Designing and Evaluating a Patient-Driven Application for Patients with Primary Brain Tumors

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Abstract

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From the time of diagnosis through treatment and follow-up, patients with primary brain tumors and their caregivers face a multitude of challenges and uncertainties. Many of these challenges and uncertainties have been attributed to the complexities of these rare and deadly tumors, coupled with the fact that there is still much to learn about the brain tumor patient experience, especially in terms of estimating prognosis, and understanding and predicting the impact of disease and treatment on these patients. These tumors, as well as the medications and treatments employed in battling this devastating disease, are often associated with severe symptoms and side effects ranging from seizures, headaches, nausea, and fatigue, to gross deficits in general cognition, changes in behavior and personality, and impairments in neurocognitive functions and abilities. In addition to challenges associated with managing and understanding these symptoms and side effects, patients and their caregivers are faced with new and often unfamiliar information and terminology, and must work to make informed decisions regarding treatments and medications in the presence of great uncertainty. Despite a recent increase in the use of personal technologies to support health-related care and self-management activities for a wide range of patient populations, there are very few tools and technologies currently available to support the needs of this unique and challenging patient population.

In this dissertation, I investigate the challenges, needs, and experiences of patients with primary brain tumors and their caregivers in working toward designing and developing tools and technologies to support these individuals in tracking, understanding, managing, and communicating health information. Throughout this process, I engaged patients, caregivers, and clinicians in semi-structured interviews to build an in-depth understanding of current challenges and behaviors, and identify motivations, as well as preliminary recommendations and requirements for design going forward. I then used Participatory Design techniques to work alongside patients and caregivers as partners in creating a prototype of a brain tumor specific smartphone and tablet application. From these user-driven contributions, I then developed a high-fidelity prototype that was evaluated by brain tumor patients, caregivers, and clinicians to explore usability, functionality and benefit, and to further overall understanding of how this tool could be implemented and used to support these and future users throughout treatment and follow-up.

Through this research, I contribute a greater understanding of the challenges, needs, and experiences of this unique patient population, as well as an investigation of current technology use in health and daily life. I compare and contrast patient, caregiver, and clinician perceptions of challenges, benefits, interests, and abilities regarding patient-driven self-tracking, management, and communication, and share my experiences in employing Participatory Design techniques in working alongside patients and caregivers throughout the research and design process. Finally, I discuss how my methods, findings, and experiences could impact future design and implementation of tools and technologies in this and other similarly challenging patient populations.

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DEDICATION

I would like to dedicate this work to the patients and caregivers who took part in and truly motivated this research, and those who will benefit from it in the future.

Chapter 1: Introduction, Background and Motivation

1. Introduction

Primary brain tumors are a complex and challenging disease. These tumors are both rare and difficult to treat, and often result in a significant burden on patients and their families. Despite extensive research aimed at identifying the causes and underlying mechanisms of these tumors, as well as advancing treatment approaches and technologies, prognosis remains poor for the majority of these individuals. As they progress through the disease and treatment process, many of these patients will experience deficits and declines in neurocognitive and functional abilities, as well as severe symptoms and overwhelming treatment- and medication-induced side effects. Throughout the course of diagnosis, treatment, and follow-up, patients and their caregivers take on new roles and responsibilities in managing health information, medications, and treatment schedules, understanding and battling harsh symptoms and side effects, researching treatment options, and participating in care, communication, and decision-making activities. At the same time, they face many challenges and uncertainties as they adjust to a new set of circumstances, and work to understand what this disease means for themselves and their families.

In recent decades, there has been increased interest in supporting and empowering patients in taking on an active role in care, health and information management, and decision making activities. As many aspects of these activities take place outside of the clinical environment, researchers have looked to personal technologies, including applications on tablet and smartphone devices, as a potential means for supporting patients and their caregivers in tracking and management activities. In order to be effective, however, these tools and technologies must be designed with a thorough understanding of the intended users and their unique circumstances, needs, interests, and abilities. In this research, I aim to investigate the challenges, needs, and experiences of patients with primary brain tumors and their caregivers, and work to design tools and technologies to support these users in tracking, managing, understanding and communicating health-related information throughout the diagnosis, treatment, and follow-up process.

In this chapter, I introduce and motivate this research, and outline the upcoming chapters of this dissertation. In section 2 of this chapter, I first present background information on primary brain

tumors, and discuss relevant information surrounding incidence, prognosis, and treatments. I then provide further context into the impact of these tumors in terms of symptoms and side effects, and briefly discuss current research in this area. In section 3, I introduce methods and challenges associated with capturing patient-reported information regarding symptoms and side effects, and discuss recent research and developing surrounding self-tracking and information management. Finally, in section 4, I provide an overview of my objectives and motivations in this research, and outline the upcoming chapters of this dissertation.

2 Primary Brain Tumors

2.1 Background

Primary brain tumors are the result of uncontrolled growth of abnormal cells within the tissues of the brain. The term primary indicates that the tumor is the result of disease originating within the brain, as opposed secondary tumors which begin elsewhere in the body (e.g. breast, bone, or lung cancers) and spread or metastasize to the brain [Recht 2016]. Unlike other forms of cancer, brain tumors tend to progress and recur within the brain, but rarely spread beyond the central nervous system (brain and spinal cord) [Greenberg 1999]. These tumors are traditionally classified based on the type of cells from which they originate and their behavior, however, molecular and genetic components are increasingly being factored into the diagnosis and classification process [Louis 2016, Greenberg 1999]. Upon diagnosis, each tumor is assigned a grade (I-IV) that is associated with malignancy and prognosis based cellular behaviors and characteristics including the degree of cellular abnormality and rate at which the diseased cells are dividing and multiplying [Louis 2007]. Grades I and II tumors are commonly termed low-grade and are typically slow growing, while grades III and IV are considered to be high-grade, and are associated with more aggressive and rapid growth and an often poor prognosis [Recht 2016, Batchelor 2016, Louis 2007]. Unlike many other cancers, these tumors are unique in that even those designated as low-grade tumors have the potential to cause severe or even life-threatening symptoms depending on their location within the brain [Recht 2016, Greenberg 1999]. Further, regardless of grade, primary brain tumors are known to progress and recur, and are typically described as incurable [Recht 2016, Batchelor 2016].

2.2 Incidence

In 2016, it is estimated that 77,670 adults in the United States will be diagnosed with some form

of primary brain or central nervous system tumor [Ostrom 2015]. Of these diagnoses, nearly 25,000 will be attributed to malignant disease [Ostrom 2015]. Although each of the malignant tumor types are considered to be rare, affecting fewer than 200,000 individuals, primary brain tumors are associated with a high degree of morbidity and mortality, as discussed in section 2.3.

According to the Central Brain Tumor Registry of the United States (CBTRUS), the most comprehensive population-based site-specific registry for these tumors in the nation, the median age at diagnosis for all primary brain and central nervous system (CNS) tumors is 59 years of age [Ostrom 2015]. Some tumors types such as glioblastoma tend to occur in slightly older adults (median 64 years of age), while others like oligoastrocytic tumors and oligodendroglioma tend to occur in younger adults (median 42 and 43 years of age, respectively) [Ostrom 2015]. Although many of these tumors tend to occur in middle to later adulthood, children and young adults are also affected. In fact, based on data from 2008-2012, primary brain and CNS tumors are the most common cancers in children aged 0-19, and the second leading cause of cancer deaths in this same age group [Ostrom 2015]. Overall, primary brain and CNS tumors tend to occur more often in females (57.9% of diagnoses, Incidence Rate: 23.95 per 100,000 vs 19.82 per 100,000 for males), however, approximately 55% of malignant tumors occur in males [Ostrom 2015]. Incidence rates for all primary brain and CNS tumors are highest for white populations, followed closely by black, Asian/Pacific Islander, and finally American Indian/Alaskan Native populations [Ostrom 2015].

2.3 Prognosis

Survival rates for primary brain tumors vary greatly, however, for a large portion of these individuals, prognosis is poor. Current estimates for overall 1-, 5-, and 10-year survival rates for all patients with malignant disease are 58.1%, 34.4%, and 28.8%, respectively [Ostrom 2015]. This means that in the first year following diagnosis, nearly 42% of patients with a primary malignant brain tumor will pass away. In the case of glioblastoma, the most common and aggressive malignant brain tumor, prognosis is especially grim, with estimates typically measured in terms of months instead of years. Overall, only 37.2% and 5.1% of patients diagnosed between 1995 and 2012 were surviving at 1 and 5 years following diagnosis, with adults over the age of 55 experiencing both lower survival rates and higher incidence rates [Ostrom 2015]. On the other hand, patients with anaplastic oligodendroglioma experienced much

higher long-term survival, with 5-year survival rates falling at 52.5% and 10-year survival at 38.9% [Ostrom 2015].

Individuals often look to registry and clinical trial data surrounding survival rates and median survival to obtain a better understanding of prognosis and likely outcomes for their own individual situation, however, these statistics can be misleading in supporting individual prognosis estimates for several reasons. First, registry data in this format provides no information about treatments received or other factors contributing to survival outcomes. Further, it is often unclear how tumors that tend to progress or recur as higher grade disease are taken into account in these numbers. Finally, there are many different subtypes of these tumors [Davis 2008], and the ways in which they are classified and defined have changed over time [Louis 2016, Greenberg 1999, Bondy 2008]. This, combined with that fact that the process for diagnosing and classifying tumors often includes subjective criteria and can be inconsistent [Davis 2008, Ostrom 2014, Coons 1997], can lead to variability in diagnoses that may impact overall interpretations and implications of this data.

2.4 Treatment

Due to the nature and behavior of these tumors, as well as their location within the primary center for control and coordination of the body, primary brain tumors are often incredibly difficult to treat. Looking specifically at high-grade gliomas, treatment typically begins with surgery to remove as much of the tumor as possible without damaging the surrounding healthy tissues and corresponding functions of the brain, coupled with a biopsy to capture a sample of the tumor for histopathological examination and tumor type and grade determination [Batchelor 2016]. Next, patients will typically undergo an intense course of radiation therapy, accompanied or followed by chemotherapy [Batchelor 2016, Omuro 2013]. While surgery is typically a one-time event, radiation is traditionally administered on a daily basis over a period of several weeks. Chemotherapy protocols vary depending on the diagnosis, drug, and patient, but commonly consist of several multi-week cycles, that may continue over the course of many months or even years. For these patients, the goal of these treatments is to remove or kill as much of the disease as possible and prevent future growth or recurrence for as long as possible, however, because the majority of these tumors are considered to be incurable, these goals eventually transition over to providing palliative care, focusing on reducing symptoms, and improving functional abilities and

quality of life, rather that aiming for complete cure [Batchelor 2016]. Unfortunately, whether curative or palliative in nature, these treatments are not without risk or consequence, and often result in some form of temporary or lasting deficit or treatment induced effect. These effects, as well as symptoms associated with the disease are discussed below in section 2.5.

2.5 Symptoms and Side Effects

Throughout the course of disease and treatment, patients will experience a wide range of symptoms and side effects, many of which can interfere with their ability to participate in normal daily activities, and have a severe impact on quality of life. As the tumor cells multiply, they act by growing and invading the tissues and spaces of the brain, a process that not only leads to damage at the tumor site, but also threatens adjacent brain areas and functions as pressure increases within the already limited confines of the skull due to growth and inflammation [Greenberg 1999, Batchelor 2016, Recht 2016]. The result of this process ultimately leads to the presentation of neurological symptoms, which are often associated with significant amounts of burden and distress. The type and severity of these symptoms will vary considerably depending on the size and location of the tumor, as different areas and regions of the brain are responsible for different functionalities [Recht 2016, Armstrong 2005]. Common symptoms include headaches, pain, seizures, nausea and vomiting, drowsiness, fatigue, changes in vision, language, or communication abilities, changes in bowel or bladder habits (e.g. diarrhea and constipation), and changes in appetite. Patients may also experience motor dysfunction, difficulty with balance, coordination, and gait, and weakness or changes in sensation on one side of the body, depending on the location of the tumor. Changes in cognition, behavior, and personality are also very common for these patients, and often include deficits in memory, concentration, and comprehension, as well as difficulty with executive functions such as task initiation or completion [Armstrong 2005, Armstrong 2006, Osoba 2000, Omuro 2013, Cahill 2012].

Treatments including radiation therapy and chemotherapy may contribute to the symptoms, side effects, and overall burden experienced by these patients. In addition to recovering from the impact of brain surgery, patients may initially experience worsening of symptoms during radiation therapy, as well as both temporary and lasting fatigue and cognitive deficits in the weeks and months following treatments [Butler 2006, Liu 2009]. Additionally, patients

undergoing radiation therapy for a primary brain tumor are at risk for late severe and potentially deadly complications including radiation necrosis and secondary tumors due to radiation exposure [Butler 2006, Dietrich 2016]. Chemotherapy drugs commonly used in treating primary brain tumors are also associated with severe side effects including nausea and vomiting, diarrhea, constipation, fatigue, lowered platelet, red, and white blood cell counts, bleeding, and headaches as well as neurological symptoms including seizures, vision changes, confusion, drowsiness, and depression [ABTA 2016]. Interestingly, many of these treatment induced effects are similar to symptoms of brain tumors themselves and may complicate the process of determining causal factors, or interfere with identification of tumor progression or recurrence.

Finally, the medications that patients are put on to manage these symptoms and treatment effects also commonly contribute additional side effects for patients to manage. For example, most patients will be put on steroids at some point during treatment to reduce inflammation in the brain and prevent further neurological symptoms or complications. These drugs, however, are associated with side effects including increased appetite, insomnia, behavior changes, night sweats, tremors, and increased risk of infection [Drappatz 2016]. Further, when tapering off of steroids, patients may experience withdrawal symptoms including headaches, lethargy, and fever [Drappatz 2016]. Medications to control or prevent seizures can contribute to headaches and fatigue, as well as dizziness, depression, agitation, and anxiety [Drappatz et al 2016]. Additional medications including those to manage pain, nausea and vomiting, and constipation, for example, also introduce their own side effects that must be managed.

2.6 Research and Clinical Trials

Research priorities in neuro-oncology have traditionally focused on understanding the underlying mechanisms of these tumors, and improving survival outcomes. Unfortunately, despite significant efforts, overall survival rates for the majority of these tumors remain incurable, and there are still many unanswered questions surrounding factors affecting risks as well as prognosis for these patients. One recent study of note, however, was an international clinical trial investigating the effects of radiation therapy and Temozolomide (chemotherapy) for patients with glioblastoma. Researchers in this study found that overall median survival for patients receiving radiation therapy with concomitant and adjuvant Temozolomide was 14.6 months, compared to 12.1 months for patients receiving radiation therapy alone [Stupp 2009]. Although

this may seem modest, it represents a major improvement for this patient population, where survival is measured in months rather than years.

Because of this emphasis survival outcomes, gold standard endpoints in neuro-oncology clinical trials have traditionally focused on objective measures such as overall survival and progression free survival [Reardon 2011, Armstrong 2013]. In recent years, however, researchers have acknowledged that these traditional endpoints may be problematic, and may not be sufficient on their own for demonstrating clinical benefit for this patient population [Armstrong 2013, Meyers 2012, Reardon 2011]. Rather, outcomes involving symptoms, neurocognitive functions, and quality of life may be just as important and meaningful to patients, caregivers, and clinicians, as those involving survival [Reardon 2011, Meyers 2012, Dirven 2104]. Recognizing the importance of this information, several major neuro-oncology clinical trials over the past decade have included measures for capturing such data as secondary endpoints. For example, in addition to overall survival, researchers in the Temozolomide study used specialized questionnaires to investigate patient-reported impact of the different protocols on health-related quality of life, finding no significant differences between the groups [Taphoorn 2005]. It should be noted, however, that as the study progressed, the number of surviving participants completing the assessment decreased significantly, reaching completion rates as low as 25%. As a result, researchers were unable to draw meaningful conclusions from this data after the fourth week of follow-up [Taphoorn 2005].

Adoption of such surveys and questionnaires to assess factors related to symptoms and quality of life, known as patient-reported outcome measures, has been slow in neuro-oncology clinical trials, as researchers have reportedly raised concerns regarding patient ability and reliability in self-reporting due to the neurocognitive impact of the disease, and have raised questions about how best to capture this information in the presence of such concerns [Armstrong 2013]. As a result, there have been organized efforts in the neuro-oncology research community to define what are being coined as clinical outcome assessment (COA) endpoints, and establish better approaches to capturing this information in clinical trials through the use of performance measures, as well as patient-, clinician-, and observer-reported outcome measures [Armstrong 2014, Armstrong 2016, Hefler 2016].

Challenges and limitations in brain tumor-related research are not uncommon. Beyond the challenges associated with capturing patient-reported outcomes, these are several other major challenges facing this population that often limit overall clinician knowledge surrounding optimal treatment approaches, and prognostication abilities. Many of these challenges are attributed to the aggressive nature and severe impact of the disease. For example, researchers have noted that the short median survival of patients with glioblastoma makes it difficult to identify prognostic factors [Bondy 2008]. In other cases, the impact of the disease associated neurocognitive deficits can interfere with patient abilities to participate in and adhere to trial protocols [Bondy 2008]. This, combined with the fact that these tumors are rare, often means that recruitment of sufficiently large sample sizes can be difficult or even impossible [Bondy 2008, Roa 2004]. Finally, inclusion, participation, and recruitment of certain demographic groups, especially older adults, is often limited in these trials, which in turn means that ideal treatment approaches for these individuals may not be well understood [Scott 2011, Chang 2002, Roa 2004, Laperriere 2013].

3. Patient Reported Outcome Measures and Patient-Generated Health Data

3.1 Patient-Reported Outcome Measures in Brain Cancer

As previously noted, patient reports regarding symptoms, side effects, and quality of life can be valuable toward understanding and quantifying the impact of the disease and treatment process on patients, both in the clinic and as a component of determining clinical benefit and drug efficacy in clinical trials. One method for capturing this information directly from patients involves the use of Patient-Reported Outcome (PRO) measures. PRO measures are developed to serve as a standardized means for capturing information about the patient experience related to symptoms, side effects, quality of life, and other health events directly from the the patient, without the interpretation of clinicians or others involved in their care [US Department of Health and Human Services 2006]. These measures typically take the form of paper-based or computerized surveys and questionnaires, and are commonly developed and validated based on the findings of extensive literature reviews and consultations with clinicians and other domain experts, as well as contributions from patients and their caregivers. There have been several PRO measures developed and validated specifically for use in this patient population. These measures include the Functional Assessment of Cancer Therapies – Brain (FACT-BR) [Weitzner 1995]

and the European Organization for Research and the Treatment of Cancer Quality of Life Questionnaire – brain cancer module (EORTC QLQC30 – BN20) [Osoba 1996] for eliciting information related to aspects of symptoms, well-being, and quality of life. Additionally, the MD Anderson Symptom Inventory- Brain Tumor module (MDASI-BT) [Armstrong 2006] and the National Comprehensive Cancer Network/Function Assessment of Cancer Therapy-Brain Symptom Index (NFBrSI-24) [Lai 2014] are symptom inventories designed to collect information about symptoms and their impact directly from patients. NeuroQOL, a quality of life assessment tool used in a range of neurologic conditions, may also be useful for eliciting this information directly from patients, although it was not originally designed to focus on patients with primary brain tumors [Cella 2012].

3.2 Patient- Generated Health Data

Patient-reported data is not only important in clinical trials, but also in patient care. As patients are increasingly being acknowledged as informed and empowered participants in their own care and decision making processes, there has also been increased recognition toward the value of the data that patients can contribute to these activities. For example, in addition to causing a significant amount of burden and distress, symptoms and side effects can act as indicators of disease progression or potential complications. As such, timely detection and reporting of this information is an important component of the treatment and follow-up process. The process of capturing this data in the clinic traditionally relies heavily on the patient and their ability to detect, store, recall, and relay relevant information related to the symptoms and side effects they are experiencing through interview-type encounters. Unfortunately, for these patients, the cognitive processes and functions necessary for these tasks may already be taxed in the clinic environment, or impaired by disease and treatment induced effects, leading to challenges in reporting this data. As an alternative, patients may be able to capture and record health information on their own outside of the clinic such that it can be accessed and shared by the patient when needed. This data, known as patient-generated health data (PGHD), is described as health-related data that is ‘created, recorded, gathered, or inferred by or from patients and their designees to help address a health concern [Shapiro 2012].’ PGHD can include data surrounding health and treatment history, symptoms, biometric data, or other information that is of interest to the patient [Shapiro 2012]. Such information may be captured through traditional PRO measures,

as described in section 3.1, on paper, or using technology-based mechanisms including health applications on smartphones, wearable technologies, or home medical devices [Petersen 2015].

In the case of patient-generated health data, data collection and reporting is a patient-driven process: patients are largely making the decisions about what they would like to track and report based on their own individual experiences, interests, conditions, and concerns, with clinicians providing guidance surrounding data collection and interpretation. Data captured through these mechanisms typically goes beyond standard outcomes of interests in research and clinical trials, instead focusing on what is important to the patient. In the longer-term, this type of patient-generated data can be helpful for understanding values and quality of life issues in cancer patients and survivors, as well as learning about individual variations in the impact and course of disease [Petersen 2015]. Information gathered through this type of data collection may be clinically meaningful and informative to patients, clinicians, and researchers alike, and provide additional insights into the patient experience outside of the clinic, from the patient perspective. Although not yet commonly implemented in a formal manner, this kind of approach could be especially relevant and beneficial for patients with primary brain tumors, a condition where it can be especially important to focus on what is important and meaningful to the patient. In order to do so, however, it is likely that patients will need additional guidance, support, and direction.

3.3 Challenges and Limitations of PRO and Patient-Reported Data Collection in Brain Tumors

There are several challenges and limitations surrounding the use of PRO measures and patient-reported data collection in this patient population. First, completion rates of PRO measures and similar assessments of symptoms and quality of life in research and clinical trials are often extremely low, making meaningful data analysis difficult or even impossible [Bae 2011, Kvale 2009, Roa 2004, Taphoorn 2005]. Although factors contributing to low survey and questionnaire complete rates in brain tumor-related studies are often unclear, several researchers have suggested or associated these challenges with high attrition rates, administration errors, patient refusal, difficulty understanding or responding to questions, burdens and inability to complete forms due to cognitive or physical impairments or decline [Dirven 2014, Bae 2011, Meyers and Hess 2003, Erharter 2010, Walker 2003, Kvale 2009].

Challenges associated with capturing data from these patients also exist outside of the context of research and clinical trials. Although PRO measures and other similar instruments may be effective in capturing data for research purposes, the value and benefit of these measures in clinical practice remains unclear. Several studies have shown that the use of these measures has lead to improved communication and aspects of patient care when used as a part of routine clinical encounters for other cancer patient populations [Detmar 2002, Velikova 2004, Kotronoulas 2014], however, results have not been as decisive in studies involving patients with primary brain tumors [Kvale 2009, Erharter 2010]. Additionally, others have noted challenges, barriers, and limitations associated with their use in the clinical context, namely that it is often unclear how to interpret and act upon the results of these measures, and question both how they are intended to impact and whether their use truly impacts patient care, outcomes, and decision making activities [Greenhalgh 2005, Howell 2015].

There are also challenges associated with PGHD and other patient-driven data collection outside of clinician or researcher initiated activities. As previously mentioned, the responsibility for detecting and reporting symptom and side effect information outside of the clinic largely falls on the patient and their caregivers. Activities surrounding tracking, managing, understanding, and communicating this information can be greatly challenging for these individuals as cognitive impairments, as well as a lack of resources, knowledge, and support may act as barriers. Despite the increased recognition of the value and benefit of patient-generated health data, there are very few methods, tools, and technologies currently available to support these patients and their caregivers in capturing and communicating this information outside of the clinic. PRO measure are not currently designed to provide support in capturing or quantifying symptom data on their own, and in their current format, are seldom intended to provide feedback or support directly to patients in terms of understanding, detecting, or tracking changes or trends in their symptoms or experiences over time. Most also require scoring by clinicians and are not freely available to patients without registration or financial compensation. While individual symptoms or side effects can be tracked using seizures diaries, headache or pain journals, consolidated tools addressing the full range of symptoms and side effects experienced by patients in this population are lacking. Although there has been little research and development for this particular patient

population, the potential benefit of tools and technologies to support PGHD collection and communication could be great.

3.4 Patient-Facing Tools to Support Self-Tracking, Health and Information Management

As personal technologies including cellphone, smartphone, and tablet devices have become increasingly pervasive in health and daily life, many patients, clinicians, and researchers have turned to these technologies to facilitate and support self-tracking and health information management activities. Technology has been heavily involved in supporting self-management activities for patients with a variety of chronic diseases, as well as personal health information management activities for cancer patients. For example, Klasnja et al developed and deployed HealthWeaver and HealthWeaver Mobile, a set of web and smartphone based applications designed to support breast cancer patients in managing care-related information and activities throughout their treatment process [Klasnja 2010, Klasnja 2011]. HealthWeaver Mobile, the corresponding smartphone application, was designed specifically to support patients in accessing and managing health information in situations where they may not otherwise have the means or access to do so, such as when they are away from the home [Klasnja 2010]. These researchers found that patients perceived great benefit from the use of these tools. Through the use of calendaring, note taking, and symptom and well-being tracking functionalities, the participants in these studies reported that they could better capture and manage information, and felt more confident and better prepared for clinic visits, as they felt that they could access the information needed to answer clinician questions, and convey information about symptoms and other health issues in a manner such that it would be taken seriously [Klasnja 2010, Klasnja 2011]. In another study involving patients with breast cancer, Jacobs et al investigated how health information tools fit into daily life for these patients using My Journey Compass, a customizable tablet-based intervention to support information and management needs [Jacobs 2014]. Interestingly, these researchers found that patients reporting higher levels of technology use in work activities had lower levels of adoption of this intervention as they were already being faced with technology all day long, and were thus experiencing what the researchers had identified as “technology burnout” [Jacobs 2014]. These findings stressed the importance of understanding technology use, both in health and daily life, in the design and implementation of health technologies.

Outside of research and development involving individuals with cancer or more common chronic

conditions, these has also been work exploring self-management interventions for individuals with mental health disorders. For example, a recent survey of self-management and self-monitoring strategies for patients with bipolar disorder revealed for these individuals, participants reported that self-tracking activities led to better understanding and management of their condition, and improved communication with clinicians. These researchers found that many of the participants were relying heavily on technology to support their self-tracking and management needs. Despite the fact that these participants felt that technology made these activities easier and more accessible, they also found that many participants were having to rely on multiple applications or tools, as comprehensive tools and technologies to meet their needs and interests were not currently available. The participants noted that future tools and technologies should be consolidated and provide more granularity in tracking information relevant to their condition, and that usability and automation should be carefully considered as user motivation and ability to interact with technologies can be compromised at times due to the impact of the disease [Murnane 2016].

A small number of studies have focused on developing applications and tools to support care and self-management activities for individuals experiencing neurological conditions and neurocognitive disorders, however, this area remains largely unexplored. This is especially true in the case of primary brain tumors, a condition that is both rare and characterized by its severe neurocognitive symptoms and side effects, and where patient involvement in research outside of clinical trials and evaluation of clinician-driven research tools such as PRO measures has been extremely limited. Although an investigation of whether existing tools designed for other patient populations, or standalone applications intended to support tracking of individual symptoms and side effects associated with these tumors such as headaches, seizures, and fatigue, could potentially lead to interesting findings, I decided to use this opportunity to instead engage patients and caregivers directly in the process of investigating needs and challenges, and designing future tools and technologies.

4 Motivations and Dissertation Overview

The goal of this research is to explore the needs, challenges, and experiences of this patient and caregiver population in working to provide meaningful tools and technologies to support these users throughout their journey through brain cancer. This work is motivated by the fact that brain

cancer is an incredibly challenging disease for patients and caregivers alike. It is extremely difficult to treat, and is characterized by complex neurological symptoms and an often poor prognosis. Throughout the diagnosis and treatment process, patients and their caregivers face many challenges and uncertainties as they work to understand and manage symptoms and health information, and determine what to expect for the future. Despite increased interest and appreciation of these outcomes, there is still much to learn about the experiences and challenges of these patients outside of the clinic, and how best to capture that information.

As patients are increasingly being acknowledged as informed partners and contributors in care and decision making activities, and patient-facing tools and technologies to support these activities are becoming increasingly available and accepted across health and medicine, I believe that there is an opportunity to create meaningful tools and technologies to support these users in capturing, understanding, and managing health information.

Dissertation Overview:

In this research, I set out to explore the challenges, needs, and experiences of patients with primary brain tumors and their caregivers in the context of designing tools and technologies to support these individuals in tracking, understanding, managing, and communicating health information.

In Chapter 2, I present an overview of the methods I employ, and explain decisions regarding my overall approach to engaging patients, caregivers, and clinicians and capturing information and insights throughout the research and design process.

In Chapter 3, I present the findings of semi-structured interviews that I conducted with neuro-oncology clinicians involved in the treatment and follow-up of patients with primary brain tumors. Here, I sought to explore how patient-reported information is currently captured and used, as well as clinician perceptions surrounding challenges and the potential benefits, uses, and need for tools and technologies to support patient-driven data collection in this patient population. These findings served to provide an understanding of current workflows and approaches, as well as preliminary information about potential usability challenges and concerns.

In Chapter 4, I discuss findings of in-depth semi-structured interviews with brain tumor patients and caregivers, in which we discussed information needs and challenges related to symptoms and side effects, as well as overall experiences throughout treatment and follow-up. I took a mixed methods approach to investigating current uses of technology in health and daily life, as well as motivations and willingness to use technology in future health-related activities. These interactions served as the initial step in the overall patient-driven design process, as the information gathered throughout these interviews served to inform future research and design activities and decisions.

In Chapter 5, I describe the process of conducting a series of Participatory Design workshops with a small group of patient and caregiver participants. In this study, I used design activities to further explore needs and interests, and to engage patient and caregiver participants in the process of identifying and designing overall content, features, and functionalities of the future application. At the end of these workshops, I created a high-fidelity prototype of a smartphone and tablet application that would be evaluated by patients, caregivers, and clinicians in the following chapter.

In Chapter 6, I present an overview of the prototype application, and share findings of an evaluation study aimed at capturing patient, caregiver, and clinician feedback and impressions of this application in terms of features, functionalities, and usability. I also once again discuss perceptions of benefits, interest, and abilities surrounding patient-driven data collection and application use, and share considerations relating to future design and implementation of patient-facing technologies in this patient population.

Finally, in Chapter 7, I conclude by discussing the overall contributions and implications of this research, as well as opportunities for future work.

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Chapter 2: Approach: Participatory Design Alongside Patients with Potential Neurocognitive Impairments

1. Introduction

This dissertation research draws on methods and works from several different domains including biomedical and consumer health informatics, medicine, human computer interaction (HCI), design, and accessibility research. In Chapter 1, I introduced background information on primary brain tumors, and discussed related work surrounding challenges and limitations associated with current approaches to capturing patient reported data and consumer health technologies in this area. After identifying gaps in current knowledge and research, and establishing research questions and motivations, it was next important to determine how best to approach this overall research process. Acknowledging the need to develop an in-depth understanding of the challenges, needs, and experiences faced by patients with primary brain tumors, and incorporate these factors and considerations into the design of future tools and technologies, I decided to take a participatory design approach to this work, engaging patients and their caregivers directly in the research and design process. Because many of these patients will experience neurocognitive deficits or impairments that will likely not only impact both interest and ability to interact with tools and technologies, but also their ability to take part in traditional research and design activities, it was important to take a structured and informed approach to the overall research process. In this case, this meant taking into consideration the goals of this research as well as the unique needs and abilities of these individuals, and carefully selecting, planning, and tailoring research and design activities accordingly.

In this chapter, I present background information on participatory design, as well as an extended review of the literature involving designing with and for individuals with neurocognitive impairments and disorders. I then discuss strategies, approaches, and considerations employed throughout these studies, and describe how I applied them to my own work as I planned and constructed my overall approach to this research.

2. Background

2.1 Participatory Design

Participatory Design is a methodology that originated in Scandinavia as a means to increase democracy in the workplace by giving workers (users) a voice in the changes being made to the systems surrounding them [Kensing and Blomberg 1998, Spinuzzi 2005]. Since its inception, participatory design has successfully been employed as a means of investigating and incorporating the skills, experiences, and interests of users in the design of systems and technologies across a wide range of domains. Through activities including brainstorming, scenarios, prototyping, and evaluation, designers and users work together as partners to explore interests, skills, values, and needs while building relationships and a common understanding of 'tacit knowledge' and the work at hand [Kensing and Blomberg 1998, Lindsay 2012, Spinuzzi 2005].

In Participatory Design, there is an underlying assumption regarding participation and the cognitive, emotional, and physical abilities of those engaged in design activities. At the most basic level, participatory design is traditionally carried out in a group setting and involves generation and communication of thoughts, ideas, and experiences between participants and researchers [Spinuzzi 2005]. For individuals with neuro-cognitive deficits and disorders, being able to perform these basic activities without modification or support can be extremely challenging or even impossible. For these populations, a mismatch between the requirements of design activities and the abilities of participants can pose barriers to participation, and result in faulty understandings of the target population, as well as frustrations on the part of researchers and participants alike.

3. Related Work

3.1 Extended Overview of Participatory Design and Neurocognitive Impairments

As methods for engaging individuals with primary brain tumors in this type of research are largely unexplored, I looked to research and design studies involving similar neurocognitive diseases and disorders for guidance. In this section, I present an overview of several studies across user populations and research areas involving designing with and for individuals with cognitive impairments.

Supporting Memory and Independence: Alzheimer's Disease, Dementia, and Amnesia

One of the most well studied areas of incorporating participatory design techniques in designing with and for individuals with cognitive impairments involves individuals diagnosed with deficits affecting memory including Alzheimer's disease, dementia, and amnesia.

Maintaining independence both inside and outside of the home environment is a major concern for individuals experiencing memory impairments and their family members. Looking first at activities outside of the home, several research groups have explored participatory design as a means of designing technologies to support 'safe walking' and getting out and about [Lindsay 2012, Robinson 2009, Holbø 2013]. Lindsay et al and Robinson et al engaged individuals with mild to moderate dementia in designing personalized digital technologies to facilitate 'safe walking,' seeking to minimize the risks of becoming lost or experiencing feelings of anxiety often associated with wandering [Lindsay 2012, Robinson 2009]. Similarly, Holbø et al used participatory design methods to design safe walking tools for individuals with memory deficits due to Alzheimer's Disease and Lewy body dementia, taking a 'person-centered' approach to exploring experiences, as well as needs, desires, and preferences towards such technologies [Holbø 2013]. In another example, Wu et al designed and developed OrientingTool, a PDA application to help individuals with amnesia in situations where they may feel disoriented, with the goal of further supporting confidence and independence [Wu 2005].

Researchers have also worked to design tools to help these individuals maintain independence in daily life within the home environment. For example, Mayer and Zach worked to develop a touchscreen based platform for supporting individuals with mild cognitive impairment and early stages of dementia in maintaining independence in daily tasks and activities [Mayer 2013]. Participatory design techniques were also involved in various aspects of designing and evaluating COGKNOW and other contributing projects aimed at supporting individuals with mild dementia and very mild cognitive impairments in daily activities in the home as a part of the European Rosetta Project [Meiland 2014, Meiland 2007, Davies 2009].

These methods have also been employed in developing tools and technologies to support activities surrounding reminiscence and communication for these populations. Gowans et al

worked to design CIRCA, an interactive multimedia system to be used in dementia care environments to stimulate memory and communication [Gowans 2004], while Cohene et al worked with individuals with Alzheimer's disease and their family members in designing interactive multimedia of personalized life stories [Cohene 2005]. In A Touch of Memory (AToM), Hendriks et al engaged individuals with dementia alongside family members and caregivers in a variety of research and design activities in working to design 'an intelligent network of objects and people to ameliorate the life of the person with dementia' [Hendriks 2013]. Hanson et al also worked with individuals with dementia and their family members in designing a technology-based system for providing these individuals with information, education, and support services [Hanson 2007].

Language and Communication Support: Brain Tumors and Stroke*

Participatory design techniques have also been used to engage individuals diagnosed with neurological conditions and disorders typically characterized by their motor impairments, such as Parkinson's disease or stroke in designing systems and technologies to support physical rehabilitation. In the vast majority of these studies, however, individuals experiencing neurocognitive deficits as a consequence of these conditions were excluded from participation, and as a result, such studies fall outside of the scope of this review. Instead, a smaller number of studies have explored deigning to support individuals with aphasia, a language disorder that impacts both written and verbal language skills and abilities, that is common amongst individuals experiencing these conditions.

There have been several notable participatory design studies involving and engaging individuals with aphasia in research and design activities. Researchers involved in the Aphasia Project, a major effort based out of the University of British Columbia and Princeton University, designed and produced a variety of technologies to support aphasic users including an electronic recipe book and daily planners (ESI Planner I and II) [Moffatt 2004, Moffatt and Davies 2004, Boyd-Graber 2006, McGrenere 2003]. Although aphasia is commonly associated with brain damage as a result of stroke, early efforts from this group also included a single individual experiencing language and communication deficits as a result of a brain tumor [Moffatt 2004]. This individual was able to take part in several preliminary design activities, however, eventually had to withdraw due to declining health and an untimely death. As a result, the researchers chose to

engage both aphasic and non-aphasic individuals in subsequent design activities [Moffatt 2004]. Other projects from this group included a file management system to help a user organize and access information on a PDA device [Davies 2004], and PhotoTalk, an application that supports users in capturing and managing images to support communication in daily life [Allen 2007].

Outside of the Aphasia Project, Kane et al designed and developed TalkAbout, a context-aware adaptive communication device that suggested word lists based on a user's location and communication partner [Kane 2012], and Daemen et al designed a multimodal system for storytelling for individuals with expressive aphasia as a means of improving communication and quality of life [Daemen 2007]. Rehabilitation and rebuilding communication skills for individuals with aphasia is also incredibly important. Acknowledging this, researchers at the City University London developed GeST, a gesture communication therapy tool, and EVA Park, an online virtual world where users can practice communication skills with partners [Wilson 2015, Galliers 2012].

Brain Injury, Parkinson's Disease and Other Examples

Finally, a small number of studies have looked to explore participatory design as a method for designing to support the needs of individuals experiencing brain injury. Elliot Cole, a researcher based out of the Institute for Cognitive Prosthetics, has a long history of working with these individuals to create systems to support cognitive rehabilitation and personal productivity, often taking a person or patient-center approach to the design process [Cole 2011, Cole 1994]. Additionally, Groussard et al recently conducted a study involving individuals with brain injuries in designing SAMI, a mobile cognitive assistant [Groussard 2015]. Finally, two research groups have presented on recent works involving the inclusion individuals with Parkinson's disease in the design of health self-management or assessment tools [deBarros 2013, Serrano 2015], although considerations of neurocognitive impairments and deficits were minimal in these studies, in comparison to those previously discussed. de Barros et al worked with individuals with Parkinson's disease as well as their caregivers and other domain experts in the REMPARK project, designing smartphone applications to support aspects of disease self-management [de Barros 2013], and Serrano et al engaged patients with Parkinson's disease in surveys, focus groups, and workshops in working to identifying symptomatic domains of interest when creating self-monitoring tools and technologies [Serrano 2015].

3.2 Strategies, Approaches, and Considerations

Throughout these studies, researchers employed different strategies, modifications and approaches to the design process and activities. In addition to reporting on the outcomes and successes of these studies in terms of systems developed and artifacts produced, several of these researchers have reported on challenges encountered and lessons learned through this type of work. From these studies, it becomes apparent that participation in research and design is inherently different for these individuals, and that there are many challenges and considerations surrounding participation that must be addressed including (1) type and degree of participation, (2) representatives and proxies, (3) challenges to participation, and (4) modifications to traditional activities. Each these is introduced and discussed below.

Type and Degree of Participation

Although participatory design is centered on the idea of engaging users throughout the design process, the degree of user involvement in these studies varied greatly. In the majority of these studies, participation from neurocognitively impaired individuals was limited to involvement in aspects of the information seeking, field testing, or evaluation stages of the research and design process [Allen 2007, Boyd-Graber 2006, Cohene 2005, Davies 2009], often due to access, ethical, privacy, and administrative considerations, as well as challenges to participation involving memory and communication. Instead, proxy or representative participants often served in the place of these users in traditional design activities. In a handful of cases, however, cognitively impaired individuals participated throughout the entire duration of the study [Lindsay 2012, Robinson 2009, Davies 2004, Kane 2012, Wilson 2015, Daemen 2007, Galliers 2012, de Barros 2013], as is typically the case in participatory design work.

Another consideration involved the type of participation. While the majority of these studies focused on creating a single generalizable solution, a handful instead took the approach of personally tailored design, focusing on the needs of one single participant at a time [Lindsay 2012, Robinson 2009, Holbø 2013]. These researchers described that personally tailored design provides an opportunity to work one-on-one with a single participant, and explore their needs and values in depth [Lindsay 2012], while the group approach instead provides input from a range of participants and stakeholders to capture a wider view of the challenges, and create more

generalizable tools and technologies. The decision to focus on designing for a single user versus a group in these studies was typically based on both participant abilities, and considerations of whether a "one-size-fits-all" solution would be appropriate or beneficial.

Representatives and Proxies

As previously noted, proxies or representatives are frequently engaged in place of or alongside individuals experiencing neurocognitive impairments in participatory design studies. This decision is typically made based on the perceived ability of target users to take part in research and design activities, as well as the preferences and skills of the research teams conducting these studies. A major consideration associated with this decision involves how to engage caregivers or other domain experts as proxies and representatives for these individuals without losing touch with the needs, interests, and preferences of the intended users. Throughout these studies, proxies and representatives have been engaged in several roles, including informant, supporter, co-participants, and true proxy. Informants are typically caregivers or other domain experts who contribute information to support overall understanding of the needs and challenges faced by the population of interest in the early stages of the research and design process. These same individuals may also serve as supporters, participating alongside participants to verify information, and help support memory and communication in later stages of the process. In other cases, these individuals can act as co-participants, supporting the participant as well contributing information regarding their own thoughts and feelings. In the final role, true proxy, non-impaired individuals speak for or act in place of these target users rather than engaging impaired users in research and design activities. Although these individuals can be helpful in facilitating the design process, there are also risks and concerns associated with their inclusion that need to be considered and addressed.

Challenges Towards Participation

Given the multidimensional nature of many of these diseases and disorders, a wide range of challenges to participation were noted by many these researchers. Many of these challenges extended beyond what was typically anticipated based on the condition they were investigating. For example, in working with individuals diagnosed with Alzheimer's disease and dementia, in addition to memory impairments, several researchers encountered challenges relating to communication [Cohene 2005, Hendriks 2013], abstract thinking [Mayer 2013, Hendriks 2013],

as well as emotions, behavior, and decision making [Mayer 2013, Hendriks 2013]. The same was true in working with aphasic individuals, especially regarding processing abstract information or concepts, and activities requiring components of executive function and attention [Galliers 2012, Wilson 2015]. In several instances, participants in these studies had difficulty understanding the purpose of certain activities [Kane 2012], and in others, it was noted that participants struggled to comprehend written and/or verbal instructions, and had difficulty expressing themselves which led to frustration and embarrassment. Additionally, some participants had lowered inhibitions and mood swings that led to outbursts, use of inappropriate language, and refusal to participate [Galliers 2012].

Others experienced more logistical and ethical challenges towards participation. In their research with individuals with dementia, Mayer and Zach noted challenges towards prolonged participation due to disease progression [Mayer 2013]. Meiland et al also planned to recruit new participants at each stage because long-term participation was unlikely due to progressive disease [Meiland 2007]. Moffatt recruited surrogate and proxy participants after their initial partner passed away during the design process [Moffatt 2004]. Ethical considerations also factored in to participation challenges, often limiting or completely restricting access and participation from individuals with more severe disease [Meiland 2014]. As a result, the majority of these studies opted to focus on and recruit individuals with more stable disease or mild impairments to better ensure meaningful engagement and participation, and avoid major challenges to participation [Hanson 2007, McGrenere 2003, Lindsay 2012, Holbø 2013].

Modifications to Traditional Activities

As a result of these challenges, modifications to traditional participatory design activities and strategies were common in these studies. Many of these researchers opted to use physical artifacts and higher-fidelity prototypes early in the research process as they were more concrete, and relied less on the abstract thinking skills [Lindsay 2012, Kane 2012, Wilson 2015]. Others used image-based strategies such as smiley faces in place of or alongside numerical or written rating scales to ease the process of evaluation and feedback capture for participants and researchers [Galliers 2012, Kane 2012, Daemen 2007]. Additionally, one group used images and visual representations, as well as physical demonstrations, throughout the design and evaluation process to support memory and reduce reliance on verbal and receptive language [Wilson 2015].

Scenarios and storyboards were also used to support information elicitation, providing context and supporting discussion in these activities [Boyd-Graber 2006, Kane 2012, Daemen 2007]. This included a photo diary technique to create scenarios based on participant captured photos [Wilson 2015], and fill in the blank storyboards to help elicit information [Lindsay 2012]. Several researchers also incorporated demonstrations, review, and visual reminders into activities and sessions to support memory and draw focus onto the topics being discussed [Allen 2007, Lindsay 2012, Wu 2004].

