**Development and implementation of a novel survey to evaluate the burden and quality of life of caregivers of patients with glioblastoma**

**Additional file 1. Final Caregiver Burden Survey**

GBM CAREGIVER BURDEN SURVEY

Site name: Huntsman Cancer Institute

Study ID number of caregiver (to be entered by study coordinator)

*Caregiver screening questions:*

Have you completed this survey previously?

* Yes
* No

In your opinion, does your loved one have cognitive dysfunction? Examples include trouble remembering things, difficulty communicating, difficulty with word recognition, lack of motivation, poor judgment, etc.

* Yes
* No

**CHARACTERIZING THE NON-MEDICAL RESOURCE UTILIZATION OF CAREGIVERS OF INDIVIDUALS WITH GLIOBLASTOMA MULTIFORME**  
    
The purpose of this research study is to understand how caregivers are affected by their experience of providing care to an adult individual living with glioblastoma multiforme (GBM). This study seeks to examine the caregivers’ quality of life and burden of care. This information can provide valuable insight into understanding the impact of caregiving specifically in GBM, which has not been studied to date. I would like to ask you to complete the following questionnaire. You will receive a $10 gift card upon completion of the survey.  
   
The questionnaire will be anonymous. We will not be able to link it to your name or any other personal information once it is received by our researchers. Your name and address used for contact will be stored safely at the office of the Pharmacotherapy Outcomes Research Center (PORC) of the University of Utah on password protected computers behind a firewall. After sending out the questionnaires, personal information will be permanently deleted. The questionnaire answers will only be viewed by researchers involved in this project and NOT distributed to a third party.  
    
However, if you disclose information that gives study staff a reason to believe that a disabled or elderly adult has been subjected to abuse or neglect, study staff will report that information to Adult Protective Services, or the nearest law enforcement agency to the extent required by law.  
    
There are some cases in which a researcher is obligated to report issues, such as serious threats to public health or safety. For example, if you indicate that you, your loved one with GBM, or someone else is at imminent risk of harm (for example suicide or serious threats toward the wellbeing of others) we will need to contact the appropriate authorities in order to protect you, your loved one with GBM, or the public. Please let the researchers know if you would like information about resources for help.  
    
It should take about 20-30 minutes to complete the questionnaire. Participation in this study is voluntary. You can choose not to take part. You can choose not to finish the questionnaire or omit any question you prefer not to answer without penalty or loss of benefits. Your decision to participate or not participate in the study does not affect the care that you or your family members receive at the University of Utah Health Systems.  
    
In addition, we will create a cohort of patients diagnosed with GBM. The clinical and treatment characteristics of these patients will also be obtained without identifying information and in aggregated form.   
    
If you have any questions complaints or if you feel you have been harmed by this research, please contact Dr. Diana Brixner at 801-581-3182. Dr. Brixner is the Principal Investigator of this study, and affiliated with PORC. Contact the University of Utah Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with any study investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at [irb@hsc.utah.edu](mailto:irb@hsc.utah.edu).   
    
**By returning this questionnaire, you are giving your consent to participate**. I appreciate your participation in this research and the time and effort you put into answering the questionnaire.  
    
Sincerely,  
    
    
 Dr. Diana Brixner

**Section 1**

**Demographics of caregiver**

Q1.1 How old are you now?  (years)

Q1.2 What year was your loved one diagnosed with GBM?  (years)

Q1.3 Gender

* Male
* Female
* Prefer to self-describe
* Prefer not to say

Q1.4 Ethnicity

* White/Caucasian
* Hispanic or Latino
* Black or African American
* Asian / Pacific Islander
* Native American or American Indian
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q1.5 What is the highest level of education you have completed?

* High school
* College or University
* Graduate School
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q1.6 What is your total household income per year?

* Less than $30,000
* $30,000 to $69,999
* $70,000 to $99,999
* More than $100,000
* I do not want to answer

Q1.7 Do you have other people help you provide care for your loved one with GBM? Mark all that apply.

* Yes, paid help
* Yes, family and/or friends
* Yes, neighbors
* Yes, work colleagues
* Yes, community service
* No

Q1.8 At the time your loved one was diagnosed, were you working?

* Yes
* No
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Do not know or do not recall

Q1.9 If you were working, were you working full-time or part-time?

* Full-time
* Part-time

Q1.10 If you were not working, what was the reason?

