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Title

Guilt, shame and perception of being a burden among older adults with multimorbidity: scoping review and qualitative Inquiry

Priority 1 (Research Category)

Multimorbidity

Presenters

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Abstract

Context: Due to an ageing population worldwide, care for older adults has become a global challenge. For many older adults living with multiple long-term conditions (multimorbidity), poor care coordination, and overwhelming burden related to the necessity of learning about, following self-management plans and lifestyle changes can be further complicated by feelings of guilt and shame of being a burden to formal and informal caregivers. Objective: This study aims to develop a better understanding of how feelings and experiences of guilt, shame, and the perception of being a burden impact on older adults' health care interactions. Study Design and Analysis: Three complementary research elements are being conducted: i) scoping review: involving a search of six databases to identify relevant studies up to November 2022. Citations were independently screened using pre-defined eligibility criteria. Extracted data were categorised and a map of existing knowledge and current gaps in literature is being profiled; ii) through interviews and focus groups, and using 'creative methods', we further explore older people's experiences of guilt, shame and self-perceived burden, and their impact on healthcare use, self-management, and overall health. A virtual art gallery will be developed, adding depth and richness to findings; iii) stakeholder engagement workshops will support co-design of strategies to reduce the potential impact of older adults' perceptions of being a burden on their overall health outcomes, and health services interactions. Settings: This is a mixed methods study, based in primary care. Healthcare professionals and patients with multiple long-term conditions formed an advisory group contributing to study design, interpretation, and dissemination of findings. Engagement of public is being guided by the UK Standards for public involvement framework. Results: 9845 unique citations were screened in the review; 52 studies were included. Early findings show that older adults with multiple long-term conditions experience self-perceived burden. Further health deterioration and failing to meet self-management goals may lead to feelings of guilt, and shame which may not often be communicated to caregivers and/or clinicians. Analysis is ongoing. Full findings will be presented at conference. Conclusions: There's need for awareness and strategies to strengthen support for the health and well-being of older adults with multiple long-term conditions in primary care.