

Rethinking continuity in primary care for people with mesothelioma

Emilie Couchman¹, Steph Ejegi-Memeh¹, Sarah Mitchell², Clare Gardiner¹

¹ Mesothelioma UK Research Centre, Division of Nursing & Midwifery, Health Sciences School, University of Sheffield, UK

² School of Medicine, University of Leeds, UK

Background

Mesothelioma is a terminal disease that is linked to asbestos exposure. It has a poor prognosis, with a median survival of 8 to 14 months. Palliative care involves management of symptoms and psychosocial concerns for people with any life-threatening condition, and those important to them. It can play an important role at all stages of the mesothelioma disease trajectory. General practitioners (GPs) have a key role in recognising patients who may benefit from palliative care, and providing such care. Continuity is difficult for GPs (and other healthcare professionals) to provide within the current NHS primary care system but is highly valued by patients with palliative care needs. More research is needed to understand the experiences of continuity in primary care among people with mesothelioma and their close persons. Specifically, there is a gap in the literature regarding understanding the ability of patients to achieve their desired level of continuity with their primary healthcare team.

Aim

To provide detailed understanding of the experiences of continuity in primary care among people with mesothelioma, their close persons and their healthcare professionals; how they achieve this (or not); and how it affects their healthcare service use.

Method

Realist case studies of patient journeys through the healthcare system (involving longitudinal interviews with people with mesothelioma, their close persons and healthcare professionals; and exploration of the organisational context). This is Phase 2 of a PhD study.

Phase 1
A systematic review of the international literature on continuity in primary palliative care for people with advanced cancer

Phase 2
Realist case studies of patient journeys through the healthcare system

Phase 3
Stakeholder workshops to discuss research findings

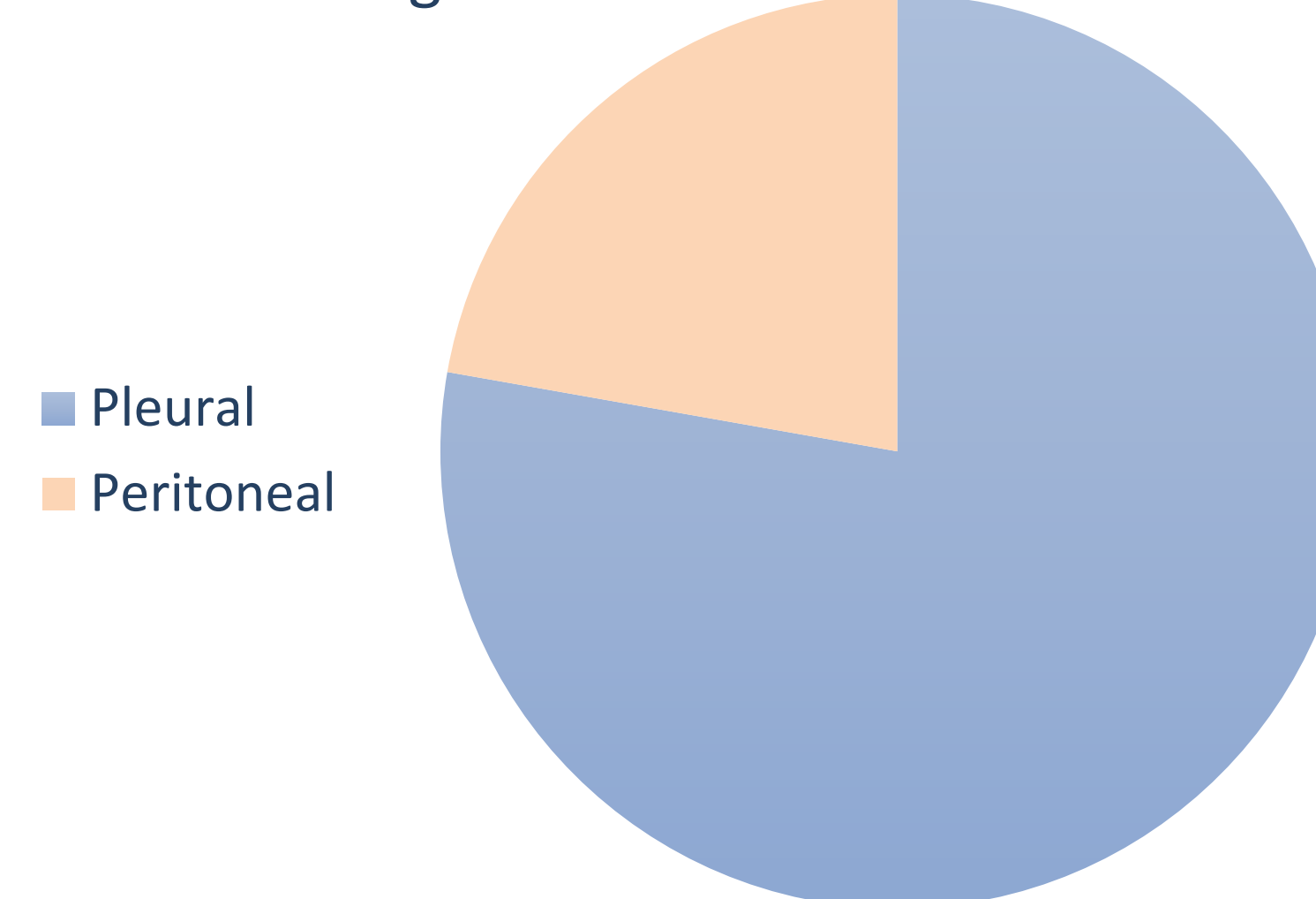
Longitudinal, qualitative interviews with people with mesothelioma, their close persons and their healthcare professionals

