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EXPERIENCE OF TERMINAL ILLNESS IN WORKING-AGE PEOPLE: A REVIEW OF THE LITERATURE AND A SURVEY OF HR PROFESSIONALS

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Introduction People of working age who have been diagnosed with a terminal illness, and those who care for them, often find themselves forced to give up work and become unemployed. In addition to the distress of dealing with a terminal illness, consequences of giving up work include financial stress and strain, and the associated negative impacts on wellbeing: in the UK, around 25,000 people a year of working age die whilst in poverty.

Aims The aim of this project was to better understand the experience of terminal illness in working-age people, with a focus on mental health and wellbeing, and the role of employer support.

Methods We carried out a scoping review of the literature searching across three databases in addition to a call for evidence. We conducted a narrative synthesis on all included papers. We conducted an online survey of 1,016 HR professionals in the UK.

Results Three core and inter-related themes were identified: social welfare legal needs, financial stress, and mental wellbeing. As a result of being diagnosed with a terminal illness, participants experienced financial stress which was partially related to unmet legal needs, both causing disturbances to mental wellbeing. The survey suggests employees with a terminal illness receive wide-ranging employer support depending on organisation size and industry sector. Support includes flexible working, paid time off to attend appointments and manage the demands of illness/treatment, and managing terminal illness outside of standard sickness reporting processes.

Conclusions People of working age with a terminal illness experience high levels of financial stress and difficulties meeting their complex legal needs, which negatively impacts their mental wellbeing. The support they receive from employers varies substantially.

Impact Exploratory work in under-researched areas that starts to fill knowledge gaps.

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HOW DOES RECEIVING A SURVIVAL ESTIMATE AFFECT THE GENERAL HEALTH AND WELLBEING OF PEOPLE LIVING WITH TERMINAL CANCER AND THEIR CARERS? FINDINGS FROM A SYSTEMATIC REVIEW OF QUALITATIVE EXPERIENCES

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Introduction We are developing a core outcome set (COS) for palliative cancer care research into prognostication (prediction of survival). Studies in this field often measure a variety of clinical and service-level outcomes, but do not routinely measure outcomes that are important to patients and carers. The experiences of these stakeholders are essential for producing a meaningful COS.

Aims To identify and synthesise qualitative data on patients' and carers' experiences of prognostication in palliative cancer care.

Methods We searched five electronic databases (MEDLINE, Embase, CINAHL, PsycINFO, and the Cochrane Library) from inception up to March 2022. The search included qualitative or mixed methods studies exploring how adult cancer patients and/or carers are affected by prognostication. Data describing outcomes and experiences of prognostication were extracted and thematically synthesised, using the Core Outcome Measures in Effectiveness Trials (COMET) taxonomy as a framework to develop themes.

Results From 8,075 results, we identified 9 papers describing patients' and carers' experiences of prognostication. We identified 28 themes from these papers and organised these into eight domains within the COMET taxonomy: 1) psychiatric outcomes; 2) spiritual, religious, and/or existential functioning/wellbeing; 3) emotional functioning/wellbeing; 4) social functioning; 5) global quality of life; 6) delivery of care; 7) perceived health status; 8) personal circumstances. The main themes identified were: avoidance/denial, maintaining hope, preparedness for end-of-life, and treatment preferences.

Conclusions We have identified 28 themes as potential candidates for inclusion in the future COS. The next stage of the study will investigate stakeholders' perspectives on these themes and other potentially suitable items for inclusion, identified through linked reviews.

Impact Standardising outcome reporting through a COS will improve the comparability of future prognostic research, and match better with patient and carer experiences. This will lead to better evidence synthesis, clinical practice, and ultimately improve access to support for those living with terminal cancer when receiving a prognosis.

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IMPORTANT OUTCOMES TO MEASURE IN TRIALS OF TOUCH-BASED COMPLEMENTARY THERAPIES IN PALLIATIVE CARE

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Introduction Complementary therapies, such as massage and reflexology, are widely used in palliative care settings. People with advanced disease report a range of physical and psychological benefits, however clinical trials evidence for effectiveness of complementary therapy is inconclusive. Developing a core outcome set (a list of outcomes deemed most important by key stakeholders) can ensure clinical trials consistently evaluate meaningful outcomes.