



Experience of terminal illness in working age people: a scoping review

Commissioned and published by
the What Works Centre for Wellbeing

Authored by
Dr Aradhna Kaushal, Mohammed Yusuf and Dr Joanna Blodgett

November 2022



Acknowledgements

We are grateful for the ongoing collaboration, support and advice from Joanne Smithson and Rahima Rahman from the What Works Centre for Wellbeing and the consultation group:

- Sam Royston, Caroline Beard and Izzie Baverstock-Poppy - Marie Curie
- Rachel Suff - The Chartered Institute of Personnel and Development (CIPD)
- Saskie Dorman - University Hospitals Dorset NHS Foundation Trust, Dorset Integrated Care System
- Clare Fuller - Advance Care Planning Advocate
- Lucy Dennis - Lived experience researcher
- Rob Johnston and Lee Barron - Trades Union Congress (TUC)
- Mike Gardner - the Advisory, Conciliation and Arbitration Service (Acas)



This work was supported by [Marie Curie](#).

Clair Fisher 1979-2022

This research was conceived in partnership with Clair Fisher, a long-time collaborator of the What Works Centre for Wellbeing. Clair was diagnosed with stage 4 bowel cancer in 2018. Throughout her treatment and palliative care, it mattered to her that the time she had was good. [Dying Well](#) was Clair's retirement project; a space for her to document her personal journey, to explore the evidence around wellbeing in terminal illness and test out some of the theories. One of Clair's missions was to make it easier for terminally ill people to keep working while they want to.

This research is one of the many lasting contributions she has made towards this aim.

Contents

Introduction	4
Methods	5
Identifying the research question	5
Identifying relevant studies	6
Selecting the studies	6
Inclusion and exclusion criteria	6
Charting the data	7
Collating, summarising, and reporting the results	7
Consultation	8
Results	9
Screening and characteristics of included studies	9
Critical appraisal	10
Main themes	12
Social welfare legal needs	12
Financial stress	14
Mental wellbeing	14
Factors affecting continuation of work	15
Quantitative measures of wellbeing	15
Discussion	17
Summary of findings	17
Comparison to the previous literature	17
Strengths and limitations	18
Implications for research, policy, and practice	19
Conclusions	20
References	21
Appendix A: Example search strategy	24
Appendix B: Mixed Methods Appraisal Tool (MMAT) appraisal by study	25
Appendix C: Overview of main themes and sub-themes	26
Appendix D: Quantitative measures used in included studies	27

Introduction

In the general population, there is evidence of strong bi-directional links between wellbeing and employment: being employed can improve your wellbeing, and having good wellbeing can make it easier to work (Weziak-Bialowolska et al., 2020). However, people of working age (defined by the OECD as people aged 15-64) 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 (Kochovska et al., 2018; OECD, 2022). There is very little information available about the number of people of working age living with a terminal illness and the employment policies and practices designed to support them.

One consequence of giving up work is the potential for experiencing financial stress and strain, and the associated negative impacts on wellbeing in addition to distress of dealing with a terminal illness: in the UK, around 25,000 people a year of working age die whilst in poverty (Marie Curie, 2022a; Hanratty et al., 2007). Factors affecting overall household wellbeing include debt, increasing every-day living expenses, and housing costs (Hiilamo, 2020; Preston et al., 2017). For people with a terminal illness, the financial impact may be worsened by declining health, barriers to accessing welfare support and challenges to maintain paid employment in a flexible manner (Marie Curie, 2019). Taken together, people of working age diagnosed with a terminal illness are at particularly high risk of psychological distress, as are members of their household. Those diagnosed are also at high risk of poverty at the end of life.

There is a lack of evidence in this area on the effective ways to support people to work while they are able, the associated impacts this has on an individual's wellbeing and life experience, and the unique challenge of financial insecurity that many face during this time (Fisher, 2021). Responding to this challenge, the What Works Centre for Wellbeing has convened experts from academia, policy and practice to share their learnings and identify where the evidence gaps are when it comes to wellbeing and living and working with a terminal illness (What Works Centre for Wellbeing, 2022). Our aim with this work was to conduct a scoping review to understand what is currently known about the experiences of terminally ill people of working age.

Methods

The methodology of this scoping review was guided by the principles outlined by Arksey and O'Malley in 2005 and expanded upon by Levac et al. in 2010, and Peters et al. in 2015 (Levac et al., 2010; Arksey and O'Malley, 2005; Peters et al., 2015). This widely used methodology includes five key steps:

1. identifying the research question
2. identifying relevant studies
3. selecting the studies
4. charting the data
5. collating, summarising, and reporting the results.

In addition to these five steps, we also conducted the optional sixth step proposed by Arksey and O'Malley (2005); stakeholder consultation. For this, we engaged with stakeholders and experts with experience from the What Works Centre for Wellbeing and Marie Curie during protocol development and during analysis and synthesis. These stakeholders contributed invaluable contextual information and interpretation of findings. The report was prepared following the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews PRISM-ScR (Tricco et al., 2018)).

Identifying the research question

To capture the relevant literature, the following research question was used to formulate the search strategy:

“What research has been carried out on the experience of terminal illness in working age people?”

Identifying relevant studies

We conducted extensive database and grey literature searches, and published a Call for Evidence, shared widely by What Works Centre for Wellbeing and their partners. On the 30th March 2022, MEDLINE (Medical Literature Analysis and Retrieval System Online), PsycINFO and CINAHL (Cumulative Index to Nursing and Allied Health Literature) were searched for all articles from inception to present using the search strategy outlined

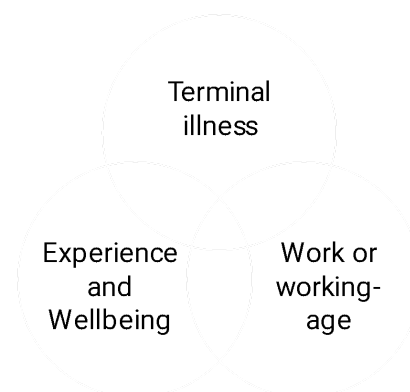


Figure . Overview of search strategy

in Appendix A. These search terms were adapted from previous reviews that examined similar topics to our own (Maulsby et al., 2020; Ngiam et al., 2021; Watson et al., 2018), and consisted of three main arms: terms related to terminal illness, work, and life experience/wellbeing. Additionally, we included a fourth arm to remove results related to medical or clinical topics (e.g. NOT doctor, nurse, Covid-19, etc.) as the focus of the review was on personal experience and psychological wellbeing. The following grey literature resources were searched on the 18th of April 2022: NHS Evidence, Open Grey, King's Fund Library, and the Health Foundation.

