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Caregivers of GBM Patients Express High Financial Burden

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Cutaia, Madison Rose, "Caregivers of GBM Patients Express High Financial Burden" (2021). *University of Montana Conference on Undergraduate Research (UMCUR)*. 11.

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Caregivers of GBM Patients Express High Financial Burden

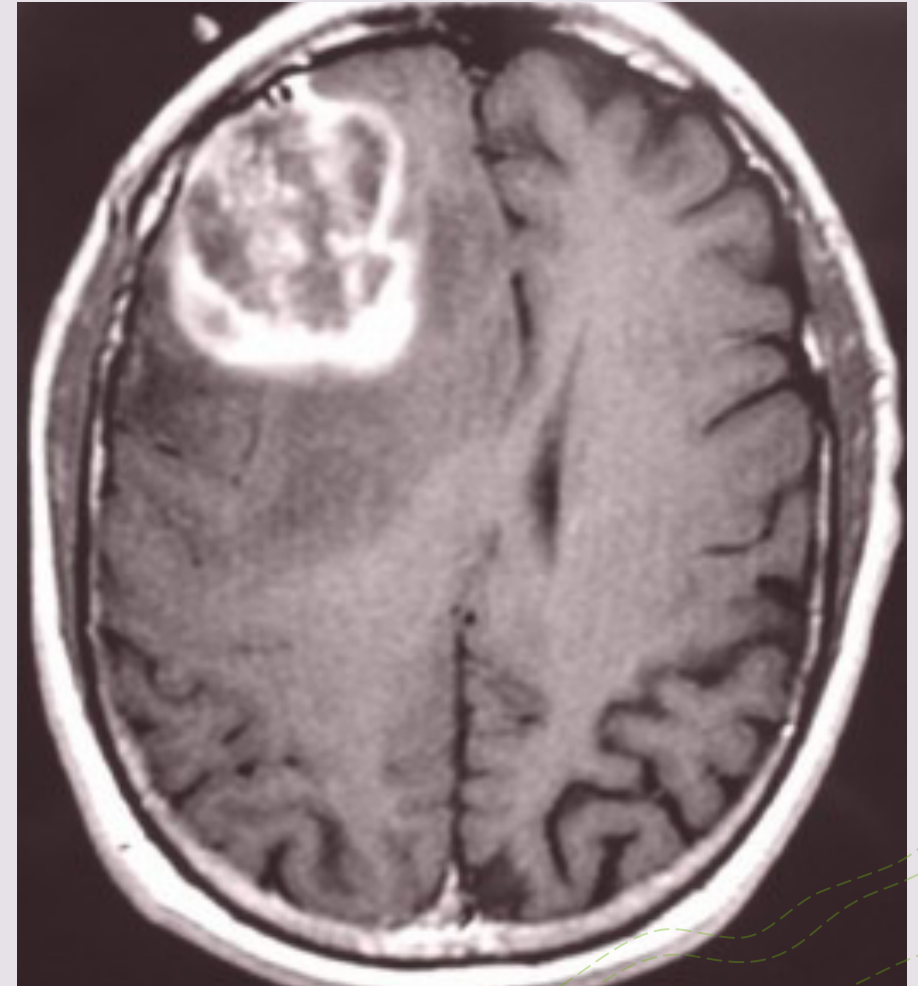
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Glioblastoma Multiforme

- Glioblastoma multiforme is a rare type of brain cancer that is very aggressive
- The affected populations are males around the ages of 40 to 60
- Survival rate is around 14-15 months
- Symptoms that may arise are headaches, seizures, cognitive deficits, sensory loss etc.
- Chemotherapy, surgeries, radiation, drug treatments are options of ways to reduce the tumor or relieve discomfort for patients



<https://www.aans.org/en/Patients/Neurosurgical-Conditions-and-Treatments/Glioblastoma-Multiforme>

Financial Burden Background

- Treatments, surgeries, chemotherapy and radiation are very high in expenses
- Drug treatment can range \$1,600 to \$4,600 per month
- Unemployment can occur to those before first initial diagnosis
- Affects patients and caregiver's insurance plans or benefits offered through job companies
- Caregivers feel a huge burden of finances and are provided with little to no help

“I was sent a bill for over \$3900 per month and it had to be paid before chemo could begin, we don't have that kind of money. I call our insurance and find that a generic is available and through a special prescription plan we can get the chemo for \$20 per bottle, OMG compared to \$3900. This is really sad in my opinion.” (Participant ID: 008)



<https://www.wallscareercoach.com/blog/2018/2/22/3-ways-to-help-deal-with-job-loss>

Insurance Policies



<https://mcdivittlaw.com/blog/insurance-policies-conflict-over-stacking-policy>

- Social Security Disability Insurance
 - Eligibility requires at least 12 months of a medical ailment to last
- COBRA
 - Federal law that offers for eligible workers to have the option to abide employer-based group health coverage when employment is terminated
- Medicaid
 - Medicaid is offered to those of low-income Americans, unable to continue working due to a disability or medical condition
- Medicare
 - Medicare is offered to those that apply over the age of 65, eligibility is considered for those with certain disabilities

