Level 3: Quantitative Observational Research Evidence: In-depth list of factors associated with caregiver mental health overall

1: Patient condition

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'patient condition'	Better mental health	Worse mental health	No change
Patient condition			
Other conditions			
Patients with heart failure			3
(patients with heart failure were compared with patients with lung cancer)			
Patient with chronic obstructive pulmonary disease (COPD)		1	
(patients with COPD were compared with patients with chronic heart failure and patients with chronic renal failure]			
Cancer			
Primary brain cancer		1	
(patients with primary brain cancer were compared with patients other cancers)			
Type of cancer			2
(lung, colon, liver, brain, prostate, stomach, pancreatic)			
Patients with rare cancers		1	1
(patients with rare cancer compared with patients with common cancers)			
Patient cancer diagnosis			1
(types of cancer were studied: prostate, lung, breast, colorectal, pancreatic)			
Patients with lung cancer		2	
(patients with lung cancer were compared with patients with breast, urogenital and other cancers)			
Tumour histology in patients with high-grade glioma			1

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1: Patient condition (continued)

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'patient condition'	Better mental health	Worse mental health	No change
Patient diagnosis			
Shorter time since diagnosis (months) in palliative cancer patients		1	
Patient disease burden			
Physical functioning			
Greater functional impairment			
Patient lower functional capacity		1	
(measured using Barthel Index)			
Patient functional capacity			1
(measured using using Palliative performance scale and Activities of Daily Living Index)			
Patient activities of daily living impairment			2
Patient ECOG 3*		1	
*An ECOG score of 3 refers to a person who is capable of only limited self-care and is confined to bed or a chair for more than 50% of waking hours			
Patient functional status			1
(measured by the amount of assistance for ADL's using Katz Index)			
Functional impairment of patient		1	
Patient functional status			3
(measured by Patient Kamofsky Performance Status Scale)			
Patient comorbidity*			1
*patient has two or more medical conditions at the same time			
Patient needing night time care			1
Cognitive functioning (a person's ability to process thoughts and remember things)			
Greater cognitive impairment*			3
*cognitive impairment is a temporary or permanent loss of mental functions, causing forgetfulness, lack of concentration, learning difficulties, and other reductions in effective thinking			
Patient disease severity			
Patient disease severity			2

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1: Patient condition (continued)

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'patient condition'	**Better mental health**	**Worse mental health**	**No change**
Patient Quality of Life (QoL)			
Patient overall QOL	6	1**	3
**study reports a positive relationship between QoL and depression but does not state if a higher score on the QoL measure relates to a lower QOL			
Patient psychological QOL (psychological wellbeing)	1		
Patient stage of disease			
Time		1	1
12 months to 1 month prior to death of patient with ovarian cancer			
Time taken for a patient with Amyotrophic Lateral Sclerosis (ALS*) to show a measurable decline** in functioning		1	
*ALS is a similar condition to multiple sclerosis **(a decline of 5 points on the Amyotrophic Lateral Sclerosis (ALS) Functional Rating Scale (ALSFRS) – this was not longer than 15 months from baseline measures			
Change over time (7, 12, 18 and 24 weeks after Quality of Life was first measured in caregivers of patients with lung cancer)		1	1
Caregivers perceived stage of the patient's cancer (PSOC)* at 4 different time points prior to the patient dying			2
* caregivers were asked the following question: 'How advanced is the patient's disease at present?'			

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1: Patient condition (continued)

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'patient condition'	**Better mental health**	**Worse mental health**	**No change**
Patient symptoms			
Patient overall symptoms			
Patient symptom burden		1	
Patient symptoms			1
Caregiver finds the patient's difficult/troubling emotional, psychological and physical symptoms stressful		1	
Patient physical symptoms			
Greater symptom burden related to appetite			1
Greater symptom burden related to drowsiness		1	
Greater symptom burden related to dyspnoea			1
*dyspnoea is shortness of breath/breathing difficulty			
Greater symptom burden related to fatigue		1	
Greater symptom burden related to nausea			1
Greater symptom burden related to pain		1	
Patients increased problems with communication measured using Brain Cancer Module (BN20), which assesses patient's neurological functioning as perceived by caregiver		1	

