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Pilot study of smartphone-based health outcome tracking (OurBrainBank) for glioblastoma patients

Jacob G. Ellen, Florien W. Boele, Bruce Hellman, Kelli Duprey, Lakshmi Nayak, and Jessica Morris*

University College London Institute of Health Informatics, University College London, London, UK (J.G.E.); Leeds Institute of Medical Research at St James's, University of Leeds, Leeds, UK (F.W.B.); Leeds Institute of Health Sciences, University of Leeds, Leeds, UK (F.W.B.); uMotif Limited, London, UK (B.H.); OurBrainBank, Brooklyn, New York, USA (K.D., J.M.); Center for Neuro-Oncology, Dana-Farber Cancer Institute, Boston, Massachusetts, USA (L.N.)

Corresponding Author: Florien W. Boele, PhD, Patient Reported Outcomes Research Group, Level 6, Bexley Wing, St James's Institute of Oncology, Beckett Street, Leeds LS9 7TF, UK (f.boele@leeds.ac.uk).

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Abstract

Background. Patients with glioblastoma (GBM) typically have high symptom burden impacting on quality of life. Mobile apps may help patients track their condition and provide real-time data to clinicians and researchers. We developed a health outcome reporting app (OurBrainBank [OBB]) for GBM patients. Our primary aim was to explore the feasibility and take-up of OBB. Secondary aims were to examine the potential value of OBB app usage for patient well-being and clinical research.

Methods. Participants (or caregiver proxies) completed baseline surveys and tracked 10 health outcomes over time. We evaluated usage and engagement, and relationships between clinical/sociodemographic variables and OBB use. Participant satisfaction and feedback were described. To demonstrate usefulness for clinical research, health outcomes were compared with corresponding items on a validated measure (EQ-5D-5L).

Results. From March 2018 to February 2021, OBB was downloaded by 630 individuals, with 15 207 sets of 10 health outcomes submitted. Higher engagement was associated with being a patient rather than a caregiver ($\chi^2(2,568) = 28.6$, $P < .001$), having higher self-rated health scores at baseline ($F(2,460) = 4.8$, $P = .009$) and more previous experience with mobile apps ($\chi^2(2,585) = 9.6$, $P = .008$). Among the 66 participants who completed a feedback survey, most found health outcome tracking useful (average 7/10), and would recommend the app to others (average 8.4/10). The OBB health outcomes mapped onto corresponding EQ-5D-5L items, suggesting their validity.

Conclusions. OBB can efficiently collect GBM patients' health outcomes. The long-term goal is to create a unique database of thousands of deidentified GBM patients, with open access to qualified researchers.

Keywords

brain cancer | glioblastoma | mHealth | mobile app | symptom tracking

Glioblastoma (GBM) is the most lethal type of glioma. Over the past few decades, a number of new treatments for GBM have been tested with modest success in extending survival. Yet, despite the development of new treatments, GBM remains incurable, with a 5-year survival rate of only 4%.[1]

Given the lack of progress in improving survival, maintaining high quality of life is critical. Patient-reported symptom or health outcome tracking data have the potential to help advance medical understanding, and ultimately treatment, of the disease. Such individualized, real-time tracking offers a potential solution to the limitations of patient self-reporting of issues in the doctor's office,[2] including poor recall and both under- or overreporting of symptoms, which can be exacerbated by cognitive deficits in some GBM patients.[3,4]

Allowing patients to track their own health data has been shown to confer several benefits in other diseases. For example, the use of patient-reported outcome measures has been associated with fewer emergency department visits, earlier symptom identification, improved patient-clinician communication, and even increased survival for cancer patients through enabling patients to monitor and engage with their condition in real-time.[5–9] Mobile apps to track symptoms or health outcomes have already been deployed for mental health disorders such as schizophrenia, anxiety, and depression,[10–12] as well as various types of cancer.[13,14] Yet, a recent review evaluated 123 cancer-related health apps and found only one that was specific to brain cancer.[15]

With the help of a board of neuro-oncologists and GBM patients, we developed the OurBrainBank (OBB) app to empower GBM patients to own and track their own health outcome data over time and export their reports directly to their medical teams. Here we describe the OBB app and report the initial findings of its feasibility, benefits of OBB app usage for patients, and the potential of using OBB app data in clinical research.

