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Dana Montroy Ray Date

Creating a Smartphone App for Use in an Outpatient Palliative Care Setting

By

Dana Montroy Ray

Degree to be awarded:
MPH
Applied Public Health Informatics
Executive Master of Public Health

Frederic J. Grant, PhD, MPH, MBA **Date**
Committee Chair

Kimberly A. Curseen, MD **Date**
Field Advisor

Monica Crubezy, PhD **Date**
Field Advisor

Laurie Gaydos, PhD **Date**
Associate Chair for Academic Affairs
Executive MPH Program

Abstract

Creating a Smartphone App for Use in an Outpatient Palliative Care Setting

By

Dana Montroy Ray

B.F.A.

Texas Christian University, Fort Worth TX

1982

Thesis Committee Chair:

Frederic J. Grant, PhD, MPH, MBA

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A thesis submitted to the Faculty of the
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ABSTRACT
Creating a Smartphone App for Use in an Outpatient Palliative Care Setting

Background: Palliative care is specialized medical care that focuses on preventing and relieving suffering for patients and their families facing illness. It is an interdisciplinary medical specialty that concentrates on optimizing quality of life through symptom management, and provides personalized relief from symptoms caused by serious, chronic or fatal disease and associated side effects from treatment of the disease. While there is an increasing demand for palliative care services, there is also a shortage of palliative care professionals, as well as a need to extend palliative care services beyond traditional boundaries. Outpatient palliative care is emerging as the next frontier in palliative medicine, and can enable patients to better manage the treatments they are receiving or have completed, with the potential to improve their quality of life and contribute to the efficacy of care. Still, many Americans living in certain geographic regions have limited access to palliative care services when confronted with serious illness. However, a mobile health revolution is changing how patients, families and caregivers manage their health and wellness, through the promotion of healthy living, education and management of disease, and remote monitoring of patients. A smartphone mobile health app has the potential to be the new delivery model for extending outpatient palliative care services, with the potential to improve healthcare delivery and efficiency, and conceivably improving patient outcomes.

Purpose: The purpose of this thesis was to design a framework for an outpatient palliative care smartphone app. The intended solution will be used by patients, family members and caregivers and should complement existing outpatient palliative care services in a traditional setting.

Methods: Using a systematic and informed approach, an evidence-based framework was selected and applied, identifying potential outpatient palliative care components that could be included in a smartphone app. A two-part mixed methods feasibility study was conducted to assess whether the palliative care components could be translated into an app. First, input on component design, functionality and use was sought through an anonymous research survey conducted in a cohort of palliative care professionals. Second, subject matter experts were identified and their input obtained through in-depth discussions on a theoretical design of an outpatient palliative care smartphone app.

Results: The research survey collected user preferences on selection of components. In the second part of the study, a cohort of five subject matter experts provided feedback on use and integration of the components. Results from these two sets of stakeholders produced a greater understanding of desired features, content and functionality, and helped answer the study's research hypothesis regarding design of a palliative care smartphone app.

Conclusions: This research study established perceptions of use and functionality of a smartphone app to be used in an outpatient palliative care setting. It identified some components that were desirous and some that were not, and additional features and functionalities that should be approached with more attention and care. The initial design of the app would be changed significantly after implementing these revisions, laying the groundwork for the next stage of development.

THESIS

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This has been a long journey for me, and now that I've finally arrived at the destination I wish to thank those who've helped and encouraged me along the way. First, let me thank my fantastic thesis chair, Dr. Fred Grant, for his kind and direct words of support and guidance, inspiration and enthusiasm, superb qualities of a great mentor. To my two highly talented thesis advisors, Drs. Kimberly Curseen and Monica Crubezy, I gratefully thank them for sharing their applied sets of expertise and advice, valuable time and patience as I worked through their manuscript revisions. To the five subject matter experts that contributed to the study, I'm grateful they shared with me their knowledge and wisdom from their respective fields. To my family and friends I thank them for their motivation and encouragement, especially my sister Carol who kept harassing me with "*git-r-done*". Well, I'm done and it does feel great! And finally, to the source/origin of this research study, I wish to acknowledge my own mother, who lost her life to metastatic cancer 10 years ago after a short battle lasting only six months. As her caretaker I helped her on that road, but at the time I had no tools and limited available resources. As I look back I clearly needed them, especially at 3 am in the morning when things sometimes go wrong and you're looking for answers. It is my sincerest hope that this project will continue to grow and develop into a tangible product that will help others like me and my mother, who will fight for the best quality of life when facing a serious or deadly disease.

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Chapter 1: Introduction and Literature Review

Introduction

Palliative care is an interdisciplinary medical specialty that focuses on preventing and relieving suffering and supporting the best possible quality of life for patients and their families facing serious illness (Meier, McCormick, 2016). Often referred to as supportive care – palliative care is personalized care that concentrates on optimizing quality of life through symptom management - providing relief from symptoms caused by serious, chronic or fatal disease and associated side effects from treatment of the disease (Kelley, Morrison 2015).

Supportive and palliative care services are delivered through traditional in-patient as well as outpatient clinical settings. While many academic medical centers and tertiary hospitals offer inpatient palliative care services, there is a paucity of palliative care services offered through an outpatient setting, and demand for outpatient palliative care services is increasing, especially in underserved, rural and frontier communities (Meier, Beresford, 2008). This presents a unique opportunity for selective delivery of outpatient palliative care services. Currently there are approximately 250,000 medical apps available as free or for purchase through the Google App Play Store. However, most of the palliative care smartphone apps are designed for use by healthcare professionals (Meghani, MacKenzie et al. 2017). This thesis seeks to identify and explore what palliative care services can be delivered through a smartphone app for use by patients and family caregivers in an outpatient setting.

Problem Statement

With the increase in the population of older persons, with the rise in the prevalence of chronic diseases and co-morbidities, and as more persons survive cancer and other serious illnesses, there is an increasing demand for palliative care services. At the same time, there is a shortage of healthcare professionals experienced in the specialty of palliative medicine. With the increase in the population there is also a need to extend palliative care services beyond traditional boundaries, especially to underserved populations - those living in rural areas or settings that are distant from medical centers.

Additionally, as insight on the use of smartphones indicates an increasing reliance of populations in general on smartphones to communicate, seek information and to monitor activities, it seems timely and important to understand whether the use of smartphone apps may help deliver palliative care effectively outside of traditional inpatient and outpatient settings.

Purpose Statement

The purpose of this thesis was to design a framework for an outpatient palliative care smartphone application (app). Through a review of evidence-based guidelines, components of outpatient palliative care were identified that complement existing palliative care services delivered in a traditional setting, resulting in a theoretical design that an app developer in conjunction with a healthcare professional will be able to use to create a mobile health application. The intended solution will be an app that patients, family members and caregivers seeking palliative care services can use in an outpatient setting via a smartphone or tablet.

Significance

Since the implementation of the Affordable Care Act, key features such as expanding coverage to health care and improving the quality and efficiency of healthcare while lowering costs are reforms that are changing the landscape of the health care delivery model. Patients with serious illnesses are living longer and with greater disabilities (IOM, 2014; McCormick, Chai et al. 2012). New health care models put greater emphasis on the role of the patient, with patients, their families and caregivers being required to self-manage side effects of the clinical care processes they are receiving.

Outpatient palliative care is emerging as the next frontier in palliative medicine. Supportive and palliative care services delivered through an outpatient setting are intended to provide patients with information about how to obtain relief from side effects such as pain, nausea and fatigue, so that they are enabled to better manage the treatments they have completed or are receiving, with a focus on improving their quality of life and emphasizing the efficacy of care. Still, many Americans living in certain geographic regions have limited access to palliative care services when confronted with serious illness.

A novel smartphone app for use in an outpatient palliative care setting could provide a cost-effective approach for improving symptom management, enhancing communications between patients and their medical team, and providing greater patient and caregiver satisfaction in the active management of the disease trajectory. It could empower patients by giving them tools to manage their condition in their own home, minimizing the need of direct healthcare personnel supervision and offering a new delivery mechanism that complements and augments traditional palliative care services. This mode of delivery could be particularly significant to under-served and minority populations, as well as patients and caregivers living in rural areas or settings that are distant from medical centers.

However, there is a paucity of palliative medicine centered resources for smartphones, and virtually none that are intended for use by patients, thus providing a great opportunity for further research and development as the mobile user society continues to grow (Nwosu and

Mason, 2012).

Research Questions

1. What outpatient palliative care services may be most appropriate for delivery through a smartphone application?
2. How comparable/compatible would an outpatient palliative care smartphone app be with palliative care services delivered in a traditional outpatient setting?

Literature Review

Background: What is palliative care?

The term *palliative care* originates from the Latin verb *palliare*, "to cloak or disguise", and refers to specialized care given to people with serious illness (ACS 2014; Zeppetella 2012). The Center to Advance Palliative Care (CAPC), a national organization established in 1999 as a resource agency with the vision of providing palliative care everywhere, defines it as “specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of palliative care doctors, nurses, social workers and others who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment” (CAPC 2017).

Palliative care services can be given to children and adults at any point during their illness, ideally starting as early as diagnosis and continuing through treatment, follow-up care, and ultimately end-of-life. Services are based in hospitals, clinics, nursing homes and ambulatory centers, but often continue in a home setting (Griffith et al, 2010). Delivery of palliative care is typically through a multidisciplinary team that includes doctors, nurses, dieticians, pharmacists, social workers, psychologists, chaplains and spiritual counselors. Specialized teams of healthcare professionals provide additional levels of support and encompass the psychosocial, spiritual, and practical (financial, legal, insurance, employment) needs to address the effects of illness on the patient and their families and caregivers.

While palliative care services provide relief and comfort from symptoms such as pain, fatigue, nausea, breathing problems, depression, they are not intended as curative and do not address the underlying disease process itself. Palliative treatments use medications to reduce or control symptoms of the disease as well as the side effects of therapeutic treatments, and may help someone to live longer and more comfortably, even if the patient cannot be cured and is in advanced stages of disease. Used effectively, palliative care in combination with therapeutic treatment can help improve the effectiveness of treatment, often promoting the patient's ability to remain active in important activities and relationships (Buss et al., 2017).

How palliative care is different from hospice care

While hospice and palliative care are often confused and mistaken as synonymous, they are historically different. Hospice care can be traced back to medieval times as a place for weary or ill travelers to shelter, and was often run by religious orders. The word hospice originated at the end of the 11th century and is derived from the Latin word *hospes* (also shared by the word hospital), which describes a specific type of lodging for traveling pilgrims (Lutz, 2011; NHCPO, 2016).

In the late 1800's many religious organizations offered hospice care centers as a place for dying patients. Hospice was formally recognized as a type of specialized care for the terminally ill in 1967 when Dame Cicely Saunders, through her work as a nurse, social worker, and physician with dying patients, helped found St. Christopher’s as the first modern hospice located in London, England (Lutz, 2011). When contrasted with hospice care, palliative care supports the emotional and spiritual needs of the patient and family members as well as palliation of physical manifestations of disease (O'Connor, 1999). While both palliative and hospice care share a unique philosophy and as well as many common qualities, values, services and settings, a main difference between them is that palliative care is provided to patients who face life-threatening illness, with services beginning at any time, at any stage of illness, whether terminal or not.

Palliative medicine – a relatively new medical field

According to CAPC, palliative medicine has become the fastest-growing medical specialty in the United States (CAPC 2015; Hughes and Smith 2014), and in 2006 was formally recognized by the American Board of Medical Specialties as a medical subspecialty under numerous boards of medicine and surgery (AAHPM 2018; ABMS 2018). Over the last decade palliative care has been one of the fastest growing trends in health care, with the number of palliative care teams situated in U.S. hospitals with 50 or more beds increasing by 164%, from 658 in the year 2000 to more than 1,700 in 2014. Almost 90% of large U.S. hospitals (>300 beds or more) now have palliative care programs (CAPC 2014). While there are now nearly 100 hospice and palliative-medicine fellowship programs around the country, as one of the newest board eligible specialties, there is already a shortage of palliative care providers (Cunningham, Travers et. al., 2017; Lupu, 2010).

Population, disease trends and their potential impact on palliative care services

Over the last 30+ years the US population has grown from 226.5 million in 1980 to over 320 million people in 2015 (U.S. Census 1980; U.S. Census 2015). According to the DHHS Administration on Aging (AoA), about one out of every seven Americans are persons 65 years or older, with older Americans numbering 46.2 million in 2014 (the latest year for which US Census data is available for this population), representing 14.5% of the U.S. population. The Administration for Community Living (ACL) projects that by 2040 approximately 21.7% of the population will be older persons, and by 2060 this number will double to approximately 98 million older persons (ACL, 2014).

There has also been an increase in the prevalence of non-communicable diseases (NCDs), principally cardiovascular and chronic respiratory diseases, diabetes and cancer, and persons living with multiple chronic illnesses (multi-morbidity). The CDC estimates that as of 2012 about 25% of all adults have multiple chronic diseases (Ward, et. al., 2014) and according to the World Health Organization (WHO), NCDs are the leading cause of death throughout the world (WHO, 2011). In the US, seven of the top 10 causes of death in 2010 were due to chronic diseases, with two of these – heart disease and cancer – attributing for nearly 48% of all deaths (CDC, 2016). The American Cancer Society (ACS) estimates that in the next 10 years - by 2026 - the number of cancer survivors in the United States will increase from 15.5 million to 20.3 million (ACS, 2016). The increase in survivorship can be attributed in part to new and improved therapeutic treatments that help people with cancer live longer, in addition to advancements in early detection.

