Assessing patient and caregiver needs and challenges in information and symptom management: a study of primary brain tumors

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Abstract
Brain cancer is a devastating diagnosis characterized by significant challenges and uncertainties for patients and their caregivers. Although mobile health and patient-facing technologies have been successfully implemented in many patient populations, tools and technologies to support these users are lacking. We conducted semi-structured interviews with 13 patients and caregivers, investigating experiences, challenges, interests, and preferences for managing symptoms and health information. We found that although current technology use in health-related activities was minimal, participants reported being highly willing to use such technologies to capture and manage information, provided they were designed according to the needs, interests, and abilities of these users. Participants felt that such tools could benefit patient care activities, and help to address information challenges for both current and future patients and caregivers. We present findings surrounding these challenges, behaviors, and motivations, and discuss considerations for the design of systems to support current and future patients and caregivers.

Introduction and Background
In 2016, nearly 78,000 US adults will be diagnosed with a primary brain tumor[1]. Although rare, these tumors are a significant cause of morbidity and mortality, and are characterized by a high symptom burden, decreased health-related quality of life, and an often poor prognosis[1-4]. The delicate and complex structure and functions of the brain make these often aggressive tumors difficult to treat, with high recurrence rates contributing to poor long-term survival[5]. Despite advances in treatment technologies and approaches, nearly 42% of patients diagnosed with malignant disease will pass away within the first year after diagnosis[1]. For these patients, overall 5-year survival rates fall at 34.4%, led by glioblastoma, the most common and aggressive high-grade tumor, which falls at 5.1%[1].

In addition to poor prognosis, primary brain tumors are also associated with high symptom burden. As these tumors grow and invade the delicate tissues and spaces of the brain, patients experience neurological symptoms including headaches, seizures, issues with language, vision, memory, and hearing, as well as cognitive and motor impairments, and changes in behavior and personality[5]. The type and severity of these symptoms depends on the histology, location, and size of the tumor[6]. Treatments for these patients involves surgery to remove as much as the tumor as possible without damaging adjacent health tissues and functions, as well as radiation therapy and chemotherapy to kill any remaining tumor cells and prevent future growth or recurrence for as long as possible. Patients are often prescribed a variety of medications including steroids to reduce swelling in the brain, antiemetics to control nausea, analgesics for pain, and anti-seizure medications to provide symptom and side effect relief and prevent additional harm and neurological complications for the patient. Each of these medications and procedures bring their own risks, discomforts, and side effects, some of which may be lasting or even present years down the road. Because of these risks presented by these medications and procedures, and the high risk for recurrence associated with many primary brain tumors, the follow-up period of these patients typically lasts years, if not indefinitely.

Patients and their caregivers face many challenges as they take on new roles and responsibilities in navigating the diagnosis and treatment process. Many of these challenges center around the need for more data and information in the face of compounding uncertainties. In addition to taking an active role in decision-making activities, patients and their caregivers must work to manage complicated medication schedules and treatment protocols, endure complex neurological symptoms and toxic side effects, all while becoming experts in their own disease and care process.

With the increasingly pervasive nature of technology in daily life, mobile health and patient-facing technologies have been proposed and implemented as solutions to many challenging health issues including increasing medication adherence among individuals with HIV in Sub-Saharan Africa[7], supporting self-management activities for patients with chronic diseases like diabetes[8], and supporting personal health information management activities in breast cancer[9-11]. Across health, reach of these technologies is great. A recent systematic review explored examples of self-tracking for health management in older adults, documenting the design and development of interventions across a wide range of health areas for these users[12]. Additionally, there a multitude of applications are available to support mental health and individuals with mental illness, including PTSD Coach, an application

design by the Veterans Administration to support education, tracking, and management surrounding PTSD symptoms[13-15]. Technology is also widely used in searching and accessing health information, with 25% of US adults acknowledging they use the internet for the purpose of self-diagnosis, and 72% of internet users reporting acknowledging using the internet to access or research health information in 2012[16]. Electronic patient portals also provide a means for supporting communication, access, and health information management. Despite these impressive undertakings in the US and around the world, patient-facing tools and technologies to support individuals with rare conditions including primary brain tumors are still lacking[17].

Due to the nature of the disease and the potential for cognitive, physical, emotional, and behavioral impacts, caregivers often take on an active role in care, decision-making, and information seeking and management activities. In working to understand and address some of the challenges, several researchers explored the information needs of patients with brain tumors, as well as their caregivers[18-21]. Although each of these studies provided a great deal of insight into different aspects of needs, challenges, and experiences for patients and caregivers, none sought to explore the use of health-related technologies in these activities in the context of designing future systems. In order to address this gap, and develop further understanding of the needs and challenges facing this population, we engaged patients and caregivers affected by primary brain tumors in semi-structured interviews. Through these interviews, we investigated symptoms and side effects, challenges, and current health tracking and information management approaches, as well as the use of technology in brain tumor related health activities. We also utilized brainstorming questions to generate ideas on how we as researchers, alongside participants serving as experts, might design tools to address some of these challenges, and better support future patients and caregivers.