Despite modifications, some participants found activities to be too difficult, and asked not to take part [Kane 2012], and in other cases, activities had to be abandoned due to these challenges [Galliers 2012, Wilson 2015, Hendriks 2013]. Acknowledging challenges, Meyer and Zach stressed the importance of being flexible and having alternate activities planned [Mayer 2013].

4. Research Methods and Approach

As evident from this brief discussion of the literature, there are many potential challenges and considerations involved in conducting participatory design alongside individuals experiencing neurocognitive impairments. In this research, I chose to carefully plan and tailor my approach to engaging patients with primary brain tumors in research and design activities based on findings, lessons learned, recommendations, and frameworks presented throughout these previous studies. I looked to the challenges and successes of these studies, both at the level of individual activities and overall results, as well as considerations posed when identifying, selecting, and recruiting participants. I chose to loosely base my approach off of a framework presented by Wu et al for conducting participatory design alongside individuals with cognitive impairments that was formulated out of research conducted in working with individuals with anterograde amnesia [Wu 2004]. This framework takes what I consider to be a cognitively informed approach to the planning process, incorporating methods for assessing the type and severity of the impairments that participants face, as well as building an understanding of how these factors might impact participation for each individual and the group. The framework calls for analyzing cognitive deficits and choosing techniques based on a combination of research goals and an understanding of the cognitive demands of the activities involved, followed by processes for adapting approaches based on these deficits, and finally attempting and refining the overall approach in order to find the ideal balance to support participation. A full description of the framework can

be found in [Wu 2004]. My overall approach to this process of planning and conducting this research incorporates many aspects of this cognitively informed approach, as well as considerations, techniques, recommendations, and lessons learned from the studies presented in this literature review. My overall approach to this research and design process is described in depth in the following sections.

Step 1: Identifying Participants and Team Members

Beginning in the early stages of the planning process, it is important to carefully identify and define the target user and participant populations. This involved forming an understanding of the disease and beginning to explore how best to engage these individuals in research and design. Taking a broad approach to gathering information through a variety of resources and techniques can provide a better understanding of the population, and help to narrow down potential issues and considerations to be addressed. Initial decisions including expectations surrounding participation, eligibility criteria, how access and recruitment will be handled, and the need for additional safeguards to protect participant rights must also be addressed at this stage. Additionally, just as it is important to form an understanding of the target user and study populations, it is also important to build an understanding of the skills and strengths of research and design team members, and identify where other support might be needed.

Step 1: Methods and Approach:

I started off this process by conducting a review of the literature surrounding primary brain tumors, focusing on incidence and impact of disease, coupled with informal shadowing in the clinic environment. These observations helped in setting preliminary expectations about recruitment and participation, and influenced decisions surrounding the role and importance of caregivers in providing support for these patients. Next, recognizing that primary brain tumors are rare and that median survival is often very short for many of these individuals, I consulted clinicians to get a better understanding of the size of the local patient population to help establish recruitment goals and timelines. I also used this opportunity to assess clinician interest and commitment to supporting recruitment activities. I then reached out to a local brain tumor support group to inquire about appropriateness as a recruitment venue, and to gather further information about the size of the local brain tumor patient population. In addition to providing a venue for recruitment, the support group environment presented an opportunity to both introduce

myself and to build further familiarity with the patient population outside of the clinical environment. Informal observations during this time were also helpful in the later planning stages when making decisions about the frequency and duration of design sessions, as well as considerations surrounding group participation.

From these initial investigations and interactions, it was clear that patient participants would likely suffer from a range of symptoms and side effects that would impact both their interest and ability to take part in research activities. For these individuals, participation during treatment was less likely as treatment is both time consuming and often leads to increased symptoms and side effects. For this reason, I decided to extend eligibility criteria beyond the typical range of previous studies to include patients within 5 years of their initial diagnosis or of a recurrence requiring treatment. This served the dual benefit of capturing participants with a range of different needs and experiences, while also increasing the total number of potentially eligible participants. I also sought to recruit participants with varying types of primary brain tumors, and include individuals who travelled to the area for treatment. Although travelers would be less likely to return for future stages of research and design, I believed they would have additional information, experiences, and insights to contribute.

I also began to make decisions about the roles of caregivers in this study. Due to the active role of caregivers both in the clinic and in the support group, and the fact that many brain tumor patients are no longer able to drive due to the effects of the disease and medications they are one, I also decided to recruit caregivers of these patients to participate as co-participants, supporting patient participation while also contributing their own insights and experiences. It was my hope that this would not only encourage patients with more severe impairments or logistical challenges to take part, but also serve to capture caregiver insights regarding these experiences, needs, and challenges as well. Although recruitment was initially limited to patients, or patient and caregiver dyads, I eventually extended eligibility criteria to include caregivers of patients who were unwilling or unable to take part as well.

Considering the small size of the patient population and the desire to include anyone wanting to take part and contribute, I did not place major limitations on participation based on cognitive impairment and let participants decide to whether they felt comfortable taking part in research

and design activities. Additionally, I gave participants the option to participate as a patient-caregiver dyad, or as individual participants, as previously noted. The sole requirement for participation was that participants had to be able to understand the purpose of the study and their rights as a participant, and provide informed consent. A brief list of questions was developed to ask participants during the consent process to ensure and verify understanding.

Finally, acknowledging that neuropsychology knowledge and skills would likely be necessary in later stages of this work, I also consulted two neuropsychology clinicians in order to gain their support for research and analysis components of this design process.

Step 2: Understanding Participants as Users and Partners

Assembling an in-depth understanding of participants, both as target users of the future systems, and as collaborators in design activities is an essential component of the participatory design process. User research methods including interviews, focus groups, contextual inquiries, and ethnographic studies are commonly employed to capture a wide range of relevant information about target user and participant populations. Although the focus of these inquiries and interactions is typically targeted towards gathering information surrounding the topic of interest to the study, non-verbal observations captured throughout these interactions can also be used to construct a more complete understanding of participants. Additionally, as working alongside these participants as partners and collaborators in the design process is a large component of participatory design, it is also important to establish a common understanding and sense of trust, respect, and empathy. This is especially important when working with individuals experiencing neuro-cognitive impairments, as it is easy to focus on understanding potential deficits at the expense of understanding the participants; these activities and interactions can also serve this purpose.

Step 2: Methods and Approach

In my approach, I initially planned on conducting focus group sessions as both an exploration of users and their needs and challenges, and as an introduction to participatory design. I believed that focus group type interactions would not only provide information related to the study, but also provide insight into the need for future potential modifications to support attention, communication, and overall meaningful participation. I quickly discovered, however, that this

was neither practical nor ideal. Scheduling multiple participants at once was very challenging, and interest in participation was lost after repeated attempts at finding a date that would work for the group. Additionally, discussing the challenges and experiences these individuals faced in their diagnosis and treatment process was deeply personal, and many participants may not have felt comfortable discussing this in a group setting. As I could not afford to lose time or participants, I quickly revised my approach and instead chose to conduct semi-structures interviews. These interviews proved to be incredibly successful in eliciting information of interest, and starting to build a relationship to support sustained interest and participation. Interviews also provided an opportunity to consult participants as experts in their own condition, challenges, and compensation strategies, revealing information that was not otherwise inaccessible, yet incredibly informative towards planning future research and design activities.

Step 3: Evaluating Abilities and Challenges

Although great emphasis has been placed on focusing on ability rather than disability in HCI and accessibility research [Wobbrock 2011], it is also important at times to understand the range and degree of impairments faced by design participants. As noted by Wu et al, using standardized assessments to capture this information, researchers are able to build a more comprehensive understanding of the challenges experienced by participants across various cognitive domains [Wu 2004]. This information, when combined with the information gathered through interviews and observations in the previous stages, is essential to not only building understanding of participant needs and challenges, but also to identifying areas where modifications to traditional design activities and approaches could be beneficial towards supporting meaningful participation. Careful attention and consideration must be given to assessment selection, however, to ensure that the factors of interest are adequately assessed without burdening participants or requiring extensive resources.

Step 3: Methods and Approach

After consulting a neuropsychology clinician, I chose to use the Montreal Cognitive Assessment (MoCA) as the basis of my assessments of neurocognitive impairments [Nasreddine 2005]. This decision was made due the the ability of this test to detect milder levels of cognitive impairment, as well as considerations of overall length, and coverage of the neurocognitive domains of interests. The MoCA test screens for impairments in skills and functions including visual

attention and processing, task switching, processing speed, visuospatial construction, attention, memory and recall, language, verbal fluency, abstraction and reasoning, and aspects of executive function including planning and organizing, sequencing, problem solving, mental flexibility, and working memory. Although I had not yet made decisions about potential activities for the participatory design sessions, the wide range of relevant information and insights that could be obtained through this assessment was ideal. Much of this information could also have been obtained through the use of several in-depth assessments or batteries, however, these were not practical or necessary for the purpose of this research.

I chose to administer this assessment to patient participants during the semi-structured interview study (Chapter 4). The assessment was conducted anonymously, and caregivers were asked to leave to room to reduce potential feelings of pressure or stigma. Further, despite the possibility that neurocognitive deficits and impairments could change over time, I decided to only conduct this assessment once per participant, rather than at each stage of the design process. A second neuropsychology clinician provided guidance and support regarding test administration and interpretation. Similar to the approach taken by Wu et al, I looked at the individual components of the deficits and areas of weakness, and investigated associated skills and functions that may also be impacted as a result. Rather than analyzing these assessments on a person by person basis to determine individual levels of cognitive impairment, however, I chose to focus on broader skills and functions that may be impacted to support future design decisions. In the end, findings from these assessments indicated deficits in areas of language and verbal fluency, memory and recall, executing function, abstraction and reasoning, as well as visuospatial and visuo-constructive abilities.

Step 4: Determining Methods and Modifications

Ordinarily, when selecting activities to carry out during participatory design sessions, major considerations in the decision-making process revolve around identifying activities that will satisfy the goals of each phase of the design process, given the allotted time, available resources, and number of participants. When engaging individuals or groups experiencing neurocognitive disorders and cognitive impairments, however, activity selection must also include a deeper analysis of the requirements and demands associated with potential activities, as noted by Wu et al in step 3 of their framework [Wu 2004]. Using the information captured throughout the

previous stages of the research process, it is possible to create a mapping between participant challenges, and the requirements of the intended activities. By breaking down and analyzing the challenges and deficits of participants and the group, and working to understand the demands of potential design activities and techniques, informed decisions can be made surrounding activity selection and modifications to ensure greater likelihood of success.

Step 4: Methods and Approach

At this stage, I once again consulted a neuropsychologist for assistance in analyzing the cognitive assumptions and skills associated with common research and design activities, and identifying potential modifications to minimize demands on certain skill areas, or further support meaningful participation. In addition to the list identified in the previous stage, interview participants also self-reported challenges and deficits involving communication and verbal language skills, attention, task completion, and multi-tasking, memory and recall. Based on this information, I selected to employ the following major activities and modifications in the participatory design workshops (**Table 1**). Further descriptions of these activities, as well as evaluations of their success can be found in Chapter 5 of this dissertation.

Step 5: Evaluating Approach

As a final step in this process, it is important to evaluate the successes and challenges of in the individual activities and overall process in order to learn where further modifications can be implemented in future activities and iterations. Evaluation of these factors should ideally be conducted by both participants and the research team to capture a wider range of perspectives.

Step 5: Methods and Approach

At the end of each design session, I asked participants to complete a feedback capture grid, noting what they liked, what could be improved, things they did not understand, and new ideas to consider. The research team took part a similar evaluation. The information captured through these forms was informative and helped to shape subsequent sessions and activities. Further information on the findings of these evaluations can be found in Chapter 5 of this dissertation.

Table 1: Methods and Modifications

Activity Name	Brief Description	Relevant Domains/Skills	Modifications
Focus Group	Moderated group discussion session to learn about user attitudes, beliefs, interests	Episodic memory Language/Communication Receptive language Verbal fluency Cognitive flexibility Social cognition Theory of mind Attention	Initially planned on incorporating moderation to ensure that participant voices and contributions were balanced, however, ultimately did not use this activity
Semi-Structured Interviews	In-depth exploration of experiences through conversation; used to identify insights and themes related to the topic of interest	Episodic memory Language/Communication Verbal fluency Receptive language Cognitive flexibility Social cognition Attention	Allowed participants to participate as patient-caregiver dyads to provide support for memory and communication
Journey Mapping	Creating a timeline of the user's experience, including important milestones, events, and interactions	Planning, organizing, and sequencing events Organization of complex information Cognitive flexibility Memory/Recall Language and verbal fluency	No major modifications employed
Persona Creation	Creating a fictional character representative of the user you are designing for	Abstraction/abstract thinking Idea generation Social cognition – relating to others, empathy Cognitive flexibility	Provided fill in the blank or template personas
Low-fidelity (paper) prototype creation	Using paper or other materials to create an early version of the system or interfaces in order to elicit early feedback	Visuospatial skills Drawing, copying and construction Planning and initiation Problem solving	Relaxed requirements regarding text vs sketching; working as partners; opportunities for review

		Language/Communication	
Medium fidelity prototype creation	Creating prototypes using computer software, focusing on the behaviors and functionality of the system	Visuospatial skills Drawing, copying and construction Planning and initiation Problem solving Language/Communication	No major modifications; considerations of time and potential for cognitive and physical fatigue; opportunities for review
Overall Prototype and Design Session Evaluation	Using a survey or a structure chart to elicit feedback from user participants	Language Planning, organizing, or sequencing actions or tasks Mental flexibility Language/Communication Task initiation Planning, organizing, or sequencing actions or tasks Error corrections Mental flexibility	Using Feedback Capture Grids to elicit information in a more structured manner
Usability Testing	Observing the user interact with a system, and follow a script of tasks or commands to evaluate usability of a system, providing feedback as required	Receptive language (respond to verbal commands) Task switching Error correction Verbal fluency/language Attention	Incorporating interview considerations and techniques, being flexible with time requirements, providing written and verbal task scripts

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Chapter 3: Exploring Neuro-Oncology Clinician Perceptions in Self-Tracking and Assessment

1. Introduction

As they progress through the disease and treatment process, patients with primary brain tumors will experience a range of complex symptoms and side effects. These health events can be a normal part of the disease and treatment process, or can be indicative of serious complications such as medication allergies or adverse events, treatment induced effects, or even tumor growth or recurrence. In the clinic, neuro-oncology clinicians look to patients and their caregivers as a source of information in working to understand and manage such health events, however, deficits involving memory and language, as well as other neuro-cognitive impairments can pose challenges to reporting for these patients. Further, there is still much to learn about these symptoms and side effects, their impact on patients, and potential correlations with outcomes including survival and quality of life, however, there are many limitations associated with currently available tools aimed at capturing such information in this patient population. These challenges, as well as potential benefits associated with self-tracking as a means of supporting these patients in capturing and communicating patient-reported data have not been well examined, and little is known about clinician perceptions of the value and future uses of this type of data. In this study, I conducted semi-structured interviews with eight neuro-oncology clinicians with the goal of capturing insights surrounding the overall symptom and side effect experience, as well as investigating perceptions of challenges, value, benefits, and uses of patient-reported data as a component of care and decision-making activities in the clinic.

2. Background and Related Work

Understanding how and why symptoms occur, and their impact on the patient, is an essential component of patient care and symptom management. In recent decades, however, several researchers have argued that what is currently known and reported in the literature regarding the symptom experience for patients with primary brain tumors is greatly limited and in need of further exploration [Salander 2000, Molassiotis 2010, Fox 2007]. Armstrong et al point out that commonly cited sources regarding symptoms for this patient population are typically based on retrospective chart reviews and descriptive studies dating back several decades, before modern

imaging technologies were available [Armstrong 2004]. These authors further point out that studies tend focus primarily on a single symptom in isolation, or the impact of treatment on that symptom [Armstrong 2004], rather than evaluating the overall symptom experience for these patients. Research findings surrounding these symptoms, as well as their impact on quality of life and prognosis, have emerged over the past decade, suggesting that there is still much to learn and new knowledge to uncover in this area, potentially leading to better treatments and management of symptoms for these patients. For example, findings from several studies suggest that certain symptoms may in fact be interrelated, or occur in clusters, both during the initial stages of diagnosis and treatment, and through survivorship and follow-up [Fox 2007, Gleason 2006, Saconn 2006].

There are also many unknowns surrounding the impact of these symptoms as well as disease and treatment effects on quality of life for these individuals. Recent reviews by Liu et al and Taphoorn et al revealed that although researchers have begun to identify relationships between certain symptoms and quality of life (QOL), there is still much to discover about potential links between these factors [Liu 2009, Taphoorn 2010]. These researchers, and several others, have acknowledged that challenges and limitations associated with current methods for capturing and interpreting patient-reported data often act as a barrier to investigating issues surrounding symptoms and QOL in this patient population [Liu 2009, Taphoorn 2010, Pelletiere 2002, Mauer 2008]. Many of these challenges involve the use of patient-reported outcome measures, as well as disease-specific concerns surrounding patient ability to reliably complete these surveys and questionnaires to support data capture and analysis throughout the course of the disease in research and clinical practice [Mauer 2008, Liu 2009, Taphoorn 2005, Dirven 2014, Kvale 2009, Bae 2011, Roa 2004]. Another factor contributing to complications in understanding and interpreting impact on QOL involves response shifts [Schwartz 2004, Rapkin 2004], a phenomenon where even though a patient may face significant impairments or continue to decline cognitively and physically, they still report high levels of health-related quality of life [Bosma 2009, Schmidinger 2003].

A large portion of the new knowledge and insights gathered over the past decade have been attributed to patient-reported data, however, as discussed here and in Chapter 1, there are still challenges associated with capturing and interpreting this data. These works, and the large

number of unknowns in this area draw attention to the need for developing both a better understanding of symptoms and the overall patient experience, as well as the need for improved methods for capturing and interpreting this data. Although the overall goal of my dissertation research is to design tools and technologies to support patients and their caregivers in capturing, understanding, managing, and communicating patient-reported data, neuro-oncology clinicians are important stakeholders in this process of investigating how best to design and implement future tools such that data can be captured, communicated, and utilized in a clinically meaningful and relevant manner. These clinicians interact with a large number of patients and as a result, can contribute unique knowledge and insights into the needs and challenges that these patients face. Despite the fact that patients and caregivers would ultimately be the primary target users of any future tool or technology designed through this study, these clinicians would likely be highly involved in implementation and contribute to the future utilization and the overall success of such an intervention. As such, I sought to interview clinicians involved in the care, treatment, and follow-up of these patients to investigate insights and perceptions surrounding current challenges in capturing and communicating symptom and side effect information, the need for better tools and technologies to support these activities, and the potential value and benefits of self-tracking and management activities for both patients and clinicians going forward.

In this chapter, I present findings surrounding challenges, perceptions, and needs, and discuss additional themes and considerations identified throughout the interview process, including concerns surrounding patient burdens and actionability of tracked data in this patient population. I conclude with a discussion of considerations for design and implementation.

3. Methods:

3.1 Eligibility and Recruitment

For the purpose of this study, I recruited neuro-oncology clinicians involved in the care of patients with primary brain tumors to participate in semi-structured interviews. In order to be eligible, clinicians were required to be actively involved in some component of the patient's treatment and/or follow-up process, and regularly conduct some sort of assessment of symptoms or neurological function as a part of their interactions with the patient. Medical residents were invited to take part in the study provided they acted independently in evaluating patients and

developing recommendations for care and decision-making, and were at least in the third year of their program. Full eligibility criteria are presented in **Table 1**.

Recruitment was largely based out of the University of Washington Medical Center and other UW Medicine facilities using a combination of convenience and snowball sampling techniques. Clinicians were contacted via email and fliers were made available to share study information with additional potentially eligible participants in an attempt to reach a broader range of participants including those outside of the UW Medicine system. University of Washington Institutional Review Board approval was obtained prior commencing this research.

Table 1. Clinician Eligibility Criteria

Clinicians:
• Practicing clinicians (MD, DO, PA, ARNP, BSN, RN) in Radiation Oncology, Neurology, Neurosurgery, and Neuro-Oncology
• Must interact directly with brain tumor patients during treatment and/or follow-up
• Routinely elicit symptom or side effect information during patient evaluations
• Medical Residents must be in year 3 or above and make independent decisions or recommendations regarding care activities
• All participants must be at least 18 years of age

3.2 Data Collection and Analysis

Demographic Survey

Participants were asked to complete a brief demographic survey to provide information related to gender, clinical specialty and role, years experience working with this patient population, average number of patients seen per week, and work setting.

Semi-Structured Interviews

The primary research activity of this study involved semi-structured interviews with neuro-oncology clinicians in order to capture information, insights, and perceptions related to understanding the symptom experience for patients with primary brain tumors. An interview topic guide outlining specific areas of focus is presented in **Table 2**. Interviews were conducted in two phases, taking placing between March 2014 and July 2014, and February 2016 and May 2016. Each individual session was conducted in person and lasted approximately 30 minutes. Interviews were audio recorded and transcribed to support data analysis.

Table 2. Clinician Interview Topic Guide

- Symptoms and side effects of interest to neuro-oncology clinicians
- Methods and challenges involved in eliciting information directly from patients
- Caregiver roles throughout the diagnosis and treatment process
- Trust and patient-reported information
- Current uses of patient-reported information
- Patient self-tracking: current behaviors, approaches, perceptions, barriers and concerns
- Perceived need for better tracking and reporting of patient data and experiences
- Perceptions of patient interest and ability in tracking and reporting
- Patients: future benefits in tracking and reporting
- Clinicians: future benefits and impact of patient self-tracking and reporting
- Potential challenges and consequences of patient self-tracking and reporting of health related data

4. Results

Eight clinicians (n = 4 female, n = 4 male) took part in this study. Five participants identified their primary department as radiation oncology, one as neurosurgery, one neurology, and one as neurology/neuro-oncology. Clinician roles included nurse practitioner, resident physician, and attending physician. These clinicians had an average of nearly 15 years of experience working with this patient population, with a range of 3 to 30+ years. They saw an average of 13 primary brain tumor patients per week, with a range of between 1-2 and 30 patients per week. All participants practiced in either a major hospital or academic medical center, with two working primarily in an inpatient setting, and the rest in outpatient clinics. The majority of the participants were affiliated with UW Medicine, and all practiced in the Seattle area.

Table 3. Clinician Demographic Information

Clinician Participants (n = 8)	
Gender	Female (4), Male (4)
Clinical specialty	Radiation Oncology (5) Neuro-Oncology (1) Neurosurgery (1) Neurology (1)
Clinical roles	Attending Physician (4) Resident Physician (2) Nurse Practitioner (2)
Years experience with CNS patients	Average 15 years, range 3-30+
CNS patients per week	Average 13, range 1 or 2-30
Practice setting	Inpatient (2) Outpatient clinic (6)

Overall Findings

Throughout the course of disease, treatment, and follow-up, patients will experience a wide range of symptoms, medication side effects, and other health events related to the disease and treatment process. Some of these will be lasting, contributing to what is considered to be a 'new baseline' for the patient, while others may resolve or worsen over time with changes in treatments, medications, and disease status. Patients and their caregivers are largely responsible for detecting and reporting information related to symptoms and side effects outside of the clinic, a process that is prone to challenges, many of which have the potential to impact the quality, quantity, timeliness, and reliability of patient-reported information. Despite these challenges, the clinician participants in this study were greatly interested in the information that patients contribute as they work to treat the disease and minimize the burden of symptoms and side effects.

In these interviews, I found that these neuro-oncology clinicians valued and used patient-reported information in different ways, often depending on their clinical specialty and the context of the decisions being made. For some, patient-reported information was invaluable in the care and decision making process; participants described great interest in developing methods and techniques to support patients in better capturing, reporting, and understanding this information. For others, unique factors related to this disease and the often limited impact of medications and treatments in altering the course of the disease and remedying symptoms and treatment effects led to concerns regarding the implications of self-tracking for patients in this particular population. Many acknowledged that neurocognitive, physical, and emotional factors and considerations would likely impact the interest and ability of patients to participate in self-tracking activities, whether on paper or through the use of technology-based solutions. Despite this, most saw great benefit for both patients and clinicians toward understanding and managing this disease. In this section I present an in-depth discussion of these findings, followed by a discussion of additional themes and considerations identified throughout these interviews.

4.1 Symptoms and Side Effects of Interest

For the clinicians interviewed in this study, the symptoms and side effects of greatest interest were typically those reported as the most bothersome for the patient, as well as anything

interfering with their ability to do the things that they wanted to be able to do. This typically included aphasia or deficits involving language, speech, or communication; excessive drowsiness and fatigue; seizures; headaches; nausea and vomiting; changes in bowel or bladder habits including diarrhea and constipation; rashes and skin reactions; changes in appetite; weakness, instability, or disturbances in balance or gait; and changes in vision or hearing. These clinicians reported that they also looked at changes and deficits in general cognition, and wanted to hear about any neurological symptoms that the patient was experiencing, including changes in behavior or personality, deficits involving memory, confusion, or impaired judgment or insight into their own condition. Patients were typically instructed to report any new neurological symptoms, as well as changes in existing symptoms that the patients or their caregivers were aware of. Finally, they noted that any indications of potential infection or allergic reaction were also important to report so that they could be addressed in a timely manner.

4.2 Methods for Eliciting Symptom and Side Effect Information

Clinicians primarily captured information directly from patients through the use of interviews and narratives, coupled with a physical examination and brief neurocognitive assessment. These interactions allowed for clinicians to capture a combination subjective and objective information. The inquiry process was largely driven by experience, with individual questions determined based on the patient, the location of their tumor, and an understanding of their current and previous treatments, symptoms, and side effects. Most relied on their knowledge of neuroanatomy and the cranial nerves in assessing symptoms, looking at functions likely to be impaired based on tumor location, as well as those associated with adjacent brain areas and functions. Others preferred using the Review of Systems method, taking a broad approach in looking for issues and concerns, then focusing in on individual symptoms and side effects to determine potential causes. One clinician reported using a questioning process based on the 'Sacred Seven' to learn more about the symptoms and side effects that patients were experiencing. This process involves asking a series of seven questions to determine and identify what/where the problem is, when it started, whether it is getting better/worse, what makes it better/worse, and any associated information or experiences.

Standardized Assessments of Symptoms, Quality of Life, and Neurocognitive Function

Although many were familiar, none of the participants reported using complete versions of named or standardized question lists, patient-reported outcome measures, symptom inventories, or neurocognitive assessments routinely in examinations, unless required by a study or clinical trial. Several participants acknowledged that the existing tools for assessing symptoms, quality of life, and neurocognitive function could be potentially useful, but felt that there were major barriers to use in the clinic. The largest of these barrier involved limited time and resources available to clinicians to conduct such assessments. Clinician 2 pointed out that many named assessments such as the Mini-Mental State Exam (MMSE) are under copyright, adding additional costs and considerations for clinicians. Several participants felt that conducting a thorough battery of these assessments would require a significant amount of time for both patients and clinicians. Clinician 3, among others, expressed concern over the fact that doing these assessments in the clinic would take away from the already limited, valuable time available to spend with patients, as described in saying:

"I would rather spend my time with the patient talking to them, counseling them, answering their questions, and building rapport than giving them lots of tests. Because in the end it is helpful but it is probably more important for me to do the first few things [talking, counseling, answering questions]."

In addition to concerns surrounding time and resource constraints, there was also question over the value of the information produced by such assessments. Clinician 4 was not convinced that the information produced would result in changes in decision making, and felt that their origins as research tools and largely unproven value in the clinic did not justify the time spent, saying:

"Statistical relevance doesn't really matter in the clinic if it doesn't help you make a decision or help you to care for your patients. A lot of people aren't going to adopt it unless you really see that oh, it's really helping patients."

4.3 Challenges Encountered in Eliciting Symptom and Side Effect Information

Participants in this study reported a range of opinions and experiences regarding challenges involved in eliciting symptom and side effect information directly from patients with primary brain tumors. Throughout these interviews, the clinician participants discussed challenges

impacting the quality, quantity, and timeliness of patient-reported information, and how these factors contributed, as detailed below. They also described factors contributing to these challenges. In some cases, the clinicians felt that patients were not aware of symptoms or side effects, either because of the often unfamiliar nature of these symptoms, or because cognitive impairment or brain compensation interfered with their ability to detect changes. In others, they felt that patients did not know what was important to track or report, and were unfamiliar with the significance of this information, especially when it came to details surrounding onset, duration, frequency, and severity of these symptoms and side effects. Further, neurocognitive deficits, especially those involving memory, language, and general cognition were also commonly cited as major contributors to these challenges, acting as a barrier to reliable reporting.

Under-Reporting of Symptom and Side Effect Information

The first major challenge identified was under-reporting of symptom and side effect information. Under-reporting was typically not perceived as an intentional act of deception, but was thought to occur either because patients were not aware of symptoms or side effects, or were not aware of the importance of reporting them. Several clinicians noted that for some patients, emotional factors may also influence decisions regarding sharing of symptom and side effect information in the clinic. In these cases, they believed that patients may not want to worry or burden their family members by bringing up certain information, or may have accepted their condition and current situation and no longer feel the need to discuss. In other cases, patients may not report certain information related to symptoms or side effects because they are no longer present or bothersome at the time of the appointment. Although this may not impact immediate patient care or decision making activities, it like affects overall clinician knowledge and understanding of how the patient is impacted by the disease and treatment process. In many of these cases, caregivers can help to supplement and verify patient-reported information, as further discussed in section 4.4 of this chapter, and illustrated by Clinician 4 in saying:

"A lot of patients come in and say 'Hey! Everything is fine <enthusiastically>' And they [family/caregiver] are like 'No it isn't! You fell three times, and your left leg isn't working well' and the patient is like 'well, today it is working fine!'"

Additionally, because of the wide range of effects and the complex and often unfamiliar nature of the brain and neurological symptoms, patients may not recognize that certain symptoms or health events may be related to the disease or treatment process, and thus, should be reported. This was illustrated by Clinician 1 in describing a situation where a patient may not immediately associate seemingly unrelated health events with their disease without clinician guidance.

"So if they have a lesion that is sort of in between the speech area and the motor area, and they are complaining of speech symptoms, you would want to know, 'well, how is your leg?' And then you know, you might be surprised to feel somebody's ankles through their pants and find out that they have an ankle brace on."

Finally, one participant felt that patients may not always report everything because they do not want to bother their clinicians. Another noted that patients often share different information with nurses than they do with physicians. For this participant, the motivations behind this behavior were unclear, but more complete and equal sharing was actively encouraged.

Over-Reporting of Symptom and Side Effect Information

The next major challenge associated with eliciting information from patients involved over-reporting, or reporting of excessive or unrelated information. For this population, over-reporting was largely linked to misattribution of everyday or benign health events to the disease. The most common examples of this involved headaches and seizures, where for some patients, every headache was assumed to be associated with tumor growth, and every twitch or sensation a seizure. Although reporting of information related to symptoms and side effects of concern was encouraged, these clinicians reported that there were many instances of day-to-day things being reported as urgent or major health events. Participants felt that this not only resulted in excess information for clinicians to process, but more importantly, led to increased anxiety and concern for the patients. Clinician 4 described this and the underlying fear motivating this challenge in saying:

"So in other words, so I think one of the challenges is truly finding things that are related to the tumor and/or the treatment, versus day to day things. You and I probably wouldn't think twice if we

had a little headache after working on a computer screen for four hours, but every little headache, some patients are going to be like, 'my headaches are getting worse!'
[Clinician]: 'Did you have these before?'
[Patient]: 'Yeah, and I had them every time I used the computer.'
[Clinician]: 'And they are still happening the same way?'
[Patient]: 'oh yeah, you're right.'
But they associate that because they have a brain tumor, it must be related to the tumor."

Similarly, the manner in which information was shared or communicated was also at times challenging and overwhelming for clinicians. Although not extremely common, Clinician 8 noted that patients would occasionally bring in lengthy handwritten diaries of their experiences over a month-long period of time for clinicians to read through and sort out relevant information. In these cases, the information presented may be important and valuable clinically, but also difficult and time consuming to parse through.

Incomplete or Incorrect Reporting of Symptom and Side Effect Information

Incomplete or incorrect reporting of health information was also noted as a challenge by these participants. Because information is not typically recorded in real-time, patients are often forced to rely on memory and recall abilities to fill in details and answer questions in the clinic. As a result, there is an increased potential that information will be recalled or reported incompletely or incorrectly, especially as patients may be overwhelmed, or experiencing cognitive deficits. Several clinicians felt that in some cases, feelings of guilt or embarrassment may also contribute to these challenges. Clinician 7 reported that many patients do not want to admit or are embarrassed that they cannot recall certain information, and instead report information that may not be accurate or truthful. Clinician 6 noted that this also occurs when discussing medication habits, where patients may not be able to remember whether they had missed a dose, or may feel guilty about missing it, and instead offer incorrect or incomplete information to compensate when asked. In these cases, the clinicians felt that it was highly likely that patients do not understand the significance of this information in decision-making surrounding determining and distinguishing the causes of symptoms and side effects. In the end, the clinicians reported that they generally trusted the information that patients reported, but acknowledged that the

combined impact of the disease, cognitive, and emotional factors could easily influence the reliability of patient-reported data. Because of this, information that was recalled during clinic visits, especially related to changes in symptoms or side effects over time, were considered to be less reliable than a written account of this same information captured at the time of the event.

Timely Reporting and Communication of Symptoms and Side Effects

The final major challenge described by these clinicians involved the fact that information was not always reported in a timely manner. Clinician 7 noted that despite being instructed otherwise, some patients wait to report important symptom or side effect information until their next appointment, which was often several weeks later. Additionally, for patients transferred to the hospital or clinic from nursing homes, clinicians must rely on nursing notes from those facilities to obtain necessary background information, as these patients may be unable to communicate of provide information for themselves. Often, these notes are handwritten as many nursing home facilities do not yet have electronic health record systems, and are not yet up to date when they are sent with the patient. The care team at the hospital must then call and track down the clinicians involved in their care at the nursing home facility, which often means more waiting due to shift changes and games of 'phone tag.'

Other Challenges in Reporting Symptom and Side Effect Information

One participant also pointed out that the overall process for how information is reported and recorded presents numerous opportunities for challenge as there are many actors and decision points where information could be misinterpreted, overlooked, or omitted. Although many of these challenges begin with the patient, they extend much further into the process. First, because reporting outside of the clinic is largely patient-driven, it is up to the patient or caregiver to detect a change, determine that it is relevant and important enough to share, and decide which clinician to contact. As Clinician 6 pointed out, these initial activities can be problematic as patients often do not have the knowledge, experience, or support to guide these decisions. Additionally, because patients with brain tumors are often seen by a range of providers, the information recorded and questions asked may vary depending on the clinician, their specialty, and the purpose of the interaction. The challenges continue as clinicians receive patient-reported information and make decisions about what is relevant and important before documenting it in

the health record. Future clinicians looking back at this information may have different opinions about what was important or of interests in the overall data, but are limited to the decisions and interpretations of the documenting clinician.

Differing Perspectives

It is also important to note that some participants had differing opinions and perspectives regarding the challenges involved in eliciting information directly from patients. During these interviews, two of the eight clinicians felt that they experienced very few challenges in capturing necessary information from these patients. Despite providing examples and anecdotal evidence suggesting otherwise, one participant reported that patients were generally upfront, honest, and reliable in reporting symptom information. This participant also felt that many of the symptoms that patients would experience, especially during follow-up, could be tested for and identified by clinicians before the patient would be able to detect them, further minimizing these challenges. The second clinician reported that the information they were interested in eliciting from patients was minimal and targeted, and that they rarely experienced challenges in doing so. This example was largely influenced by the clinician's role and the context of their decision making process.

4.4 Caregiver Roles in Tracking and Reporting

Caregivers play an important role in supporting these patients throughout the course of diagnosis, treatment, and follow-up. The clinicians in this study reported that in most cases, caregivers are present during clinic visits and are often considered to be a vital component of the reporting process. Many of these clinicians saw the primary role of the caregiver in these visits as helping to supplement and verify patient-reported information, as well as acting as a 'second set of ears,' especially early on as the information presented is often overwhelming, unfamiliar, and unexpected. They noted that for some patients, caregivers take on a predominant role in these activities, as disease and treatment effects can often lead to deficits in neurocognitive and communication abilities. In cases where the patient was stable and free of cognitive impairments, however, caregivers were mainly there to convey their own concerns and provide additional perspective.

Several clinicians also pointed out that caregivers may not always be able to provide what is considered to be an accurate and complete representation of the symptoms and side effects that patients experience. In some cases, this information is deeply subjective, and impossible to quantify without direct patient input, as is the case with pain and depression, for example. Although caregivers can provide insights from their own perspective, this information often cannot be considered complete. Additionally, family caregivers may not always be directly involved in day to day care activities for these patients, as is often the case for patients living in rehabilitation or nursing home facilities. In these cases, caregivers may struggle to pinpoint the exact nature of symptoms and side effects, especially if they are not able to visit regularly, or may be unable to provide important contextual information in the clinic.

4.5 Perspectives of Patient Challenges Involving Symptoms, Side Effects, and Medications

In addition to investigating challenges involving reporting and eliciting information from these patients, I also sought to identify the aspects of the disease and treatment process that these clinicians believed to be the most challenging for patients in order to capture additional context and insights into the overall brain tumor patient experience. I investigate this topic in depth from the perspective of patients with primary brain tumors and their caregivers in Chapter 4, however also looked to capture the clinician perspective based on their own experiences interacting with these patients over time. The participants in this study acknowledged that brain cancer is an extremely devastating and burdensome disease, and that patients and caregivers face a multitude of challenges throughout diagnosis, treatment, and follow-up. These participants felt that many of the challenges these patients face center around dealing with the shock of diagnosis and sudden changes in circumstances and responsibilities, as well as managing expectations.

For the majority of these patients, being diagnosed with brain cancer is shocking and unanticipated. Not only are these patients faced with an uncertain prognosis, they are also faced with new information, decisions, and responsibilities that they must work to understand and manage. Clinician 4 explained this in saying:

"I think that most people with brain tumors, especially high grade, are mostly overwhelmed by everything. Its not like they expected to be sick, and they go from being healthy to being... what is

perceived as very sick, very quickly. You know, they may not have been on any medications and then they are on pain medications, an anti-seizure med, chemotherapy, an anti-nausea med, and they are kind of overwhelmed by all they are trying to incorporate."

Several clinicians noted that these changes and responsibilities are often overwhelming for patients. They reported that despite good intentions, medication management is a major challenge for many patients due to an often large number of medications and complicated dosage schedules. Some participants felt that deficits in memory and cognition further contribute to these challenges. For example, Clinician 7 explained that these factors can interfere with the patient's ability to recall relevant information discussed in the clinic such as why they are taking a given medication, under what circumstances they should be taking it, and whether certain symptoms or side effects were common or anticipated. Clinician 6 added that patients occasionally struggle to understand the side effects of the medications they are taking, and noted that information about medications found online can be scary and overwhelming, leading to confusion and anxiety.

Another area of challenge identified by these clinicians involved managing expectations surrounding symptoms, side effects, and prognosis. Participants noted that certain symptoms such as chronic headaches were extremely common among brain tumor patients, and often proved difficult to manage for patients and clinicians alike. In some cases, patients and clinicians may be able to work together to find the right balance of medications to address certain symptoms, while in others, the challenge becomes helping the patient to understand and accept what is likely their new baseline in life in terms of their symptoms and functional abilities. Participants agreed that setting realistic expectations through honest conversation is important for this patient population and emphasized that misinformation and misunderstandings could easily cloud expectations, and increase frustrations for these patients in the future.

4.6 Current Uses of Patient-Reported Information

Another major focus of these interviews involved investigating current uses of patient-reported information. For the majority of these clinicians, patient-reported information was considered to be an important component of the patient care process. Although all were interested in this

information, there were clear differences in how it was currently valued and used in care and decision-making activities. These differences appear to be associated with clinician specialty and role, with participants typically falling into two major groups, as described below.

Group 1: Nursing, Neurology, Neuro-Oncology Clinicians

In this first group, clinicians considered patient-reported information to be highly valuable, noting that the information contributed by patients and their caregivers often played a central role in care and decision-making activities. These clinicians were interested in changes in symptoms, side effects, and functional abilities, and reported that this information was an important factor in understanding how the patient was impacted by treatments, medications, symptoms, and side effects, and in making decisions about how to proceed. Participants reported using this information to determine likely causes of certain symptoms and side effects, or to rule out other potentially unrelated causes such as the flu or another illness. They also reported using patient-reported information when making decisions about changes to medications or treatments. In many cases, this meant assessing whether a side effect in question was indicative of medication intolerance, or determining whether additional or alternate medications would be necessary or beneficial for the patient. One clinician also discussed using patient-reported information in justifying decisions regarding the need to consider more aggressive treatments, as well as in initiating discussions and decisions surrounding quality of life and balancing the benefits and detriments of continuing with aggressive treatments going forward. These clinicians reported that although they typically looked to imaging reports and lab results, they felt that in many cases, patient reports of symptoms and experiences could be more valuable for these kinds of decisions.

Group 2: Radiation Oncology, Neurosurgery

The second group of clinicians, on the other hand, reported that patient-reported information was rarely the primary determinant in treatment-related decision making. Instead, these clinicians primarily looked to imaging studies to guide their decision making process. This was not to say that patient-reported information was not interesting or informative, however, it was typically used in a more secondary role in verifying suspicions and supplementing understanding of the extent and impact of the disease. The was especially true during follow-up, where patient-reported information could support symptom management and decisions regarding imaging

schedules, but further treatment decisions were largely based on imaging results and formal clinical assessments and testing. One clinician reported that for patients in follow-up, it was much more likely that changes would be detected during imaging or through testing, than for patients to detect changes first on their own, unless it was an acute change, as follow-up schedules were typically tailored based on the natural history of the disease in order to detect changes and identify potential interventions as early as possible.

One exception to this included decision-making surrounding lower grade or slower growing tumors, as well as in working to distinguish pseudo-progression from actual disease progression. One clinician explained that with pseudo-progression, imaging after radiation therapy treatment may initially look worse, but not be truly indicative of disease progression. This clinician explained that patient-reported information can often play a larger role in determining how to proceed in this case, especially if there are significant changes in symptomology. The same was reportedly true for patients with slow growing tumors accompanied by minimal symptoms, where radiation therapy treatments may actually result in higher burden and less benefit for the patient. Clinician 4 emphasized the importance of understanding the impact of symptoms on the individual patient, and balancing the potential risks and side effects of treatment in this situation by saying:

"I mean, it's a slow growing tumor, so when do you pull the trigger to go do something else and potentially give the patient more symptoms? Or make things worse quicker than just kind of allowing the natural history of the tumor… When do you draw that line to say if it's worse enough to do something that justifies the risk of the side effects of what we do?"

4.7 Patient Self-Tracking: Current Methods, Behaviors, Perceptions, Barriers and Concerns

Current Methods and Behaviors: Patient Self-Tracking and Management of Health Information

In addition to exploring uses of this data, I also surveyed clinicians to capture their impressions regarding the methods and approaches currently used by patients for tracking and managing health information. Nearly all of the participants reported that formal tracking of symptom and side effect information in real-time was rare amongst their patients. In fact, one clinician speculated that less than 2% of their patients recorded symptoms and corresponding dates or contextual information either on paper or electronically. They did see some patients and

caregivers bringing journals or notebooks to appointments, but believed that those primarily contained notes about treatments, imaging dates and test results, and appointments, similar to a medical record. Instead, they felt that patients and their caregivers were largely relying on memory to keep track of symptom and side effect information. In the rare instances where information was tracked or recorded formally, it was largely limited to discrete, significant events such as seizures, or chronic symptoms that were getting significantly worse or bothersome for the patient. Patients occasionally kept dedicated seizure, headache, or pain diaries or journals, but these were rare unless specifically requested, and even then, were inconsistently used.

Role of Technology in Patient Tracking and Management Activities

Participants in this study reported that technology use was relatively infrequent amongst their patients. Clinicians occasionally saw patients or caregivers using spreadsheets, and noted that some brought computers or tablets with them to take notes during appointments. They also saw patients using medication reminder applications, and noted that some patients and caregivers stored information on their smartphones, but it was unclear whether they were using a dedicated health application or a generic text/notepad program. Other mentions of technology in health related activities included the patient portal system, however, it was acknowledged that this was used solely for viewing information or sending messages rather than for supporting symptom tracking and data collection activities.

Clinician Experiences, Perceptions and Usage of Patient Self-Tracking and Reporting Tools

As reported in section 4.2, the majority of these clinicians did not routinely use standardized instruments or patient-reported outcome measures as a part of their assessments of patients in the clinic, however, I was also interested in whether they had prior experience with the use of Patient Reported Outcome (PRO) measures, patient self-reporting tools, and self-tracking tools for capturing information from patients outside of the clinic. The majority of clinician participants reported that were familiar with such tools, however, these experiences were largely related to other patient populations. In closely related fields, at least two had used tracking tools or diaries for epilepsy patients, one for fatigue, one related to symptoms of Parkinson's disease, and one for migraine headaches.