Improvements to standards of living and advancements in diagnosis and treatment of chronic diseases over the last 30 years have provided the US population with the opportunity to grow old, accumulate multiple chronic illnesses, and to die slowly (Lynn and Forlani, 2001). However, palliative care services are not available to all patients with serious chronic illness (CAPC, 2015), as many live in areas with limited access. With the growing and aging population, greater life longevity, increases in the prevalence of chronic diseases and multi-morbidities, and increases in cancer survivorship, these trends present a challenge to public health policies and strategies regarding the allocation of available resources to disease management and prevention.

Impact of palliative care on health and outcomes

Groundbreaking research into the palliative care delivery model was begun in the early 2000's in a rural, National Cancer Institute-designated comprehensive cancer center setting by researchers at the Dartmouth-Hitchcock Medical Center. A randomized controlled trial (RCT), Project ENABLE II [Educate, Nurture, Advise, Before Life Ends] was conducted from 2003 through 2008 in 322 patients. It was a multicomponent, psycho-educational intervention that delivered a spectrum of palliative care and hospice services from diagnosis to end of life, and targeted patients with the most common advanced cancers (advanced lung cancer, metastatic gastrointestinal cancer or metastatic breast cancer) who had a poor prognosis and were expected to die from their disease within two years. The program had three components: it placed a palliative care coordinator at each of the three clinical sites to provide case management-like services. Second, it aggressively addressed pain and symptom control with a baseline assessment and ongoing monitoring of all patients; and lastly, the project offered patients and caregivers a series of seminars aimed to enable participants to take charge of their illness, help them navigate the health system, and to make decisions and better manage symptoms and emotional stress.

Patients and their caregivers were given access to a broad range of education and palliative care, including services related to life completion, from the time of their diagnosis.

Outcomes from the Project ENABLE II RCT demonstrated the clinical benefits of palliative care. Compared to the control group, the intervention participants had improved quality of life, better quality of care with less aggressive end-of-life care, and less emotional stress (Bakitas, Lyons et al. 2009). The researchers also noted that for those receiving palliative care outside of cancer centers and in their own communities, palliative care was often not available.

Integration of palliative care into good clinical practice guidelines

In 2017 the American Society of Clinical Oncology (ASCO) released an update to their Clinical Practice Guidelines, affirming the definition of palliative care as “care which optimizes quality of life by anticipating, preventing, and treating suffering” (Ferrell, Temel et al. 2017). These recommendations superseded the 2012 Provisional Clinical Opinion (PCO) regarding integration of palliative care into standard oncology care. The new “*Integration of Palliative Care into Standard Oncology care: ASCO Clinical Practice Guidelines update*” revised the PCO based on evidence of the benefits of palliative care. ASCO convened an Ad Hoc Palliative Care Expert Panel and conducted systematic reviews of: 1) nine randomized controlled trials (RCTs); 2) review of a quasi-experimental trial published in the New England Journal of Medicine regarding delivery of early palliative care in patients with metastatic non-small cell lung cancer; and 3) five secondary analyses from 2012.

Outcomes from these studies showed the benefits of early palliative care when added to oncology care. The new ASCO guidelines provide evidence-based recommendations for oncology healthcare professionals, for patients, their family members and caregivers, and to palliative care specialists. The new recommendations include offering palliative care concurrently with antitumor therapy, beginning palliative care in newly diagnosed patients with advanced cancer within eight weeks of diagnosis, that delivery of palliative care should be delivered through an interdisciplinary team, and that, as key providers of patient care, family caregivers need additional education, support, and skills preparedness. The recommendations also noted growing evidence of the cost benefits of palliative care, in addition to better quality of care and equal or longer survival.

Effectiveness of Palliative Care delivered through Outpatient Services

Supportive and palliative care delivered in an outpatient setting can provide patients with tools that help provide relief from side effects such as pain, nausea and fatigue, so they are enabled to better manage the treatments they are or have received, with a focus on improving their quality of life and emphasizing the efficacy of care (Cunningham, Ollendorf, et al. 2017). Demand for outpatient palliative care services is increasing, especially in underserved, rural and frontier communities (Lynch 2013). While many academic medical centers and tertiary hospitals offer inpatient palliative care services, very few offer services in an outpatient setting.

Several randomized control trials have been conducted exploring the efficacy of palliative care in an outpatient setting with regard to patient satisfaction, clinical outcomes, mortality, and healthcare utilization. Through a methodical review of peer-reviewed literature, Rabow et al (Rabow, Kvale et al. 2013) identified four well-designed RCTs (Kaiser-Permanente, Project ENABLE, the TEMEL study [NSCLC], and UCSF’s Comprehensive Care Team) that met defined inclusion criteria. Study outcomes were reviewed, assessing the following domains: satisfaction (patients, family members, caregivers and clinicians); clinical outcomes (symptom management, quality of life and mortality); and healthcare utilization outcomes. Research findings from the Rabow study showed benefits to patients and families through higher satisfaction, better symptom control and quality of life; and improvements in the efficiencies in healthcare utilization through avoidance of unnecessary or unwanted hospitalizations, readmissions, emergency room and intensive care visits.

A comparative effectiveness final report was released in April 2016 by the New England Comparative Effectiveness Public Advisory Council (CEPAC), part of the Institute for Clinical and Economic Review (ICER). This is an independent non-profit research organization whose mission is to evaluate medical evidence and to convene deliberative bodies to interpret and apply evidence in order to improve patient outcomes and control costs. The CEPAC ICER study convened medical experts, practicing clinicians, methodologists, patient engagement and advocacy leaders and produced a final report entitled "*Palliative Care in the Outpatient Setting*" (Cunningham, Travers et al. 2017). It reviewed the history and evolution of palliative care, its structure and settings, barriers and opportunities, existing approaches to palliative care conducted outside the traditional hospital setting, and outcomes on the costs and cost-effectiveness of outpatient palliative care. The researchers performed an exhaustive literature review, assessing and screening studies, abstracting data, and selected 13 clinical research studies that described outpatient palliative care interventions. Their review focused on eight specific clinical benefits derived from palliative care: Quality of Life (QoL), Resource Use, Survival, Symptom Burden, Patient Satisfaction, Psychosocial outcomes, Mood, and Caregiver Impact. While the number of studies they evaluated was limited, their overall analysis showed an improvement to quality of life relative to usual care, a decrease in the utilization of hospital or acute care services, an increased utilization of hospice benefits, and the ability to transition death to a home setting. At the conclusion of the report, the researchers made recommendations to guide experts on implementing policies that support outpatient palliative care. One approach they identified was the ability to be flexible in how palliative care is delivered, noting that technology is key to helping reach more patients in rural areas.

Smartphone Ubiquity

The use of mobile devices has become almost universal, and over the last decade, smartphones have become more than just communication devices, they have become portable personal computers.

In 2014 the Pew Research Center conducted two omnibus polls surveying the role of smartphones in users' lives. The first poll, conducted through telephone interviews in a nationally representative sample of 2,002 adults living in the U.S., sought information about awareness of and type of smartphone used (if any). The second survey, referred to as an "experience sampling" poll, gathered data about how Americans use their smartphones on a daily basis. Key themes of this report showed that nearly two-thirds of Americans (64%) own a smartphone, which was significantly up from 35% from a similar survey conducted in 2011 (Anderson 2015). The surveys also showed that younger adults, non-whites, and people with relatively low income and educational attainment levels were especially likely to be "smartphone-dependent", while also noting an increase in smartphone ownership in older adults (27%). Nineteen percent of those polled relied to some degree on smartphones for access to online services and information, and for staying connected to the world around them — either because they lacked broadband at home, or because they had fewer options for online access other than their cell phone. The top three services utilized with a smartphone were text-messaging services, accessing the internet, and voice/video calling. Another interesting finding from this study was that while 57% of smartphone users have used their phone to conduct online banking, 62% have used their phone to look up information about a health condition (Smith 2015).

Mobile Health and Smartphone Apps

Through smartphone applications (apps) and other handheld devices, a mobile health revolution is ongoing and changing how patients, families and caregivers manage their health and wellness, how physicians, hospitals and clinics run their practices, and how the community connects to information when and where needed (Kumar et al. 2013; Nwosu and Mason 2012). Mobile health apps can promote healthy living, support patient education and management of disease, and enable remote monitoring of patients (Mosa, 2012). Examples of popular smartphone apps and their respective devices include pedometers and walkers, weight management, exercise and calorie counting, and tobacco cessation. Popular medical apps include cardio, heart rate and blood pressure trackers, management of medical conditions such as diabetes, drug and disease reference apps, and doctor visit and medication reminder/alerts.

In 2014 The Nielsen Group, a global consumer market research company, conducted and published a study about smartphone mobile app usage. They found that on average, U.S. smartphone users accessed 26.7 apps per month (The Nielsen Company, 2015).

As of 2017, more than 318,000 mobile health apps are available on the Google Play or Apple Store marketplace. Most of these apps are focused on general wellness issues such as fitness, lifestyle and stress, and diet. However, the number of apps focused on health condition management and patient care is increasing and accounts for 40% of all apps (IQVIA, 2017).

Research 2 Guidance (R2G), a global mobile health app strategic advisory and market research company, conducted and published a study on the current and future state of mobile health care. Their findings showed that while many health apps are available, only 36 apps (not percent) represent nearly 50% of all those downloaded, and that in 2015 approximately 500 million smartphone users worldwide used or had downloaded a mobile health app. They forecast that by 2018 approximately 50% of the more than 3.4 billion smartphone and tablet users will have downloaded at least one mobile health application (R2G, 2017).

Intersection of Palliative Care with Technology - Palliative Care Smartphone Apps

A 2017 study published in the Journal of Palliative Medicine identified 46 palliative care apps targeting healthcare professionals. The range of the apps included clinical care guidelines, advance care planning, training materials, pharmaceutical tools, and current news topics (Meghani, 2017). An informal survey of palliative care smartphone apps was undertaken by the PI on the Google Play and Apple Store marketplaces. While there were many palliative, supportive and hospice care apps available as referral aids or palliative care quick facts, almost all were created to augment an existing palliative care program hosted by a medical organization, or to aid patients, family members and caregivers in selecting an appropriate hospice.

However, one app was identified that focuses on patient wellness through supportive care and is currently available on the Apple Store and Google Play. *TapCloud* provides a two-way mobile communications platform between patients and their healthcare team, and offers customized care plans for over 100 medical conditions. Through daily prompts it gathers key patient data input by patients who are in-between doctor visits. Patients enter their well-being, pain levels, symptoms, side effects, medication compliance and vitals into the app, which then connects to a web-based clinician dashboard. This information is then presented in a comprehensive dashboard that allows clinicians to rapidly interpret key insights into a patient's overall well-being. While the app is not specific to palliative care, it does utilize patient reported information, allowing the healthcare team to update patient-specific clinical protocols and to decide whether a specific patient needs to be seen, or to schedule a home health visit or adjust medications (TapCloud, 2018).

A literature search for material on smartphone apps and outpatient palliative care did not yield much published literature. Two interesting papers published in the Indian Journal of Palliative Care explored palliative care smartphone apps used in a cancer setting (Jamwal and Kumar 2016) and in homecare (Dhiliwal, 2015). Both authors note the rapid development of smartphones and mobile health apps, and their potential use in an outpatient palliative care setting as a new delivery model.

The very real possibility exists that mobile medical apps can ease the communications gap and facilitate decision-making between the doctor and patient by allowing access to more information when needed. They have the potential to improve healthcare delivery and efficiency, increase compliance rates, and conceivably improve patient outcomes and overall satisfaction.

CHAPTER 2: METHODOLOGY

Introduction

This is a feasibility study to assess components of palliative care that can be translated into a smartphone app. The methodology used is designed to answer the study's research hypothesis regarding design of a palliative care smartphone app to complement and augment existing outpatient palliative care services delivered in a traditional setting. This chapter serves two purposes: 1) using a systematic and informed approach, apply an evidence-based framework to identify potential components of a palliative care smartphone app; and 2) using a mixed methods approach, obtain input on component design and use from healthcare professionals and subject matter experts through survey and in-depth discussions. The sections below describe the evidence-based framework applied to selection of the app's components, and a mixed methods approach explores their feasibility.