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1: Patient condition (continued)

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'patient condition'	**Better mental health**	**Worse mental health**	**No change**
Patient symptoms *(continued)*			
Patient psychological symptoms			
Patient anxiety		7	
Patient depression		9	3
Greater symptom burden related to anxiety		1	
Greater symptom burden related to depression		1	
Greater symptom burden related to reduced sense of wellbeing			1
Patient exhibits psychological or psychiatric symptoms		1	
Patient symptom global distress*		1	
*measures the distress a patient with cancer experiences in response to the severity and frequency of symptoms			

1: Patient condition (continued)

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'patient condition'	Better mental health	Worse mental health	No change
Patient treatment			
Patient admitted to hospital or long term care within previous 7 days		1	
Patient awaiting new line of treatment			1
Patient receiving no cancer therapy		1	
Medical care provided			1
No past surgery		1	1
Past chemotherapy			2
Patient frequently visited emergency outpatient clinic			1
Patient follow up method (oncologist*-led follow-up compared with multidisciplinary group follow-up)			1
*oncologist is a doctor who specializes in diagnosing and treating people who have cancer			
Patient receiving Specialized Palliative Care (SPC)			1
*According to National Institute of Clinical Excellence (NICE), **Specialist palliative care** encompasses hospice care (including inpatient hospice, day hospice, hospice at home) as well as a range of other specialist advice, support and care such as that provided by hospital palliative care teams.			

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2: Impact of caring responsibilities

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'Impact of caring responsibilities'	**Better mental health**	**Worse mental health**	**No change**
Caregiver workload			
Caring for patient			
Caregiver burden measures:			
Bakas Caregiving Outcomes Scale (BCOS*) score – changes have worsened.		5	
BCOS measures carers' perception of changes in their lives as a result of providing care and covers social functioning, physical health and subjective wellbeing.			
Oberst Caregiving Burden Score - D (OCBS-D*) score - tasks of greater difficulty		2	
OCBS-D measures difficulty of caregiving tasks			
Oberst Caregiving Burden Score -T (OCBS-T*) score -more time spent on caregiving tasks *OCBS-T measures time spent on caregiving tasks*		2	
Perceived burden (measured by Caregiver Strain Index)		1	
Zarit Burden Inventory 12 (ZBI-12) *(measures subjective burden)*		3	
Burden Scale for Family Caregivers (BSFC) *(measures burden of care)*		3	

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2: Impact of caring responsibilities (continued)

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'Impact of caring responsibilities'	Better mental health	Worse mental health	No change
Caregiver workload *continued*			
Caring for patient			
Caregiver assists with activities of daily living (ADL*)		1	
*ADLs are the essential tasks that each person needs to perform, on a regular basis, to sustain basic survival and well-being.			
Caregiver assists with medical tasks		1	
Number of days spent on caregiving tasks		1	
Physical strain		1	
Demands* on caregiver		1	
*caregiving demands include acknowledged tasks such as activities of daily living; preparing and administering medication; maintaining nutritional care; transporting; giving emotional support; conducting family business; and, less recognized, acting as a source of data about the patient to professional healthcare providers.			
Impact on caregiver's schedule – (measured by Carer Reaction Assessment (CRA)		1	
Number of hours per week providing care			1

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2: Impact of caring responsibilities (continued)

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'Impact of caring responsibilities'	Better mental health	Worse mental health	No change
Caregiver workload *(continued)*			
Length of caring			
Duration of care			
Duration of care			1
Period of home care (months)			1
Number of months of caregiving			1
Other demands on time			
Other demands on time		1	
Support for others			
Additional caring responsibilities			
Caring for others			1
Children of minor age			2
Caregiver with childcare responsibilities		1	
Caregiver lifestyle adjustments			
Caregiver has made greater lifestyle adjustments to accommodate the caregiver role		1	
Caregiver sleeping hours			
Caregiver sleeping hours			1
Caregiver sleep problems			
Caregiver has sleep problems*		1	
*family caregivers were asked how often in the prior 2 weeks they had experienced having 'trouble falling or staying asleep or sleeping too much'			