Responses from these clinicians were mixed when asked if they regularly asked patients to track or record information related to symptoms or side effects outside of the clinic using paper-based methods, applications, or otherwise. Several of the participants reported asking patients to record certain information throughout the course of treatment and follow-up, primarily related to seizures, headaches, nausea and vomiting, fatigue, and constipation, as well as any major changes that have occurred. Despite good intentions from patients, these clinicians reported that formal tracking or recording of this information was typically inconsistently and infrequently done. Others had not or did not regularly request formal tracking or documentation of information related to symptoms, side effects, or other health events. Of these participants, some acknowledged that it could be helpful, if approached properly, while others felt that it was not necessary. Instead, rather than structured or formal symptom tracking, most reported asking patients to make note of any time a specific health event occurred, or call their care team if certain severe or concerning symptoms or side effects presented.

Clinician Identified Barriers and Concerns in Patient Self-Tracking

Several clinicians discussed concerns impacting their decisions to request tracking, as well as barriers affecting patient follow-through with these requests. In general, the clinicians recognized the fact that patients were already overwhelmed with accepting and managing their condition, and were concerned that asking patients to formally track symptom, side effect, or medication information would just result in more responsibilities for patients to take on. Clinician 3 described this in saying:

"Unfortunately, for a lot of our patients, a brain tumor is a big trauma for them and their family, and I feel like they can hardly get it together to take their medications, and so I wonder if that [structured tracking] would be just be another added thing for them."

Emotional considerations also played into these decisions. Despite using diaries and tracking tools with other patient groups affected by neurological conditions, Clinician 6 infrequently made the same request of this patient population. This decision was largely based on the fact that for these patients, tracking could be perceived as a constant reminder of their condition, leading to increased anxiety and burden.

In addition to potential cognitive and emotional considerations, logistical barriers were also identified. Clinician 6 pointed out that when asking patients to keep track of health information, they typically did not provide these patients with specific instructions or tools for supporting them in doing so. This participant felt that this was a barrier to both requesting and patient ability to follow-through with these requests. Amongst other participants making such requests, it was unclear as to whether any provided patients with handouts or tools to support these activities. Beyond pain, headache, and seizure diaries and journals, no other symptom or side effect specific tools or resources were mentioned, and no methods or tools for tracking multiple events were noted, suggesting that dedicated, consolidated tools may not be available.

Perceived Need for Better Tracking and Reporting of Patient Data and Experiences

The majority of the clinicians involved in this study saw benefit and believed there was a need for better tracking and reporting of patient data and experiences outside of the clinic for this patient population, and acknowledged challenges and limitations associated with current tools and approaches for capturing or eliciting this information. They felt that having this data could help in identifying trends and relationships in health data, and could help them in providing better care and support in symptom and side effect management. Most believed that having more information about time course and severity of events, as well as contextual information about medications and medication habits would be invaluable. While it was not always clear to what extent the information would impact decision making, it was generally agreed that a more accurate and complete representation of the events outside of the clinic could easily be used in understanding and managing certain symptoms and side effects.

4.8 Perceptions of Patient Interests and Abilities in Tracking and Reporting

In response to whether they believed that patients would be interested and able to reliably and consistently track and report symptom and side effect information outside of the clinic, responses were mixed, though largely positive.

There was concern amongst several of the clinicians about whether some patients would be able to complete symptom assessments or conduct self-tracking activities on their own outside of the clinic due to cognitive and physical impairments, as well as the overwhelming stress and burden

placed on them by the disease and treatment process. They felt that as cognitive and functional abilities declined over time due to disease progression, patient ability to take part in tracking would also decline. These clinicians also acknowledged that a certain percentage of patients may not be interested in tracking their own symptoms or side effects. This may be because they feel that they are already aware of what is going on, or because their symptoms are stable and do not feel the need to record this information. Further, unique factors associated with this disease including poor prognosis and short median survival, coupled with cognitive impairments and eventual decline may also contribute to disinterest for certain patients. Clinician 3 felt that interest for these patients may be lower than other cancer patient populations due to a combination of these factors, as described in saying:

"A lot of our patients are neurocognitively impaired, and they have less volition to do that type of thing. I just think on the whole, compared to breast cancer or some other 'curable' cancer, [like] prostate cancer, they are a much different population. They are a much sicker population so it's just harder to get any [data/interest]. They are barely trying to stay alive and stay [active in] doing what they can, so I think there will be a segment [who are interested], but not as many as other diseases."

Although perceptions varied, the consensus was that many patients would be both interested and able to assess, track, and report symptom and side effect information, provided they were given clear methods and structured means to do so. They felt that although some patients may not be able to participate on their own, caregivers could assist when needed in order to help maintain a more complete record over time.

4.9 Future Benefit and Impact of Patient-Driven Self Tracking and Reporting

Despite the fact that the majority of these participants saw clear value and need for better tracking and reporting of patient-reported information, many were also adamant that in order to be successful and worthwhile, patients must benefit from any tool, technology, or activity implemented to gather this information. Acknowledging the challenges and overwhelming burden that patients with primary brain tumors face throughout the disease and treatment process, they emphasized the need for focusing on what is in the best interest of the patient, and what is going to help and provide benefit to these patients. At the same time, the participants

identified aspects of tracking that would be beneficial for themselves as clinicians, and discussed the potential impact of this data on decision-making, as discussed below.

Benefits for Patient

The vast majority of the participants in this study felt that many patients could benefit from structured self-tracking or assessment activities. According to these clinicians, the biggest benefit for the patient would likely be that having a more complete and accurate record of symptoms, side effects, medications, and health events over time would help in care and decision-making activities for patients as well as clinicians. Others believed that being able to look back and see trends in their own data would be helpful for certain patients. Two clinicians felt that this could potentially decrease anxiety by providing something to focus on, or in giving patients a sense of control. Clinician 8 described this in saying:

"I think [patient-driven self-tracking] could streamline care better as well as give patients some control over their own management, which is always helpful. And I think it would also help them feel as if someone was listening."

Several clinicians noted that self-tracking could also help to reduce the need for memory and recall in the clinic, and would be helpful in managing information surrounding medications, for example. They felt that tracking and having a record of patient experiences could be useful in the case where a patient was unable to recall which medications did and did not work well for them. Because these patients are often taking a multitude of previously unfamiliar medications, having a documented record of medications and corresponding side effects and notes would be extremely helpful for patient and clinicians in these circumstances.

Benefits for Clinicians

In addition to exploring the benefits of capturing this data for patients, I also explored the potential benefits for clinicians. Overall, the clinicians felt that this data would be very informative and helpful, and likely of greater benefit and use to them than to patients. Most clinicians saw great benefit towards patient care and felt that this data could help create a better history and understanding of changes occurring over time and between clinic visits. They appreciated the possibility of being able to view trends and identify correlations in patient-

reported data, and felt that it would streamline the care process. While most agreed that having this data would be interesting and helpful, it was unclear as to what extent it would impact decisions being made. It was agreed that improved patient-reported information could be greatly beneficial in managing symptoms, side effects, and medications, and could potentially play an increased role in treatment related decision making for certain patients and scenarios. While many felt this would not represent a major change in terms of the usage of this information, they felt the process could be much more streamlined and informed. For example, a patient presenting with symptoms including fever, fatigue, headaches, and body aches may be suffering from the flu, or may be experiencing withdrawal symptoms while tapering or missing doses of steroid medications. This may not be something that patients immediately associate with their disease or medications and know to bring up, but for the clinicians, knowing this up front would be helpful and save time and resources when determining likely causes of potential symptoms, side effects, and health events.

The value of patient-reported information to support future research was also noted. Clinician 7 felt that having large scale access to patient-reported data, and the ability to easily query that data, could lead to developing guidelines and identifying practice changes that would be beneficial to patients and clinicians alike. Others saw great benefit for improving overall understanding of the disease and the impact of treatment, as well as in improving overall understanding of outcomes and the patient experience. At the same time, these clinicians again acknowledged that their own personal interests in the data must also be balanced with the needs and interests of the patient.

When considering technology use in these tasks, many felt that electronic capture and transmission of patient-reported information would make data more accessible for analysis, and easy to share between providers. Several clinicians also noted that tracking using smartphone or similar technologies would allow for the inclusion of features to support more timely intervention including alerts to make clinicians aware of situations where patients might need to be seen sooner, or to help patients recognize when they need to contact their care team rather than waiting for an upcoming visit.

4.10 Potential Challenges and Consequence of Patient Self-Tracking and Reporting

Concerns Regarding Patient Burden and Anxiety

Along with discussing benefits of such systems or tools for both patients and clinicians, several of the participants also acknowledged the potential for consequences or negative implications. Although they felt that it could be beneficial for some patients, three participants also noted that structured tracking may lead to increased anxiety for others. Upon further exploration, one clinician reported that this might serve to reinforce the idea that every symptom, side effect, or other health event was related to the tumor, while another felt that it could increase obsessive behavior for certain patients. Others felt that tracking might also place an additional burden on patients who are already overwhelmed mentally, physically, and emotionally by their current circumstances. Clinician 6 described this in saying:

> *"They are so eaten up by their disease anyway. It seems like constantly having them be aware of it and writing it down [could be] more of an impediment to their life than [the disease] already is."*

Surprisingly, concerns about being presented with too much data were minimal in this group. Several clinicians pointed out that some patients, by nature, tend to report more information than others; Clinician 7 noted that giving patients an application or tool to capture and track data would likely result in the same continued behavior, as opposed to a representing a major change in behavior. Clinician 6 initially expressed concern over the potential of being presented with excessive amounts of data, but quickly acknowledged that this was exactly what they were looking for. They agreed that having patients capture and share all potentially related data for clinicians to sort through to determine what is relevant and important was truly the goal, as this would take potentially problematic responsibilities and decisions out of the hands of patients, and provide a more complete view to clinicians.

Actionability

Another major theme identified in these interviews involved concerned surrounding for these actionability and whether clinicians should ask patients to capture and track information related to symptoms and treatment effects when it was unclear whether there was anything that clinicians could do to act upon that data. Several clinicians noted that in many cases, there was very little that could be done to reverse or manage certain symptoms or treatment induced effects

affecting these patient. The number of symptoms and treatment effects falling into this category was not well defined, as there were differing opinions as to whether each was truly 'actionable' or modifiable with further time, treatment, medications, or therapies, however, the majority of these participants agreed that irreversible impacts exist and cause burden for these patients. These clinicians described conflict and potentially competing interests between the desire to have access to patient-reported information, and the potential implications associated with asking patients to track data related to symptoms or side effects that could not likely be remedied or acted upon. Clinician 2 described an example of this situation in saying:

"From a radiation oncology perspective, there is not much we can do about this [deficits in global cognition], but it is something we want to follow and is usually related to the areas of treatment and the volume of the brain that was treated to what dose. So its really for our own education and understanding of how to help patients in the future. That said though, it would be nice to show that there is a clear progression or that things were stable."

Several other clinicians, primarily in radiation oncology, discussed similar concerns, and noted the need to balance the interests of the patient versus the potential benefits for clinicians. In contrast, the clinicians from neurology and neuro-oncology tended to be much more optimistic in this area. Although they acknowledged the conflict, they felt that in their areas of practice, symptoms and side effects were much more modifiable, and in cases where little could be done, noted that this information could be useful in counseling patients, helping them to understand their new baseline, set expectations, and make decisions about the future. Both groups agreed that regardless of whether they were asking patients to formally assess or track this information, it was still important to hear about these symptoms, especially if it was something of concern or importance to the patient.

For others, actionability concerns centered around the fact that they felt that there were few, if any, modifiable markers that could be revealed through tracked symptom or side effect data that could be used to alter or influence the course of the disease. Clinician 1 explained that tracking health indicators for chronic disease populations, such as individuals with high blood pressure of those at risk for heart disease, could be incredibly valuable and informative as once detected, there are interventions that could be implemented to prevent further progression of the disease

and to avoid complications. This clinician felt that for patients with primary brain tumors, however, there were very few health indicators that could be detected by the patient and acted upon to somehow "circuitously impact the disease process." Clinician 5 felt that there was potential to learn from this data, but noted that current evidence was not clear in identifying actionable associations. This clinician cited potential relationships between depression, quality of life, and survival time as an example, but explained that unclear and conflicting evidence, as well as underreporting from patients, limits clinician ability to act upon this information and know that it has an impact.

5 Discussion

5.1 Considerations for Design and Implementation

Design: Technology Use in Brain Tumor Patient-Self Tracking

It was generally accepted that the use of technology would be beneficial for supporting patients in capturing information surrounding symptoms, side effects, and neurocognitive functions. Several participants reported that many of these patients and their caregivers already had access to technologies including computers, laptops, tablets, or smartphones, and that the flexibility and capabilities of these devices would be ideal in supporting these tasks. They felt that the use of technology would increase the type and number of features that could be offered, and could potentially reduce burden on users by simplifying tracking and reporting tasks. It was noted that having information in an electronic format could also facilitate sharing of data, and would most likely be easier for both patients and clinicians to work with. At the same time, Clinician 7 noted that some patients may have physical and neurocognitive impairments that impact their ability to easily interact with both paper and technology-based approaches, so accessibility needs must be considered in the design process in either case.

Design: Accessibility and Usability Considerations

Although many felt that technology-based tools to support tracking and communication of health information held great potential, they also emphasized the need for consideration of design, usability, and the demands that such tools could place on these patients as users. Participants cited the need for consideration of the cognitive and motor deficits experienced by many patients in this population, as well as the overwhelming burden that these patients faced as the navigated

the disease and treatment process. Clinician 4 felt that first and foremost, future tools would need to be both simplistic and intuitive for patients to see a benefit from use. This participant emphasized the importance of designing systems that are easy to use, and take into consideration the needs and challenges faced by these individuals. They noted that the process of interacting with such technologies and providing data should not be intrusive, overwhelming, or frustrating for these users. This included avoiding ambiguity in features or text, and ensuring that tasks were as streamlined and efficient as possible. Other participants emphasized that the process of capturing and viewing data would have to be extremely user friendly, noting that content, features, and data that are overly complex or verbose would be challenging for both patients and clinicians. These requirements are summarized in **Table 4** below.

Table 4. Clinician Identified Requirements for Self-Tracking Tools and Technologies

- Must be simplistic and intuitive
- Must be efficient for patients and clinicians
- Must not contribute significant burden for users
- Must provide clear benefit for patient users
- Must accommodate for neurocognitive and physical/motor deficits whenever possible
- Output must not but cumbersome for patients or clinicians

Design: Features and Content

Recommendations and considerations for features and content were also raised by several of the participants. Some participants felt that having written information or guidelines included alongside tracking activities to remind patients of what to do and when to be concerned about certain symptoms or side effects would be helpful for patients, and could prevent delays in seeking care. Alerts notifying clinicians that they should potentially see the patient sooner, or indicating to patients that they should contact their care team based on tracked data were also proposed. Similarly, one clinician also felt that data and alerts could be used to notify clinicians of changes in patient condition that could indicate the need for further discussion about the future.

Others felt that tracking information related to functional abilities could be informative for helping clinicians to understand any changes in the patient's ability to take part in activities they enjoyed, and help with early detection of potential safety issues such as instability that could lead to falls. Several clinicians also felt that features for tracking medication information were also

important, as this could not only provide insights into whether patients were taking medications as prescribed, but also indicate whether the medications were effective for the patient, especially when displayed alongside tracked symptom and side effect data.

Implementation: Frequency of Data Capture and Review

Another important consideration involved how patient-reported data would be presented to clinicians, several of the participants in this study also discussed considerations for how often patients should capture information, and when this information would be shared. In general, the neurology and neuro-oncology clinicians felt that daily check-ins would be beneficial for getting a sense of how things were going day to day, and would be helpful for assessing how symptoms and side effects changed over time. They also felt that the daily approach would be helpful in increasing the quality and quantity of reported data, as tracking would become a routine activity rather than something that needed to be remembered.

Some of the radiation oncology clinicians, on the other hand, expressed concern that conducting assessments too frequently or too early in the treatment and follow-up process would lead to 'noisy' data that would not provide meaningful information until further out. This was especially relevant in evaluating radiation induced treatment effects and identifying signs of tumor growth or recurrence. Two clinicians noted that symptoms may worsen initially during radiation therapy treatment but would likely dissipate or return to baseline levels over time. In this case, immediate daily assessments may not be very meaningful or informative for patients or clinicians. Other symptoms may progress slowly over time, so monthly assessments would likely be more valuable than daily assessments these cases. These clinicians also considered the purpose of the data, saying that decisions about tracking frequency might vary depending on whether the data would be used for research purposes, or if the intent was purely clinical in looking to identify patients who would benefit from rehabilitation or intervention of some sort. One participant also noted that in some cases, more immediate and routine monitoring or assessment of certain symptoms or side effects could be beneficial, but this would likely be on a case by case basis.

In the end, the clinicians agreed that viewing this data at intervals aligning with regularly scheduled visits would be ideal, unless there was an urgent issue that should be reported right

away. In that case, they would like to see the patient-tracked information, but emphasized that the patient should also call and notify their care team, and not rely on the application for communication of this information. Further considerations involving implementation and integration of these future tools and technologies into care activities and clinical workflows would be explored again during the Evaluation study (Chapter 6).

6 Limitations

There are two limitations to be acknowledged when considering the overall findings of this research. First, neuro-oncology is a small field of highly specialized clinicians. As a result, it was challenging to recruit a large number of participants to take part in this study within a reasonable amount of time. Several clinicians initially expressed interest, but were ultimately unable to participate due to repeat scheduling conflicts. Further, despite efforts at more widespread recruitment, I was largely unable to recruit and retain clinicians from institutions outside of the Seattle area. In the end, I was able to recruit 8 clinicians representing each of the specialty areas of the neuro-oncology team to take part in the study; all were located in the Seattle area, and the majority were either employed by or affiliated with the University of Washington and UW Medicine. Due to the relatively small number and limited geographic reach, questions of generalizability and representativeness come into play. In the end, the participants provided a wide range of responses and insights that were highly valuable towards understanding challenges and perceptions in this topic area. Despite offering differing opinions and experiences in some areas, the findings of these interviews converged around many of the same general notions and themes, with very few new insights and opinions arising out of the final interviews.

7. Conclusions

It was clear throughout these interviews that patients with primary brain tumors face a multitude of challenges in managing, understanding, and reporting information associated with symptoms and side effects of their disease. Despite these challenges, the majority of the clinicians recognized the value of this data, and described both the need for and potential benefits of tools designed to support self-tracking for this patient population. In order to be successful, it was acknowledged that benefits must be clear, and that the design of future tools or technologies to support these activities must take into consideration the unique needs, interests, and abilities of

these patients. Although concerns regarding burden and actionability remained, many felt that giving patients something to focus on, and providing a sense of control, and a feeling that they were being heard would be valued by patients. This, coupled with potential benefits in streamlining care activities, as well as value in research and patient care led to a largely positive impression regarding the future design and implementation of such tools and technologies.

Although there have been several studies investigating information challenges and needs from the perspective of patients and caregivers, few have captured clinician perspectives, and none have done so in the context of designing future tools and technologies to support patient-driven tracking, managing, understanding, and communication of health information. This research contributes new findings about clinician perceptions of patient interests and abilities, as well as considerations for future design, development, and implementation. These findings not only contribute new knowledge, but serve as a basis for further exploration and comparison with patient and caregiver perceptions in upcoming chapters.

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Chapter 4: Investigating Challenges, Needs, and Uncertainties in Patients with Primary Brain Tumors and their Caregivers as Motivations for Design: An Interview Study[1]

[1]*This chapter is adapted from Hazen 2016 with permission*

1. Introduction

As highlighted and discussed in the chapters leading up to this study, brain cancer is a devastating diagnosis characterized by significant challenges and uncertainties for patients and their caregivers. Throughout the course of diagnosis, treatment, and follow-up, responsibilities for detecting and reporting information related to symptoms and side effects, as well as managing information, medications, and care activities outside of the clinic primarily fall on patients and their caregivers. Although mobile health and patient-facing technologies have been successfully implemented for supporting tracking and self-management activities in many patient populations, tools and technologies to support these users are limited. Further, little is known about the role of technology in health and daily life for these individuals, or patient and caregiver perceptions of interest and potential benefits of such tools for this population.

In order to explore needs, challenges, and uncertainties faced by these individuals, I conducted semi-structured interviews with 13 patients with primary brain tumors and their caregivers. In these interviews, I investigated challenges involving managing, understanding, and reporting symptoms, side effects, and health information, as well as those involving communication throughout the disease and treatment process. I investigated current methods of capturing and managing health information, and explored patient and caregiver perceptions of benefits, interests, and abilities surrounding self-tracking and management activities. I took a mixed-methods approach, incorporating a survey alongside interview questions, to analyze the use of technology in health and daily life, as well as current usage of health applications in disease, symptom, and health information management activities. Finally, I used brainstorming questions to generate ideas regarding how we as researchers, alongside patients and caregivers, might design tools and technologies to address some of these challenges, and better support patients and caregivers as they navigate the disease and treatment process.

In this chapter, I present findings and themes from these interviews involving current challenges and behaviors related to understanding, managing, and tracking health information, and discuss future motivations for self-tracking and patient-driven data collection. I conclude this chapter by comparing the perceptions of patients and caregivers versus clinicians, and by discussing requirements and considerations surrounding design and usability of future tools and technologies in this area.

2. Background and Related Work

In recent years, there has been increased interest in capturing and developing a better understanding of the patient experience, as well as the impact of disease and treatments on symptoms, functional abilities, and quality of life directly from the patient perspective. At the same time, there has also been great interest across many domains of health toward designing interventions and tools to support and empower patients in managing their own health information and care activities outside of the clinical environment. As discussed in Chapter 1 of this dissertation, Patient-Reported Outcome measures as well as mobile health and patient-facing technologies have been designed and implemented in a wide range of patient populations to support these activities. For patients with primary brain tumors, however, there is still much to learn about patient experiences, needs, and challenges, both for improving overall understanding of the disease and treatments, and for informing the design of future interventions, tools, and technologies to support these individuals. Acknowledging the importance of understanding these factors, several researchers have taken both qualitative and quantitative approaches to investigating experiences, information, and support needs for patients with brain tumors and their caregivers. The findings of these studies inform and motivate this research, illustrating the range and magnitude of the challenges faced, and highlighting areas of still unmet need.

Throughout these investigations, researchers found that patients experience a wide range of challenges, needs, and uncertainties, many of which are uniquely associated with the nature and impact of this disease. Patients diagnosed with brain tumors are often forced to undergo surgery and make treatment decisions within days of finding out that they likely have a malignant brain tumor. In a series of focus groups and telephone interviews, Janda et al found that because diagnosis is typically sudden and unanticipated, patients and their caregivers frequently

experience unmet information needs during the extremely brief time period between diagnosis and treatment initiation [Janda 2006]. Cavers et al also reported high levels of distress and uncertainty amongst patient participants during this time, both as they waited to receive a confirmed diagnosis and prepared for the impending news, and as they dealt with what they felt to be limited, missing, or unclear information about what was happening [Cavers 2013].

Although many of these challenges, needs, and uncertainties emerged in the earliest stages of the diagnosis and treatment process, they often persisted over time. In a series of semi-structured interviews aimed at exploring information and support needs in high-grade glioma patients across the course of disease, Halkett et al found that these patients experience a great deal of uncertainty surrounding their diagnosis and prognosis, as well as in understanding and anticipating the impact of the disease and treatment process on symptoms, side effects, and quality of life [Halkett 2010]. Molassiotis et al took a longitudinal approach to understanding aspects of the patient experience over time, conducting a series of four interviews at distinct time points across the first year following diagnosis [Molassiotis 2010]. These researchers faced an unfortunate, but not unfamiliar challenge as many participants passed away or became unable to take part due to declining condition or neurocognitive function as the study progressed. Nonetheless, these researchers uncovered several important findings including the fact that participants in this study experienced a range of symptoms, side effects, and deficits that were associated with significant burden and had a major impact on mood, social interactions, and participation in daily activities. For these participants, it was apparent that expectations surrounding symptoms and side effects were unclear, as many felt that they were more severe, and lasted longer than they were led to anticipate or were prepared to manage [Molassiotis 2010].

In several of these studies, challenges involving clinician communication, as well as accessing and understanding information led to frustrations and difficulties in knowing what to expect and how to prepare for the future, especially when it came to diagnosis and prognosis [Halkett 2010, Cavers 2013, Molassiotis 2010, Philip 2014]. In their study, Molassiotis et al discovered during the second interview (3 months after initial diagnosis) that three of the six remaining participants did not initially understand the terminal nature of their diagnosis, which resulted in a great deal of anger and frustration. This was partially attributed to the use of unfamiliar medical

terminology or jargon, as well as "misregistering of information" due to shock and inattention during the delivery of this information [Molassiotis 2010]. Cavers et al reported similar findings, noting that some patients may not be ready, willing, or able to process and retain this information in the early phases of the diagnosis and treatment process [Cavers 2013]. Additionally, in some cases, neurocognitive deficits related to the disease and treatments may impact patient ability to take in or process information. For example, Halkett et al found that in addition to a strong need for clear and personalized information, the ways in which information is presented must also be tailored to support understanding and accommodate individual impairments such as those involving language comprehension or vision [Halkett 2010].

For many of the patients involved in these studies, the combined cognitive, physical, emotional, and behavioral effects of the disease and treatment process contributed to a loss of independence, as well as challenges taking part in care, communication, and decision-making activities [Halkett 2010, Philip 2014, McConigley 2010]. Because of these factors, caregivers were often highly involved in patient care and decision making activities. As such, the information and support needs of family caregivers were also examined. McConigley et al noted this time as a time of rapid change for caregivers in terms of roles, responsibilities, and relationships [McConigley 2010]. These researchers found that shock of diagnosis and sudden change in circumstance was often just as significant for caregivers as it was for patients. Because these patients commonly face severe neurocognitive symptoms and deficits early on in the disease and treatment process which often become progressively worse following surgery and as the disease progresses, these caregivers were faced with many sudden changes in roles, relationships, and circumstances. For some patients, deficits in cognitive and communication abilities meant that caregivers were left to take on roles in supporting communication, advocating for the patients they cared for, and even making major decisions in their place. They found that becoming the caregiver of a patient with a brain tumor was extremely challenging, and that finding information about what to expect, how to provide care and support, and how to manage specific symptoms and the overall condition was a major challenge [McConigley 2010]. Aoun et al found that caregivers of patients with primary brain tumors experienced significantly higher levels of caregiver strain, lower levels of mental wellbeing, and higher levels of workload in assisting with activities of daily living when compared to caregivers of other cancer patient populations [Aoun 2015]. Using an

intervention designed to identify and initiate action to address caregiver support needs and priorities, these researchers found that these caregivers felt the need for additional support in many areas including knowing what to expect for the future and understanding the patient's illness. In corresponding interviews, caregivers reported feeling overwhelmed, with one describing their experience as "a tsunami of tragedies," but felt that the structured assessment provided through the intervention helped them to better identify and communicate needs during this time [Aoun 2015]. Similarly, Janda et al found unmet caregiver needs involving addressing fears, managing and adjusting to changes in cognitive and physical abilities, decision-making in the context of uncertainty, understanding the patient experience and accessing information about treatments and side effects, as well as being involved in care activities and working with clinicians [Janda 2008]. Schubart et al also found that the information needs of caregivers were often unmet, and questions unaddressed [Schubart 2008]. These caregivers felt unprepared and unsupported in adjusting to becoming a caregiver. They experienced significant challenges related to understanding and assessing neurocognitive symptoms, and faced difficulties associated with managing changes and deficits involving emotions, behavior, and personality [Schubart 2008]. In fact, feeling inadequately prepared for the changes that patients would experience as a result of the disease and treatment process was identified as a challenge and frustration for caregivers in nearly all of these studies [McConigley 2010, Janda 2006, Schubart 2008, Cavers 2013]. Many caregivers felt unsupported in their role and struggled to adjust to new responsibilities such as managing symptoms and medications, providing care and transportation, making decisions, communicating with clinicians, and researching treatment options [McConigley 2010, Schubart 2008, Janda 2006, Janda 2008, Aoun 2015].

Educational and psychosocial interventions designed to support patients and their caregivers in addressing many of the challenges and needs identified by researchers in these studies are increasingly being developed and implemented in neuro-oncology practice [Langbecker 2015], however, other aspects of information and self-management challenges remain understudied. Development of patient-facing tools and technologies to support tracking and assessing symptoms and side effects and management of health information has been very limited for this population, with most examples remaining limited to computerized versions of Patient-Reported Outcome measures and symptom inventories or checklists. Although some of these tools have

been implemented to support data collection outside of the clinic environment, very few are designed with the intention of supporting or providing data to patients and caregivers directly. Opportunities for further research and design of tools, technologies, and interventions to support these activities were identified in several of these studies. For example, patient participants in the study by Janda et al discussed the need for an objective means of capturing a better understanding of the effects of the disease and treatment process, especially in terms of cognition and behavior, although the medium of these measures were not discussed [Janda 2006]. Further, a paper-based brain tumor specific Patient Concerns Inventory tool designed to help patients identify symptoms, as well as practical, spiritual, family, and emotional concerns, and formulate questions to be addressed in the clinic showed promising results toward supporting communication and creating a focused, patient-driven agenda for these visits [Rooney 2014].

The findings from these studies show that having the information and support necessary to make decisions, understand and manage symptoms and side effects, and provide care is incredibly important, but often missing for these patients and caregivers. Although each of these studies provides a great deal of insight into different aspects of the needs and experiences of these patients and caregivers, none have sought to explore these issues in working toward designing tools and technologies to support support self-tracking and management activities as a means of addressing challenges and uncertainties. As the use of technology in health-related activities continues to increase, new opportunities for supporting these individuals have emerged that are worthy of examination. As such, in this study, I sought to investigate the challenges, behaviors, and motivations of these participants in the context of designing future systems to support patients with primary brain tumors and their caregivers in managing, understanding, and communicating health information throughout diagnosis, treatment, and follow-up.

3. Methods

3.1 Eligibility and Recruitment

For the purpose of this study, I recruited patients diagnosed with a primary brain tumor as well as caregivers of individuals meeting these criteria to participate in semi-structured interviews coupled with a demographic, health, and technology use survey. Full eligibility criteria for patient and caregiver participants are presented in **Table 1**.

Recruitment took place over a 9-month period during which time clinicians at several University of Washington (UW) Medicine associated neuro-oncology clinics were asked to share recruitment flyers with potentially eligible participants. In addition to in-clinic recruitment, I also made several presentations at a local brain tumor support group, and shared study information through the support group mailing list. Because of the small patient population and the associated challenges regarding access, participants were also invited to share flyers with others who might be interested in taking part in the study. In these cases, individuals interested in participating or learning more about the study were directed to contact the research team for additional information.

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[1]
- 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

[1] This requirement was not used to exclude patients with aphasia or communication disorders, provided they were comfortable taking part in the study, and could provide informed consent.

In this study, participants were not screened or excluded based on the presence of disease or treatment related neurocognitive impairments including those involving memory or communication abilities. Rather, after introducing the study and discussing eligibility criteria, participants were allowed to decide on their own if they were interested and comfortable taking part in the study. Due to the increased potential for neurocognitive impairments, however, additional safeguards were put into place during the consent process, as described in Chapter 2. University of Washington Institutional Review Board approval was obtained prior to commencing this research process.

Data Collection

Demographic, Health, and Technology Use survey

Participants were asked to complete a survey to provide basic demographic information, as well as details surrounding their diagnosis and treatment history. The second part of the survey consisted of questions aimed eliciting information about technology use in health-related activities, with questions based on the 2012 Pew Health Tracking survey [Health Tracking Survey 2012]. Patient and caregiver survey materials are available in Appendix A.

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 also 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 communication or memory, for example. Because many individuals travel long distances to the Seattle are for care and then return home following the end of treatment, both in person and phone interviews were offered. Interviews were audio recorded and participants were compensated for their time. **Table 2** presents an outline of the topic guide used during the interview sessions. Because these interviews were semi-structured in nature, and in order to allow participants to share their stories, this was not intended as a strict guide.

Table 2: Interview Topic Guide

Symptoms and experiences during treatment and follow-up
• Overall experience thus far, starting with diagnosis
• Most challenging aspects
• Symptoms/side effects: biggest impact/concern
• Symptoms/side effects: management
Tracking, understanding, and communicating symptom information
• Challenges understanding symptoms/side effects experienced
• Methods for learning more information about symptoms and side effects
• Challenges understanding information about symptoms and side effects
• Challenges conveying/communicating information about symptoms and side effects to clinicians (in the clinic, between visits)
• Methods for managing health information
• Tracking health information (symptoms, medications, etc.) - approaches and interests

Technology use
- Role of technology in daily life
- Changes in technology use sign diagnosis

Tools and technologies in health
- Use of tools and technologies in health (general)
- Use of tools and technologies related to brain tumors
- Reasons for use or disuse
- Comfort/trust surrounding health technologies (current and future)
- Sharing of health information
- Patient portals (use, satisfaction with access to personal health information)

Brainstorming (How might we…)

Data Analysis

Interview data was transcribed and verified prior to data analysis. Two coders conducted a thematic analysis, analyzing transcripts to identify codes and themes, and compiling them into codebooks. The resulting codebooks were merged midway through the analysis process, and additional codes were added and reconciled as the remaining transcripts were coded.

4. Results

Participant Demographic Information

A total of 13 participants (7 patients, 6 caregivers) took part in this study, representing approximately 11 hours of interview data. Twelve individuals participated via in-person interviews, while one chose to do a phone interview due to current location. Six participants opted to take part in patient-caregiver dyad interview sessions, while one dyad participated separately, and 5 individuals participated independently of their patient or caregiver. All in-person interviews were conducted at the University of Washington Medical Center (UWMC), however, many participants were seen by clinicians outside of the UW Medicine healthcare system for part or all of their diagnosis and treatment process. As such, information captured during these interviews was not limited to experiences at UWMC or its entities. Whenever possible, interviews were conducted in a neutral location outside of the clinic in order to encourage participants to share information related to experiences and challenges more openly.

Participant demographic information is presented in **Table 3**. Patient-reported diagnoses ranged from grade II to grade IV disease, and included oligodendroglioma, anaplastic

oligodendroglioma, oligodendroastrocytoma, astrocytoma, anaplastic astrocytoma, and glioblastoma. Time since diagnosis ranged from 2 months to 4 years, 10 months; one participant was initially diagnosed outside of the 5 year cut off, but had experienced disease recurrence and tumor growth requiring further treatment within the time frame of interest. All seven patient participants had undergone radiation therapy, while six had also undergone surgery, and four had chemotherapy as a component of their treatment process. Four patient participants were currently in treatment, and three of the seven participants had reported recurrence or disease progression requiring further treatment. Participants represented a range of educational backgrounds with three having earned associate's degrees, four with bachelor's degrees, and six holding graduate or professional degrees. Technology use information is discussed in section 4.2.3 of this chapter.

Table 3: Demographic Information

	Patients (n = 7)	***Caregivers (n = 6)***
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)
Education	Associate's Degree (1) Bachelor's Degree (3) Grad/Professional Degree (3)	Associate's Degree (2) Bachelor's Degree (1) Grad/Professional Degree (3)

Overall Findings

Throughout this study, I found that patients and caregivers faced a multitude of challenges as they worked to develop a better understanding of their disease, adjusted to complicated medication schedules and treatment protocols, and battled severe symptoms and side effects. Patients and their caregivers wanted to know what to expect in terms of symptoms and side effects, as well as what the future held for them. These individuals often worked to interpret available information in terms of their own situation, and make decisions based on their own values and preferences, but faced significant challenges in doing so. As a result of these experiences, nearly all participants reported feeling lost, alone, scared, or overwhelmed at least once during the process. 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 needs and challenges. Even with a wide range of information sources, many issues,

challenges, and questions remained. In fact, in some cases, access to information resulted in increased confusion and anxiety.

These participants reported that their current methods for tracking and managing health information were typically informal in nature, but met their needs. Most relied on memory or paper-based approaches; technology use in brain tumor-related health activities was extremely limited for these participants. Despite general satisfaction with their current methods, the majority of participants felt that structured self-tracking and management activities could be beneficial in supporting their own understanding and management, facilitating reporting and communication activities, and lead to improved patient care. Many were optimistic about the role of technology in supporting these activities, and described great interest, motivation, and perceived benefits in these activities and resulting data for themselves, their clinicians, and future patients and caregivers. In this section, I present and in-depth discussion of these findings and the themes identified throughout these interviews, as outlined in **Table 4**.

Table 4. Interview Findings and Interpretations

Themes	Findings and Interpretations	Summary
Current Challenges	Symptom and side effect challenges	Complex neurocognitive symptoms and side effects are difficult to understand and manage; these participants noted many uncertainties and unmet information needs, especially regarding the impact of disease and treatment, and prognosis
	Information challenges	
	Communication challenges	
Current Behaviors	Tracking and managing health related information	Current tracking activities are informal, and technology use n health-related activities is limited,; caregivers play an important role throughout the process, and experience their own needs and challenges
	Caregiver roles in care/management	
	Technology use in symptom tracking and information management	
Future Behaviors and Motivations	Technology based self-tracking to support patient care and understanding	There is great potential for future technology design and development in this area, but barriers as well as the needs and abilities of these patients require careful consideration
	Benefits of viewing previous patient and caregiver data and experiences	
	Future tracking: willingness and motivation	

4.1 Current Challenges

4.1.1 Symptom and Side Effect Challenges

Throughout these interviews, participants reported experiencing over 60 different symptoms, side effects, and health events ranging from seizures, headaches, fatigue, insomnia, nausea, diarrhea and constipation, to gross impairments in motor functions, and severe changes in behavior and personality. Several patients had experienced neurocognitive impairments or deficits involving memory, language, or communication, as well as difficulties with attention and concentration, inability to multi-task, and challenges with decision-making. While some of these symptoms and side effects proved to be temporary in nature, several of the participants experienced severe lasting effects from both the disease and treatment process. These symptoms, side effects, and deficits had a major impact on patient ability to take part in normal daily activities and presented new limitations for participants to accept and learn how to accommodate.

Challenges Identifying, Detecting, and Understanding Symptoms and Side Effects

Many patients and their caregivers reported challenges identifying, detecting, and understanding the symptoms and side effects they were experiencing. Part of these challenge stemmed from the fact that symptoms can vary widely depending on the size and location of the tumor, and may be subtle in nature, or present slowly over time. A major contributing factor, however, was the fact that participants were not familiar with many of these neurological symptoms prior to their diagnosis. Of these participants, five had experienced what they initially believed to be a stroke or dizzy spell, but was later identified as a seizure. Interestingly, only a single participant in this study reported experiencing what they thought to be a seizure, but was instead a benign occurrence associated with tapering off of a medication. Because this participant had been warned repeatedly about seizures, but had never previously experienced one, this sensation was cause for great anxiety and concern until they could meet with their clinicians and seek reassurance. Reports of changes in cognitive abilities, behavior, and personality were also common amongst these participants, but several participants noted that were often challenging to detect and understand. Caregivers often reported noticing these types changes before the patient became aware. In many cases, these caregivers also felt responsible for detecting symptoms and changes and assessing when intervention was necessary, although several noted feeling frustrated and alone when it came to knowing how to do so.

Although many of these challenges were more common early in the diagnosis and treatment process, they often persisted as new symptoms and side effects emerged as a result of new medications, disease progression or recurrence, and even treatment induced effects. In one instance, a patient had been experiencing numbness on one side of their body for several weeks after completing radiation therapy. Because this patient was initially diagnosed with a low-grade tumor, and because they had not previously experienced motor symptoms or impairments of any sort, they did not associate these new events with the tumor, or to report it to their clinicians. This symptom quickly progressed and was determined to be the result of a recurrence of the disease, this time as a much more severe and aggressive type in a different area of the brain.

Challenges Determining the Causes of Symptoms and Side Effects

During this time, many participants were greatly concerned with understanding the causes of the symptoms and side effects they were experiencing. For many, these concerns centered around being able to determine whether the symptoms and side effects they were experiencing were related to tumor growth or recurrence, their medications and treatments, or just random occurrences that they should not worry about. Several participants noted that there were so many changes happening in their lives and overall health situation, that it was often difficult to determine exactly why these things were happening. This was a major source of anxiety and concern for many. While clinicians were typically able to provide explanations surrounding likely causes to ease these concerns, there were also times when patients were left without clear answers. For some, understanding the causes of these health events would provide reassurance, and for others, knowing and distinguishing the causes of these symptoms and side effects was important in making decisions surrounding treatment going forward. Caregiver 3 described the complexities of this challenge in saying:

"Sometimes it's hard to tell if it's related to the cancer or the treatment because there's so many treatments and medications that he has been on that it is hard to tell what is causing it. But I realize it's just kind of impossible with brain cancer. There will be symptoms of seizures, headaches, fatigue, and short term memory loss, but then the chemo and the radiation cause those things as well. It would be nice to know though. It would be nice for people to know exactly what's going to happen, or what's causing what so that they can make more informed choices with their treatment."

Two participants reported looking to medication leaflets to help determine whether the events in question were related to any of their current medications, but found the seemingly endless lists of potential side effects to be overwhelming and essentially useless for this purpose. Others turned to resources including the internet and trusted friends or family members when looking for information to bring back into discussions with their clinicians as they felt the final determination or verification of such suspicions should be handled by these individuals.

Challenges Knowing What to Expect and When to be Concerned

Knowing what to expect and when to be concerned was also a major challenge for patients and caregivers in this study. As none of the participants had prior experience or exposure to brain tumors and the medications and procedures employed throughout the treatment process, many described experiencing challenges and uncertainties in determining what was normal or to be expected, and knowing when they should contact their clinicians with concerns. The unfamiliar and overwhelming nature of the diagnosis and treatment process combined with the magnitude and burden of symptoms and side effects led to a great deal of uncertainty for patients and their caregivers. Caregiver 6 summarized this sentiment in saying:

"They are in such a down beaten state that you don't know what's a concern and what just sucks because [they] are in chemo."

Although participants typically acknowledged that they been warned about likely side effects, many felt that the information they received did not emphasize the impact that these side effects would have on their overall quality of life and ability to function on a day-to-day basis. This was especially true when it came to managing and anticipating the severity, duration, and overall impact of certain symptoms and side effects. For many, the physical, mental, and behavioral effects of steroid and anti-seizure medications were much more severe than anticipated. Others noted that fatigue and other side effects of chemotherapy drugs stayed with them for a year or longer following treatment. For one participant, this was especially unfortunate as they had finally begun to feel better and get back into the activities that they enjoyed when they discovered that their tumor was once again growing and that they would need to return to treatment.

Challenges in knowing what to expect and when to be concerned were often further complicated by conflicting, unclear, or vague information. For example, one participant reported that conflicting information between medication leaflets and clinician recommendations for how to respond to certain side effects made it impossible to know when to be concerned and how to react. In another example, a patient was told to call right away if they experienced a specific side effect as it could be a serious threat to their health, but when they did, they felt as though their concerns were dismissed as if this was not a major concern. In other cases, not having clear information or guidelines about when to be concerned presented a challenge. For Patient 2, being told that a bothersome side effect was normal unless it became "too much" was a major cause of uncertainty and anxiety. This patient did not know how to measure or quantify changes in this side effect on their own, or how to define "too much", and did not know who to contact with questions or concerns as they had completed surgery, but had not yet decided on the next steps in their treatment process. Once they had decided on the next steps and were being seen by clinicians on a weekly basis, this patient had a great sense of relief stating:

"I was very happy that someone was actually following up and looking at it because I felt completely at a loss recognizing when exactly I should start worrying and come back to the hospital."

Finally, for others, not experiencing the side effects that they were warned about also became a source of concern. One participant was concerned that something could be wrong when they had not experienced any of the side effects that their clinicians had warned them of or asked about on a weekly basis, despite their diligent note taking and reporting.

4.1.2 Information Challenges

Availability and Presentation of Information

Patients and their caregivers looked to neuro-oncology clinicians as the primary source of information to address needs and concerns throughout diagnosis, treatment, and follow-up. Many of these needs surrounded wanting to know what to expect in terms of symptoms or medication and treatment side effects, as well as what this diagnosis meant for them in terms of prognosis. There was a considerable amount of variation 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 therapy treatment than while on at home chemotherapy. This was attributed to the fact that during radiation therapy, 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 address questions. In contrast, patients on oral chemotherapy reported that they typically only saw their doctor 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, or report changes and concerns.

Additionally, during home chemotherapy, the responsibility for administering the chemotherapy drugs and accompanying medications fell on the patient, or more often, their caregiver. Several caregivers noted that the process of managing these medications and the subsequent side effects was overwhelming, as it was not simply a matter of 'popping a pill,' as explained by Caregiver 6. This caregiver went on to explain that they had not been provided with necessary information regarding medication timing, diet and nutrition, and also had not been prescribed essential anti-nausea medications. Caregiver 5 reported receiving much more complete information and preparation, but still noted that it was scary feeling as though they were the primary person responsible for the patient's health and wellbeing during this time, especially as the side effects experienced during chemotherapy were much more severe than those experienced during other phases of the treatment process.

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, treatments, medications, side effects, and potential complications, especially early on. Patient 3 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 Patient 6 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, Caregiver 6, the other half of this patient-caregiver dyad, countered this sentiment, expressing frustrations over often missing or limited information, 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. 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, physically, or emotionally to process the information being presented, especially immediately after surgery, when receiving their diagnosis, or during certain parts of treatment when they are especially impacted by symptoms and side effects. Additionally, as diagnosis is typically unexpected and sudden, the overall shock of the situation, combined with new terminology and limited time for research before these conversations also contributed to barriers in processing this information for some.