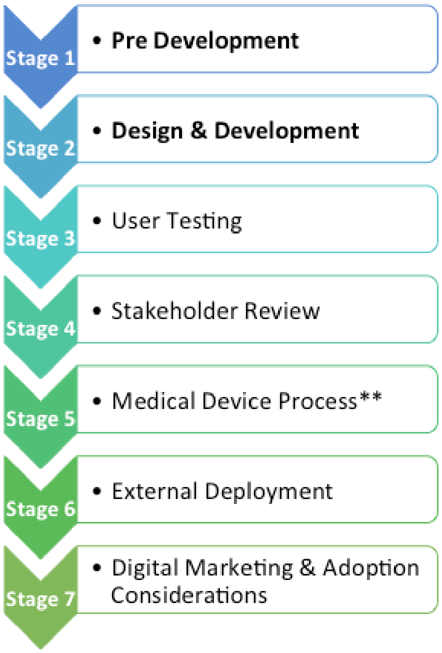
Research Questions

1. What outpatient palliative care services may be most appropriate for delivery through a smartphone application?
2. How comparable/compatible would an outpatient palliative care smartphone app be with palliative care services delivered in a traditional outpatient setting?

Framework and Methodologies

Several existing frameworks and methodologies have been used to create and develop mobile health apps. In 2014 the NHS Innovations South East Ltd (NISE) published "*App Development: An NHS Guide for Developing Mobile Healthcare Applications*" in response to the increasing demand to develop and support mobile health apps within the National Health Service

(NHS) - one of four national healthcare service providers in the United Kingdom. NISE works within the NHS on healthcare innovation projects, in part to facilitate technology transfer and ultimately to improve healthcare delivery throughout the UK, and has been in operation since 2005 and helping facilitate over 1350 healthcare innovation projects. They published a white paper shortly after the successful launch of a "healthy app" – an app that targeted both health conscious consumers and healthcare providers. The purpose of the NHS white paper was to share basic guidance on app development as a sustainable platform in the healthcare environment. Below are stages of the Mobile App Guide framework as described by NISE (NISE 2014), of which stage 1 "Pre-Development" is applied to the methodology section underlying this research study:



Methods

1. Review of evidence-based guidelines

A literature search identified best practice delivery models advanced by both national and international palliative care organizations. Below are evidence-based guidelines that are currently used to define clinical standards of palliative care.

a. **The National Hospice and Palliative Care Organization (NHPCO)** is the largest nonprofit membership organization that represents hospice and palliative care programs and its professionals in the United States. According to the NHPCO 2015 Facts and Figures (NHPCO, 2016), a report that provides an annual overview of trends in the growth, delivery and quality of supportive care throughout the United States, the majority of palliative care services provided to patients and families are:

    i. Management of the patient's pain and physical symptoms;
    ii. Emotional, psychosocial and spiritual care;
    iii. Pharmacy (drugs), medical supplies and equipment;
    iv. Patient care instructions to family members;
    v. Specialty services;
    vi. Inpatient care when needed;
    vii. Bereavement and counseling services to survivors.

b. **National Quality Forum (NQF)** is a not-for-profit, nonpartisan, membership-based organization located in Washington DC that works to catalyze healthcare improvements. Measures and standards endorsed by the NQF serve as a critically important foundation for initiatives to enhance healthcare value, to make patient care safer and achieve better outcomes. The *National Framework and Preferred Practices for Palliative and Hospice Care Quality* was a project undertaken in 2006 that identified and created a national consensus framework for evaluating the quality of palliative and hospice care across all health settings and professions (NQF, 2006). The project was able to achieve national consensus on a set of 38 preferred practices that were endorsed for implementation by palliative care and hospice programs. Subsequently, these 38 preferred practices were further distilled by the next organization shown below.

c. The **International Association for Hospice & Palliative Care (IAHPC)** is a global organization dedicated to the promotion and development of palliative care throughout the world. It provides guidance and technical assistance with palliative care policy, advocacy, clinical guidelines, and service implementation on an international scale. Also through a similar multi-phased consensus project, IAHPC created a *List of Essential Practices in Palliative Care* in 2012 (De Lima et al, 2012), which serves to identify, evaluate, diagnose, treat and apply treatment and solution measures for appropriate primary palliative care delivery with the goal of improving the quality of care delivered globally. The essential practice domains include:

   i. Physical care needs
   ii. Psychological / Emotional / Spiritual care needs
   iii. Other: care planning and coordination issues
   iv. Communication Issues

d. The **National Consensus Project (NCP) for Quality Palliative Care** in 2013 released the third edition of the *Clinical Practice Guidelines for Quality Palliative Care* (NCHPC, 2013). NCP, based at the Hospice and Palliative Nurses Association (HPNA) and located in Pittsburgh, Pennsylvania, formed a task force of six partner organizations, which include the American Academy of Hospice and Palliative Medicine (AAHPM), The Center to Advance Palliative Care (CAPC), the Hospice and Palliative Nurses Association (HPNA), the National Association of Social Workers (NASW), the National Hospice and Palliative Care Organization (NHPCO) and the National Palliative Care Research Center (NPCRC) to review and update clinical practice guidelines, to ensure consistency and quality of palliative care and to guide development of new and existing services. Eight domains of care were defined in the third edition, and include:

    i. Domain 1: Structure and Processes of Care: Accentuates the current state of the field with emphasis on interdisciplinary team engagement and collaboration with patients and families.
    ii. Domain 2: Physical Aspects of Care: Management of symptoms is multidimensional with pharmacological, interventional, behavioral, and complementary interventions
    iii. Domain 3: Psychological and Psychiatric Aspects
    iv. Domain 4: Social Aspects of Care
    v. Domain 5: Spiritual, Religious, and Existential Aspects of Care: Promotes spiritual and religious rituals and practices for comfort and relief.

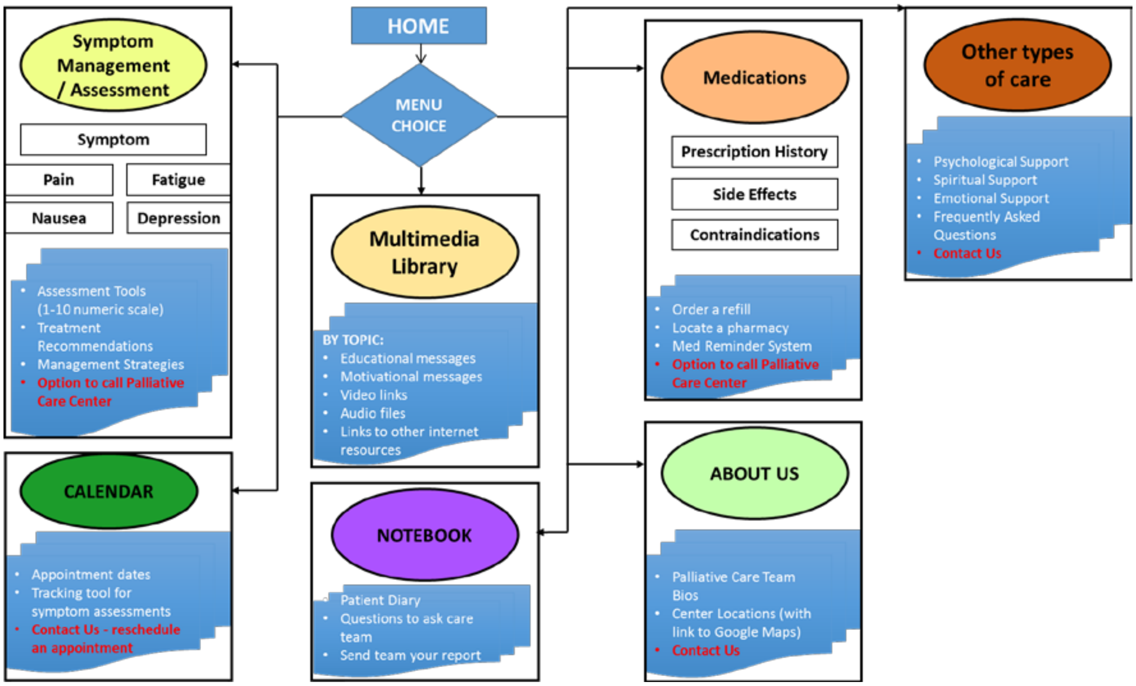
vi. Domain 6: Cultural Aspects of Care: Accentuates cultural and linguistic competence including plain language, literacy, and linguistically appropriate service delivery.

vii. Domain 7: Care of the Patient at the End of Life

viii. Domain 8: Ethical and Legal Aspects of Care (includes advance care planning)

2. Selection of Key Components

Distilling distinct sets of clinical practice guidelines into a foundation for selection of the smartphone app components should incorporate the NQF-endorsed aims of safety, benefit, equity, timeliness, patient-centeredness, and efficiency. Key components of the smartphone app will be aligned under the framework developed by the NCP's *Clinical Practice Guidelines for Quality Palliative Care*, ensuring that the philosophy, principles, and requirements of palliative care are addressed across the continuum of care. Below is a schematic of key components to include in design of the app:



3. Stakeholder Identification

The PESTEL methodology was slightly modified and applied as a tool to identify and establish a creditable framework of stakeholders. PESTEL is a strategy used to identify and analyze environmental influences that can affect business performance. The acronym stands for "Political, Economic, Social, Technological, Environmental and Legal" domains of expertise, and is used in business and strategic planning, marketing planning, organizational change, business and product development and research reports. Healthcare professionals and subject matter experts were aligned under the PESTEL methodology domains:

a. Professionals [palliative care and healthcare] (*replaces political*)

b. Economic/environmental [impact on business operations and healthcare management]

c. Socio-cultural [social workers, chaplain/spiritual counselors]

d. Technological [data storage, mobile app developers, informaticians {EMR integration, standards & interoperability}]

e. Ethical (*replaces environmental*)

f. Legal [privacy, security, HIPAA)

4. Research Survey Design

A descriptive study was conducted in a cohort of palliative care professionals to determine feasibility of components of an outpatient palliative care program that can be provided through a smartphone app. The goal of the assessment was to identify user preferences to guide development of key features and components that could be incorporated into a smartphone app that support and complement existing outpatient palliative care services.

The study instrument was created by the study's principal investigator, with assistance from Dr. Frederic Grant, Thesis Study Chair, and the study's two field advisors, Dr. Kimberly Curseen (Director, Emory Outpatient Palliative Care Center), and Dr. Monica Crubezy (Director of Research Informatics, Emory Library and Information Technology Services [LITS]). The study was administered by *SurveyMonkey* – an online survey development cloud-based software as a service company (SAAS). It was distributed via two listservs maintained by two Emory palliative care healthcare professionals.

5. Stakeholder Consultations

One-on-one meetings were conducted with identified subject matter experts. They were presented the project narrative, a high level summary of the intent and design of components to include in the smartphone app. Their input was sought on components featured in the smartphone app, and domain-specific guidance on the technical solutions to support app development such that the product meets the needs and expectations of patients and caregivers, is easy to use, and will provide the palliative care team with useful and valid information.

6. Analysis of Findings

Results from the quantitative survey were analyzed using Microsoft Excel. Frequency distributions were used to describe the respondents’ roles and their respective settings in palliative care, their utilization and expertise with devices and smartphone apps, and the rankings of components to be included in the app.

Results from the qualitative interviews with subject matter experts included subjective comments and guidance on components of the app relative to their respective sets of expertise and were recorded and/or transcribed.

CHAPTER 3: RESULTS

Outpatient Palliative Care Smartphone App Survey (n = 42 / 165)

Conducted 4/25/2017 – 5/10/2017

Introduction

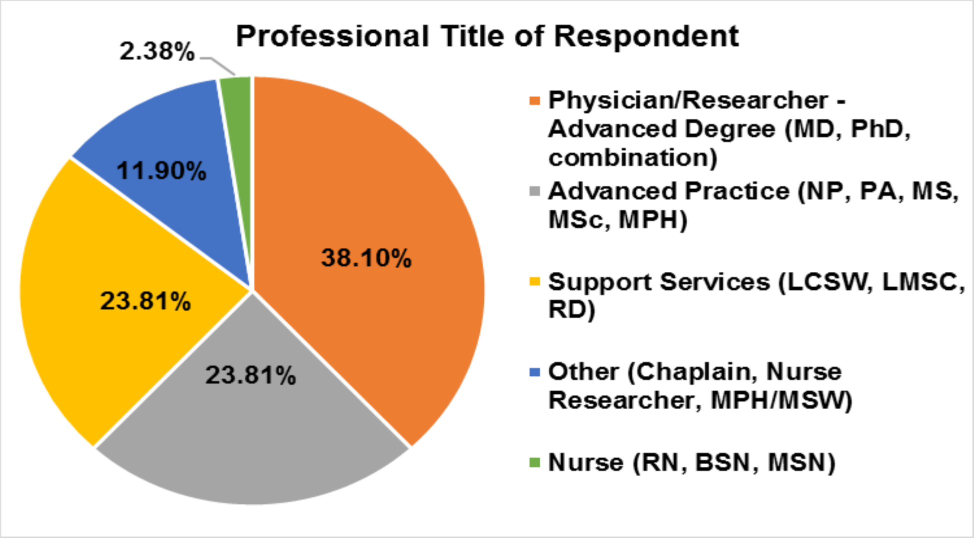
This chapter presents the initial data and results from a two-part mixed methods study. In the first part of the study, a survey entitled “Outpatient Palliative Care Smartphone App” was conducted in Spring 2017 (IRB00095094). The survey was open in Survey Monkey for two weeks and was deployed as a web link through two Emory University listservs to ~165 palliative care professionals affiliated with the Emory University Outpatient Palliative Care Clinic and the Emory University School of Nursing. The survey was anonymous, and approximately 42 / 165 (25%) palliative care professionals responded over a two-week period. The complete survey with the introduction can be found in Appendix 1.

