### Themes and subthemes

### Black text - Factors from qualitative evidence

**Blue text-** Factors from quantitative information that showed a relationship with carer mental health (quantitative information includes both observational and intervention research findings)

Highlighted purple text – Factor identified both in qualitative and quantitative information

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## Strategies to support mental health

## 1. Patient condition

### Patient condition

Cancer

Other conditions

Patient diagnosis

Patient disease severity

Patient disease stage

Patient treatment

Patient physical decline

Patient Quality of Life

**Emotional response** 

Fear of decline

Uncertainty over how the illness will progress

No light at the end of the tunnel

Distress when observing physical decline

Impact of the patients cognitive

**decline/**cognitive functioning (=a person's ability to process thoughts, remember things etc.)

Physical functioning

**Symptoms** 

Overall

Physical

Psychological

- Improving depression in patients
- Improving social wellbeing in patients

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# Strategies to support mental health

# 2. Impact of caring responsibilities

Workload/ Physical burden/Carer workload:

Caring for patient

Supporting other family members/support for others

Conflicting responsibilities/other demands on time

Taking on extra roles/responsibilities that the patient would have previously done

Length of caring

### **Emotional impact:**

Exhaustion/ Impact on mental health

Crisis

### **Emotional impact:**

Impact on physical health

### Other general life impact:

Lifestyle adjustments

Impact of employment (lack of flexibility, understanding etc.)

No energy to socialise

No time for self-care

Lack of respite/ unable to plan for respite

Loneliness and isolation

Sleep deprivation (carer required through the night)/sleep problems/sleeping hours

Themes and subthemes		Strategies to support
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3. Relationships	Relationships with the patient/ quality of patient-carer relationship	<ul> <li>Improving quality of patient-carer relationship</li> </ul>
	Carer attachment style (= how the carer relates to people)	Telationship
	Cohesion (=the level of commitment and support in the relationship)	
	Communication	
	Change in roles/quality of the relationship	
	Lack of understanding or gratitude about the impact of caring from the patient/Conflict	
	Patient non-compliance	
	Family dynamics	
	Coherence (=the ability of family members to successfully cope with family stressors)	
	Cohesion (=the level of commitment and support within the family)	
	Communication	
	Conflict	
4. Finances	Current finances/ Cost of equipment	
	Impact on work	
	Difficulty accessing benefits	
	Distress over future financial situations/ Financial situation	
	Mode of transport	

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## Strategies to support mental health

# 5. Carer internal processes

Loss of self-determination and autonomy

Why me?

Lack of care experience/ preparedness for caregiving/previous experience of informal caregiving

Mastery

Self-esteem

Lack of confidence/ Self-efficacy (=the carer's belief that they can be successful when carrying out a particular task)

#### Lack of control

Control over the care situation

Anxiety about what they will be told at appointments

### Coping patterns

Positive impact

Negative impact

No impact

#### Transitions/ crisis

Acceptance of patient condition

Shock of the diagnosis

Grieving of a previous life

Becoming a carer

Pre loss grief

Positive aspects of caring

Time for respite

- Time for respite (journaling, time to yourself, employment, treats, alternative therapies, reducing the quality of care provided)
- Positive self-talk (looking to the future, knowing this will end,, coming to terms with the situation/thinking of what you still have, gentle with yourself on bad days, positivity from others-feeling appreciated)
- Ignore own emotions and needs
- Spirituality: acceptance of a lack of control, reduces a sense of isolation/ someone is listening
- Increasing autonomy
- Decrease in use of an avoidant coping strategy (i.e. denial)
- Healthy behaviours (e.g. exercise, nutrition and adequate sleep)
- Communicating stress within the carer-patient relationship (where the carer is the partner of the patient)
- Increasing support for and satisfaction with involvement in joint decision making for the patient
- Increasing self-efficacy
- Improving mastery

### Themes and subthemes

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## Strategies to support mental health

### 6. Support

Lack of professional/formal support/ formal support/satisfaction with support

Healthcare system challenges

Disjointed care/quality of care

Lack of empathy

Health care professionals do not recognise carers expertise/ Lack of collaboration between health professionals and carers

Health care professionals not listening to the wishes of patients and carers/health professionals understanding of patient needs

Poor communication from health care workers/communication with care professionals

Lack of skill

Inadequate pain management/patient pain management

Cultural barriers

Lack of information/accessible information
Lack of informal support

Perceived support

Unmet needs

- Professional support (mental health professionals, social workers, nurses, physicians, palliative care nurse, telephone helpline services, private carer
- Informal support (support from friends and family, sense of community, shared responsibility/validation)
- Support groups: Support from others in the same situation, source of information
- Accessing information
- Spirituality: Provides a sense of community

### Themes and subthemes

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## Strategies to support mental health

## 7. Contextual factors

### Carer

Age

Education

**Employment** 

Unemployment

**Employed** 

Retired

**Ethnicity** 

Gender

Health status

Poor physical health

Overall health

Marital status

Socio-economic status (= a combined measure of the carer's work experience and individual's or family's economic and social position in relation to others, based on income, education, and occupation)

Composition of household

Length of patient-carer relationship

Lives with patient

Relationship to patient

Spouse

Not a spouse/partner

Child

Other relationship

Rural location

#### Patient

Age

Educational level

Gender

Lives with carer