



Spouse caregivers of patients with glioblastoma multiforme report unmet needs throughout the disease trajectory

Diana L Coman¹, Megan P. Chard¹, Lisa Desautels², Barbara J. Lutz³, Laurie A. Minns^{1,2,4}

¹Clinical Research Program, School of Nursing, University of North Carolina Wilmington, ²Glioblastoma Support Network, ³School of Nursing, University of North Carolina Wilmington;

⁴Corresponding author; minnsl@uncw.edu

ABSTRACT (AACR 5540)

Glioblastoma (GBM) is a devastating and terminal cancer that results in memory loss, cognitive declines, personality changes, neuropsychiatric symptoms, and physical impairments that greatly affect quality of life of both the patient with GBM and their primary caregiver, who is often a spouse or partner. In this qualitative study, female spouse primary caregivers were recruited through a private Facebook support group to write letters describing their experiences in caring for their loved ones with GBM. Using a reflexive thematic analysis, 101 letters from caregivers were analyzed for unmet needs, challenges, and opportunities for better care and support. Caregivers expressed feeling unsupported and poorly prepared and described different levels and types of needs and challenges throughout the GBM disease trajectory. Challenges included difficulties adapting to sudden life changes, the need for more education on what to expect, feelings of sudden loss, relationship strain, and not having enough knowledge about GBM. Associated emotional responses included feelings of fear, lack of control, agony, disappointment, and exhaustion. These challenges and emotional impact were greatest during the acute and living with disease progression phases. Caregivers described relying heavily on friends, community supports (such as faith groups), and peer-support through the Facebook group during this living with disease progression phase, but still experienced high levels of relationship strain and other unmet needs. These findings on the primary caregivers' experiences provide opportunities to guide more timely and tailored interventions to provide support and improve care for patient/caregiver dyads to help mitigate the burden of this progressive disease and improve quality of life for caregivers.

CONTACT

Laurie Minns, PhD (she/her/hers)
Assistant Professor of Clinical Research
School of Nursing
College of Health and Human Services
University of North Carolina Wilmington
601 South College Road
Wilmington, NC 28403-5915
910-962-3824
minnsl@uncw.edu
PreClinical_Research_Group(uncw.edu)

INTRODUCTION

- Glioblastoma multiforme (GBM) is the most common and deadly brain cancer with an incidence of 3.19 per 100,000¹; it affects males at nearly double the rate as in females with the median survival of 12-18 months after initial diagnosis ².
- GBM patients experience a host of irreversible and progressive neuropsychological symptoms including cognitive decline, personality changes, headaches, seizures, and focal neurological changes depending on tumor location and due to treatment ³⁻⁶.
- Patients with GBM rely on a caregiver; 67% of the time the caregiver is a spouse and 73% of caregivers are female ⁷.
- Unlike other cancers, GBM caregiver burden is largely due to the psychosocial symptoms unique to brain diseases like GBM ⁸. Importantly, improved GBM survival is linked to family caregivers' mastery demonstrating the essential role of caregivers for patients with GBM ¹⁰.
- Social media platforms such as Facebook provide patients and caregivers with serious illnesses a place to share experiences and concerns and improve patient and caregiver coping ¹⁰. Social media-based support groups for GBM spouses exist, yet their role in supporting caregivers is not well understood.

Study Purpose: To identify the needs and concerns of female spouses/long-term partner caregivers of patients with GBM purposefully sampled and analyzed using a reflexive thematic analysis. from a private Facebook caregiver support group.

SETTING AND METHODS

Research Design: Qualitative secondary using reflexive thematic analysis in 2021-2022
Purpose: To give voice to the female partners/spouses who were the primary caregivers of their male patients with GBM about their unmet needs and concerns to share with the medical community (Table 1).

Data Set:

- 101 open-ended letters written by female spouse caregivers in summer 2019
- Recruited from "We are the wives of GBM and this is our story" ¹¹, a private Facebook support group (1800k members)
- Informed consent obtained (University of Montana IRB 224-19; University of North Carolina Wilmington IRB 22-0103).

Data Analysis:

Reflexive thematic analysis guided by a constructivist theoretical framework

6 Phases of Reflexive Thematic Analysis

- 1) data familiarization,
- 2) systematic data coding,
- 3) generating initial themes,
- 4) developing and reviewing themes,
- 5) refining and naming themes
- 6) report writing to provide insight to the caregiver's life-worlds^{13,14}.

- Members of the research team independently coded the data using Nvivo software.
- Consensus of coding structure and themes was determined during weekly group research meetings
- Seven main themes were identified encompassing preliminary codes from the letters.

Table 1. Demographics

Participant Demographics (n=101 letters)	Mean	Range	N (%)
Female Caregiver Age at Dx			
Widowed (age)	52.1	30-73	73 (72%)
Non-widowed (age)	51.5	38-66	14 (14%)
Age of Male pt at Dx	56.2	28-77	77 (67%)
Mean months since Dx			
Dx-death (months)	14.4	2-37	68 (67%)
Still alive (months)	18.7	2-48	22 (21%)
Surgical Resection			
Craniotomy			88 (87%)
Inoperable tumor			13 (13%)

RESULTS

Figure 1. Seven themes identified from open coding of the letters.

