

**Title:** Impacts on employment, finances and lifestyle for working age people facing an expected premature death: A systematic review

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## **ABSTRACT**

**Title:** Impacts on employment, finances and lifestyle for working age people facing an expected premature death: A systematic review

*Objectives:* The working ages (25-65 years) are a period when most people have significant work, financial and family responsibilities. A small proportion of working age people will face an expected premature death from cancer or other life-limiting illness. Understanding the impact an expected premature death has on this population is important for informing support. The current study set out to summarise research describing the impacts that facing an expected premature death has on employment, financial and lifestyle of working age people and their families.

*Methods:* A systematic review using narrative synthesis approach. Four electronic databases were searched in July 2016 for peer-reviewed, English language studies focusing on the financial, employment and lifestyle concerns of working age adults living with an advanced life-limiting illness and/or their carers and/or children.

*Results:* Fifteen quantitative and 12 qualitative studies were included. Two-thirds (n=18) were focused on cancer. All studies identified adverse effects on workforce participation, finances and lifestyle. Many patients were forced to work less or give up work/retire early due to symptoms and reduced functioning. In addition to treatment costs, patients and families were also faced with childcare, travel, and home/car modification costs. Being younger was associated with greater employment and financial burden, while having children was associated with lower functional well-being. Changes in family roles were identified as challenging regardless of diagnosis, while maintaining normalcy and creating stability was seen as a priority by parents with advanced cancer. This review is limited by the smaller number of studies focussing on the needs of working age people with non-malignant disease.

*Significance of Results:* Working age people facing an expected premature death and their families have significant unmet financial, employment and lifestyle needs. Comparing and

contrasting their severity, timing, and priority for people with non-malignant conditions is required to better understand their unique needs.

**KEYWORDS:** Palliative care, End of life, Employment, Financial concerns, Family

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## INTRODUCTION

Most people in the developed world who are aged 25-65 years ('working age') are busy building a career, buying or renting a home, establishing and maintaining relationships with a partner, having a family, and often also caring for ageing family members. Working age people frequently 'juggle' these responsibilities with other contributions to society through social and organisational networks (e.g. schools, churches).

A small proportion of people at this stage in their lives will be faced with a premature death, which has potential not only to diminish their capacity to manage their responsibilities but also to threaten family well-being and financial security. Prevalence data shows that 23,600 UK parents with dependent children died in 2015 (Childhood Bereavement Network, 2017), while 4,400 Australian parents with dependent children died in 2005 (Financial Services Council, 2005). In the US in 2008, 1.5M children lived in a single-parent household because of the death of one parent (Owens, 2008). While many of these deaths are likely to be due to unexpected causes (i.e. accidental, suicide or homicide) and cannot be prepared for, an unknown proportion will be due to an expected premature death.

Previous studies have shown that, regardless of age, life-limiting illnesses are associated with increased needs and significant burden due to interrupted employment and ongoing financial expenditure, which span the whole trajectory of terminal diseases, from diagnosis and treatment (Harrison et al., 2009), through to palliative/end of life care (Hanratty et al., 2007; McPherson et al., 2007; Gardiner et al., 2014; Ventura et al., 2014), and into bereavement (Stephen et al., 2015). Early stage cancer diagnosis and/or survivorship have been noted to have a detrimental effects on work, finances, family roles and social aspects, especially for those who are younger age or have dependent children or mortgages to pay (Amir et al., 2012; Catt et al., 2016). However, little is known about the challenges of

working age people facing an expected death from both malignant and non-malignant disease.

The current study set out to describe research on the impacts that facing an expected premature death has on the employment, financial and lifestyle of working age people and their families. “Lifestyle” is used here as a broad term for the way individuals and families (or households) live and cope with their physical, psychological, social and economic environments on a day-to-day basis (Business Dictionary, 2017).

## METHODS

A systematic review was conducted and reported in accordance with the guidelines for Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) (Moher D et al., 2009).

### Eligibility Criteria

Eligible peer-reviewed English language articles from 2000 onward reporting empirical data from an Organisation for Economic Cooperation and Development (OECD) country on: workplace participation, employment, financial and/or household and lifestyle concerns of working age adults (25-65 years of age) living with an advanced terminal illness (malignant and/or non-malignant). Age criteria were designed to accommodate a range of reporting styles and could be satisfied where:  $\geq 50\%$  of the sample were aged between 25-65; the sample mean age was within 25-65; or the sample median age was between 25-65 and the upper and lower inter-quartile age included 25-65 years. Studies reporting on families experiencing unexpected deaths such as suicide, motor vehicle accidents or acute medical events were excluded. Only studies reporting issues and/or concerns from a patient’s perspective or studies with mixed cohorts where patients consisted 50% or more of participants were included.

## Information Sources

Four electronic literature databases (MEDLINE, CINAHL, PsycINFO, PubMed) and CareSearch (the Australian palliative care knowledge network) were searched between 19<sup>th</sup> and 29<sup>th</sup> July 2016 from their earliest records. Reference lists of included articles were searched manually for additional relevant studies.

## Search

Databases were searched via medical subject headings (MeSH) and keywords relating to palliative care as defined by CareSearch (Palliative Care Search, 2016a; Palliative Care Search, 2016b), together with terms for working age and domains of interest ('needs', 'employment', 'finance', 'end of life', 'bereavement'). MeSH descriptor data was used to define the terms 'adult' and 'middle aged' and corresponding age ranges (Kastner et al., 2006; U.S. National Library of Medicine, 2016). This review adopted the MeSH age definitions, with 'young adult' (those aged between 19-24) being excluded and 'adult' (25-44 years) and 'middle age' (45-65 years) included (U.S. National Library of Medicine, 2016). The MEDLINE search strategy is given in Supplementary Table 1.

## Study Selection

Search results were imported into EndNote version X7 software, and eligibility criteria applied independently by two reviewers (SK, TL). Titles and abstracts of papers were reviewed and full text articles retrieved where in doubt.

## Data Collection

Data were extracted by three reviewers using a Microsoft Excel (2010) electronic proforma under the following headings: author, year, aim, setting, demographics, age, health condition, study design, outcomes, results, conclusions.

### Risk of bias across studies

The methodological quality of included studies was assessed independently by two reviewers (SK and TL) using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Kmet et al., 2004). This tool enabled appraisal of the varying study designs.