Methods
Eligibility & Recruitment
Patients diagnosed with a primary brain tumor and primary caregivers of these patients were recruited to participate in semi-structured interviews coupled with a demographic, health, and technology use survey to explore needs, challenges, and experiences, as well as current and future use of health-related technologies. In addition to the eligibility criteria presented in **Table 1**, participants had to be able to understand the information presented during the consent process and make an informed decision regarding participation. In instances where cognitive impairment was a concern, participants were asked a series of questions during the consent process to ensure understanding of the purpose of the study and their rights as a participant. Patients could participate regardless of whether their caregivers chose to take part, and vice versa. Participants were recruited over a 9-month period through a local brain tumor support group as well as in the clinic at radiation therapy treatment centers in the Seattle area. University of Washington Institutional Review Board approval was obtained prior to commencing this research.

Table 1: Eligibility information

Patients:
- Diagnosed and treated for a primary brain tumor within the past 5 years OR experienced a recurrence that required any form of treatment within the past 5 years
- Treatment involved some form of radiation therapy
- Able read, write, and speak English*
- At least 18 years of age

Caregivers:
- Primary caregiver of a patient meeting the patient eligibility criteria
- Able to read, write, and speak English
- At least 18 years of age

*This requirement was not used to exclude patients with aphasia or communication disorders, provided they were comfortable participating in the study, and could understand information presented and provide informed consent.

Data Collection
Demographic, Health, and Technology Use survey
Participants were asked to complete a survey to provide information surrounding demographics, diagnosis, and treatment history. The second component of this included questions regarding current use of technology in health related activities, with survey questions based on the 2012 Pew Health Tracking survey[22].

Semi-Structured Interview
Interviews were conducted as either 1-hour individual sessions (patient OR caregiver), or 2-hour patient-caregiver dyad sessions, according to participant preference. Individual interview sessions allowed patient and caregiver perspectives to be shared more freely and equally, and allowed for participation from individuals who did not have a patient or caregiver who was interested or able to participate (e.g. paid caregiver, severely impaired patient). Patient-caregiver combined sessions were offered both as a convenience, and as a way to allow for participation from individuals who may need extra support with language or memory, for example. Because many individuals travel long distances for care and then return home following the end of treatment, both in person and phone interview sessions were offered. Interviews were audio recorded and participants were compensated for their time.

Data Analysis
Interview data was transcribed and verified prior to data analysis. A thematic analysis was conducted with two separate coders analyzing the transcripts to identify codes and themes; each coder generated a codebook based on themes and codes. Codebooks were merged into a single codebook, and additional codes were added and reconciled as additional transcripts were coded.

Results
A total of 13 participants (7 patients, 6 caregivers) were recruited to take part in this study, representing approximately 11 hours of interview data. Twelve individuals participated via in-person interviews, while one opted to do a phone interview due to location. Six participants opted for patient-caregiver dyad sessions, while one dyad participated separately, and 5 individuals participated independently. All interviews were conducted at the University of Washington Medical Center, however, many participants were treated outside of the UW Medicine system for part or all of their care. As such, information captured during these interviews was not limited to experiences at UWMC or its entities.

Demographic information for participants is presented in **Table 2**. Diagnoses included oligodendroglioma, anaplastic oligodendroglioma, oligodendroastrocytoma, astrocytoma, anaplastic astrocytoma, and glioblastoma, ranging from grades 2 to 4. Time since diagnosis ranged from 2 months to 4 years, 10 months, with one participant falling outside of the 5 year cut off, but having had a recurrence within the time frame of interest. All seven patient participants had undergone some form of radiation therapy, while six had also undergone surgery, and four had done chemotherapy. Four participants were currently in treatment, and three of the seven participants had reported recurrence or progression of disease. Participants represented a range of educational backgrounds with three participants having associate's degrees, four with bachelor's degrees, and six with graduate or professional degrees. Technology use information is discussed in findings section of this paper.