In the second part of the study, informal discussions with five subject matter experts took place over a period of one month. Results of the study are presented in this chapter. Analysis and key findings of the results of the survey and SME discussions are discussed in greater detail in Chapter 4.

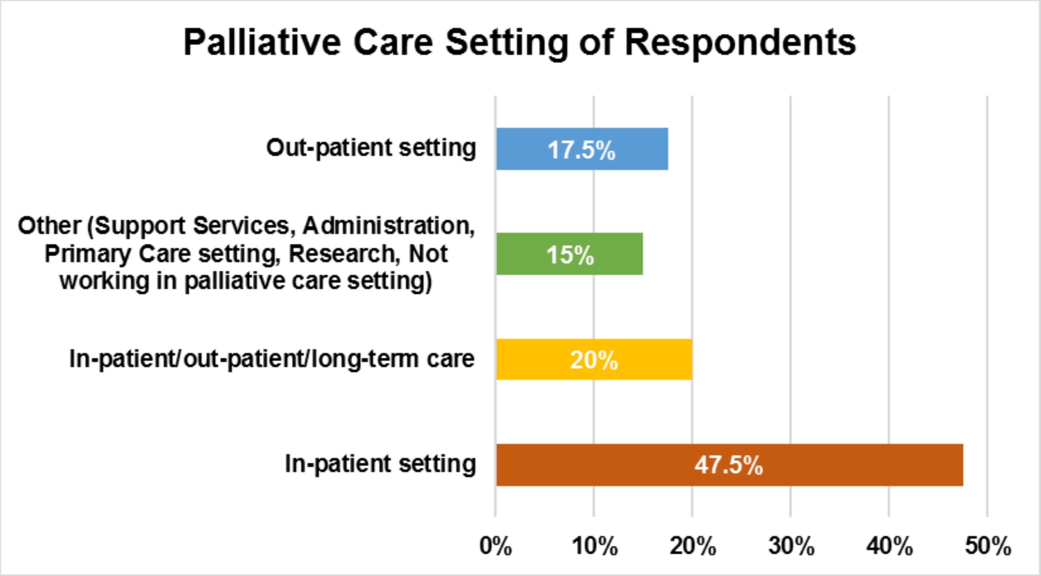
Survey Results:

Quantitative Questions

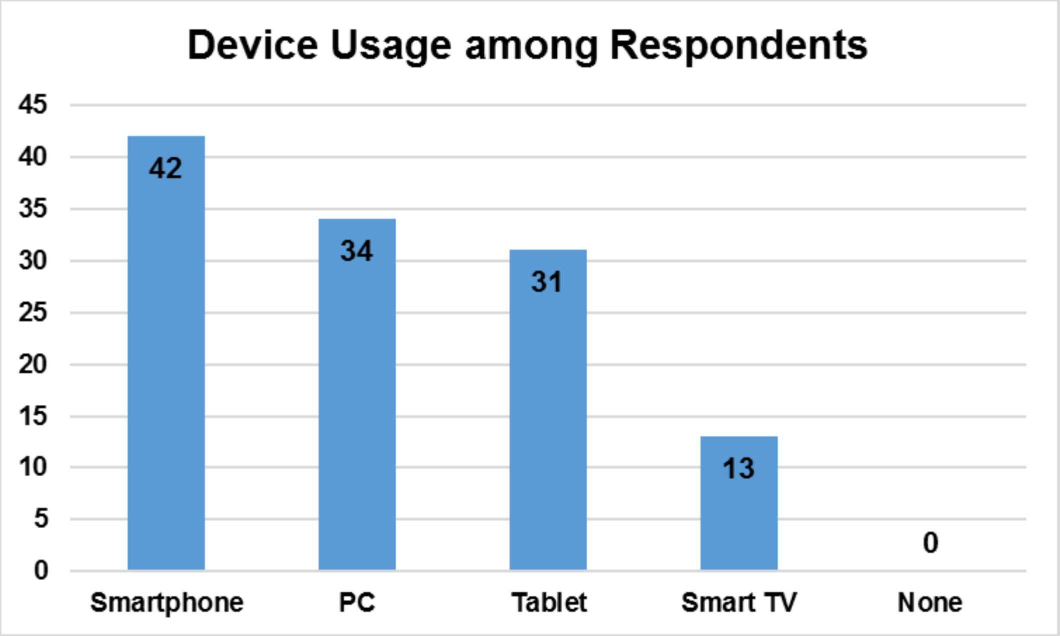
Question 1: Please select an affiliation that represents your professional title.



Question 2: Please select the palliative care setting you currently work in. (Two respondents did not reply to this request.)



Question 3: Which of the following devices do you own?



Question 4 (n=42): Subjects were asked if they had ever used an app on a smartphone or tablet. 100% answered yes.

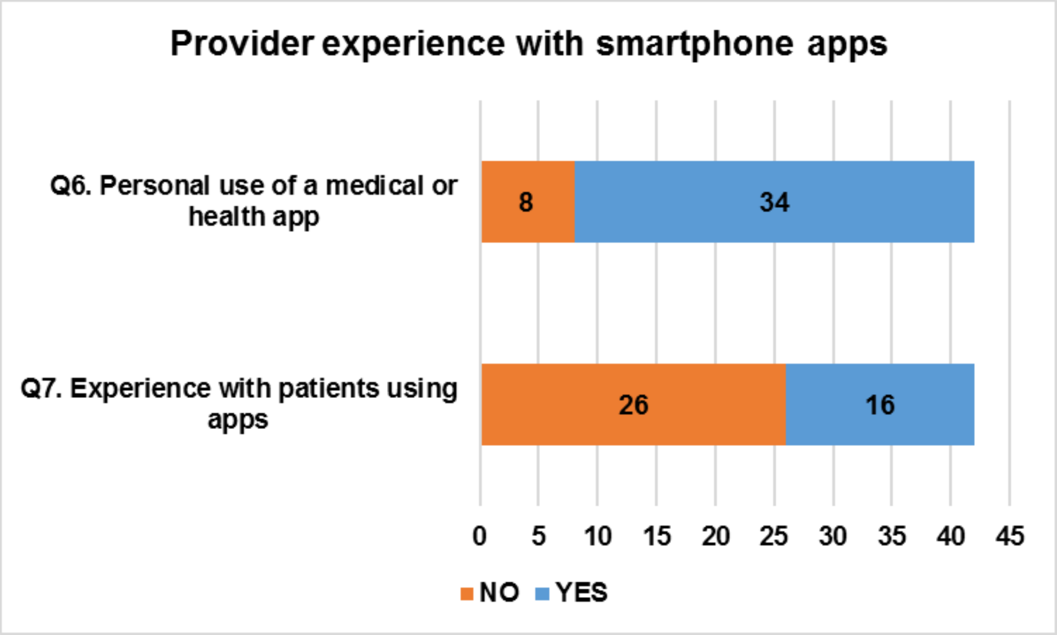
Question 5 (n=42): Subjects were asked if they have a favorite smartphone app. 21 respondents (50%) answered no and 21 respondents (50%) answered yes. Respondents who answered yes were asked to describe why it was their favorite app:

- *Easy to use, visually appealing, integrated two other features on my phone.*
- *Whatsapp*
- *Waze*
- *eBay, Amazon (both are very easy to use and to navigate)*
- *iTunes*
- *Fast facts. Easy access. Straightforward.*

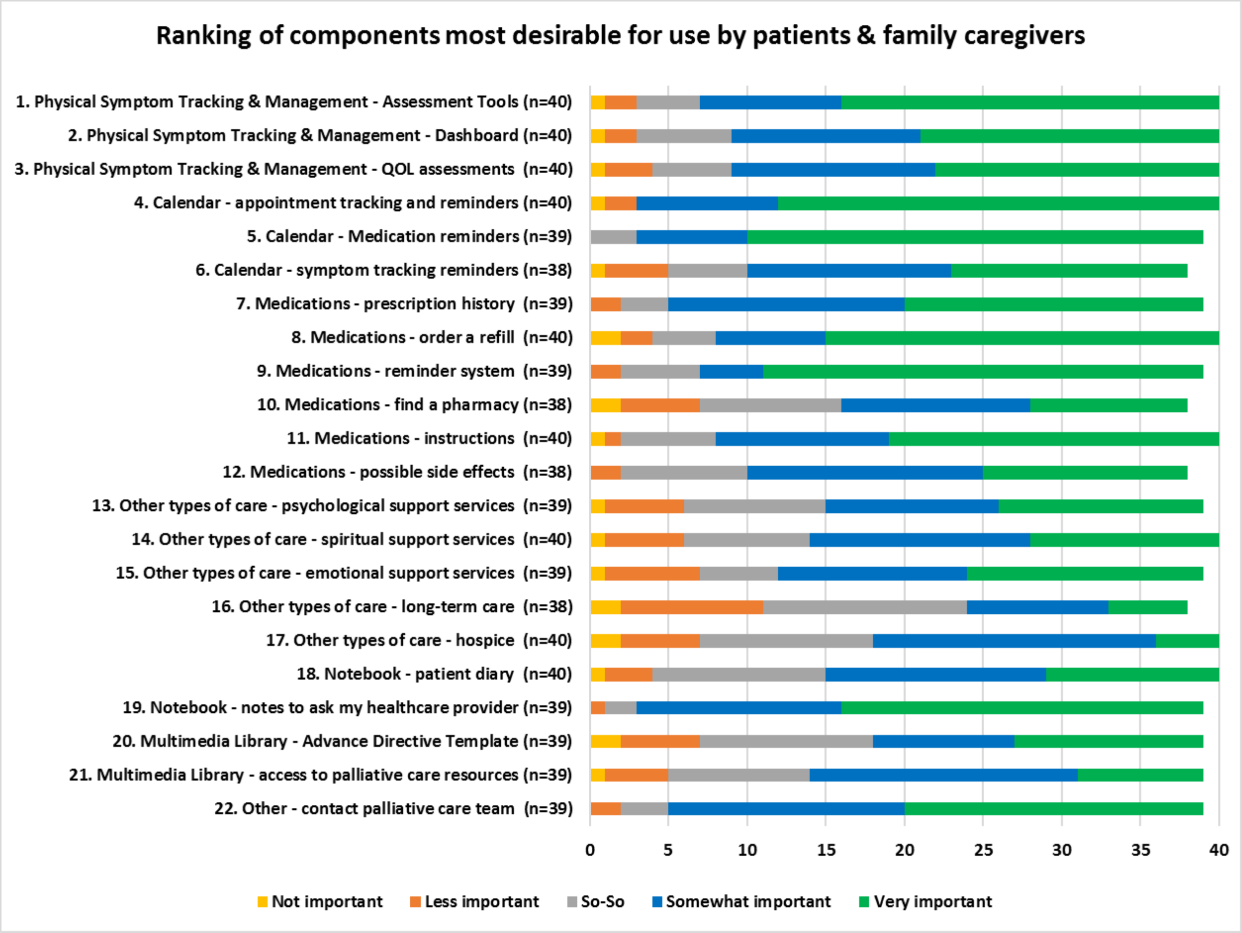
- *Redbox, I can reserve a movie at any location and just want my card to pick it up.*
- *Walgreens, because all I have to do is click and it will refill my prescriptions.*
- *Podcast, Fit bit, banking.*
- *Facebook to connect with friends far and wide.*
- *iPhone*
- *Social media apps, can interact with family and friends*
- *Genius scan*
- *Google. It is all encompassing in our use it throughout the day for various needs.*
- *Instagram, enjoy images*
- *Weather app*
- *Makes life easier, more organized and efficient*
- *Podcasts, subscription-based and I learn something while being entertained*
- *GPS*
- *iPhone*
- *Cozi*

Question 6 (n=42): Subjects were asked if they have ever downloaded and used a medical or health app on their smartphone or tablet.

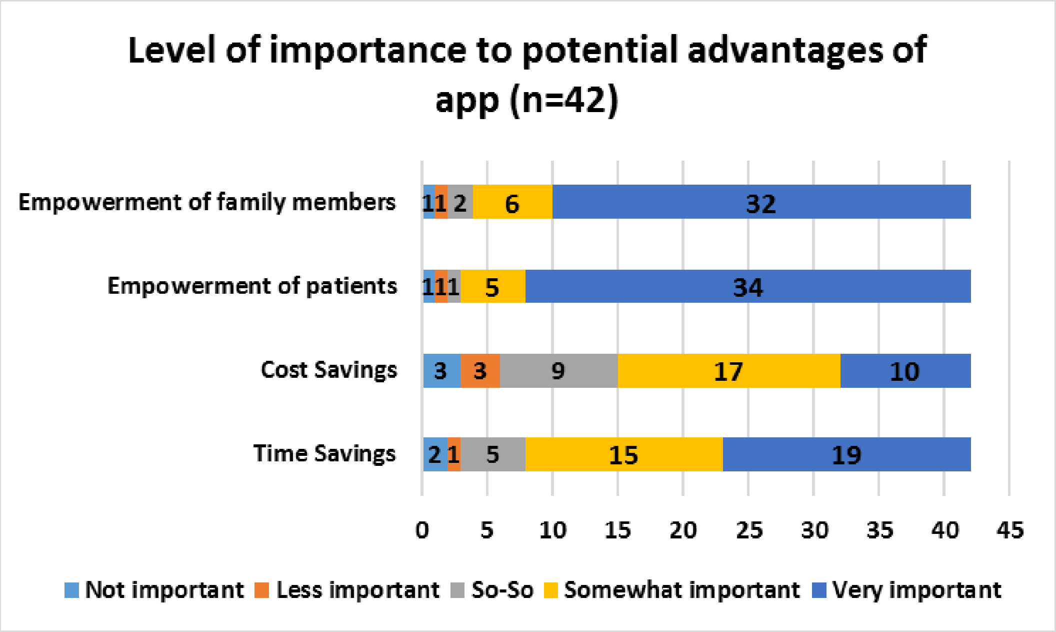
Question 7 (n=42): Subjects were asked if they have experience with patients who use medical apps on their smartphone.