The level of evidence of quantitative studies was determined by two authors independently (SK, TL) using the Australia National Health and Medical Research Council (NHMRC) evidence hierarchy (National Health and Medical Research Council, 1999), and a qualitative studies evidence guide developed for the Australian Palliative Residential Aged Care Project (APRAC) Guidelines (Australian Department of Health and Ageing, 2006). Studies were not excluded based on their quality assessment scores. Studies were graded to be of higher quality if their combined score was >75%, and lower quality if their combined score was <75%, the cut-off point for inclusion (Kmet et al., 2004).

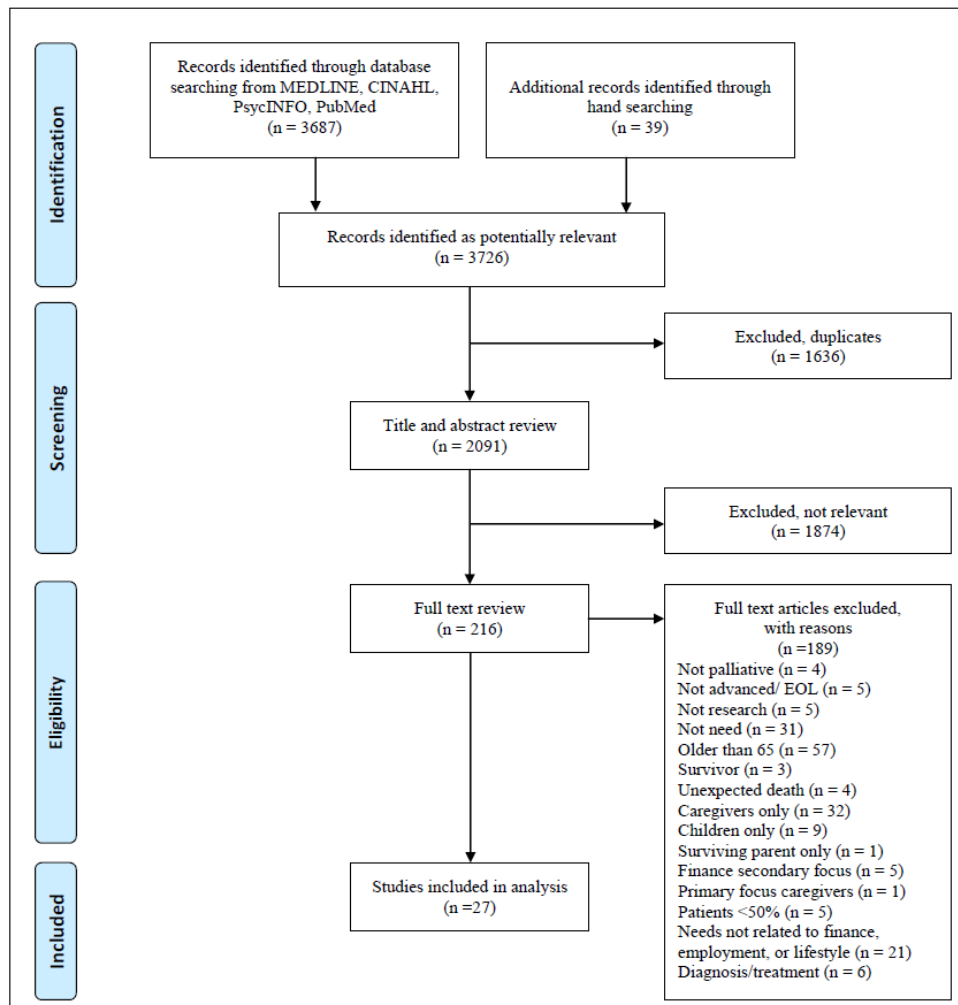
### Synthesis of Results

A narrative synthesis using methods described by Popay et al. (2006) including tabulation and textual summary was used to accommodate the variety of included research designs.

## RESULTS

### Study Selection

The search identified 3726 references, of which 1636 were duplicates, leaving 2091 title and abstracts to be screened. A total of 1874 records did not meet the inclusion criteria, leaving 216 records for full-text review. Of those, a further 189 records were excluded, leaving 27 studies for final analysis (see Figure 1).



**Figure 1.** PRISMA flow diagram of included and excluded studies

### Study Characteristics

These studies used a variety of methods within both quantitative (n=15) (McCarthy et al., 2000; Osse et al., 2005; Koopman et al., 2006; Kristjanson et al., 2006b; Kristjanson et al., 2006a; Forbes et al., 2007; O'Connor et al., 2007; Janda et al., 2008; Geyer et al., 2009; Rainbird et al., 2009; Reed et al., 2012; Halman et al., 2014; Boland et al., 2014; Mack et al., 2015; Tucker-Seeley et al., 2015) and qualitative (n=12) (Raynes et al., 2000; Osse et al., 2002; Murray et al., 2004; Elmberger et al., 2005; Houldin & Lewis, 2006; Janda et al., 2006; Wollin et al., 2006; Turner et al., 2007; Kennedy & Lloyd-Williams, 2009a; Kennedy & Lloyd-Williams, 2009b; Galushko et al., 2014; Halkett et al., 2010) approaches (refer Table 1); and originated from a number of OECD countries, including: Australia (n=9) (Janda et al.,