* Because of disability
* Because of caregiving
* Because retired

Q1.11 Are you employed now?

* Yes
* No
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Do not know or do not recall

Q1.12 Is this a full-time job or part-time job

* Full-time
* Part-time

Q1.13 Why are you not employed?

* Disability
* Caregiving for my loved one with GBM
* Retired

Q1.14 Are you also a primary caregiver for others?

* Yes
* No

Q1.15 If you currently work, has your work changed since becoming the primary caregiver?  Mark all that apply.

* I work less
* I work more
* I do a different kind of work
* No changes
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q1.16 If your work status has changed with respect to work hours or job activities, what is the reason for this change? Mark all that apply.

* I resigned from my previous job due to the demands of being a caregiver
* I was let go from my previous job due to absenteeism or poor performance
* I needed a more flexible job so that I could be a caregiver
* I maintain employment as a break from caregiving
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Section 2**

**Characteristics of Loved One with GBM**

Q2.1 What is their current age? (years)

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q2.2 Sex

* Male
* Female
* Prefer to self-describe \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Prefer not to say

Q2.3 Ethnicity

* White/ Caucasian
* Hispanic or Latino
* Black or African American
* Asian / Pacific Islander
* Native American or American Indian
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q2.4 What is the highest level of education your loved one has completed?

* High school
* College or University
* Graduate School
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Do not know or do not recall

Q2.5 Were they working at time of diagnosis?

* Yes
* No
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Do not know or do not recall

Q2.6 Was this a full-time job or part-time job?

* Full-time
* Part-time

Q2.7 Why were they not employed?

* On disability
* Have supplemental income
* Retired

Q2.8 Do they work now?

* Yes
* No
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Do not know or do not recall

Q2.9 Is this a full-time job or a part-time job?

* Full-time
* Part-time

Q2.10 Why are they not employed?

* On disability
* Have supplemental income
* Retired

Q2.11 What was their health insurance at time of diagnosis? Mark all that apply.

* Government plan (Medicare, Medicaid, Military)
* Supplemental insurance to Government plan
* Private plan (Employment insurance, or direct-purchase)
* Social Security Disability
* No health insurance
* Do not know or do not recall

Q2.12 Since diagnosis with GBM, has your loved one switched health insurance?

* Yes
* No
* Do not know or do not recall

Q2.13 If your loved one switched health insurance, why did he/she do this? Mark all that apply.

* Change in employment (new job)
* Change in employment status (change in hours)
* New insurance provides better coverage for GBM
* New insurance is less expensive
* Loss of job, i.e. unemployment
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Do not know or do not recall

Q2.14 What is their health insurance now? Mark all that apply.

* Government plan (Medicare, Medicaid, Military)
* Supplemental insurance to Government plan
* Private plan (Employment insurance, or direct-purchase)
* Social Security Disability
* No health insurance
* Do not know or do not recall

Q2.15 How are you related to your loved one with GBM?

* Spouse/partner
* Sibling
* Child
* Parent
* Grandparent
* Friend
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q2.16 How long have you been the primary caregiver?

* Less than 3 months
* 3 to 6 months
* 7 to 12 months
* 1 year to 23 months
* 2 years to 5 years
* More than 5 years

Q2.17 What year was your loved one diagnosed with GBM?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q2.18 What is their current treatment status?

* Receiving treatment for initial diagnosis
* Receiving treatment for GBM that has come back
* Not currently receiving treatment. Reason for not currently receiving treatment \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Hospice or symptom management
* Do not know or do not recall

Q2.19 After **initial diagnosis**, what medicines(s) did they receive? Mark all that apply.

* Surgery
* Radiation therapy
* Chemo therapy
* Clinical trial enrollment for new treatments
* Medical devices
* Supportive therapy
* Did not receive treatment for initial diagnosis
* Do not know or do not recall
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q2.20 After initial diagnosis, what type of surgery did they receive?

* Partial resection
* Total resection
* Do not know or do not recall

Q2.21 After initial diagnosis, what type of chemotherapy did they receive?

* Temozolomide (Temodar, TMZ)
* Lomustine (CCNU)
* Bevacizumab (Avastin)
* Other chemotherapy or targeted therapy \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Do not know or do not recall

Q2.22 Please indicate name of investigational treatment in the clinical in known. If you don’t know the name of the investigational treatment, write ‘Do not know’

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q2.23 After initial diagnosis, what type of medical devices did they receive?