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3: Relationships

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'Relationships'	**Better mental health**	**Worse mental health**	**No change**
Family dynamics			
Coherence *(ability of family members to successfully cope with family stressors)*			
Family sense of coherence* perceived by caregiver is high (measured by Family Sense of Coherence Scale)	2		
*family sense of coherence relates to the ability of family members to successfully cope with family stressors			
Cohesion *(the level of commitment and support in the family)*			
Family cohesion* perceived by caregiver is low (measured by family environment scale)		1	
*family cohesion relates to the degree of commitment, help and support family members provide one another			
Family cohesion* perceived by patient is low (measured by family environment scale)		1	
*family cohesion relates to the degree of commitment, help and support family members provide one another			
Supportiveness of family relationships	1		
Communication			
Family expressiveness* perceived by caregiver is low (measured by family environment scale)		1	
*family expressiveness is the extent to which family members are encouraged to express feelings directly			
Family expressiveness* perceived by patient is low (measured by family environment scale)		1	
*family expressiveness is the extent to which family members are encouraged to express feelings directly			
Conflict			
Family conflict* perceived by caregiver is high (measured by family environment scale)		1	
*family conflict relates to the amount of openly expressed anger and conflict among family members			
Family conflict* perceived by patient is high (measured by family environment scale)		1	
*family conflict relates to the amount of openly expressed anger and conflict among family members			

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3: Relationships (continued)

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'Relationships'	**Better mental health**	**Worse mental health**	**No change**
Quality of patient-caregiver relationship			
Caregiver attachment style (how the caregiver relates to people)			
Caregiver has an insecure-anxious attachment style*		1	
*attachment style relates to the different ways of interacting and behaving in relationships			
Caregiver has an insecure-avoidant attachment style*			1
*attachment style relates to the different ways of interacting and behaving in relationships			
Cohesion (the level of commitment and support in the relationship)			
Caregiver gets on with the patient			1
Communication			
Caregiver communication with patient about both their illness and approaching death is high	1		
Conflict			
Caregiver dissatisfaction with caregiver-patient partnership		1	
Number of unresolved family conflicts perceived by family member		1	
Number of unresolved family conflicts perceived by patient		1	

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4: Finances

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'Finances'	**Better mental health**	**Worse mental health**	**No change**
Caregiver finances			
Sufficient family budget	1		
Caregiver income (US dollars)			1
Annual income during care (US dollars)			1
Financial difficulties due to patients' disease		1	
Financial strain related to providing informal care		1	
Caregiver mode of transport			
Means of transport (private car)		1	1
Impact on work			
Change in work situation (includes: less hours worked, quit job, on leave, changed job, lost job)		1	

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5: Carer internal processes

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'Carer Internal proceses'	Better mental health	Worse mental health	No change
Acceptance of patient condition			
Difficult for caregiver to emotionally accept that the patient's condition was rapidly worsening		1	
Coping patterns			
Positive impact			
Optimistic	1		
Secular* caregivers	1		
*non-religious			
Negative impact			
Suppression of competing activities* (measured using COPE Inventory)		1	
* coping style which is based on solving problems, such as concentrating efforts on doing something about a problem or thinking about what steps to take for solving a problem			
Seeking for emotional social support (measured using COPE Inventory)		1	
Disengagement through substance use* (measured using COPE Inventory)		1	
Dysfunctional* coping strategies (measured using Brief COPE)		1	
*coping style which is based on not accepting a problem or not wanting to think about it, such as avoiding dealing with the problem or not accepting that the situation has happened			
Venting of emotions (measured using COPE Inventory)		1	

5: Carer internal processes (continued)