Table 2: Demographic Information

Patients	*Patients (P##)*	*Caregivers (C##)*
Gender	Female 4, Male 3	Female 5, Male 1
Age	Average 52.86, range 42-66	Average 50.3, range 39-63
Time since diagnosis	Average 20.2 months	N/A
Race	Caucasian 6, Not listed 1	Caucasian 5, Asian Indian 1

Overall Findings
Patients and caregivers faced a multitude of challenges as they worked to understand and manage complicated symptoms, side effects, medications, and treatment protocols. Participants looked to many different sources for information including clinicians, the internet, pamphlets and brochures, support groups, medication packaging information, scientific literature and clinical trials, patient advocacy groups, webinars, blogs and cancer forums, as well as trusted friends and family members to address different aspects of these challenges. Even with a wide range of information sources, many issues remained and in some situations, new challenges arose with increased access to information. Patients wanted to know what to expect in terms of symptoms and side effects, as well as what the future held for them. As a result of these experiences nearly all participants reported feeling lost, alone, scared, or overwhelmed at least once during the process. In this section, we present our findings, as outline in **Table 3**.

Table 3. Interview Findings and Interpretations

Themes	Findings and Interpretations	Summary
Current Challenges	Symptom and side effect challenges	Patients and caregivers often struggle with unmet information needs and uncertainties, especially early in the diagnosis and treatment process
	Information challenges	
Current Behaviors	Tracking of health information	Current technology use is limited in these activities is minimal, as participants perceived many barriers and limitations; caregivers play an important role in many situations
	Communication of health information	
	Caregiver role in management and care	
	Technology use	
Future Behaviors and Motivations	Self-tracking to support patient care and understanding	There is great potential for future technology design and development in this area, but barriers and needs of this population require careful consideration
	Benefits of viewing previous patients data and experiences	
	Willingness and motivation	

Current Challenges

Symptom and side effect challenges
Throughout these interviews, participants reported experiencing over 60 different symptoms, side effects, and health events ranging from seizures, fatigue, nausea, anxiety and depression, to gross impairments in cognitive and motor functions, as well as changes in behavior and personality. While some were anticipated, others came as a surprise in terms of presence, severity, and duration. Many patients and their caregivers experienced challenges identifying and detecting these symptoms and side effects. Part of this challenge stemmed from the fact that symptoms can vary widely depending on the size and location of the tumor, and that they may be subtle in nature, or present slowly over time. A major contributing factor, however, was the fact that participants were not previously familiar with neurological symptoms. For example, five patients had experienced what they believed to be a stroke or dizzy spell, but was later diagnosed as a seizure. Additionally, one patient had been experiencing weakness on one side of their body during follow-up, but because they did not previously have any motor symptoms or impairments, they did not know to associate it with the tumor and report it to their clinicians. This later turned out to be a recurrence of the disease in another region of the brain. In several situations, caregivers noticed symptoms that patients were not aware of, mainly related to changes in cognition, behavior, and personality. In addition to challenges identifying and detecting symptoms, participants were also concerned with understanding the causes of the symptoms and side effects they were experiencing, and knowing how to manage and react to them. This involved trying to determine whether their experiences were related to the disease (i.e. progression or recurrence), or whether treatments or medications were responsible. Similarly, knowing what was normal or to be expected, when to be concerned, and what to do in response to these events was also a major challenge.

Information Challenges: availability, depth, and presentation of information
Having access to information was incredibly important to all participants across this study. There was a considerable amount of variation however, between participants in regards to overall satisfaction with the quality and quantity of information provided by their clinicians. In general, participants felt that they received more and better information during radiation treatment than while on chemotherapy at home. This was largely attributed to the fact that during radiation, patients were at the treatment center daily over a 6 to 8-week period, and met with clinicians once a week to discuss progress and questions. In contrast, patients on oral chemotherapy typically only saw clinicians once during each 6 to 8-week chemo cycle. The difference in quantity of face-to-face interactions, and the extended periods of time between appointments meant that patients and caregivers often waited longer to receive information, ask questions, and report concerns.

Participants also noted challenges involving the level of detail and presentation of information. Many participants stated that they would have appreciated more information surrounding diagnosis, treatment procedures, medications, side effects and potential complications, especially early on. P06 explained this in saying *"I think [knowing more about] the medications [and] the treatments would have been helpful because you feel like you are jumping out of an airplane without a parachute when you start this journey."* For others, the amount and presentation of information was overwhelming, as described by P06 in saying *"It's actually kind of hard from my viewpoint, going*

through this. I think they are talking at you a lot, and we're both pretty much in a little state of denial or something... You can't keep track of all the information they are giving you and be able to register it enough to keep everything in your head." Interestingly, C06, the other half of this patient-caregiver dyad, countered this, expressing frustrations over missing information several times, and summarizing in saying *"Well, I would say that is true for you. I could keep track of everything they said because they didn't tell me very much [both laughing]. I felt a lack of information, and you were overwhelmed by everything because of your state."* This feeling was most likely due to the fact that patients may not always be in a state cognitively or emotionally to take in and process the information being presented, especially following surgery and during treatment. At the same time, some caregivers felt they did not always receive the information they wanted or needed. One caregiver reported doing research on her own to learn the information and terminology so the clinicians would know and trust that she wanted more information.