Selecting the studies

Inclusion and exclusion criteria

Studies were eligible for inclusion if they involved individuals of working age who were terminally ill and reported on activities and experiences related to work. We included original research of any study design (including quantitative, qualitative, and mixed methods approaches), reports from grey literature and research which was not peer-reviewed. We excluded studies which did not specify a terminal illness, studies reporting on experiences of carers and health professionals, and activities and experiences not related to work, and studies which were not in English. Working age was not specified in any papers and so any paper which included any participants under the age of 65 were included. No country or year limitation was imposed on the search strategy.

Duplicates from the searches above were removed and remaining studies were managed using Rayyan (Ouzzani et al., 2016). In the first stage, two reviewers (MY and JB) independently screened the title and abstracts of 20% of all records. Any disagreements were resolved through discussion with a third reviewer (AK) after which the inclusion and exclusion criteria were further refined. Subsequently, one reviewer (MY) screened the remaining 80% titles and abstracts. In the second stage, two reviewers (MY and AK) independently screened the full text of all remaining articles. As before, any disagreements were resolved through discussion.

Charting the data

Data from the included papers were extracted by one researcher (MY, AK or JB) on key study information such as the authors, location, study objective, sampling method, data collection method, data analysis approach, participant information

(age, sex, ethnicity), employment information (type of work and workplace), illness and diagnosis information (type and duration), quantitative measures, the main results and key findings. The main results were coded by one researcher (AK) into broad themes and sub-themes and each paper was assessed for quality (JB) using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018).

Collating, summarising, and reporting the results

We collated descriptive summaries of the studies which were included in the review. We expected the evidence for this review to be heterogeneous in nature and so we opted to conduct a narrative synthesis using guidance produced by the Economic and Social Research Council Methods Programme (Thomas and Harden, 2008; Popay et al., 2006; Dixon-Woods et al., 2005). We approached the analysis of quantitative and qualitative data using a convergent synthesis design, where both types of data are analysed concurrently (Hong et al., 2017; Pluye and Hong, 2014). Narrative synthesis was completed by AK which involved familiarisation with the data by reading and re-reading each paper, coding and recoding of themes to identify themes and sub-themes.

Consultation

We consulted with stakeholders at three stages of the scoping review process. The first meeting was to discuss our approach to the review and the search strategy. Input at this stage was used to refine the scope of the research question and to include additional terms. At the second meeting, we had completed the screening process and presented a summary of the included papers. We reviewed the data charting process and the stakeholder group provided insights for additional data to extract e.g. information about work and workplace. At the final meeting, we presented the results of the review and received valuable input on the interpretation of the results, as well as the implications for research, policy, and practice.

Results

Screening and characteristics of included studies

The initial search for literature identified 2952 papers of which 2313 titles and abstracts were screened after duplicate records were excluded (n=639). A total of 18 articles were reviewed for full-text screening, with six meeting the eligibility criteria. Figure 2 summarises the primary reason for exclusion and the flow of studies through the identification and screening process.