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'Carer Internal proceses'	Better mental health	Worse mental health	No change
Coping patterns (continued)			
No impact			
Emotion-focused* coping strategies (measured using Brief COPE)			1
* coping strategies which aim to reduce or eliminate negative feelings such as accepting the reality or trying to see the situation positively			
Problem focused coping strategies (measured using Brief COPE)			1
* coping strategies which aim to solve problems, such as concentrating efforts on doing something about a problem or thinking about what steps to take for solving a problem			
Active coping*(measured using COPE Inventory)			1
* coping style which is based on solving problems, such as concentrating efforts on doing something about a problem or thinking about what steps to take for solving a problem			
Humour* (measured using COPE Inventory)			1
Fighting spirit coping style* (measured using Mini-Mental Adjustment to Coping Scale)			2
Seeking for information support (measured using COPE Inventory)			1
Religious coping (measured using COPE Inventory)			1
Denial (measured using COPE Inventory)			1
Cognitive avoidance coping style* (measured using Mini -Mental Adjustment to Coping Scale)			2
* cognitive avoidance relates to avoiding feeling or thinking about events or experiences such as unpleasant or distressing thoughts or memories			
Mental disengagement* (measured using COPE Inventory)			1
* coping style in which a person turns to other activities (including daydreaming, sleep, work or other substitute activities like watching TV) when they experience a stressful event			

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5: Carer internal processes (continued)

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'Carer Internal proceses'	Better mental health	Worse mental health	No change
Control over the care situation			
Control over the care situation (measured using the Carer Experience Scale)			1
Caregiver feels helpless or guilty because they could do nothing for the patient		1	
Self-efficacy			
Self efficacy*	1		
Caregiver has greater confidence in caring for themselves (as a measure of their self-efficacy*)	1		
Caregiver has greater confidence in managing caregiving demands (as a measure of their self-efficacy*)	1		
*confidence in one's ability to carry out a task			
Self-esteem			
Esteem		1**	
** author's confirmed higher scores on caregiver esteem were unexpectedly related to higher scores on depression".			
Positive aspects of caregiving			
Fulfilment from caring			1
Happy to care			1
Pre-loss grief			
Pre-loss grief		1	
Preparedness for caregiving			
Preparedness for caregiving	2		1
Previous experience of informal caregiving			
Provided care to a loved one in the past		2	
Time for respite			
Activities outside caring			1
Enough time for self	1		

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6: Support

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'Support'	**Better mental health**	**Worse mental health**	**No change**
Accessible information			
Accessible information for carers	1		
Accessible information for patients	1		
Caregiver support			
Formal support			
Previously received formal support:			
Caregiver previously accessed support services			1
Currently receiving formal support:			
Caregiver receiving support services	1		
Caregiver accessing professional psychological help		1	2
Institutional support - assistance from organisations and the government			1
Caregiver receiving formal help			1
Interested in receiving support:			
Caregiver interested in accessing future support services		1	
Caregiver requesting home care for patient	1		
Type of formal support service used and frequency			1
Home-visit physicians and nurses provide no help in symptom management		1	

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6: Support *continued*

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'Support'	**Better mental health**	**Worse mental health**	**No change**
Caregiver support *continued*			
Informal support			
Currently receiving informal support			
Social support : from family and friends	2		
Instrumental support : presence of a sub caregiver	1		
Caregiver receiving informal help			1
Availability of someone who could stay with patient			1
Caregiver working in pairs			2
Perceived support			
Caregiver perceived support			2
Satisfaction with support			
Caregiver support satisfaction	1		

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6: Support (continued)

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'Support'	**Better mental health**	**Worse mental health**	**No change**
Communication with care professionals			
Faster dialogue pace**		1	1
Language complexity**			2
Length of interaction (in minutes)**			2
Team taking turns to speak**			2
** in care planning sessions between informal caregivers and hospice team members			
Health professionals understanding of patient needs			
Because symptoms are not severe in daytime, physicians or nurses do not understand their severity			1
Quality of Care			
Caregiver satisfaction with care	1		
Caregiver satisfaction with home care	1		
Patient satisfaction with home care	1		
Instrumental support services received considered necessary by caregiver			1
Carer reports of quality of care: more problems in patient emotional and spiritual support	1		
Carer reports of quality of care: more problems with patient unmet needs		1	
Unmet needs in caregiver			
Number of important unmet needs by health professionals		1	
Total number of unmet needs (psychological, social and physical needs)		3	