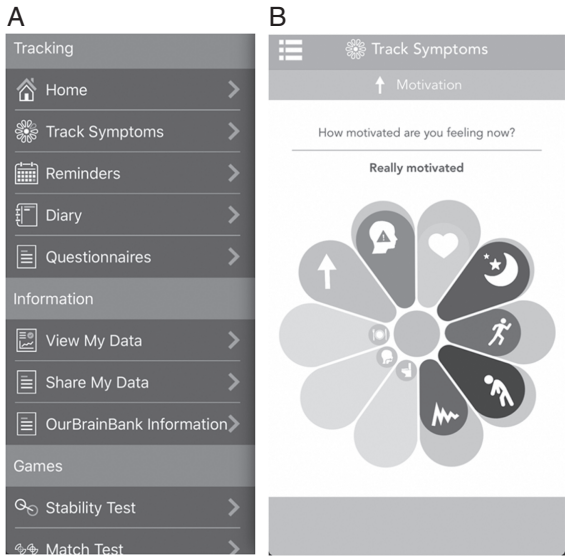

Figure 1. Screenshots of (A) the OBB app menu layout and (B) the "petal" motifs, each consisting of 10 health outcomes. Abbreviation: OBB, OurBrainBank.

Materials and Methods

App Development

The app was developed in consultation with multiple clinicians and GBM patients. The health outcomes included were informed by a survey (with 170 GBM patients responding) conducted in 2017 prior to the app launch. The OBB app asks patients to report on each of the 4 most commonly mentioned health outcomes in the survey (sleep quality, exercise, mood, and fatigue), and it also allows patients to report on other additional health outcomes drawn from the survey (see Procedure and Data Collection sections). Ten months into the study (January 2019), the app was modified to include an interactive "Shiny" web app (can be found at: https://jellen.shinyapps.io/OBBApp/), allowing patients to examine aggregate data from the study.

App Design

The OBB app is based on an existing software platform designed for patients to capture data about their health, symptoms and outcomes. The software platform from uMotif Limited (London, UK) has been proven to engage patients to capture large volumes of data in other conditions, including Parkinson's disease.[16,17] The app consists of 3 main menu tabs: "Tracking," "Information," and "Games." The Tracking section allows participants to track their health outcomes, create diary entries and answer OBB questionnaires. Health outcome tracking takes the form of "motifs," which allow the user to indicate increasing or decreasing severity through a sliding scale (Figure 1). The Information tab allows users to view their own data and export custom reports for their clinicians. This tab also allows patients to compare their own health outcome scores to aggregated outcomes for the whole sample. The Games section contains a physical responsiveness test (through a speed tapping task), as well as a pattern recognition test. Mobile notifications to remind patients to track outcomes are sent to users a minimum of once weekly. All of the personal and health outcome tracking data from the OBB app are anonymized and pooled in a Health Insurance Portability and Accountability Act (HIPAA) compliant database.

Participants

Participants were primarily recruited through social media (support) groups. Eligibility criteria included adults (≥18 years) with GBM who were English speaking, resided in the United States, had access to an iOS or Android smartphone or tablet device (which is needed to download the OBB app), and provided informed consent. Patients were removed from the study after their baseline survey if they did not respond to basic questions about their GBM diagnosis, including the number of months since diagnosis. Family members or caretakers could complete data on a patient's behalf, provided the patient met the eligibility criteria.

Data Collection

Participants completed a mandatory baseline survey covering sociodemographic and clinical history. Participants were also prompted to complete the EQ-5D-5L survey,[18] a health-related quality of life questionnaire. The EQ-5D-5L questionnaire records 5 categories (mobility, self-care, usual activities, pain/discomfort, and anxiety/

depression) with 5 different levels of severity (no problems, slight problems, moderate problems, severe problems, and extreme problems), as well as a global self-rated measure of health on a 0-100 point scale.[18] Other health-related quality of life questionnaires were offered on a voluntary basis including the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30)[19] and the EORTC Quality of Life Questionnaire for Brain Neoplasms (EORTC QLQ-BN20)[20]; these results are not included in the present manuscript). OBB conducted 2 additional study-specific follow-up surveys part way through the study called the Community Viewpoints Survey and the Satisfaction Survey (made available on May 8, 2018 and June 26, 2019, respectively) aimed at measuring participant satisfaction, suggestions, and usage (Table 1).

