | National Institute for Health and Care Research

Health and Social Care Delivery Research

Check for updates

Extended Research Article

How lived experiences of illness trajectories, burdens of treatment, and social inequalities shape service user and caregiver participation in health and social care: a theory-informed qualitative evidence synthesis

Carl R May,[1*] Katja C Gravenhorst,[1] Alyson Hillis,[1] Mick Arber,[2]
Carolyn A Chew-Graham,[3] Katie I Gallacher,[4] Frances S Mair,[4]
Ellen Nolte[1] and Alison Richardson[5]

[1]Department of Health Services Research and Policy, London School of Hygiene and Tropical Medicine, London, UK
[2]York Health Economics Consortium, University of York, Heslington, York, UK
[3]School of Medicine, Keele University, Staffordshire, UK
[4]General Practice and Primary Care, School of Health and Wellbeing, University of Glasgow, Glasgow, UK
[5]NIHR ARC Wessex and School of Health Sciences, University of Southampton, Southampton, UK

[*]Corresponding author carl.may@lshtm.ac.uk

Published June 2025
DOI: 10.3310/HGTQ8159

Plain language summary

How lived experiences of illness trajectories, burdens of treatment, and social inequalities shape service user and caregiver participation in health and social care: a theory-informed qualitative evidence synthesis

Health and Social Care Delivery Research 2025; Vol. 13: No. 24
DOI: 10.3310/HGTQ8159

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

Plain language summary

When we become ill or need to look after others, we may have to do a lot of work. We may need to check, manage and record our symptoms: do different diets or physical activities; obtain and use different drugs, dressings and medical devices. We may also need to learn new skills to look after ourselves and others. Sometimes, we have to work out how we are going to pay for care. Doing this work may be affected by the inequalities and differences that we start out with when we are ill, for example, our incomes, ethnicity, housing, education, gender and age. The kinds of illnesses we have, and how these change over time as symptoms progress, can make this work harder, and we may find it difficult to look after ourselves or others.

To understand these challenges, and how they affect people's experiences of health and illness, we looked at 279 studies by other researchers. They told us about people's everyday experiences of living with six health problems. These were long-term conditions (Parkinson's disease and schizophrenia); diseases that change over time (bipolar disorder and inflammatory bowel disease); and rapidly progressing diseases (brain cancer and young-onset dementia). These studies explored the ways in which people – and their caregivers – described their experiences of illness in their own words.

The 279 studies we looked at did not say much about the advantages and disadvantages that people start out with, but they did tell us about what is lost when people become sick. They lose 'social capital': this is their income, access to transport, and access to employment and networks of friends. They lose their 'personal capacity'; this happens when people find it difficult to access care, find their diagnosis shocking and become fearful about the future. Symptoms can make it difficult to manage and may also make people think differently about them. Finally, they may need to take responsibility for their care, as diagnoses and symptoms become more difficult over time. This study has identified key 'pressure points' that are opportunities for supporting people as they travel through pathways of illness and care. Interventions that fit these pressure points are likely to effectively solve problems around their ability to influence the organisation and delivery of their care.

Health and Social Care Delivery Research

ISSN 2755-0079 (Online)

A list of Journals Library editors can be found on the NIHR Journals Library website

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), NCBI Bookshelf, Scopus and MEDLINE.

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

Manuscripts 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 www.nihr.ac.uk/explore-nihr/funding-programmes/health-and-social-care-delivery-research.htm

This article

The research reported in this issue of the journal was funded by the HSDR programme or one of its preceding programmes as award number NIHR130407. The contractual start date was in January 2021. The draft manuscript began editorial review in February 2024 and was accepted for publication in December 2024. 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' manuscript and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this article.

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