Another major finding was that both patients and caregivers reported that clinicians were often vague, unwilling, or unable to provide answers to their questions, especially when it came to discussions surrounding to prognosis. They acknowledged that at times, the information they wanted was not yet available, as was the case before biopsy and determination of tumor type and grade. In other cases, they attributed the reluctance of these clinicians to provide the level of information desired to the individualized nature of the disease, 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 often 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 Patient 4 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 explain that this information was very important and necessary for setting expectations and making decisions about the future. In the end, several participants reported that providing upfront and honest information was essential for setting clear expectations, and helping patients and caregivers to prepare for and accept future possibilities, as discussed in the following section.

Expectations and the need for personalized and applicable information

The participants nearly unanimously reported that they wanted to know what to expect throughout treatment and into the future, and that more and better information was necessary to make this happen. This went beyond understanding and anticipating immediate symptoms and side effects, and often included wanting to know what to expect for their individual situation in terms of survival, quality of life, and the potential for both long- and short-term neurocognitive deficits. In some cases, participants felt that they did not receive enough information or preparation to help set expectations, and in others, they felt that the information they received was not personalized, relevant, or detailed enough to answer these important questions. For example, several of the longer-term survivors and their caregivers described lasting symptoms and side effects that they had not anticipated including fatigue, cognitive impairments, and dramatic changes in behavior and personality as a result of the disease and treatment process. Caregiver 1 explained that the patient they provided care for was not expected to survive the first year following diagnosis, but was still living 4 years later. This patient, however, had severe lasting cognitive and behavioral deficits that the caregiver and their family members were not prepared for. Both the longer-term survival and severe lasting effects of the disease and treatment process led this participant to question whether they had made the right decisions along the way.

Participants frequently wanted to be able to compare their situations to information they found online or in the scientific literature but experienced challenges in doing so, especially when it came to prognosis. Patient-oriented websites typically do not provide information relating to prognosis, meaning that patients and their caregivers are forced to look to the scientific literature for this information. The majority of these participants noted that they were either unable to find relevant information or unable to compare themselves to the little clinical trial data available as it

was difficult to assess factors including age, exact diagnosis or tumor type, tumor size or location, or previous treatment history. Many participants also felt that their individual situation was unique, primarily due to age at diagnosis or treatment history, which furthered these challenges. Patient 4 described their experience with this in saying:

"The first thing I found out is that I am not like any clinical study group ever. So there I was, I couldn't draw a parallel between my case and anything in the literature. It's like 'oh, you did what?! You did chemo without radiation? Ok, so you're on your own dude."

This participant had based their initial treatment decisions off of currently available data and the advice of a pervious clinician, however, the results of a long-term study had since been released that indicated better outcomes for patients who had undergone a different treatment protocol. Without any sort of data indicating likely outcomes or prognosis for patients who had experienced recurrence following the treatment protocol that this participant had undergone for their specific diagnosis, this participant was now left wondering whether they should be planning their future in terms of months, years, or even decades.

Many participants felt that despite good intentions, clinicians often contributed to challenges in understanding how they relate to available information by emphasizing that every patient and every tumor is unique. Although likely intended to provide reassurance and discourage participants from reading into what they were finding without knowing whether it was valid or applicable, this type of communication led to more confusion and uncertainty than relief. The frustrations associated with this type of communication were described by Patient 7 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. Because progression or recurrence of disease is common for many types of

primary brain tumors, the follow-up period was also a time of anxiety and great uncertainty for participants in regards to knowing what was next, what options they may have in case of a recurrence, and what they should be prepared for.

Credibility and Relatability: The internet, cognitive impairments, and emotions

In addition to the information they were receiving in the clinic, patients and caregivers often looked to others for information, guidance, and support throughout the journey. As most participants did not know anyone else with brain tumor prior to their own diagnosis, they were often forced to look to the internet for information. These participants noted challenges associated with finding trustworthy sources of information online. Several noted experiencing difficulties in determining whether sources were presenting credible scientific information, or whether it was *"just some kind of hoo-ha thing that somebody said you should drink carrot juice and it will cure your cancer,"* as exclaimed by Caregiver 1. These concerns, along with the potential for finding information that was scary or upsetting led many of these participants to make a conscious decision to no longer look up information about brain tumors online.

Patients and caregivers also looked to blogs, personal websites, and online forums for information about experiences and what to expect throughout the disease and treatment process. Despite the potential for hosting valuable information, 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. There was also concern that the information shared would not be applicable, as some felt that there were too many factors and variables that would be difficult to assess in these types of forums. This sense of distrust and skepticism was more common amongst patient participants, whereas several caregivers reported more positive impressions. This difference was primarily due to differences in the types of information that were they were interested in gathering from these sources. There was an overwhelming sense of conflict because most participants felt that they would appreciate seeing data as well as information about the experiences of people who had been through this before them, but challenge in assessing credibility and applicability posed major barriers to acceptance.

Participants also reported looking to in-person and online support groups as a source of information. Because this is a small patient population, dedicated support groups are rare and often difficult to find. The majority of participants who took part in an in-person support group felt that they benefitted greatly from the experience of learning from others. Several participants noted that it was easier to assess the source of information in person and determine what they could take away from the interaction. One participant noted however, that attending brain tumor support groups and being faced with the realities and inevitabilities of the disease was often uncomfortable. Two participants, one patient and one caregiver, were unable to attend in-person groups and looked instead to online support groups. The patient participant felt that the information was helpful, primarily because it was all they could find at the time. The caregiver, on the other hand, joined a general caregiver specific cancer support group but found it difficult to relate to the other members given fundamental differences in experiences, disease characteristics, challenges, and prognosis.

4.1.3 Reporting and Communication Challenges

There were several challenges related to communication and reporting of health information amongst these participants. When it came to accurate reporting of symptom and side effect information, most participants felt that they did not experience major challenges, but acknowledged that barriers did exist. For some, cognitive deficits including impaired memory, recall, and communication abilities interfered with their ability to convey information. Two participants also noted challenges describing the symptoms or health events they were experiencing, and two others reported that at times, they were unable to answer questions being asked in the clinic, typically related to onset and duration of these symptoms or side effects, or details about how they were changing over time. For others, not wanting to discuss potentially stigmatizing symptoms like depression resulted in incomplete reporting of health events. One participant acknowledged that in general, they tended to underreport information in the clinic. This participant and their caregiver suggested that at times, the patient was not fully aware of their neurocognitive or behavioral symptoms, and was thus unable to report them. They also felt that a combination of factors including impairments involving judgment and aspects of social cognition as well as misinterpretation of clinician intentions when asking these questions (i.e.

just being social versus looking for actual medical information) led to more impulsive and less informative responses from the patient.

Caregivers typically attended appointments alongside these patients and were able to fill in or clarify information that may have been unclear or overlooked by patients. In some cases, however, reporting challenges persisted even with caregiver contributions and support. One caregiver explained that the patient they cared for would often get angry when anyone talked about their symptoms, and would downplay or contradict themselves in the clinic, making it difficult for caregivers and clinicians to discuss symptoms and assess the overall situation. This was partially attributed to ongoing challenges with denial, but was also thought to be an act of defiance and an opportunity to exert power over the situation. Further discussion of caregiver roles and challenges in care and reporting activities is included in section 4.2.2 of this chapter.

The second major component of these challenges involved knowing how to contact clinicians with questions and concerns, and how to get help when needed. Communication activities, preferences, and experiences varied among participants. Most participants preferred email as their primary method of communication with clinicians for both routine requests and detailed questions outside of the clinic as it was both convenient and provided written documentation of responses. Despite being familiar and convenient, several participants also experienced challenges when using email. One participant reported feeling conflicted because they wanted to contact their clinicians via email, but worried that this would create more work for clinicians as they would have to access their medical record and research responses. Others had abandoned it as a method of communication after failing to receive a response, instead relying on phone calls, or waiting for an upcoming appointment. The participants noted that 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 remained a challenge.

Finally, participants reported very different experiences related to reaching clinicians when help was needed. This was especially relevant when urgent questions arose outside of normal business hours. Some had been given information about 24/7 services offered through their healthcare organizations where they could call and speak with clinicians about questions and issues that came up. The participants who knew about and used these services appreciated them greatly. For

others, however, these services were either not available or not well advertised, leaving them without access to help when it was needed.

4.2 Current Behaviors: Tracking and Managing Health Information, Caregiver Roles, and Technology Use

4.2.1 Tracking and Managing Health Related Information

Five of the seven patient participants involved in this study reported that they took on an active role in tracking or managing their own health information, while two relied on caregivers to support these activities. For the patients tracking their own health information, three reported relying on memory, and two were using paper-based approaches. All six caregivers reported that they were involved in these activities, either to support patients or for their own knowledge and peace of mind. Two of the caregiver participants were relying on memory, two were using paper-based approaches, and two were using a combination of paper and memory-based approaches (**Table 5**). For all participants, current tracking activities were typically informal in nature. Participants reported primarily recording information related to their diagnosis, treatments, symptoms and side effects. For the majority of these participants, recording of this information was not intended to serve as a comprehensive record, but was instead used to support memory, communication, and organization of information. These participants primarily recorded information when they had noticed changes in a certain symptom or side effect, or if something unexpected had occurred that they wanted to bring up with their care team. One caregiver was mentally tracking concerning symptoms and side effects for the patient they cared for in order to help determine the cause, and in hopes of finding some sort of 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. Additionally, one caregiver was sharing caregiving responsibilities with a family member and noted that for them, tracking came about as a byproduct of communication and comparing notes rather than a deliberate decision to track or record information.

Reasons for why formal tracking or recording of health related information did not take place, using technology and mobile health applications or otherwise, typically fell into three categories: (1) participants were not explicitly asked to capture this data by their clinicians, (2) participants felt as though they were seeing their clinicians frequently enough that symptoms and side effects

were being adequately assessed, or (3) participants felt that they did not know how or what to track. 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 of the treatment process. As previously mentioned, patients were seen far more frequently when undergoing radiation therapy, as compared to at home oral chemotherapy. During radiation therapy, patients and caregivers felt as though they had access to adequate information and that their needs and questions were being addressed. Two participants explicitly stated that they felt they did not need to track or record information related to their symptoms during this time because the clinicians were already assessing and keeping track of that information. In contrast, during oral chemotherapy, patients were seen far less frequently, and often felt like they did not know how or what to track. They also reported that often times, when something would come up that they wanted to discuss with the clinicians, it had typically resolved by the time their next appointment came around, so it was never mentioned. At the same time, one caregiver described how during this time, they wanted more insight into the status and condition of the patient than what they felt they could currently capture on their own at home. They again noted feeling responsible for the overall wellbeing of the patient during this time, and felt that insights and information that could help them to provide better care and support would be appreciated.

Information management techniques and preferences also varied across participants, as many noted that they were figuring it out as they went along. Seven of the participants used paper-based methods for recording information, while two relied solely on memory. Two participants relied on caregivers to record and keep track of information for them, and two others used a combination of memory-based methods alongside notes on a calendar or in email. Of the seven participants taking paper-based approaches, three had notebooks that they recorded information in diligently. One participants reported writing questions and notes on pieces of paper then storing them in a box. This participant would then compile them into a list to bring to their next appointment. Another reported taking notes on the appointment schedules that they received each week during radiation therapy, again bringing them to the next appointment. Paper was clearly the preferred method for recording information and questions for the majority of the participants.

Table 5: Patient and Caregiver Health and Technology Use Information

	Patient (n = 7)	**Caregiver (n = 6)**
Use internet, at least occasionally	Yes (7)	Yes (6)
Own/use smartphone regularly	Yes (6) No (1)	Yes (6)
Have applications (apps) on phone to track or manage health	Yes (2) No (5)	Yes (4) No (1) Other: Former (1)
Types of health applications	Exercise/fitness/pedometer (2) Diet/food/calorie counter Weight Period of menstrual cycle Blood pressure WebMD Pregnancy Blood sugar or diabetes Mood Sleep Other: Meditation (1) Other: Asthma (1)	Exercise/fitness/pedometer (3) Diet/food/calorie counter (1) Weight (1) Period of menstrual cycle (2) Blood pressure WebMD Pregnancy Blood sugar or diabetes Mood Sleep (1) Other: Meditation (1)
Number of health applications	1-3 (2) 4-6 7-10 11+	1-3 (4) 4-6 7-10 11+
Frequency of health application use	Several times a day Daily (1) Weekly (2) Once or twice a month Less than once a month Other: as needed	Several times a day Daily (1) Weekly (2) Once or twice a month (1) Less than once a month Other: as needed
Tracking health indicators for patient	Yes (5) No (2)	Yes (6)
Methods for **tracking brain tumor related health indicators**	Paper (2) Computer program Website/online tool App/tool on mobile device (1) Medical device Memory (3)	Paper (4) Computer program Website/online tool App/tool on mobile device Medical device Memory (4)
Frequency of **tracking for brain tumor related health indicators**	Several times a day Daily (2) Weekly (1) Once or twice a month (1) Less than once a month Other: as needed (1) No response (2)	Several times a day Daily (1) Weekly Once or twice a month (1) Less than once a month (2) Other: as needed (1) No response (1)

4.2.2 Caregiver Roles in Management and Care

Throughout these interviews, it was clear that the cognitive, physical, and emotional effects of the disease and treatment process on patients with primary brain tumors were often severe. As a result, some patients were unwilling, unable, or needed additional support from caregivers in managing information and care activities during parts or all of their treatment process. Caregiver participants in this study reported taking on a range of new roles and responsibilities throughout this time to address these challenges and support patients including managing health information, accessing test results, refilling prescriptions and administering medications, researching treatment options, as well as dealing with insurance and managing financial obligations. Caregivers were often present during clinic visits to ask questions and gather information, as well as to support memory and communication for the patient when needed. These caregivers often handled many logistical aspects of the care process, such as arranging or providing transportation as many patients are no longer able to drive following their diagnosis, as well as scheduling appointments and transferring recording between healthcare organizations. In addition to being highly involved in logistical and care-related activities, these caregivers also reported that they provided emotional support for patients throughout this time.

Despite being highly involved in these activities, several caregivers felt that they faced challenges and barriers in accessing the information, resources, and support necessary to do so. Several participants noted that caregiver questions and concerns typically did not take priority during clinic visits, and often went unaddressed. In some cases, caregivers felt as though they could not ask sensitive questions in front of the patient, or patients felt that their questions were more important to address given the limited amount of time available to meet with their clinicians. In other instances, patients were feeling well enough to take on the majority of the care and information management responsibilities, and did not feel that they needed caregiver assistance or participation in appointments. During these times, caregivers reported having even less access to clinicians, despite the fact that they still had their own questions and concerns. In three cases, participants suggested that caregiver be provided separate appointments to address their own questions, needs, and concerns regarding the care process.

Another interesting and challenging situation arose in the case co-caregiving. Because caregiving is often time consuming and demanding, some caregivers shared responsibilities with another family member. This meant that several people were involved in activities such as scheduling and attending appointments, monitoring symptoms and side effects, and managing medications, with each capturing information and comparing notes over time. This was also the case when patients could no longer live independently at home, and were moved into nursing home or memory care facilities. In this case, both caregivers and healthcare professionals were involved in these activities, each capturing and storing different sets of information in separate locations. In each of these cases, shared responsibilities often led to disparate or scattered knowledge and information, which created challenges for managing and reporting information in the clinic, and made it difficult to assess how symptoms and side effects were changing over time. For these participants, having established tools or resources to support these shared responsibilities would have been greatly beneficial.

4.2.3 Technology Use in Symptom Tracking and Information Management

The participants in this study reported high levels of technology use in daily life outside of health. Many of the participants reported that technology was essential in daily work activities, while others appreciated such personal technologies for entertainment purposes. Many reported using email and text messaging on regular basis, both for work and in their social and personal lives. 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, use of these technologies in health activities related to their cancer diagnosis was limited (**Table 5**). Throughout these interviews, two participants reported using electronic calendars for managing appointment information. One participant noted using spreadsheets for managing medication information and dosage schedules, especially for chemotherapy and steroid medications, and another used spreadsheets for keeping track of financial information. Several of the participants used email and text messages for sharing information with family members and friends, citing that it could easily be done at their own convenience, instead of at the convenience of others, as was typically the case with phone calls. In two cases, email was used as a means of communication as well as a method for documentation and management of information.

Looking specifically at the use of health-related applications, six (2 patients, 4 caregivers) of the thirteen participants reported having apps on their phones to support tracking and managing their overall health, with one additional participant reporting being a former health app user. These apps largely pertained to tracking exercise and fitness, diet, menstrual cycles, and meditation, as well as tracking information related to other health conditions (**Table 5**). Although many of the participants reported frequent use of these applications in other aspects of health, only a single participant reported using applications or smartphone based tools for tracking or managing brain tumor related health information; this participant was not using a dedicated health application, but rather, was tracking seizure frequency on a generic calendar application on their phone. One caregiver reported that they had tried using a medication reminder application for the patient they cared for, but quickly found that it was difficult to maintain and easy to ignore. They chose to abandon these kinds of technologies as they felt it was not worth the effort of making updates to reflect frequent changes in medication type, dose, and frequency, especially when the patient was not responding to the alerts.

Despite everyday use of technology including smartphones and computers in other aspects of life, paper was considered to be the fastest, easiest, and most convenient option for recording and managing information related to the brain cancer disease and treatment process. For several participants, paper was more likely to be on hand and immediately available compared to cellphones, computers, or tablets. Other participants were concerned that they could not navigate devices quickly or efficiently enough to record the information of interest. With paper, participants could write out their questions beforehand, and quickly jot down responses alongside those questions during appointments. Another benefit of paper, for one participant at least, was that they could practice cognitive and motor skills including hand eye coordination when writing in a notebook. For these participants, limited technology use in health was not related to distrust, but was a matter of availability, functionality, and convenience.

Patient portal usage was also explored in this study. The majority of the participants had accessed their own patient portal at least once, or the portal of the patient they were providing care for. They reported accessing the portal to view lab results, radiology reports, and visit summaries, and occasionally to verify appointment information. They felt that in general, the features and information were useful, but often limited. There were also challenges and

limitations associated with patient portals. Access was an issue for several participants, as they had experienced difficulties with system failures or struggled to remember 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 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. Several participants also expressed frustrations related to missing data and the often limited nature of the information provided in reports made available through the patient portal. Participants felt that they should have immediate access to their own health data, and that delays in posting this information were unacceptable. In many cases, patient and caregiver already the information by the time it was posted to the portal. Others 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 phone calls and emails, or 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, as well as access to information and resources about the patient's diagnosis and resources would be helpful to have.

4.3 Future Behaviors and Motivations

4.3.1 Technology based self-tracking to support patient care and understanding

The majority of the participants in this study were satisfied with their current methods for tracking and managing health information, but saw great potential benefit and value in having structured tools and approaches to support these activities. Participants felt that structured tracking of health data would help create a more complete record of information for clinicians to work through when making decisions and in determining causes of symptoms and side effects, for example. Despite the fact that participants were not typically looking back or reflecting on recorded data, several felt that this could help them in understanding and finding correlations in their own data. One caregiver was uncertain of the clinical benefit, but felt that ensuring that data

was available for clinicians to review would provide great psychological comfort to patients. Some felt that this would simplify reporting activities, and would likely reduce cognitive load and the need for memory and recall in clinic. Several participants also felt that this would help with providing more complete and reliable answers to questions related to symptom and side effect onset, severity, frequency, duration, and changes over time; two participants felt that clinicians would more likely trust tracked data than patient reports from memory, and that as a result, patients may feel more confident in reporting these things. Others felt that this might help with remembering and communicating questions and other information related to their experiences in the weeks and months between appointments.

Many of the participants were optimistic that technologies such as health applications could be used to support these activities, provided they were designed to meet the needs, interests, and abilities of this user population. Participants noted very few concerns related to interests and abilities, rather, both patient and caregiver participants saw great benefit in the inclusion of technology, noting that structured tools could help simplify many aspects of the current activities and responsibilities. Participants reported that technology-based tools could help to consolidate and facilitate tracking activities, and make it easier to communicate and share information about symptoms or side effects with clinicians between appointments. They felt that technology could minimize burdens associated with capturing data, and could allow users to easily see measurable changes or improvements in their own data and potentially better identify when they should react or seek help in regards to specific symptoms or side effects, for example. Similarly, one participant noted that technology-based solutions could also provide an opportunity for clinicians to detect problems and potentially intervene earlier, especially if they were able to access and review tracked data ahead of appointments. Two of the patient participants also suggested that technology-based approaches could help with organization, and eliminate the need for tracking down and consolidating information from ‘100 bits of paper.’

Although most were open to the idea, a few of the participants were initially reluctant to say whether they would switch over from their current methods if tools or technologies to support these activities were to become available. Some of this reluctance came from the fact that participants were not currently using applications or tools for tracking or managing their brain tumor related health information, and because of negative experiences associated with health

applications in the past. A large portion of this reluctance, however, was due to resistance to change as many had already developed methods that worked well for them over time. Others cited technology itself, and the fact that it was often not convenient, as a major factor. As a result, current behaviors and motivations, as well as the needs, interests, and abilities of these patients and their caregivers would need to be carefully examined and considered as a component of future technology design. In the end, the majority of these participants reported that if such tools became available and their clinicians asked that to use them, they would most likely do so.

4.3.2 Benefits of viewing previous patient and caregiver data and experiences

Thinking back on the challenges they faced, many of the participants felt that having access to patient-reported symptom and side effect data as well as information surrounding experiences throughout diagnosis, treatment, and follow-up from previous patients would have been greatly informative and beneficial. Participants explained that this data could help them in determining what to expect from treatments and medications, making decisions surrounding medications and treatments, and in understanding whether what they were experiencing was normal. One caregiver felt having access to such data, as hosted by their clinicians, would have helped to ensure that they were not being naïve in their expectations, while another felt that this would have helped in reassuring and supporting the patient that they were caring for, especially early in the disease and treatment process.

Interests in this data varied. Some of the participants were primarily interested in data related to symptom and side effect type, frequency, severity, onset and duration, as well as whether they resolved on their own or if interventions were necessary and effective. Some were very interested in quality of life data, while others wanted to see information and experiences related to functional abilities, such as whether patients were able to return to work, and when they were allowed to drive again. These participants also felt that this information could be helpful for patients, caregivers, and clinicians in estimating prognosis, and understanding what to expect as the disease progresses. As clinical trial data is limited for patients with primary brain tumors, especially in terms of understanding the symptom experience, 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 the potential of this data and felt that having the option of knowing the likely trajectories, as backed by real data and statistics, would be of great comfort and benefit to themselves and their family members.

Although the majority of participants felt that they would have appreciated seeing any and all available 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 the experiences of previous patients with their diagnosis because of the personal nature, and the uncomfortable reality that this is a terminal condition. The same participant was comfortable with viewing data, but confirmed that they were not interested in anything related to personal experiences or quality of life. They did feel that the experience information may be helpful and of interest to their caregiver, however.

In addition to the value and benefits of this data in supporting current and future patients and caregivers, two participants also felt that this data could be beneficial to clinicians. One participant suggested that data surrounding symptoms associated with primary brain tumors, especially early on, could be useful for clinicians outside of neuro-oncology, especially those in more rural areas who may not interact with these patients on a regular basis. Another participant felt that this data would likely also be beneficial for knowledge and educational purposes for neuro-oncology clinicians and those more familiar with these tumors, as the symptoms and experiences of these patients can be very diverse, and there is still much to be learned.

4.3.3 Willingness and Motivations

Acknowledging the potential of this data, both to support their own care and understanding, and the needs of future patients and caregivers, the participants in this study were nearly unanimous in reporting that they or their caregivers would be willing to track health related data, given acceptable methods and tools. The majority of the participants reported that they would be willing to take part in self-tracking activities to support their own interests and benefits, especially if asked by a clinician; only two of the thirteen participants reported being uncertain or unable to see clear the benefits in these activities. Further, many of the participants were especially motivated by the opportunity to contribute or give back to future patients and

caregivers, acknowledging that the data they captured could help to provide information and support to future patients and caregivers diagnosed with this disease. This sentiment was described by Patient 07 in 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."

5. Discussion

Considerations for Design and Implementation

In addition to the previously discussed findings, I identified several considerations involving design and implementation going forward. First, when discussing the design of technologies for users with complex medical or neurological conditions, the interests, needs, challenges 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 abilities, incorporating this information into design discussions from early in the research and design process is important. Although there were no concrete decisions or discussions surrounding what these future technologies would look like, the participants provided several preliminary recommendations based on considerations of these factors and their own experiences. In terms of design and usability, several participants noted that for individuals with potential motor impairments or challenges with language, for example, multiple methods of data entry (e.g. text, speech, pick list) may be necessary. Others noted that these same methods and considerations surrounding data entry could serve a dual benefit in acting to support capture or more relevant, reliable, and credible data, especially when compared to free text or extensive narratives. Minimizing the need for memory, and streamlining tasks and activities to avoid redundancy were also noted as important. Others felt that technology should be 'smart' enough to pull relevant data directly from the medical record with minimal effort required from patients and caregivers. Finally, participants noted that considerations for shared access for caregivers were also necessary as some patients would likely be unwilling or unable to participate in tracking activities during parts or all of their treatment process; these same functionalities could also be used to support co-caregiving situations.

There was also discussion of considerations for design beyond those involving neurocognitive deficits. First, the fact that patients and caregivers would likely both be target users of any future tools or technologies developed as a component of this research would need to be taken into consideration. Currently, caregivers were primarily accessing information and systems such as patient portals through patient logins, rather than having their own dedicated access. It was also reported that their needs, concerns, and contributions were often regarded as secondary to those of the patient. It was unclear how issues of access and priority would be handled in the design of these future systems, however, this would be explored in future stages of the design process. It is also important to recognize that these individuals are already overwhelmed with new activities and responsibilities, and that although tools and technologies could be designed to include a wide range of new activities, features, functionalities, the true interests and needs of the target population must be considered. Several of the participants expressed interest in the use of technology to support tasks surrounding medication management, for example, however, at the same time, others emphasized that providing access to trustworthy information, and methods for facilitating communication were just as important as potential technological features and functionalities. These findings and considerations are summarized in **Table 6.**

Table 6: Considerations and Requirements Summary

Features and Functionalities
• Simple, convenient methods for capturing data
• Must support shared access for contributing and consolidating data
• Easily capture and share data with clinicians
• Ability to send questions or tracked data ahead of appointments
• Reminder functionalities
• Support for medication management
Design and Usability
• Must be easy to use
• Must be convenient for users – ideally more convenient that paper based methods
• System must not be slow
• Multiple/flexible methods for accessing system (phone, tablet, web)
• Multiple/flexible methods for data entry (voice, text, drop down, pick list)
• Pre-populated information to minimize typing/data entry
• Shared access for patients and caregivers
• Easy to update (medications, health information, etc.)
• Allow user to provide information they believe is relevant without having to fill out lengthy forms

Another area of focus involved considerations surrounding implementation and acceptance of these future tools or technologies. Because participants were generally satisfied with their current methods of tracking and managing health information, there will likely be barriers to overcome in incorporating such activities and technologies into current workflows and routines. As many of the participants were motivated by the potential benefits of having a more complete record to support care, communication, and decision-making, integrating and reinforcing the use of this data into routine clinical encounters was identified as one way of overcoming such barriers. The use of this data in the clinic provides a dual benefit of supporting communication and reporting, as well as providing an opportunity for clinicians to review the information with patients and their caregivers to ensure reliability and completeness prior to submitting it to any future repository. Although issues involving reliability and credibility of patient-reported data can be an issue with many patient populations, it is especially a concern here due to the cognitive, emotional, and behavioral factors associated with the disease. Another potential benefit of integrating these activities and data into the clinical encounter is that patients may feel like they have the tools to better covey information surrounding symptoms and side effects, and engage in discussions surrounding likely causes or correlations between side effects and medications. Issues and perceptions surrounding trust and communication of patient-reported data would be explored in later stages of the design and evaluation process.

Comparing and Contrasting Perceptions of Challenges, Interest, Ability, and Benefit: Patients and Caregivers vs. Clinicians

There were many similarities between the experiences and challenges reported by these interviews participants, and the reports provided by the neuro-oncology clinicians in Chapter 3. Both groups reported that patients experience many symptoms and side effects that have a large impact on their ability to function in daily life, and create a sense of burden for patients and caregivers alike. They agreed that understanding the underlying causes of symptoms, and determining whether they were related to the tumor or not was a major cause of concern and anxiety. They also agreed that the disease and treatment process is often overwhelming, and that cognitive and emotional factors can contribute to challenges in understanding and managing information, especially early on. Despite agreement on many issues, there were also areas where perceptions differed between these groups. For example, while both groups agreed that patients

face challenges in reporting health information, the clinicians perceived far greater challenges than the patient and caregiver participants. This may have been due to the fact that clinicians were answering these questions in the context of patient challenges, whereas many of the patient and caregiver participants were participating together and considered themselves to be a team in these activities and responded accordingly.

The most significant of these differences, however, surrounded perceptions of patient interest and ability in regards to self tracking, as well as the potential benefits of tracking for patients. Several of the clinician participants expressed concerns surrounding patient involvement in self-tracking, both with and without the use of technology, due to cognitive and motor impairments. They noted that patients with primary brain tumors are often highly overwhelmed and burdened by the overall situation and wondered whether self-tracking would contribute to those burdens, cognitively, emotionally, and physically. There were also concerns regarding actionability, and whether they should be asking patients to track information related to things that they may not be able to do anything about. Despite these concerns, they believed that technology driven self-tracking could be informative and beneficial in helping to streamline the care process, and further understanding of the patient experience. They felt that the data gathered would likely provide more benefit to clinicians than patients and caregivers, but felt that certain patients would benefit greatly from these activities.

Patient and caregiver participants, on the other hand, acknowledged many of these same challenges and considerations, but were much more optimistic. They noted that at times, patients would be unwilling or unable to participate, but this concern was minimized by the fact that caregivers could easily support these activities. Most felt that they were already performing similar activities, and none reported feeling as though more formal self-tracking would represent a major change in responsibilities or contribute a significant burden. One of the most significant differences however, came in terms of perceived benefits towards patients and caregivers. These participants felt that tracking and recording health information could lead to better understanding of their own data, and help in working to identify potential causes of symptoms and medication side effects. Others felt that technology based approaches could help to consolidate information, and contribute to a more complete and usable record over time that would be helpful for

themselves and their clinicians. They also felt that this data could be very valuable in helping to support future patients and caregivers, as they noted that currently, many of their own questions could not be answered based issues of data availability. In the end, both groups agreed that systems or tools to support patient-driven self-tracking activities could be beneficial, but acknowledged that any future systems, tools, or technologies put into place must be easy to use, and provide clear benefit to users in order to be adopted.

6. Limitations

There were several limitations to note in this study. First, despite efforts to recruit a diverse sample, many of the participants were treated within a single healthcare system. This was a consequence of challenges with recruitment, a common theme when working with small, rare disease populations. In this case, recruitment challenges were amplified by the impact of the disease, as well as the often poor prognosis. Several individuals who expressed interest in participation were unable to take part in the study due to changes in condition or availability due to treatment schedules. Because participants were treated at different points in time, had different clinicians, and underwent different treatment protocols, however, their experiences were very different. Additionally, because some had been diagnosed elsewhere and traveled to the Seattle area for specialized treatments, and others had completed parts or all of their treatment elsewhere in the region, I feel confident that I was able to capture a broad set of experiences, perspectives and opinions. One benefit of this study over other previous studies, however, is that participants were not screened or excluded on the basis of neurocognitive or communication deficits. This allowed for participation from a wider range of participants with different deficits and challenges, and resulted in a broader understanding of patient needs, experiences, and considerations for design.

Another potential limitation is that these participants tended to be slightly younger than the median age at diagnosis for the overall brain tumor population, and potentially more highly educated. There was also very little variation in terms of race, although it is not entirely clear how this might impact or influence findings. Finally, these participants all had experience using technology and the internet, and all but one reported owning and using a smartphone device on a regular basis. This is not unusual for this demographic or age, but it is unclear as to whether

these participants were representative of the 'average' brain tumor patient as this is the first study to explore personal and health technology use in this particular population.

7. Conclusion

Mobile-health and patient-facing technologies are not yet readily available for this patient population, however, the potential for tool design in this area is vast. Not only could 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, it may also support the need of those who will be stricken with this disease in the future. The participants in this study identified benefits for themselves in supporting tracking and reporting activities, while minimizing the need for memory and recall in the clinic. They also felt that structured tracking activities could provide a sense of control and reassurance, and help patients to better understand their own health data. One of the most significant findings from this study, however, was the participants strong desire for more information, and willingness to participate in self-tracking activities both as a component of their own care process, and to support the needs of future patients and caregivers. 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 patients diagnosed with a primary brain tumor. These participants felt that having access to actual data to compare against their own situation and to identify possible trajectories would be incredibly empowering. They felt that this data could help patients, caregivers, and clinicians to have these honest conversations, even if there were still some uncertainties involved. Acknowledging that this data does not yet exist motivated these participants to be an active part of the data collection process, providing benefit to others in the future.

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Chapter 5: Participatory Design alongside Patients with Primary Brain Tumors and their Caregivers

1. Introduction

Throughout the previous interviews with patients, caregivers, and clinicians, it was apparent that many participants saw benefit in specifically designed tools and technologies to support activities related to tracking, managing, and communicating health information throughout the care process. Despite minimal technology use in current brain tumor related health activities, these participants were open to using technology, provided that it was easy to use and took into consideration the interests, needs, and abilities of this patient and caregiver population.

In analyzing these interviews, I identified several requirements for future systems and technologies that would need to be explored and addressed during the design and evaluation stages of this research. To briefly summarize the findings from Chapters 3 and 4, the clinician participants felt that any system, tool, or technology put into place must be easy for patients and their caregivers to use, and must not place an additional burden on the user. Further, they were clear that in order to be recommended or adopted, there must be a clear benefit for patients as users. There were concerns regarding accessibility and usability, especially as increasing disease and treatment related neurocognitive and motor deficits would likely impact both interest and ability to take part in self-tracking and management activities for certain patients. These participants felt that technology could be easily leveraged in providing a method and support for capturing and managing data, but noted that any future application or tool should be simplistic, intuitive, and efficient. In Chapter 4, patient and caregiver participants provided additional information and insights regarding requirements and recommendations for future systems. These participants agreed that any system or technology put into place must be easy to use or else it would be abandoned. Several participants went beyond this in saying that ideally, any future tool or technology should be faster, easier, and more convenient than paper and pencil, the current preferred method for recording information. Methods and approaches to overcoming this barrier would be explored further in the upcoming design workshops. Other requirements included having flexible methods for application access and data entry, both for convenience and to

accommodate users with neurocognitive or motor impairments that may make typing on a computer or smartphone device difficult or impossible, for example. Providing a means for both patients and caregivers to access the systems and contribute information was also necessary, especially during times of extreme illness or cognitive and physical fatigue. In technology-based solutions, they noted that the system should be pre-populated with relevant health information, and should be easy to update with minimal effort as circumstances regarding medications and treatment schedules often change. Finally, the interview participants wanted to be able to provide additional information or context that they felt to be relevant or beneficial, but did not want be required to fill out lengthy forms or answer questions that they deemed irrelevant or burdensome.

The goal of the current study was to build off of the knowledge gathered throughout these interview studies, and create a prototype of a system or tool designed to support patient-driven data collection, management, and communication. As many of the requirements laid out in the interviews would be difficult to achieve without further input and consideration from target users of this future system, I recruited four patient and caregiver participants from the previous interview sessions to participate as collaborators in a series of Participatory Design workshops. These participants would serve as experts, sharing information, ideas, insights, and experiences in the process of working to design specialized tools and technologies to support this population. In these workshops, we reviewed themes from the previous patient and caregiver interviews, and took part in a series of brainstorming, design, and prototyping activities, with activities selected and carefully tailored according to the approach presented in Chapter 2. At the end of the second workshop session, I used the information, insights, and designs contributed by the participants to create a high-fidelity prototype of a smartphone and tablet application to be evaluated by patients, caregivers, and neuro-oncology clinicians in the final stage of this research (Chapter 6).

In this chapter, I present my work conducting Participatory Design alongside patients and caregivers affected by primary brain tumors to design a tool to support patient-driven data collection, management, and communication. I begin by describing the methods and activities employed to engage participants in further identifying and shaping functional requirements and the overall design of this future system, and then present findings and discussion surrounding these activities and contributions to the overall design of the application. I conclude with a brief

analysis and discussion of the successes and challenges associated with these activities, and discuss additional themes and considerations.

2. Methods

Eligibility and Recruitment

Design workshop participants were recruited from the larger group of individuals involved in the patient and caregiver interview study; interview participants were asked to complete a form indicating interest in being contacted with information about participation in the design workshops and/or evaluation study. Of the 13 interview participants, 9 indicated interest, and were contacted with potential dates and times for each of the two workshop sessions. In order to take part in the design workshops, participants were required to commit to attend both sessions. Final dates were selected based on availability rates. In the end, three participants were unable to attend on the dates selected due to travel or scheduling conflicts, and two others were unable to attend as they were no longer in the Seattle area.

Each session lasted two hours, and was held at the University of Washington Medical Center. The workshops were conducted in a meeting room that was easy to access and close to parking facilities. As with the interviews, the meeting location was separate from the clinic area to support more open and carefree participation. Sessions were conducted three weeks apart to allow time for development of research materials and prototypes, while minimizing the potential for attrition. University of Washington Institutional Review Board approval was obtained prior to engaging in research activities, and informed consent was obtained at the beginning of the first design workshop. Participants were compensated with a $50 gift card for their time at the end of each session. Sessions were audio and video recorded. The activities selected and overall approach are presented in **Table 1**, and described in detail in the following sections.

Table 1. Participatory Design Workshop Activities

Workshop Session 1	Workshop Session 2
Journey Mapping (15 min) Group Discussion (15 min) Persona Creation (15 min) Low Fidelity Prototyping (45 min) Session Evaluation (15 min) Optional Homework	Discussion and Review (10 min) Medium Fidelity Prototyping (90 min) Session Evaluation (10 min)

Demographic, Health, and Technology Use Survey

As with the previous patient and caregiver interviews, participants were once again asked to complete a brief demographic, health, and technology use survey. This survey was a shortened version of the initial survey, with questions again based on the 2012 Pew Health Tracking Survey [Health Tracking Survey 2012].

2.1 Participatory Design Workshops: Methods and Techniques

Workshop Session 1:

Activities conducted during the first session included journey mapping, group discussion of themes identified throughout the patient and caregiver interview study, persona creation, low fidelity prototype development, and an overall evaluation of the workshop. In all cases, instructions were presented verbally and provided in writing to support understanding, and minimize demands placed on memory. Additionally, examples and structured templates were made available to participants in instances where they felt they needed additional structure or direction. The overall session was broken down into individual activities with time guidelines and reminders provided to help keep the session on track, and to maintain focus and attention. Examples of written instructions and handouts are available in Appendix B. Participants were given paper, pens, markers, stamps, magazines, scissors, tape and glue, as well as other assorted craft supplies to use in each of these activities. Two researchers, both with a background in health informatics and design were present during this session. One researcher was responsible for leading research and design activities, and the other recorded notes and observations, and facilitated the flow of the overall session.

Activity 1: Journey Mapping

The first activity selected was a journey mapping exercise. Journey maps, or customer journey maps, are commonly used to illustrate a user's journey through a particular event or experience of interest [Howard 2014, Crandall 2010]. These map are used to depict the user's actions, and often include details surrounding major milestones and steps taken, as well as emotions, needs, motivations, challenges, and frustrations encountered, from the perspective of the user or customer [Richardson 2010, Temkin 2010, Boyd 2012]. Journey maps can be used as a communication tool, providing a common understanding of the user's experience to different stakeholders [Howard 2014], and serve to identify 'pain points' as well as opportunities for

improvement [Temkin 2010, Boyd 2012]. Methods for developing these maps may vary depending on the intended use and user population. In many cases, journey maps are created by groups of multi-disciplinary stakeholders using various research methods to form an in-depth understanding of users and their processes [Temkin 2010]. In others, these techniques have been used to capture and summarize the experiences of small groups of individuals representing the user population of interest [Boyd 2012], or employed as a means of capturing an understanding of an individual's journey through an event or experience of interest.

For the purpose of this study, I chose to use journey mapping as a way to encourage participants to illustrate their experiences as a patient or caregiver throughout the disease and treatment process. I asked participants to draw a timeline or map of their journey, thinking about major events and milestones, as well as their individual experiences, challenges, and needs. Participants could focus on a single aspect of the process (e.g. radiation therapy treatment), or their overall journey from the time of diagnosis up until the day of the workshop. Once completed, I asked participants to introduce themselves and share their journey map with the group.

Activity 2: Reviewing Themes

The next activity involved reviewing findings and themes identified throughout the patient and caregiver interview study. This would serve to refresh memory and share information that came out of interview sessions with other participants, as well as to validate the overall findings. Information about findings and themes was presented on posters displayed on the walls of the meeting room that could be referenced throughout the design workshops. Participants were encouraged to provide feedback, discuss items they felt needed clarification, and contribute any information that they felt was missing. I chose not include findings from the clinician interviews at this stage as it was previously noted during several of these clinician interviews that patients were often highly willing to do whatever clinicians asked of them, suggesting that the finding from the clinician study may lead to potential biases or influence design decisions being made.

Activity 3: Persona Creation

The third activity of the workshop involved creating a persona, or a fictional character representing a future user of the system that we would be designing throughout these workshops. Persona creation and use are widely adopted techniques in design, with popular examples dating

back to Alan Cooper's work, as presented in his 1999 book 'The Inmates are Running the Asylum [Cooper 1999]'. These characters are commonly developed based on an in-depth understanding of target users, as captured through interviews, observations, and ethnographic studies, and provide details ranging from name, age, and other demographic information, to explanations of professions and activities, relevant skills and interests, attitudes, goals, motivations, and challenges [Pruitt 2003]. Personas play a valuable role throughout the research and design process. For example, the creation and use of these characters allows researchers and designers to focus on the needs, characteristics, and goals of a single character rather than an entire diverse population [Cooper 1999]. Pruitt and Grudin also explain that the process of creating these personas can help to clarify and solidify assumptions about the target users, which can be helpful in future decision-making activities [Pruitt 2003.] Personas also serve as a tool support communication between stakeholders and team members, promoting a shared understanding of the user and their needs, and providing a common frame of reference for collaboration and discussion [Pruitt 2003, Cooper 1999, Miaskiewicz 2011]. Further, they can be used to prevent 'self-referential design,' forcing designers to think beyond their own individual situation or needs, and can help to support collaboration, and create empathy for the future users [Miaskiewicz 2011].

In this study, I chose to engage the workshop participants directly in the process of creating a persona that would be used throughout the design and evaluation process. This decision was based on three major considerations. First, there are many unique experiences and aspects of this disease that are difficult for researchers to relate to and understand. As such, having participants lead the persona creation process can help to avoid researcher assumptions and intuitive leaps, and further reinforce the role of participants as experts in the design process. Second, in working as group to create the persona, participants would be pushed to think beyond their own situation and preferences and consider the needs, challenges, and abilities of other future users. Finally, certain individuals with primary brain tumors, including several of the participants in the previous interview study, may experience challenges related to abstract thinking and empathy. It was my hope that for these individuals, having a role in creating this character would help to make the persona feel more concrete, and allow them to relate and build empathy. At the conclusion of the activity, participants were asked to present and introduce the persona. The

resulting persona would then be displayed as a visual reminder of the characteristics, experiences, and needs of the future user, and would be referenced in future activities throughout the research and design process.

Activity 4: Low Fidelity Prototyping

The final major activity of the first workshop consisted of creating early representations of potential features, functions, content, and interfaces for the system being designed in the form of low-fidelity prototypes. These prototypes typically consist of sketches on paper or simple constructions, and are used in the process of brainstorming and communicating concepts and ideas, as well as in capturing feedback and gathering requirements [Snyder 2003, Rudd 1996]. Low fidelity prototypes are ideal in the early stages of the research and design process as they can be created and revised rapidly, allowing for several iterations of brainstorming and design to be conducted in a short period of time [Snyder 2003, Rudd 1996, Hosseini-Khayat 2010]. Additionally, because they are created quickly and often shared alongside many other ideas, emotional, time, and financial investments are minimized, allowing for greater flexibility to explore alternative designs and pathways [Rudd 1996, Hosseini-Khayat 2010]. Finally, the paper-based nature of these prototypes eliminates the need for specialized skills or software tools [Rudd 1996, Snyder 2003].

Keeping with the participatory nature of the overall research and design process, I chose to engage participants in the process of creating these prototypes, rather than focusing on evaluation of previously designed prototypes or materials. In this activity, participants were presented with a brief scenario, and given the task of designing a system to support the newly created persona in tracking, understanding, managing, and communicating symptom information throughout treatment and follow-up. The definition of 'system' was left intentionally vague to encourage participants to think freely without major constraints surrounding feasibility, functionalities, or technologies and platforms involved.