* Optune therapy
* Gliadel (carmustine implanted wafer)
* Do not know or do not recall

Q2.24 After initial diagnosis, what type of supportive therapy did they receive?

* Steroids
* Anti-seizure medications
* Antidepressant medications
* Anti-anxiety medications
* Insomnia medications
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Do not know or do not recall

Q2.25 When did they receive the most recent/last treatment for initial treatment? (if exact date unknown, put mm/01/yyyy)

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q2.26 Has your loved one had a recurrence of GBM, i.e. GBM that has come back after initial diagnosis?

* Yes
* No
* Do not know or do not recall

Q2.27 What type of recurrence did your loved one had?

* Local recurrence: new growth at initial tumor site
* New lesion(s): new growth at site other than initial site
* Do not know or do not recall

Q2.28 For **recurrence**, what treatment(s) did he/she receive? Mark all that apply.

* Surgery
* Radiation therapy
* Chemo therapy
* Clinical trial enrollment for new treatments
* Medical devices
* Supportive therapy
* Did not receive treatment for initial diagnosis
* Do not know or do not recall
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q2.29 For recurrence, what type of surgery did they receive?

* Partial resection
* Total resection
* Do not know or do not recall

Q2.30 For recurrence, what type of chemo therapy did they receive?

* Temozolomide (Temodar, TMZ)
* Lomustine (CCNU)
* Bevacizumab (Avastin)
* Other chemotherapy or targeted therapy \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Do not know or do not recall

Q2.31 Please indicate name of investigational treatment in the clinical in known. If you don’t know the name of the investigational treatment, write ‘Do not know’

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q2.32 For recurrence, what type of medical devices did they receive?

* Optune therapy
* Gliadel (carmustine implanted wafer)
* Do not know or do not recall

Q2.33 For recurrence, what type of supportive therapy did they receive?

* Steroids
* Anti-seizure medications
* Antidepressant medications
* Anti-anxiety medications
* Insomnia medications
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Do not know or do not recall

**Section 3**

**Cognitive State of Loved One and Associated Burden**

***The following questions ask about cognitive symptoms that your loved one with GBM has had IN THE LAST 14 DAYS and how much these symptoms impact your day-to-day life.***

Q3.1 Did your loved one have difficulty with any of the following symptoms in the last 14 days?

|  |  |  |  |
| --- | --- | --- | --- |
|  | Yes (1) | No (2) | Do not know or do not recall (3) |
| Memory problems (1) |  |  |  |
| Language problems (2) |  |  |  |
| Confusion (3) |  |  |  |
| Completing familiar tasks (4) |  |  |  |
| Completing mental tasks (5) |  |  |  |
| Changes in personality or mood (6) |  |  |  |
| Poor judgment (7) |  |  |  |
| Body function or motor coordination (8) |  |  |  |

Q3.2 Memory problems.  How much does your loved one’s memory problems interfere with your day-to-day life as a caregiver?  Examples of how problems interfere with your day-to-day life include affecting your ability to concentrate, complete tasks at home or work, attend to other things, complete daily chores, etc.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Does not apply (1) | Not at all (2) | A little bit (3) | Somewhat (4) | Quite a bit (5) | Very much (6) |
| Trouble remembering recent events or things they heard, read, or saw recently (1) |  |  |  |  |  |  |
| Forgets names of friends, everyday objects, important dates or events (2) |  |  |  |  |  |  |
| Asks for the same information over and over (3) |  |  |  |  |  |  |
| Misplaces things or leaves things in unusual places (4) |  |  |  |  |  |  |
| Unable to retrace steps (5) |  |  |  |  |  |  |

Q3.3 Language problems.  How much does your loved one’s language problems interfere with your day-to-day life as a caregiver? Examples of how problems interfere with your day-to-day life include affecting your ability to concentrate, complete tasks at home or work, attend to other things, complete daily chores, etc.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Does not apply (1) | Not at all (2) | A little bit (3) | Somewhat (4) | Quite a bit (5) | Very much (6) |
| Unable to understand step-by-step instructions or follow logic (1) |  |  |  |  |  |  |
| Difficulty forming thoughts into words (2) |  |  |  |  |  |  |
| Calls things by wrong name or substitutes unusual words, making their speech or writing hard to understand (3) |  |  |  |  |  |  |
| Repeats themselves (4) |  |  |  |  |  |  |
| Trouble following or joining a conversation (5) |  |  |  |  |  |  |

