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

**Additional file 4.** Increase in CD symptoms associated with more caregivers experiencing greater emotional health burden

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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 |
| *Do you have negative feelings (like anger and resentment) toward your loved one with GBM?* | Not at all | 113 (62) | 45 (74) | 45 (56) | 23 (55) | 0.16 | **<0.01** | **0.01** |
| A little bit | 39 (21) | 10 (16) | 23 (29) | 6 (14) |
| Somewhat | 22 (12) | 6 (10) | 11 (14) | 5 (12) |
| Quite a bit | 7 (4) | 0 (0) | 1 (1) | 6 (14) |
| Very much | 2 (1) | 0 (0) | 0 (0) | 2 (5) |
| *Do you have positive feelings (like appreciation and love) toward your loved one with GBM?* | Not at all | 3 (2) | 0 (0) | 1 (1) | 2 (5) | 0.06 | 0.34 | 0.10 |
| A little bit | 4 (2) | 2 (3) | 1 (1) | 1 (2) |
| Somewhat | 7 (4) | 0 (0) | 4 (5) | 3 (7) |
| Quite a bit | 38 (21) | 9 (15) | 23 (29) | 6 (14) |
| Very much | 131 (72) | 50 (82) | 51 (64) | 30 (71) |
| *How confident are you that your loved one would take care of you if your roles were reversed?* | Not at all | 4 (2) | 0 (0) | 2 (3) | 2 (5) | 0.21 | **<0.01** | **<0.01** |
| A little bit | 11 (6) | 0 (0) | 3 (4) | 8 (20) |
| Somewhat | 18 (10) | 7 (11) | 4 (5) | 7 (17) |
| Quite a bit | 8 (15) | 9 (15) | 14 (18) | 5 (12) |
| Very much | 121 (66) | 45 (74) | 57 (71) | 19 (46) |
| *Do you feel criticized by others for the time you spend with your loved one?* | Not at all | 148 (81) | 54 (90) | 63 (79) | 31 (74) | 0.33 | 0.37 | 0.09 |
| A little bit | 14 (8) | 3 (5) | 9 (11) | 2 (5) |
| Somewhat | 11 (6) | 1 (2) | 5 (6) | 5 (12) |
| Quite a bit | 6 (3) | 2 (3) | 2 (3) | 2 (5) |
| Very much | 3 (2) | 0 (0) | 1 (1) | 2 (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 | 1 (1) | 0 (0) | 0 (0) | 1 (2) | 0.15 | 0.28 | 0.13 |
| A little bit | 4 (2) | 0 (0) | 2 (3) | 2 (5) |
| Somewhat | 19 (10) | 5 (8) | 12 (15) | 2 (5) |
| Quite a bit | 62 (34) | 27 (44) | 23 (29) | 12 (29) |
| Very much | 96 (53) | 29 (48) | 42 (53) | 25 (60) |
| *Do you feel embarrassed about your loved one’s behavior?* | Not at all | 98 (54) | 40 (66) | 41 (52) | 17 (40) | 0.11 | 0.27 | **0.01** |
| A little bit | 49 (27) | 16 (26) | 22 (28) | 11 (26) |
| Somewhat | 34 (19) | 5 (8) | 16 (20) | 13 (31) |
| Quite a bit | 0 (0) | 0 (0) | 0 (0) | 0 (0) |
| Very much | 1 (1) | 0 (0) | 0 (0) | 1 (2) |
| *Do you get upset that your loved one has changed so much?* | No | 60 (33) | 28 (47) | 24 (30) | 8 (19) | **0.03** | **0.01** | **<0.01** |
| Yes, sometimes | 99 (55) | 30 (51) | 48 (60) | 21 (50) |
| Yes, on a regular basis | 22 (12) | 1 (2) | 8 (10) | 13 (31) |
| *Has your relationship with your loved one changed?* | Not at all | 47 (26) | 25 (41) | 18 (23) | 4 (10) | **0.03** | **<0.01** | **<0.01** |
| A little bit | 39 (21) | 17 (28) | 17 (22) | 5 (12) |
| Somewhat | 43 (24) | 13 (21) | 24 (30) | 6 (14) |
| Quite a bit | 39 (21) | 6 (10) | 16 (20) | 17 (40) |
| Very much | 14 (8) | 0 (0) | 4 (5) | 10 (24) |
| *Do you wish that you and your loved one had a better relationship at the present/current time?* | Not at all | 81 (44) | 35 (57) | 34 (43) | 12 (29) | **0.02** | 0.06 | **<0.01** |
| A little bit | 35 (19) | 13 (21) | 16 (20) | 6 (14) |
| Somewhat | 39 (21) | 12 (20) | 14 (18) | 13 (31) |
| Quite a bit | 17 (9) | 1 (2) | 12 (15) | 4 (10) |
| Very much | 11 (6) | 0 (0) | 4 (5) | 7 (17) |

*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.