Question 8: Subjects were asked to assign a level of importance to components in a phone app that they consider most desirable for use by patients and family caregivers. Components were ranked based on a five-point Likert scale.



<u>Question 9 (n=42):</u> Subjects were asked to assign a level of importance to potential advantages of using a palliative care smartphone app using a five-point Likert scale.

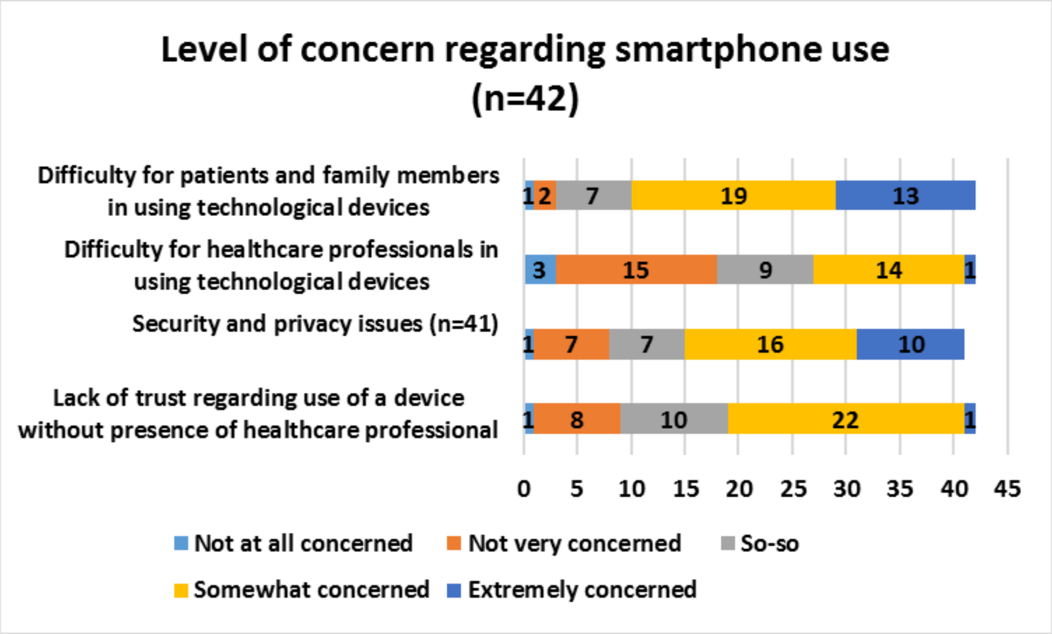


A qualitative field was added to allow subjects to provide more detail to their answers.

a. <u>Other (please describe (n=5).</u>

- *Availability of information, easy access to info. Allows for more accurate monitoring of patient's symptoms.*
- *Accurate data to work from.*
- *Patients and families will feel better informed and better able to articulate their needs or concerns.*
- *Convenience for contacting team, requesting refills.*
- *Feel it depends on the goal of the app but I think mostly patient centered is most helpful.*

Question 10 (n=42): Using a 5-point likert scale, subjects were asked to assign a level of concern about use of the smart phone.

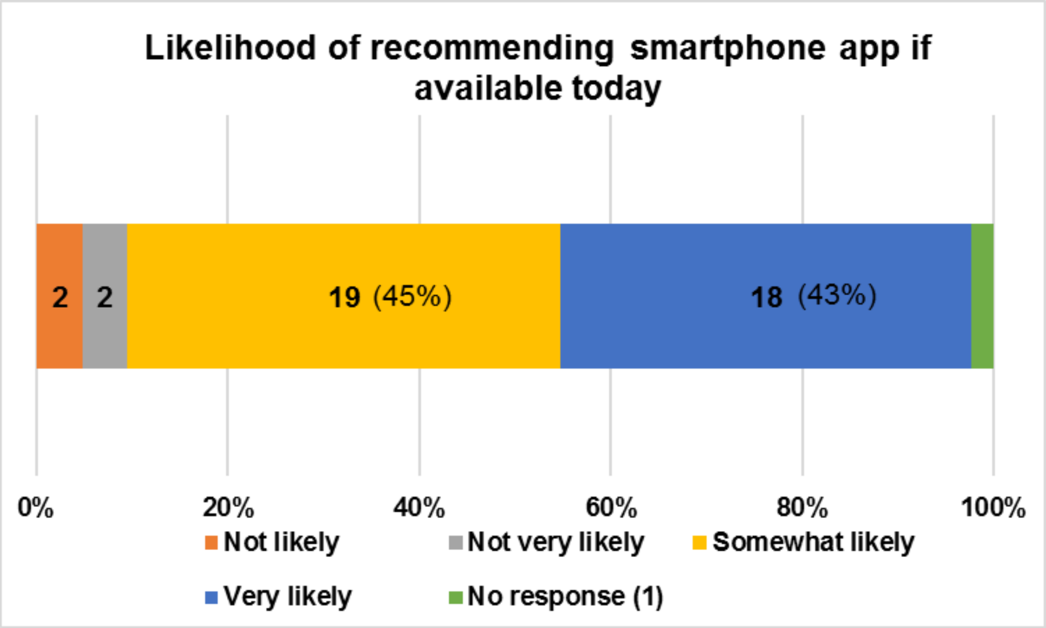


A qualitative field was added to allow subjects to provide more detail to their answers.

a. Other (please specify) (n=5):

- *May overwhelm the provider if too much information is collected. Or may overwhelm the patient.*
- *If the app contains contradictory information to what the MD, PA, or NP is telling the patient.*
- *Older patients and doctors will need training on how to use the app.*
- *I would not see the need or relevance.*
- *I work with the pediatric population, technology is generally not a barrier. I think the one significant barrier I foresee is language, we have a significant proportion of non-English speakers (primarily Spanish, but other languages are a consideration).*

Question 11 (n=41): Using a 4-point likert scale, subjects were asked how likely they would be to use or recommend the app if available today.



Qualitative (Open-ended) Survey Questions

Question 12 (n=8): Subjects were asked to offer their response on why they were not likely to use or recommend the smartphone app:

- *I wouldn't want to have to train them on it. If there was someone else to do that I might recommend it.*
- *It seems impersonal.*
- *Not applicable.*
- *Not useful on a daily basis.*
- *Would depend on the patient and caregiver, my perception of their comfort level.*
- *No substitute for direct conversation.*
- *My clinical practice is focused on young rather healthy kids.*

Question 13 (n=15): Subjects were asked to recommend additional information, education, resources, or tools that could be integrated into the smartphone app:

- *Information on hospice and palliative care benefits and services and the out of pocket costs for patients*
- *Tips for how to create a plan of care for yourself or loved one. Tips for how to recognize when a Palliative Care discussion needs to shift to a Hospice care discussion.*
- *Resource database (e.g., other aps that are helpful or links to other info that would be helpful). Data dump so the patient can print diary or symptom tool.*
- *N/A*
- *Language options (as noted above).*
- *Assistance in teaching patients how to utilize the app if they are not very tech savvy (detailed instructions, videos, etc.)*
- *Nutritional information (negative with certain medications, and helpful with certain illnesses)*
- *I think mostly information about medication ask reminders. But also notes on other support services may be helpful. And basic information (not super detailed but meant to spur conversation) about certain things like hospice, advanced directives, health care agent, etc.*
- *Links to online Support groups - Code status*
- *Spiritual support resources (such as CareNotes) Gone from My Sight: The Dying Experience Information on The Five Wishes*
- *Not sure, have not given this a lot of thought*

- *I think it would be very useful if the information added by a patient in this app could be seen by the physician*
- *Health history of surgeries etc.*
- *When to alert your PCP, Specialist or Palliative Care Team*
- *Secure messaging to the team, video vignettes or lessons*

Question 14 (n=18): Subjects were asked to offer their advice on what they see as features of a good app that are relevant to outpatient palliative care services:

- *Hospice/palliative care locator where patient/family can input their zip code to obtain a list of facilities within a selected radius.*
- *A GREAT app would allow patients the option to set an appointment right there in the app. They could see available timeslots for clinic and choose whichever fits their needs/availability.*
- *Simplicity is key*
- *Simple interface with easy access.*
- *Simple and clean looking. Design with current trends. IPhone and Android*
- *None*
- *Security and ease of use would be important to most busy parents (check box: symptoms present or not present, etc). A notebook option would be very important, too.*
- *Simplicity - Ability to ask questions, like the CVS app*
- *Connect hospital and community providers. Connect patients to their lead physicians and documents that are important to go across multiple health settings.*

- *Most about meds, appointment reminders, keeping things on track. How to contact people you need, and some basic info on other resources.*
- *Very easy to navigate, appealing visually, simple, large font for older people.*
- *Ability to email chaplain (or other team members) to ask a question or request a call back.*
- *Two way video conferencing*
- *I find technology a poor substitute for human interaction/communication.*
- *User friendly and simple*
- *Intuitive, for free, secure*
- *Easy use for a non-medical person (i.e. low health literacy); adaptable for illiterate patients/families*
- *The primary thing people in outpatient care want from their team is access--anything you can do to make that better is a good thing.*

Qualitative Discussions with Subject Matter Experts

The PI presented an overview of the smartphone app and discussed its applicability with five subject matter experts (SME) representing the domains of ethics, socio-cultural (patient advocacy), technology, economics, and legal (compliance). Four discussions were conducted face-to-face and one took place over the telephone. Discussion lengths ranged from 45 to 90 minutes, averaging 60 minutes. Two discussions were recorded and transcribed, with detailed notes summarizing the other three.

Ethical Domain

The Ethics SME is a Professor of Research Ethics at Emory University School of Medicine, with experience in conducting empirical quantitative and qualitative ethics research, focusing on health literacy, early drug development, informed consent, biobanking, return of results and genetic testing. The Ethics SME was presented with an overview of the smartphone app, and asked to provide feedback from an ethical perspective on the use and integration of the components.

Physical Care Needs

- Suggested using a 5-point instead of a 10-point scale for symptom assessment. Base this on CTCAE criteria for the 12 most common symptoms experienced in chemotherapy
- Automate a weekly email reminder system requesting the patient/family caregiver to provide input if none has been entered within the past 7 days.
- If symptom assessment worsens by +2 points over a specified amount of time, or reaches a grade of >3, the app will auto-send a notification to the healthcare team informing them of the increase in severity of the symptom.
- Incorporate depression/anxiety into symptom management.

Psychological/Emotional/Spiritual Care Needs

- Incorporate a depression-scale measurement tool into this component, and move to the “symptom management component”.
- Use a 5-point scale for symptom assessment for depression, if depression increases by 2 points over a specified amount of time, or reaches a grade of >3, the app will auto-send a

notification to the healthcare team/social worker informing them of the increase of severity of the symptom.

- How to embrace everyone regarding the “Spiritual” app subcomponent? This will be difficult to parse out with respect to multiplicity of religions as well as those who do not espouse a faith community.

Care Planning & Coordination

- Completion of an Advance Care Directive will require a face-to-face meeting with a counselor, social worker or attorney, in order to review and understand the document among all parties. Completion of ADs can still be difficult to enact after they have been completed – often the family dynamics involving multiple children or family members can be problematic and challenging in a stressful environment.

Communications

- A multi-media library may present the patient or caregiver with too much information.
- Present all resource materials on a 6th grade level in order accommodate low health literacy knowledge.
- If videos are offered as resource materials they should be 3 minutes or less in viewing length.

Socio-Cultural Domain

This SME is a former cancer patient who was successfully treated at Winship Cancer Institute of Emory University, and who has been a patient advocate on behalf of Emory University for over ten years and the National Cancer Institute. The SME is currently a member of two national steering committees that support development of clinical trials by presenting the patient perspective during concept evaluation and related activities. The Patient Advocate SME was presented with an overview of the smartphone app and asked to provide feedback from a patient advocacy perspective.