Q3.4 Confusion.  How much does your loved one’s state of confusion interfere with your day-to-day life as a caregiver? Examples of how problems interfere with your day-to-day life include affecting your ability to concentrate, complete tasks at home or work, attend to other things, complete daily chores, etc.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Does not apply (1) | Not at all (2) | A little bit (3) | Somewhat (4) | Quite a bit (5) | Very much (6) |
| Disoriented to time, i.e. forgets the current time, forgets what comes next in the day (1) |  |  |  |  |  |  |
| Disoriented to place, i.e. gets lost in a familiar environment, not sure how they got there (2) |  |  |  |  |  |  |
| Wanders or gets lost (3) |  |  |  |  |  |  |
| Loses sense of direction, i.e. forgets regularly used directions, does not recognize familiar landmarks (4) |  |  |  |  |  |  |
| Difficulty adapting to change (5) |  |  |  |  |  |  |

Q3.5 Completing familiar tasks. How much does your loved one’s difficulty with completing familiar tasks interfere with your day-to-day life as a caregiver? Examples of how problems interfere with your day-to-day life include affecting your ability to concentrate, complete tasks at home or work, attend to other things, complete daily chores, etc.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Does not apply (1) | Not at all (2) | A little bit (3) | Somewhat (4) | Quite a bit (5) | Very much (6) |
| Self-care activities, i.e. eating, brushing teeth, bathing, combing hair, wearing same clothes over and over (1) |  |  |  |  |  |  |
| Making a meal (2) |  |  |  |  |  |  |
| Household chores, i.e. vacuuming, folding clothes, making bed, putting away dishes (3) |  |  |  |  |  |  |
| Driving (4) |  |  |  |  |  |  |
| Perform activities in proper order, i.e. putting on clothes in right order, following recipe instructions (5) |  |  |  |  |  |  |

Q3.6 Completing mental tasks.  How much does your loved one’s difficulty with completing mental tasks interfere with your day-to-day life as a caregiver? Examples of how problems interfere with your day-to-day life include affecting your ability to concentrate, complete tasks at home or work, attend to other things, complete daily chores, etc.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Does not apply (1) | Not at all (2) | A little bit (3) | Somewhat (4) | Quite a bit (5) | Very much (6) |
| Plan or organize, i.e. making a grocery list (1) |  |  |  |  |  |  |
| Make decisions (2) |  |  |  |  |  |  |
| Pay bills or manage budget (3) |  |  |  |  |  |  |
| Remember house rules (4) |  |  |  |  |  |  |
| Poor concentration, i.e. becomes easily distracted (5) |  |  |  |  |  |  |

Q3.7 Personality or behavior changes.  How much does your loved one’s changes in personality or behavior interfere with your day-to-day life as a caregiver? Examples of how problems interfere with your day-to-day life include affecting your ability to concentrate, complete tasks at home or work, attend to other things, complete daily chores, etc.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Does not apply (1) | Not at all (2) | A little bit (3) | Somewhat (4) | Quite a bit (5) | Very much (6) |
| Appears withdrawn, depressed, or display decreased energy and motivation, i.e. behaves passively, stares into the distance, removes themselves from social activities, hobbies, favorite sports, sleeps more than usual (1) |  |  |  |  |  |  |
| Anxiety, aggression, agitation, irritability, feels upset (2) |  |  |  |  |  |  |
| Delusional behavior or paranoia, i.e. accuses others of stealing (3) |  |  |  |  |  |  |
| Obsessive behavior (4) |  |  |  |  |  |  |
| Mood swings or unpredictable behavior (5) |  |  |  |  |  |  |

Q3.8 Poor judgment. How much does your loved one’s poor judgment interfere with your day-to-day life as a caregiver? Examples of how problems interfere with your day-to-day life include affecting your ability to concentrate, complete tasks at home or work, attend to other things, complete daily chores, etc.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Does not apply (1) | Not at all (2) | A little bit (3) | Somewhat (4) | Quite a bit (5) | Very much (6) |
| Spends money foolishly, i.e. gives money to strangers, telemarketers (1) |  |  |  |  |  |  |
| Dresses inappropriately, i.e. does not dress according to outside weather condition (2) |  |  |  |  |  |  |
| Does not recognize danger, i.e. crosses busy street, leaves stove on, leaves house in middle of night (3) |  |  |  |  |  |  |
| Visual problems, i.e. judging distance, determining color (4) |  |  |  |  |  |  |
| Disregards proper hygiene and grooming, i.e. does not understand need for this (5) |  |  |  |  |  |  |