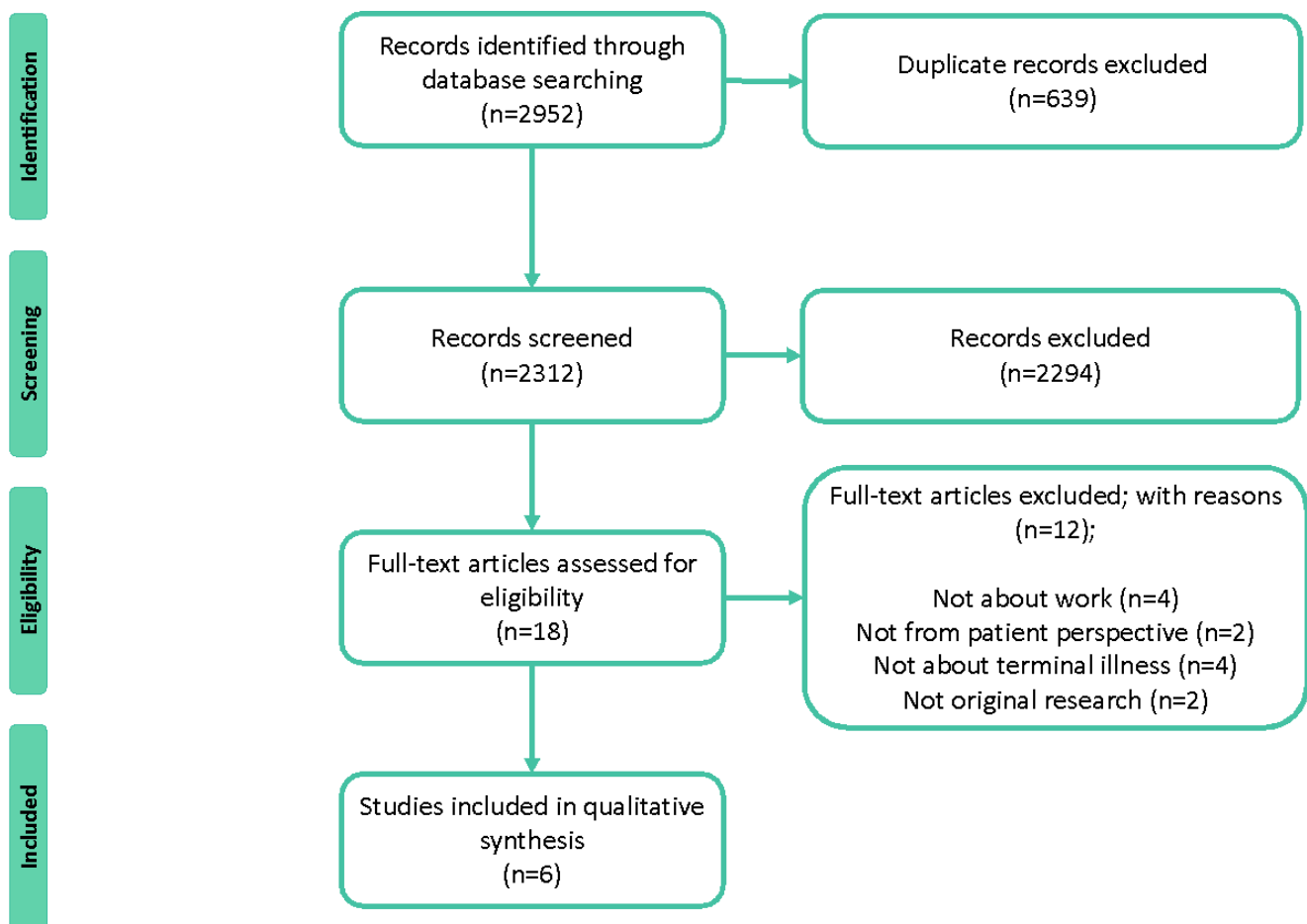


Figure 2. Flow diagram of studies

The six studies which were included in the review are summarised in Table 1. Two studies took place in the USA, one in Australia, one in Germany, one in India, and one in the UK. Three of the papers focused on the financial and economic impacts of terminal illness. Two investigated antecedents and predictors of continuing work. The final study explored the experience of everyday legal needs towards the end of life. Three studies employed qualitative research methods and three quantitative methods. The sample size ranged from eleven to 176, and participants had a range

of diagnoses including cancer, amyotrophic lateral sclerosis, Chronic Obstructive Pulmonary Disease (COPD), and muscular dystrophy.

Critical appraisal

Four studies (Emanuel et al., 2010; Cagle et al., 2016; Oechsle et al., 2011; Westaby et al., 2005) had an MMAT score of 3, indicating moderate quality, with the remaining two receiving a score of 5, indicating high quality (Close et al., 2021; Essue et al., 2015). For the three quantitative studies, we estimated a high likelihood of response bias as no studies examined differences in characteristics between those who did and did not participate in the study. Two out of three qualitative studies were considered high quality. The third qualitative study did not provide any participant quotes and therefore we were unable to determine if there was coherence between the original data sources, the analysis, and the interpretation of results (Emanuel et al., 2010). Appendix B provides the individual MMAT item scores for each study.

Table 1. Summary of included studies

First author year (ref)	Aim	Sample size, country	Employment information	Age	Sex	Ethnicity	Illness and diagnosis information (e.g. type, duration)	MMAT review
Financial								
Cagle (2016) (Cagle et al., 2016)	Establish an understanding of the drivers of financial burden at the end of life.	n=176, USA	Not reported	Mean: 55.9 SD=17.8	64% F	85% White 7% Black 3% Other	Cancer	Moderate
Essue (2015) (Essue et al., 2015)	Measure sources of financial stress, the extent of economic hardship, and explore the factors that contribute to economic hardship	n=30, Australia	Not reported	Mean: 68 Range: 58-78	57% F	Not reported	Cancer	High
Emanuel (2010) (Emanuel et al., 2010)	Explore the economic impact of terminal illness on families and on the feasibility of training caregivers as a method of stemming illness-related poverty.	n=11, India	Not reported	Range: 32-57	18% F	100% Indian	Cancer (n= 8) Diabetes (n=2) Tuberculosis meningitis (n=1)	Moderate
Factors affecting decisions to work								
Oechsle (2011) (Oechsle et al., 2011)	To analyse the impact of physical activity and self-instructed training in patients with incurable malignancies undergoing palliative chemotherapy on an outpatient basis on the quality of life and subjective physical well-being.	n=53, Germany	Not reported	Median: 58 Range: 29-76	55% F	Not reported	Cancer	Moderate
Westaby (2005) (Westaby et al., 2005)	Intentions to work during terminal illness: an exploratory study of antecedent conditions	n=125, USA	Currently employed (n=31)	Mean: 57.8 years	55% F	Not reported	Amyotrophic lateral sclerosis	Moderate
Legal needs								
Close (2021) (Close et al., 2021)	To investigate the nature, impact and management of legal needs in the context of end of life care	n=14, UK	Not reported	Mean: 70.3 Range: 38-87	57% F	Not reported	Cancer (n=10) COPD (n=2) Multiple System Atrophy (n=1) Muscular Dystrophy (n=1)	High
F=Female; MMAT=Mixed Methods Appraisal Tool ; COPD: Chronic Obstructive								

Main themes

Three core and inter-related themes were identified in the included studies: social welfare legal needs, financial stress, and mental wellbeing (see Figure 3). As a direct result of being diagnosed with a terminal illness, participants experienced financial stress which was partially related to unmet legal needs, both of which caused disturbances to mental wellbeing. A separate theme, not shown in Figure 3 but reported later, concerned factors affecting continuation of work. A more detailed figure of the main themes and sub-themes can be found in Appendix C.

Social welfare legal needs

People with a terminal illness were found to have particular social welfare legal needs such as applying for benefits, writing a will, preparing a lasting power of attorney, and making funeral preparations (Close et al., 2021). Several barriers to meeting legal needs, as well as facilitators, were identified.

Patients reported difficulties in accessing the support they were entitled to. This included a lack of awareness of what was available and encountering complicated processes and procedures for navigating information when applying for support. Some did not feel they were able to address their legal needs as they had too many other things to worry about, such as financial issues, or feeling psychologically unprepared to begin making end of life arrangements. Others cited the high cost of making a will or assigning power of attorney and feeling like this was not within their budget or worth the expense. A further barrier that was mentioned was not having a formal diagnosis to obtain support, particularly in relation to employment rights.