Both patients and caregivers reported that they felt clinicians were often vague, unwilling, or unable to provide answers, especially related to prognosis. They acknowledged that at times, the information they wanted was not yet available, as was the case before biopsy to determine the type and grade of the tumor. In other cases, they attributed the hesitancy of clinicians to provide the level of information desired to the individualized nature of the disease and number of variables involved, as well as the lack of available clinical trial data for this small, rare disease population. Emotional considerations also came into play as participants believed that clinicians at times held back information or emphasized the positive extremes because they did not want to depress or upset the patients and their caregivers. This scenario was described by P04 in saying *"Well I got the distinct impression that he was trying to invoke the power of positive thinking. He didn't want to put any negative sort of doom-saying scenarios into the works because that can probably turn into a self-fulfilling prophecy."* Although this participant understood and appreciated the concern of their clinician, they went on to further describe that this information was also very important and necessary for setting expectations and making decisions about the future, as they often wanted to know whether they should be planning in terms of months or years.

Information Challenges: Applicability and the need for personalized information
It was nearly unanimously reported among patients and caregivers that they wanted to know what to expect throughout the treatment process and into the future, and that more and better information was necessary to make this happen. This included wanting to know what to expect for their individual situation in terms of symptoms, side effects, survival, quality of life, and the potential both long-term and short-term cognitive deficits. Participants frequently wanted to be able to compare their situations to information they found online or in the literature but experienced challenges in doing so. This was especially common when looking into information surrounding prognosis, where many factors can contribute to the likely outcome. Some participants were unable to find relevant studies or information at the time of decision-making, while others found that they were unlike the patients in the clinical trials due to factors including age, tumor size or location, and treatment history. Factors behind these challenges and frustrations extended beyond lack of availability in the literature, and into the clinic. Many patients reported repeatedly being told that every patient and every tumor is unique. Although likely intended to provide reassurance and discourage participants from reading into what they are finding in trials and on the internet, this type of communication lead to more confusion and uncertainty than relief. The frustrations associated with this type of communication were described by P07 in saying *"What most of the doctors say is like... 'oh well this is your tumor, and there is no other tumor like it. So your experience is your experience, and there's no such thing as an average.' And so they make these projections as to how I might or might not respond, but they don't know, and they always quantify it saying 'I can't tell you because it's you and your tumor, and it's not somebody with their tumor that's had the experience that's in the statistics.' And so the trouble with that is you come away without any knowledge whatsoever..."* Concerns and the desire for in-depth, personalized and relatable information did not end once treatment was over. For certain participants, setting clear expectations relieved stress, and helped them prepare for and accept future possibilities.

Information Challenges: Credibility, cognitive impairment, and emotions
Patients and caregivers often looked to others for information, guidance, and support throughout the journey. As most participants did not know anyone else who had a brain tumor prior to their own diagnosis, they were often forced to look to the internet for information to learn about patient and caregiver experiences by way of blogs, personal websites, and online forums. Several participants felt that without being able to interact with the source of the information and assess their cognitive and emotional state, they could not be certain of the credibility of the information being shared. This concern was linked to the fact that changes in personality, behavior, and cognition are common in individuals with brain tumors, thus, there is increased potential for sharing of misinformation,

whether intentional or not. Interestingly, this sense of distrust and skepticism was more common amongst patient participants, whereas several caregivers reported more positive impressions, likely due to the fact that they were interested in learning different types of information from these sources. There were also great concern involving the internet, both in terms of the potential for discovering information that is scary or upsetting, as well as finding incorrect information. Most participants reported using the internet to look up information in the early stages of the disease and treatment process, but had since significantly decreased or completely stopped to avoid the stress and reduce the potential for misinformation.

Current Behaviors: Tracking, Communication, Caregivers and Technology Use in Information Management
Tracking and recording health information
Keeping track of health, symptom, and side effect information can be a valuable component of health information management. The majority of current tracking activities were informal in nature with participants largely relying or memory, or taking notes in journals or on pieces of paper. Participants primarily noted when they noticed changes in a certain symptom or side effect, or if something unexpected occurred that they wanted to bring up with their care team. For the majority of these participants, recording of information related to symptoms, side effects, and experiences was not intended to serve as a written record, but was used instead to support memory, communication, and organization of information. Motivations and reasons for tracking or taking notes varied. One caregiver was mentally tracking concerning symptoms for the patient in order to help identify the cause, and hopefully find some sort of solution or resolution. For another participant, tracking of seizure information led to the discovery of a correlation between the frequency of her seizures and her menstrual cycle. For the participant who was sharing caregiving responsibilities with another family member, tracking came about as a byproduct of communication and comparing notes rather than a deliberate decision to track or record information.

