The New Frontier: How Smartphone Data Can Revolutionize Cancer Care

Forbes



OurBrainBankBrand Contributor

May 6, 2024

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The potential of patient-generated data in glioblastoma (GBM) research represents a paradigm shift in how we approach the study and treatment of the most aggressive and deadly form of brain cancer.

Progress in GBM research and treatment has been painfully slow. Median life expectancy at diagnosis is a devastating 12 to 16 months, with only 5% of patients surviving beyond five years. Traditional methods of monitoring the progression of the disease, such as imaging and clinical exams, are conducted infrequently at follow-up appointments in the clinic. Meanwhile, self-reported patient questionnaires offer only a snapshot in time, and can be compromised as the person experiences gradual cognitive decline.

There is another way.

Patient-generated "passive data," collected from smartphones, offers an alternative – continuous, real-time insights into the health and behavior of those living with GBM that can be aggregated to create a more comprehensive assessment of a patient's disease progression.



Passive data is the information that you and I generate through our smartphones often without realizing it. Its beauty lies in the fact that it is produced by definition without a patient's active participation.

Yet it can encompass a wide range of information about the person, such as their physical activity levels, sleep patterns, and geographical data like daily distance traveled and screen time data. This kind of data is ubiquitous, but often overlooked. It can provide insight into the daily lives and health statuses of individuals.

And this data is especially important in the context of GBM, a disease that forces changes in cognitive function and physical mobility that are progressive, although often subtle at first.

One of the primary benefits of passive data collection is its ability to provide a comprehensive picture of a patient's cognitive and physical health without requiring active self-reporting, which can be burdensome for patients. For example, alterations in physical activity patterns or daily routines, as detected through GPS data, could signal a decline in physical health or the onset of new symptoms.

Similarly, a decline in the speed and accuracy of responding to texts or changes in the complexity of language used in digital communication could indicate an alteration in cognitive function. Indeed, the ability to continuously monitor these aspects can lead to a deeper understanding of the impacts of GBM and different treatment regimens on daily quality-of-life for patients.

This is a new frontier that could be particularly useful in certain patient populations, including those who may not be able to make it to the hospital for regular follow-up visits, who do not speak English and/or who struggle with technology and may not find an online quality-of-life survey easy to complete.

A new collaboration between OurBrainBank, a non-profit founded by GBM patients and their families, Harvard scientists and neurosurgeons, and neuro-oncologists at the Dana-Farber Cancer Institute, is moving towards harnessing this type of passive data for GBM patients. OurBrainBank is the only patient and caregiver-led GBM non-profit that focuses on patient-led research and data collection.

The project in development has a few main goals:

The first is to use smartphone data to improve the clinical management of GBM.

By providing a continuous stream of real-time data, healthcare providers can gain insights into the effectiveness of treatments and their side effects, hopefully leading to more personalized and adaptive treatment plans that consider the evolving nature of the disease and the unique response of each patient.



More specifically, our collaboration will investigate whether we can use

these individual patterns to detect tumor recurrence earlier, possibly even before it shows up on a scan. This could lead to earlier treatments and ultimately better patient outcomes.

The second goal is to investigate quality-of-life in GBM patients with a focus on loneliness and social isolation as the disease progresses.

Social isolation is a major difficulty for GBM patients and can occur due to diminished social support, reduced energy and time for socializing due to treatment demands, and the stigma associated with GBM.

We aim to use passive data to better characterize the social isolation of GBM patients over the entire disease course, with the ultimate goal of increasing support mechanisms and targeted interventions to enhance the quality-of-life of GBM patients. We also hope to learn more about the quality-of-life of GBM caregivers, a group that is too often ignored in studies to date.

This multidisciplinary initiative to harness passive data for GBM research could represent a significant leap forward in the fight against this challenging disease, and complex diseases more generally. By embracing the capabilities of modern smartphones and the wealth of data they generate, researchers, clinicians, and patients can work together more effectively to improve outcomes.

This approach not only empowers patients by making them participants in their own care, but also paves the way for more responsive, personalized, and effective treatment.

Jacob Ellen is a Harvard medical student and a member of the US board of OurBrainBank, an international non-profit that is advocating on behalf of GBM patients and families in both the US and the UK. Please contact us at info@ourbrainbank.org if you would like to help or donate, visit our website www.ourbrainbank.org for more information.

To find out more about OurBrainBank, or to support OBB's work, visit its website. Follow OBB on Twitter or LinkedIn.



OurBrainBank

OurBrainBank is an innovative, patient-led movement designed to move glioblastoma from terminal to treatable, powered by patients. It's the first non-profit created by, with, and for people living with glioblastoma, an aggressive and rare brain cancer. Founder Jessica Morris (1963-2021) survived for five years after her diagnosis. The five-year survival rate is 5%. We believe in patient power and the importance of donating data to medical research. Patient-driven data is the new currency in medical research.OurBrainBank is a registered nonprofit 501(c)3 based in the US and registered charity in the UK.

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