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7: Contextual factors

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'Support'	**Better mental health**	**Worse mental health**	**No change**
Caregiver age			
Caregiver age - increasing age	6		8
Carer age >=75	1		
Caregiver education			
Number of years of education completed			1
Caregiver educational level			3
Caregiver education			5
Caregiver employment status			
Unemployed			
Unemployed		1	
Employed			
Caregiver employment			6
Employed – on leave		1	
Retired			
Retired	2		
Caregiver ethnicity			
Non-European ethnicity			1
White	1		1
Caregiver gender			
Female caregiver		6	13
Wife caregiver		1	
Husband caregiver			1

To note:
The numbers in each column do not relate to the total number of research studies that investigated each factor. Rather, the numbers in each column relate to the total number of times the relationship was investigated between the individual factor and a single mental health outcome (anxiety, depression, distress or psychological wellbeing/Quality of Life) and where the individual factor was identified as having a positive impact, negative impact or no change on the mental health outcome investigated. This way of reporting the numbers is intended to bring together all the individual factors within a theme and therefore purposely does not take into account where one research study looks at several outcomes for the same factor.
(For details on the total number of research studies that looked at the individual factor for each different type of mental health outcome (anxiety, depression, distress, psychological wellbeing/Quality of Life), please refer to the Level 4 information: 'Observational research – In-depth factors for different outcomes')

7: Contextual factors continued

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'Support'	**Better mental health**	**Worse mental health**	**No change**
Caregiver health status			
Poor physical health			
Caregiver comorbidity*			1
* comorbidity is the presence of two or more medical conditions at the same time			
Physical health condition of carer - poor		1	
Caregiver disability or chronic illness			1
Caregiver chronic disease			1
Overall health			
Overall health status			1
Caregiver marital status			
Caregiver marital status			4
Caregiver socio-economic status			
Higher socioeconomic status (SES)	1		
*SES is a combined measure of a person's work experience and of an individual's or family's economic and social position in relation to others, based on income, education, and occupation			
Composition of household			
Composition of household members who live with caregiver			1
Length of patient-caregiver relationship			
Date of marriage			1

To note:

The numbers in each column do not relate to the total number of research studies that investigated each factor. Rather, the numbers in each column relate to the total number of times the relationship was investigated between the individual factor and a single mental health outcome (anxiety, depression, distress or psychological wellbeing/Quality of Life) and where the individual factor was identified as having a positive impact, negative impact or no change on the mental health outcome investigated. This way of reporting the numbers is intended to bring together all the individual factors within a theme and therefore purposely does not take into account where one research study looks at several outcomes for the same factor. (For details on the total number of research studies that looked at the individual factor for each different type of mental health outcome (anxiety, depression, distress, psychological wellbeing/Quality of Life), please refer to the Level 4 information: 'Observational research – In-depth factors for different outcomes')

7: Contextual factors continued

Factor (Overall theme)	Impact on mental health		
Individual factor/s contributing to 'Support'	**Better mental health**	**Worse mental health**	**No change**
Patient age			
Patient age	1		2
Patient educational level			
Patient educational level			2
Patient gender			
Patient gender			2
Male patient		2	
Patient lives with caregiver			
Patient lives with caregiver		2	2
Relationship to patient			
Spouse/partner			
Spouse	1		
Spouse or partner			4
Relationship to patient			3
Child			
Daughter			1
Child	1		
Other relationship			
Not a spouse/partner of the patient		1	1
Caregiver other than wife, husband or daughter	1		
Nature of relationship			2
Rural location			
Living in a rural area			3

To note:
The numbers in each column do not relate to the total number of research studies that investigated each factor. Rather, the numbers in each column relate to the total number of times the relationship was investigated between the individual factor and a single mental health outcome (anxiety, depression, distress or psychological wellbeing/Quality of Life) and where the individual factor was identified as having a positive impact, negative impact or no change on the mental health outcome investigated. This way of reporting the numbers is intended to bring together all the individual factors within a theme and therefore purposely does not take into account where one research study looks at several outcomes for the same factor. (For details on the total number of research studies that looked at the individual factor for each different type of mental health outcome (anxiety, depression, distress, psychological wellbeing/Quality of Life), please refer to the Level 4 information: 'Observational research – In-depth factors for different outcomes')