Reasons why formal tracking or recording health related information did not take place, using mobile health applications or otherwise, typically fell into three categories: (1) participants were not explicitly asked to capture data by their clinicians, (2) participants felt as though they were seeing the care team frequently enough that symptoms and side effects were being adequately assessed, or (3) participants felt that they did not know what or how to track health information. Category two was especially interesting with this population as this lead to the discovery that tracking and reporting needs and behaviors varied significantly depending on the stage in the treatment or follow-up process. As previously mentioned, patients are seen far more frequently when undergoing radiation therapy, as compared to at home oral chemotherapy. Two participants explicitly stated that they felt they didn't need to track or record information related to their symptoms during this time period because the clinicians were already keeping track of the information that they were interested in. In contrast, during oral chemotherapy, patients were seen far less frequently, and often felt like they didn't know how or what to track.

Communication of Health Related Information
Communication activities, preferences, and behaviors varied among participants as well. Email was by far the preferred method for contacting clinicians with routine questions and prescription refill requests. Several participants appreciated when clinicians were willing to use email, avoiding the inevitable game of phone tag that typically ensued when patients called in with questions. Despite being convenient and familiar, participants also experienced some issues with using email. Patients and caregiver feared overlooking important symptoms, but also did not want to burden healthcare providers with unnecessary or 'stupid' questions, despite their need for information. P07 described a situation where they had attempted to reach out to a clinician via email, but was conflicted and worried about being a bother. Others also reported that they had reached out to certain clinicians via email, but abandoned it as a method of communication after failing to receive a response. Clinician preferences for communication during treatment and follow-up, especially regarding email, were rarely made clear, thus, knowing who to contact, and how to reach them when help was needed remained a challenge. The use of secure messaging through the patient portal was used much less frequently, and was seen as much less convenient than email.

Caregiver roles, responsibilities, and challenges in care and information management
In several cases, patients were either unable, or unwilling, to participate in managing and capturing this information during parts or all of their care process due to the cognitive, emotional, and physical impact of the disease and treatment process. This meant that caregivers took on much of the responsibility for managing information provided by clinicians, accessing test results through the patient portal, transferring records between healthcare organizations, scheduling appointments, researching treatment options, medications, diets and nutrition, refilling prescriptions, dealing with insurance and managing financial and logistical aspects of the care process. At the same time,

caregivers faced unique challenges in that their questions and concerns often did not take priority, and at times went unaddressed despite the fact that they were often heavily involved in research, decision-making, and patient care activities. In several cases, caregivers felt as though they could not ask sensitive questions in front of the patient, or patients felt that their questions were more of a priority given the limited amount of time they had with the clinicians. In other instances, patients were feeling well enough to take on all of the information management activities, and didn't feel that they needed caregiver assistance or participation in appointments, and may have blocked caregiver access to clinicians, despite the fact that they may have had their own questions and concerns. Additionally, cognitive impairments and issues with behavior and personality led to at least one patient becoming confrontational, and not wanting caregivers to talk about symptoms or ask questions during appointments. In three cases, participants felt that separate caregiver appointments might have been beneficial to getting caregiver questions answered. Another aspect of information management that arose was the issue of co-caregivers. Because caregiving is often time consuming and demanding, some caregivers shared responsibilities with s sibling or spouse. This meant that multiple people were involved in activities like scheduling appointments and managing medications, as well as capturing information about the patient's condition, and comparing notes over time.

Technology Use
Despite the fact that all participants reported using technology in their daily lives, with 12 of the 13 participants owning and using a smartphone regularly, the use of personal technologies in health activities related to their cancer diagnosis was very limited. From the technology use survey, we found that all 6 caregiver participants reported helping to keep tracking of information for the patient, with 4 relying on memory, and 2 using paper. For the patients tracking their own health information, three relied on memory, and two used paper. Additionally, two patient participants reported using smartphone applications for other aspects of health and well-being, unrelated to their cancer treatment. A few participants mentioned using electronic calendars for managing appointment information, as well as spreadsheets for keeping track of appointment schedules, medications, and financial information. In two cases, email was used as a means of communication as well as a method for documentation and management of information. One caregiver had tried using a medication reminder application for the patient they cared for, but found that it was difficult to maintain, and easy to ignore. It was not worth the effort of making updates to reflect frequent changes in medication type, dosage, and frequency, especially as the patient was not responding to the alerts.