- Embed a Nurse Navigator onto the healthcare team to function as a contact person for patients and caregivers, and as a trainer for both the healthcare team and patients and caregivers on how to use the app.
- Add a Financial Advisor to the healthcare team.
- Offer links to support groups.
- For text editing, suggests the ability to highlight (similar to that of Kindle). Would be helpful to cut/paste from website resource into patient diary.
- Create a shared portal for the PCP and PC team to enhance communications between patients and family caregivers.
- Incorporate a nutrition log into the Patient Diary for meals and reminders as nutrition is vitally important to patients.
- Would like the ability to order medical supplies.
- Calendar: would like the ability to track when pharmaceutical patches (pain) are applied.
- Suggests an Emergency Contacts list.

Technology Domain

The Technology SME has experience working as a Senior Web Developer with Emory University Web Design Services and has extensive knowledge and proficiency in creating, designing, testing and deploying smartphone apps. The Technology SME was presented with an overview of the smartphone app, and asked to provide feedback from a developer/graphic user interface perspective on design, functionality, development and integration of the components.

- App components should reflect the individual’s daily use.
- Medications component: The medications component will require another security level as sub-components will require personal health information input. Recommends building this component into daily management of symptoms rather than as an individual component.
- Multimedia library: this component should function as a background element to all components, with the option to view more information if desired.
- Keep business objectives in perspective when designing the graphic unit interface
- App design must reflect the unique user journey. Create two to three personas: one for the patient, one for the family caregiver, and one for the healthcare provider. This reflects the unique user journey in the smart phone app.
- When building the feature set, the persona should ask “as a user (…), I want to do (something) so that I will be able to do (something)”. The personas should also be designed for males, females, young adults and older adults.
- When designing a smartphone app, a mobile user journey map is first created. This is a design framework that facilitates the mapping of the sequence of user activities and touch points that characterize a mobile app user experience. A journey map is a graphical visualization that charts the users’ level of confidence and patience when performing various touch points in a mobile interaction flow. This tool helps the creator look at the complete mobile app user experience from the users’ perspective, from understanding their situation, actions, thoughts, feelings, emotional experience to touch points that allow your users to reach their goals. The graphic interpretation incorporates user expectations and business requirements.

- When building a smart phone app a minimal viable product is first created, incorporating the most essential business processes to include.
- Application Program Interfaces (API) key allows the use of application program interfaces some have user caps example google maps requires term of use and some of the API keys will also have expiration dates I also version control of API updates
- Best practice for app development is to deploy Google App Analytics in tandem with the mobile app. This allows the developer to evaluate the effectiveness of the app, how users interact and engage it, and discover any technical issues or UX problems throughout the development cycle. Google's App Analytics tool aids in collecting, processing, configuring, and reporting website and mobile app data, producing results that provide actionable insights about the use of the website or mobile app. The developer can also build a feedback function into the app so that the user can be prompted to comment on the functionality of the app when testing the app to see if it was working as intended or not.

Economic Domain

The Economics SME is a former CDC Epidemiologist and current the founder and Chief Executive Officer (CEO) of a commercially available smartphone medical app. The Economics SME was presented with an overview of the smartphone app and asked to provide feedback from an entrepreneurial perspective regarding the collection and use of health data, and development of components that support data collection.

- Self-care and monitoring has become very important to a large segment of the US population
- For a mobile app to work effectively it must be able of capturing various streams of data

    - Input by user
    - GIS coordinates (contextual) – time and place
    - Duration and frequency of data point (for example: pain)
- Identifying components of the app – identify inputs needed to make it work
- Data storage, encryption, piggyback, API
- Supply chain management for administering layers in developing app
- SBIR grants, angel investors, how to partner with someone
- How to program app: Apple Health Kit and research and care kit
- Android research stack (guide on app development) – open source
- Service delivery: smartphone PC app
- What do I want to deliver with my app? Better QOL. Use pieces that are already available.
- Active data (how are you feeling right now)? Uses GPS input (place & time)
- Prospective collection of data.

Legal Domain

The Legal SME is a Research Compliance Manager with Emory University's Office of Compliance, which ensures that Emory University's activities adhere to the highest legal, professional, and ethical standards and assists with complying with the laws, regulations and policies that govern research and higher education institutions through education, assessment, assistance with policy, process development, auditing and monitoring. The Legal SME was presented with an overview of the smartphone app, and asked to provide feedback from a compliance perspective on the use and integration of the components.

- Psychological Component: Harder to quantify depression

- Care Planning & Coordination: Portability of an Advanced Care Directive is very important.
- Overall: Where is source of data that is included in the app? How to get information from healthcare team that is specific to patient? Not customized.
- The app must address the needs of both patients and caregivers as these will have distinct and separate needs. To accommodate this the app must be capable of assigning roles to users.
- Recommended having less component options.
- Record keeping and history are an asset, but this may be too much information for the healthcare team to manage. If a patient sends a report every 12 hours, unfair expectation that the team will be able to respond to each and every report. As an alternative, should tie report to an in-person visit.
- Technology can be a barrier to the population. Other concerns include device security and who has authority and access to use it.
- Have a patient portal exclusive to palliative care with a system set up to handle this information
- Do not want to encourage patients to provide information to the healthcare provider exclusively through smartphone.
- Will need to train healthcare team on inward-facing use of app.

CHAPTER 4: ANALYSIS AND DISCUSSION OF RESULTS

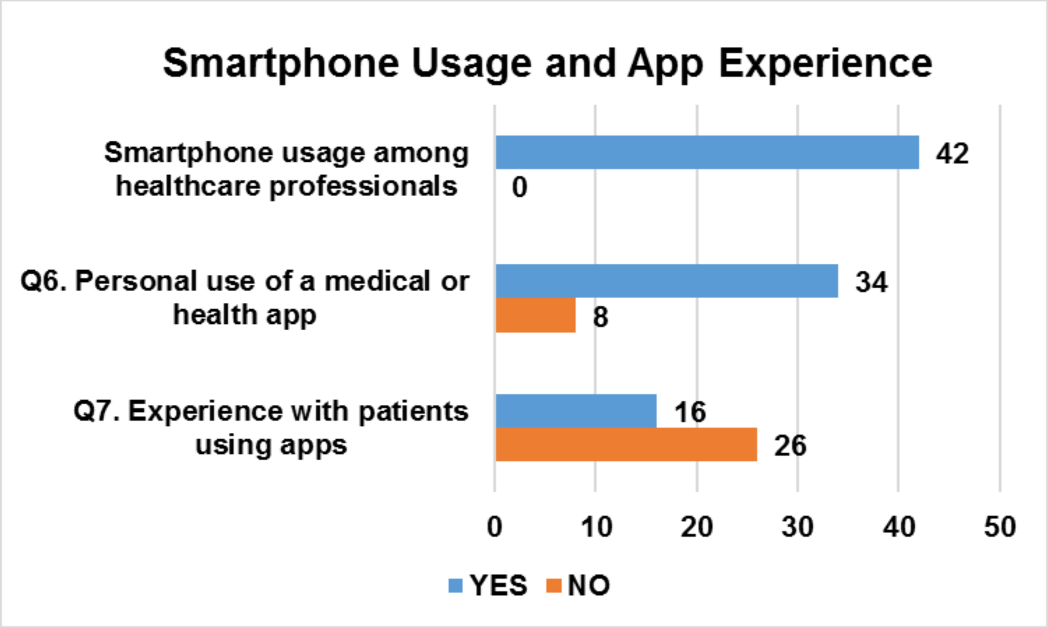
Introduction

A two-part mixed methods research study was conducted to obtain a greater understanding of desired features, content and functionality on the theoretical design of a palliative care smartphone app to be used by patients and family caregivers in an outpatient setting. First, a research survey was conducted in a cohort of palliative care healthcare professionals at Emory University in Atlanta, Georgia. It collected user preferences on selection of components and also explored respondents' exposure to mobile technology. Second, a cohort of five subject matter experts were presented with wireframe mockups of the initial design of the app's components, and were asked to provide feedback on the use and integration of the components from their respective sets of expertise. Results of this study will help guide development of key features and components that will be incorporated into a smartphone app to support and complement delivery of existing outpatient palliative care services to patients and family caregivers.

Analysis of Findings

Respondent Distribution and Exposure to Mobile Technology

The professional title for the majority of respondents was physician/researchers with advance degrees (n=16: MD, PhD, combination). Advanced Practice (NP, PA, MS, MSc, MPH) and Support Services professionals (LCSW, LMSC, RD) represented the second highest number of respondents (n=10 each). Exposure to mobile technology was high: 100% of this group own a smartphone, 81% reported owning a PC, 74% reported owning a tablet, and 100% of respondents have used an app on a smartphone or tablet. Half of this group listed a favorite app or described why it was their favorite. Almost 81% of the respondents reported having previous experience with a medical or health app, but only 38% reported having experience with patients using medical or health apps. When asked about their favorite app, only one respondent noted a medical app as a favorite. This cohort of respondents were technologically savvy in terms of their knowledge and use of mobile technology through an assortment of devices.



Ranking of components most desirable for use by patients

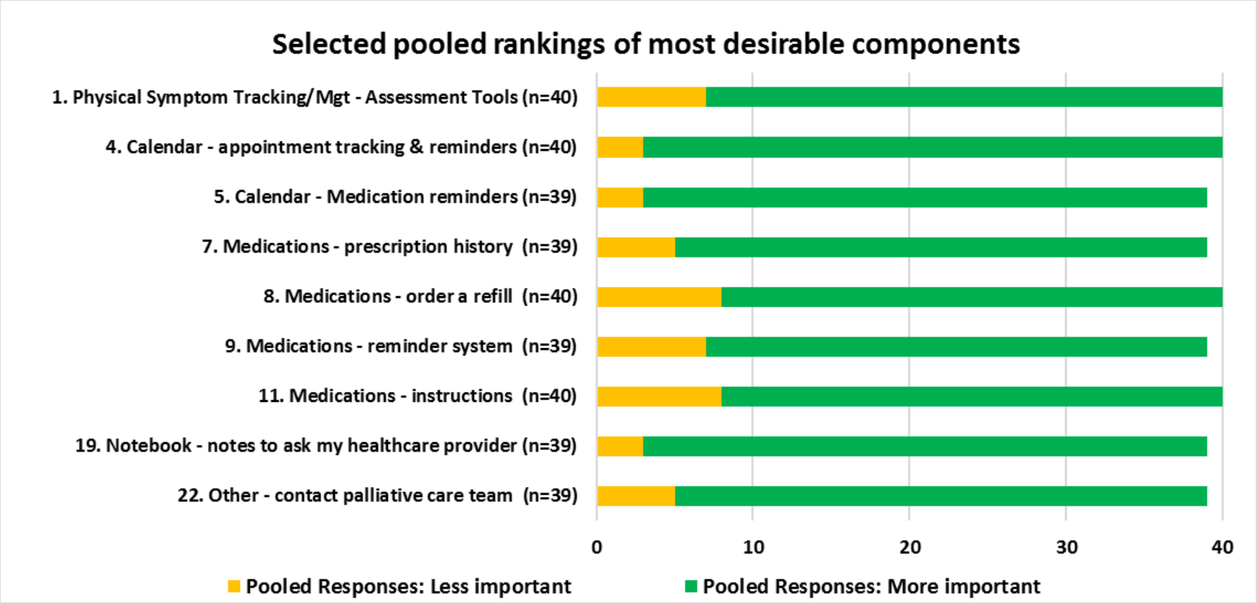
The overall response rate to this set of questions was 93.4%. The most important subset of components ranked by respondents as *very important* (above 50%) were:

1. Assessment tools for physical symptom tracking and management: 60% (n=24/40)
2. Calendar:
   a. Appointment tracking and reminders = 70% (n=28/40)
   b. Calendar - medication reminders: 74.36% (n=29/39)

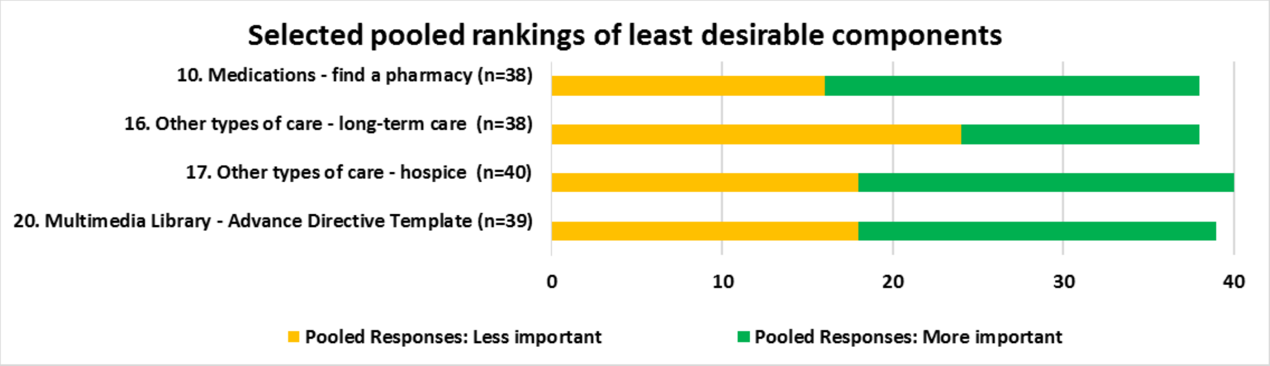
3. Medications:
    a. Order a refill: 62.5% (n=25/40)
    b. Reminder system: 71.79% (n=28/39)
    c. Instructions: 52.5% (n=21/40)
4. Notebook – notes to ask my healthcare provider: 58.97% (n=23/39)

Pooling the *somewhat important* and *very important* categories, a secondary analysis of this dataset identified two additional sub-components that were favorably viewed by respondents in importance. They include:

1. Medications:
    a. Prescription history: 87.18% (n=34/39)
2. Other – contact the palliative care team: 87.18% (n=34/39)



Of note, pooling the three sub-categories of *not important, less important* and *so-so*, a secondary analysis of the same dataset identified four additional sub-components that were the least desirable (greater than 40% pooled responses). They include: *Medications – find a pharmacy* (n=16/38 [42%]); *Other types of care – long-term care* (n=24/38 [63%]) and *Hospice* (n=18/40 [45%]); and *Multi-media Library – Advance Directive Template* (n=18/39 [46%]).