Q3.9 Body function or motor coordination. How much does your loved one’s difficulty with body function or motor coordination interfere with your day-to-day life as a caregiver? Examples of how problems interfere with your day-to-day life include affecting your ability to concentrate, complete tasks at home or work, attend to other things, complete daily chores, etc.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Does not apply (1) | Not at all (2) | A little bit (3) | Somewhat (4) | Quite a bit (5) | Very much (6) |
| Large motor skills, i.e. feels unsteady on feet, poor balance, walking (1) |  |  |  |  |  |  |
| Fine motor skills, i.e. buttoning clothing, tying shoe laces, unlocking and opening a door (2) |  |  |  |  |  |  |
| General muscle weakness or frailty, i.e. trembling hands (3) |  |  |  |  |  |  |
| Uncontrolled movements, i.e. loss of bowel and bladder control, loss of sensation (4) |  |  |  |  |  |  |
| Difficulty swallowing (5) |  |  |  |  |  |  |

Q3.10 Please rank the cognitive symptoms (from 1 to 8) in order from those that affect you most to those that affect you least.  One (1) is the symptom that affects you the most and eight (8) is the symptom that affects you least.

\_\_\_\_\_\_ Memory problems

\_\_\_\_\_\_ Language problems

\_\_\_\_\_\_ Confusion

\_\_\_\_\_\_ Completing familiar tasks

\_\_\_\_\_\_ Completing mental tasks

\_\_\_\_\_\_ Changes in personality or mood

\_\_\_\_\_\_ Poor judgment

\_\_\_\_\_\_ Body function or motor coordination

Q3.11 For the cognitive symptom that you ranked as number 1 in the question above, indicate how much this symptom affects your emotional health, social health, general health, etc. Zero means the cognitive symptom does not affect health at all. Ten means the cognitive symptom extremely affects health.

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | 0 | 1 | 2 | 3 | 4 | 5 | 5 | 6 | 7 | 8 | 9 | 10 |

|  |  |
| --- | --- |
| Emotional health (1) |  |
| Social health (2) |  |
| General health (3) |  |
| Ability to gather information needs about GBM (4) |  |
| Ability to perform caregiving tasks for your loved one (5) |  |
| Ability to perform caregiving tasks for others (6) |  |
| Ability to work at your job (7) |  |
| Confidence in your family’s finances (8) |  |
| Overall quality of life (9) |  |

Q3.12 In general, how much does your loved one’s overall cognitive dysfunction affect you? 0 (zero) means the change(s) in your loved one’s mental state or how they think do not affect you at all and 10 (ten) means the change(s) affect you significantly.

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

|  |  |
| --- | --- |
| Emotional health (1) |  |
| Social health (2) |  |
| General health (3) |  |
| Ability to gather information needs about GBM (4) |  |
| Ability to perform caregiving tasks for your loved one (5) |  |
| Ability to perform caregiving tasks for others (6) |  |
| Ability to work at your job (7) |  |
| Confidence in your family’s finances (8) |  |
| Overall quality of life (9) |  |

**Section 4**

**Caregiver burden**

***Emotional Burden***

Q4.1 Do you have negative feelings (like anger and resentment) toward your loved one with GBM?

* Not at all
* A little bit
* Somewhat
* Quite a bit
* Very much

Q4.2 Do you have positive feelings (like appreciation and love) toward your loved one with GBM?

* Not at all
* A little bit
* Somewhat
* Quite a bit
* Very much

Q4.3 How confident are you that your loved one would take care of you if your roles were reversed?

* Not at all
* A little bit
* Somewhat
* Quite a bit
* Very much

Q4.4 Do you feel criticized by others for the time you spend with your loved one?

* Not at all
* A little bit
* Somewhat
* Quite a bit
* Very much

Q4.5 Do you feel you are doing the best job you can do being a caregiver to your loved one with GBM?