Several participants had used smartphone applications for tracking exercise and fitness, diet, menstrual cycles, meditation, and information related to other health conditions. Despite everyday use of technology, paper was largely considered to be the easiest, fastest, and most convenient option. For several participants, paper was more likely to be on hand and immediately accessible compared to cellphones, computers, or tablets. Other participants felt that they could not navigate these devices quickly or efficiently enough to record the information of interest. With paper, participants could jot down questions or notes whenever they came to them without having to go find a device, log in, and access a feature for recording information. In the clinic, participants could write out their questions beforehand, and quickly record responses alongside those questions during the appointment. Another benefit of paper, for one participant, was that they could practice cognitive and motor skills including hand eye coordination when writing in their notebook. For these participants, limited technology use in health was not related to distrust, but convenience was a matter of functionality and convenience.

Patient portal usage was also explored in this study. The majority of participants had accessed their own patient portal at least once, or the portal of the patient they were providing care for. They felt that in general, the features and information was useful, but often limited. They reported accessing the portal to look at blood work, radiology reports, and other test results, and occasionally to verify appointment information. There were also challenges and limitations associated with patient portals, however. Access was an issue for several participants, as they had experienced difficulties with the system failures or had forgotten their log in information. For some participants, patient portal access was not offered until later in their treatment process, and historical information was not available through the system. Additionally, many caregivers did not know whether they could receive access to the portal of the patient they provided care for, and instead had to rely on having the patient log in and allow them to view the information. Some patients were receiving care from providers across different healthcare systems, or at healthcare systems without integrated portals so information was inaccessible or dispersed across portal systems. They also expressed frustrations related to missing data and the often limited nature of the information provided in reports. Participants felt that they should have immediate access to their own health data, and that delays in posting this information was unacceptable. In some cases, the patient and their caregiver already knew all of the information

by the time it was posted to the portal. Other noted challenges and frustrations involving systems not being user friendly. Many of these challenges and limitations led to users to abandon the portals, instead relying on other means of communication or information access such as requesting print outs in during clinic visits. Several participants noted that these portals could be much more useful if they provided additional information, features, and functionalities including the ability to record their own information and notes, and access to information and resources about the patient's diagnosis and resources would be helpful to have.

Future Behaviors and Motivations
Self-tracking to support patient care and understanding
Many participants felt that technology could potentially be beneficial for supporting tracking and managing health information, provided that it was designed to meet their needs, interests, and abilities. They felt that having a more complete record of information for clinicians to work through in making decisions and determining causes of symptoms and side effects could be helpful. Additionally, some felt tracking could be helpful in understanding and finding correlations in their own data, and could reduce the need for memory in recalling questions and information related to experiences in the days and weeks between appointments. However, because participants were not currently using any sorts or applications or tools in tracking or managing their health information, and because the only reference they had was the limited functionality of current patient portals, there was some reluctance to say with confidence that they would switch over if tools were to become available. Some of this was resistant to change as they had already developed methods that worked well enough for them, relying on paper and memory. As such, current behaviors and motivations, as well as the needs, interests, and abilities of these patients and their caregivers would need to be carefully considered in future technology design.

Benefits for future patients and caregivers
Thinking back on the challenges they faced, many participants felt that they could have benefitted greatly from the data and experiences of previous patients and caregivers, especially in helping to know what to expect, and to determine whether what they were experiencing was normal. One caregiver felt having access to such data, through the mediation and interpretation of clinicians, would have helped them to ensure that they were not being naïve in their expectations, while another felt that this would help them in reassuring and supporting the patient they were caring for, especially early on. Data of interest included quality of life and survival, and information surrounding type, severity, and duration of symptoms and side effects, as well as whether they resolved on their own or if intervention was necessary and effective.

Another area where this would have been useful is in working through information surrounding prognosis and what to expect as the disease progresses. As clinical trial data is incredibly limited for patients with primary brain tumors, clinicians are often forced to rely on their own experiences and anecdotal evidence when providing this information. Several participants felt having access to more complete tracked data could potentially help clinicians in providing more confident estimates of prognosis. Many participants were highly motivated by data and felt that having the option of knowing the potential possibilities, and having statistics to back that up would be of great comfort and benefit to themselves as well as future patients and caregivers. Although the majority of participants would have appreciated seeing such data or experience information, others had strong preferences about what they did and did not want to see. One participant indicated that they were not at all interested in seeing or hearing about experiences of previous patients with their condition because of the personal nature, and the eventual uncomfortable reality that it is a terminal disease. The same participant was comfortable with viewing data, but reaffirmed that they were not interested in anything related to personal experiences. They felt that the experience information may have been helpful for their caregiver, however.

