

“My Family Assumed I Was Going to Fight It”: Experiences of Social Support & Relationships After a Brain Tumor Diagnosis

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Primary brain tumor can be a devastating diagnosis and cause higher distress compared to other types of cancer. Because the unique symptoms can affect cognition, memory, and communication, it can pose challenges to social functioning, social roles, and networks (Cubis et al., 2017). Despite an existing body of literature on the significance of social support for quality of life when adjusting to living with a chronic condition, evidence on coping with a brain tumor rarely focuses on the role of social relationships (Dahlberg et al., 2022). The current study sought to explore individuals' perceptions of social support, and the experiences within social relationships, following a diagnosis of a brain tumor. Interpretative Phenomenological Analysis (IPA) was used as a theoretical framework guiding study design and data analysis. In-depth semi-structured interviews were conducted with 12 individuals (n=10 female) aged ranging from 29 to 54 years diagnosed with primary brain tumor (n=10 low-grade) who were on average 3.5 years post-diagnosis. There were five themes identified following the analysis: (1) Coping together in the family; (2) Being concerned about others; (3) Giving and receiving support; (4) Needing to share the experience; and (5) Negotiating independence. The results highlighted that the illness affected a whole network of closest relationships, and that adjustment was not an individual task. Instead, coping was deeply socially embedded. The findings portrayed a complex interplay between the perceptions of family dynamics and coping. Participants did not always ask for support, even when needed, in order not to burden friends and family. Engaging with others with similar diagnoses through the support groups offered a crucial sense of validation and belonging. The findings help inform occupational therapy practice and interventions for clients with a brain tumor, by highlighting the importance of including informal caregivers in the rehabilitation process.

References

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