Methods

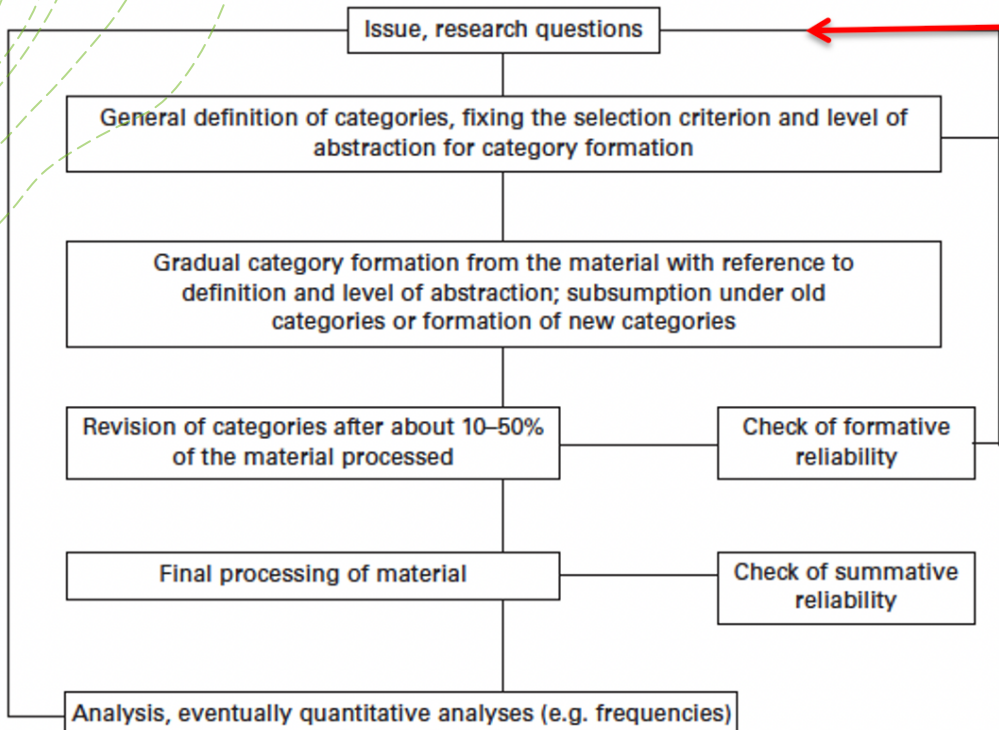
- A 102 letters of female caregivers of male GBM patients were collected for this study
- Specific words were chosen and identify in each letter relating to financial burden or resources that benefit this process
- Gather information for future recommendations about finances
- This study was approved by the Institutional Review Board (224-19) of the University of Montana
- The participants gave informed consent for further research to be conducted

We are compiling letters to give to the medical community expressing the challenges and needs for Caregivers dealing with GBM.

The letters can include recommendations should consider the criteria below:

1. The letter should not exceed 500 words.
2. You could share the challenges you faced
3. You can include what you wished you knew going into the care for a person with this disease
4. Identify resources you found helpful during your experience
5. What you wished you knew before that you learned after; add anything else you feel may be relevant.