2006; Kristjanson et al., 2006a; Kristjanson et al., 2006b; Wollin et al., 2006; O'Connor et al., 2007; Turner et al., 2007; Janda et al., 2008; Rainbird et al., 2009; Halkett et al., 2010), United Kingdom (n=7) (Raynes et al., 2000; Murray et al., 2004; Forbes et al., 2007; Kennedy & Lloyd-Williams, 2009a; Kennedy & Lloyd-Williams, 2009b; Reed et al., 2012; Boland et al., 2014), United States (n=4) (McCarthy et al., 2000; Houldin & Lewis, 2006; Mack et al., 2015; Tucker-Seeley et al., 2015), Germany (n=3) (Elmberger et al., 2005; Geyer et al., 2009; Galushko et al., 2014), Canada (n=2) (Koopman et al., 2006; Halman et al., 2014), and the Netherlands (n=2) (Osse et al., 2002; Osse et al., 2005). The majority of studies included cancer populations (n=18) (McCarthy et al., 2000; Raynes et al., 2000; Osse et al., 2002; Elmberger et al., 2005; Osse et al., 2005; Houldin & Lewis, 2006; Janda et al., 2006; O'Connor et al., 2007; Turner et al., 2007; Janda et al., 2008; Kennedy & Lloyd-Williams, 2009a; Kennedy & Lloyd-Williams, 2009b; Rainbird et al., 2009; Halkett et al., 2010; Reed et al., 2012; Boland et al., 2014; Mack et al., 2015; Tucker-Seeley et al., 2015); while a smaller number focused on neurodegenerative disorders (n=6) (Forbes et al., 2007; Koopman et al., 2006; Kristjanson et al., 2006a; Kristjanson et al., 2006b; Wollin et al., 2006; Galushko et al., 2014). The remainder involved congenital heart disease (Geyer et al., 2009), HIV (Halman et al., 2014), or combined lung cancer/heart failure (Murray et al., 2004) populations. Most studies included only patients (n=18) (McCarthy et al., 2000; Raynes et al., 2000; Murray et al., 2004; Elmberger et al., 2005; Osse et al., 2005; Houldin & Lewis, 2006; Forbes et al., 2007; O'Connor et al., 2007; Turner et al., 2007; Geyer et al., 2009; Rainbird et al., 2009; Halkett et al., 2010; Reed et al., 2012; Boland et al., 2014; Galushko et al., 2014; Halman et al., 2014; Mack et al., 2015; Tucker-Seeley et al., 2015), while nine studies had mixed samples of patients/caregiver (n=7) (Osse et al., 2002; Janda et al., 2006; Koopman et al., 2006; Kristjanson et al., 2006a; Kristjanson et al., 2006b; Wollin et al., 2006; Janda et al.,

2008), or patients/children (n=2) (Kennedy & Lloyd-Williams, 2009a; Kennedy & Lloyd-Williams, 2009b).

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**Table 1.** Summary of included studies reporting the impact on employment, financial, and lifestyle from the patient's perspective (n=27)

Authors, Year, Country	Focus	Method	Participants	Identified impact	Quality assessment	Level of evidence
Tucker-Seely et al. (2015) United States	Financial hardship and intensive care of advanced cancer patients in the last week of life.	Interviews (baseline assessment and post-mortem); medical chart audit	Patients (n=281) $\bar{X}$ age 59 (SD±12.37)	Patients reporting financial hardship had higher likelihood of receiving more intensive end-of-life care, potentially due to hidden costs of caring for someone at home (i.e. care that incurs less out-of-pocket expenses for the patient/family). Health insurance did not seem to be associated with this outcome.	H	IV
Mack et al. (2015) United States	Treatment decision-making preferences of young vs middle aged adults with lung and colorectal cancer.	Interviews (survey on decision-making)	Patients (n=592) Age range 21-40* (n=148); age range 41-60* (n=444)	Patients <40 years were more concerned about time away from family ( $p=0.002$ ) and about cancer treatment side effects ( $p = 0.02$ ). Those with dependent children were most concerned (odds ratio [OR] 1.55, 95% CI = 1.07–2.24, $p=0.02$ ), which was not age related.	H	IV
Galushko et al. (2014) Germany	Unmet needs of patients severely affected by Multiple Sclerosis.	Interviews	Patients (n=15) $\bar{X}$ age 47*	Unmet needs: (1) support of family and friends (e.g. decreasing networks of friends); (2) health care services (e.g. better access and service coordination, financial needs); (3) managing everyday life (e.g. housekeeping, adaptation of physical environment); (4) maintaining biographical continuity (e.g. interruptions of employment and leisure activities, coping with changes in identity).	H	QE
Halman et al. (2014) Canada	Medical, psychiatric and psychological care needs of patients living with HIV disease.	Retrospective chart audit	Patients (n=83) $\bar{X}$ age 49.2 (SD±10.5)	Complex set of medical, psychiatric, and psychosocial needs. Housing: 13.6% were homelessness and/or living in a shelter, 6.1% staying with family/friends. Financial: 88.7% relied on disability/pension plan; only 2.2% employed.	L	IV
Boland et al. (2014) United Kingdom	Holistic needs of patients with advanced multiple myeloma.	Survey (SPARC screening tool)	Patients (n=32) $\bar{X}$ age 55*; age range 41-71 (at assessment); $\bar{X}$ age 60*; age range 36-69 (at diagnosis)	Main needs: 44% symptom management; 40% worried about the impact the disease had on their families/other people; 31% felt that the disease had impact on their sexual life; 25% reported loss of independence (inability to perform usual household tasks).	L	IV

Authors, Year, Country	Focus	Method	Participants	Identified impact	Quality assessment	Level of evidence
Reed et al. (2012) United Kingdom	Quality of life, care and support needs of women with metastatic breast cancer.	Cross-sectional survey; open and closed free-text questions	Patients (n=235) $\bar{X}$ age 58* (age range 25-84 years); Aged 25-44 (23.4%), aged 45-54 (34.9%), aged 55-64 (23/4%), aged $\geq 65$ (17%)	Poor overall quality of life and significant symptom burden (esp. pain). Social well-being: significantly better for women >65 years but lower in women with bone metastases only ( $p=0.004$ ). Functional well-being: significantly better for women without children ( $p=0.004$ ). Majority of women (68%) felt well supported psychologically by family and friends; 33% felt unable to speak to loved ones to avoid burdening them.	H	IV
Halkett et al. (2010) Australia	Understanding the experiences and information and support needs of patients with High Grade Glioma (Grade III-IV).	Interviews	Patients (n=19) $\bar{X}$ age 55 (age range 31-74, SD = 10)	Increased physical and cognitive deficits from the point of diagnosis onward. Main needs: uncertainly about the diagnosis and disease progression; dependence on carers due to cognitive deficits; loss of balance; inability to drive; need for individualised information; difficulties communicating with health professionals due to complex language deficits. Needs may change as the disease progresses.	H	QE
Rainbird et al. (2009) Australia	Describing the needs of patients with advanced incurable cancer.	Survey	Patients (n=246) $\bar{X}$ age 61 (age range 27-89, SD=11.9); greater portion of patients in age brackets 40-49 and 50-59; smaller portion in age brackets 70-79 and 80+ years	High level of unmet needs, esp. psychosocial, medical communication and/or information needs. Most dominant problems: tiredness and lack of energy; coping with fears about the cancer spreading; coping with frustration about inability to perform usual tasks (e.g. doing housework).	H	IV
Geyer et al. (2009) Germany	Chances of employment of men and women with operated congenital heart disease.	Interviews	Patients (n=314) Age range 17-45*	Chances of full-time employment decreased with increase in disease severity. Compared to the general population, men had lower rates of full-time employment, and higher rates of part-time/minor employment. Women had lower full-time employment, regardless of patient status.	H	IV
O'Connor et al. (2007) Australia	The relationship between spiritual well-being, quality of life, and psychological adjustment in leukaemia patients.	Questionnaire	Patients (n=40) $\bar{X}$ age 49.2 (age range 22-80; SD=12.97)	Factors contributing to spiritual well-being and better quality of life: having a reason to live; having a sense of meaning and purpose in life; making life more productive; finding comfort in oneself, in faith or spiritual beliefs; being determined to control the environment.	L	IV