Consider the implications of findings for service design and delivery
Form recommendations to support continuity for people with mesothelioma in primary palliative care

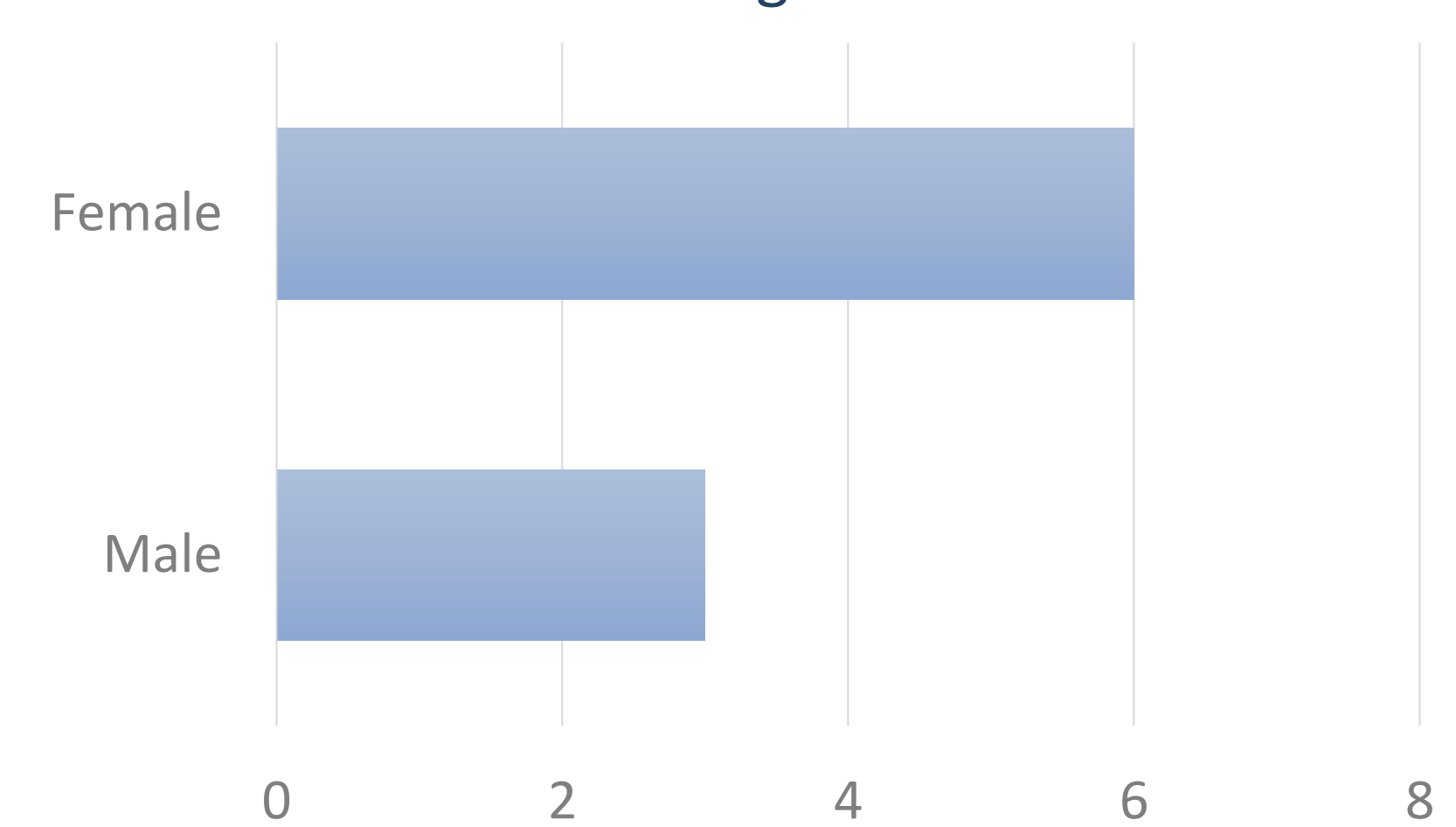
Contact Details

Dr Emilie Couchman, PhD Student at Mesothelioma UK Research Centre, Email: emcouchman1@sheffield.ac.uk
Twitter: @DrEmilieCouch,
Website: <https://www.sheffield.ac.uk/murc/our-research/rethinking-continuity-primary-care-people-mesothelioma>