In order to provide structure and maximize exploration of ideas in a limited amount of time, I employed a modified version of the *Share Multiple* rapid prototyping technique presented by Dow et al. These researchers found that the approach of creating and sharing multiple prototypes

with a partner for critique led to improved outcomes, increased sharing and exploration of diverse ideas, and greater rapport in the group [Dow 2011]. In this study, participants were given 10 minutes to sketch out three ideas or designs for addressing challenges related to symptom tracking and communication. They would then share their sketches with a partner for discussion and critique before working individually once again to create one or two more sketches, expanding on their original ideas or developing new sketches based on the discussions and feedback. In the final 15 minutes, participants would share their designs with the full group for discussion and critique. In addition to providing verbal feedback, the participants were given feedback capture grid worksheets to record their thoughts. Feedback capture grids are used in 'design thinking' work as a method for eliciting feedback on prototypes or presentations, covering categories of 'things I liked', 'things that could be improved', 'things I did not understand', and 'new ideas to consider.' The participants were given instruction sheets outlining the overall process and time guidelines for each of these activities.

Activity 5: Session 1 Evaluation

At the conclusion of the first session, I asked participants to complete a second feedback capture grid worksheet, this time focusing on evaluating their overall experience throughout the design workshop that day. The purpose of this activity was to understand what went well and how things could be improved for the second design workshop and subsequent evaluation study (Chapter 6). This would supplement researcher observation and evaluation of the session, and help to identify any challenges in understanding activities, working with materials, or communicating information and ideas, for example. Although participant evaluations of designs and prototypes and researcher evaluations of methods and overall successes are common in participatory design work, evaluations of methods and activities from the perspective of the participants are much less common. For this patient and caregiver population, this can be especially important and informative as participants may face unique challenges that may not be easily detected by the research team, or have differing opinions about what worked well and how things could be improved to better meet their needs.

Optional Homework

Before concluding, a brief optional homework assignment was discussed. The assignment was intended to provide an opportunity to continue thinking about aspects of this design research in the weeks between sessions, while requiring minimal time and effort from participants. Because it was not mandatory, there was no impact on participation or design activities if not completed.

Workshop Session 2:

The second design workshop was conducted three weeks after the first, and included the same participants as Session 1 and the lead researcher. In this session, the lead researcher was responsible for facilitating activities but aimed to have participants lead discussion as much as possible. Activities in this session included a group discussion of challenges and motivations surrounding health-tracking in brain tumors, followed by further discussion and design of a medium-fidelity prototype that was developed based on the discussion and prototypes created during the first workshop session. As with the first session, this session again concluded with an evaluation of the overall workshop using feedback capture grids.

Activity 1: Group Discussion and Review

The first activity of the second workshop involved reviewing work done as a part of the optional homework assignment, and following up on topics of discussion from the previous session. This would serve to review and refresh memory, and provide an opportunity to discuss anything that came up in the weeks between the two workshop sessions.

Activity 2: Medium-Fidelity Prototyping

The majority of the second design workshop focused on furthering the design of the medium-fidelity, moderately interactive prototype that was created based on the low fidelity prototypes and discussions from the previous workshop. This prototype was developed using Proto.io (www.Proto.io), a flexible web-based prototyping tool that supports development of mobile and web application prototypes for nearly any device. Participants were given printed copies of the individual application interfaces (**Figure 8**), and an interactive version of the prototype was projected on a wall to illustrate interactions and basic navigation. The participants were asked to work together to further design and discuss necessary content, features, and functionality. Participants were encouraged to build off of the current prototype, or completely redesign components that they felt would benefit from an alternate approach or presentation.

Activity 3: Session 2 Evaluation

The final activity was an evaluation of the overall workshop and design process, once again using the feedback capture grids. This information would be used to support data analysis and in preparation for the final evaluation study.

3. Results

3.1 Demographic, Health, and Technology Use Survey

Demographic and Health Information

A total of four participants, two patients and two caregivers, from the initial interviews took part in the participatory design sessions. Two of the participants were part of a patient-caregiver dyad, and the others were participating individually. Three participants were female, and one was male. The patient participants had both been diagnosed with a high-grade brain tumor and had undergone surgery and radiation therapy, but represented different stages of the disease and treatment process; one was recently diagnosed and had just completed radiation therapy treatment, and the other was a longer-term survivor who had experienced several instances of tumor growth or recurrence requiring further treatment. One caregiver had under a year of experience, while the other had spent several years caring and providing support for a patient who was no longer able to care for themselves. Demographic information is provided in **Table 2.**

Table 2: Demographic and Health Information

Participants (D1, D2 = Patient participants, D3, D4 = Caregiver participants)	
Gender	Female 3, Male 1
Role	Patient 2, Caregiver 2
Diagnosis	Oligodendroastrocytoma, grade 3 Anaplastic astrocytoma
Age (years)	Patient: average 43 Caregiver: average 50
Time since diagnosis or recurrence requiring treatment (months)	Average 13.5 months

Technology Use

Technology use information was again captured in this study. All participants reported that they accessed the internet and regularly used a smartphone device. Three had used health-related smartphone applications for the purpose of diet, fitness, weight, or menstrual cycle tracking, and

one reported using the calendar on their smartphone to track information related to their diagnosis. Additionally, patient participants reported using a combination of paper (notebook or journal) and memory to track information related to their diagnosis and treatment, and the caregiver participants reported relying on memory for capturing and managing this information.

3.2 Participatory Design Findings and Discussion

3.2.1 Results: Workshop Session 1

Results: Journey Mapping

The journey mapping activity provided an opportunity for participants to introduce themselves and share their journey through the brain cancer diagnosis and treatment process with the group. Through this activity, participants were able to illustrate and describe their journey from their own perspective as a patient or caregiver, indicating major steps and milestones in the process, and highlighting instances of challenge and need. The participants described major events as well as challenges and uncertainties across medical, financial, social, and emotional domains, providing insights and perspectives that are often not well captured or represented from the clinician point of view. Each participant took a different approach to designing their journey map, with some incorporating more artistic or visual components and others choosing milestone-driven approaches. The participants shared a great deal of information in a limited amount of time, and contributed new insights surrounding their experiences. In addition to revealing information about the patient and caregiver journey, this also served as an ice-breaker type activity, introducing participants and their experiences to each other, while helping to build empathy and trust, and to get into a creative mindset.

D1, a patient participant, took an artistic approach, using stamps, drawings, and colors to depict events and emotions. This participant used stars to represent the number of MRI scans she had undergone to date, and drew pictures of herself with arrows or beams pointing to her head to represent undergoing radiation therapy for the initial tumor, and then again with the metal frame on her head while undergoing the gamma knife procedure. The map she created was somewhat reminiscent of the game Chutes and Ladders ® (Milton Bradley/Hasbro), as new growth had twice sent her out of follow-up, referred to on the map as “MRI Land,” and back into treatment.

Figure 1. Journey Map Findings

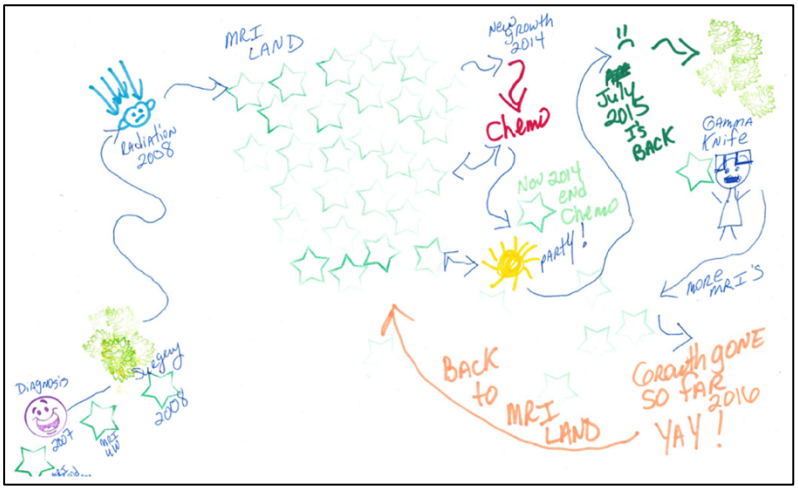

Figure A: D1 Patient Journey Map

D2, another patient participant, presented her journey as a timeline, highlighting important events, dates, and milestones. In this representation, she shared additional information beyond what was shared in the interview, providing a detailed and expansive report. This participant included the precise date for every event or milestone from diagnosis to her most recent follow-up visit, emphasizing the magnitude, memorability, and significance of these events.

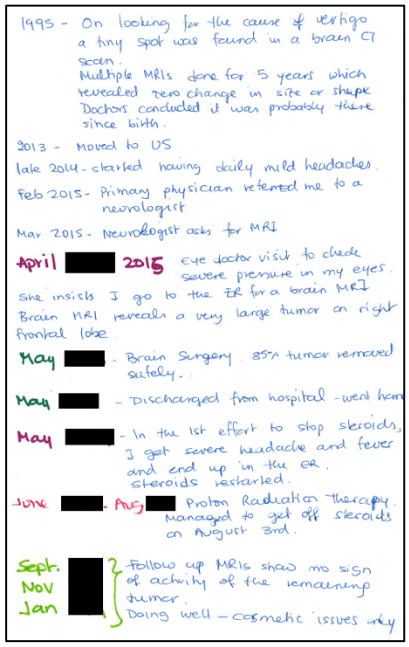

Figure 1B: D2 Patient Journey Map

D3 illustrated his journey as a caregiver in the form of a flow chart. Important events were documented as steps with additional contextual information written below. Colors and boxes were used to highlight challenges encountered throughout the journey. A red box was used to depict the initial shock experienced during a trip to the Emergency Room where the preliminary brain tumor diagnosis first conferred. Blue boxes around subsequent events indicated a need for information and support; these were points in time where information or an intervention of some sort would have been helpful for this participant.

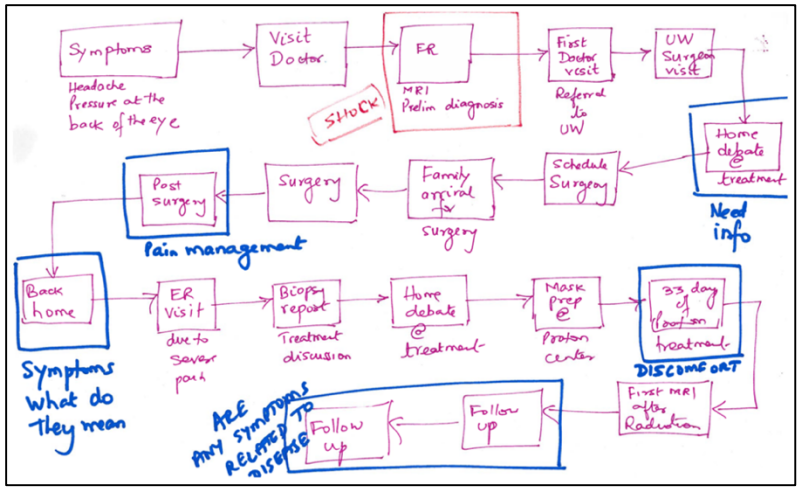

Figure 1C: D3 Caregiver Journey Map

D4 also took an artistic approach to depicting her journey as a caregiver from the point of first noticing concerning changes in the patient's behavior and personality, through diagnosis, surgery, and the eventual decision to undergo radiation therapy treatment. In this case, the map and accompanying description illustrated a journey that was not straightforward, with the patient and caregiver facing difficult decisions and situations ranging from challenges understanding and identifying early symptoms, to transfers to different cities and healthcare facilities, complications following surgery, and severe lasting impairments from the disease and/or treatment process.

Figure 1D: D4 Caregiver Journey Map

Similar to findings from the patient and caregiver interviews, these journey maps and subsequent discussions revealed a range of experiences amongst participants ranging from handling the initial shock of diagnosis, to challenges accessing information, understanding symptoms and side effects, and managing the long-term impact of the disease and treatment process. Further supporting the idea that each journey is unique to the individual experiencing it is the fact that the maps created by the two participants representing a patient-caregiver dyad were not identical or even obviously linked. Although they were present for the same events, the maps tended to highlight different aspects and components of their journeys to date. In this case, the patient tended to highlight major medical events, contributing information about symptoms and side effects, and how they were affected by the disease and treatment process. The caregiver, on the other hand, focused on major events, concerns, and decision points, including intermediate steps such as meeting with clinicians and making decisions about how to proceed, as well as logistical and personal events like family arriving in town before surgery. These events were not insignificant for the patient, but rather, the exercise showed a difference in perceptions relating to the overall experience and major milestones or events, as well as differences in concerns and responsibilities along the way.

Results: Reviewing Themes

In the second activity, we reviewed findings and themes from the previous patient and caregiver interview study. Information was presented on posters displayed on the walls and a group discussion was conducted to validate themes, and explore completeness and the need for

clarification (**Figure 2**). Participants reported that the information presented was very thorough and reflective of their experiences, and noted few places where information was lacking.

Figure 2. Example Information Poster

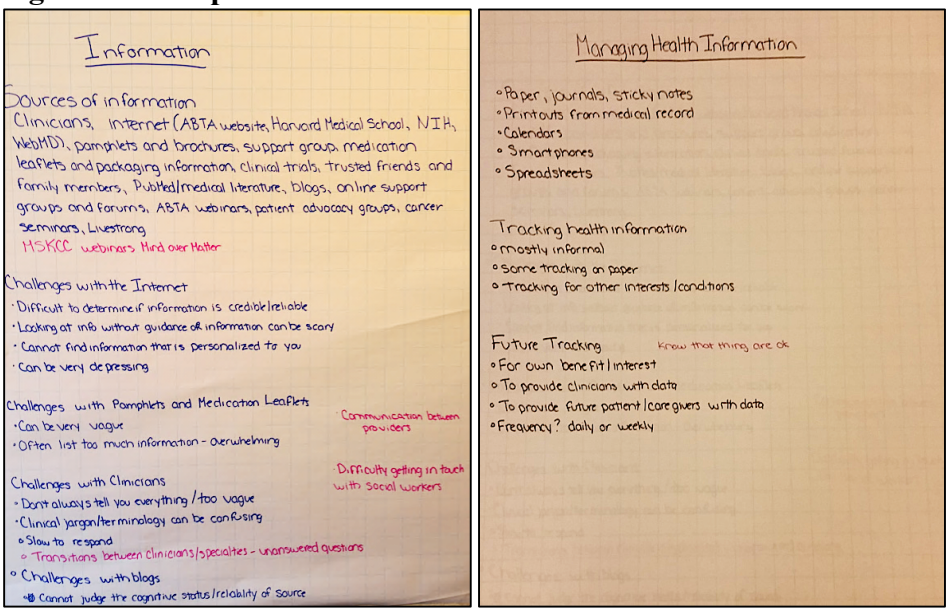

Figure 2: Examples of theme boards covering Information and Managing Health Information

For example, in addition to the challenges identified during the interview studies, several participants had also experienced challenges knowing who to contact to get answers, care, and support during transitions in their care process, especially in the time between surgery and making decisions about how to proceed with treatment. They also discussed the importance of, as well as current challenges involving accessing and communicating with social workers and others involved in similar aspects of navigating the disease and treatment process. Similarly, we discussed challenges involving resources and sources of information, with participants again noting that it is often difficult to determine whether information is relevant or trustworthy. This was largely discussed in the context of interpreting information that participants found on their own, especially in relation to medication side effects or information found on the internet. Lastly, we briefly discussed findings related to tracking and managing health information. In addition to the motivations listed, the participants also felt that self-tracking would be helpful for providing reassurance in knowing that everything was alright, and could potentially help patients and caregivers in recognizing when they should be seen by their care team. These topics would again

be discussed at the beginning of the second design workshop, and throughout subsequent design activities.

Results: Persona Creation

The third activity, persona creation, was a valuable experience for participants and researchers alike. In this activity, participants were able to further share knowledge and experiences while working to develop a persona representing the brain cancer patient they would be designing tools and technologies to support. Although originally intending to create a single persona, the participants acknowledged that patients and caregivers would likely have different needs and interests, and as such, decided to create separate patient and caregiver personas. Working in pairs, the participants discussed demographic, social, emotional, and health information based on their understanding of the disease and how the individual might be affected. At the end of the time period, the groups had created two distinct personas: Claudia and Molly (**Figure 3**).

Figure 3. Patient and Caregiver Personas

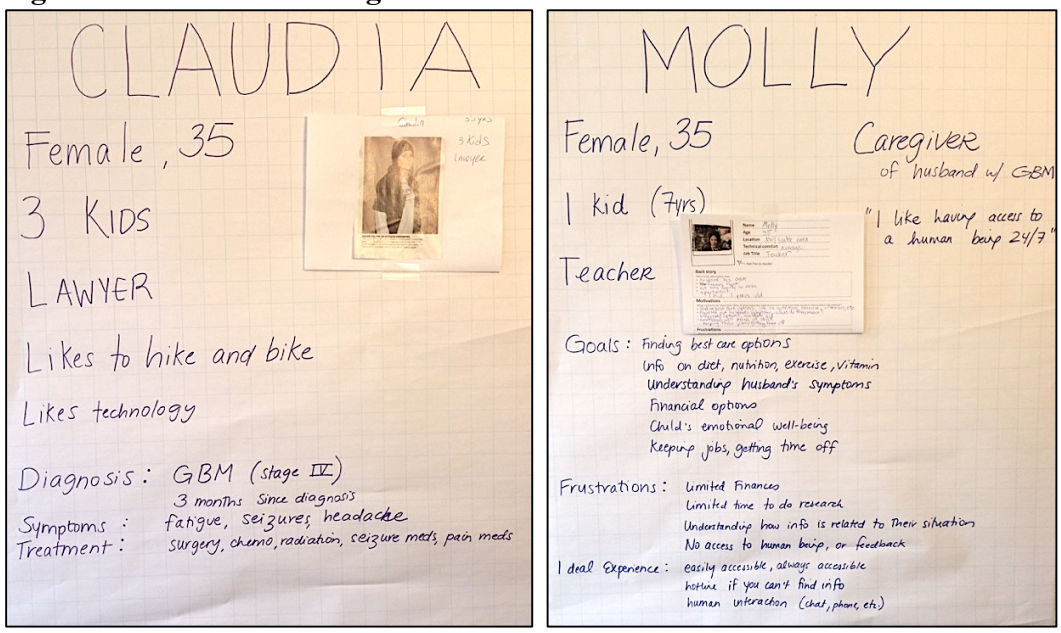

Figure 3A. Claudia, patient persona; Figure 3B. Molly, caregiver persona.

The patient persona, Claudia, is a 35-year-old mother of three and lawyer who was recently diagnosed with glioblastoma, the deadliest form of brain cancer. She is local to the Seattle area and has family and friends nearby. Claudia enjoys technology and outdoor activities, but has been experiencing severe fatigue, seizures, and headaches that are interfering with her daily life

and ability to take part in these activities. Her greatest concerns at the moment involve questions about her symptoms and side effects, and the medications she is taking to manage them.

The caregiver persona, Molly, is the primary caregiver for her husband who was also recently diagnosed with glioblastoma. Molly is 35 years old and has one child. Finances are tight for Molly and her family, and on top of handling her husbands condition, she is concerned about whether they will be able to keep their jobs, and the impact on their child's emotional well-being. Finding the best care options, learning about diet, nutrition, and exercise, and understanding her husband's symptoms are important to Molly. Molly also expressed frustrations regarding understanding and interpreting information and accessing clinicians. Given limited time and resources, Molly feels that direct interaction and communication with her husband's clinicians would be the best way to address her questions and concerns. She believes that this could be mediated or supported by technology, but feels that human interaction is essential.

In addition to creating characters that would be referenced throughout the design and evaluation process, the persona creation activity also revealed further information about differences in needs and concerns between patients and caregivers. Although most patients and caregivers considered themselves to be a team, there were times when responsibilities, needs, and concerns diverged. In this activity, the patient participants focused primarily on the impact and challenges associated with symptoms, side effects, and medications. This further supported the notion that patients tend to be more heavily burdened and concerned with managing and understanding symptoms and medications, especially early on, as was noted in both the patient and caregiver interviews, and the clinician interviews. The caregiver team also explored aspects of the disease, but tended to focus more on challenges experienced in their new role as a caregiver. In creating this persona, the caregiver participants discussed responsibilities and concerns ranging from researching treatment options and understanding symptoms, to those involving managing finances, providing care and support for children, and trying to maintain employment while getting time off to care for and provide transportation for the patient during treatment.

Results: Low Fidelity Prototyping

The next major activity involved creating low fidelity paper prototypes of a system designed to support Claudia and Molly in their journeys through brain cancer. Following the previously

described protocol, participants again worked in patient and caregiver teams during this activity to create early prototypes and share feedback.

The caregiver team moved quickly through their sketches and discussions, generating ideas including a superficial brain implant that records relevant data and stores it in a smartphone device before transmission to clinicians; a health band (fitness tracker) that captures biometric data and stores it in a smartphone application where additional data can be entered manually before transmission to clinicians; and a device (likely a smartphone) that captures audio recordings to be stored or sent to clinicians (**Figure 4A**). The second caregiver participant contributed ideas included a personalized smartphone application and website where patients and caregivers could jointly track information on a calendar, generate personalized alerts, and access clinician and emergency contact information; a diary for non-technology users that could be used to capture symptom information which would later be uploaded to an application or website by someone else; and a fitness tracker integrated with the personalized smartphone application to track biometric data and detect changes in heart rate or seizure activity (**Figure 4B**). The ideas shared by the two caregiver participants contained several similarities including the use of smartphones as a central point for storage and transmission of data, and the incorporation of fitness trackers or health bands for capturing biometric data and minimizing manual data entry.

Figure 4. Caregiver Low-Fidelity Prototypes

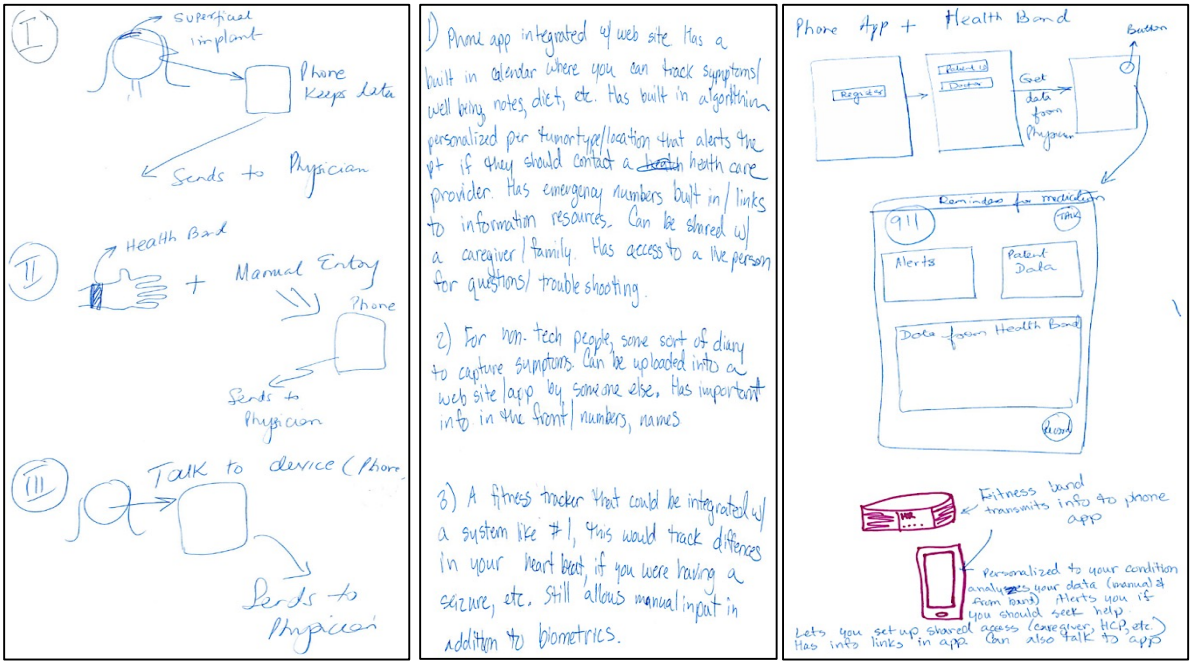

Figure 4A: Caregiver prototype. 4B: Caregiver prototype. 4C: Combined low-fidelity prototypes.

After sharing their ideas and providing feedback, the caregiver team decided to create one single design incorporating aspects of each of their initial ideas. The end result was a smartphone application coupled with a health band. The user would register in the application using their hospital patient ID which would pull all relevant health information into the application. The health band would capture data of interest and transmit it to the application where it could be viewed, and additional data could be entered as either text or voice recordings. The application would be personalized and learn from the user, generating customized alerts when changes or issues were detected, and providing information or recommended actions based on those alerts. For example, if Claudia's body temperature is elevated and she is on a medication that weakens her immune system, she would receive an alert notifying her of a potential infection and advising her to contact her care team. They also suggested providing links to relevant information based on the patient's diagnosis. These participants emphasized that the application would feature clean interfaces and a very simple user experience. They wanted important information like medication reminders displayed across the top of the application, and features to simplify the process, including a method to contact clinicians with a single click. They also noted that the application would allow shared access for caregivers, and support easy transmission of data to healthcare providers (**Figure 4C**).

The prototypes created by the patient team included a smart watch that automatically tracks information including vital signs, activity level, and sleep, and supports manual reporting and transmission of data related to pain, seizures, and other symptoms; a website that connects all stakeholders (patients, caregivers, clinicians) across healthcare systems so that information can be accessed and transmitted seamlessly; and a paper, application, or web-based guidebook that would be distributed to patients and caregivers upon arrival, providing basic information on trustworthy sources of information, available services and resources, and frequently asked questions, as well as providing a place for taking notes and recording questions to prepare for upcoming appointments (**Figure 5A**). This participant also noted the need for a mechanism to allow patients and caregivers to connect with clinicians separately if needed as caregivers often have their own questions and concerns that need to be addressed. The second patient participant chose to focus on content and features for the future system without defining a specific platform

or potential technologies involved. This prototype was similar to the guidebook detailed above and contained information in the following topic areas: information for contacting clinicians with questions or in emergency situations; resources and information about medications, diagnosis, second opinions, support groups, insurance, and childcare; tailored information for each stage or component of the treatment process; information on how to prepare for surgery, and major changes such as hair loss and weight gain, and advice on exercise and nutrition, possibly from the perspective of others who have been through the process (**Figure 5B**). This participant also included the idea of a worksheet or tool for recording side effects between visits for clinicians to evaluate to determine significance and relevance to the disease and/or medications. This participant noted that patients may forget or be reluctant to offer up this information, but felt that recording it ahead of time might help to overcome that barrier. Finally, they suggested including a calendar containing follow-up information and results.

Both patient participants acknowledged that when they first started out, they faced challenges involving accessing information, managing medications, symptoms, health information, and care activities, and knowing what resources and services were available for themselves and their caregivers. Each had established their own methods, but felt that future patients like Claudia would benefit greatly from information and guidance from the beginning. After discussion and critique, the patient participants agreed that technology could facilitate many aspects of their design ideas, and that a smartphone application was likely the most probable and feasible solution. During the second round of design, the patient participants each built off of their previous prototypes and the discussion, ultimately creating a guidebook and a medication search tool that could be incorporated into the guidebook application or used as a standalone application. In creating the guidebook prototype, the first patient participant expanded on their initial ideas, sketching out potential interfaces and discussing content and organization (**Figure 5C**). This iteration incorporated content featured in the initial prototypes created by each of the patient participants, as well as new content including a welcome section stating "*Welcome to the club you never wanted to be a part of…*", and additional resources that patients and caregivers like Claudia and Molly may not think of right away. The second participant chose to focus on symptoms and side effects and helping to support new patients like Claudia in learning about these health events. In addition to idea of capturing symptom and side effect information to share

with clinicians, this participant described an approach to helping patients better understand the medications they are taking, and the side effects they are experiencing as a result of those medications. First, the system would provide access to copies of the patient's medication leaflets in a format that was clear and easy to read. Next, the prototype featured a mechanism for accessing lists of common and rare side effects by medication, and a feature where users could enter side effects and determine potential causes based on their current medications (**Figure 5D**).

Figure 5. Patient Low-Fidelity Prototypes

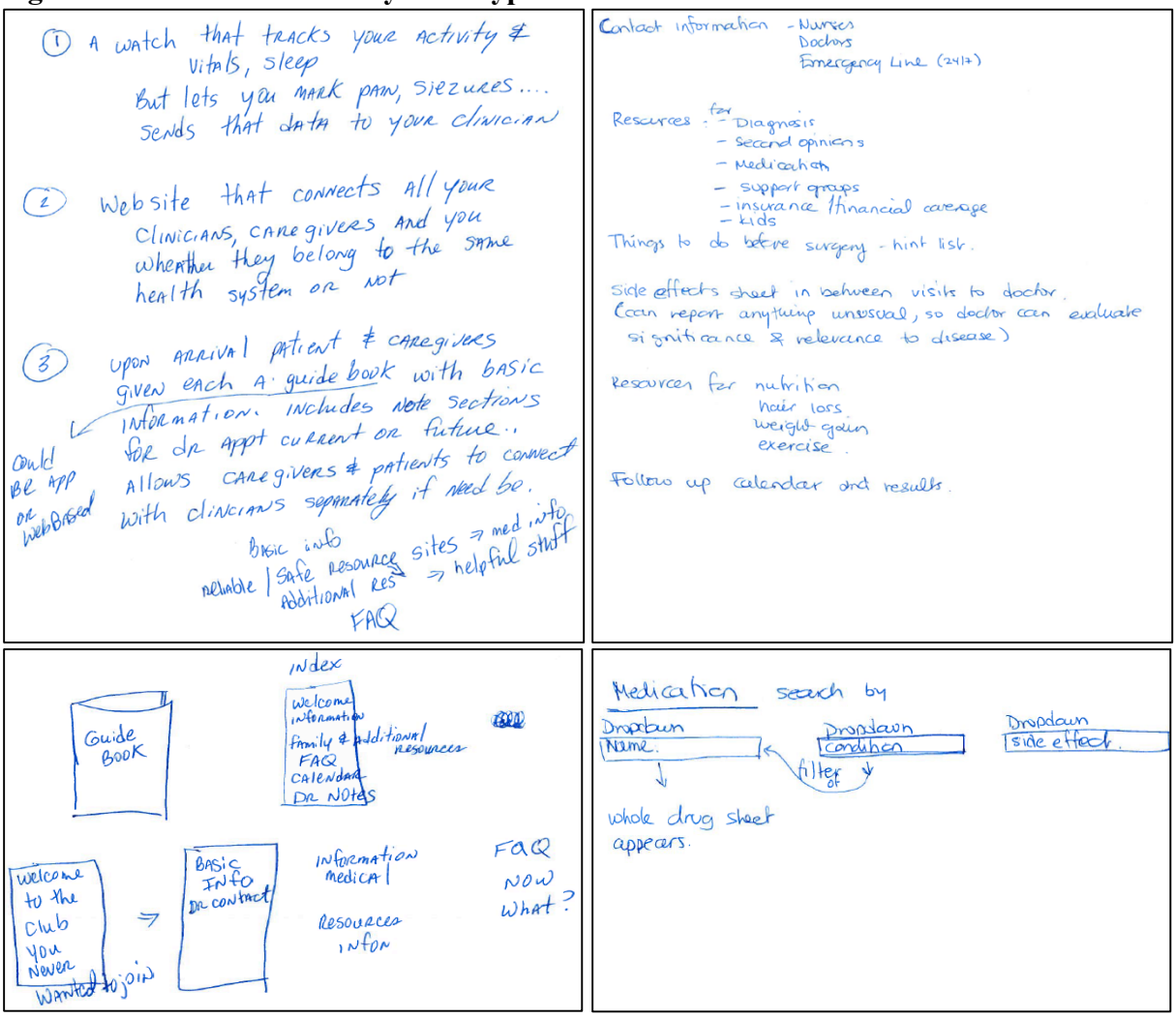

Figure 5A: Patient Prototype List. 5B: Patient Content and Features List. 5C: Guidebook Prototype. 5D: Medication Search Tool.

At the end of the activity, the participants were asked to provide additional feedback using the feedback capture grid handouts. Responses on the feedback capture grids did not yield much

information in terms of design feedback or new ideas to consider, but the discussion amongst participants was helpful for contributing new ideas and considerations. A summary of the features, functionality, and content highlighted for the future application is provided in **Table 3.**

Table 3. Low-Fidelity Prototyping Features, Functionality, and Content Summary

Questions and Notes	• Record questions and notes between visits • Record responses to questions during appointments • Record notes during appointments to archive or revisit later
Medications	• Access patient medication information (medication list) • Access medication leaflets in a format that is easy to read and understand • Mechanism for searching/correlating medications and side effects • Prominent medication reminders
Symptom and Side Effect Tracking	• Manual tracking and recording of symptoms, side effects, and other health events (e.g. seizures, headaches, pain, fatigue) • Automatic tracking of biometric data (e.g. vital signs, activity level, sleep)
Resources and FAQ	• Resources tailored based on the individual patient and their stage in the disease and treatment process • Resources: Understanding diagnosis, medications, procedures Requesting second opinions Support groups Understanding insurance/financial options Resources for patients travelling to the area for treatment Family and caregiver specific resources Diet, nutrition, exercise • Access to Frequently Asked Questions (FAQ)
Information and Education	• Links to trustworthy and reliable sources of information • Educational information tailored based on the individual patient and their stage in the disease and treatment process • Information or recommendations on how to prepare for medical procedures or changes patients may experience (e.g. fatigue, weight gain/loss, hair loss, wearing the head mask during radiation therapy); potentially from the perspective of previous patients and caregivers • Information/guidance for how to manage health information, especially early in the diagnosis and treatment process
Emergency and Contact Information	• Simplified access to clinician contact information • Direct method of contacting clinicians after hours/in case of an emergency
Calendar	• Store follow-up information and results • Attach notes about what is going on between visits, and what happened during each visit • Track/display information related to symptoms, well being, diet

Caregivers and Shared Access	• Supports sharing and access to health information for patients, caregivers, and clinicians, regardless of healthcare organization • Allows caregiver access to information, features, and functionalities to support activities including tracking, questions and notes • Includes caregiver specific information and resources
Alerts	• Personalized alerts: to notify user when entered or detected data deviates from norm or is concerning – based on tumor characteristics (type and location), medications, treatments, and patient's trends • Information and recommendations for how to respond to alerts
Data Entry and Transmission	• Flexible methods for manual data entry (e.g. click, text, speech) • Automatic transmission of data between external tracking devices and central storage (likely smartphone application) • Quick/easy transmission of patient-generated data/notes to clinicians

Results: Workshop 1 Evaluation

At the end of the first workshop, feedback capture grids were again used to evaluate the overall session. The participants reported that they appreciated the overall structure of the workshop and activities, and felt that the poster boards presenting themes from the interviews were very thorough. They also enjoyed the collaborative aspects of the workshop and coming up with ideas. These grids also helped to identify opportunities for improvement and ideas to consider. One participant noted that the instructions for the persona activity were a bit confusing. Additionally, during the low-fidelity prototyping activity, details were left intentionally vague to encourage participants to think outside of the box in terms of form and functionality, and to see whether ideas beyond smartphone applications would emerge, however, at least one participant wanted more information and constraints surrounding the future system during this activity. In terms of ideas to consider for future stages of this research, one participant suggested using technology to make the iterations go faster, and another suggested seeking input from clinicians to see what they thought about the systems being designed. Research team observations were also factored into this evaluation. Both researchers noted instances where participants were unsure or believed that they had completed the activity incorrectly, even after being reassured that there was no 'wrong' way to approach these activities. This was likely due to a combination of the fact that the resulting design artifacts between the patient and caregiver pairs were often very different, and that this was a new experience for the participants. Some were aware of user research methods, but none reported previous participation in these types of activities or participatory design work, especially in the context of designing for health.

3.2.2 Results: Workshop Session 2

Results: Discussion and Review

The second workshop began with a brief review of the previous session, and an overview of the goals for the day. None of the participants had formally completed the optional homework assignment, but several mentioned things they had thought about between the sessions. In particular, one participant discussed starting to track data related to a side effect of interest and concern to bring to her doctor at an upcoming appointment.

Next, we briefly discussed current motivations and behaviors surrounding tracking of health information. The primary motivations for tracking, as identified during the patient and caregiver interviews (Chapter 4), included tracking to support knowledge and understanding; tracking to capture more reliable and complete data to share with clinicians; and tracking to provide data to support future patients and caregivers. For this group, some participants were motivated by certain purposes more others, however, in the end, all agreed that structured tracking of health information in this patient population could provide great value and benefit.

To further explore motivations and behaviors, we discussed how each of these motivations might influence the likelihood of tracking, as well as the potential impact on the type and amount of data recorded and shared. One participant was highly motivated by the benefits of tracking towards improving her own understanding of medication side effects as well as the impact of the disease, and to support patient care. This participant was diligent in taking notes, preparing lists of questions, and reporting anything that happened between visits as she saw clinic visits as an opportunity to address questions and concerns with her care team. As such, she was willing to record any and all information that she or her clinicians deemed important, and felt that there would be no difference in likelihood, type, or amount of data tracked if she was also asked to capture data such that it could be used to support future patients and caregivers. One of the caregiver participants also reported being highly motivated to track data, but explained that having external motivations would likely lead to increased tracking, both in terms of the frequency and quantity of data captured. Being held accountable and knowing that this information could potentially impact patient care for the patient this participant served as a caregiver for, and knowing that this data could also help clinicians to provide better answers for

future patients are caregivers was a clear motivation for this participant. None of the participants indicated that they would be likely to provide less data in any of these scenarios, but two discussed concerns related to privacy and whether they would be identifiable in the data that would be made available to support future patients and caregivers.

Results: Medium-Fidelity Prototyping

The primary goal of the second workshop was to further the design of a medium-fidelity interactive application prototype that was created based on the findings and ideas generated during the low-fidelity prototyping activity in the previous session. As a group, we worked through nearly 20 interfaces, discussing purpose and generating ideas to improve content and design. The prototype had varying levels of completeness for each interface depending on the level of discussion and agreement in the previous interviews and design workshop. Many interfaces were intentionally left blank to encourage participants to provide solutions and recommendations on how the system should look and feel, while others were more complete, or offered examples of how information and features might be presented. Participants were engaged and provided a great deal of insight and constructive feedback throughout the process while thinking beyond their own situations and considering the needs and challenges that Claudia and Molly might be facing. In several situations, this lead to co-questioning, with participants looking to each other for input in topic areas where they felt others would have valuable insights. In this section, I present an overview of the core content, features, and functionalities of this future system, as designed and discussed by the workshop participants.

Figure 6. Questions and Notes

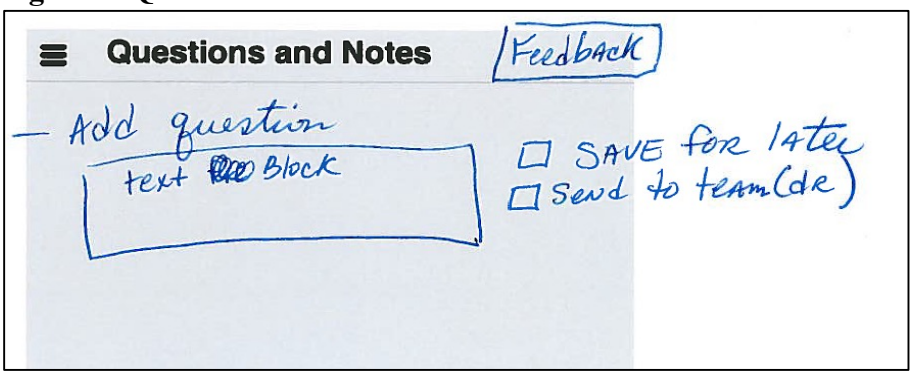

Figure 6: Participant sketch of design for capturing questions and notes.

Questions and Notes (**Figure 6**)*:* The Questions and Notes category remained similar to what was envisioned in the low fidelity prototypes, allowing users to record questions and notes to bring to appointments, and providing a place to record information and responses received in the clinic. Participants suggested that these could either be recorded as a list, or attached to tracked symptoms, calendar dates, or appointments. The participants added an option to send question lists to clinicians ahead of regularly scheduled appointments; they felt that this would help clinicians to better anticipate, prepare, and prioritize questions and needs during appointments as time with clinicians is often limited. One participant felt that it would be helpful to have a reminder to prompt users to prepare and send their questions, while another remarked that reminders and sending the data in advance would only be worthwhile if clinicians would actually review the information before appointments. The participants also added a feature to send more urgent questions between appointments, as needed.

Medications (**Figure 7**)*:* In the medications feature, participants wanted to see a list of current and previous medications from the patient's medical record, as well as a picture of the tablets, dosage information, and administration instructions for each medication. They noted that drug information including contraindications and side effects should be available in a format that is clear and easy to read. The participants also wanted to be able to update or change information in their medication lists as this information can become quickly outdated, and a way to add new medications, vitamins and supplements to their list to consolidate this information and support better record keeping. These participants felt that customizable reminders to take or refill medications would be helpful for some users, along with an option to acknowledge that they had indeed taken that dose. For medications that need to be taken according to a strict protocol, they wanted clinicians to be able to upload a schedule and information to provide guidance for the patient and caregiver. This was especially relevant for tapering off of steroid medications as patients may experience severe side effects if not done carefully. One participant also suggested adding a feature where users could add notes or indicate that a particular medication did not work well for them so that it would not be prescribed again in the future; this participant noted that she had been on so many different medications over time that she often forgot which ones worked and which did not. She felt that this would be helpful for future users like Claudia to

record from the beginning, especially since recurrence and the need for further treatment is extremely common for these patients.

Expanding on discussions from the first workshop, several of the participants were interested in methods to help with understanding medications, and identifying potential correlations between the medications they were taking and the side effects they were experiencing. In addition to being able to view a list of side effects associated with each medication, the participants wanted a mechanism to add relevant side effects directly to the list of symptoms and side effects they would be tracking. Some felt that common side effects should be automatically added to the user's Symptom Tracking List, while others preferred adding them manually based on the side effects they were currently experiencing. Additionally, because some side effects may not appear until several weeks into taking certain medications, one participant also suggested that users be prompted at different time intervals to see if any of these side effects had presented.

Figure 7: Medication Information and Features

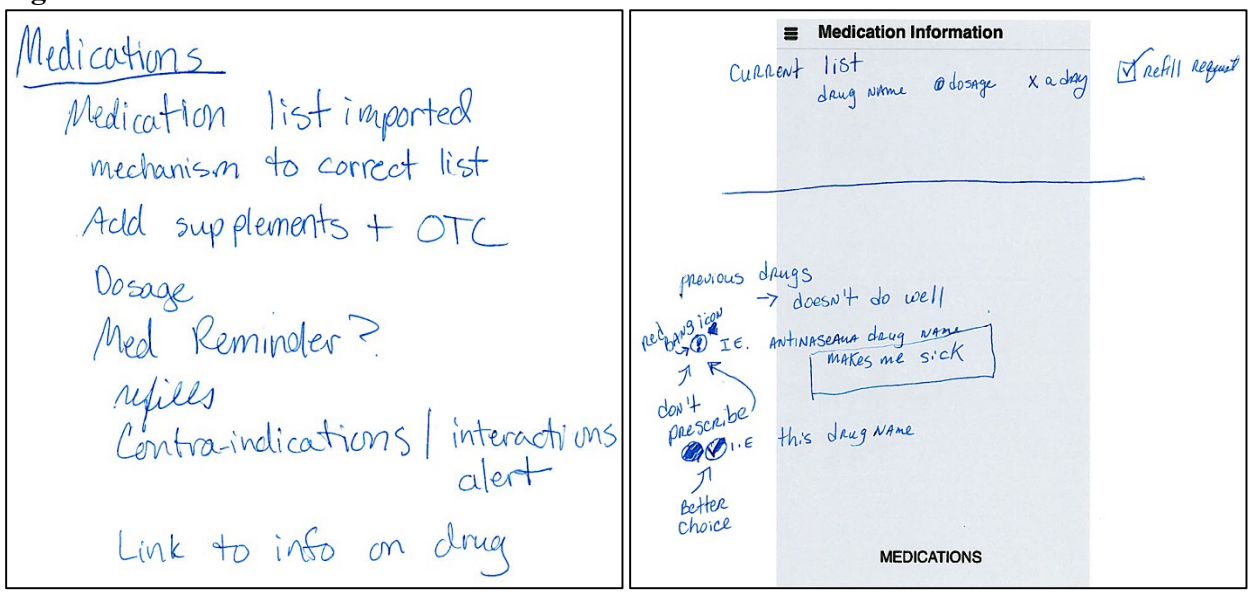

Figure 7A: List of potential content. 7B: Expanded description of feature to indicate that previous medication did not work well for patient.

Symptom Tracking (**Figure 8**)*:* The symptom tracking feature was designed to support structured tracking of information related to symptoms, side effects, and other health events. The participants felt that tracking should be done regularly during the early stages of treatment and follow-up to help patients in understanding and detecting symptoms and side effects, but could eventually be transitioned to an as-needed basis as the patient moved further into follow-up.

Most participants wanted to choose items to track from a comprehensive list of all possible symptoms and side effects, and add them to their personal Symptom Tracking List. They also wanted to be able to add additional symptoms and side effects to their list as new things came up, and recommended having a 'custom' option to track symptoms not listed in the application, or in case they were unsure of how to describe or classify a symptom they were experiencing.