Authors, Year, Country	Focus	Method	Participants	Identified impact	Quality assessment	Level of evidence
Turner et al. (2007) Australia	Developing a resource for parents diagnosed with advanced breast cancer to guide and support discussions with their children.	Interviews	Patients (n=8) Age range 39-57*	Women received minimal assistance from health professionals in how to discuss the diagnosis with their children. They needed practical coping strategies, information on the impact of cancer on their children, and how to deal with difficult questions (e.g. parental death).	L	QE
Forbes et al. (2007) United Kingdom	Needs of people with Multiple Sclerosis.	Survey	Patients (n=445) $\bar{X}$ age 48.3 (SD=10.9)	Patients' needs correlated with the disease severity. Majority of patients (67%) identified problems with household adaptation, transport, re-housing, financial and employment. Care coordination and medical treatment were also important. Those with higher physical disability (i.e. moderate and severe disease) needed help with daily tasks (at home, with childcare).	L	IV
Houldin et al. (2006) United States	Experiences identified by patients newly diagnosed with advanced colorectal cancer (Stage III-IV).	Interviews (face-to-face, semi-structured)	Patients (n=14) Age range 27-67 (SD=11.8); male patients $\bar{X}$ age 49.5 years; female patients $\bar{X}$ age 49 years	Disruption of normal life, struggles with parenting, feeling unprepared to deal with the disease. Main focus: creating and maintaining normalcy; having or maintaining a positive outlook; concentrating on how to manage distress and physical symptoms. Dominant theme - "Salvaging their normal lives".	H	QE
Elmberger et al. (2005) Germany	How women with (lymphoma) cancer deal with their parenting responsibilities.	Interviews (individual and focus group)	Patients (n=10) Age range 24-54*	Main issues: interrupted parenting (i.e. cancer intruding on family life and interrupting parents' ability to provide care); facing a life-threatening illness; dealing with their children's reaction to the illness; keeping a positive attitude to protect their children; the impact of the disease on their ability to perform household tasks (e.g. cleaning, cooking).	H	QE
Osse et al. (2005) The Netherlands	Needs and unmet needs of cancer patients in palliative care.	Survey	Patients (n=94) $\bar{X}$ age 58 (age range 30-87; SD=12.3)	Common issues: fatigue; loss of autonomy (due to limited activities; dependence on others; not having control over one's life); coping with unpredictable future. Problems with: heavy housework (identified by more than 85% of patients); shopping; personal transportation. Patients aged <60 years (n=60) vs patients aged >60 years (n=34) reported more difficulties with employment (53% vs 24%); experienced more psychosocial, employment, and financial problems; and needed more professional attention.	H	IV

Authors, Year, Country	Focus	Method	Participants	Identified impact	Quality assessment	Level of evidence
Murray et al. (2004) United Kingdom	Spiritual needs of people dying of lung cancer or heart failure.	Interviews; chart audit; cancer registry	Patients: lung cancer (n=20), heart failure (n=20) $\bar{X}$ age 65 (lung cancer)*; $\bar{X}$ age 74 (heart failure)* Data reported for lung cancer only	Issues identified: treatment side effects (e.g. fatigue, nausea); disrupted ability to deal with important 'illness work' (e.g. sorting out family and practical issues, healing rifts in relationships). Cancer was seen as taking over people's lives. For some, engaging with the battle to defeat the cancer gave them a sense of purpose. Many felt useless, dependent and excluded from their usual family and social roles.	H	QE
Raynes et al. (2000) United Kingdom	Needs of terminally ill cancer patients receiving palliative care at home.	Survey; focus groups	Patients (n=27); focus groups attended (n=17) $\bar{X}$ age 56* (age range 37-78)	Main needs: help with transport to/from hospital; help with meals; concerns about being burden to the family and wanting to minimise that effect; lack of welfare and/or financial benefits knowledge. Valued services included: Macmillan nurses; receiving financial help for housework and maintaining standard of living. Families were the most valued source of help and support.	L	QE
McCarthy et al. (2000) United States	Symptoms and care preferences of cancer patients in the last six months of life.	Interviews; chart audit	Patients (n=1063) $\bar{X}$ : 25-75*; Colon cancer metastatic to the liver (n=316/520), non-small cell lung cancer Stage III-IV (n=747/939)	Patients reported severe symptom burden (esp. pain) and experienced significant functional decline and capacity to perform personal and household tasks, and recreational activities. Patients and carers/family sustained significant financial burden.	H	IV
Janda et al. (2008) Australia	Unmet supportive care needs of patients with a brain tumour and their carers.	Survey	Patients (n=75); carers (n=70) Patients: aged <50 (53.5%)*; carers: aged $\geq$ 50 (56.9%)*	Most frequently reported needs: support to overcome fatigue; unable to do things as before; uncertainty about the future.	H	IV
Wollin et al. (2006) Australia	Supportive and palliative care needs of patients with Multiple Sclerosis and their carers.	Interviews	Patients (n=13); carers (n=11) Patients: age range 23-55*	The disease had a significant impact on patients' everyday life (due to loss of personal independence and loss of employment), requiring service support (help with personal care, housework, children). Change of family roles as the disease progresses; loss of income and social contact had broader implications for their personal and financial circumstances.	H	QE
Kristjanson et al. (2006b) Australia	Supportive needs of people with neurodegenerative disorders (MND, MS, HD, PD) and their families.	Self-administered questionnaire	Patients (n=503); carers (n=373) Patients: $\bar{X}$ age 60.8 (SD=14.06); carers $\bar{X}$ age 60.2 (SD=13.28)	MND and HD patients needed help with: services (transportation, housekeeping, finances, social activities, support groups); information about the disease; equipment; support workers; and financial assistance. Employment was	H	IV