* Not at all
* A little bit
* Somewhat
* Quite a bit
* Very much

Q4.6 In the past 14 days, how has the emotional burden of caring for your loved one changed?

* Decreased a great deal
* Decreased somewhat
* Holding steady
* Increased somewhat
* Increased a great deal
* Do not know or do not recall

Q4.7 Do you feel embarrassed about your loved one’s behavior?

* Never
* Rarely
* Sometimes
* Quite frequently
* Nearly always

Q4.8 Do you get upset that your loved one has changed so much?

* No
* Yes, sometimes
* Yes, on a regular basis

Q4.9 Has your relationship with your loved one changed?

* Not at all
* A little bit
* Somewhat
* Quite a bit
* Very much

Q4.10 Do you wish that you and your loved one had a better relationship at the present/current time?

* Not at all
* A little bit
* Somewhat
* Quite a bit
* Very much

***Your Responsibilities***

Q4.11 **Before diagnosis with GBM**, what caregiving activities did you do for your loved one? Mark all that apply.

* Mobility and transportation
* Meal preparation
* Bathroom needs
* Medication organization/administration
* Other household tasks, for example cleaning, grocery shopping
* No caregiving activities
* Other activity \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q4.12 **After diagnosis with GBM**, what caregiving activities have you been doing for your loved one? Mark all that apply.

* Mobility and transportation
* Meal preparation
* Bathroom needs
* Medication organization/administration
* Other household tasks, for example cleaning, grocery shopping
* No caregiving activities
* Other activity \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q4.13 On average, how many hours each week do you spend directly providing care as a result of the GBM diagnosis? Examples of include preparing meals, grooming, lifting, administering medication.

* 1 to 3 hours
* 4 to 6 hours
* 7 to 9 hours
* 10 to 12 hours
* More than 12 hours
* Do not know or do not recall

Q4.14 Overall, how has the time you spend caring for your loved one changed since their initial diagnosis?

* Greatly increased
* Somewhat increased
* About the same
* Somewhat decreased
* Greatly decreased
* Do not know or do not recall

Q4.15 Are you now responsible for tasks that your loved one used to do, such as paying bills, home maintenance?

* Not at all
* A little bit
* Somewhat
* Quite a bit
* Very much

Q4.16 In the past 14 days, the burden of your caregiving tasks for your loved one with GBM has

* Greatly increased
* Somewhat increased
* About the same
* Somewhat decreased
* Greatly decreased
* Do not know or do not recall

Q4.17 Does the time you devote to your caregiving responsibilities negatively impact your relationships with others around you?

* Not at all
* A little bit
* Somewhat
* Quite a bit
* Very much

Q4.18 I still get to do things that I enjoy.

* Strongly disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

Q4.19 I still see other family and friends socially.

* Strongly disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

***Your Health Needs***

Q4.20 Since my loved one’s diagnosis of GBM, I am still able to maintain a healthy lifestyle as much as I used to.

* Strongly disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

Q4.21 I have not been able to keep up with my own medical care. For example, I have missed or had to reschedule my medical checkups and appointments.

* Strongly disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

Q4.22 My health has worsened in the past 30 days.

* Strongly disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

Q4.23  It is much more difficult to take care of myself.

* Strongly disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

***Work and Finances***

Q4.24 I am preoccupied at work with my caregiving responsibilities.

* Strongly disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree
* Does not apply to me, because I am currently not working

Q4.25 My job performance has suffered because of my caregiving responsibilities.

* Strongly disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree
* Does not apply to me, because I am currently not working

Q4.26 I worry that my caregiving responsibilities will impact my job security.

* Strongly disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree
* Does not apply to me, because I am currently not working

Q4.27 I feel financially stable, despite the demands of being a caregiver.

* Strongly disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

**Survey Satisfaction Questions**

Q1 I think that not enough is being done to understand what caregivers with GBM are going through

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly Agree

Q2 The survey asked questions that were relevant to how I am feeling as a caregiver

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly Agree

Q3 The questions were clear and easy to understand

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly Agree

Q4 The questionnaire was appropriate in length in order to ask about the different parts of my life that are affected by GBM

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly Agree

Q5 I was overall satisfied with the questionnaire about how GBM has changed my life

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly Agree

Q6 Please provide any additional comments and suggestions in the space below:

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