"...the frustration is massive when you don't know what to ask for... It's not just the information, it's also where to ask, who do you contact when you settle on those things that are available, how do you make those connections about what you need, how do you write the right letter and also trying to get help and how do you get follow-up?" Close et al. (Close et al., 2021)

"It was going to cost £200 each for a will, just to say that if I die first my husband gets everything." Close et al. (Close et al., 2021)



Figure 3. Main themes identified relating to experience of terminal illness in working age people

"...they've called us a hypochondriac saying I'm trying to get out of late finishes." Close et al. (Close et al., 2021)

Several patients mentioned the help provided by health care professionals in supporting their legal needs. This came in the form of advice and sometimes direct support to complete and submit paperwork on the patient's behalf. Some of these facilitations were related to everyday legal needs such as applying for a permit badge to park in disabled parking spaces, or referral to the Citizens Advice Bureau to receive professional support.

In relation to long-term planning of wills and advance care planning, participants noted that this was a largely positive experience to be able to provide peace of mind and relieve pressure from family members at a time of stress. Many patients cited serendipitous access to information, support, and advice on their legal rights, by knowing people with professional experience or coming across information incidentally, for example through advertisements.

"[The specialist palliative care nurse] said "You have your mobility sticker for the car?" and I said "They knocked us back" and she said "You what? It will be through the door within two days" and it was." Close et al. (Close et al., 2021)

"So I had to fill some forms in, well actually I filled them all in wrong, so the doctor said to take it to the Citizens Advice Bureau and they've got specialist people there to help." Close et al. (Close et al., 2021)

"There was a patient in the next bed to me. She worked for the Probation Service and she was in [hospital] poor lass, a lovely girl, and she said you are entitled to some money, she said get in touch with this ..." Close et al. (Close et al., 2021)

"So it's little things like that which have made a massive difference to our lives. It has taken the stress off so we can focus on living our lives. ... Don't get me wrong ... it's not about the money. It's [that] I can't put a price on the peace of mind that brings." Close et al. (Close et al., 2021)

Financial stress

Three studies explored the economic impact of terminal illness and the associated financial stress (Emanuel et al., 2010; Essue et al., 2015; Cagle et al., 2016). These studies showed that many patients experienced financial stress due to combination of:

1. a sudden loss in household income from the patient stopping work
2. partners reducing their working hours to fulfil caring responsibilities,
3. and an increase in expenses such as fuel and parking costs (required as public transport gradually became inaccessible), prescriptions and mobility aids.

Financial strain was more common when the person with terminal illness was a man, from an ethnic minority group, or did not have health insurance (Cagle et al., 2016).

Efforts towards managing this financial stress led to families using up savings that were originally intended for retirement, remortgaging homes, and borrowing money (Essue et al., 2015). Participants in this study acknowledged the damaging consequences for the carer, often a spouse, and the household in the long-term. In one study based in India, patients reported feeling pressure to take jobs which would have been harmful to their health and in some cases engaging in illegal activity to supplement their income (Emanuel et al., 2010).

"I can't work full time [anymore]. My wife has given up her job to look after me. Now we're living on our savings and it's hard... My operation will cost \$1000...my business is virtually non-existent. So we have living costs, and have to eat and pay our bills but have nothing coming in." Essue et al. (Essue et al., 2015)

"The pension doesn't go anywhere near the cost of living and especially rent. With a pension of \$1600 per month I pay \$1043 in rent" Essue et al. (Essue et al., 2015)

Mental wellbeing

Mental wellbeing was not directly assessed or measured by any study included in this review. Nevertheless, there were several references to the psychological distress, not necessarily caused by the illness, but resulting from having to manage complex and financial challenges at an already challenging time. The studies reported participants often referred to stress and anxiety, caused by managing their legal needs, experiencing depression and sleep disturbances as a result.

"I need to apply for the sickness allowance but I haven't done so yet as I am very overwhelmed by the number of forms and amount to read. I'm mentally very tired and want to stay away from stress." Essue et al. (Essue et al., 2015)

"Because at the time ... I was worried about everything and I was starting to get upset and anxious about it all. It is just you don't know what you are eligible for. How

are you meant to know? Making sense of the information ... and how it relates to you is virtually impossible." Close et al. (Close et al., 2021)

Factors affecting continuation of work

One study explored the reasons people with a terminal illness had for working. It found intrinsic reasons, i.e., those motivated by personal enjoyment, purpose and passion, were more likely to be associated with continued working compared to extrinsic reasons such as financial reward (Westaby et al., 2005). This same study found that continuing work was more likely for people who were younger, those who had a higher quality of life, those who were less fatigued, those who were physically able, and those with access to travel.

Quantitative measures of wellbeing

After extracting and reviewing the quantitative measures used in the included studies, we were able to group these into four categories; employment, income, and finance; physical health; health care; and psychological. Three studies measured the effects of terminal illness on employment, income and finances (Cagle et al., 2016; Emanuel et al., 2010; Westaby et al., 2005). They specifically measured changes in employment, income, household assets, education, and personal relationships, in addition to financial strain and financial stress. Physical health was assessed by four studies which included measures of physical activity undertaken in work, daily life and through sports by measuring both frequency and intensity, disability severity, functional status, and symptoms experienced due to treatment (Cagle et al., 2016; Emanuel et al., 2010; Westaby et al., 2005; Oechsle et al., 2011). Health care measures included experience of cancer care and treatment, and the number of caregivers and their relationship with patients (Cagle et al., 2016; Emanuel et al., 2010). There was one quantitative psychological measure used which measured the 'will to live' (Westaby et al., 2005). A detailed summary of the quantitative measures used in these included studies can be found in Appendix D.