Authors, Year, Country	Focus	Method	Participants	Identified impact	Quality assessment	Level of evidence
				affected across the board: 36.4% of patients gave up work/retired early and 8.6% reduced their work hours.		
Kristjanson et al. (2006a) Australia	Supportive and palliative care needs of people with neurodegenerative disorders (MND, MS, HD, PD) and their families.	Descriptive survey; self-administered questionnaire	Patients (n=503); carers (n=373) Patients: <i>X</i> age 60.8 (SD=14.1); carers <i>X</i> age 63.0 (SD=13.6)	Employment was greatly affected across the board: paid employment (less than 1/4 of both patients and carers); relying on social security to live (60%). Two thirds of both patients and carers had to make adjustments to their living environments; 34-44% had to self-fund those adjustments. Great need for financial assistance to cover healthcare costs. All patients needed help with housekeeping and transportation to/from appointments; MND and HD patients needed help with finances/bills/accounts and attending social activities/support groups. MS patients needed help with personal care (dressing, washing).	L	IV
Koopman et al. (2006) Canada	Needs of people with Multiple Sclerosis and their carers.	Questionnaire	Patients (n=353); partners (n=240) Patients: <i>X</i> age 48*; partners: <i>X</i> age 48*	Main needs: psychosocial, interpersonal, and information. Psychosocial needs included: to feel productive and have control over one's life, have financial security, and have information about the disease and its progression. Interpersonal needs included: support from the healthcare team, healthcare community, friends and family.	L	IV
Janda et al. (2006) Australia	Supportive needs of patients with brain tumours and their carers.	Telephone interviews or focus groups	Patients (n=18); carers (n=18) Patients: <i>X</i> age 51* (age range 27-79); carers: <i>X</i> age 55* (age range 30-83)	Needs for: information and how to cope with uncertainty; practical support (from family, friends, with financial issues); support to return to pre-treatment responsibilities (e.g. daily living activities, work) or prepare for long-term care; support to deal with social isolation and how to organize respite care; support to overcome stigma/discrimination; support to discuss potentially reduced life expectancy. Patients worry about placing burden on their carers (they become depressed and want carers to take time off).	H	QE
Osse et al. (2002) The Netherlands	Palliative care needs of patients with advanced cancer.	Interviews (in-depth and using a checklist)	First sample: patients (n=9) & relatives (n=7); Second sample: patients (n=31) & relatives (n=15) Age range 42-80 (first sample)*; age range 29-82	Physical symptoms severely affected their: daily life activities (personal care, heavy housework, shopping); role activities (with work, leisure, and study outside of the home becoming impossible during the palliative stage, leading to feelings of futility and causing major stress); social and	H	QE

Authors, Year, Country	Focus	Method	Participants	Identified impact	Quality assessment	Level of evidence
			(second sample)*; even distribution with approx. 2 patients/decade	psychological well-being. Patients reported difficulties coping with care, financial concerns, and fear of suffering.		
Kennedy et al. (2009b) United Kingdom	Information and communication needs of children when a parent has advanced cancer.	Interviews	Family participants (n=28): ill parents (n=10); well parents (n=7); children (n=11) Ill parent: age range 37-60*; well parent: age range 31-73*; children: age range 8-18*	Main challenge for ill parents: informing their children of their diagnosis and dealing with their children's questions and concerns.	L	QE
Kennedy et al. (2009a) United Kingdom	How children cope with a parent's diagnosis of advanced cancer.	Interviews	Family participants (n=28): ill parents (n=10); well parents (n=7); children (n=11) Ill parent: age range 37-60*; well parent: age range 31-73*; children: age range 8-18*	Main challenges for parents: dealing with the response to diagnosis; limiting the impact of illness on their children by maintaining normality; coping strategies. Positive aspects identified by both parents and children included: relationship strengthening, learning to value family and important things in life.	L	QE

**Glossary:** \* – Standard Deviation (SD) not reported in paper;  $\bar{X}$  – Population Mean; HD – Huntington's Disease; HIV – Human Immunodeficiency Virus; MND – Motor Neurone Disease; MS – Multiple Sclerosis; PD – Parkinson's Disease; SD – Standard Deviation; SPARC – Stroke Prevention in Atrial Fibrillation Risk Tool.

**Evidence levels:** I – systematic review of all relevant randomised controlled trials (National Health and Medical Research Council, 1999); II – at least one properly designed randomised controlled trial (National Health and Medical Research Council, 1999); III-1 – well-designed pseudo-randomised controlled trials (alternate allocation or some other method) (National Health and Medical Research Council, 1999); III-2 – comparative studies with concurrent controls and allocation not randomised (cohort studies), case-control studies, or interrupted time series with a control group (National Health and Medical Research Council, 1999); III-3 – comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel control group (National Health and Medical Research Council, 1999); IV – case series, either post-test or pre-test and post-test (National Health and Medical Research Council, 1999); QE – qualitative evidence (Australian Department of Health and Ageing, 2006).

**Quality assessment:** H – Higher quality (>75%); L – Lower quality (<75%). Scores for quantitative studies were calculated based on scoring of 11 (out of 14) items ('yes'=2, 'partial'=1, 'no'=0); three items did not enter in the final calculation as N/A (Kmet et al., 2004). Scores for qualitative studies were calculated based on scoring of 10 (out of 10) items ('yes'=2, 'partial'=1, 'no'=0) (Kmet et al., 2004).



### Methodological Quality of Studies

The highest level of level of evidence was generated by Level IV studies (National Health and Medical Research Council, 1999) and all qualitative studies met the QE evidence criteria (Australian Department of Health and Ageing, 2006). The methodological quality varied across studies and the heterogeneity of the reported data precluded a meta-analysis from being undertaken (Deeks et al., 2008).