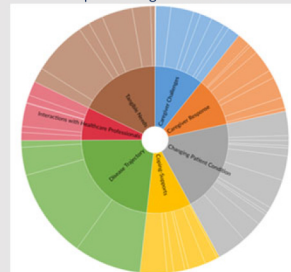


Figure 2. Caregiver needs are greatest in the living with Progression Phase

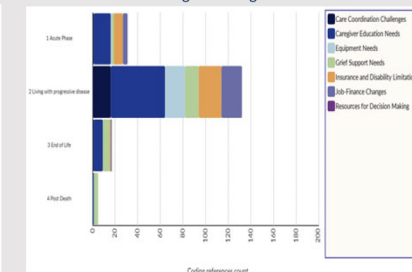


Table 2: Examples of Tangible Needs expressed by caregivers of GBM patients.

Education (n=66)	<ul style="list-style-type: none"> • We...had to make hard decisions with little to no information. We were encouraged NOT to read internet articles because everyone is different. (011) • Medical care teams need to have honest, forthright communication so we have as much information as possible for this journey. (018)
Insurance and Disability Limitations (n=47)	<ul style="list-style-type: none"> • My husband spent over 20 years in the Navy retiring as a Lieutenant Commander ...VA (Veteran's Affairs) did nothing to offer any kind of support. (004) • GBM is a diagnosis that allows faster processing of a claim under SSDI 'compassionate allowances'. The patient becomes eligible for Medicare after 2 years. Many patients do not survive to see ...these dates. (012)
Job/Finance changes (n=35)	<ul style="list-style-type: none"> • With diagnosis, I quit my job ...I was a full-time, round the clock caregiver (009) • We were left with astronomical hospital and doctor bills. In addition we had to pay the ridiculous monthly premium of COBRA insurance, not only for but for myself and our sons. I also had to quit my job to be his 24/7 caretaker. (010)
Care Coordination Challenges (n=30)	<ul style="list-style-type: none"> • I had to create an excel spreadsheet to keep track of all of his meds...there was no way [he] could keep track, he was already being affected with memory issues and personality changes...(013) • During our first meeting with the [medical] team, after his surgery, probably 20 different people came in, spoke to us, gave us a business card, and left... (041)
Grief Support Needs (n=29)	<ul style="list-style-type: none"> • watching his personality change, watching as almost daily he declined physically, mentally and emotionally, I was told I was experiencing "anticipatory grief" but not given much advice on how to handle this. (076)
Equipment needs (n=23)	<ul style="list-style-type: none"> • 120 lb woman moving 250 lb man from bed to chair to potty (043) • If patients want insurance to cover any supplies [walkers, wheelchairs, commodes, etc], an order is required and the wait begins. I've ordered many supplies on my own because we don't have the luxury of time. (083)

CONCLUSIONS

- 7 main themes: caregiver challenges, caregiver needs, changing patient condition, coping responses, GBM disease trajectory, interactions with health care providers, and tangible needs (Figure 1).
- Greatest caregiver needs are during the " living with progression phase" (Figure 2).
- Tangible needs such as more education, insurance and disability limitations, job/finance changes, care coordination challenges, grief support and equipment are areas in need of improvement (Table 2, Figure 2).
- Caregivers of GBM patients would benefit from assessment of understand of a GBM diagnosis, needs assessment, and individualized intervention¹².

REFERENCES

1. Thakkar, I.P., et al. Epidemiologic and molecular prognostic review of glioblastoma. *Cancer Epidemiol Biomarkers Prev* 23, 1985-1994 (2014).
2. Bergo, E., et al. Neurocognitive functions and health-related quality of life in glioblastoma patients: a concise review of the literature. *Eur J Cancer Care (Engl)* 28, 1-14 (2019).
3. Hill, C., et al. Primary Caregiver Factors Impacted after Glucose Surgery and Associated Brain Regions. *Behav Neurosci* 2020, 794588 (2020).
4. Collins, A., et al. The challenges and suffering of caring for people with primary malignant glioma: qualitative perspectives on improving current supportive and palliative care practices. *BMJ Support Palliat Care* 6, 68-76 (2016).
5. Kroll, B., et al. Predicting distress among people who care for patients living longer with high-grade malignant glioma. *Support Care Oncol* 24, 431-439 (2016).
6. Macgregor, R., Haines, G., Lobb, L. & Rowan, A. Caring for someone with high-grade glioma: a time of rapid change for caregivers. *Palliat Med* 24, 474-479 (2010).
7. Bock, F.M., Klein, M., Hejzelmeyer, J.C., Verdoso-de-Lencastre, I.M. & Heinemann, J.J. System management and quality of life in glioma patients. *Onk Oncol* 3, 37-47 (2014).
8. Siskind, B., et al. Screening for symptom burden and supportive needs of patients with glioblastoma and brain metastases and their caregivers in relation to their use of specialized palliative care. *Support Care Oncol* 28, 2162-2169 (2020).
9. Gage-Bourchard, E.A., LaVitaro, S., Molloy, M. & Borenstein, L.R. Cancer Communication on Social Media: Examining How Cancer Caregivers Use Facebook for Cancer-Related Communication. *Cancer Nurs* 46, 323-330 (2017).
10. (let us) "We are the wives of GBM and this is our story" Private Facebook group (last. January 17, 2015)
11. Carstairs, M., et al. Improving Caregiver Health through Systemic Assessment and Tailored Care. *World J Neuro Sci* 10, 1034-1040 (2019).
12. Braun V, Clarke V. Novel insights into patients' life-worlds: the value of qualitative research. *Lancet Psychol*. Sep 2016;8(9):750-751. doi:10.1016/S2215-0020(16)00286-2
13. Braun V&V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3:77-101.