Discussion

Summary of findings

There is very limited evidence available about experiences and wellbeing related to work among people of working age who have a terminal illness. This review found only six studies which reported relevant information, with very few exploring the role of work and the workplace directly. Only one of the six studies included any details about employment status or information about the workplace, and only one study took place in the UK.

Despite the small number of studies found, the findings indicate that as a direct result of terminal illness, people of working age experience significant financial and legal challenges, in addition to the challenges of their diagnosis. These challenges can interact and compound the mental wellbeing of patients and their close family members. Although no studies focused on the wellbeing of people of working age, we found evidence that factors unique to this age group, such as loss of family income, cost of childcare, and mortgage and rent costs, may cause additional strain compared to older populations. We found evidence that the financial stress experienced by this group of people can vary depending on individual characteristics which suggests inequalities by gender, ethnicity, and access to health insurance. The quality of the evidence was moderate to good with some potential for selection bias observed.

Comparison to the previous literature

The main findings are in line with previous literature which has shown that people with terminal illness face significant financial stress towards the end of life, often precipitated by discontinuing work, a reduction in household income, and additional living costs. For example, a systematic review by Kochovska et al. (2018) on the impacts on employment, finances and lifestyle for working age people facing an expected premature death found that many patients were forced to work less or give up work/retire early due to symptoms and reduced functioning (Kochovska et al., 2018).

The social legal issues highlighted in this review have previously been acknowledged in the UK where it has been reported that people diagnosed with a terminal illness have been required to undergo capability assessments to receive financial support. It is estimated that 17,000 people died in the UK between 2013 and 2019 while they were waiting for support they were entitled to (Macmillan Cancer Support and Citizens Advice, 2009; All-Party Parliamentary Group for Terminal Illness, 2019). Not

having a formal diagnosis has previously been raised as a barrier to accessing support, particularly for people with long-standing chronic diseases which slowly deteriorate and where it is not possible for a doctor to say how long a person can expect to live. Although the study by Close et al (2021) recruited participants from both rural and urban settings, no direct comparisons were made in terms of access to legal support. Doing so may have indicated an impact of place, as recent statistics show that 80% of the population in England do not have access to welfare legal aid providers and live in so-called 'legal deserts' (The Law Society, 2022). A key factor not explored by any of the papers included in this review is the approach of the employer and the role of employee assistance programmes, which are likely to differ by sector.

Stress, anxiety, and depression were mentioned by people of working age with a terminal illness, often in relation to the financial and legal strain they were experiencing (Essue et al., 2015; Close et al., 2021). There was little evidence available about the benefits to mental wellbeing gained by continuing to participate in work which could impact wellbeing via financial security, positive relationships with colleagues, or through personal satisfaction, sense of identity, enjoyment and a sense of purpose from their work.

There may be inequalities in experiencing financial strain across age, sex, ethnicity, and access to health insurance. These findings are supported by a recent report by Marie Curie which found that being a woman, being of working age, being of working age with children, and being from ethnic minority group are risk factors for dying in poverty towards the end of life (Marie Curie, 2022a).

Strengths and limitations

This rapid scoping review followed a rigorous pre-defined protocol following well-established guidance, initially outlined by Arksey and O'Malley (2005). To minimise publication bias, we searched grey literature sources and disseminated a call for evidence. A further strength of the review is that its development was guided throughout in consultation with a group of experts on terminal illness, employment, and wellbeing.

The main limitation of this review is the small number of heterogeneous studies, set across different countries, making it difficult to draw strong conclusions. All but one of the studies was conducted over seven years ago which can also limit generalisability if social policy and practice has changed in recent years. Although we aimed for the review to be limited to people of working age, this was challenging

to determine as most studies did not conceptualise their participants as such. In fact, no study used the term 'working age' to describe their participants, suggesting a lack of direction and focus on the needs of this specific population. To address this issue we adopted an inclusive approach and accepted any paper in which any of the participants were under the age of 65. However, this limits our ability to specify that the findings are specific to people of working age. No studies included participants under the age of 29 and so we did not need to adopt a minimum age limit.

Implications for research, policy, and practice

This review has highlighted an evidence-gap in our understanding of the role of work in supporting the wellbeing among people with terminal illness. When exploring the range of quantitative measures used to assess health at the end of life, there were several objective and subjective measures of physical health and health care used, but very little focus on emotions, mental health, and wellbeing. Future studies should specifically explore personal motivations to work in the context of a limited life expectancy, focussing on the role of work in personal identity, purpose and meaning in life, personal enjoyment, social connections, and autonomy, in addition to financial motivations. It is important to determine whether the experience is positive or negative, what factors are significant to improve wellbeing, and how these vary depending on the employment sector and type of work being undertaken.

On a structural level, research should aim to understand: how and why experiences at work for people with terminal illness varies depending on the diagnosis; the economic impact of supporting people with terminal illness to continue work; how often employers are required to support an employee with a terminal illness, and training and support needs of employers. On a societal level, future research should further explore the inequalities in access to legal support, experience of financial strain, and the impact of terminal illness on mental wellbeing. There is an urgent need to improve and streamline access to legal and financial information for people with terminal illness. This could be achieved through formal incorporation of legal and financial health checks in the workplace. Specific considerations will have to be made to account for the different types of employment and workplaces e.g. self-employed to ensure equity in access to support.

Since the conception of this review, there have been two significant changes in policy which will impact the wellbeing of those diagnosed with a terminal illness. The first is the Social Security (Special Rules for End of Life) Bill which allows people in

the UK who are at the end of life to receive support if they are thought to have a life expectancy of 12 months or less, replacing the previous threshold of 6 months life expectancy (Hobson, 2022). The second is the Health and Care Bill which is a change in law requiring palliative care services in every area of England (Marie Curie, 2022b). There is also the Terminal Illness (Support and Rights) Bill which at the time of writing is under development and aims to compel utility companies to provide financial support to customers with a terminal illness, and to make provision about the employment rights of people with a terminal illness (UK Parliament, 2022). These recent policy changes in England and the UK, as demonstrated by this review, are sorely needed, and indicate continued interest and concerted efforts towards addressing the severe financial stress people face at the end of life.