The number and type of health outcome motifs submitted were tracked over time for each patient. Participants were asked to submit as many motifs as they could for the length of the study period, with a maximum of daily and a minimum of monthly. Sleep quality, exercise, mood, and fatigue were captured for all patients. In addition, patients selected 6 additional health outcomes (for a total of 10) most relevant to their individual clinical condition out of the following options: hair loss, seizures, healthy eating, appetite, hydration, stress, sickness, tingling hands and feet, constipation, taste changes, memory and concentration, motivation, completion of daily activities, anxiety, dizziness, and pain. Health outcome severity is measured on a scale from 1 to 5, with "1" being the worst outcome and "5" being the best outcome.

Study Design and Statistical Analysis

Feasibility of the OBB app for different groups of GBM patients was evaluated by exploring app uptake. Study participants were asked to submit motifs (sets of health outcome ratings) for a period of 100 days (and longer if desired). We tracked app usage over time and examined baseline differences between never users, 1- or 2-time users, and those who used more frequently (at least 3 times) using chi-square tests of independence for categorical variables and one-way ANOVAs for continuous variables.

To capture patient benefit, we analyzed patient feedback from the Satisfaction and Community Viewpoints Surveys (Table 1), which were available to all users of the OBB app. In addition, we also examined the correlation between length of app usage and improvements in health outcome ratings over the study period using Pearson's correlations. The first week of app usage for each patient was set to the first week that the patient submitted a motif. When multiple motifs were submitted in a single week, those motifs were averaged to get one overall score for the week. Only patients who submitted 10 or more motifs over the study period (100 days) and used the app for a minimum of 10 weeks were included in the analysis of health improvements (ie, correlations between length of app usage and improvements in health outcome ratings).

To validate the data collected through the OBB app for research (secondary aim), we explored the correlation (using Pearson's correlations) between the OBB health outcome severity scale and the 5-point scale of the EQ-5D-5L survey taken by OBB participants at baseline. Since these scales work in opposite directions of outcome severity, we expect moderate negative correlation coefficients for this analysis. Specifically, we examined relationships between "Completion of Daily Activities" (OBB) and "Usual Activities" (EQ-5D-5L), between "Pain" (OBB) and "Pain/Discomfort" (EQ-5D-5L), and between "Anxiety" (OBB) and "Anxiety/Depression" (EQ-5D-5L) as an indication of validity of OBB outcome scores.

The New England Institutional Review Board (IRB) approved the study and all participants provided informed consent. *P* values were considered significant at a 0.05 threshold, and missing data were not present due to the use of dropdown menus and mandatory responses in the app. All analyses and visualizations for this paper were performed using R statistical software.[21]

Results

Participants

Between March 2018 and February 2021, a total of 630 individual participants from 46 US states gave consent to enter the study. Approximately a third of users were caregivers (31.2%), and 52.6% were male (see Table 2). The median age at GBM diagnosis was 50, while the median time from diagnosis to enrollment was 8 months. At registration,

Table 1. Surveys Conducted by OBB

Surveys	Number of Respondents	Number of Questions	Percentage of Study Participants	Dates Available
Baseline Survey (required for motifs)	611 (26 removed)	26	100	March 9, 2018-Present
Community Viewpoints Survey	66	6	11.3	May 8, 2018-October 30, 2018
EQ-5D-5L Survey	334	6	57.1	March 9, 2018-Present
Satisfaction Survey	47	16	8	June 26, 2019-Present

Abbreviations: EQ-5D-5L, European Quality of Life Five Dimension Five Level Scale; OBB, OurBrainBank.