Figure 8. Symptom Tracking

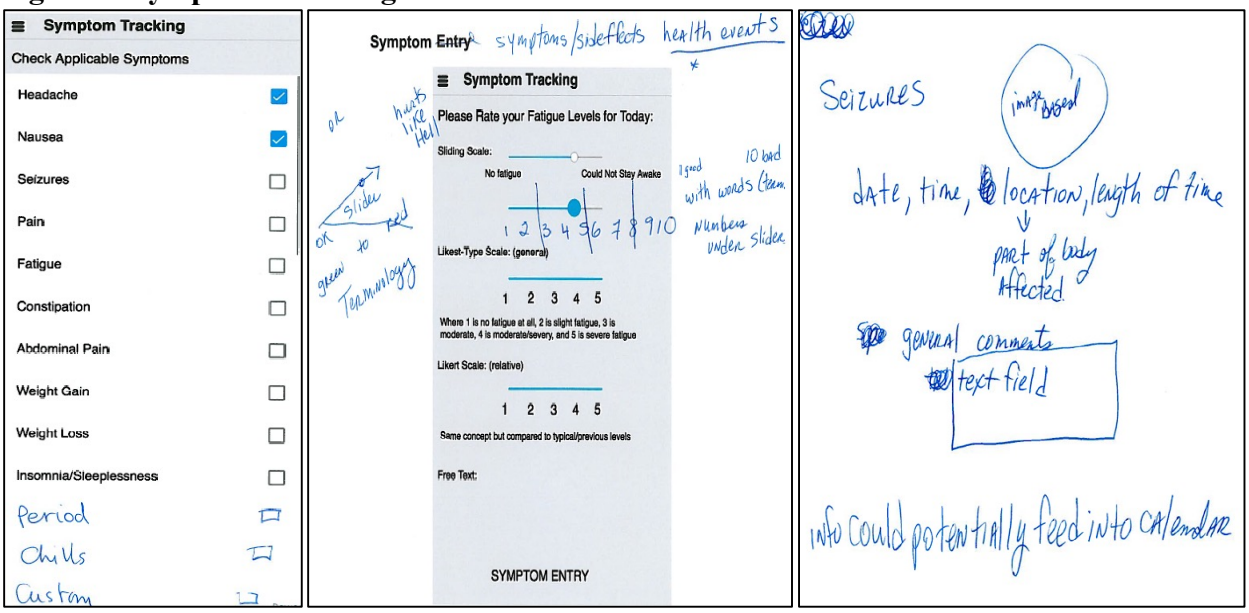

Figure 8A: Menu for selecting symptoms to track. Figure 8B and C: Options and recommendations for entering symptom data.

As a part of this design and discussion process, the participants were given copies of several patient-reported outcome (PRO) measures designed to assess brain tumor symptoms and quality of life. The participants felt that these standardized questionnaires were not ideal for this application as they were lengthy and did not cover information or capture the level of detail they felt to be necessary for this purpose. They agreed that using structured forms would be the best approach to capturing necessary information while minimizing the amount of free text, but noted that a short section for notes on each form would add flexibility and help users to convey or record any additional information they felt relevant. They also felt that the forms should be customized for each individual symptom. In the case of seizures, for example, they suggested capturing information including time, date, and duration of the seizure, as well as body part(s) affected, and any information related to potential triggers, medications taken, and their effectiveness (**Figure 8C**). When rating severity, they participants felt that scales should have a

combination of numbers and text descriptions to provide clarity and context for their rating (**Figure 8B**), and noted that color or other visual indicators may also be helpful for this purpose. The participants also recommended the use of images to indicate things like where pain or a certain sensation started, rather than relying text descriptions. No matter what, participants felt it was essential that data entry to be simple, easy, and convenient in order to capture the greatest amount of data from users.

Finally, the need to understand why symptoms and side effects were occurring was noted by participants in this study, as well as in both the clinician interview (Chapter 3) and the patient and caregiver interview studies (Chapter 4). Similar to the concept of adding a note or flag to indicate that a medication did not work well for a patient, several participants wanted clinicians to be able to verify and attach a flag or note to the symptoms and side effects they were tracking to indicate whether they were likely due to a specific medication, treatment, or the disease itself. The participants felt that this would be helpful for their own knowledge and reassurance, and would also help in making treatment and medication decisions, especially in the case of a recurrence or progression of the disease.

Resources and FAQ: The medium-fidelity prototype originally included separate sections for *Education* and *Resources and FAQ*, however, the participants unanimously felt that this content should be merged under the title *Resources and FAQ* as the title *Education* was ambiguous and could easily be misinterpreted. The overall purpose of this feature was to assist users in accessing trustworthy information, and making them aware of available resources that may be of benefit or interest to them. In addition to the previously discussed content, the participants also suggested the inclusion of information on legal needs and services, places to buy medical supplies, mentor programs, webinars, as well as patient advocacy group, and brain tumor related community organizations and events.

There was some debate as to whether patient and caregiver resources should be separated, however, most felt that the majority of the content included would be applicable to both types of users, and that organization should be based on the type of resource rather than the type of user. The participants felt that some components could be customized based on the individual patient and their diagnosis and treatment options, so not as to overwhelm users with excessive or

potentially irrelevant information. They also felt that links to external resources and information would support ease of use and organization while minimizing the amount of text within the application.

Emergency and Care Team Information (**Figure 9**)*:* This next feature was devoted to providing easy access to relevant information regarding members of the patient's clinical care team. Participants suggested including basic contact information including phone numbers and email addresses, as well as physical address and a fax number for each clinician, as this was often needed when filling out paperwork (transferring records, insurance, etc.). Because of previous challenges in determining the best method for contacting clinicians, the participants also wanted clear indicators to denote clinician contact preferences. Some felt that contact information beyond the preferred method should not be made available as it likely should not be used, but others felt that individual clinicians should be responsible for making such decisions. Beyond knowing how to reach clinicians, there was also discussion involving knowing who to contact. Because these clinicians typically work in teams, the participants also wanted to include information indicating which nurses worked with which doctors, and how communication should be handled (e.g. whether all communication should go through the nurse, or whether doctors will respond to emails). They also felt that a link to available bio pages or websites would be useful to provide additional information surrounding areas of expertise, care locations, and research interests without cluttering the application. They noted that all information should be automatically populated, and that the application should also allow the user to add additional information or notes to support memory.

In addition to having access to contact information and preferences, the participants appreciated the ability to add new care team members to the application, regardless of whether they were affiliated with their current healthcare system. They felt that whenever possible, users should be able to search clinicians and add their information automatically, but also valued the ability to manually enter contact information for individuals who are not in the system. There was concern that some patients may abuse a search function as a means to collect contact information from clinicians, as they felt that this information was often guarded and should be respected. It was unclear how large of an issue this was, or how to best address it other than allowing clinicians to determine and control what information they wanted to make available through the application.

There was also debate about how the list of care team members should be organized and displayed within the application (**Figure 9A**). Most felt that they should be grouped, but no consensus was reached as to how that should be done (e.g. doctor vs nurse, by specialty, by visit frequency).

Figure 9: Care Team

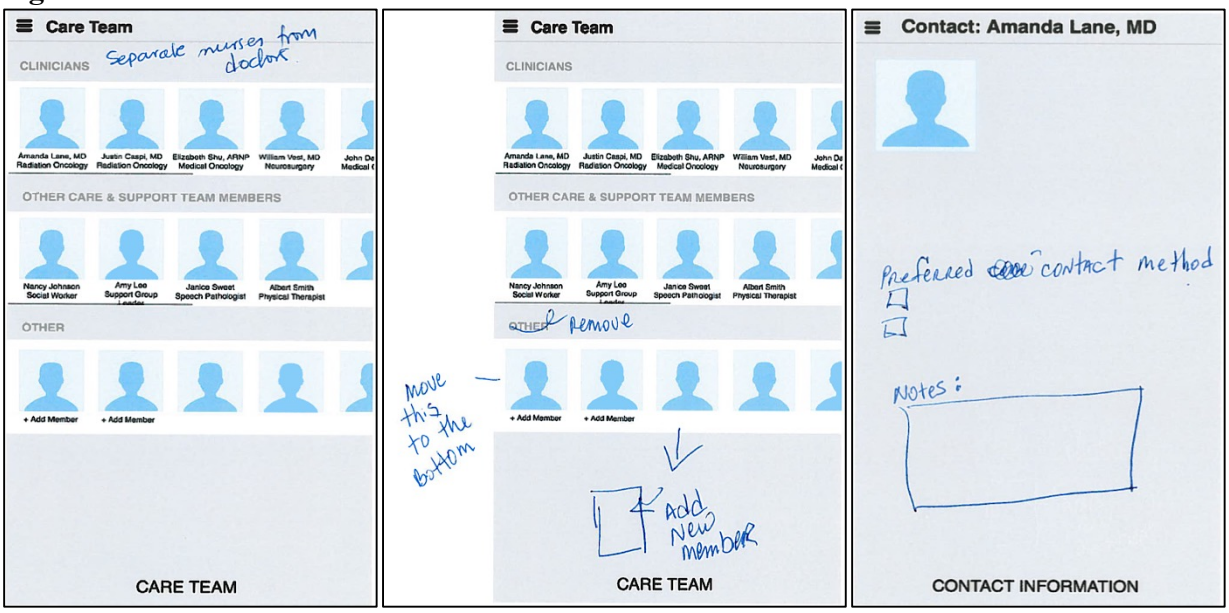

Figure 9A and 9B: Care Team organization. Figure 9C: Clinician contact information

During this phase, the participants again emphasized the need for information and support when reaching out for help in an emergency or when questions or complications came up outside of normal business hours. They felt that this information was very important and should not be mixed in with the rest of the care team information, or should at least be duplicated elsewhere in the application so it was easy to access in a direct and intuitive manner.

Calendar: The participants also wanted a calendar function to support tracking and management of information related to symptoms, medication schedules, and appointments. Some participants felt that a calendar view could help to visualize changes in frequency of symptoms and side effects such as headaches, seizures, or pain, for example, and would be the ideal method for tracking information associated with certain health events like menstrual cycles. They also felt a calendar for displaying medication schedules could be helpful, especially for those that require a strict protocol such as steroids or chemotherapy, and those that may change in terms of dosage or

frequency over time. With the exception of appointment information, the participants did not want this information integrated into the general calendar application on their smartphones; this was both due to privacy and security considerations, and because this data could be overwhelming and clutter their calendars, interfering with their ability to view and schedule other calendar events.

Caregivers and Shared Access: Finally, the participants saw great value for both patients and caregivers in supporting shared access to relevant information and resource, and benefit in allowing both users to view and/or contribute data. They felt that given their own account and access, caregivers could easily take over or share responsibilities in instances where a patient is unwilling or unable to learn new systems or take part in tracking or management activities. They also felt that this could be helpful in co-caregiving situations where information and responsibilities are shared across several individuals. In this situation, having joint access to a shared repository could mean that information is stored in one central location, and available to each of the users during clinic visits or when questions come up.

Beyond these uses, the participants also discussed benefits in terms of sharing health information with others not directly involved in their care. In the early stages of the diagnosis and treatment process, several workshop and interview participants reported that they sent medical information surrounding their diagnosis, test results, and treatment options to knowledgeable friends or family members to seek help with further interpretation and explanation of this information. Others described situations where they were unsure if what they were experiencing was normal, and wanted another opinion from a trusted friend or family member. In each of these situations, they were having to relay information over the phone, track down medical records, and scan notes and handouts to send to these individuals. The participants felt that given an option to grant 'read only' type access to the application, this could be used to not only facilitate the process of sharing information, but would also provide a more consolidated and complete view of their medical information including symptoms, side effects, and medications, and would provide a better idea of how they were doing overall.

*Additional Content and Features (**Figure 10**):* In addition to the content, features, and functionality presented above, there was also discussion of several other features including an

indexed *Help* section with information on how to navigate and use the application, as well as the need for Help icons on each page. Further, the participants agreed that clinicians should not be responsible for troubleshooting technical issues within the application, and that a separate section for submitting questions and feedback to the application development team would be helpful (**Figure 10A**). This was originally listed as *Contact Research Team*, but the participants felt *Report Application Issue* would be more intuitive.

Figure 10. Additional Content and Features

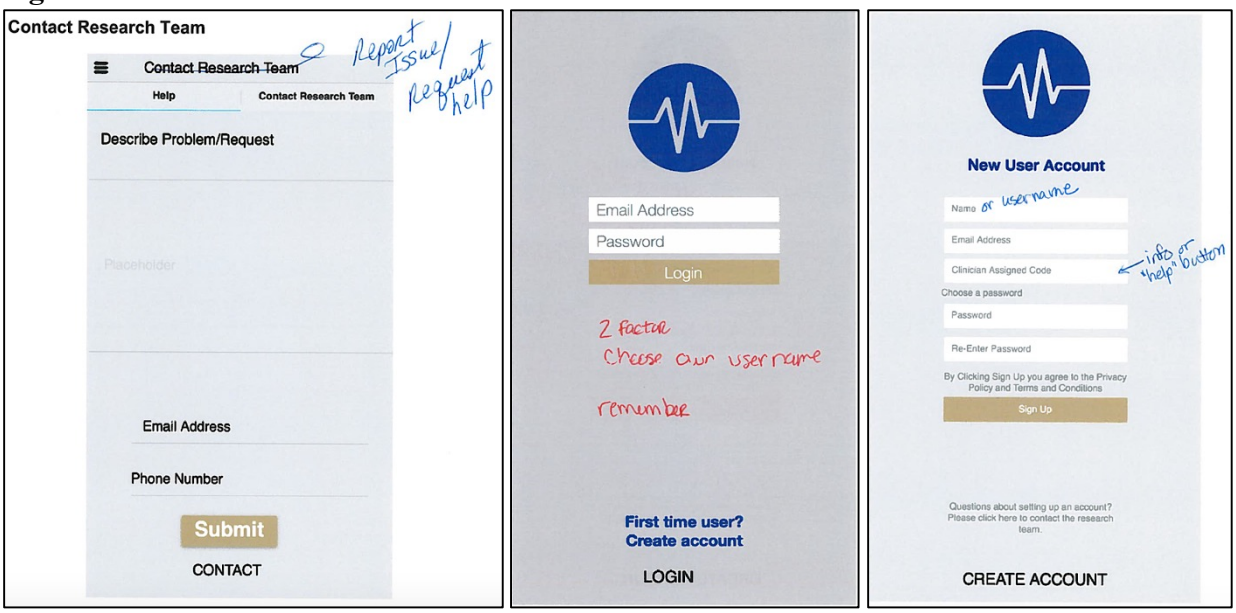

Figure 10A. Help and Report Application Issue;10B, Log In screen; 10C. Create User Account

We also discussed the process for logging in to the application (**Figure 10B**), and creating a new user account (**Figure 10C**). The participants felt that users should be able to choose their own username instead of using an email address to log in, as email addresses may be lengthy or difficult to type on a smartphone; they also noted that the option to save the username would simplify the process. The participants discussed the need for security measures as personal health information would be stored within the application. Some felt that the application should have password strength requirements, while others felt that additional measures like two factor authentication were necessary, although there was concern that this would complicate the process for many users, especially as it was not yet clear what type of device(s) this application would be supported on. Looking next at the process for creating a user account, we discussed the purpose and perceived need for the clinician assigned code (**Figure10C**). This code was intended

to create a link between the patient's account within the application and their hospital medical record, allowing the application to be populated with relevant data from the health record. They felt that this was very useful, but also felt that users should also be able to sign up and use the application without a code, even if it meant that the application would not be prepopulated, or that users would be unable to transmit data directly to clinicians through the application. In this case, a function to download and print a summary of the data could still be of value and use.

Results: Workshop 2 Evaluation

At the end of the second workshop, feedback capture grids were used to evaluate the overall session. This method was again successful in eliciting feedback with minimal time and effort required of participants. Overall feedback was once again positive. Participants reported that they appreciated the opportunity to collaborate and contribute, and were looking forward to being able to interact with the final prototype and see the outcomes of this work. No written feedback was provided in terms of suggested improvements, ideas to consider, or things that were unclear in the overall session or design activities.

4. Discussion

4.1 Analysis of Methods

In addition to the analysis and discussion of content and themes presented above, I also examined challenges and successes associated with the methods and activities employed in this research. As previously noted, activities were selected based on the findings of neurocognitive assessments conducted with patient participants during the interview study, as well as participant self-reports and researcher observations related to challenges and methods of compensation, as discussed in Chapter 2 of this dissertation. At the end of each session, participants used feedback capture grids to indicate areas of challenge, which were then coupled with researcher observations to evaluate the overall success of each of these activities and approaches. In this section, I discuss considerations and modifications employed when selecting and conducting these design activities, as well as an analysis of the successes and challenges encountered.

In the first workshop, the primary cognitive concerns involved with the Journey Mapping activity include impairments associated with memory or recall, as well as deficits in executive function (planning organizing, sequencing events) that could impact the participant's ability to

create a timeline or representation of their journey. Impairments in these areas were not found to be prevalent amongst interview participants, so there were minimal concerns or needs for modifications going into the activity. During the workshop, no challenges were observed or reported. Instead, participants enjoyed the activity, and it successfully yielded a great deal of insights and information about experiences and challenges faced by participants.

The second activity, persona creation, posed a slightly higher risk of challenge or difficulty as aspects of this activity would likely draw on a range of skills across several neurocognitive domains including abstraction/abstract thinking, cognitive flexibility, and social cognition, as well as idea generation and components of executive function. Persona creation and use requires the ability to think beyond your own situation, and consider the needs, challenges, and emotions of another individual. The fact that this character is not real or concrete can further complicate the process for individuals with cognitive impairments. Impairments in these areas may also lead to challenges in understanding the purpose of the activity. Challenges associated with the creation and use of personas or similar fictional characters, as well as anticipating and articulating the needs and abilities of others, have been described in several participatory design studies when working with individuals with neurocognitive impairments [Galliers 2012, Hendriks 2013]. In this study, the initial assessments and observations of interview participants indicated some difficulties with abstraction and cognitive flexibility for a small number of interview participants. As such, in addition to the printed instructions, I also chose to have templates available to participants if they felt they needed more direction or structure in creating the persona. During the session, one participant initially expressed slight confusion regarding the instructions and purpose of the activity, as this was a new and unfamiliar concept. This was noted in both the observations and feedback capture grid evaluations, and was resolved by repeating the instruction and providing reassurance throughout the process. Despite concerns that participants might potentially struggle with abstract thinking, or model their persona directly after their own situation, these participants were able to think beyond their own situations and circumstances, instead considering the needs, interests, and values of the future users they were creating. In the end, both groups created well developed personas that were referenced repeatedly throughout each of the activities and design sessions.

In the low-fidelity prototyping activity, I considered potential challenges involving visuospatial ability, drawing, copying, and constructing, as well as problem solving, planning and initiation, and communication, as initial assessments indicated that several of the participants struggled in these areas. As a result, I avoided forcing participants to draw or sketch out their ideas, and chose not be strict in about limiting the use of words in the prototypes. This resulted in several all text, or text-heavy low-fidelity prototypes, which may have impacted overall creativity, and resulted in less aspects of participant "design" being incorporated into the resulting medium-fidelity prototypes. It was not clear whether neurocognitive factors contributed to the decision to use text rather than creating image-based representations, or whether this was a matter or personal preference. There was some concern surrounding communication abilities, as several of the interview participants described moderate to severe disease-related impairments associated with language and communication. Plans for working in partners, allowing for more time, and moderating discussions to ensure that each participant was able to share their thoughts and opinions were put into place, however, were not needed as none of the design workshop participants experienced such impairments. The largest challenge during the low-fidelity prototyping activity turned out to be related to overall duration of the activity and session. Time guidelines and reminders helped to support attention and focus throughout the process and working in partners was also helpful to keep participants engaged and sharing ideas during the 45-minute activity, however, several participants noted being fatigued and all took breaks to stretch and refresh cognitively and physically. Similar challenges were noted during the medium-fidelity prototyping activity in the second design workshop.

In both workshop sessions, rather than relying on researcher observations as the sole source of information for evaluation, I used feedback capture grids to encourage participants to think about different aspects of the overall session and provide feedback accordingly. This approach to eliciting feedback was very successful, and resulted in constructive suggestions and revealed information that otherwise would have been missed.

In the end, only minor modifications to traditional activities and protocols were employed during these workshops, as many of the activities were selected because they were naturally flexible and accommodating, and because there was only minimal concern over the deficits or impairments faced by these particular participants. Although only minor, these modifications helped to

minimize cognitive demands, and maximize participation. For example, I found that providing both written and oral instructions for each of the activities was helpful to provide guidance and reassure participants that they were on the right track. Additionally, including multiple opportunities for review, similar to the approached detailed by Wu et al [Wu 2004], and displaying the interview themes and personas on the walls of the meeting room helped to support and reduce the need for memory. The largest challenge involved overall session duration and the resulting cognitive and physical fatigue. In each of the workshops, at least one participant noted that participation in the workshop would take a toll on them for the rest of the week as their cognitive and physical stamina was much decreased as a result of the disease and treatment process. This should be considered when planning these kinds of workshops, but often cannot be avoided. In some cases, it may make sense to have multiple shorter duration sessions with participants to avoid these challenges, but in this case, I opted to maximize time with participants over a shorter period of time to minimize levels of attrition to due the fact that some participants chose to travel to take part in different phases of this overall research, and as disease-related challenges often pose threats to long-term participation for this patient population.

4.2 Collaboration, Co-Learning and Support

Throughout this process, participants appreciated interacting with other patients and caregivers, sharing their knowledge and experiences, and learning from each other. They talked about experiences with specific clinicians, and invited each other to participate in events and support groups outside of the design workshops. There were several instances when they looked to each other for input regarding topics where they felt they did not have as much information or expertise, or where they felt another participant might have interesting perspectives. There were also several instances where participants offered advice, encouragement, and support regarding their own health and prognosis.

The different experiences of the participants contributed greatly to the design process. For example, on caregiver was in a co-caregiving situation, where responsibilities were shared with a sibling. This participant contributed unique insights regarding access and the potential benefits of consolidating information between co-caregivers, as well as considerations involving patient's who may not be willing or able to track or manage health information for themselves. Another participant had previous experience with tracking seizure information on a calendar, and could

share methods as well as examples of how that helped in better understanding potentially related health events. And finally, one patient participants deep interest and concern for understanding these kinds of health events and potential correlations drove the design of additional features to help future patients facilitate this process.

4.3 Design Considerations: Technology, Feasibility, and Usability

Throughout the design process, several considerations involving the use of technology as well as overall feasibility and usability for this user population were discussed. During the low-fidelity prototyping activity, nearly all of the initial sketches and ideas involved technology of some form. Three of the participants created prototypes that utilized a health band, fitness tracker, or smart watch for capturing and transmitting data, and nearly all incorporated the use of a smartphone application or web-based solution in some component of their prototypes. This was largely because they felt that these technologies would support desired functionalities and simplify activities, and that most individuals would already have access to them. Several of the prototypes did not require technology, however, acknowledging that not all patients and caregivers would be willing or able to use technology as a part of their care process. Other than working to minimize the amount of typing or manual data entry, and providing alternate methods of data entry (e.g. voice) when possible, there was little discussion of usability at this point in the brainstorming and design process.

In the second workshop, aspects of technology use, as well as overall design and feasibility considerations were also discussed. For these participants, the current extent of technology use in their care and management process was largely limited to patient portal access to their electronic health records. There were questions regarding potential integration with these existing systems so that information related to medications, health history, test results, and upcoming appointments could be incorporated into the application, and tracked and recorded information could be sent back to clinicians and incorporated into the medical record. They acknowledged that this functionality was not currently available, and that although integration would be highly valuable, it would also likely be complex, costly, and as a result, unlikely to happen at this point in time. They felt that having information at least come out of the electronic health record or patient portal to populate the application would be beneficial as it would reduce the amount of time and effort required to set up the application, and minimize the amount of manual data entry

which can be highly prone to errors. The issue of having information stored in two separate systems was also acknowledged as something to be addressed in the future.

Usability and accessibility were also addressed at this stage of the prototyping process. The participants acknowledged that the disease impacted people in different ways, and that providing multiple methods for entering data would be beneficial (i.e. text, voice). They also agreed that granting access to caregivers to support patients in tracking and managing health information was also necessary and beneficial component of accessibility for this population. They felt that because brain tumors affect individuals in very different ways depending on the type and location of the tumor, it would be difficult to anticipate and address every users' unique situation in the initial prototypes and design iterations, and that future research and design into these aspects would be necessary over time. In the current iteration, they felt that interfaces should be clean and easy to read, and that navigation should be simple and intuitive to avoid confusion or cognitive burden. They also felt that data such as medication information or time and date for symptom entry should be auto-populated whenever possible to minimize cognitive demand, and reduce the likelihood of error associated with manual data entry. They noted the importance of minimizing lengthy text, and recommended using large fonts along with images, icons, and other cognitive cues to replace or supplement text whenever possible.

4.4 Addressing Challenges and Barriers to Increase Adoption

From the early stages of this dissertation research, it was clear that current limited use of technology in symptom tracking and health information management activities posed challenges and barriers towards future adoption of health-related technologies. The fact that several of the participants came into the process satisfied with their current methods and moderately skeptical of the potential benefits of health-related technologies in this area provided an opportunity for extended discussion surrounding features, functionalities, and use-cases that could help to overcome barriers and resistance to change.

The participants also saw benefit in technology-based self-tracking, but because most were already satisfied with their current methods and approaches, it was difficult to promote technology-based self-tracking as an improvement over current methods as the immediate primary benefit of the application. Instead, focusing on the benefits and potential uses of the

features and data were emphasized. One area of particular interest throughout this work involved understanding symptoms and side effects, and being able to determine likely causes or correlations. As nearly all of the interview and design workshop participants had experienced such concerns at one time or another, the participants felt that being able to track, record, and view information related to symptoms and side effects alongside medications would be helpful in expanding their own understanding, and greatly beneficial for their clinicians as they worked to identify the causes of these health events. Additionally, several patients and caregivers had noted times when they were caught off guard and did not have answers to clinician questions surrounding the symptoms and side effects they were experiencing and felt that tracking in this way would help to avoid such situations in the future. Another major benefit included having all of the patient-reported information in one central, easily accessible location. Paper can be messy and difficult to organize and work with at times, as it is often unstructured and difficult to search. They felt that having this data all in one place, and accessible to both patients and clinicians would help alleviate stress and uncertainty

These participants also agreed that being able to prepare questions and record responses was incredibly valuable. Although this could and often already was done on paper, preparing and submitting a list of questions to clinicians several days before appointments was seen as a major benefit associated with using technology. Unlike email or secure messaging through the patient portal, they did not expect clinicians to respond to these questions immediately, but instead felt that sending the list in advance could help the clinicians to better prepare or anticipate some of the questions and topics of discussion for the upcoming appointment. At the same time, this would also help patients and caregivers to think about what they would like to discuss ahead of time. This was seen as especially applicable for patients undergoing chemotherapy who were meeting with their care team much less frequently, and were more likely to accumulate questions, or forget them over time. They suggested that integrating this activity with appointment reminders would help streamline the process. Another topic that was noted frequently in the interviews and throughout the design workshops involved communication of health information and the ability to contact clinicians. Experiences with contacting clinicians varied amongst participants with some being given minimal information and experiencing significant challenges, and others feeling as though they had exceptional information and access.

They felt that a feature to present contact information in an easily accessibly consolidated format could be a major selling point, especially for patients and caregivers who had previously experienced these challenges.

Finally, the participants felt that having access to trusted information and resources was incredibly valuable for new patients and caregivers like Claudia and Molly. Each participant noted challenges involving information seeking and knowing what resources were available to them. They felt that providing access to such resources and information would provide immediate benefit in the early stages of the disease and treatment process, and suggested that for some, presenting resources and information alongside the other features and functionalities may even promote increased usage of those features and functionalities as well.

4.5 Comparisons Between Patient and Caregiver Participants

Several differences in interests, approaches, and considerations between patient and caregiver participants were noted during these workshops, beginning in the initial stages of journey map and persona creation, and lasting throughout each of the prototyping activities. These included differences in perceived information needs, approaches to the design process, and the incorporation of technology.

During the low-fidelity prototyping activity, despite creating a caregiver persona, both of the caregiver participants opted to complete the activity in the context of designing to support Claudia, the patient persona. All three initial low-fidelity prototypes from one caregiver participant were designed solely for patient users with no mention of caregiver interests or needs. The second caregiver did incorporate some considerations of caregiver users, however, largely in a supportive role. The patient participants, on the other hand, tended to create designs that incorporated the needs and interests of both patient and caregiver users. This extended beyond providing joint access, and included dedicated information and resources to address caregiver-specific information and support needs. Their prototypes acknowledged that patients and caregivers often have different questions and information needs, and that access to information is incredibly important for caregivers as well as patients.

There were also notable differences in the role and perceived importance of technology between the groups. For the caregiver participants, technology was incorporated into nearly every aspect of the prototyping process. They believed that technology could simplify the process of tracking and accessing information for many future users, and envisioned technologies that would support maximal automatic data capture through the use brain implants and fitness trackers, whereas patients largely created prototypes that could be implemented on paper as well as in an electronic format. The patients agreed that technology could facilitate many of these activities and support access to important information and resources, but placed a higher value on ensuring that content and information were available to users.

Finally, there were also differences between these sets of participants in balancing versus content versus user experience. In the early stages, the caregiver participants were less concerned with the individual symptoms to be tracked, and more interested in providing a simple, clean user experience with minimal requirements for manual data entry. The patient participants, on the other hand, placed more emphasis on the content rather than the platform for delivering that content. They focused heavily on providing features and resources to address information needs and challenges, especially for new users, noting that these individuals often do not discover important information or services until later in the treatment process. Patient discussions surrounding symptom and side effect tracking were primarily targeted at increasing understanding, and decreasing uncertainties related to the causes of these health events. The patient participants did not express the same concerns about the user experience, especially at the expense of reducing the amount of content or information made available. Interestingly, the initial prototypes created by the patient participants were very similar to each other, as were those produced by the caregivers, however, the prototypes created across the groups included very different content, features, and functionalities. In the end, rather than indicating the need for two separate systems, the differences were complementary and resulted in a comprehensive application.

5. Limitations

Overall, this study represents a successful example taking a participatory design approach to engaging patients with primary brain tumors and their caregivers in the process of designing of tools and technologies to support future users. In addition to the successes of this research, there are potential limitations to acknowledge and consider, however. The majority of these limitations

stemmed from the number of participants taking part in this study. Although there is no generally agreed upon ideal sample size for Participatory Design studies, researchers often self-acknowledge sample size as a limitation in studies with fewer than 10. Smaller groups or even individual sessions are common in these design studies, especially in the context of designing to support individuals with neurocognitive impairments or disorders [Moffatt 2004, Robinson 2009, Lindsay 2012, Davies 2004, Galliers 2012, Hanson 2007]. In this study, our sample size was small, both to facilitate participation, and as it was impossible to recruit and involve a large enough group to be considered representative of the larger brain tumor patient and caregiver population. Part of these recruitment challenges were a consequence of the relatively small number of participants recruited to take part in the previous interview study, however, changes in health status and overall circumstance (e.g. location, availability) also contributed. I would argue that the number of participants, however, was not outside of reasonable expectations for participation in a study involving this patient population.

Challenges involving small sample size were addressed in the following ways. First, I worked to incorporate findings from the previous patient and caregiver interviews into discussions throughout the workshops to provide a broader view and understanding of the challenges and perspectives of the larger patient and caregiver population. Next, I used the concept of a persona to push participants to think beyond their own situations and consider the needs of other future patients and caregivers throughout the design process. And finally, I would attempt to recruit additional patient, caregiver, and clinician participants not previously involved in this research to take part in the subsequent evaluation study to capture additional feedback and perspectives, and identify considerations that may have been overlooked.

Despite good representation of user types and stages in the disease and treatment process, there were areas where we likely did not achieve good representation, however. First, the workshop participants were currently experiencing very minimal self-reported levels of disease and treatment related impairments, with cognitive and physical fatigue, challenges with attention and concentration, and minor difficulties with reading lengthy or fine print text (vision/discomfort) being the only relevant lasting issues. Both of the patient participants, however, had experienced a wide range of symptoms and side effects throughout the course of disease and treatment, some of which were cognitive in nature, and thus could provide some perspective in that respect.

Additionally, one caregiver provided care and support for a family member who had severe lasting impairments, and had a deep understanding of how this might impact other similar users.

Additionally, technology use was high for this group. Although information regarding technology use in patients with primary brain tumors and their caregivers is not available, it was likely safe to assume, based on age and other demographic features, that these individuals represented a higher level of adoption than would likely be found in the general brain tumor population. According to data available from the Pew Internet Research reports for 2012 and 2015, 83% of adults between the ages of 30 and 49 owned a smartphone, as did 58% of adults between 50 and 64. Although the participants in my study had higher rates of smartphone ownership, they also had a higher education level, which was linked to higher likelihood of smartphone ownership in this data [Fox 2013, Anderson 2015]. The only data available for comparison of technology use characteristics was that of the participants in the patient and caregiver interviews. In comparison, health application usage was higher in the design group, however, no participants in either study were using dedicated health-applications for tracking brain-tumor-related information. Participants in both studies relied primarily on paper and memory for tracking information related to the disease. There were more iPhone users in the design group as compared to Android users, however, all device groups were again represented. We did not focus on developing for a specific operating system in the design workshops, so this likely had no impact on the findings.

6. Conclusions

In this chapter, I presented findings of a Participatory Design study aimed at designing tools and technologies to support patients with primary brain tumors and their caregivers in tracking, understanding, managing, and communicating health information. The findings of this study are encouraging, both in terms of the progress made towards translating needs, challenges, and experiences into interfaces for future tools and technologies, and in the fact that the participants were able to engage in these activities in a meaningful manner with few challenges towards participation. Throughout these activities and workshops, the participants explored requirements and usability considerations, and discussed the role of technology in supporting these activities. During this time, the individual features and the overall understanding of purpose and potential of the application evolved as participants became increasingly engaged in the design activities.

In the end, this was a valuable and successful experience for the participants and the research team alike, as collaboration in design and discussion activities drove the design of these future technologies, and created a sense of co-learning and support. In the final stages of this research, the designs, knowledge, and insights gathered throughout this study will inform the design of a high-fidelity application prototype that will be evaluated by patients, caregivers, and clinicians.

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Chapter 6: Overview and Evaluation of a Patient-Driven Self-Tracking Application to Support Patients with Primary Brain Tumors and their Caregivers

1. Introduction

In the final stages of this dissertation research and design process, I developed a high-fidelity interactive prototype of a smartphone and tablet application designed to support patients and their caregivers in tracking, managing, understanding, and communicating health information through the brain tumor disease and treatment process. The design and development of this prototype was driven by the findings of the previous patient, caregiver, and clinician interview studies, and the outcomes of the patient and caregiver Participatory Design workshops. I then recruited nine patients, caregivers, and neuro-oncology clinicians to take part in an evaluation study aimed at investigating overall usability, as well as perceived benefits and challenges associated with this application. I used a combination of methods and techniques to elicit, capture, and quantify participant feedback throughout this study. I engaged participants in scenario-based tasks coupled with a Think Aloud technique to explore how users navigated and interacted with the application, followed by a quantitative assessment of subjective usability and a semi-structured interview to determine whether this application met user needs and expectations, and to gather additional insights into overall user experience, and considerations for further design and implementation.

Through these evaluation tasks and activities, I found that all participants were able to successfully navigate the prototype application and provide feedback on their experiences. Impressions of this application were largely positive, with each participant reporting on ways in which the application could be used to address current challenges, and support patient care, communication, and decision-making activities. Participants across each of these user types reported feeling that this application met their needs and expectations, and could easily be integrated into current workflows. There were few concerns regarding usability as well as patient interest and ability to interact with the application, however, the participants identified several areas and opportunities where changes could be made to increase usability and improve overall

user experience. At the conclusion of the study, all participants reported that they would use a fully functional version of this application in their own care process, and would recommend it to future patients and caregivers, as they felt it provided information and support that was essential to this population during this time.

I begin this chapter by presenting an overview of the application prototype, and describing major features and functionalities examined throughout this evaluation study. Next, I introduce methods and discuss major findings regarding usability and impressions over the overall application, as well as perceptions of benefits, and considerations involving adoption and integration into current workflows and care activities. I then discuss challenges and recommendations for features, functionalities, and navigation going forward, and conclude by discussing future design and development work for this application.

2. Application Overview and Feature Descriptions

This application was developed based on the findings of the previous research and design sessions. Before introducing findings from the evaluation study, I present a brief overview of the application, and describe major features and functionalities.

The final prototype created for this evaluation was developed using proto.io (www.proto.io, Nicosia, Cyprus, version 5.17), a web-based prototyping platform designed to support users in creating flexible prototypes for a wide range of devices. With this product, prototypes can be designed to reflect various degrees of interactivity, and include a wide range of features and functionalities. These prototypes can be published and viewed on the web, or accessed using the Proto.io application on supported Android and iOS devices. Proto.io also includes a variety of features to support collaboration, as well as integration with usability testing tools to support both in person and remote user testing. This specific prototype was created to display the overall design, content, features, and functionality, and demonstrate the interactivity of the application. This was not intended to represent a fully-functional application, however, as user-entered data would not be stored, and a small number of features and functionalities were not fully implemented (**Section 6.5**).

2.1 Application Home Screen and Navigation Menu

*Application Home Screen (**Figure 1a**):* After logging into the system, the first major screen that users will reach is the Application Home Screen. This screen is the central hub for users to navigate through the major features and functionalities of the application. These features are listed by text descriptions and are accompanied by large, simple icons to further support intuitive navigation. An icon to return to the Application Home Screen is available on each of the interfaces throughout the application to allow quick and intuitive navigation back to this hub.

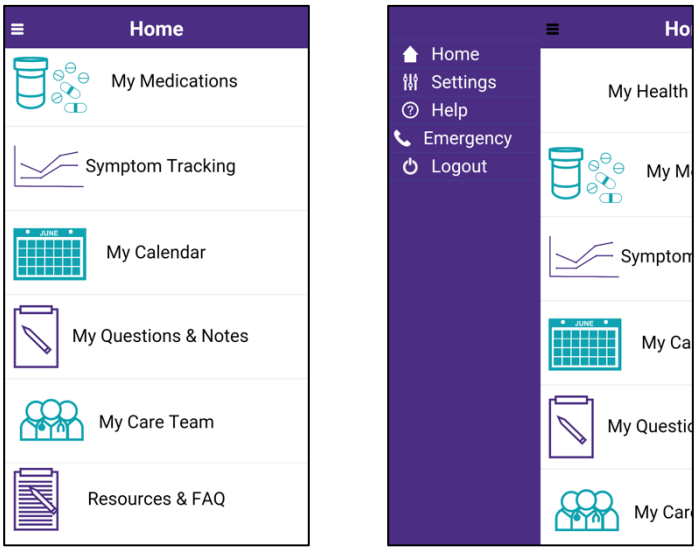


Figure 1 Home Screen and Navigation. 1a. Application Home Screen. 1b. Navigation Menu

*Navigation Menu (**Figure 1b**):* The Navigation Menu is used for accessing additional features and functionalities that are not currently displayed on the Home Screen including Settings, Help, Emergency Contact Information, and Logout. This can be accessed by clicking on the menu icon on each of the application interfaces.

2.2 My Medications

The goal of My Medications is to provide access to a complete listing of the medications that a patient is taking, or has taken in the past as a part of their treatment process, as well as information about these medications, as described below. Additional features and functionalities such as reminders and tools to explore potential side effects are included to help support user understanding, memory, and medication compliance.

*Viewing Current Medications (**Figure 2**):* This section contains a list of the patient's current medications, including those automatically imported from the patient's medical record, and those manually entered by patient and/or caregiver users (**Figure 2a**). Clicking on the name of a medication leads to expanded information including instructions, an image of the medication tablet, additional clinician notes about the medication, and links to further medication information from the manufacturer (**Figure 2b**). This page also contains features for viewing potential side effects of the given medication, and the ability to add relevant medication side effects to the list of symptoms and side effects being tracked. The user can also request medication refills, set medication and refill reminders, and record notes about their experience with the medication for future reference directly from this page (**Figure 2c**).

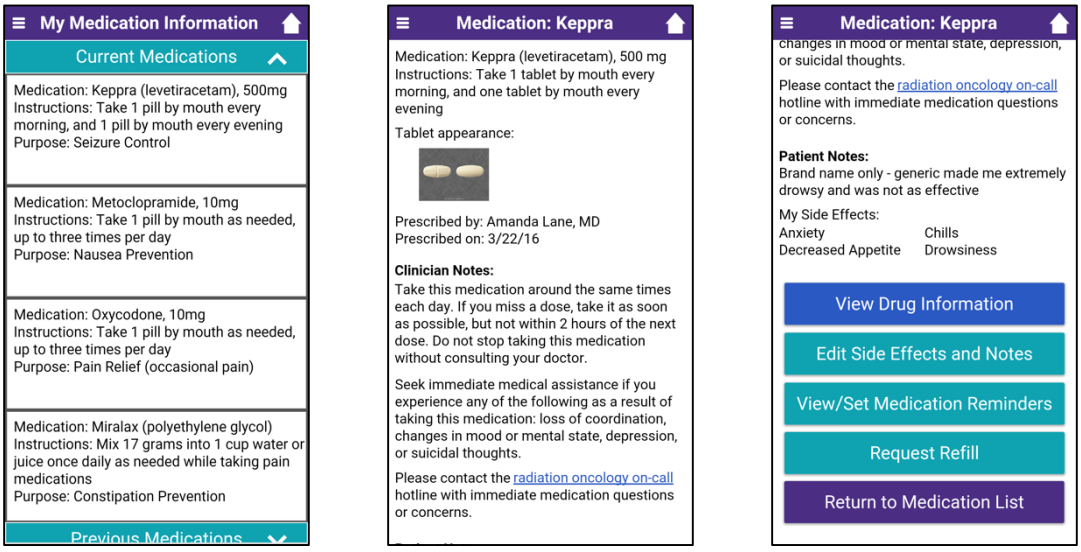


Figure 2a. Current Medications. Figure 2b and 2c. Medication Information

*Viewing Previous Medications (**Figure 3a**):* A list of previous medications and corresponding information is also included to support memory and record keeping (**Figure 3a**). Because patients with primary brain tumors often take many different medications to battle the disease and its associated symptoms and side effects, it can be difficult to keep track of and recall which mediations were problematic and why. As such, an icon is displayed alongside these medications to alert users of previously noted negative experiences. This is especially useful for patients who experience recurrence and return to treatment as they may once again need to consider these medications.

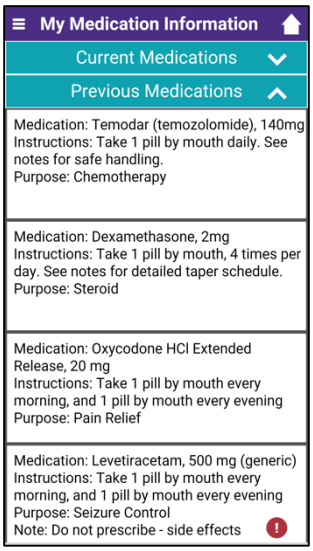


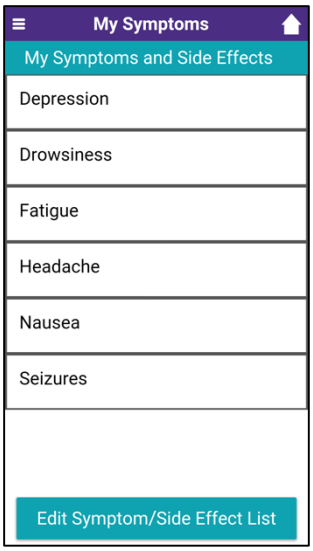
Figure 3a. Previous Medications. Figure 3b. Add New Medication.

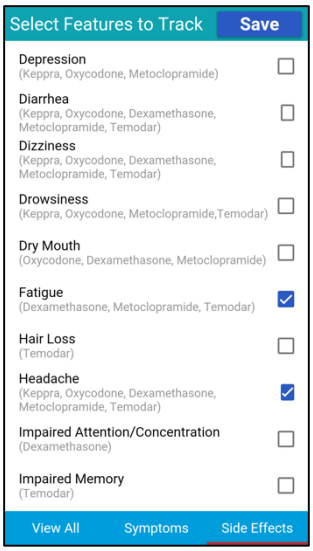
*Adding New Medications (**Figure 3b**):* A feature is also included so that users can add new medications, vitamins, or supplements to their medication lists. This allows users to provide more complete information about the medications they are taking both for their own records and to share with their clinicians (**Figure 3b**).

2.3 Symptom Tracking

In Symptom Tracking, users create a list of relevant symptoms, side effects, and other health events that they would like to track and capture information about, and uses structured templates to enter data such that information and trends can be viewed and shared over time.