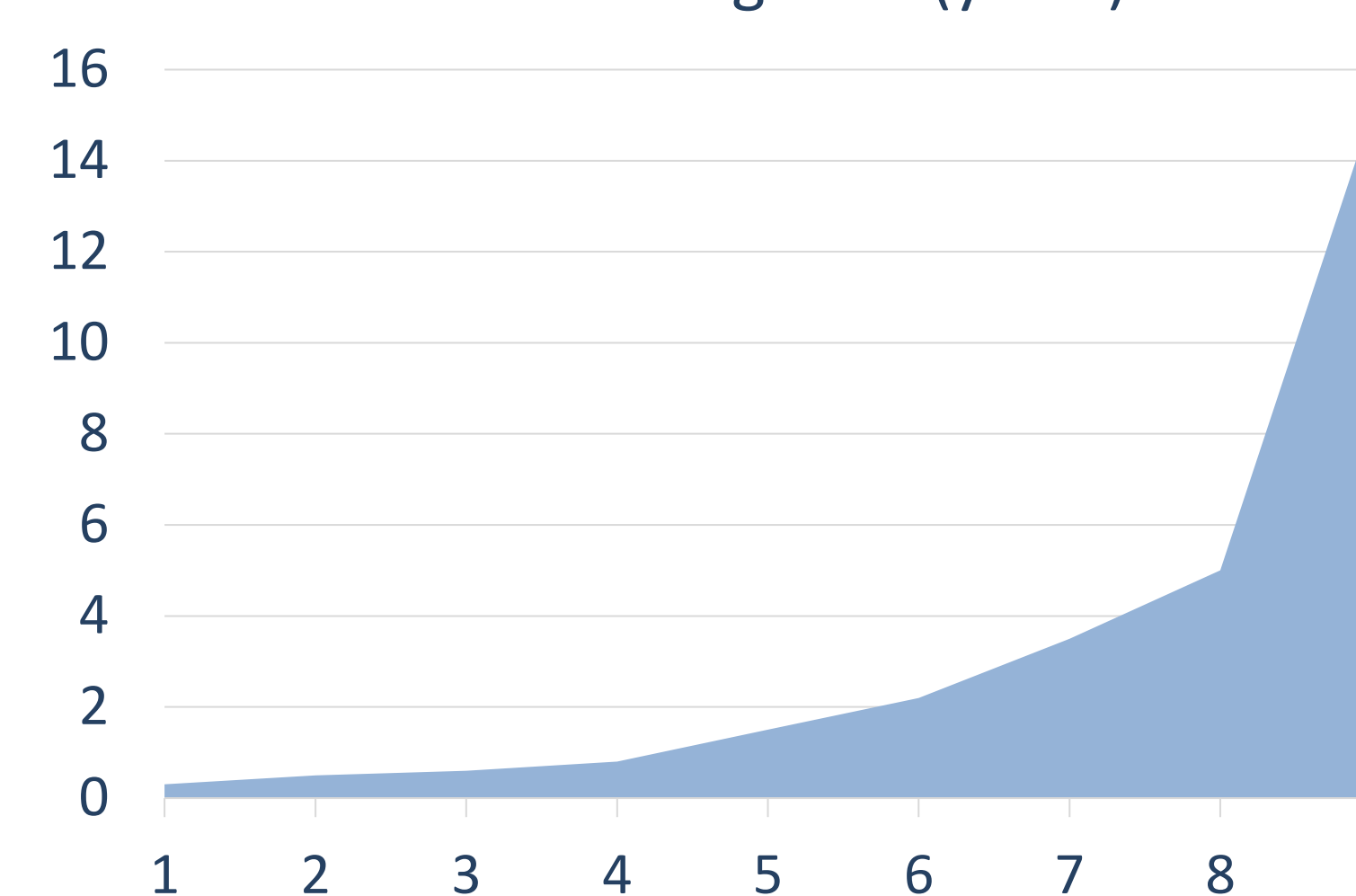
Patient diagnosis



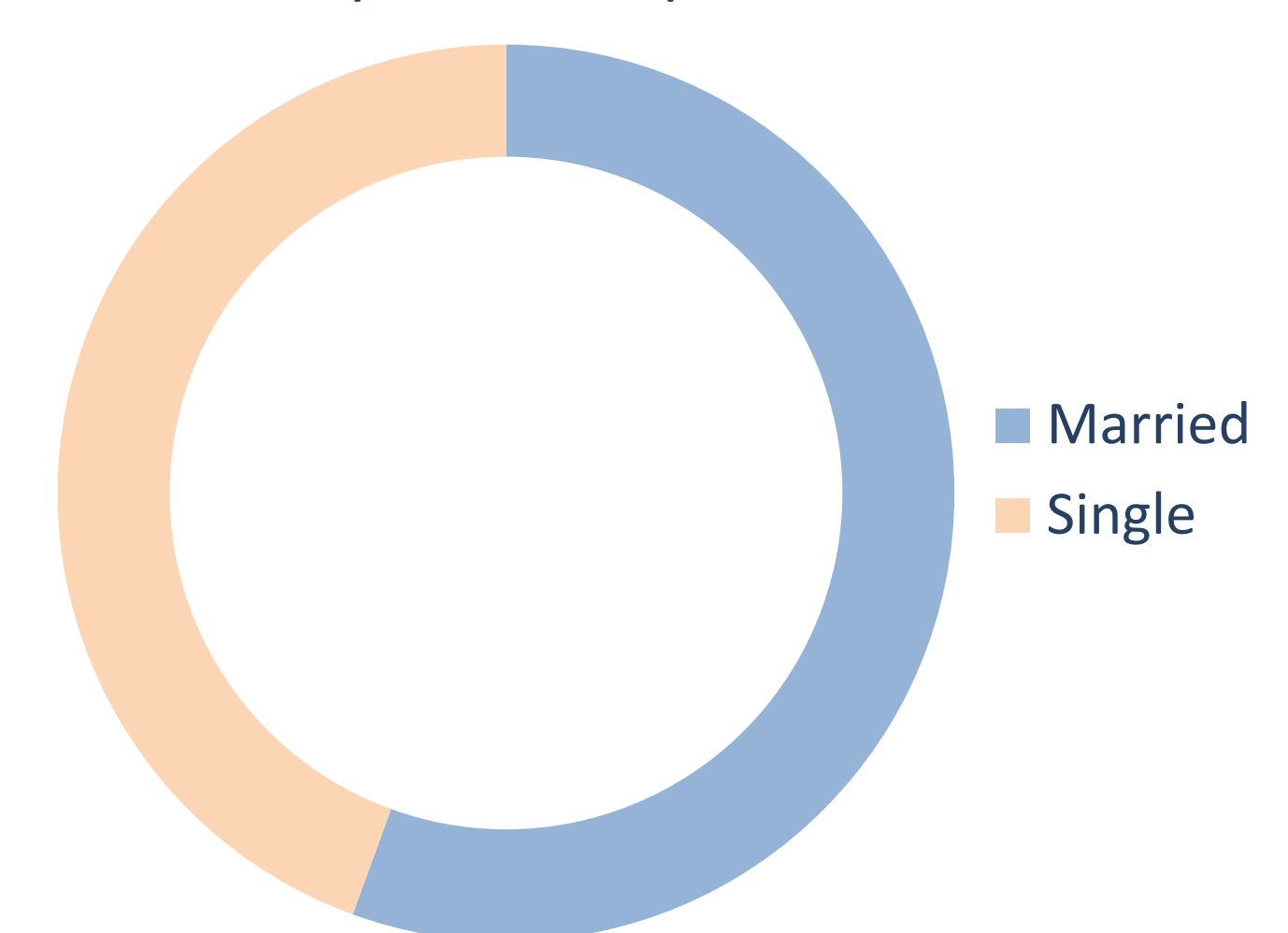
Patient gender



Time since diagnosis (years)



Patient partnership status



Results

Nine patients formed the centre of each case study. The age range of patient participants was 63 to 81, with an average age of 69. All patients were White British, except one who identified as White European. Duration since diagnosis varied from 4 months to 15 years. Eight patients nominated a close person that was also interviewed, and eight participants provided contact details of at least one healthcare professional who was interviewed (Oncologist or Meso UK nurse specialist). Five GPs were approached, but at the time of poster printing, no responses had been received.

Developing themes and application of theory

The coding framework includes themes relating to: the initial programme theories; the Candidacy Framework; components of capacity; researcher reflexivity and other disease- and service-specific themes.

Patients perceive their continuity needs to be largely unmet by the inflexible primary care system, which needs drastic change to adapt to a society in which patients receive increasingly novel treatments and live longer with more complex healthcare needs.

Conclusion

This research will deepen understanding of NHS primary care continuity for people with mesothelioma. Fragmentation is palpable in the recent history of the NHS, current practice and society in general. Such a complex topic needs in-depth research to understand how care is delivered at an organisational level, and how it is experienced by patients and professionals at an individual level.

References

Please contact Dr Emilie Couchman for the full reference list.