Willingness and motivation for Future Tracking
Recognizing that patient and caregiver tracking and reporting of these data and experiences would be essential to having it available to address these challenges for future patients and caregivers, these participants were almost entirely unanimous in their willingness to provide that data. Some participants like P07 felt that this would be a good way to contribute, saying *"I said right from the beginning, I would be happy to help down the road... I am not the last one that's going to get this diagnosis, there's people coming up all the time with it. If I can help somebody else, I would be happy to do that."* For others, the major motivation was mainly in having the data available for current patient care activities and psychological comfort.

Discussion

Some of the significant findings from this study was the participants strong desire for more information, a willingness to contribute to their own care and that of future patients and caregivers, and the desire for a better understanding of their current situation and potential future with this disease. Due to the number of variables involved and problematic uncertainty, it is currently impossible for clinicians to provide detailed estimates of prognosis for the majority of these participants, which is a major point of confusion and frustration. Optimism and positivity from clinicians was appreciated at times, but also detracted from overall understanding. Although likely intended to inspire optimism to 'defy the median survival rates,' the approach and telling patients that they are unique, and not like other patients was not helpful. Rather, participants felt that having access to actual data through clinicians, and to compare themselves to know whether their experiences were as expected, and to identify possible trajectories was incredibly empowering. They felt data could help patients, caregivers, and clinicians to have these honest conversations, even if it meant that there were still many possible trajectories and outcomes. Also, acknowledging that this data likely does not yet exist motivated these participants to be an active part of the data collection process, providing benefit beyond their own patient care.

In addition to these findings, we identified three major considerations for future design and development in this space. First, when discussing the design of technologies for users with complex medical conditions, the interests, needs, and abilities of the intended users require special attention. This is not unique to brain tumors, but because the brain controls so many functions, and these tumors can impact a wide variety of abilities, incorporating this information into design discussions from the start is important. For individuals with potential motor impairments or challenges with language, requirements for multiple methods of data entry (e.g. text, speech, pick list) may be necessary. Minimizing the need for memory, and streamlining the process to avoid redundancy was important. Participants felt that the technology should be 'smart' enough to pull relevant data directly from the medical record with minimal efforts from the patients and caregivers. They also emphasized that methods of data collection would be important for assessing reliability, preferring subjective measures over long narratives. Additionally, processes for verifying information would also be beneficial. Ultimately, data entry has to be convenient or else it will not occur. Considerations for shared access for caregivers was also necessary as some patients may be unwilling or unable to participate in tracking activities during part or all of their treatment process.

Second, because participants were satisfied with their current methods of tracking and managing information, there will likely be a barrier to overcome in incorporating technologies into their routines. For these participants, the potential benefits of having a more complete record to support discussions, and the potential that this data might help patients to support their own discovery process was valuable. Integrating the use of this data into clinical encounters might be one way of overcoming that barrier. Incorporation into the clinical encounter also provides an opportunity for clinicians to review the information with patients and their caregivers to ensure reliability and completeness prior to submitting it to a repository. Patients and caregivers were more trusting of the information that they were given when it came directly from or was verified by their clinicians. Although data integrity can be an issue with many types of patient-reported data, it is especially a concern here where cognitive, emotional, and behavioral factors may influence the data, and where the amount of data available is likely to be very small. Another benefit of integration of these applications and discussions into the clinical encounter is that patients may feel like they have the tools to help lead discussions surrounding likely causes or correlations between side effects and medications. Clinicians can also control the conversation and interpretation of data, and can guide conversations based on an understanding of patient values and preferences. As a final consideration, participants felt that any solution that is put into place needs to be easier and more convenient than pen and paper, which for these participants, would be very difficult to achieve. To overcome this, there must be significant motivation and benefit for them. For these participants, some saw benefit for patient care activities, while others were incredibly motivated by the chance to provide data and give back to future patients and caregivers. This may be generalizable to other patient populations where there are few patients, and many uncertainties.

There are two main limitations to acknowledge in considering the findings of this study. First, this study involved a relatively small number of participants due to challenges with recruitment, the rare nature of primary brain tumors, and the severe impact and burden they place on patients and their caregivers. Several potential participants were unable to participate due to demanding treatment schedules and the lasting effects of the disease. Additionally, these participants may not be truly representative of the overall brain tumor patient population, especially in terms of education and race. This was largely due to the fact that the patient population is small to begin with, and we only recruited within the Seattle area. Several of these participants however traveled from surrounding areas and states for specialized treatment at facilities in the Seattle area.