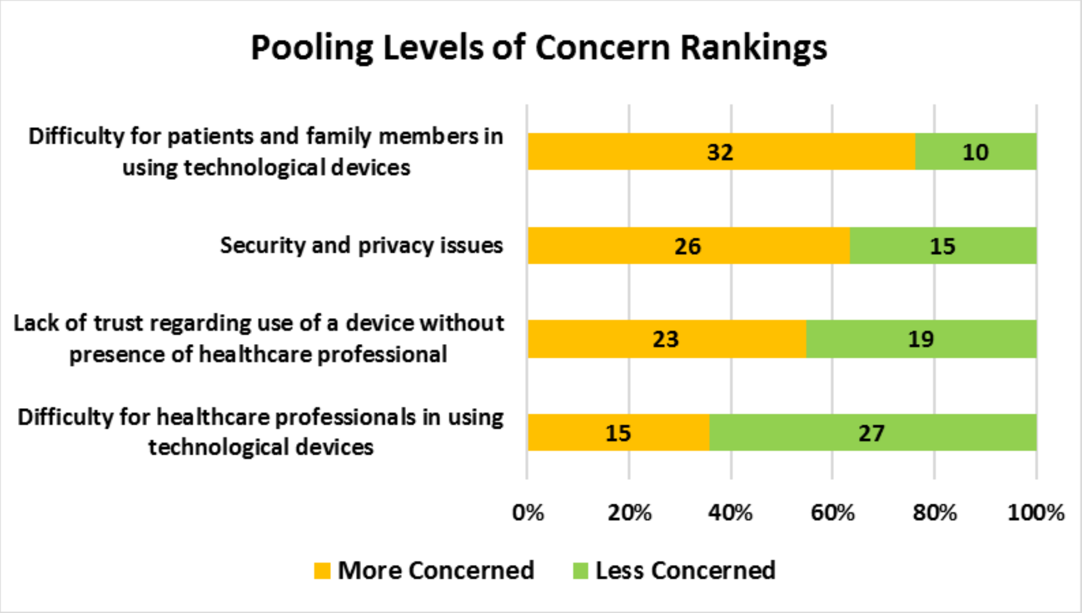
<u>Level of importance to potential advantages using a palliative care smartphone app</u>

The majority of respondents indicated that empowerment of patients (n=34/42) and family members (n=32/42) were very important, while savings in cost and time were not ranked as high. The favorable rankings indicate from a healthcare provider viewpoint the value of empowerment and patient-centeredness, and its potential return on satisfaction and quality. The lesser-ranked savings in cost and time could indicate the value healthcare professionals place on the quality of time delivered to their patients and family members, and may be reflective as a positive attribute of their preference towards ensuring overall patient satisfaction.

The qualitative field provided more background on the patient-centeredness of the app being a positive attribute. While only five respondents provided additional information, their responses indicate they believe the app would be capable of providing easier access to information, and improving communications between all parties.

Level of concern regarding smartphone app use

This question explored the level of concern regarding technical difficulties or security and privacy issues that might be faced by patients, family members and healthcare professionals when using the app, and using the app without a healthcare professional being present. All respondents answered this question (with the exception of one respondent in the security and privacy issues sub-category) and ranked their level of concern. Pooling the *extremely concerned* and *somewhat concerned* categories, 76% of respondents were more concerned about technological difficulties that patients and family members might experience when using the app, rather than by healthcare professionals (35.7%). Respondents also felt that security and privacy issues were of concern (61.9%), but were less concerned about using the app in the absence of a healthcare professional (54.7%). Of note is that respondents were less concerned about the difficulties they might face when using technological devices. This observation pairs with Survey Question 2 in which 100% of the respondents reported having used a smartphone or tablet, in addition to Survey Question 8 in which 81% of the respondents reported having personal experience working with a medical or health app.



The qualitative field provided more background about these concerns with technology – namely that the information provided by the app may be overwhelming to both groups of users, especially if the information contradicts what the healthcare team has communicated to the patient and family caregivers. It also highlighted the need for providing training on how to use the app to patients – especially older ones – as well training the healthcare team so that lines of communication and understanding are positively maintained.

Likelihood of recommending the smart phone app

This question explored the likelihood of healthcare professionals recommending the app to patients and family caregivers should it become available today. All but one respondent answered this question. The answers were split between very likely (43.9% (n=18)) and somewhat likely (46% (n=19)).

The qualitative field provided more background about these concerns – namely that respondents were concerned about additional responsibilities being added to the healthcare professional workload, that the app may not directly support the relationship between the healthcare team and the patient, and that it may be perceived as being too impersonal.

Recommendations and Advice

The last two questions were open-ended. The first asked for recommendations about additional components to include in the app, and the second advice on salient palliative care features. Language options, previous health histories, financial (out-of-pocket) costs, and nutritional guidance were additional recommendations, among others. Simplicity, ease of use and navigation, user-friendliness, being able to instantly access and connect information between multiple health settings, and making the app adaptable for those with low health literacy were noted. However, one respondent indicated that technology is a poor substitute for human interaction and communication, which again underscores the value placed upon the doctor-patient relationship.

Discussions with Subject Matter Experts

Five subject matter experts (SMEs) were identified using the PESTEL design. SME expertise represents the domains of Ethics (E), Socio-Cultural (S), Environmental (E), Technology (T), and Legal (L). Discussions with subject matter experts ranged in length from 45 to 90 minutes, with SMEs providing comments and guidance on design and use of the app's components.

Symptom Management and Assessment

It was suggested to replace the 10-point scale for assessing symptoms with a 5-point (0=not present; 1=mild; 2=moderate; 3=severe; 4=disabling), which is a scale similar to the Common Terminology Criteria for Adverse Events (CTCAE), a grading scale used by the National Cancer Institute to grade adverse events that describe the severity of organ toxicity for patients receiving therapeutic treatment for cancer.

The recommendation for this was based on a 5-point assessment system used in a recently published study that assessed patient-reported outcomes using tablet computers in a randomized controlled trial (RCT) (Basch, Deal et al. 2017) conducted by researchers at Memorial Sloan Kettering Cancer Center. In the RCT, patients report their symptoms using the 5-point scale through a web-based symptom reporting system. If symptom assessment worsens by +2 points over a specified amount of time, or reaches a grade of >3, the app will auto-send a notification to the healthcare team informing them of the increase in severity of the symptom. Additionally, if no assessments have been entered within the past 7 days an automatic email reminder system will request the patient/family caregiver to provide symptom assessment input. Primary outcomes from the trial showed an improvement in the health-related quality of life (HRQL) at six months compared to baseline.

Using a simpler tool for assessing physical symptoms, as opposed to the standard 1-10 assessment scale, potentially offers patients and family caregivers an easier approach for the timely monitoring of physical systems. Pairing this with an automated alert system, functionality can be expanded temporally, underscoring the app's objective for ease of use for the patient but also providing timely data. This feature, however, could potentially overwhelm healthcare professionals with too much data, and might need to be modified so as to collect information within a set number of time points over a range of hours or even days.

It was also suggested to use the 12 most common symptoms experienced by patients undergoing chemotherapy in the symptoms management component design, as this component contained too much detailed information requiring input. Overall, the recommendation was to make the Symptoms Management component much less complicated and simpler in design, with options for input of free text and voice recording.

Psychological/Emotional/Spiritual Care Needs

Often patients and family caregivers do not realize they are in psychological distress and in need of counseling, or medical or psychological support services. Caregivers frequently neglect their own health to focus on that of the patient (Girgis, Lambert, et al. 2013). It was suggested to incorporate a depression-scale measurement tool into the physical symptom management component for psychological assessments using the same 5-point scale to assess depression. If depression increases by 2 points over a specified amount of time, or reaches a grade of >3, the app will auto-send a notification to the healthcare team/social worker informing them of the increase of severity of the symptom, and a consult with a LCSW could be scheduled.

Regarding the *Spiritual Care Needs* component, it was noted that it would be difficult to parse out with respect to the multiplicity of religions as well as those who do not espouse a faith community. As alternatives, it might better serve the patient or caregiver in search of spiritual counseling with the ability to link the website of their home faith community to this component, or to provide them with contact information of a spiritual advisor connected to the app's palliative care program, or to simply make a request for spiritual counseling and route the request to the program's counseling center (if one is available).

Calendar/Patient Diary

Nutrition is very important to patients as they progress through treatment and therapeutic interventions. It was suggested to offer a nutrition log as part of the calendar function for tracking meals, and the ability to set reminders to enter data for this component. Another suggestion for adding functionality to the Calendar component was the ability to track when pharmaceutical patches (ex: pain) are applied. This function could also be tied to symptom management and the medications component, and could be tracked longitudinally providing additional correlative data. It was also suggested to enable text editing on the app, especially the ability to highlight, cut and paste text (similar to that of Kindle). The ability to cut and paste text from a website resource into patient diary would be very helpful, and may facilitate communications between the patient and the healthcare team.

Advance Care Planning & Coordination

It was suggested to include Advance Care Planning as an additional component in the app. An important foundation to palliative and hospice care – in advance care planning the patient makes important decisions in advance about the care they would want to receive if they become unable to speak (NHPCO, 2017). It involves legally executed documents intended to be used by the healthcare team, such as an *Advance Directive* (AD) that communicate end-of-life wishes to healthcare professionals, or *Do-Not-Resuscitate* (DNR) orders which informs healthcare professionals to not resuscitate if the heart stops beating. Other documents include a *Living Will* and a *Medical Power of Attorney*. These legal documents provide instructions that help guide healthcare professional and caregivers if a person is terminally ill, seriously injured, in a coma, in the late stages of dementia, or near the end of life. However, portability of ADs is very important, especially when a patient enters a new healthcare setting. Having on hand this type of document aids in planning ahead to get the care the patient truly desires and avoiding any unnecessary suffering. It also relieves caregivers from the burden of decision-making in times of stress, crisis, or grief, and reduces unnecessary confusion or disagreement about possible treatment choices.

However, completion of an AD generally requires a face-to-face meeting with a counselor, social worker or attorney, in order to review and understand the document among all parties. Fulfillment of ADs can still be difficult to enact after they have been completed – often the family dynamics involving multiple children or family members can be problematic and challenging in a stressful environment. A resolution to the dilemma of offering an AD component on the app would be to offer portability of an AD only – allow the import and/or export of executed ADs. This would allow the patient or caregiver the ability to email completed and signed AD documents to healthcare organizations if there is not one on file where the patient is receiving treatment, and would be especially useful and important if the patient has entered several medical facilities that cross county or state boundaries.

Additional Resources

Offering a multi-media library as a separate component in the app may present the app developers and/or host institution with the responsibility of keeping the resource continually active and updated, requiring additional resources and technical support. It was also noted that resource materials should be presented on a 6th grade level in order to accommodate low health literacy knowledge, and any videos offered as resources should be three minutes or less in viewing length. A potential resolution to this dilemma would be to link a resources component to an approved third-party provider via an Application Program Interface (API). Immediate examples here include Winship Cancer Institute of Emory University's *Cancer Quest* (https://www.cancerquest.org/), the Center to Advance Palliative Care *Get Palliative Care* (https://getpalliativecare.org/resources/) and other national palliative care organizations.

Communications

To enhance communications between patients, family caregivers and healthcare providers, creation of a shared data portal between the patient and the primary and palliative care teams was recommended. Patient web portals are password-protected online websites offering patients 24-hour access to personal health information from anywhere with an Internet connection. Patients create an account using a secure username and password, and can view health information such as recent doctor visits, discharge summaries, medications, immunizations, allergies and lab results. Additional services allow patients to exchange secure emails with their health care teams, request prescription refills, schedule non-urgent appointments, update contact information, download and complete forms, and view educational materials (HealthIT.gov. 2015). A patient portal can facilitate better communication by providing convenient and secure access from the comfort and privacy of the home or office. It is possible to link a patient portal to the app, but must be done through a HIPAA-compliant server to ensure secure messaging between the patient and healthcare team. This feature, however, will require additional resources, especially if a patient portal is not available at the institution hosting the smartphone app.