### Risk of bias across studies

A third of included studies scored <75% on quality assessment, with quantitative studies tending to score poorly on controlling for confounding, and qualitative studies tending to score poorly on reflexivity. See Table 1 for scores for each study.

### Synthesis

#### *Impact on employment*

Being diagnosed with cancer when of working age causes major disruptions to employment (Osse et al., 2002; Osse et al., 2005; Janda et al., 2006; Janda et al., 2008). More than 60% of Australian patients with brain tumours (n=75) in one study were not working, with more than half unable to work due to their disease (Janda et al., 2008), while more than a quarter (27.6%) of all patients reported moderate to high supportive needs due to changes in their ability to work (Janda et al., 2008). More than a half (53%) of younger Dutch cancer patients (<60 years) reported employment difficulties compared to 24% of older working age cancer patients (≥60 years) (Osse et al., 2005), with income problems also reported more often in younger (40%) versus older (6%) patients (Osse et al., 2005). Advanced cancer also influences life roles through changes at work, with another Dutch study reporting that a significant loss of income created feelings of incompetence and shame, and contributed to patients feeling socially dependent on their family (Osse et al., 2002).

Employment was also disrupted for people living with non-malignant conditions (Kristjanson et al., 2006a; Kristjanson et al., 2006b; Wollin et al., 2006; Forbes et al., 2007; Geyer et al., 2009; Galushko et al., 2014; Halman et al., 2014). Only a small percentage (2.2%) of Canadian patients with HIV were employed, with the majority (88.7%) relying on a disability or national pension plan for income (Halman et al., 2014). Full-time employment decreases for people in Germany living with congenital heart disease as their disease progresses (Geyer et al., 2009). This decrease was more prevalent for men than women, who have a lower full-time employment regardless of their clinical status (Geyer et al., 2009). People living with Multiple Sclerosis were found to experience underemployment (Forbes et al., 2007) or interrupted employment (Galushko et al., 2014), with impacts on their self-image (Wollin et al., 2006). An Australian study found that employment was also significantly affected for other progressive life-limiting neurodegenerative disorders (including Motor Neurone Disease, Huntington's Disease, Parkinson's Disease and Multiple Sclerosis), with more than a third (36.4%, n=503) having to give up work/retired early, and 8.6% reducing their work hours (Kristjanson et al., 2006b). Only a quarter of these patients living with progressive neurodegenerative diseases and/or their carers were in paid employment, with 60% relying on social security as their main source of income (Kristjanson et al., 2006a).

#### *Impact on finances*

Financial concerns were universally experienced by patients living with advanced cancer (McCarthy et al., 2000; Raynes et al., 2000; Osse et al., 2002; Osse et al., 2005; Tucker-Seeley et al., 2015) and other non-malignant diseases (Koopman et al., 2006; Kristjanson et al., 2006a; Kristjanson et al., 2006b; Wollin et al., 2006; Forbes et al., 2007; Galushko et al., 2014; Halman et al., 2014). One study reported that cancer patients aged <60 years had more significant financial problems compared to those  $\geq$ 60 years of age (Osse et al., 2005). UK

cancer patients receiving community palliative care identified needing financial assistance to afford to pay for housework assistance (Raynes et al., 2000). Many lacked the necessary welfare and financial benefit knowledge to access their entitled benefits, causing them to worry about their being a burden to their families (Raynes et al., 2000). A Dutch study reported that palliative cancer patients struggled with financial issues not necessarily related to their daily life, but to future expenses such as funeral costs (Osse et al., 2002). A US study reported that both patients and carers sustained significant financial burden during the last 6 months of life (McCarthy et al., 2000). Financial hardship in the US has been found to be a stronger predictor of use of intensive end-of-life care than insurance, sociodemographic factors or patient preferences (Tucker-Seeley et al., 2015).

Financial insecurity was also felt by people living with HIV (Halman et al., 2014), while the need for financial assistance for care was significant across a variety of debilitating progressive neurodegenerative diseases (Koopman et al., 2006; Kristjanson et al., 2006a; Kristjanson et al., 2006b; Wollin et al., 2006; Forbes et al., 2007; Galushko et al., 2014). An unintended consequence of having a significant disability was financial insecurity as a result of loss of employment (Wollin et al., 2006), costs associated with travelling to/from appointments (Galushko et al., 2014), vehicle adjustment (Galushko et al., 2014), and/or adaptation of their environment and mobility support (Forbes et al., 2007). An Australian study found that 2/3 of patients and carers made adjustments to their living environments with more than a third (34-44%) self-funding the required modifications (Kristjanson et al., 2006a). Another study found that people with Motor Neurone Disease and Huntington's Disease required help with finances, and information about financial assistance (Kristjanson et al., 2006b), while need for financial security was also identified by people with Multiple Sclerosis (Koopman et al., 2006).

### *Impact on lifestyle*

Facing an expected premature death during working age also impacts adversely on cancer patients' coping abilities, family roles and relationships. Increasing disability and cancer-related symptom burden led to a loss of independence and autonomy (Osse et al., 2005; Boland et al., 2014), loss of control over one's life (Osse et al., 2005), and increased dependency (Murray et al., 2004; Osse et al., 2005). Cancer patients reported struggling to cope with their uncertain future (Osse et al., 2005; Janda et al., 2006; Janda et al., 2008), frustration associated with managing their interrupted/changed lives (Rainbird et al., 2009), and with increased care requirements and fear of suffering (Osse et al., 2002). They also struggled with feelings of futility and stress (Osse et al., 2002), uselessness (Murray et al., 2004), and felt excluded from roles, family and social life (Murray et al., 2004). They wished not to be a burden to others and to minimise that effect of their illness on their families (Raynes et al., 2000). Cancer was described as taking over their lives (Murray et al., 2004), and severely impacted on their usual roles at work, leisure and study (Osse et al., 2002).