Table 2. Demographic and GBM Progression Data by Number of Motifs Submitted

Variable	Levels	Zero Motifs Submitted (n = 103)	1 or 2 Motifs (n = 132)	3 or More Motifs (n = 350)	*P* Values
Sex	Male	54 (52.4%)	68 (51.5%)	186 (53.1%)	.94[a]
	Female	49 (47.6%)	64 (48.5%)	164 (46.9%)	
Age	Mean (±SD)	48.9 (±17.5)	48.6 (±16.2)	48.5 (±14.8)	.20[b]
Patient or caregiver?	Patient	56 (56%)	70 (56%)	265 (77.3%)	<.0001[a]
	Caregiver	44 (44%)	55 (44%)	78 (22.7%)	
Presence of other (non-GBM) health conditions	Yes	57 (55.3%)	78 (59.1%)	187 (53.4%)	.54[a]
	No	46 (44.7%)	54 (40.9%)	163 (46.6%)	
Do you use apps on your smartphone or tablet?	Yes	87 (84.5%)	121 (91.7%)	329 (94.0%)	.008[a]
	No	16 (15.5%)	11 (8.3%)	21 (6.0%)	
How did you hear about OBB?	Social Media	77 (81.9%)	95 (81.9%)	257 (87.8%)	.086[a]
	Doctor	7 (7.4%)	7 (6.0%)	6 (2.0%)	
	Patient	10 (10.7%)	14 (12.1%)	30 (10.2%)	
Tumor recurrence	Yes	32 (34.0%)	40 (33.3%)	93 (30.7%)	.77[a]
	No	62 (66.0%)	80 (66.7%)	210 (69.3%)	
Number of months since diagnosis	Mean (±SD)	17.9 (±30.6)	13.3 (±22.3)	14.2 (±16.6)	.23[b]
Self-rated health status from EQ-5D-5L survey	Mean (±SD)	62.2 (±26.4)	70.8 (±21.3)	74.1 (±20.3)	.009[b]

Abbreviations: GBM, glioblastoma; OBB, OurBrainBank.
P values represent the results of statistical tests with each independent variable in the rows and the categorical number of motifs submitted (columns) as the dependent variable.
[a]Chi-square test.
[b]One-way ANOVA test.

31.9% of OBB patients had already had GBM progression or recurrence.

Uptake and Engagement

Of the 630 users who registered on the app, 611 (97.0%) completed the baseline survey, and 585 (92.8%) filled out the baseline survey with adequate detail (see methods). Due to our recruitment methods, it is not known how many GBM patients learned of OBB in total. An average of 4 new users registered for the app each week and 15 522 total motifs were captured during the study period, each consisting of a set of 10 health outcomes. The median duration of usage for those who submitted at least 1 motif was 32 days, with a median of 4 motifs submitted per user.

In terms of usage, 103 (17.6%) participants did not submit any motifs, 132 (22.6%) submitted a motif once or twice, while 350 (59.8%) participants submitted 3 or more motifs. Average baseline health outcome ratings are shown in Figure 2. Caregiver or patient status ($\chi^2(2,568) = 28.6$, $P < .001$), prior use of smartphone or tablet apps ($\chi^2(2,585) = 9.6$, $P = .008$) and overall self-rated health from the EQ-5D-5L survey ($F(2,460) = 4.8$, $P = .009$) were all associated with level of app usage (Table 2). Specifically, patients (rather than caregivers), those who used apps on their smartphones or tablets, and those who had better self-rated health at baseline were more likely to submit motifs and engage with the app. There were no significant associations found between age, sex, tumor recurrence, months since diagnosis, method of hearing about OBB, presence of comorbidities, and the level of app usage (Table 2).

Patient Satisfaction

Among the 66 participants who completed the Community Viewpoints Survey, most reported that health outcome tracking was useful, with an average rating of 7 on a 0-10 scale (mode 8). Among those completing the Satisfaction Survey (47 respondents), when asked how likely (out of 10) they were to recommend the OBB app to someone with GBM, the average was 8.45 out of 10. When asked what they appreciated most about the app, 12 respondents (25.5%) highlighted the ability to track their condition especially in conjunction with new medications, 10 (21.3%) stated that it helped make them more aware of their own body and condition and 4 (8.5%) responded that it served as a reminder of how to feel better.