User Training

Another recommendation was made to include a Nurse Navigator on the palliative care team who is tasked with the additional responsibility of training patients, family caregivers, as well as healthcare professionals on how to use to app. Typically the nurse navigator's role is to assist patients through hospital and human services bureaucracies. Among their many duties, Nurse Navigators provide psychosocial support, assist patients with treatment decision making, provide insurance assistance or make referrals; transportation coordinate services, track interventions and outcomes; and build relationships with other navigators involved (Shockley 2016). As a contact person between patients and healthcare providers, the nurse navigator would serve as a resource for both in training and utilization of the app. However, this position would require additional resources if there is no one assigned to this role on the palliative care team.

Technical

Concerns about the privacy and security of patient data on the app are well founded. Technical safeguards will need to be put into place to protect personal health information (PHI) that might be stored on the device. To ensure HIPAA compliance, tools for data encryption and decryption, implementing security access controls with a unique user ID and PIN code for each user, implementing user roles and permissions for access or contribution to stored content, and procedures for data authentication will be necessary. Additional safeguards to ensure the safe transmission of data and/reports should be done through Hyper Text Transfer Protocol Secure

(HTTPS) - a secure version of HTTP which is a protocol over which data is sent between an internet browser and the website that you are connected to, and Secure Sockets Layer (SSL), a standard security protocol for establishing encrypted links between a web server and a browser which is needed for online communications. Additional safeguards include assigning a passcode in tandem with user roles in order to access and use the app.

Discussion

Strengths

A distinct advantage of the app is its prospective collection of data at the point of care, which potentially can provide the healthcare team the opportunity to deliver more personalized services when they are actually needed, thus the potential to improve the quality of life and health-related outcomes, reinforcing the tenets of palliative care.

Using the app in a home setting (or away from a medical facility) is another potential benefit as patients and family caregivers' desire and are motivated to self-manage their symptoms. Another benefit is the ability to offer services such as symptom assessment and to triage patients outside of business hours and/or outside of geographical boundaries.

There is also the possibility that data entry mistakes might be reduced by allowing patients or family caregivers to enter the information directly at the point of care, and to transmit information (or keep notes) which can help strengthen communications between the patient and the healthcare team in times of stress.

Another benefit the app may provide is the ability to nudge patients and caregivers in the direction of contemplating and making decisions about the type of care they wish to receive should they become incapacitated. Completing advance care directives and having these sets of documents available at any point of care would be invaluable to the healthcare team, and through the app it may be able to prompt much needed family discussions regarding these issues, further circumventing stress and anxiety to the family when a positive health outcome may not be possible.

An effective smartphone app requires an understanding of the populations that will use it, and so to accommodate this the app must be capable of assigning roles to users. Representing the outward facing side will be the patients and family caregivers, and on the inward facing side the palliative care team. Each set of users will have unique sets of expectations, so all components of the app will need to be modeled incorporating their input to ensure the app's overall use and functionality.

Study Limitations

Some of the respondents in the survey were concerned that use of the app by patients and family caregivers "*may overwhelm the provider if too much information is collected, or may overwhelm the patient.*" While record keeping, history and the ability to output reports are an asset, this may provide too much information for the healthcare team to effectively manage. For example, if a patient produces and sends a report every 24 hours, it presents an unfair expectation to the patient that the team will be able to respond to each and every report. As an alternative, reports can be automated and sent prior to an in-person visit.

Another challenge with the ability to collect and report data on a daily basis is to not encourage patients to provide information exclusively to the healthcare provider through the app. Data captured should reflect certain time points in the disease and treatment trajectory, but should not circumvent the healthcare's team of discussing and assessing the patient's condition with them in face to face meetings.

An unintended and potentially undesirable consequence might occur by providing the patient or caregiver with access to too much information through the ability to review retrospective data collected by the app. This may induce a negative effect, especially if the patient's quality of life begins to or continues to decline, and might prompt the patient to forego using the app if there is no improvement to their condition.

Results from this study are generalized to inward facing users of the app (healthcare professionals), rather than the outward facing users (patients and family caregivers). Additionally, the survey was conducted in a single academic medical center among a small subset of palliative care professionals in a fairly small sample size (n=42), and not all respondents answered every question on the survey.

Future Directions

Through this initial feasibility study, core functionalities of the app have been identified based upon inputs from survey respondents and subject matter experts (Phase 1). The next steps involve multiple stages, starting with selection of the initial operating system for the app (Android, iOS). Technical components will be constructed through creation and design of user interface flows, detailed wireframe mockups, framework selection, and writing code (Phase II). Testing and deployment of the app will be an iterative process, working with both inward facing users (healthcare team) as well as with outward facing users (patient and family caregivers), to be assembled as focus groups in order to provide and gather ongoing feedback on functionality (Phase III), before the app is formally launched (Phase IV). This phase would be conducted as a clinical research study through a randomized controlled trial, in a population of patients utilizing palliative care services through an outpatient clinic. After use of the components have been studied and analyzed for frequency and duration (Phase V), other components can be added, revised or deleted, to enhance to app's overall sophistication and utility in a V2 model.

Conclusion and Recommendations

This research study was novel and established some initial perceptions for the use and functionality of a smartphone app to be used in an outpatient setting. A survey deployed to a subset of palliative care professionals identified components that were desirous and some that were not. Discussions with subject matter experts also identified additional features and functionalities of the app that were desirous or should be approached with more attention and care. After further analysis of results from the two sets of quantitative and qualitative responses, the initial design of the mobile app would be changed significantly after implementing these revisions.

The app must address the needs of the patient and caregiver as well as the healthcare team members delivering palliative care services, as these users have distinct and separate needs and expectations. The app must be easy to use and to navigate. It must also adhere to best practice standards, not only in terms of good clinical practice but also technology, information security and privacy as well. One of the goals of the app is to make healthcare management easier, more organized and efficient, and should not overwhelm patients, caregivers, and the healthcare team. It should offer users opportunities to learn something if desired, and be reflective of the individual's daily use of the app.

As previously indicated, some respondents felt that healthcare services cannot be delivered effectively through a technological device, and that administration of services through the app would be perceived as lacking in compassion and empathy by healthcare professionals, and that nothing can replace the doctor-patient relationship experienced through face to face meetings. However, as baby boomers age and the number of people entering the healthcare system rises, along with the increasing use of outpatient palliative care services as well as staffing challenges and shortages in the field of palliative care, extending selected palliative care services beyond urban or suburban areas can potentially alleviate some of the supply and demand challenges.

Findings from this study have shed light on the initial design of the app. For it to be successful and achieve uptake and continuity, it is important to consider how to streamline development of the components so that they are easily understood, present few barriers, and gather useful health data. Consideration must be given to design and content of the app, with a minimalistic approach taken. The final app should be user friendly, patient-centered, and minimally burdensome to clinicians.

While this study revealed some concerns about the impact on the doctor-patient relationship, it is clear that these concerns can be managed--many important tasks can be supported by a palliative care smartphone app in an outpatient setting. These tasks include: information and time management; health record maintenance and access; communications and consulting; reference and information gathering. Overall the app can aid in patient management and monitoring, and inform clinical decision-making. Offering the convenience of a smartphone app at point of care hopefully will increase efficiency of services, contribute to better health outcomes, and improve patient satisfaction as they travel through a palliative care setting.

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GLOSSARY OF TERMS

Caregiver	A family member, partner, or close friend who helps care for a person who is suffering from a disease, disability, impairment or mental disorder, or is elderly, and is unable to fully care for themselves.
Hospice Care	A type of specialized care for the terminally ill.
Likert Scale	A psychometric rating scale used in research survey questionnaires to measure attitudes or opinions among a group of respondents.
Morbidity	The condition of being diseased. A person with co-morbidities is a person who has two chronic diseases or medical conditions simultaneously, while a person with multi-morbidities is a person who has three or more simultaneous chronic diseases or medical conditions.
Mobile applications	A software program that can be downloaded and run on a mobile device such as a smartphone or tablet, rather than a desktop or laptop computer.
Quality of Life	A subjective reference standard measuring a person's relative state of health and well-being, both as negative and positive features of life. It measures one's satisfaction with life in general, and includes physical health, family, education, employment, wealth, religious beliefs, finance and the environment.
Palliative Care	Specialized care given to people living with serious, chronic, or terminal illness that focuses on providing relief from the symptoms and stress of that illness.
Patient Centeredness	Healthcare given to a patient that is respectful of and responsive to the patient's preferences, needs and values, and ensures that patient values guide all clinical decision making.
Randomized Controlled Trial	A type of clinical research study in which individuals are randomly assigned to receive one of two or more clinical interventions, of which one of the interventions being measured is a standard of comparison or control (a standard practice, a placebo, or no intervention at all).
Smartphone	A mobile phone (communications device) that is also capable of performing computer functions and possesses an operating system that is capable of connecting to the internet and downloading and running a mobile application.
Subject Matter Experts	A person who is an expert or authority in a particular field or topic, and who possesses professional knowledge regarding a specific business process, function, technology, machine, material or type of equipment.
Symptom Management	Care given to improve the quality of life of patients who have a serious or life-threatening disease.
Symptom Burden	The subjective experience by a patient of the severity of a disease or chronic illness and the patient's perception of its impact on his or her overall health status.

APPENDIX 1: Survey

Introduction

You are being asked to provide feedback on the design of a palliative care smartphone app to be used by patients, family members and caregivers in an outpatient setting. The goal of this survey is to identify user preferences among palliative care healthcare professionals that may guide development of key features and components incorporated into the a smartphone app that supports and complements existing outpatient palliative care services. This survey is completely anonymous.

1. Please select one that represents your professional title

○ Physician/Researcher - Advanced Degree (MD, PhD, combination)
○ Advanced Practice (NP, PA, MS, MSc, MPH)
○ Support Services (LCSW, LMSC, RD)
○ Nurse (RN, BSN, MSN)
○ Other (please specify)

2. Please select the palliative care setting you currently work in

○ In-patient setting
○ Out-patient setting
○ In-patient/out-patient/long-term care
○ Other (please specify)

3. Which of the following devices do you own (more than one answer is allowed)

☐ Smartphone
☐ PC
☐ Tablet
☐ Smart TV
☐ None of these
☐ Other (please specify)

4. Have you ever used an app on a smartphone or tablet?

○ Yes

○ No

5. Do you have a favorite smartphone app?

○ No

○ Yes (please describe why this is a favorite)

☐

6. Have you ever downloaded and used a medical or health app on your smartphone or tablet?

○ No

○ Yes

7. Do you have experience with patients who use medical apps on their smartphone?

○ No

○ Yes

8. Please rank components of a smartphone app that are most desirable for use by patients and family members:

	Very important	Somewhat important	So-so	Less important	Not important
Physical Symptom Tracking & Management - Assessment Tools	○	○	○	○	○
Physical Symptom Tracking & Management - Dashboard visualization of tracking results	○	○	○	○	○
Physical Symptom Tracking & Management - Quality of Life assessments	○	○	○	○	○
Calendar - appointment tracking and reminders	○	○	○	○	○
Calendar - Medication reminders	○	○	○	○	○
Calendar - symptom tracking reminders	○	○	○	○	○

	Very important	Somewhat important	So-so	Less important	Not important
Medications - prescription history	○	○	○	○	○
Medications - order a refill	○	○	○	○	○
Medications - reminder system	○	○	○	○	○
Medications - find a pharmacy	○	○	○	○	○
Medications - instructions	○	○	○	○	○
Medications - possible side effects	○	○	○	○	○
Other types of care - psychological support services	○	○	○	○	○
Other types of care - spiritual support services	○	○	○	○	○
Other types of care - emotional support services	○	○	○	○	○
Other types of care - long-term care	○	○	○	○	○
Other types of care - hospice	○	○	○	○	○
Notebook - patient diary	○	○	○	○	○
Notebook - notes to ask my healthcare provider	○	○	○	○	○
Multimedia Library - Advance Directive Template	○	○	○	○	○
Multimedia Library - access to palliative care resources	○	○	○	○	○
Other - contact palliative care team	○	○	○	○	○

9. What level of importance would you assign to the following potential advantages of a palliative care smartphone app?

	Very important	Somewhat important	So-so	Less important	Not important
Time savings	○	○	○	○	○
Cost savings	○	○	○	○	○
Empowerment of patients	○	○	○	○	○
Empowerment of family members	○	○	○	○	○

Other (please describe)

10. What level of concern about the smartphone app do you have regarding the following issues:

	Extremely concerned	Somewhat concerned	So-so	Not very concerned	Not at all concerned
Lack of trust regarding the use of a device without the presence of a healthcare professional	○	○	○	○	○
Security and privacy issues	○	○	○	○	○
Difficulty for healthcare professionals in using technological devices	○	○	○	○	○
Difficulty for patients and family members in using technological devices	○	○	○	○	○

Other (please specify)

11. If the app were available today, how likely would you be to use or recommend it?

○ Very likely
○ Somewhat likely
○ Not very likely
○ Not likely

12. If you are not likely to use or recommend the smartphone app, why not?

13. What additional information, education, resources, or tools could be integrated into the smartphone app that you would recommend?

14. What advice can you offer our team on what you see as features of a good app that is relevant to outpatient palliative care services?