*Selecting Symptoms to Track (**Figure 4**):* Each user's tracking list is customized based on the symptoms and side effects that the patient is currently experiencing (**Figure 4a**). Users can add symptoms and side effects to their list from My Medications, or through the Edit Symptom/Side Effect List feature on the Symptom Tracking page (**Figure 4b**). These larger lists contain an extensive catalog of symptoms that patients with primary brain tumors may experience, as well as potential side effects based on the patient's medication list. An "Other" field is also available to allow users to add and track new health events not currently included in the master list. The tracking list can be edited over time as symptoms and side effects change.





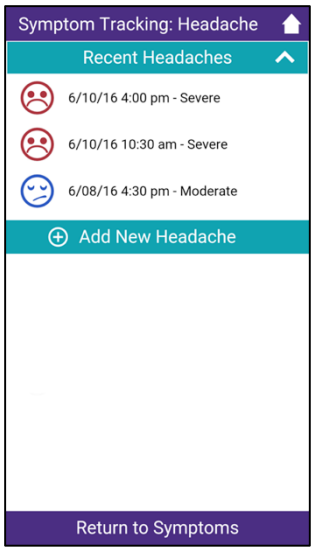


Figure 4a. Tracking List. Figure 4b. Edit List Figure 4c. Recent Headaches.

*Entering Symptom Data (**Figure 5**):* In this application, data entry is tailored for each specific symptom or side effect such that relevant information in an efficient and intuitive manner. For example, if a user wishes to enter data about a headache, they can select Headache from their tracking list (**Figure 4a**) and then click on 'Add New Headache' and fill in the corresponding information. Headache date and time default to the current date and time, but can be changed when entering data after the fact. A slider bar is used to enter information about headache severity, with a combination of colors, numbers, and text descriptions to help support data entry (**Figure 5b**). Users can indicate the location of their headache on an image of a head, and use checkboxes to convey information related to suspected triggers and whether medical assistance was needed. Users can also indicate whether they took any measures to resolve the headache such as sleep, quiet, or medications, and if those measures were effective. For each of these questions, users can add notes and additional information that they feel is important. Additionally, as participants in the previous interview and design sessions noted that they did not want to complete lengthy forms or answer questions that they felt were not applicable, none of the data entry fields were required, allowing users to contribute as much or as little information as they felt relevant.

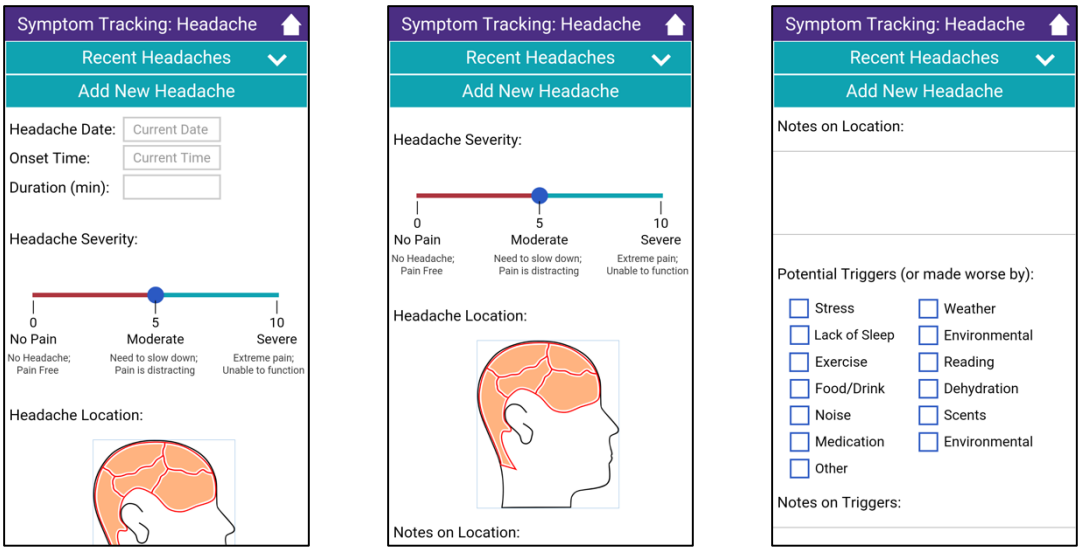


Figure 5a-c. Headache Data Entry

2.4 My Questions and Notes

The Questions and Notes section is intended to support users in recording questions and information that they would like to discuss with clinicians as they research and prepare for upcoming appointments (**Figure 6a**).

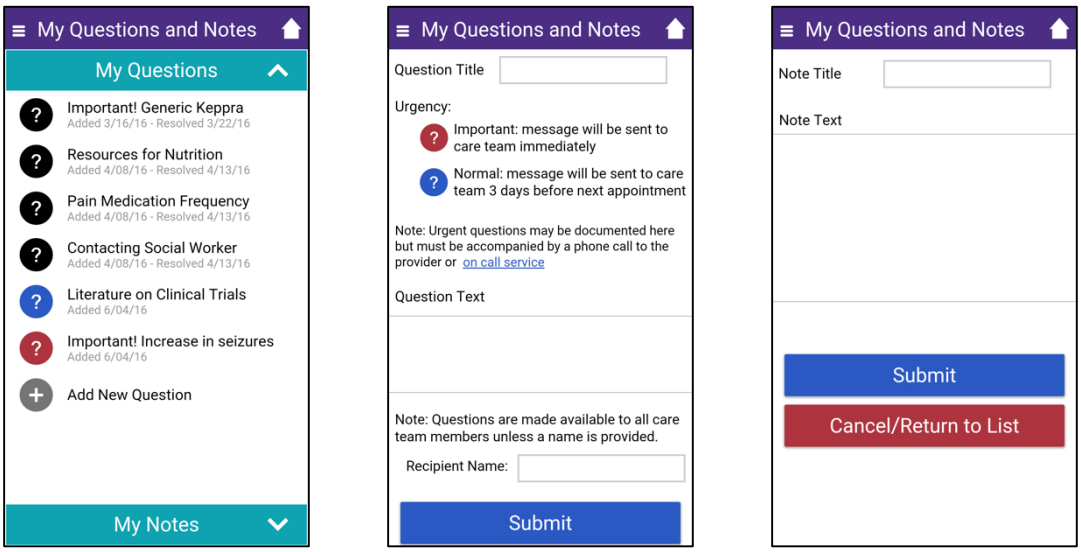


Figure 6a. My Questions. Figure 6b. Question Entry. Figure 6c. Notes Entry.

Adding New Questions: Users can add new questions to their question list by clicking "Add New Question" and filling in the corresponding information (**Figure 6b**). Questions can be marked as Important and sent to the care team immediately, or Normal, in which case they will be transmitted alongside tracked data 3 days before the patient's next appointment. Although

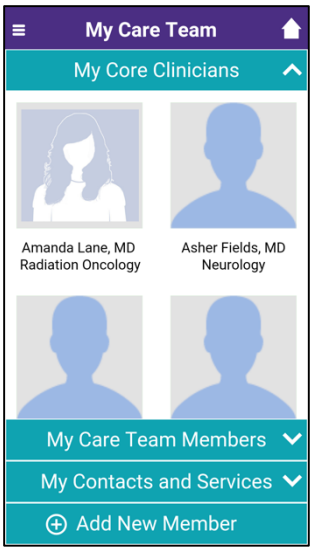
questions can be directed to a specific clinician or the patient's entire care team, this feature is not intended to be a communication tool, and clinicians are not expected to respond directly through the application. Rather, this serves as a way to collect questions over time and consolidate the information to send in preparation for upcoming appointments. Clinicians can view these questions before and during appointments, and users can record responses and mark questions as resolved as they go along.

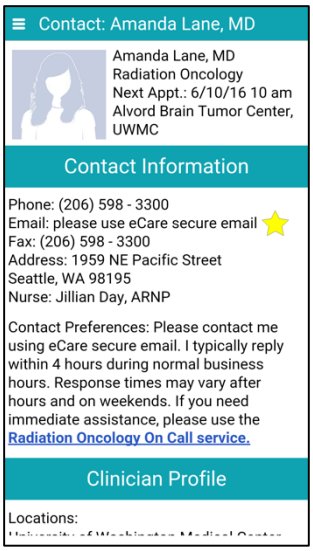
Adding New Notes: The process for adding notes is similar, however, as Notes are not intended to be transmitted to care team members, users do not indicate urgency or address them to specific clinicians (**Figure 6c**). These notes are intended to be stored within the application for the user's own knowledge and reference, and can be used for compiling information to accompany questions, or for recording information about topics discussed in clinic visits, for example.

2.5 My Care Team

The goal of the My Care Team feature is to provide a single, consolidated source for accessing clinician contact information (**Figure 7a**). In this feature, users can view a list of clinicians involved in their care process, as automatically imported from the medical record, and add new members to their list by searching them in a directory, or entering their information manually. Care Team information is broken down into three major categories: My Core Clinicians (main neuro-oncology clinicians), My Care Team Members (e.g. extended members including social work, nutrition, and rehabilitation specialists), and My Contacts and Services (e.g. scheduling, transportation or medical cab services, pharmacy information hotline).

Basic contact information for each clinician on the patient's care team is provided as well as pictures, clinical titles, and information about upcoming appointments (**Figure 7b**). Preferences for contacting these clinicians are clearly stated, and link to information for reaching on call services in case of an emergency are also provided. Links to clinician profiles on departmental webpages are also included to reduce the amount of text while still providing access to this information. Finally, a space to enter notes is provided so that users can make notes for themselves about clinicians, such as reminders about directions to their office or notes about personal interactions, in order to support memory (**Figure 7c**).





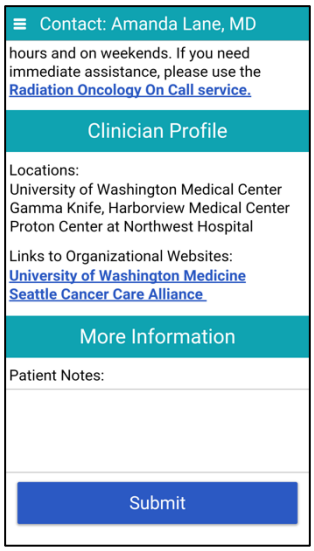


Figure 7a. My Care Team. Figure 7b-c. Clinician Contact Information.

2.6 Resources and FAQ

This feature serves as a central location for learning about available resources for patients and caregivers, as well as trustworthy sources for researching disease and treatment related information. Other resources included information local or healthcare organization specific services and resources, information on diet, nutrition, and exercise, as well as information on support groups and services that may be available and beneficial for these individuals.

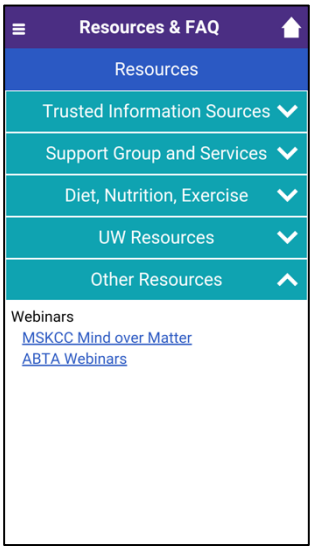


Figure 8. Resources and FAQ.

2.7 My Reminders

Several types of reminders are available through this application including reminders for entering symptom data, alerting users about upcoming appointments, and those for taking and refilling medications (**Figure 9a-b**). For each, users have the option to customize the time of day for the alerts, as well as the type of reminder (**Figure 9c**). Users can also set the frequency of alerts for symptom tracking, and the timing of appointment and refill reminders.

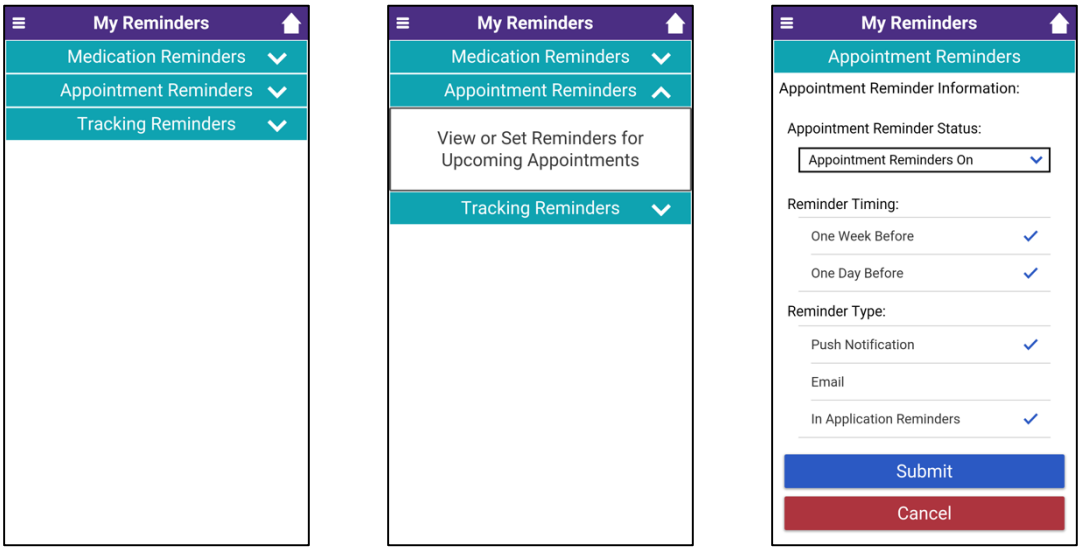


Figure 9a. My Reminders. Figure 9b-c. Viewing or Setting Appointment Reminders.

2.8 Emergency Contact Information

In the early prototypes, emergency contact information was mixed in with Care Team information, however, because of the importance of having the information accessible with minimal clicks, it was clear this information should be available separately. As a result, a standalone feature for reaching on call services after hours or in case of emergency was added to the navigation menu in addition to being available alongside clinician contact information.

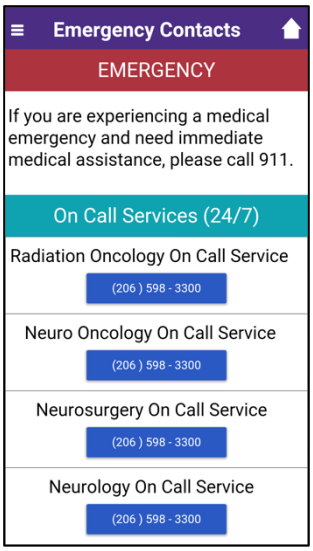


Figure 10. Emergency Contacts

2.9 Settings, Access and Sharing

Finally, an option for adjusting Settings and allowing shared access to the application is accessible through the Navigation Menu. Through this option, users can edit account information including usernames, email addresses, or passwords, and can make changes to general settings including notification types, font size, alert sounds, and volume levels (**Figure 11a**).

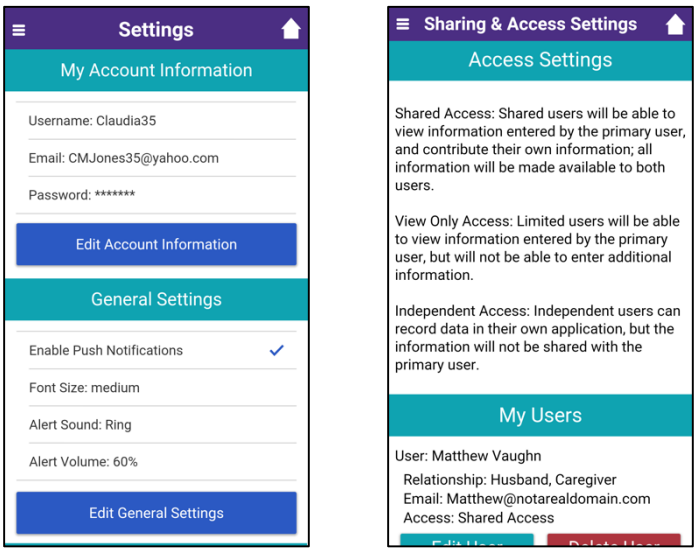


Figure 11a. Settings. Figure 11b. Shared Access

Access and Sharing: One major feature included within Settings is Access and Sharing. Through this feature, users can grant caregivers and others involved in components of their care process shared access to the application and the data they have collected. Different levels of access allow

users to choose the types of permissions they would like to grant to these users, ranging from full access to view and enter data, to read only access (**Figure 11b**).

3. Methods

3.1 Eligibility and Recruitment

The primary objectives of this study were to evaluate the application prototype to assess usability and determine whether participants felt that future patients would be interested and able to use the application, and identify ways in which user needs and expectations and needs were met through the application design. In order to do so, I sought to recruit patients with primary brain tumors, as well as their caregivers, and neuro-oncology clinicians involved in the treatment of this patient population to participate in a usability evaluation study. Considering previous challenges with recruitment of all three participant types, and the necessity of conducting this evaluation study within a reasonable timeframe to minimize the potential for further attrition, I sought to recruit between 9 and 15 participants to take part in this study over a two-month recruitment period. I aimed for a range of between 3 and 5 individuals per participant type, with even representation across the groups. I also aimed to include a combination of participants who took part in previous stages of this research and design process, as well as individuals who were new to this research.

Similar to the recruitment methods used for the Participatory Design workshops (Chapter 5), participants from the initial patient and caregiver interviews (Chapter 4) who indicated interest in participation in the final evaluation were contacted and provided with study information via email. Additional patient and caregiver participants were recruited through a local brain tumor support group, and through fliers made available in local neuro-oncology treatment centers and clinics. Clinicians were primarily contacted via email, and in each case, snowball sampling was used in an attempt to recruit participants who had not previously taken part in this research, as well as those working or being treated outside of the UW Medicine system. Eligibility criteria for all participants was consistent with the criteria implemented in the previous studies, and is listed in **Table 1.**

Table 1: Eligibility Criteria

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

Clinicians:

- Practicing clinicians (MD, DO, PA, ARNP, BSN, RN) in Radiation Oncology, Neurosurgery, Neurology, or Neuro-Oncology
- Must interact directly with patients during treatment and/or follow-up for a primary brain tumor
- Routinely elicit symptom or side effect information during patient evaluations
- Medical Residents must be in year 3 or above and make independent decisions or recommendations regarding care activities
- All participants must be 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.

University of Washington Institutional Review Board permissions were obtained prior to conducting this research. All evaluation sessions were conducted individually and in-person at the University of Washington Medical Center. Each session lasted approximately 45 minutes, and all research activities were audio and video recorded to support data analysis. Patient and caregiver participants were compensated with a $25 gift card for their time. Research materials are provided in Appendix C.

3.2 Data Collection and Analysis

3.2.1 Demographic, Health, and Technology Use Survey

Participants were asked to complete a brief survey to capture basic demographic and technology use information at the beginning of the evaluation session. Information elicited surrounding health and demographic information again varied slightly depending on participant type, while technology use questions were the same for all participants. Technology use questions were

adapted from the 2012 Pew Internet & American Life Project's Health Tracking Survey and focused on internet use, as well as smartphone ownership and use [Health Tracking Survey 2012]. Additionally, as a part of this survey, all participants were asked to indicate whether they had participated in previous stages of this research.

3.2.2 Evaluation Research Activities

In the first major component of the evaluation study, participants were asked to complete a series of scenario-based tasks in order to assess overall navigation, features, functionality, and usability. These tasks were conducted primarily using an Apple iPad device provided by the research team (Apple iPad 4th generation, 64GB, iOS 9.2, 9.7-inch Retina display); an Android smartphone was also made available to participants to further assess usability, interaction, and application navigation on a smaller device (Samsung Galaxy S5, Android version 6.0.1, 5.1-inch AMOLED display). Tasks varied slightly depending on user type, and were designed to be representative of typical user activities, and highlight important aspects of functionalities, as identified throughout previous research and design activities. The scenario and tasks were based on Claudia, the patient persona created during the previous participatory design workshops. The application was pre-populated with Claudia's information and participants were given a handout displaying the persona and presenting other relevant information, including symptoms and side effects, and log-in information. All participants interacted with a patient- and caregiver-facing version of the application for this activity. Patient and caregiver users were asked to provide information from their own perspective; clinicians completed the tasks using the same application, and were asked to contribute their own insights and perceptions based on their knowledge of Claudia and the patients they treat.

In order to capture additional information and feedback regarding navigation and usability, participants were instructed to use the Think Aloud protocol to narrate their thoughts and actions while completing these tasks, a method that has been commonly adopted and adapted in usability research over the past several decades [Ericsson 1984, Nielsen 2002, Kaikkonen 2005, Olmsted-Hawala 2010]. In this study, the protocol was explained and introduced using an example, and then participants were given a sample task to complete using the application. Researcher intervention was primarily limited to non-intrusive reminders to verbalize thoughts and actions

when necessary, however, assistance was provided when requested in order to minimize frustrations and distress.

Participants also completed a System Usability Scale questionnaire to further assess overall usability of the application. This 10-item Likert-type scale was developed as a 'quick and dirty' means of capturing 'a global view of subjective assessments of usability [Brooke 1996].' This scale was selected because it addresses aspects of usability of interest to this study without being overwhelming or time consuming. Additionally, the pattern of alternating negative and positive sentiments (strong agree, strongly disagree) requires users to read each question and think about their responses before responding, potentially eliminating some biases. Because of the increased potential for cognitive impairments or deficits among participants, however, questionnaires were visually scanned to detect any apparent issues involving confusion, misunderstandings, or misinterpretations of questions. Once all sessions were complete, the results were computed and analyzed using the scoring method provided by the test instrument.

Finally, I conducted a brief semi-structured interview with each participant in order to debrief participants, and capture additional information surrounding perceptions and experiences. During this time, participants were encouraged to explore the application features and functionalities further, as not all were included in the tasks due to time constraints and to avoid overwhelming participants. In these interviews, I examined whether participants felt that the application met their needs and expectations, and whether they would recommend it to future patients and caregivers. I also investigated benefits for different users and stakeholders, and discussed how each participant imagined using the application as a part of their own care and management process. Additionally, I examined perceptions related to patient interest and ability to use the application, areas of concern, and suggestions for changes or improvements.

4. Results

4.1 Demographic, Health, and Technology Use Information

A total of 9 participants took part in this study: 3 patients, 3 caregivers, and 3 clinicians. Five additional participants (2 patients, 2 caregivers, and 1 clinician) initially expressed interest and scheduled or attempted to schedule a time for participation, but were later unable to participate due to changes in health status, availability, or living situation. Demographic, health, and

technology use information is provided for the nine participants who completed the evaluation research activities is introduced below, and presented in **Tables 2 – 5.**

4.1.1 Patient Participants

All three patient participants were female, with an average age of 48 (range 43-56). Diagnosis information was provided by two participants an included anaplastic astrocytoma and oligodendroastrocytoma. One participant was originally diagnosed 13 months prior and had no new growth or recurrences, while the other two participants were both originally diagnosed outside of the time frame of interest, but had experienced new growth or recurrence requiring treatment within the past 5 years. Of the patient participants, one was currently in treatment, and another had finished a month prior to their participation in the study. Two participants had taken part in both the interview and design workshops, and one was new to this research. Patient participant health and demographic information is presented in **Table 2**.

Table 2. Patient Demographic and Health Information

Patient Participants (n = 3)	
Average age (years):	48 (range: 43-56)
Gender:	Female (3)
Race:	Caucasian/white (3)
Education:	Bachelor's Degree (2) Graduate or Professional Degree (1)
Diagnosis:	Anaplastic astrocytoma (1) Oligodendroastrocytoma (1) Brain tumor – type not specified (1)
Time since diagnosis:	Average 15 months
Currently in treatment:	Yes (1) No (2)
Treatment history:	Radiation therapy (3) Chemotherapy (2) Surgery (3)
Previous participation	Interview + Design (2) No previous participation (1)

4.1.2 Caregiver Participants

Three caregiver participants took part in this study, representing an average age of 49 (range 46-52). One participant was female and two were male. As with the patient participants, two of these participants had taken part in both the interview and design workshops, and one participant was new to this research. Caregiver demographic information is presented in **Table 3**.

Table 3. Caregiver Demographic Information

Caregiver Participants (n = 3)	
Average age (years):	49 (range: 46-52)
Gender:	Female (1) Male (2)
Race:	Caucasian/white (2) Asian Indian (1)
Education:	Bachelor's Degree (2) Graduate or Professional Degree (1)
Previous participation	Interview + Design (2) No previous participation (1)

4.1.3 Clinician Participants

Three clinician participants took part in this study, representing specialty areas of radiation oncology and neuro-oncology/neurology. These participants had an average of 5 years of experience working with this patient population, and saw an average of 8 patients with primary brain tumors per week (range 1 – 20). All three participants were female. Two participants had taken part in the clinician interview study, and the other was new to this research. Clinician demographic information is presented in **Table 4**.

Table 4. Clinician Demographic Information

Clinician Participants (n = 3)	
Gender:	Female (3)
Clinical role:	Resident Physician Attending Physician
Clinician specialty:	Radiation Oncology Neuro-oncology/Neurology
Practice setting:	Academic Medical Center/Major Hospital
Years of experience:	Average 5 years (range: 2-10 years)
Patients per week:	Average 8 (range: 1-20)
Previous participation	Interview (2) No previous participation (1)

4.1.4 Technology Use

All participants in this study reported that they used the internet, at least occasionally, and had accessed the internet of a cell phone, tablet, or other mobile handheld device, at least occasionally. Eight of the nine participants owned a smartphone, with the final participant reporting that they did not own a cell phone or smartphone. This and further technology use information is displayed in **Table 5**.

Table 5. Technology Use Information

	Patient (n = 3)	Caregiver (n = 3)	Clinician (n = 3)
Uses internet, at least occasionally	Yes (3)	Yes (3)	Yes (3)
Accesses internet on cell phone, smartphone, or tablet	Yes (3)	Yes (3)	Yes (3)
Owns smartphone device	Yes (2) No (1)	Yes (3)	Yes (3)
Device ownership	iPhone (1) Windows Phone (1)	iPhone (2) Android (1)	iPhone (3)

5. Evaluation Findings

Nine participants took part in this study, evaluating the application prototype while navigating and exploring features, functionalities, and content, and providing feedback on usability and overall experience. These participants reported that they were impressed and satisfied with the application, and optimistic about the potential for addressing challenges in different aspects of care and information management activities for this patient population. They discussed features that they felt were particularly helpful, and identified ways in which this application could help to address challenges they had experienced over time.

In this section, I present the major findings from each group of participant groups, and discussing features and functionalities of relevance and important for each of these participant groups, as well as findings from the System Usability Scale questionnaire.

5.1 Patient Findings

Three patient participants took part in this study. As previously noted, two patient participants had prior involvement in both the interview and participatory design studies, and were familiar with the goals and motivations of this work. All three participants were able to navigate the application successfully and provide meaningful feedback. One participant initially experienced difficulties interacting with the application on the tablet and smartphone, primarily due to lack of familiarity with these technologies, but in the end was able to learn how to use the devices, and navigate the application to identify benefits and uses for themselves and future users.

Throughout the evaluation process, these participants reported that the application was easy to use, and that the features and functionalities were well thought out and organized. They felt that

navigation was intuitive, and that the text was large enough to read comfortably without magnification. They reported that the application met their needs and expectations, and felt that the features, functionalities, and resulting data were not only useful for themselves, but also for caregivers and clinicians. Each participant acknowledged instances where this application could address challenges that they had previously faced, or were currently facing in managing, understanding, tracking, and communicating health information and care activities as a part of their brain tumor treatment and follow-up process.

Although these participants reported valuing aspects of each of the features and functionalities included within the application, they highlighted several features as particularly helpful or beneficial, especially for this patient population, as described below.

My Medication: All three patient participants expressed great interest in the My Medications feature. Interestingly, each valued and highlighted different aspects of the content and information included. Patient 1 especially appreciated the medication reminders, noting that lasting deficits involving memory led to daily challenges remembering to take medications. Patient 3 noted that although they would not likely use these reminders as they had developed their own strategies over time for both remembering to take medications, and confirming that they had taken them, they felt that having a simple, reminder-based method for keeping track of this information from the beginning would be greatly beneficial to patients like Claudia. Patient 3 also felt that the ability to request medication refills through the application was helpful as it further consolidated information and services, and did not require accessing multiple systems.

For Patient 2, the greatest benefit of this feature came from being able to easily view information about medication side effects within the application. In this application, all possible side effects for the medications that the patient is currently taking are presented in a list so that users can quickly scroll through and see which medications may be contributing to each of the individual side effects (**Figure 4b**). For Patient 2, this meant no longer having to find and search through multiple medication leaflets with a magnifying glass every time a new side effect emerged, greatly improving their ability to access and understand important side effect information.

Symptom Tracking: These participants also saw great value in the Symptom Tracking feature. All felt that this feature would help with keeping track of the various symptoms and side effects they were experiencing over time, and would serve to support memory and communication. The participants appreciated being able to choose what to track from the larger list of potential symptoms and medication side effects based on their own health situation. They also reported that the information elicited for each of the individual symptoms they were tracking was thorough, and felt that the methods used and questions asked were effective for capturing information that was helpful and relevant for patients and clinicians alike.

In addition to benefits and uses involving capturing data to identify potential correlations between medications and side effects, these participants reported that tracking and recording of symptom data within the application would likely help with organization and ensuring that information was available and accessible during clinic visits. One of the greatest benefits reported by these participants, however, was that structured symptom tracking would facilitate communication surrounding what was happening and how things were going for the patient. They felt this, and many other features within the application, would help to reduce the need for memory and recall in the clinic, and better ensure that issues and concerns were raised.

My Questions and Notes: The patient participants also appreciated the My Questions and Notes feature. These participants felt that recording questions and notes within the application would not only help them to remember their questions in the clinic, but could also help with organization and capturing responses. They felt that this feature would be useful for newer patients who are facing an abundance of new information and uncertainties, as well as those who are in follow-up or not interacting with their clinicians as frequently.

Resources and FAQ: Resources and FAQ was also highly valued by the patient participants. Patient 3 explained that in the beginning, patients are typically overwhelmed, and often experience challenges finding relevant and trustworthy information. This participant described how this feature could provide patients and caregivers with a place to start in their research process, and introduce them to valuable resources that they are likely not yet aware of. One participant also felt that having a consolidated list of resources and FAQ would be helpful for

taking notes and preparing questions for upcoming visits, and for helping patients to determine what questions to ask, especially at the beginning of the diagnosis and treatment process.

My Care Team and Emergency Contact Information: My Care Team and Emergency Contact Information were also reported as essential features within this application. Although these features were separated in the application. These participants felt that in both cases, having this information in a central consolidated location was helpful, and meant that patients and caregivers would not have to search for this information when it was needed. The participants noted that these features were not only helpful for new patients and those more likely to be experiencing immediate questions and concerns (e.g. patients coming out of surgery or those starting new medications or treatment protocols), but would also benefit patients across the course of treatment and follow-up. Patient 3, for example, had recently changed clinicians after several years of treatment and follow-up under a different care team. This participant received a piece of paper with contact information for reaching care team members with questions or in case of an emergency, which they stashed away as they did not anticipate needing it any time soon. The participant had previously noted challenges with memory as a result of the disease and treatment process, especially when it came to finding things, and acknowledged that knowing that the information was easily available if it was ever needed without having to search through notes and stacks of paper would be greatly beneficial.

My Reminders: In addition to reminders to take medications, these participants appreciated that they could activate reminders to refill medications and enter symptom data, as well as those to remind them of upcoming appointments. Patient 3 felt that the medication refill reminders would be especially helpful for managing medications, as insurance companies are often strict about how soon prescriptions can be refilled; brain tumor patients are often taking many different medications, and renewal schedules for these medications may not always line up nicely.

5.2 Caregiver Findings

As with the patient participants, three caregivers took part in this evaluation study; two participants were previously involved in the interviews and design workshops, and one was new to this research. Throughout their interactions with the application, these participants reported that the application was both useful and usable for patients and caregivers alike. They

appreciated that the application was simple and easy to interact with, and that measures such as minimizing manual data entry by pre-populating personalized information into the application were taken to reduce the burden on users. They felt that navigation was generally intuitive, and appreciated that the text was large and easy to read on both the smartphone and tablet devices. These participants also reported that the application was visually appealing, and the icons were clear and intuitive, supporting visual understanding. One participant noted that the combination of these factors made it so the application would likely be easier to use than current paper-based approaches, even for older adult users.

The participants felt that overall the application met their needs and expectations as a caregiver for this patient population, and highlighted several features that they felt to be especially valuable. Many of these overlapped with those highlight by the patient participants, however, several unique findings were identified and discussed below.

Shared Access: Having shared access to this application was valued by all three of the caregiver participants, whether it be for supporting patients in tracking and managing health information and care activities, or for accessing the features, information, and resources for their own knowledge and use. Caregiver 3 described how they had taken on an active role in different care and management activities over the years, and felt that shared access to the application would facilitate many of these activities and responsibilities, and allow them to provide additional support for the patient. Caregiver 1 noted that brain tumor patients often experience decline in cognitive abilities and overall health status over time and need increased support from caregivers in tracking and managing health information. This participant felt that allowing both users to access to the features and functionalities, and sharing information and responsibilities between these users to was very beneficial for ensuring that data was captured and maintained over time. This participant also appreciated that users could grant access to multiple caregivers, as caregiving responsibilities may be shared between individuals or family members at times, especially as the patient becomes no longer able to care for themselves.

My Medications: Because medications and medication schedules are often complex for patients with primary brain tumors, caregivers frequently take on responsibilities related to managing medications and medication information alongside of or in place of these patients. As such, these

participants were greatly interested in the My Medications feature. They felt that the ability to simplify activities such as reminding patients to take medications or requesting refills was incredibly helpful. Caregiver 1 appreciated that personalized medication information was already populated into the application, minimizing the need to manually enter data and further simplifying medication management tasks and responsibilities. This participant also enjoyed that users could easily add new medications, vitamins, or supplements to their medication lists, and that side effect lists and reminders would automatically update with the corresponding information, once again simplifying the process while allowing users to maintain a more accurate and up-to-date list of medications.

Symptom Tracking: All three caregiver participants reported that Symptom Tracking was one of the features they appreciated most, nothing that it would help with organization, understanding, and communication of health, symptom, and side effect information. They felt that storing information as tracked data would be easier to access during clinic visits, meaning that it would be less likely to be forgotten or overlooked in their notes. All three participants appreciated the overall structure and techniques used for capturing data surrounding the individual symptoms and side effects, noting especially the use of images to indicate the location or body parts affected by the symptom of interest, and felt that the information elicited was appropriately thorough without being overwhelming. Caregiver 1 also appreciated the option to add notes alongside symptom data entry, and that there were no required fields, meaning that users could contribute additional information they felt relevant, while not getting hung up when something was not applicable.

My Questions and Notes: The caregiver participants also appreciated the My Questions and Notes feature. Caregiver 1 appreciated being able to record notes over time to help keep track of information regarding the patient they cared for. Similarly, Caregiver 2 appreciated that because questions could be transmitted to clinicians ahead of appointments, so even if they had forgotten to bring something up, the clinician would have access to their question list and know the questions and concerns to be addressed. Overall, these participants felt that preparing these questions and notes, and transmitting them alongside tracked data would lead to more productive dialog in the clinic.

5.3 Clinician Findings

Finally, three neuro-oncology clinicians took part in the evaluation, with two having participated in the previous interview studies, while one was new to this research. Overall, the clinician participants reported that the application provided features, functionalities, information, and support that could be greatly beneficial for patients with primary brain tumors. The participants felt that this application covered the content that they would expect from a self-tracking application designed for this patient population, and captured the information they are interested in eliciting from these patients in a much more reliable and concrete manner. They felt that the application would provide access to more information from patients' day to day lives than they would have otherwise, and would further facilitate patient-clinician communication.

Two of the three clinician participants felt that the application was clean, visually pleasing, user friendly, and easy to use. They felt that the amount of text was appropriate for conveying information without being overwhelming, and reported that the information and features were well organized, and that navigation was intuitive. The third participant found the application to be generally text heavy, and reported minor concerns involving navigation, however, all three participants agreed that the application provided features and functionalities that would benefit and support patients as users, and provide clinicians with valuable data to support patient care and decision-making activities.

Similar to the previous two participant groups, the clinician participants identified several features and functionalities that they felt were particularly beneficial, many of which overlapped with the findings and sentiments of the previous participants. For example, the clinician participants noted that contact information was consolidated and easy to access through My Care Team, and felt that including this information alongside clinician images and titles would help patients to remember who their clinicians were, and what they did. They also agreed that My Questions and Notes would likely help patients to remember their questions and concerns during clinic visits, and suggested that having this integrated into the application may encourage users to write down questions in advance, and record the responses during visits. These participants also contributed new findings, as well as those relevant to their own roles and experiences, as highlighted below.

My Medications: All three clinician participants greatly valued and appreciated the My Medications feature, describing benefits for patients and clinicians alike. In addition to the benefits previously described by patient and caregiver participants, these participants felt that the My Medications feature would help to provide clinicians with a current list of medications from the patient perspective, noting that this would be helpful for medication reconciliation, a routine clinical activity that involves ensuring that the patient's medication list is as accurate and complete as possible, and that there is agreement between the patient and clinician regarding this information. Participants also noted that medication reminders would likely be helpful for patients in improving compliance, and at the same time, would support data capture surrounding medication habits in terms of how and when patients were taking certain medications. They felt that this, alongside symptom tracking data, could be used to identify correlations involving medication side effects, and could help to determine whether medications were working as intended for the patient, or if they would potentially benefit from a change in medication or dosage. They agreed that having actual data to analyze in these situations would be an improvement over current methods, which typically rely on the patient to recall and communicate this information to the best of their ability, and would likely allow for improved decision making and better patient care.

Symptom Tracking: All three clinicians felt that the Symptom Tracking feature would also be very helpful for patients, and provide clinicians with information to support overall understanding and to provide focus in communication and decision-making activities. They appreciated the content of what was being captured, and felt that this would be helpful for keeping track of symptom information, and for patients to be able to see how symptoms were changing over time. All three reported that tracking in this manner could facilitate more reliable and complete communication of symptom and side effect information, especially in terms of details related to onset, duration, and severity of symptoms and side effects. They felt that this information could be valuable in identifying correlations in health events, and understanding patterns and trends in symptoms. Clinician 2 emphasized that patients typically want to be able to provide this information to their clinicians but face challenges in doing so. This clinician reported that this application could be an ideal solution for supporting these patients, and provide an easy and convenient means to capture and communicate important health data.

Clinician 2 also described how this application could be very useful for providing better support and care for patients, even as they move towards end of life and as they are in hospice care. This participant described a scenario is which family caregivers could look at a symptom such as nausea and alert clinicians to changes such that the patient can be made more comfortable.

5.4 System Usability Scale Findings

Following the interview, participants were asked to complete a System Usability Scale (SUS) to provide further feedback on usability of the prototype. SUS scores were primarily used to capture an assessment of overall usability that would guide future decisions about the acceptability of the overall application, and the extent of usability issues that would need to be addressed going forward. The small number of participants in this study limits the ability to draw significant conclusions from the data, especially at the level of participant type, however, these scores were highly informative towards understanding current perceptions of usability, and can be used as a benchmark in future design iterations.

Interpretation of SUS Findings

Although there is no official standard for interpreting the total scores of these assessments, several researchers have proposed scales for correlating SUS scores with more familiar metrics of success and acceptability. In a series of works over the greater part of a decade, Bangor, Kortum, and Miller developed scales for interpreting SUS results and determining acceptability of products and systems. These researchers noted a natural tendency to associate SUS scores with familiar university grading scales in which a score in the 90s would be considered an A grade, a score in the 80s a B, and so on, and sought to determine whether it was possible to map this type of association and other correlations such as adjective ratings (worst imaginable, poor, ok, good, excellent, best imaginable), and acceptability ranges (not acceptable, low marginal, high marginal, acceptable) to SUS scores to aid in interpretation and communication of results [Bangor 2008, Bangor 2009]. They found that there was in fact close correlation between each of these metrics, and that any score over 70 would likely be acceptable and considered good; scores falling around 85 would be considered excellent and assigned a B grade, and anything between low 90s and 100 would be fall into the category of ‘best imaginable.’

The overall average SUS score in this study was 84.4, suggesting that the application would be considered acceptable and described as excellent. Patient and Caregiver average SUS scores were 87.5 and 89.2, respectively, also suggesting a usable product at the higher end of the excellent range. Clinician participant scores were considerably lower, falling at 76.7, suggesting that the application is acceptable, but likely has usability issues that need to be addressed (**Table 6**). This result was highly skewed by the ratings of a single participant, further suggesting that additional participants would be necessary if statistically significant statements about usability were required.

Next, acknowledging that prior exposure to the application concept or components by interview and design group participants may have resulted in biases [McLellan 2012], I also looked at the scores for the participants who were not previously involved in this research. These participants contributed a lower average SUS score than the other groups, falling into a range indicative of potentially major usability issues. The range of scores from these participants indicates that some were highly satisfied, while others perceived major issues and challenges (**Table 6**). It is important to recognize that with only three participants, drawing statistically significant conclusions from this data is impossible. Rather, because these scores were varied, it may be worthwhile to attempt to recruit a larger number of participants who were not previously familiar with this research in design and evaluation studies going forward.

Table 6. System Usability Scores

	Average	**Range**	**New User**
Patient Participants	87.5	(62.5 – 100)	62.5
Caregiver Participants	89.2	(77.5 – 97.5)	92.5
Clinician Participants	76.7	(45-97.5)	45
All Participants	84.4	(45-100)	
New Participants	66.7	(45-92.5)	--
Prior Participants	93.3	(77.5 – 100)	--

Although individual questions are not intended to be assessed as meaningful statements regarding usability on their own, the ratings for these questions did help to provide some clarity and understanding into the overall scores, and further validated findings from the concluding

semi-structured interviews. For example, eight of the nine participants reported that they agreed or strongly agreed that they would like to use this system frequently, and that they felt confident using it. The participants did not find the system to be cumbersome or overly complex, and felt that it was easy to use. Eight of the nine participants felt that the various functions of the application were well integrated, and that issues with inconsistency were minimal. These findings were not only encouraging, but were largely in line with researcher observations and interview findings, as described in the following sections of this chapter.

Recent work has also suggested that two questions within this scale can be used to assess learnability [Lewis 2009]. In the first of these questions, all participants reported that they disagreed or strongly disagreed with the statement "I think I would need the support of a technical personal to be able to use this system." In the second, "I needed to learn a lot of things before I could get going with this system," seven of the nine participants disagreed or strongly disagreed, while one was neutral, and one patient participant felt strongly that they would need to learn a lot before being able to use the application. As learning new systems and technologies can be a major challenge for patients with primary brain tumors, these results would need to be taken into consideration for future design, development, and implementation.

6. Discussion

6.1 Benefits in Care, Management, Communication and Decision Making

One of the requirements highlighted by previous interview participants in Chapters 3 and 4 was that in order to be adopted, any future system would have to provide clear benefit to the users. This concern was primarily expressed by clinician participants, as they worried that asking patients to capture data without providing benefit in return could present additional burden on already overwhelmed patients, and would likely result in lack of adoption. As such, I explored perceptions of benefit associated with the application through semi-structured interviews with each of the participants.

The patient participants felt that using the application to track and manage health information provided several major benefits. These participants saw great benefit in supporting their own understanding and management of medications, symptoms, side effects, and other health information. Many patients with primary brain tumors will experience temporary or lasting

deficits involving memory due to the disease, or as consequences of the medications and treatments they are on. These participants noted that tracking and recording information in real-time would reduce the need for memory, as would the use of medication, tracking, appointment, and refill reminders. They also felt that having access to the information, features, and functionalities included in the application would help to satisfy information needs, and simplify many of the activities and responsibilities they were taking on. Two participants discussed how they had developed their own methods for managing information and responsibilities related to their disease and treatment process over time, but felt that having access to this application from the beginning would have been very helpful and saved them a great deal of trouble and stress.

The patient participants also described benefits surrounding communication, both in terms of knowing how to reach care team members, and in being able to share questions and tracked data with clinicians and others involved in their care. They noted that tracking within the application would help with organization and ensuring that information was available during clinic visits. The participants felt that this would not only support communication and improved understanding and management of information and their overall health condition, but would also be beneficial for patients and clinicians alike in decision-making activities. These participants did not any negative implications of the application, or that tracking or using the application would place additional burden on themselves as users or patients.

In addition to the benefits afforded to patient users, the caregiver participants also identified several benefits regarding this application and their own needs and expectations. For these participants, the biggest benefits included the fact that the application simplified many care and management activities, and that the features, functionalities, and information were consolidated into a single application that could be accessed by multiple users. One caregiver emphasized that providing information, resources, and support in a single concise application was a major benefit for patients and caregivers, especially early on as they worked to understand information surrounding the disease and treatment options and learn unfamiliar terminology. This caregiver explained that when the patient they cared for was originally diagnosed, they were unable to find a single resource that provided the information, support, and guidance they needed for understanding and navigating the brain cancer diagnosis and treatment process. This participant felt that the application would simplify the process of finding information and resources,

reducing the demands and anxieties that patients and caregivers face during that time. The caregiver participants also appreciated that the application could easily support sharing of responsibilities and allow caregivers to support patients in managing medications, health information, and care activities. They also appreciated that the application was well integrated; one caregiver noted that side effect information and reminder functionalities were automatically populated when new medications were added, further helping to simplify and support management activities for both patient and caregiver users.