Cancer patients' ability to perform everyday tasks was compromised (Osse et al., 2005; Janda et al., 2008; Rainbird et al., 2009) across various domains, including: driving/ability to catch public transport (Raynes et al., 2000; Osse et al., 2005), shopping (Osse et al., 2005), housework (Osse et al., 2005; Rainbird et al., 2009; Boland et al., 2014), meal preparation (Raynes et al., 2000; Boland et al., 2014), and personal care (Osse et al., 2005). Severe symptom burden (especially pain) and a significant functional decline during the last 6 months of life was reported to impact adversely on the ability of advanced cancer patients to perform personal and household tasks, and participate in recreational activities (McCarthy et al., 2000). People's ability to take care of practical and family issues (including healing rifts in relationships) was compromised due to cancer treatment side effects (such as fatigue and nausea) (Murray et al., 2004). Social and psychological well-being were also

affected (Osse et al., 2002). For some cancer patients, spiritual well-being was found to correlate with a more productive life due to a determination to have a sense of control over their environment, meaning and purpose in life (O'Connor et al., 2007).

The high level of disability associated with progressive neurodegenerative diseases was found to have a significant impact on patients' independence (Wollin et al., 2006) and affect their ability to manage everyday tasks, including: personal care (Kristjanson et al., 2006a; Kristjanson et al., 2006b), child care (Forbes et al., 2007), housework (Kristjanson et al., 2006a; Kristjanson et al., 2006b; Forbes et al., 2007; Galushko et al., 2014), and transportation (Kristjanson et al., 2006a; Kristjanson et al., 2006b; Galushko et al., 2014). Assistance with social activities and support groups (Kristjanson et al., 2006a; Kristjanson et al., 2006b), and access to equipment for daily living (Kristjanson et al., 2006b) was equally important. Managing household tasks was found to be easier if patients had assistance from a network of family or friends (Raynes et al., 2000).

People with Multiple Sclerosis reported struggling to cope with changes in their identity due to interrupted work and/or lifestyle (Galushko et al., 2014), family roles (Wollin et al., 2006), diminished ability to perform daily tasks such as personal care, housework and childcare (Kristjanson et al., 2006a; Wollin et al., 2006; Forbes et al., 2007), and need for assistance with service coordination (Galushko et al., 2014) and transportation (Kristjanson et al., 2006a; Forbes et al., 2007). Leisure activities were also affected (Galushko et al., 2014), while household adaptation and re-housing was often required (Forbes et al., 2007). Similar to cancer, people with Multiple Sclerosis wanted to be productive, have control over their lives, and require information about the disease progression (Koopman et al., 2006).

Results from another study found that working age Canadians living with HIV were more likely to face homelessness and interrupted living conditions: out of 81 patients, 13.6%

reported living on the street or in a shelter and 6.1% reported staying with family or friends (Halman et al., 2014).

In a US study, working age women with metastatic breast cancer reported lower social/family well-being, and were less satisfied with their personal experience of care and support from health professionals compared to those >65 years (Reed et al., 2012). The same study reported that working age women without children (compared to those with) had significantly higher functional well-being in the last year of life (Reed et al., 2012). Age was reported to also influence decision-making preferences, with younger patients (<40 years) being more concerned about time away from family and side-effects of their cancer treatment (Mack et al., 2015). A UK study reported that 40% of patients (n=32) worried about the impact their progressive illness had on their family, while 31% reported that their illness had impacted adversely on their sexual life (Boland et al., 2014).

Working age parents with cancer reported being unprepared for the disease and experiencing challenges dealing with this diagnosis whilst also managing their children's needs (Elmberger et al., 2005; Houldin & Lewis, 2006). Parents reported trying to cope and limit the effects of the illness on their children by: creating as normal and stable life as possible (Houldin & Lewis, 2006; Kennedy & Lloyd-Williams, 2009a), maintaining a positive outlook (Houldin & Lewis, 2006), accepting help from others (e.g. a partner or other family members) (Houldin & Lewis, 2006), and discussing all issues relating to the disease with their children, whilst also concentrating on management of their physical symptoms and distress (Houldin & Lewis, 2006).

They identified discussions with their children as one of the most difficult issues, including: telling their children about the diagnosis (Turner et al., 2007; Kennedy & Lloyd-Williams, 2009a), dealing with their questions about the progressive illness (Kennedy & Lloyd-Williams, 2009a) and initiating conversations about the parents' expected death

(Turner et al., 2007). Cancer was also reported to interrupt their parenting and family life (Elmberger et al., 2005; Houldin & Lewis, 2006) and decrease their social activities with their children (Kennedy & Lloyd-Williams, 2009a). Their ability to perform household tasks (e.g. cleaning or cooking) was also affected (Elmberger et al., 2005), resulting in their older children assuming more household and/or shopping responsibilities (Kennedy & Lloyd-Williams, 2009a). Parents required practical coping strategies to deal with these challenges (Turner et al., 2007). They also desired practical help from health professionals on how to navigate the disease journey (Turner et al., 2007) and information about how the disease would impact their children (Elmberger et al., 2005; Turner et al., 2007). Strengthening the relationship with their children and learning to value what was important was seen as a positive aspect of their disease journey (Kennedy & Lloyd-Williams, 2009a).

## DISCUSSION

This systematic review has highlighted that facing an expected premature death adversely impacts workforce participation, financial security, and lifestyle for working age people with life-limiting illnesses and their families. Changes in patients' daily routines and lives as their disease progresses and their symptoms become more pronounced alters the family dynamics and redefines the roles of patients, their partners and children. These lifestyle changes are accompanied by a change in the patient's perception of self, their loss of independence and increased dependence on others. Although the evidence mostly comes from studies on cancer, these adverse impacts appear to be equally prevalent and cover similar domains and issues for people living with non-malignant progressive conditions, albeit played out over a more extended timeframe.

Symptom burden also impacts on patients' ability to maintain employment and perform everyday tasks. Less obviously, there is evidence that people often end up working longer hours to meet additional financial demands to cover illness related expenses (Zafar et

al., 2013), before being forced to reduce their working hours or to cease working altogether due to escalating physical dependence (Halkett et al., 2015). Thus, for this population, continuing employment is likely to be dependent both on physical well-being and a desire to maintain financial security, which can be greatly affected if employment is interrupted.