Conclusions

Despite limited evidence, 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. Further and more detailed investigation is needed to better understand the experiences this group faces to develop effective interventions, drive cultural change, and to inform policy and practice.

References

- All-Party Parliamentary Group for Terminal Illness (2019) Six months to live?: Report of the All-Party Parliamentary Group for Terminal Illness inquiry into the legal definition of terminal illness. . Reportno. Report Number|, Date. Place Published|: Institution|.
- Arksey H and O'Malley L (2005) Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology* 8(1): 19-32.
- Cagle JG, Carr DC, Hong S, et al. (2016) Financial burden among US households affected by cancer at the end of life. *Psycho-Oncology* 25(8): 919-926.
- Close H, Sidhu K, Genn H, et al. (2021) Qualitative investigation of patient and carer experiences of everyday legal needs towards end of life. *BMC Palliat Care* 20(1): 47.
- Dixon-Woods M, Agarwal S, Jones D, et al. (2005) Synthesising qualitative and quantitative evidence: a review of possible methods. *J Health Serv Res Policy* 10(1): 45-53.
- Emanuel N, Simon MA, Burt M, et al. (2010) Economic impact of terminal illness and the willingness to change it. *J Palliat Med* 13(8): 941-944.
- Essue BM, Beaton A, Hull C, et al. (2015) Living with economic hardship at the end of life. *BMJ Support Palliat Care* 5(2): 129-137.
- Fisher C (2021) How can wellbeing evidence improve the lives of people living with terminal illness? Available at: <https://whatworkswellbeing.org/blog/how-can-wellbeing-evidence-improve-the-lives-of-people-living-with-terminal-illness/>
- Hanratty B, Holland P, Jacoby A, et al. (2007) Financial stress and strain associated with terminal cancer—a review of the evidence. *Palliative medicine* 21(7): 595-607.
- Hiilamo A (2020) Debt matters? Mental wellbeing of older adults with household debt in England. *SSM Popul Health* 12: 100658.
- Hobson F (2022) Social Security (Special Rules for End of Life) Bill [HL] House of Commons Library.
- Hong QN, Fàbregues S, Bartlett G, et al. (2018) The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. *Education for Information* 34: 285-291.
- Hong QN, Pluye P, Bujold M, et al. (2017) Convergent and sequential synthesis designs: implications for conducting and reporting systematic reviews of qualitative and quantitative evidence. *Syst Rev* 6(1): 61.
- Kochovska S, Lockett T, Agar M, et al. (2018) Impacts on employment, finances, and lifestyle for working age people facing an expected premature death: A systematic review. *Palliat Support Care* 16(3): 347-364.

- Levac D, Colquhoun H and O'Brien KK (2010) Scoping studies: advancing the methodology. *Implementation Science* 5(1): 69.
- Macmillan Cancer Support and Citizens Advice (2009) Failed by the system: Why the Employment and Support Allowance isn't working for people living with cancer. Reportno. Report Number|, Date. Place Published|: Institution|.
- Marie Curie (2019) The cost of dying: The financial impact of terminal illness. Reportno. Report Number|, Date. Place Published|: Institution|.
- Marie Curie (2022a) Dying in poverty: Exploring poverty at the end of life in the UK Reportno. Report Number|, Date. Place Published|: Institution|.
- Marie Curie (2022b) *Make end of life care fair*. Available at: <https://www.mariecurie.org.uk/policy/campaigns/health-care-bill>
- Maulsby CH, Ratnayake A, Hesson D, et al. (2020) A Scoping Review of Employment and HIV. *AIDS Behav* 24(10): 2942-2955.
- Ngiam LXL, Ong YT, Ng JX, et al. (2021) Impact of Caring for Terminally Ill Children on Physicians: A Systematic Scoping Review. *Am J Hosp Palliat Care* 38(4): 396-418.
- OECD (2022) *Working age population (indicator)*, (accessed on 31 August 2022).
- Oechsle K, Jensen W, Schmidt T, et al. (2011) Physical activity, quality of life, and the interest in physical exercise programs in patients undergoing palliative chemotherapy. *Support Care Cancer* 19(5): 613-619.
- Ouzzani M, Hammady H, Fedorowicz Z, et al. (2016) Rayyan-a web and mobile app for systematic reviews. *Syst Rev* 5(1): 210.
- Peters MD, Godfrey CM, Khalil H, et al. (2015) Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc* 13(3): 141-146.
- Pluye P and Hong QN (2014) Combining the power of stories and the power of numbers: mixed methods research and mixed studies reviews. *Annu Rev Public Health* 35: 29-45.
- Popay J, Roberts HM, Sowden AJ, et al. (2006) Guidance on the conduct of narrative synthesis in systematic Reviews. A Product from the ESRC Methods Programme. Version 1.
- Preston L, Cantrell A, Paisley S, et al. (2017) Housing and Wellbeing: A rapid scoping review on the evidence on housing and its relationship to wellbeing. Reportno. Report Number|, Date. Place Published|: Institution|.
- The Law Society (2022) *Welfare benefits – legal aid deserts*. Available at: <https://www.lawsociety.org.uk/campaigns/legal-aid-deserts/welfare>
- Thomas J and Harden A (2008) Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* 8: 45.