Conclusion

Mobile-health and patient-facing technologies are not yet readily available for this population, however, the potential for tool design in this area is vast. Not only would a smartly designed tool, created to overcome barriers and designed with the needs and abilities of these particular users in mind, support current patients and their caregivers, but also those who will be stricken with this disease in the future. These patients and caregivers face numerous challenges and uncertainties, for which this data could provide a tremendous amount of insight and relief. Designing a patient facing tool for this area of healthcare has great potential to benefit not only this subset of patients, but also provide insight into the overwhelming number of little understood diseases.

References:

1. Ostrom QT, Gittleman H, Fulop J, et al. CBTRUS statistical report: primary brain and central nervous system tumors diagnosed in the united states in 2008-2012. Neuro-Oncology. 2015;17(4).
2. Osoba D, Brada M, Prados MD, Yung WK. Effect of disease burden on health-related quality of life in patients with malignant gliomas. 2000;2(4):221-228.
3. Klein M, Taphoorn MJB, Heimans JJ, et al. Neurobehavioral status and health-related quality of life in newly diagnosed high-grade glioma patients. Journal of Clinical Oncology. 2001; 19(20):4037-4047.
4. Pelletier G, Verhoef MJ, Khatri N, Hagen N. Quality of life in brain tumor patients: the relative contributions of depression, fatigue, emotional distress, and existential issues. Journal of Neuro-Oncology. 2002;57:41-49.
5. Wen PY, Kesari S. Malignant gliomas in adults. New England Journal of Medicine. 2008. 359:492-507.
6. Liu R, Page M, Solheim K, Fox S, Chang SM. Quality of life in adults with brain tumors: Current knowledge and future directions. Neuro Oncol. 2009 Jun 1;11(3):330–9.
7. Lester RT, Ritvo P, Mills EJ, et al. Effects of a mobile phone short message service on antiretroviral treatment adherence in Kenya (WelTel Kenya 1): a randomised trial. Lancet. 2010. 376(9755):1838-1845.
8. Quinn CC, Clough SS, Minor JM, Lender D, Okafor MC, Gruber-Baldini A. WellDoc™ mobile diabetes management randomized controlled trial: change in clinical and behavioral outcomes and patient and clinician satisfaction. Diabetes Technology and Therapeutics. 2008;10(3):160-168.
9. Klasnja P, Hartzler A, Powell C, Phan G, Pratt W. HealthWeaver mobile: designing a mobile tool for managing personal health information during cancer care. AMIA Annual Symposium Proceedings. 2010:392-396.
10. Klasnja P, Pratt W. Health in the pocket: mapping the space of mobile-phone health interventions. Journal of Biomedical Informatics. 2012;45:184-198.
11. Free C, Phillips G, Galli L, et al. The effectiveness of mobile-health technology-based behaviour change or disease management interventions for health care consumers: a systematic review. PLOS Medicine. 2013.
12. Joe J, Demiris G. Older adults and mobile phones for health: a review. Jounral of Biomedical Informatics. 2013;46(5):947-954.
13. Anthes E. Mental health: three's an app for that. Nature. 2016;523:20-23.
14. Luxton DD, McCann RA, Bush NE, Mishkind MC, Reger GM. mHealth for mental health: integrating smartphone technology in behavioral healthcare. Professional Psycholoy: Research and Practice. 2011;42(6):505-512.
15. Owen JE, Jaworski BK, Kuhn E, Makin-Byrd KN, Ramsey KM, Hoffman JE. mHealth in the wild: using novel data to examine the reach, use, and impact of PTSD coach. JMIR Ment Health. 2015;2(1):e7
16. Fox S, Duggan M. Health online 2013. Pew Research Center: Internet, Science, and Tech. Internet. Available: http://www.pewinternet.org/2013/01/15/health-online-2013/
17. MacLeod H, Oakes K, Geisler D, Connelly K, Siek K. Rare world: towards technology for people with rare diseases. In Proceedings of the SIGCHI Conference on Human-Factors in Computing Systems (CHI). 2015.
18. Wideheim AK, Edvardsson T, Pahlson A, Ahlstrom G. A family's perspective on living with a highly malignant brain tumor. Cancer Nursing. 2002; 25(3): 236-244
19. Newton C, Mateo MA, Uncertainty: strategies for patients with brain tumor and their family. Cancer Nursing. 1994; 17(2):137-140
20. Schubart JR, Kinzie MB, Farace E. Caring for the brain tumor patient: family caregiver burden and unmet needs. Neuro-Oncology. 2008; 10(1):61-72
21. Halkett GKB, Lobb EA, Oldham L, Nowak AK. The information and support needs of patients diagnosed with High Grade Glioma. Patient Education and Counselling. 2010; 79:112-119.
22. Health Tracking Survey 2012. Pew Research Center. 2013. Available: http://www.pewinternet.org/files/old-media//Files/Questionnaire/2013/Surveyquestionsandmethodology.pdf