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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.

REFERENCE(S)

- Hanratty B, Holland P, Jacoby A, *et al*. Financial stress and strain associated with terminal cancer—a review of the evidence. *Palliative Medicine* 2007;**21**(7):595–607.
- Kochovska S, Luckett T, Agar M, *et al*. Impacts on employment, finances, and lifestyle for working age people facing an expected premature death: a systematic review. *Palliat Support Care* 2018;**16**(3):347–364.
- Marie Curie. (2019). The cost of dying: the financial impact of terminal illness.

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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.

Aims To develop a core outcome set for touch-based complementary therapies in palliative care.

Methods Potentially relevant outcomes were identified by screening published randomised control trials of touch-based therapies in clinical populations identified in a systematic review, and qualitative studies of complementary therapies in people with advanced disease. Semi-structured interviews were conducted with patients and complementary therapists to identify additional relevant outcomes. Patients, complementary therapists and academics rated the importance of the identified outcomes in a modified online Delphi survey. Outcomes for which $\geq 70\%$ of the group agreed were critically important and were discussed and voted on in a consensus meeting.

Results 59 unique outcomes were identified from published literature and interviews. Of these, 17 were deemed critically important in the Delphi survey. From voting in the consensus meeting, five outcomes were selected for inclusion. An additional three outcomes were identified as important to patients and were incorporated. The final core outcome set comprises; Anxiety, Sleep quality, Overall mental wellbeing, Pain, Muscle relaxation, Mental resilience, Enjoyment and Patient satisfaction.

Conclusions A Core Outcome Set reflecting the priorities of patients, complementary therapists and academics has been developed to be used in palliative care clinical trials.

Impact Use of the core outcome set in future trials will standardise outcomes and allow for better data comparison and synthesis. Improving the evidence base will help us bridge the gap between patient experience and trial outcomes and better understand the effect of complementary therapies for patients receiving palliative care.

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WHAT KINDS OF SPIRITUAL AND/OR RELIGIOUS INTERVENTIONS FOR THE WELLBEING OF PEOPLE LIVING WITH TERMINAL ILLNESSES DID RCTS INVESTIGATE IN 2011–22? FINDINGS FROM A COCHRANE REVIEW, UPDATING A PREVIOUS REVIEW (CANDY ET AL. 2012)

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Introduction People with terminal illnesses may have spiritual and/or religious concerns and often value professional assistance with addressing these. It is again being increasingly recognised that, as Cicely Saunders originally argued, attending to the spiritual and/or religious needs of people approaching the end-of-life benefits their health and wellbeing overall.

Aims To explore the detail of spiritual and/or religious interventions for the wellbeing of adults with terminal illnesses in randomised controlled trials (RCTs) included in a 2011–22 Cochrane review.

Methods We systematically searched six databases (AMED, CENTRAL, CINAHL, EMBASE, MEDLINE, and PsycINFO) for RCTs of spiritual and/or religious interventions for the wellbeing of adults with terminal illnesses between 2011 and 2022. Our primary outcomes were spiritual wellbeing, psychological wellbeing, quality of life, coping, death distress, and quality of death/dying.

Results We identified 2569 citations, retrieved 98 full-texts, and included 40 studies, a much larger number and proportion than the 2012 review (40/2569 vs 5/3868).

Studies were conducted globally: in Africa, the Americas, Asia, Australasia, and Europe. Interventions varied. Most involved psychotherapy (14) or life reflection (13). Five were explicitly spiritual or religious, e.g., Islamic prayer, or Buddhist chanting. Five comprised explicit spiritual/religious elements within a palliative care intervention. The remaining three investigated meditation or mindfulness.

Studies also varied in their comparators, outcomes assessed, and outcome measures used. This variability between studies restricted and limited inter-study comparisons.

Conclusions Increasing numbers of RCTs in this field are being conducted internationally. However, they vary widely in the interventions they investigate, the outcomes they address, and the measures they use.

Impact This important, under-researched field is growing, with increasing numbers of RCTs investigating spiritual and/or religious interventions for wellbeing. However, studies are highly diverse, and, while variation is to be expected in a developing field, too much prevents comparisons of study findings. More consistency of design would enable more inter-study comparability.

REFERENCES

1. Candy B, Jones L, Varagunam M, Speck P, Tookman A, King M. Spiritual and religious interventions for well-being of adults in the terminal phase of disease. *Cochrane Database of Systematic Reviews* 2012;(5). Art. No.: CD007544. DOI: 10.1002/14651858.CD007544.pub2.
2. Clark D. (2018). Cicely Saunders: a life and legacy. Oxford, England: Oxford University Press.
3. Saunders CM. (1981). The founding philosophy. p. 4 in Saunders CM, Summers DH, Teller N (eds.), *Hospice: The Living Idea*. London: Edward Arnold.
4. Knaul FM, et al, on behalf of the Lancet Commission on Palliative Care and Pain Relief Study Group. Alleviating the access abyss in palliative care and pain relief – an imperative of universal health care: the Lancet Commission report. *Lancet* 2018;**391**:1391–454.
5. Radbruch L, et al. Redefining palliative care – a new consensus-based definition. *Journal of Pain and Symptom Management* 2020;**60**(4):754–64.

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BURDEN AND CHALLENGES OF MALIGNANT BOWEL OBSTRUCTION: A QUALITATIVE STUDY

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Introduction Malignant bowel obstruction (MBO) is a distressing complication of cancer, causing symptoms including nausea, vomiting, pain, and constipation. It has a profound effect on quality of life, often requiring hospitalisation. There is a lack of data indicating how outcomes used to evaluate MBO in research and clinical practice are related to the patient experience, and what key features are important to them and their caregivers.

Aims To explore key features of the lived experience of people with MBO, their caregivers, and perspectives of healthcare professionals.