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

**Additional file 5.** Increase in CD symptoms associated with more caregivers having more responsibilities

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| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Survey question | Survey question answer options | All (*n* = 185) | Number of CD symptoms perceived by caregiver\* | | | *p* value† | | |
| Low: 0–3 (*n* = 62) | Intermediate: 4–6 (*n* = 80) | High: 7–9 (*n* = 43) | Low vs. Intermediate | Intermediate vs. High | Low vs. High |
| *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 | 26 (14) | 16 (27) | 9 (11) | 1 (2) | 0.11 | 0.09 | **<0.01** |
| 4 to 6 hours | 26 (14) | 12 (20) | 12 (15) | 2 (5) |
| 7 to 9 hours | 13 (7) | 4 (7) | 6 (8) | 3 (7) |
| 10 to 12 hours | 21 (12) | 8 (13) | 8 (10) | 5 (12) |
| More than 12 hours | 88 (49) | 18 (30) | 40 (51) | 30 (73) |
| Do not know or do not recall | 6 (3) | 2 (3) | 4 (5) | 0 (0) |
| *Overall, how has the time you spend caring for your loved one changed since their initial diagnosis?* | Greatly increased | 91 (50) | 16 (26) | 43 (54) | 32 (78) | **0.02** | 0.10 | **<0.01** |
| Somewhat increased | 45 (25) | 21 (34) | 20 (25) | 4 (10) |
| About the same | 23 (13) | 13 (21) | 6 (8) | 4 (10) |
| Somewhat decreased | 11 (6) | 5 (8) | 5 (6) | 1 (2) |
| Greatly decreased | 9 (5) | 5 (8) | 4 (5) | 0 (0) |
| Do not know or do not recall | 2 (1) | 1 (2) | 1 (1) | 0 (0) |
| *Are you now responsible for tasks that your loved one used to do, such as paying bills, home maintenance?* | Not at all | 9 (5) | 6 (10) | 2 (3) | 1 (2) | **<0.01** | 0.26 | **<0.01** |
| A little bit | 33 (18) | 19 (31) | 11 (14) | 3 (7) |
| Somewhat | 34 (19) | 15 (25) | 15 (19) | 4 (10) |
| Quite a bit | 30 (17) | 11 (18) | 14 (18) | 5 (12) |
| Very much | 75 (41) | 10 (16) | 37 (47) | 28 (68) |
| *In the past 14 days, the burden of your caregiving tasks for your loved one with GBM has* | Greatly increased | 24 (13) | 0 (0) | 12 (15) | 12 (29) | **<0.01** | 0.26 | **<0.01** |
| Somewhat increased | 35 (19) | 8 (13) | 16 (21) | 11 (27) |
| About the same | 109 (61) | 50 (82) | 43 (55) | 16 (39) |
| Somewhat decreased | 11 (6) | 3 (5) | 6 (8) | 2 (5) |
| Greatly decreased | 1 (1) | 0 (0) | 1 (1) | 0 (0) |
| *Does the time you devote to your caregiving responsibilities negatively impact your relationships with others around you?* | Not at all | 70 (39) | 38 (2) | 26 (33) | 6 (15) | **<0.01** | 0.21 | **<0.01** |
| A little bit | 33 (18) | 12 (20) | 14 (18) | 7 (17) |
| Somewhat | 54 (30) | 11 (18) | 26 (33) | 17 (41) |
| Quite a bit | 14 (8) | 0 (0) | 7 (9) | 7 (17) |
| Very much | 9 (5) | 0 (0) | 5 (6) | 4 (10) |
| *I still get to do things that I enjoy* | Strongly disagree | 19 (11) | 3 (5) | 9 (12) | 7 (17) | **<0.01** | 0.31 | **<0.01** |
| Disagree | 44 (24) | 6 (10) | 26 (33) | 12 (29) |
| Neither agree nor disagree | 39 (22) | 15 (25) | 15 (19) | 9 (22) |
| Agree | 62 (34) | 27 (44) | 26 (33) | 9 (22) |
| Strongly agree | 16 (9) | 10 (16) | 2 (3) | 4 (10) |
| *I still see other family and friends socially.* | Strongly disagree | 15 (8) | 2 (3) | 5 (6) | 8 (20) | **<0.01** | 0.16 | **<0.01** |
| Disagree | 31 (17) | 4 (7) | 16 (21) | 11 (27) |
| Neither agree nor disagree | 31 (17) | 7 (11) | 18 (23) | 6 (15) |
| Agree | 80 (44) | 33 (54) | 34 (44) | 13 (32) |
| Strongly agree | 23 (13) | 15 (25) | 5 (6) | 3 (7) |

*CD* cognitive dysfunction, *GBM* glioblastoma.

\*Caregivers were asked to identify CD symptoms in their loved one in the past 14 days, including memory problems, language problems, confusion, problems completing familiar tasks, changes in mood, judgment problems, and problems with motor coordination.

†Fisher’s exact test.