When asked about limitations of the app, the most common response (23 out of 47 respondents) was that the games were either confusing or too difficult. Only 14 out of those 47

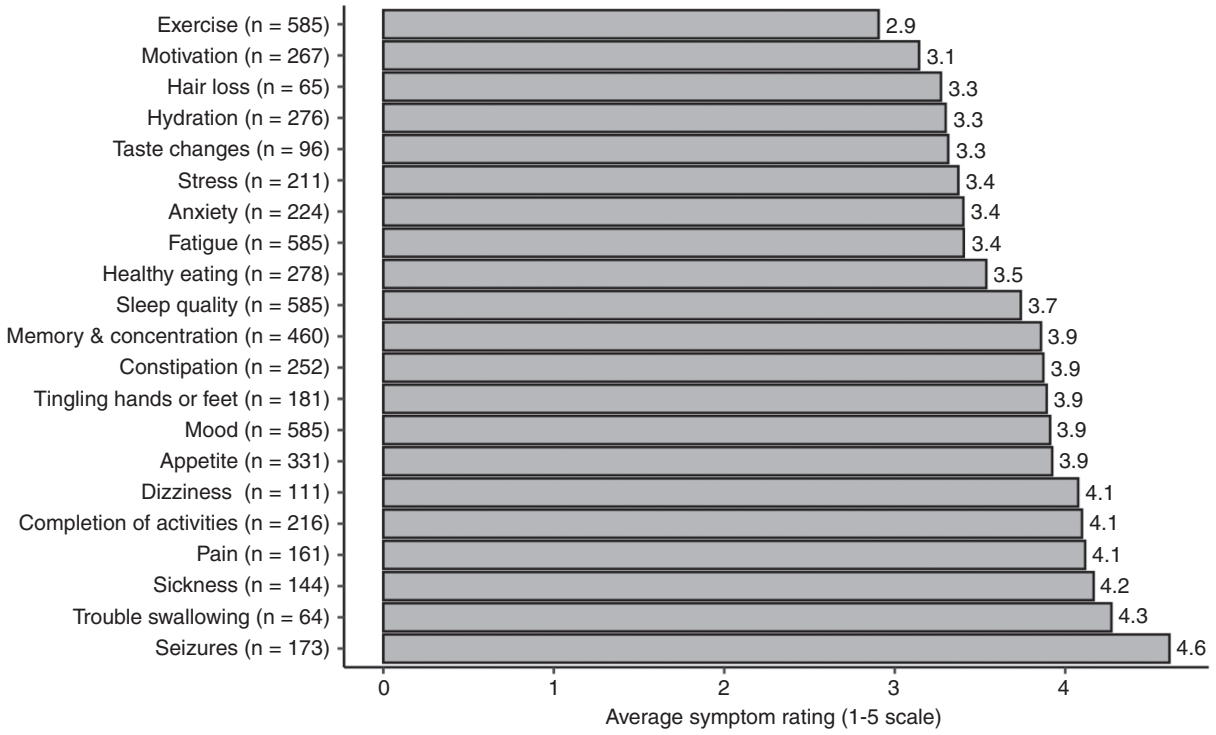

Figure 2. Average baseline OBB Health outcome ratings (scale of 1-5, with "1" being most severe) with the number of participants tracking each symptom represented in parentheses. Abbreviation: OBB, OurBrainBank.

(29.8%) respondents played the games at all. Other respondents (8) voiced a preference for ways either to change the health outcomes tracked midway through the study or to track other metrics, such as weight or sugar intake.

Health Outcome Correlations

For participants who used the app at least 10 times for at least 10 weeks, the length of time using the app over the study period was positively correlated with higher self-reported hydration outcome ratings available for 78 patients ($r(78) = .83$, $P < .001$). A weaker, but a similar positive correlation was found for the relationship between length of app usage and healthy eating outcome ratings available for 68 patients ($r(68) = .44$, $P = .10$). No significant improvements or deteriorations for stress, anxiety or motivation were observed.

