

**Submission Id:** 4937

**Title**

*Treatment burden in individuals living with and beyond cancer: a systematic review of qualitative literature*

**Priority 1 (Research Category)**

Cancer research (not screening)

**Presenters**

Katie Gallacher, PhD, BSc, MBChB, Esyn Yeoh, Joanne Chan, Revathi Nair, Lisa Duncan, Rosalind Adam, PhD, BSc, MBChB

**Abstract**

Context: Individuals with cancer are being given increasing responsibility for the self-management of their health and illness. In other chronic diseases, individuals who experience treatment burden are at risk of poorer health outcomes. Less is known about treatment burden and its impact on individuals with cancer. Objective: To investigate perceptions of treatment burden in individuals living with and beyond cancer. Study Design and Analysis: Systematic review. Medline, CINAHL and EMBASE databases were searched for qualitative studies that explored treatment burden in individuals with a diagnosis of breast, prostate, colorectal, or lung cancer. Descriptive and thematic analyses were conducted. Study quality was assessed using a modified CASP checklist. The review protocol was registered on PROSPERO (CRD42021145601). Setting or Dataset: Community setting. Population Studied: individuals with a diagnosis of breast, prostate, colorectal, or lung cancer at any stage of their diagnostic/treatment trajectory. Intervention/Instrument: N/A. Outcome Measures: The experience of treatment burden, defined as the workload of healthcare and the impact on wellbeing. Results: Forty-eight studies were included. Health management after cancer involved cognitive, practical, and relational work for patients. Individuals were motivated to perform health management work to improve life-expectancy, manage symptoms, and regain a sense of normality. Performing health care work could be empowering and gave individuals a sense of control. Treatment burden occurred when there was a mismatch between the resources needed for health management and their availability. Individuals with chronic and severe symptoms, financial challenges, language barriers, and limited social support are particularly at risk of treatment burden. For those with advanced cancer, consumption of time and energy by health care work is a significant burden. Conclusion: Treatment burden could be an important mediator of inequities in cancer outcomes. Many of the factors leading to treatment burden in individuals with cancer are potentially modifiable. Clinicians should consider carefully what they are asking or expecting patients to do, and the resources required, including how much patient time will be consumed.