

# Existential Distress among Informal Caregivers of Patients with Brain Tumors: A Review of the Literature

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## Background

- Informal caregivers (ICs) of patients with brain tumors (BTs) are at risk for severe burden due to the devastating neurologic and oncologic sequelae of BTs.
- ICs face existential challenges because of loss of the premorbid relationship with the patient, well in advance of patient death.
- Attention to spiritual and existential needs is a critical component of palliative care, and understanding these needs in this vulnerable group is necessary to provide comprehensive psychosocial care.

## Methods

- A systematic review of studies related to existential distress among ICs of patients with BTs was conducted.
- Databases searched were MEDLINE, Embase, The Cochrane Library, Web of Science, PsycINFO, and CINAHL.
- The search strategy included terms associated with: cancer and brain tumors; caregivers (e.g., spouses, partners); and unique needs and burden (e.g., unmet needs, emotional distress)
- Of 245 full text articles reviewed, 51 met inclusion criteria and were included in subsequent analyses.

## Results

### Existential themes among caregivers of patients with brain tumors

Existential Theme	Study Design	Key Findings
Identity and Role Change	Qualitative: 22 Quantitative: 7	<ul style="list-style-type: none"> <li>ICs quickly become enmeshed with the patient and lose a sense of their own identity.</li> <li>The patient's ongoing loss of cognitive function and unique personality leads to dominance of the IC's role and loss of reciprocity in the relationship. This, too, impacts ICs' sense of identity.</li> </ul>
Isolation	Qualitative: 13 Quantitative: 2	<ul style="list-style-type: none"> <li>ICs become rapidly isolated as patients' cognitive and personality changes lead to a deterioration in the IC-patient relationship. Isolation increases over time.</li> <li>Isolation and loneliness are exacerbated when medical professionals avoid discussing how the disease impacts the family and the IC-patient relationship.</li> </ul>
Responsibility and Guilt	Qualitative: 20 Quantitative: 6	<ul style="list-style-type: none"> <li>BT ICs' responsibilities are greater than those of other cancers due to patients' significant limitations.</li> <li>Paradoxical experience of complete responsibility for patient yet feeling complete powerlessness.</li> <li>ICs experience guilt when they acknowledge their own limitations and needs; as a result, their self-care appears to be extraordinarily poor.</li> </ul>
Death	Qualitative: 18 Quantitative: 4	<ul style="list-style-type: none"> <li>Death anxiety is experienced as "existential crisis" for ICs.</li> <li>Loss of personality and cognitive capacity are experienced as ongoing and repeated "mini-deaths."</li> <li>Medical professionals are generally avoidant of EOL discussions, while ICs desire information to manage expectations.</li> </ul>
Growth, Meaning and Purpose	Qualitative: 22 Quantitative: 8	<ul style="list-style-type: none"> <li>ICs experience feelings of increased closeness, love, and admiration for the patient.</li> <li>Providing care allows ICs to derive meaning, purpose, and personal growth from their experience.</li> <li>Providing care is seen as an opportunity to reframe priorities and values, and to find inner strength and courage.</li> </ul>
Spirituality and Religion	Qualitative: 15 Quantitative: 8	<ul style="list-style-type: none"> <li>S/R facilitates coping and meaning-making and is source of comfort, hope, optimism and strength.</li> <li>Attention to spiritual and religious beliefs are identified as a critical unmet need among ICs.</li> <li>S/R often evoked when asking "Why did this happen?"</li> </ul>
The Child with a Brain Tumor	Qualitative: 6 Quantitative: 2	<ul style="list-style-type: none"> <li>Significant challenge for parents is facing the disconnect between the perceived harshness of instilling pain/discomfort associated with treatment versus the protective instinct of parenthood.</li> <li>The brain tumor creates an even larger gap in authority than naturally exists between parent and child.</li> </ul>

## Conclusions

- The majority (n=48) of studies did not identify existential distress as a key outcome of interest, despite it being addressed by all studies reviewed here.
  - Existential distress is a significant concern for ICs of patients with BTs.
  - Existential distress emanates from ICs' changing responsibilities and self-perception in light of the patients' often rapidly shifting personality and cognitive capacity and eventual decline to death.
  - The caregiving role is an opportunity for deriving meaning, purpose, and for improving the IC-patient relationship.
  - In their emphasis on immediate medical treatments and goals, health care professionals are experienced as avoiding and overlooking existential and spiritual dimensions of care.
- ### Future Directions
- Psychosocial interventions that target existential distress among ICs of patients with BTs are needed.
  - Clear communication by medical professionals about prognosis and acknowledgment of the impact of patients' limitations on the quality of life of ICs has the potential to mitigate existential distress.