Usefulness of OBB Data for Clinical Research

Correlations between the 5-point scales of selected analogous OBB health outcomes and EQ-5D-5L survey questions found statistically significant negative relationships between the 2 measures. Specifically, the correlation between the "Completion of Daily Activities" OBB outcome and the "Usual Activities" EQ-5D-5L question was negative and statistically significant ($r(92) = -.55$, $P < .0001$). Similarly, we observed significant negative relationships between "Pain" and "Pain/Discomfort" ($r(67) = -.57$, $P < .0001$) and between "Anxiety" and "Anxiety/Depression" ($r(95) = -.38$, $P < .001$).

Discussion

Mobile app technology is a promising way to help patients track their own medical condition(s) over time, but little is known about take-up and usage in the real world. We found through surveys that many GBM patients (or their caregivers as proxies) appreciated the OBB app and its health outcome tracking functionality. Most survey respondents found it useful to monitor their health outcomes as they tried new medications and many found that it made them more aware and in control of their health.

However, certain kinds of patients were more likely to use the app than others. Patients with better self-rated health, those who used the app directly (rather than through a caregiver), and those who had previously used apps on their smartphone or tablets were all more likely to engage with the app. Other studies have measured the association between demographics and health app usage,[22,23] and have found a correlation between usage and both age and sex.[22,23] By contrast, our study did not

find an association with age or sex, but it is possible that we nullified the effect of age through the study design, as we only evaluated patients who downloaded the app. In addition, known common barriers to web-based interventions in neuro-oncology include lack of technical skills and cognitive difficulties,[24] and we may not have reached the part of the GBM population hindered by these barriers.

We found that time of app usage was strongly correlated with increased hydration health outcome ratings and more weakly correlated with increased healthy eating. While more work needs to be done to confirm any causal effects, other studies have demonstrated that mobile app usage can alter behavior patterns, including by increasing the ability to meet physical activity regulations.[22] More broadly, a review article found that 17 of 23 papers on health mobile app usage in a variety of conditions reported a positive and significant association with targeted behavioral changes (examples included weight control, alcohol addiction, medication management, and lifestyle improvement apps/studies).[25]

We validated the data collected through the app by examining correlations with previously validated measures. The correlation between the OBB health outcome tracking scale and corresponding items of a validated survey (EQ-5D-5L) suggests that the data from the app is useful for scientific research. More concretely, the OBB app could be used in future clinical trials to gather baseline data and monitor specific health outcomes longitudinally after different forms of treatment.

This app-based study is inherently limited because it excludes patients without mobile devices or the ability to navigate them effectively. Indeed, a patient survey about mobile apps for cancer patients showed that 16.3% of patients did not own a phone, and 9.1% only used a personal computer.[26] This may explain the lower median age of patients in our study (50 years) compared with the overall median age of GBM patients (64 years).[27] Another limitation is that the medical information is self-reported, which limits the amount of scientific analysis possible. The app was also more heavily used by patients with better self-rated health scores, which represents a possible selection bias for healthier patients (although recurrence status and the number of months since diagnosis did not confer any differences in usage). Lastly, the Satisfaction and Community Viewpoints Surveys were only completed by a small subset of participants, so it is possible that those engaged enough in the app to answer the surveys may not represent the opinions of all the other participants. We are considering adding a user feedback section to capture the views of all participants. Moreover, further research is needed to investigate what constitutes useful engagement with, or dosage of, OBB app use.

There are aspects of the OBB app that could be improved. For example, while the games were intended to be an engaging way to track patients' cognitive state over time, they were rarely used and patients found them too confusing and difficult. Going forward, we will work to design more user-friendly games. Other patients requested ways to either change the chosen outcomes or to track alternative metrics. Future versions of the app could be adapted to allow for such flexibility. A caregiver-specific app could also be explored.

Conclusion

The OBB app is a new option for GBM patients, and to our knowledge, the only mobile app tailored specifically to GBM patients. Our pilot study reveals that the app benefits patients by helping them manage their condition through health outcome tracking, but also supports research by creating a deidentified database for exploration. Going forward, OBB plans to expand this study to other countries in order to reach as many GBM patients as possible. OBB is also in discussion with researchers and pharmaceutical companies to use the OBB app to facilitate GBM clinical trials.

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