- Tricco AC, Lillie E, Zarin W, et al. (2018) PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med* 169(7): 467-473.
- UK Parliament (2022) *Terminal Illness (Support and Rights) Bill*. Available at: <https://bills.parliament.uk/bills/3201>
- Watson D, Tregaskis O, Gedikli C, et al. (2018) Well-being through learning: a systematic review of learning interventions in the workplace and their impact on well-being. *European Journal of Work and Organizational Psychology* 27(2): 247-268.
- Westaby JD, Versenyi A and Hausmann RC (2005) Intentions to work during terminal illness: an exploratory study of antecedent conditions. *J Appl Psychol* 90(6): 1297-1305.
- Weziak-Bialowolska D, Bialowolski P, Sacco PL, et al. (2020) Well-being in life and well-being at work: Which comes first? Evidence from a longitudinal study. *Frontiers in Public Health*. 103.
- What Works Centre for Wellbeing (2022) *Dying Well - work and employment: The role of work in wellbeing at the end of life*. Available at: <https://whatworkswellbeing.org/projects/dying-well-work-and-employment/>

Appendix A: Example search strategy

Source: Pubmed

Interface: Medline

Database coverage dates: inception to present

Search date: 30 March 2022

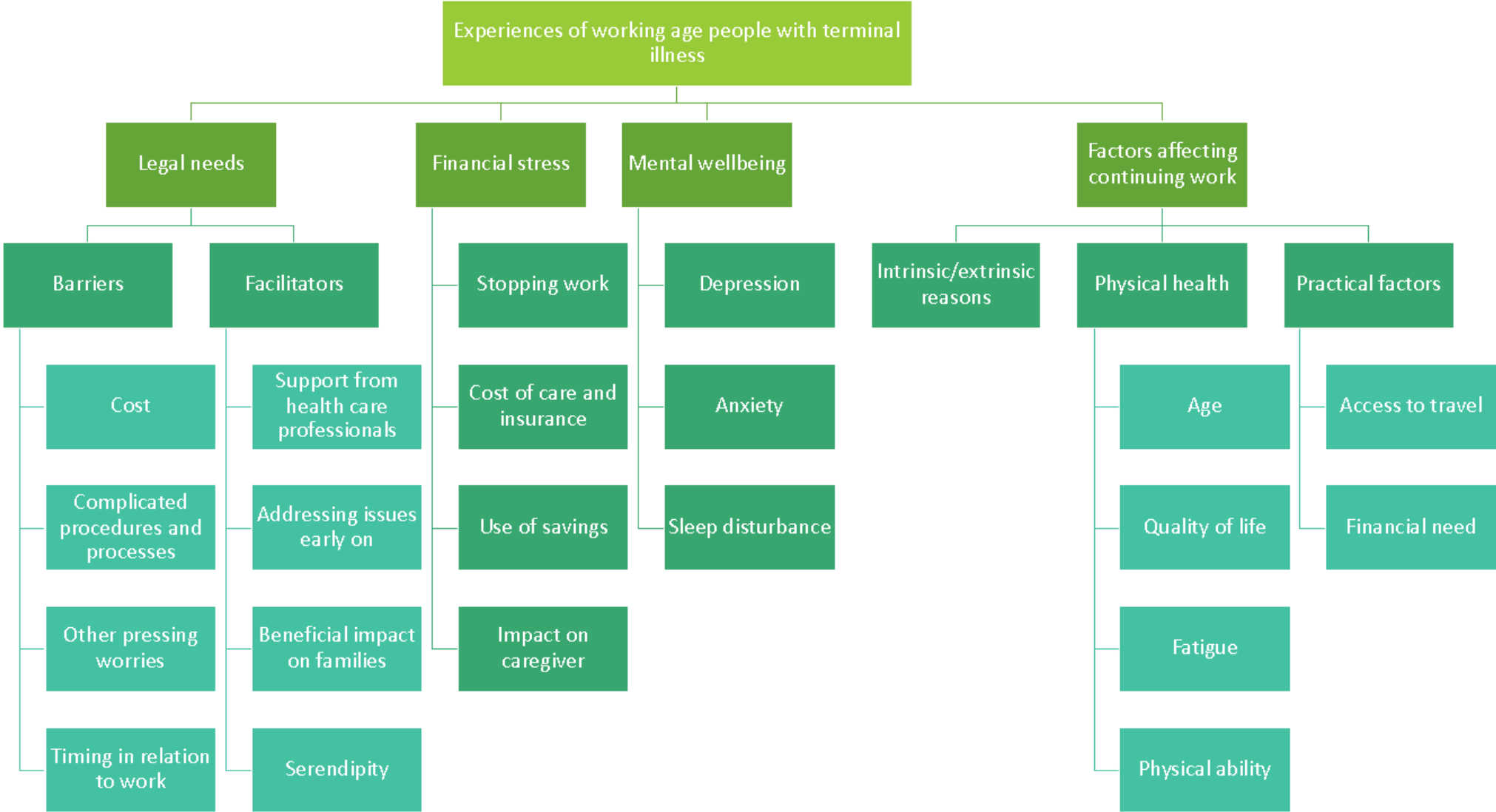
MeSH is Mesh heading, tiab is abstract and title

Terminal illness		Work		Experience/well-being		Medical
"Terminally ill" [MeSH] OR "Clinical Deterioration" [MeSH] OR "Terminal Care" [MeSH] OR "Hospices" [MeSH] OR Dying [tiab] OR terminal illness*[tiab] OR life?limiting illness* [tiab] OR palliative [tiab] OR end?of?life [tiab] OR hospice* [tiab] OR end?stage?disease [tiab] OR metastatic cancer [tiab] OR stage 4 cancer [tiab] OR stage four cancer [tiab] OR Degenerative neural disease [tiab] OR Motor neuron diseases [tiab]	AN D	"Employment" [MeSH] OR "Vocational guidance" [MeSH] OR "Employment, Supported" [MeSH] OR Work [MeSH] OR Rehabilitation, Vocational [MeSH] OR Occupational Status [tiab] OR Underemployment [tiab] OR Vocational education [tiab] OR Career Counseling [tiab] OR Vocational Guidance [tiab] OR supported employment [tiab] OR Vocational Rehabilitation*[tiab] OR vocational counselling [tiab] OR unemployment [tiab] OR unfair dismissal [tiab] OR sick pay [tiab] OR insurance [tiab] OR work policy* [tiab] OR compassionate leave policy [tiab] OR job train* [tiab] OR unemploy* [tiab] OR jobless* [tiab] OR employ* [tiab] OR occupational status [tiab] OR ((family or medical or sick) adj leave)	AN D	"Health" [MeSH] OR "Mental health" [MeSH] OR "Anxiety" [MeSH] OR "Quality of life" [MeSH] OR "Advance care planning" [MeSH] OR stress [tiab] OR well-being [tiab] OR experience [tiab] OR well being [tiab] OR life satisf* [tiab] OR psychological health [tiab] OR depress* [tiab] OR emotion* [tiab] OR mood [tiab] OR resilience [tiab] OR self-efficacy [tiab] OR self-esteem [tiab] OR empowerment [tiab] OR confidence [tiab] OR job satisf* [tiab] OR (economic adj (stability or well-being or wellbeing)) OR ((allowance? or benefit? or social security or (los? or reduce? or stress)) adj1 (earning? or income or financ*)) OR (social depen* or ((socioeconomic or socio-economic) adj (impact or burden))) OR poverty [tiab] OR Finance [tiab] OR debt [tiab] OR insurance [tiab]	NO T	"Physicians" [MeSH] OR "Nurses" [MeSH] OR "Allied Health Personnel" [MeSH] OR nurse* [tiab] OR doctor* [tiab] OR COVID-19 [tiab] OR "COVID-19" [MeSH] OR physician* [tiab]