Similar to the patient participants, the caregiver participants also discussed benefits involving communication, noting that the application would likely help with organization of information, improve reporting, and ensure that symptoms, side effects, questions, and concerns were communicated and addressed during clinic visits. They felt that tracking health data and recording questions through the application would likely lead to more productive conversations in the clinic, especially given the often limited amount of time they have to meet with clinicians. One caregiver added that being able to capture and consolidate information from multiple sources including nursing home staff and other family members acting as co-caregivers within the application would also be greatly beneficial to communication and patient care. In this case, the participant felt that gathering the information, either directly or indirectly (e.g. entering information from nursing home medical notes and staff reports), would help this caregiver to better answer questions in during appointments as the patient they cared for was typically not able to answer for themselves due to the impact of the disease and treatments over time.

Finally, the clinician participants contributed their perceptions towards patient and clinician benefits associated with the application. In line with the previous participant groups, these participants also felt that patients would likely appreciate and benefit from the fact that the data, features and functionalities were consolidated into a single application. They also noted that this application would help reduce reliance on memory for many, and felt that having this application would not only encourage patients to track and record information, notes, and questions as they came up between visits, but would also provide them with a means to do so, addressing a challenges noted by clinician participants in the previous interview study. In turn, they felt that this would help patients with better organizing, managing, and communicating information about what was happening between visits, which would be helpful for patients and clinicians alike.

These participants also acknowledged benefits for clinicians as a result of patient and caregiver use of the application. These benefits primarily centered around the presentation and availability of patient-reported data that this application would provide. They felt that tracking symptoms and medication habits in the application would provide access to information currently not available or accessible through current methods. Participants reported that this would be informative for understanding symptoms, identifying correlations, and supporting medication decision-making, especially surrounding nausea, pain, and steroid medications, by providing more accurate and thorough data surrounding symptom or side effect onset, severity, duration, and possible contributing factors. They also felt that having the patient-reported information captured and communicated through the application would help to guide conversations and focus attention and decision-making in clinic visits, and that the combined effects would lead to better patient care.

6.2 Interest and Ability to Use and Interact with the Application

In the previous interview studies (Chapter 3, Chapter 4), there was also discussion regarding patient interest and ability to take part in patient-driven health tracking activities. The majority of the patient, caregiver, and clinician participants felt that many patients would be both interested and able to take part, however, they also acknowledged barriers and concerns. In these studies, patient and caregiver participants mainly cited concerns involving ease of use and convenience, especially compared to current paper-based approaches. The clinician participants reported that neurocognitive and motor impairments as well as decline in health condition over time may make it difficult for these patients to take part in self-tracking or assessment, and that certain patients may also face challenges when learning and interacting with technologies. Although many of these challenges are an unfortunate consequence of the disease, interview participants suggested that creating systems that were simple, intuitive, and easy to use would increase the likelihood that patients were interested and able to take part. As such, I sought to further investigate these aspects of usability to determine whether participants felt that future patients and caregivers would be interested and able to use the application, and identify ways in which they could be further addressed through design.

In these interviews, the patient participants reported that they believed most patients would be both interested in using the application, and able to do so in a meaningful manner. They did note, however, that patients may experience challenges at certain times, especially immediately after surgery, and in the early stages of the disease and treatment process. At the same time, they felt that the application would provide a great deal of benefit in terms of features, functionalities, and content for patients during this time period. Patient 3, for example, described being incredibly overwhelmed and traumatized early on. Although this participant acknowledged that they may not have been in a state to fully use the application for themselves at that point, they felt that it provided information they would have been very interested in, and that their caregivers definitely would have used it as a part of their care and management process until they were better able to take on more of these activities and responsibilities. This further reinforced the importance and necessity of including shared access for caregivers, and the importance of providing features and information to support caregivers as major users of the application as well. One participant also expressed concerns regarding how quickly patients would be able to learn to use the system in order to take part in these activities, noting that many patients with primary brain tumors struggle with learning as a consequence of the disease and treatment process. These concerns primarily centered around technology use, especially for patients who may not have prior experience interacting with smartphone or tablet technologies and health applications.

Aspects of patient interest and ability were also discussed with caregiver participants. Although minimal overall, the caregiver participants expressed greater concern related to patient interest and ability to learn and interact with the application. Much of this concern was attributed to the disease and treatments, and the associated challenges they had witnessed the patient face, rather than issues with the design of the application. These participants felt that most patients would be interested and able to use the application, but also noted that there may be times when patients are unable to interact with the application for themselves. Similar to the patient participants, caregiver participants felt that application use would be most challenging during the first few weeks following diagnosis as patients are processing the shock, and faced with medications, surgery and other harsh treatments. Caregiver 3 was especially concerned, noting that the patient they cared for faced numerous struggles, even in day to day activities, and wondered whether learning to use new tools or technologies would be too overwhelming or challenging. Despite

initial struggles, this caregiver felt that patients would eventually be interested and able to use the application without difficulty.

Finally, looking to the clinician perspective, all three clinicians believed that many patients would be willing, interested, and able to use the application. They felt that a fully functional version of the application would be simple enough for these patients to interact with, and that the features and functionalities would be both beneficial and appealing. The clinicians felt that decisions surrounding application adoption and use would primarily depend on the individual patient and their preferences. Interestingly, all three participants cited age as the foremost factor in determining whether patients would be interested in using the application, based on the assumption that older adults may be less comfortable or familiar with using technology and mobile devices. This represented a major change from the initial clinician interview findings (Chapter 3), where previously cited concerns centered around neurocognitive and physical deficits, decline in cognitive and functional abilities, and disease-related challenges impacting patient ability to learn new systems and technologies. Additionally, despite being a major theme in the previous interviews, none expressed concerns regarding burden associated with the application and asking patients to track and record health information between visits.

Despite previous hesitations from each of the participant groups, concerns regarding interest and ability were minimal in this study, especially when it came to the impact of neurocognitive and motor deficits and declines. One interesting finding was that many of the concerns in the current study involved age as well as the impact of disease and treatment early in the process, primarily as patients are recovering from surgery. In contrast, disease-related factors, and deficits and impairments in the late stages of the disease, were no longer cited as a major concern or perceived barrier for these participants. It is likely that a combination of perceived ease of use and benefit toward patient users contributed to minimizing these concerns, as did provisions for shared caregiver access as it likely did not matter who was entering the data.

6.3 Application Adoption and Integration into Care Activities and Workflows

In the preliminary interview studies, there was some concern about whether patients and caregivers would be comfortable adopting new methods and approaches to recording and managing health information as a part of their care process. The majority of the participants had

developed their own methods and techniques over time, most of which relied on memory or paper-based approaches, and reported that they may be reluctant to transition to a different system, despite the fact that current approaches may have weaknesses. Additionally, the fact that technology use in these activities was very limited, contributed addition concern towards adoption. As such, in the third component of these interviews, I sought to further investigate whether hesitations surrounding adoption remained for any of the participants, and discussed how participants envisioned integrating the application into their current care activities and workflows.

Looking first to the patient participants, all three patient participants reported that they would use this application as a part of their care process and in information management activities, and would recommend it to future patients. Patients 2 and 3 were confident, seeing immediate benefit for themselves, their caregivers, and clinicians. Patient 2 exclaimed that they wished the application had been available when they were initially diagnosed, as it would have made the process of managing, understanding, and communicating information much easier for them, especially compared to their current paper-based approach. Neither participant expressed concerns regarding adoption or integration into current care activities and information management processes. Patient 1, on the other hand, was initially uncertain as to whether they would be would use the application, mainly due to the demands involved in learning new systems and technologies. This participant was eventually able to identify ways in which the application could address challenges they were currently experiencing, and reported they would use it, especially if asked by a clinician.

Similarly, all three caregivers reported that they would use a fully functional version of this application for managing information and supporting care activities, and that they would recommend this application to future patients and caregivers. The participants were generally enthusiastic about their willingness to adopt the application, with one participant describing the various ways in which they would use it for preparing for an upcoming appointment. At the same time, the caregiver participants also contributed considerations surrounding adoption based on their own experiences. Caregiver 3 raised questions surrounding implementation, and when users would have access to the application. This participant had previously discussed challenges that the patient they cared for experienced following surgery and in the first weeks of treatment as

they struggled to recover from their craniotomy, and adjust to harsh medications and treatments. This participant explained that many patients have very little time between discovering they have a brain tumor and undergoing surgery, so the window for introducing the application prior to surgery when they may be better able to learn new systems and technologies, would likely be limited. At the same time, they acknowledged that patients and caregivers want and need information and resources immediately, suggesting that perhaps caregivers would be more perceptive to adoption during that time frame. Other concerns involved marketing and how patients and caregivers would know that this application existed. Caregiver 3 again pointed out that brain tumor patients and caregivers may not think to look to technology or health applications to meet these needs, and that in this incredibly small patient population "there is no word of mouth." This participant further suggested that unless clinicians or the literature were championing the application, adoption would likely suffer.

The clinician participants in this study were also impressed and satisfied with the application, and reported that they would consider recommending a fully functional version to interested patients and caregivers. Two of the clinician participants expressed great interest and excitement over the potential of this application, noting benefits for patients, caregivers, and clinicians alike, while the third was more reserved in their recommendations, mainly citing concerns surrounding patient preferences and current issues with usability and navigation of the application.

These clinicians felt that this application would be easy to integrate into current workflows. One clinician currently recommended a smartphone application for tracking symptoms with another patient population that they worked with, and envisioned using this application in the same way. This participant described that they would have patients download the application while in the clinic, instruct them to track and capture as much data as possible, and bring it with them to their next appointment to review and discuss. Another clinician felt that tracking using an application would not be very different from current paper-based approaches using notebooks, and that it would not impact workflows or how they interacted with patients. Overall, the clinicians had very few concerns about adoption and workflows, but did note that institutional policies may impact implementation of certain features and functionalities such as medication refill requests.

6.4 Usability Challenges and Recommendations for Features, Functionalities, and Navigation

In addition to the benefits and considerations regarding interest, ability, and implementation highlighted in the previous section, there were also areas where participants outlined challenges involving navigation and usability, and identified opportunities to improve upon current features and functionalities to better meet the needs and interests of these users.

Navigation and Usability Challenges

The majority of the participants felt that overall, the application was successful in meeting the requirements for creating an application that is easy to use, and provides for a simple and intuitive user experience. They appreciated that typing and manual data entry were minimized by pre-populating patient information into the application, and through to use of images, slider bars, and checkboxes in Symptom Tracking, for example. There were several places, however, where participants identified remaining usability and navigation issues, and opportunities for improvement.

The participants identified instances where navigation and interaction with the application was not intuitive. Several participants did not initially realize that they could scroll for more information or features, and felt that the scroll bar was not visible enough. Three of the participants also wanted back buttons or arrows included in the design. The omission of these navigation options was an intentional design decision, as participants in the Participatory Design sessions emphasized the importance of clean interfaces and minimizing unnecessary text, information, or features on the screen. With one erroneous exception, an option to return to the previous screen was available in all instances where a user had navigated more than one click away from the Home screen, however, these were not labelled with the traditional Back or arrow that some users may have been familiar with or looking for [**e.g. see Figure 2c, Figure 6c**]. Device specific considerations also contributed to the decision to not incorporate back buttons into each of the interfaces. Android devices, including the smartphone used in this evaluation, traditionally have a back button built into the phone, whereas iOS devices, including the iPad tablet used in the study, do not. This meant that for one device, including a back button would be redundant, and for the other, it would add additional flexibility for navigation. It is likely that this would be easily resolved with minimal effort in future device specific design iterations.

There were also instances where terminology and organization of features and information was confusing for certain participants, detracting from overall usability. One major example of these issues involved the notes section on the individual clinician contact information pages within My Care Team (**Figure 7c**). This feature was initially intended as a place where users could make notes for themselves to support memory, however, several participants interpreted this as a way to send secure messages to their clinicians regarding questions or medication refills, similar to the functionality of a patient portal. In another example, two participants had difficulties distinguishing the difference in purpose between questions and notes. In the original design, notes were intended to be stored but not transmitted, whereas questions would be sent to care team members prior to scheduled appointments. Some of the confusion may have been related to terminology; Clinician 3 recommended having a 'Save' button for notes instead of 'Submit', as for this participant, 'Submit' conveyed a sense that the data was being transmitted.

In some cases, participants felt that factors initially identified as usability issues may have instead been the result of individual user preferences. For example, four of the nine participants noted that the organization individuals under My Care Team was confusing. This was initially raised during the Participatory Design workshops, but a consensus surrounding organization was not reached. Opinions once again varied, with some participants preferring including all individuals in one list, and others appreciating the current organization. In other cases, they felt that issues may be resolved given more time to interact with the application. In another example, none of the participants were able to find the Settings or Access and Sharing features in the navigation menu without guidance. Once shown, they agreed that this was in fact the proper location, despite the fact that they initially did not notice or think to check this menu. They did not want to change the location of these features, suggesting that they likely would have been discovered given additional time to interact with the application and explore the features and functionalities on their own. Instead, several participants suggested changing that name to My Account instead of Settings would be more intuitive.

Recommendations for Improving Navigation and Usability

These participants also provided recommendations for improving overall navigation and usability. Although several participants noted that many of the features and functionalities could be accessed in multiple ways (e.g. setting medication reminders from My Medications or My

Reminders, or adding symptoms and side effects to tracking lists from Symptom Tracking or My Medications), they felt that additional cross links to navigate between associated features could be helpful. For example, Caregiver 3 initially looked to My Calendar to capture information related to symptoms and side effects, as this was how the patient they cared for currently recorded that information. Others looked to My Calendar to see a visual representation of symptom frequency, further suggesting the need for a direct link between these two features. Another participant felt that being able to link directly from Symptom Tracking and My Medications to My Questions and Notes would be helpful, as users may want to record a question or note based on their experiences related to these subjects. Others felt that links to Resources and FAQ from My Medications would be helpful, providing a to link to relevant information on diets for specific chemotherapy regimens, for example. There were also suggestions to have Resources and FAQ linked to appointment reminders so that users could access information to prepare for upcoming appointments.

Two participants (one caregiver, one clinician) believed that further effort to minimize the number of clicks and amount of text presented within the application would be beneficial for improving navigation and overall usability. They felt that eliminating the need to scroll, and taking features that may not be as valuable or frequently used off of the home page would be beneficial in improving user experience and visual appeal. Because user needs, interests, and preferences may vary over time, allowing for customization in terms of the content and organization of features on the Home screen might be beneficial. Additionally, two of these participants suggested having a dashboard displaying important information, such reminders for upcoming appointments, medications, or tracking, as well an indicator for whether medications had been taken would be helpful. Other recommendations included the use of a calendar pop-up for selecting date information when entering symptom information retroactively, and including a quick method for selecting AM or PM when entering time information.

Opportunities for Improving Features and Functionalities

Finally, the participants provided several recommendations to improve upon current features and functionalities, based on the interests and needs of this patient population. Although the participants appreciated the medication reminders, they suggested that greater ability to customize these reminders was necessary. In this prototype, the number of reminders for a given

medication per day was based on the written prescription, however, participants noted that patients may take some medications on an as needed basis or may change the frequency of medications based on clinician recommendations or their own experiences over time.

Additionally, although many of the participants enjoyed the ability to choose which symptoms and side effects to include on their tracking list, participants suggested that either the application or clinicians could also provide recommendations or guidance on what symptoms and side effects patients may want to be aware of or capture data about, based on their treatments, medications, or disease status and location. Finally, although the participants appreciated the information and content that was currently included, one participant suggested that because this is a small patient population and finding reliable information and resources is often difficult, a mechanism for allowing users to submit recommendations surrounding information or resources that they found to be beneficial would be helpful for aggregating content from the larger community of users.

6.5 Future Development: Additional Features and Functionalities

Two of the features within this application, My Health Summary and My Calendar, were not fully developed in this prototype as time constraints during the participatory design workshops limited the amount of discussion and design work possible. My Health Summary was initially envisioned as the place where summaries of tracked data would be displayed, potentially alongside data imported from the patient's electronic medical record. During this evaluation, however, several participants felt that the My Calendar function would instead be an ideal place for consolidating and displaying tracked data and summaries. Participants felt that a calendar view and accompanying filters would provide a quick understanding of frequency of health events, and make it easy to see what happened in between appointments and milestones. They felt that attaching questions and notes to either the dates that they were captured on, or specific calendar events or appointments would make it so users did not have to go through each of the application features to ensure they had not overlooked or forgotten anything during appointments. This was especially relevant for questions about about symptoms and side effects, or medications. One caregiver also suggested that attached question lists to appointments would help to direct and focus questions, as often questions were intended for specific providers. Future iterations of design and evaluation would be necessary to determine how My Health Summary

should be revised, or whether it should be eliminated as the majority of the intended content was reportedly more valuable and accessible in My Calendar.

Additionally, the participants in this research were particularly interested in having tailored templates for each individual symptom and side effect being tracked as they felt this would simplify data entry, and help users to better identify and capture information that was truly relevant. In the current prototype, only a handful of symptom and side effect templates were fully built out and activated (**Figure 5**). This is an area where further research, design, and development are needed. Although the process of identifying relevant information and building out tailored templates for what is expected to be in excess of 60 different symptoms and side effects will take a significant amount of time going forward, the perceived benefits to users and stakeholders make this effort necessary and worthwhile.

7. Limitations

In considering these findings, it is important to acknowledge potential limitations involving the study participants. The fact that that six of the nine participants had prior involvement in the research that motivated and drove the design of this prototype may have lead to biases in their evaluations and likely furthered this motivation and desire to see it succeed. To lessen any associated biases and gather new perspective, three additional participants were recruited to take part in the study. Additionally, although only three individuals of each participant type took part in the evaluation study, the total number of participants was within the acceptable and recommended range for usability studies, and proved to be sufficient for capturing necessary feedback and critique regarding overall usability. Additional participants may have been valuable towards capturing further insights regarding patient interest and ability, especially from newly diagnosed patients or those in the later stages of the disease process, however, at this phase of the design and development process, it is unlikely that additional participants would have resulted in a significant increase in the number of usability issues identified.

Another potential limitation involved the fact that this study was conducted in a lab environment rather than as a deployment study, and that users only had 30-45 minutes to interact with the application. The lab environment allowed for easier data collection and convenience for the majority of participants, however, may have minimized the potential for distinguishing usability

and learnability issues. One participant acknowledged that although they were highly satisfied with the current application, they would likely be better able to identify and provide feedback on aspects that did not meet expectations if they had more time to interact with the application on their own. Given that this was a high-fidelity prototype that did not have the ability to store entered data, and considering the potential for cognitive impairments among participants, a longer term deployment evaluation at this level was not feasible. Going forward in the development process, however, more in-depth evaluations would be conducted.

8. Conclusions:

Throughout this evaluation, participants reported that the application was easy to use, and met their needs and expectations. They described benefits of the application towards support patients and caregivers, as well as those involving decision-making, communication, and patient care. Contrary to prior concerns, none of these participants saw tracking as a burden or overwhelming responsibility. They reported that it would like be easier to use and provide more benefit than paper-based approaches, especially in ensuring that information was available and accessible during clinic visits, and when it was needed most. They felt that the application would reduce the need for memory, a function that is often impaired by the disease and/or treatment process, and would simplify many care and information management activities for patients and caregivers alike. SUS scores revealed a largely acceptable product, with good and excellent ratings, but also room for improvement. Participants identified recommendations to improve overall user experience for this patient population, but reported that they would use this application in their own care and health management processes, and would recommend the application to future patients and caregivers.

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Chapter 7: Conclusions, Contributions, and Future Work

In this final chapter, I summarize the findings of this dissertation research, and highlight contributions of each study. I then discuss the overall successes and contributions this research, before introducing opportunities for future work.

1. Overview of Findings and Contributions

In this research, I conducted a series of studies aimed at understanding the needs, challenges, and experiences of patients with primary brain tumors and their caregivers in working alongside these individuals to design tools and technologies to better support interests and needs in this extremely challenging patient population.

In Chapter 1, I introduced background information as well as some of the current challenges, gaps in knowledge, and opportunities that motivated this dissertation research.

In Chapter 2, I worked to develop and outline my approach to engaging these individuals in design research. I presented an overview of relevant research, highlighting previous challenges, recommendations, and lessons learned from these studies, and discussed how these considerations were used in formulating my overall approach.

In Chapter 3, I conducted semi-structured interviews with neuro-oncology clinicians. Through this study, I expanded upon current knowledge regarding clinician perceptions of challenges and opportunities related to patient-reported data. I found that these clinicians used patient-reported data for a variety of purposes including patient care and decision-making, but felt that there were challenges associated with current methods for capturing and reporting of this information. Looking to the future, the majority of these participants felt that better methods for tracking and communicating patient-reported information would be beneficial; participants reported that data from patient-driven self-tracking and assessment activities could be beneficial for supporting patient care and decision making activities, and could also play a vital role in furthering research into understanding the impact of the disease and treatment process on these patients. At the same time, some reported concerns regarding patient interest and ability to take part in these activities,

as well as potential cognitive, physical, and emotional burdens and implications that may result from asking them to do so.

In Chapter 4, I engaged patients and caregivers in semi-structured interviews to capture their perceptions surrounding challenges, needs, and experiences throughout diagnosis, treatment, and follow-up. In this study, participants discussed a wide range of challenges and uncertainties related to understanding and managing symptoms, side effects, medications, and health information. They also described lasting frustrations and unmet information needs when it came to knowing what to expect, especially in terms of the impact of the disease and treatment process on functional abilities, and prognosis. These participants largely felt that a lack of currently available data was likely a major contributing factor toward these uncertainties. In looking at current behaviors, I found that current tracking and information management activities were typically informal in nature, and did not involve the use of technology. Despite satisfaction with current methods and approaches, the vast majority of these participants saw great value in structured technology-based self-tracking and management activities. They identified benefits toward improving their own understanding of their condition, as well as organization of information, and felt that tracking in this manner would provide more complete, reliable, and trustworthy information for clinicians to work with in care and decision-making activities. These participants were also highly motivated by the potential to capture data so that it could be made available to clinicians so as to decrease uncertainties, and provide better information surrounding impact and prognosis for future patients and caregivers. These findings motivated the continuation of this work into the design phase.

In Chapter 5, I was able to successfully engage patient and caregiver participants in participatory design activities to design a system to support patients and their caregivers in tracking, understanding, managing, and communication health information throughout diagnosis, treatment, and follow-up. In these workshops, we reviewed findings from the previous interview study, and worked through a series of design activities, eventually creating a medium-fidelity prototype of a smartphone and tablet application Not only did this uncover even more knowledge about patient and caregiver needs and experiences, it also showed that given proper planning and consideration into modifications, these individuals can participate and take on an active and meaningful role in design research.

Finally, in the concluding study of this dissertation research, I engaged patients, caregivers, and clinicians in an evaluation of a high-fidelity prototype that I developed based on findings and design work from these previous studies. After interacting with the application, the majority of the participants provided positive remarks, noting few major issues with usability. The patient and caregiver participants felt that the application met their needs and expectations, and reported very few concerns regarding future patient interest and ability. Despite the fact that the majority of these participants were not current tracking and recording information regarding symptoms, or using technology as a part of current care and information management activities, they saw great benefit in using this application to do so. The clinician participants were also welcoming of the application, and felt that many of patients and their caregivers would be able to use it, and that clinicians could easily incorporate it into current workflows. All participants reported that they would use a fully functional version of the application, and would recommend it to future patients and caregivers.

In addition to creating a high-fidelity prototype of an application to support these users, and the individual conclusions and contributions of each of these studies, there are also methodological contributions that arise from this overall dissertation research. Prior to this study, patient participation in this research at this level has been minimal for this patient population. Through this work, I was able to show that it is not only possible to engage patients with primary brain tumors, a condition characterized by severe neurocognitive symptoms and side effects as well as overall poor prognosis, in research and design in a meaningful manner, but that participants could even perceive benefit from doing so. By taking the approach of carefully planning and analyzing assumptions, I experienced very few major challenges in conducting this work. These methods and my overall approach would likely be generalizable to other similar patient populations, including those with neurodegenerative diseases.

2. Future Work

Throughout the course of this research, I identified several potential extensions of this work. First, as I am concluding this current study at the level of a high-fidelity prototype, there is still further design and development work that must be completed before this application can be implemented in the clinic. Once the fully functional application is developed, additional

evaluation and deployment studies with a larger number of participants will be necessary. Researchers conducting these studies should make a dedicated effort at recruiting participants to represent a wider range of demographic considerations (e.g. age, race), and should seek participants representing different types and levels neurocognitive deficits and impairments, as well as individuals who are not currently familiar or comfortable interacting with these technologies. Further, longer-term deployment studies could also be helpful toward understanding how factors relating to usability as well as patient interest and ability to interact with health applications change over time. For example, participants in the interview studies cited concerns about the impact of these impairments and deficits towards end of life, whereas those in the evaluation study felt more strongly about challenges immediately following diagnosis and surgery. This would likely also reveal information and insights into caregiver roles and transitions in responsibilities in this patient population.

Prior to developing the fully functional application, however, there is still much to learn about how different users would like to view and interact with tracked data. This was briefly discussed in the clinician interviews and again in the design sessions, however, in-depth research of visualization needs and preferences for these users would be beneficial going forward. For example, researchers could explore how neurocognitive impairments impact user abilities to understand and interact with different types of data visualizations. There is also an opportunity to examine how patient preferences for viewing trends in their tracked data vary over time, especially as symptoms as well as neurocognitive and functional abilities decline. It would be interesting to know whether emotional considerations associated with seeing such declines would lead to depression or decreased motivation to track and capture data, and whether changes in visualization strategies may be able to mitigate these circumstances. From the clinician standpoint, it could also be interesting to explore whether preferences vary across clinical specialties, or whether they different when seeing patients at weekly visits during radiation therapy, or in intervals of several weeks or months during chemotherapy and follow-up.

Finally, there is also great opportunity and potential in exploring the value of patient-reported data towards increasing knowledge, and reducing some of the challenges and uncertainties that patients and their caregivers in this population face, especially those highlighted in Chapter 4 involving understanding and anticipating the impact of the disease and treatment process, and

better estimating prognosis. The research questions and opportunities resulting from having access to this additional source of data are worthy of intense instigation, and could potentially lead to significant findings about the overall patient experience, and future design and development of interventions to support these individuals.

3. Closing Remarks

Throughout this research I sought to build a better understanding of the needs, challenges, and experiences of patients with primary brain tumors and their caregivers in working towards designing tools and technologies to support these individuals in tracking, understanding, managing, and communicating health information throughout treatment and follow-up. This is a patient population that faces numerous challenges in health and daily life, and is burdened heavily by uncertain prognoses and severe symptoms and side effects. Although participants were not currently using technology-based systems to support tracking and managing of health information, they were optimistic about the potential for supporting their own needs, as well as those of future patients and caregivers. Through this work, I was not only able to develop and evaluate a high-fidelity prototype of an application designed to support patients and caregivers, I was also able to formulate an approach, and meaningfully engage these individuals throughout the research and design process. It is my hope that this work has not only made important steps towards ensuring that carefully designed tools and technologies are made available to these individuals, but will also encourage researchers across health and design to take on similar endeavors in working with and for complex and challenging populations, providing these individuals with an opportunity to take part in and contribute to meaningful and valuable work.

Appendix Materials

Appendix A. Patient and Caregiver Interview Study: Patient Demographic Survey Questions

Patient Participant Demographic, Health and Technology Use Survey

This information is being collected for research purposes only. Individual responses will not be linked to your identity in any way, and all data will be properly de-identified prior to use in any future presentation or publication. Answer the questions to the best of your ability. If you do not wish to answer a specific question, simply leave it blank.

Demographic Questions:

Age:

Gender:

Race:

Highest level of education (circle):

12th grade or less, no diploma
GED or High school diploma
Some college
Associate's Degree
Bachelor's Degree
Graduate or Professional degree

Occupation (or former occupation):

Diagnosis:

Time since diagnosis (months):

Are you currently undergoing treatment? Yes No

Treatment history (circle): Radiation Therapy Chemotherapy Surgery Other:

Health and Technology Use[1]:

1. Do you use the internet, at least occasionally?

Yes No

2. Do you access the internet on a cell phone, tablet, or other mobile handheld device, at least occasionally?

Yes No

3. Some cell phones are called "Smartphones" because of certain features they have.
Is your cell phone a Smartphone, such as an iPhone, Android, Blackberry, or Windows phone?

Yes No I do not have a cell phone

4. What kind of cell phone do you own or use on a regular basis?

iPhone Android Blackberry Windows phone

Other:

5. Do you ever use your cell phone to (circle all that apply):

Send or receive email Send or receive text messages

Take a picture Access the internet

Look for health or medical information online

Check your bank account balance or do any online banking

6. On your cell phone, do you have any software applications or "apps" that help you to track or manage your health?

Yes No*

**Alternatively, if you have a tablet with health apps installed, please indicate the type of tablet, and answer the questions below based on that device. Otherwise, you may skip questions 7-9.*

7. What kind of health apps do you currently have on your phone? (Circle all that apply)

Exercise, fitness, pedometer or heart rate monitoring

Diet, food, or calorie counter

Weight

Period or menstrual cycle

Blood pressure

WebMD

Pregnancy

Blood sugar or diabetes

Medication management (tracking, alerts, etc.)

Mood

Sleep

Other:

8.* Approximately how many health apps do you have on your phone?

0 – I do not currently have any health apps on my phone

1-3

4-6

7-10

11 +

9. *How often do you use these health apps?

Several times a day

Daily

Weekly

Once or twice a month

Less than once a month

Other:

10. Now thinking about your overall health, do you keep track of your weight, diet, or exercise routine?

Yes No

11. Do you track health indicators or symptoms such as blood pressure, blood sugar, sleep patterns, or headaches?

Yes No

12. Thinking about the health indicator you pay the most attention to, how do you keep track of changes? (Circle all that apply)

On paper, like a notebook or a journal

Using a computer program, like a spreadsheet

Using a website or other online tool

With an app or other tool on your phone or mobile device

Using a medical device, like a glucose meter

Keep track just in your head

Other:

13. How often do you update your records or notes about this health indicator?

Several times a day

Daily

Weekly

Once or twice a month

Less than once a month

Other:

14. Do you share this information with your doctor or anyone else? If yes, who?

Yes, I share this information with: Family/Friend Health Professional

Other:

No, I do not share this information with others

15. We'd like you know if you've looked for information online about certain health or medical issues, either for yourself or for someone else. Specifically, in the last 12 months, have you ever looked online for information about (circle all that apply):

A specific disease or medical problem

A certain medical treatment or procedure

Health insurance, including private insurance, Medicare or Medicaid

Pregnancy or childbirth

Food safety or recalls

Drug safety or recalls

Medical test results

How to lose weight or how to control your weight

How to reduce your healthcare costs

Caring for an aging relative or friend

A drug you saw advertised

Any other health issues

16. Thinking about the last time you went online for health or medical information, how did you begin looking?

At a search engine like Google, Bing or Yahoo

At a site that specializes in health information like WebMD

At a more general site like Wikipedia that contains information on all kinds of topics

At a social network site like Facebook

Other:

17. Did you to talk with a medical professional about what you found online?

Yes No

18. Thinking about the past 12 months, have you posted a health-related question online or shared your own personal health experiences online in any way?

Yes No

19. The last time you posted or shared health material online, did you post it somewhere specifically to get feedback from a health professional, or did you post it somewhere it would be read by a more general audience of friends or other internet users?

Health professional

More general audience

Other:

Caregiver Participant Demographic, Health and Technology Use Survey

This information is being collected for research purposes only. Individual responses will not be linked to your identity in any way, and all data will be properly de-identified prior to its use in any future presentation or publication. Answer the questions to the best of your ability. If you do not wish to answer a specific question, simply leave it blank.

Demographic Questions:

Age:

Gender:

Race:

Highest level of education (circle):

12^{th} grade or less, no diploma
GED or High school diploma
Some college
Associate's Degree
Bachelor's Degree
Graduate or Professional degree
Other:

Occupation (or former occupation):

Health and Technology Use[1]:

1. Do you use the internet, at least occasionally?

Yes No

2. Do you access the internet on a cell phone, tablet, or other mobile handheld device, at least occasionally?

Yes No

3. Some cell phones are called "Smartphones" because of certain features they have.
Is your cell phone a Smartphone, such as an iPhone, Android, Blackberry, or Windows phone?

Yes No I do not have a cell phone*

**Note, if you do not have a cell phone, please skip questions 4-8. Alternatively, if you have a tablet device on which you have installed health tracking apps, please indicate which device, and answer the questions accordingly.*

4. What kind of cell phone do you own or use on a regular basis?

iPhone Android Blackberry Windows phone
Other:

5. On your cell phone, do you have any software applications or "apps" that help you to track or manage your health?

Yes No

6. What kind of health apps do you currently have on your phone?

Exercise, fitness, pedometer or heart rate monitoring
Diet, food, or calorie counter
Weight
Period or menstrual cycle
Blood pressure
WebMD
Pregnancy
Blood sugar or diabetes
Medication management (tracking, alerts, etc.)
Mood
Sleep
Other:

7.* Approximately how many health apps do you have on your phone?

0 – I do not currently have any health apps on my phone

1-3

4-6

7-10

11 +

8. *How often do you use these health apps?

Several times a day

Daily

Weekly

Once or twice a month

Less than once a month

Other:

9. Changing topics, in general, how would you rate you own health?

Excellent Good Only Fair Poor

10. Thinking about your overall health, do you keep track of your weight, diet, or exercise routine?

Yes No

11. Do you track health indicators or symptoms such as blood pressure, blood sugar, sleep patterns, or headaches?

Yes No

12. Thinking about the health indicator you pay the most attention to, how do you keep track of changes?

On paper, like a notebook or a journal

Using a computer program, like a spreadsheet

Using a website or other online tool

With an app or other tool on your phone or mobile device

Using a medical device, like a glucose meter

Keep track just in your head

Other:

13. How often do you update your records or notes about this health indicator?

Several times a day

Daily

Weekly

Once or twice a month

Less than once a month

Other:

14. Do you share this information with your doctor or anyone else? If yes, who?

Yes, I share with: Family/Friends Health Professionals Other:

No, I do not share this information

15. In the past 12 months, have you provided unpaid care to an adult relative or friend to help them take care of themselves? Unpaid care may include help with personal needs or household chores, managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing.

Yes No

16. Do you manage medication for the person you help care for, such as checking to be sure they are taken properly or refilling prescriptions?

Yes No

17. When managing their medication, do you use any online or mobile tools, such as websites or apps, to research or keep track of medications?

Yes No

18. Do you keep track of any health indicators or symptoms for the person you care for?

Yes No

19. Thinking about the health indicator you pay the most attention to for the person you care for, how do you keep track of changes?

On paper, like a notebook or a journal

Using a computer program, like a spreadsheet

Using a website or other online tool

With an app or other tool on your phone or mobile device

Using a medical device, like a glucose meter

Keep track just in your head

Other:

20. How often do you update records/notes about this health indicator in the person you care for?

Several times a day

Daily

Weekly

Once or twice a month

Less than once a month

Other:

21. Overall, would you say the internet has been helpful or not helpful in your ability to provide care and support for the person you are taking care of?

Helpful Not helpful

22. And overall, has the internet been helpful or not helpful in your ability to cope with the stress of being a caregiver?

Helpful Not helpful

[1]Select Health and Technology Use questions adapted from:

Health Tracking Survey 2012. Revised Topline 11/27/2012. Princeton Survey Research Associates International for the Pew Research Center's Internet & American Life Project.

Appendix B. Participatory Design Study Materials

Journey Mapping Instructions

Journey Mapping Activity (15 minutes)

The purpose of this activity is to create a map or timeline of your journey throughout treatment and follow-up. Use the materials provided to create a representation of your journey. Think about major milestones and experiences involved in the process. You can choose to focus on a specific aspect of your journey, such as the radiation treatment process, or the overall picture. After 10 minutes of working on these, we will meet back up again and share these journeys.

Materials:
Paper
Markers
Stamps

Persona Creation Instructions

Persona Creation Activity (15 minutes)

Now that we have talked (or thought) about your individual journeys, we are going to make a single character that we will use to represent the user we are designing for going forward. Use the template provided, or your own paper, to fill in the details about this user.

Consider the following:
- Name, age, gender
- Family and friends
- Profession and hobbies
- Comfort with technology

Disease related:
- Diagnosis
- Time since diagnosis (newly diagnosed)
- Symptoms and side effects experienced
- Treatment details

Materials:
Paper/Template
Markers
Magazines
Scissors
Tape/Glue

Low-Fidelity Prototyping Instructions

Low-Fidelity Prototyping (45 minutes)

Now that we have discussed some of the themes coming out of the interviews and focus groups, we are going to begin to develop ideas for solutions to some of these challenges. A scenario will be provided to help identify the goal of the design. Using the paper and supplies in front of you, create a representation of your 'solution'.

Procedure:
1. Split into 2 groups
2. Individual Design: Take 10 minutes to come up with 3 designs on your own – don't worry about detail or being perfect, the point is to be quick and come up with many ideas
3. Partner Share: Take 10 minutes to share with partner – present each idea and give feedback
4. Individual Design: Design 1 or 2 more each, starting from scratch or building off of previous designs and conversations
5. Group share: In the last 15 minutes, present your designs to the group for feedback and discussion

Materials:
Paper
Markers
Scissors
Tape/Glue
Stamps
Magazines

Scenario

Scenario:

[PERSONA NAME] has recently been diagnosed with [DIAGNOSIS]. [HE/SHE] is about to start treatment

Your goal is to design a system to support patients like [**INSERT NAME**] in tracking, understanding, and communication symptom information throughout treatment and follow-up.

Details:
- Include as many features as you would like
- Broaden the scope to add more features and functionality that you feel is useful and important for future users
- Focus on one specific aspect or the whole system
- The system does not have to be a smartphone application – it can take any form
- Be creative! Don't be critical of your own work or of others

Optional Homework

Optional Homework Assignment

Now that we have completed the first design session, it is time to start preparing for the next session! Between now and the next time we meet, we (the research team) will be working to prepare more activities, and compile some moderately interactive prototypes based on the feedback, ideas, requirements, and features you have provided us today.

We want to encourage you to keep thinking about the important work we are doing together. In order to do so, we came up with a few activities for you to work on between now and the next time we meet. **Choose one and give it a try**! The assignment is completely optional, and is not intended to take a significant amount of your time. If you are unable to work on the assignment, you will still be able to participate in the next session without falling behind.

Activity 1: Tracking Journal
For this activity, choose a symptom or two that are of particular interest to you at this moment. Keep track of that symptom between now and next session using the notebook provided. Think about things like how often you are interested in collecting data about this symptom, and what recording this data involves. For example, if you are interested in tracking headaches, you may find it helpful to have a structured way of classifying headaches based on severity, duration, location and type.

Activity 2: Representations of Data in Your Life
For this activity, we would like you to look for examples of data representations in your daily life. These can include graphs or charts, or even visualizations of data such as heat maps or word clouds. Although you may not recognize them right away, you may soon be surprised to find them everywhere. Keep track of the different types of representations or visualization you find! Write them down, snap a picture with your phone, or even cut them out of a magazine or the newspaper. Bring these examples with you to the next session when we talk about how information is presented, and how to get the most meaning out of your data.

Medium Fidelity Prototyping Instructions

2. Prototype Evaluation/Design

Based on the interviews and last session, I have put together some prototypes of what an application for this activity might look like. We will look through these now, with you guys serving as the experts contributing content and feedback. I will give you a print out of each of the interfaces. Many of these interfaces are placeholders – in those cases, I will ask you to draw how you would imagine that screen looking, and make notes about content on the papers I have provided. This is just a shell of what the application would be, I need you guys to fill in content and provide feedback on visual aspects of the design.

There is a code on the bottom of each prototype screen – reference that when providing feedback and when sketching the new pages.

Appendix C. Evaluation Study
Patient Tasks
Activity 1. Think Aloud
During this activity, I will provide you with a series of tasks to carry out. I am going to have you 'think aloud' as you go along, narrating your thoughts and actions.

Scenario: Today you are acting as Claudia, a patient who has recently been diagnosed with a brain tumor. You were told about this application, and you have decided to check it out. I have provided a flyer with more information on Claudia for you to use throughout this activity.

I am going to give you a series of tasks to work through using the think aloud protocol. We will start out with a sample task to get oriented and practice thinking aloud.

Sample Task. "*You just downloaded the application and would like to get started. Set up a username and password using the information provided."*

Task 1. *"Review and request a refill for your Keppra prescription."*

Task 2. *"You believe that your pain medication is causing itching and rash, but aren't sure what to do or what to take to resolve the issue. How would you capture that information such that you can discuss it during your upcoming appointment?"*

Task 3. *"You would like to capture some information about a headache you had earlier today. Show me how you would go about doing that."*

Task 4. *"Determine the best way to contact Amanda Lane, MD, the radiation oncologist overseeing your treatment."*

Task 5. *"You would like to be prompted to report symptom information on a daily basis. How would you go about doing that?"*

Task 6. *"Add a caregiver or second user to your account."*

Task 7. *"Find out more information about recommendations for diets and nutrition while on chemotherapy."*

Activity 2. Interview & Questionnaire
Now I will give you a few minutes to explore the application in more depth. Try to 'think aloud' as you navigate the features and functionalities, and provide any feedback you may have.

Questionnaire: System Usability Scale

Patient Interview Questions
Q1. What did you like most about this application?

Q2. In what ways does the application meet your needs and expectations? Where does it fail?

Q3. Are the features and functionalities useful?

Q4. What would you change? How would you do that?

Q5. Was the navigation clear and intuitive? Did the icons make sense?

Q6. Would you use this application as a part of your care process? Would you recommend it to other patients?

Q7. Do you believe this would help you in decision-making? Communication?

Q8. How satisfied are you with the overall design, functionality, and experience?

Caregiver Tasks

Activity 1. Think Aloud

Scenario: Today you are acting as Molly, the caregiver of a patient who has recently been diagnosed with a brain tumor. You were told about this application, and you have decided to check it out. I am going to give you a series of tasks to work through using the think aloud protocol. We will start out with a sample task to get oriented and practice thinking aloud.

Sample Task. "*You just downloaded the application and would like to get started. Set up a username and password using the information provided."*

Task 1. *"Review and request a refill for the Keppra prescription."*

Task 2. *"[Patient] is experiencing itching and discomfort, but you are not sure of the cause and want to discuss it during an upcoming appointment. How would you record that so you remember to discuss it?"*

Task 3. *"You would like to capture some information about a headache [patient] had earlier today. Show me how you would go about doing that."*

Task 4. *"Determine the best way to contact Amanda Lane, MD, the radiation oncologist overseeing [patient's] treatment." Alt "Determine the best way to contact a clinician in radiation oncology with a question after hours."*

Task 5. *"You would like to be prompted to report symptom information for [patient] on a daily basis. How would you go about doing that?"*

Task 6. *"Add another caregiver to your account."*

Task 7. *"Find out more information about recommendations for diets and nutrition for [patient] while on chemotherapy."*

Activity 2. Interview & Questionnaire
Questionnaire: System Usability Scale

Interview Questions
Q1. What did you like most about this application?

Q2. In what ways does the application meet your needs and expectations? Where does it fail?

Q3. Are the features and functionalities useful?

Q4. What would you change? How would you do that?

Q5. Was the navigation clear and intuitive? Did the icons make sense?

Q6. Would you use this application as a part of your care process? Would you recommend it to other patients or caregivers?

Q7. Do you believe this would help you in decision-making? Communication?

Q8. How satisfied are you with the overall design, functionality, and experience?

Clinician Tasks
Activity 1. Think Aloud
Scenario: You are a clinician who recently learned about an application being deployed in your clinic to help support patients with primary brain tumors, and you would like to check it out before recommending it to patients.

I am going to give you a series of tasks to work through using the think aloud protocol. We will start out with a sample task to get oriented and practice thinking aloud.

Sample Task. "*You just downloaded the application and would like to get started. Set up a username and password using the information provided."*

Task 1. *"Review and request a refill for the Keppra prescription."*

Task 2. *"You recently read about a new clinical trial that you might be eligible for, but are unsure what it involves. How would you capture that information such that you can discuss it during your upcoming appointment?"*

Task 3. *"You would like to capture some information about a headache you had earlier today. Show me how you would go about doing that."*

Task 4. *"Determine the best way to contact Amanda Lane, MD, the radiation oncologist overseeing your treatment." Alt "Determine the best way to contact a radiation oncology clinician with an important question after hours."*

Task 5. *"You would like to be prompted to report symptom information on a daily basis. How would you go about doing that?"*

Task 6. *"View information about nausea over the past month and determine whether its has improved, stayed the same, or worsened."*

Task 7. *"Find out more information about recommendations for diets and nutrition while on chemotherapy."*

Activity 2. Interview & Questionnaire
Questionnaire: System Usability Scale

Interview Questions:
Q1: What did you like most about this application?

Q2: What would you change? [Add/Remove/Modify]

Q3: How would you integrate this into your workflow?

Q4: How would you like to see the information presented to you? What level of detail?

Q5: Do you have concerns about having another source of data?

Q6: Are you comfortable with the type and amount of information presented in this application?

Q7: Do you have concerns about functionality? Which?

Q8: Are there any features that you feel are greatly beneficial?

Q9: Do you believe this would help you in decision-making? Communication?

Q10: Would you recommend this application to future patients and caregivers?

Q11. How satisfied are you with the overall design, functionality, and experience?