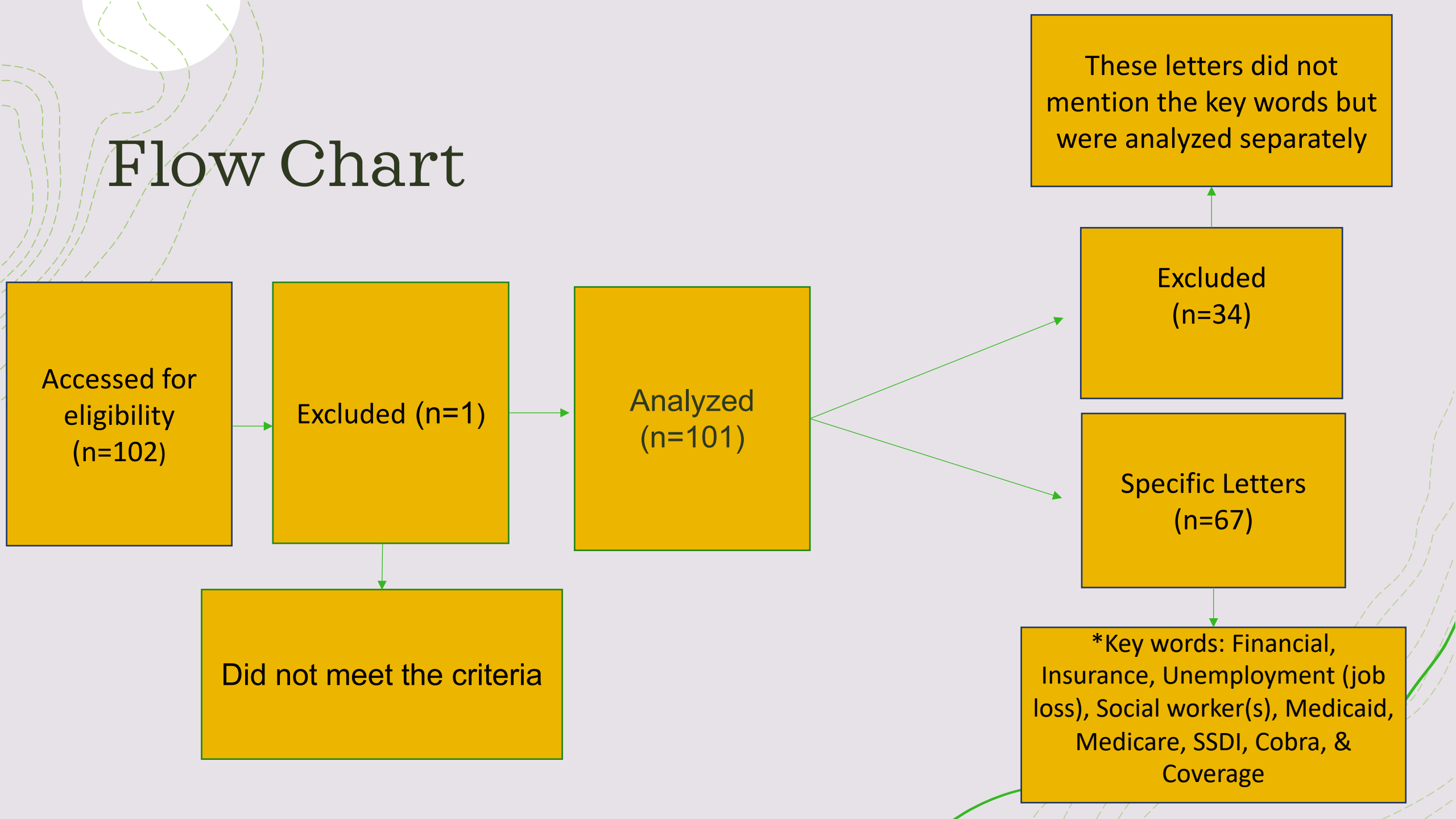
Qualitative Analysis



- The first steps to conducting this specific research
- Using a mixed method approach to analyze the data set
- The data was analyzed twice and eventually focused on those that mentioned the key words
- Key words selected that related to financial burden

Mayring P (2004) Qualitative content analysis. In: Flick U, von Kardoff E, Steinke I (eds) A companion to qualitative research. Sage, London, pp 266–269

Flow Chart



Demographics

Characteristic	Caregivers that mention Financial Burden (n=67)	
	Patient	Caregiver
Total Sample (age range, years)	32-72 (n=51)	30-66 (n=30)
Median Age	57	52
Age > 50	78.4% (n=40)	66.7% (n=20)
Age < 50	21% (n=11)	33.3% (n=10)

- Caregivers specified the financial struggles they endured on this journey
- Caregivers described timelines of symptoms and medical visits
- “A GBM diagnosis can lead to loss of income. Who is there to inform the caregiver about Social Security Disability Insurance? Where can she easily get complete and accurate information? Who can guide her through the application process?” (Participant ID: 012)

Demographics continued

	Caregiver that did not mention Financial Burden (n= 34)	
Characteristic	Patient	Caregiver
Total Sample (age range, years)	28-77 (n=20)	31-73 (n=11)
Median Age	60	60
Age > 50	85% (n=17)	72.7 % (n=8)
Age < 50	15% (n=3)	27.2% (n=3)

- The letters mentioned more emotional burden aspect
- Described various timelines of what exact procedures were done to their loved one
- “It was so very, very, hard. It was exhausting. It was soul depleting to give and get and give some more when your own brain and body were melting from overuse, lack of sleep and the inability to make the outcome different.” (Participants ID: 043)

Frequencies

Key Words	Number of Word Used in the Letters
Financial/ Finances	25
Unemployment/ Job loss	29
Insurance	44
Social Worker	19

Frequencies continued

Key Words	Number of Word Used in the Letters
Medicare	11
Social Security Disability Insurance	16
COBRA	5
Medicaid	5
Coverage	6

Reflection

- Why were these key words chosen?
 - Narrow the focus of financial burden aspect of female caregivers
 - Offer more information, support, clarity to this topic for current or future caregivers of GBM patients
 - The frequencies represent a pattern that occurred throughout different caregivers in this study that also struggled with similar aspects
 - By collecting this data can influence more information and resources to help caregivers that face financial burden during this process



<https://braintumor.org/take-action/act-on-gbm-day/>

Acknowledgments

- Laurie Minns Ph.D
 - Emily Burke
 - Karlee Trebesch
 - Dishanna Miller
 - Mark Hirschfelder
 - Parminder Singh (Sunny) Mathaun
 - Molly Massman
- Special thanks to all the participants in this study

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