Appendix B: Mixed Methods Appraisal Tool (MMAT) appraisal by study

	SCREENING QUESTIONS									
			QUALITATIVE STUDIES							
Study	S1. Are there clear research questions ?	S2. Do the collected data allow to address the research questions?	Is the qualitative approach appropriate to answer the research question?	Are the qualitative data collection methods adequate to address the research question?	Are the findings adequately derived from the data?	Is the interpretation of results sufficiently substantiated by data?	Is there coherence between qualitative data sources, collection, analysis and interpretation?	MMAT Score	Overall Quality	
Emanuel et al. (2010)	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	3	Moderate	
Essue et al. (2013)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	5	High	
Close et al. (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	5	High	
			QUANTITATIVE DESCRIPTIVE STUDIES							
Study			Is the sampling strategy relevant to address the research question?	Is the sample representative of the target population?	Are the measurements appropriate?	Is the risk of nonresponse bias low?	Is the statistical analysis appropriate to answer the research question?	MMAT Score	Overall Quality	
Cagel et al. (2015)	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	3	Moderate	
Westaby et al. (2005)	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	3	Moderate	
Oechsle et al. (2009)	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	3	Moderate	

Appendix C: Overview of main themes and sub-themes



Appendix D: Quantitative measures used in included studies

Theme	Measures	Details	Paper
Employment, income, and finance	Intentions to work:	Assessed by asking "Do you intend to work over the next six months?" and "Do you plan on working in the future?" (Yes/No).	Westaby (2005)
	Actual employment	Assessed by asking participants or caregivers whether the participants had been recently employed (Yes/No).	Westaby (2005)
	Effect on assets, work and education	Not described by the authors	Emanuel (2010)
	Effect on income and employment	Respondents were asked whether the diagnosis/treatment of cancer caused someone in the household to: (a) be unable to work or perform usual activities; (b) lose/change a job or work fewer hours; (c) have a lower income; (d) suffer emotional or psychological problems; and (e) have severe strains with other family members (Yes/No).	Cagle (2016)
	Financial strain	Evaluated using responses to the following survey item: "How much of a burden is the cost of overall medical care, including any services needed to cope with cancer?" 1=not a burden at all; 2=minor burden; 3=major burden.	Cagle (2016)
	Financial stress	Assessed using nine (1=Yes/0=No) responses to the following stem question: "Did any of the following things ever happen as a result of the financial cost of dealing with cancer?: (1) used up most of savings; (2) unable to pay for basic necessities like food, heat or housing; (3) borrowed money or got a loan or another mortgage on home; (4) borrowed money from relatives; (5) contacted by a collection agency; (6) declared bankruptcy (7) sought the aid of a charity or public assistance (8) lost health insurance and (9) couldn't buy health insurance because of having cancer." These nine items were summed (range 0–9) with a score of 9 indicating the highest possible financial stress.	Cagle (2016)
	Insurance coverage	Respondents answered whether they were surprised to find that the limit of costs covered by the health insurance plan for cancer treatment was reached (Yes/No).	Cagle (2016)
Physical health	Habitual Physical Activity	Assessed by asking questions related to physical activity at work (seven questions, e.g., sitting, standing, or walking while working), sports (four questions), or leisure time (three questions). Response options were graded from 1 = never to 5 = always.	Oechsle (2011)
	Physical Activity	Assessed by asking about physical habits over the past seven days. This information was converted into a standardised measure of physical activity frequency per week, and physical activity intensity using metabolic equivalent (MET) time.	Oechsle (2011)
	Disability severity	Assessed by asking participants "Does speaking tire you?", "Do you have episodes of slurred speech?" and "Did you need some assistance completing this survey?". A single question was used to assess accessibility of travel by asking participants whether they have frequent access to transportation (Yes/No).	Westaby (2005)
	Functional status	Not described by the authors	Emanuel (2010)
	Symptoms	The severity of patient's side effects to cancer treatment were rated on a four-point scale ranging from 0=not severe at all to 3=very severe. Specific side-effects included pain, nausea, and stress/anxiety.	Cagle (2016)

Theme	Measures	Details	Paper
Health care	Cancer Care Experience	Family members provided (Yes/No) data on whether: health professionals provided conflicting information during treatment; doctor(s) paid attention to non-medical factors; there was confusion about prescribed medications; important questions went unanswered; and duplicate tests/diagnostic procedures were performed.	Cagle (2016)
	Cancer Treatment	The survey included information about four types of cancer treatment the decedent may have had: chemotherapy, radiation, prescription drugs related to cancer treatment, and/or surgery (Yes/No).	Cagle (2016)
	Number of caregivers	Not described by the authors	Emanuel (2010)
Psychological	The will to live	Assessed by asking participants "Do you have something to look forward to each day?", "Do you have a strong will to live?" and "Do you find meaning in your life?" using a 3-point response format (1=no, 2=uncertain, 3=yes).	Westaby (2005)