Exploring patient, informal carer & care professional perspectives to understand the key clinical & non-clinical care needs of those living with multiple long term conditions (MLTC)



Glenn Simpson¹, Leanne Morrison¹, Miriam Santer¹, Andrew Farmer², Hajira Dambha-Miller¹

¹ Primary Care Research Centre, University of Southampton, Southampton ² Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford



Introduction

- MLTC is the co-occurrence of two or more chronic LTCs.
- MLTC patients often have multifaceted care needs requiring a combination of clinical interventions, social care & wider social support.
- By understanding the experiences of patients, informal carers & care professionals, & analysing these perspectives, it is possible to gain a fuller picture of the wide-ranging & complex care needs of this cohort.

Methods

We used purposive sampling to capture a range of participant views. We interviewed 29 participants, recruited from:

- primary and secondary care
- adult social services
- 3rd sector/charities
- patients
- informal carers
- MLTC researchers

We used snowball sampling from the initial round of interviews to identify further participants. Telephone & video interviews were conducted during 2022.

Analysis

Thematic analysis was used based on Braun & Clarke's (2006) method. Team members independently coded a sample of transcripts of the interviews, then met to discuss their interpretations until consensus was reached leading to the formulation of a coding framework. Subsequent rounds of coding were conducted to refine the framework. Key themes were identified based on recurring patterns in the data.

Perspectives on clinical and non-clinical care needs among those living with MLTC

Perspectives on patients

- Physically restricted & mental health issues caused or exacerbated by MLTC.
- Importance of self-management of care.
- Developing coping mechanisms & strategies.
- Patients feeling empowered.
- Supporting independence.

Social care and social perspectives

Social care:

- A need for more specialist providers & skilled staff.
- Patients prefer same carer/care team for continuity of care.

Social issues:

- Limited awareness of services available to support social needs.
- Poor lifestyle & health behaviour contributing to poor health.
- Social isolation, participation & diminished quality of life.

Perspectives on informal carers

- Restricted lives.
- Health/wellbeing impacts associated with caring responsibilities, especially detrimental to mental health.
- Informal carer involvement in care decision-making.
- Carers needs rarely considered in discussions relating to care.

Clinical Perspectives

- Lack of services & consideration of mental health in MLTC.
- Availability/accessibility of services locally (travelling, waiting times, short consultations).
- Care continuity, especially seeing the same clinician.
- Single disease focus in care provision which is working against holistic, personalised care for MLTC patients.
- Limited understanding of MLTC among some care providers.
- Challenges for patients navigating the care system.

Personalised care options & interventions Holistic and co-ordinated care approach Promoting selfmanagement & independent living Suggested areas to enhance care in MLTC Whore awareness of MLTC & the varied care needs of this cohort The key role of informal carers – involving & engaging with them

Acknowledgement

The authors wish to thank all participants and our public contributors for their contributions.

This report is independent research funded by the National Institute for Health Research (Artificial Intelligence for Multiple Long-Term Conditions (AIM), "The development and validation of population clusters for integrating health and social care: A mixed-methods study on Multiple Long-Term Conditions", "NIHR202637"). The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the National Institute for Health Research or the Department of Health and Social Care.