In addition to under employment, working age patients face multifaceted financial burden due to health care costs, as well as the hidden costs associated with homebased care, all of which are often compounded by limited access or lack of financial assistance. Other studies have shown that financial considerations (such as increased healthcare costs and out-of-pocket expenses) significantly affect their medical treatment, including nonadherence to medication (Neugut et al., 2011; Ubel et al., 2013; Zafar et al., 2013) and quality of life (Lathan et al., 2016). Our review further supports those findings. For example, when faced with competing financial priorities, patients often opt for care that incurs fewer out-of-pocket expenses to reduce the impact on family finances (Tucker-Seeley et al., 2015). Better understanding the relationship between financial burden and care decisions is important to reducing unnecessary and medically futile treatment at the end-of-life.

The need for financial assistance for care and support services for working age patients with progressive illnesses occurs in all countries, including those with universal healthcare and welfare systems (Raynes et al., 2000; Kristjanson et al., 2006a; Kristjanson et al., 2006b). While the financial toxicity of cancer treatment in countries without universal health care cover is well documented (Zafar & Abernethy, 2013a; Zafar & Abernethy, 2013b; Huntington et al., 2015; Zafar, 2016), out-of-pocket healthcare treatment costs are rising in countries with universal health care (Gordon et al., 2015; Currow & Aranda, 2016), especially with the advent of new generation cancer treatments, prompting calls for full disclosure of costs for the whole episode of care (Currow & Aranda, 2016). Patients face an ever increasing demand on their personal finances due to costs of treatments (including new



unsubsidised therapies) (Ubel et al., 2013; Currow & Aranda, 2016), innovations (sometimes with marginal benefits) (Currow & Aranda, 2016), and/or failure to access less costly alternatives (Ubel et al., 2013; Currow & Aranda, 2016). Health professionals need to provide opportunities for discussions on financial issues at all stages of the patient's illness trajectory (Amir et al., 2012; Ubel et al., 2013), especially as many patients avoid initiating these conversations during the early stages of the illness as they focus on their diagnosis, treatment and recovery (Amir et al., 2012).

The impact of loss of income on the family is a high priority requiring urgent social work input, especially in the context of the patient and family not having access to other income streams. There also needs to be consideration of the longer-term financial implications particularly in relationship to the carer returning to work post bereavement. In addition to impacting on spousal health (Currow et al., 2011; Jassem et al., 2015), a prolonged bereavement can impact adversely on the longer term employment of carers and their financial well-being, including retirement savings (Girgis et al., 2012). Also of concern, the premature death of a parent has been found to have a detrimental effect on the future wealth and employment of their children as adults (Australian Bureau of Statistics, 2010). Better understanding how education and health services can collaborate to ensure that school age children are appropriately supported before and after their parent's death is urgently required. Optimising their chances of successfully completing their schooling is central to their future financial security and emotional wellbeing.

Findings from our review suggest that patients living with debilitating neurodegenerative diseases, including brain tumours experience significant physical disability and cognitive impairment (brain tumours) often early in their illness trajectory. Their disability greatly affects their ability to perform household/personal tasks. Living with advanced cancer has a huge impact on people's independence, family interactions and

especially parenting roles. Sometimes, the disruption of normal household routine caused by the disease creates a ripple-effect within the family with children taking up the responsibilities around the house (Kennedy & Lloyd-Williams, 2009a). Other studies have shown that this can be particularly evident in homes where there is a lack of domestic help, so household duties become an additional burden for adolescent children (Huizinga et al., 2003). Given the daily struggle with loss of independence and increased reliance on their partners and other family members, patients with life-limiting illnesses may experience additional emotional and psychological burden. Studies have shown that adequate rehabilitation and prehabilitation have positive effect on function of cancer survivors and also may improve their employment rates and reduce early retirement (Silver & Baima, 2013; Silver et al., 2013; Silver, 2014). Thus, providing adequate support services to promote independence for as long as possible, as well as timely rehabilitation and prehabilitation, should be integral to health care provision for working age people living with life-limiting illnesses.

The impact that a life-limiting illness has on families' overall quality-of-life is complex. From the time the working age patient is diagnosed with a progressive illness, their family's life changes dramatically and irreversibly. Their day-to-day lives change in terms of work engagement, housework chores, interruptions caused by going to medical appointments and ongoing treatments. Changing roles and responsibilities in the family unit (patient vs their partner vs their children) alter the family dynamics. Many of these observed changes persist into the palliative stages of the patient's illness and into bereavement. Although the severity, timing, and priority placed on these issues may vary between malignant and non-malignant conditions, comparing and contrasting their trajectories and priorities would be helpful to better understand people's needs and inform health policy and practice.

Having a better understanding of the impact an expected premature death has on working aged patients and their families provides an opportunity for specialist services,

including palliative care to address the holistic needs of patients and their families. This may be particularly important for families who are navigating the final stages of the illness without adequate resources and support systems and where health professionals' involvement would help mitigate the often hidden, but detrimental, effects of the life-limiting illness on that family's financial and emotional welfare (Payne, 2017). At the same time, comprehensively addressing the employment, financial and lifestyle needs is likely to fall outside the jurisdiction of palliative care providers and healthcare more generally. Cross-sector partnerships may be needed to provide appropriate advice and support.

## LIMITATIONS

This review has a number of limitations. Restriction to studies that explicitly stated the age of their participants may have resulted in relevant articles being missed. Also, more than half of the included studies focused on cancer; given that non-malignant conditions like cardiovascular and chronic respiratory diseases are leading causes of premature death for working age people (Organisation for Economic Co-Operation and Development, 2006; Office for National Statistics, 2013; Australian Institute of Health and Welfare, 2016; Heron, 2016), there is scope for further studies on how impacts might vary. Finally, none of the studies considered impacts on extended social networks or described interventions to address this population's unmet needs.

## CONCLUSIONS

Working age patients facing an advanced progressive disease experience significant underemployment, workforce displacement, financial security and changes to family dynamics. Further research is needed to better understand the financial and employment concerns of working age patients and their carers, especially as they impact their relationships and roles within the family and extended social networks. Further research is also needed to understand the broader economic implications this has on health policy and the provision of

health/palliative care. There is also a need for prospective population based studies to inform understanding of how impacts may change over time (Burns et al., 2011). Finally, evaluative studies are needed of interventions developed to support working age people and their families to overcome the challenges identified in this review. Interventions that explore cross-sectoral partnerships within the context of policy are urgently needed to better address these families' needs.

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## CONFLICTS OF INTEREST

The authors declare no conflict of interest.

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