5-2014

Development of an application for patient-centered dementia care.

David Collar Alston
University of Louisville

DEVELOPMENT OF AN APPLICATION FOR

PATIENT-CENTERED DEMENTIA CARE

By

David Collar Alston

B.S., University of Louisville 2013

A Thesis

Submitted to the Faculty of the

University of Louisville

J.B. Speed School of Engineering

as Partial Fulfillment of the Requirements

for the Professional Degree

MASTER OF ENGINEERING

Department of Bioengineering

May 2014

DEVELOPMENT OF AN APPLICATION FOR

PATIENT-CENTERED DEMENTIA CARE

Submitted by: _____

David Collar Alston

A Thesis Approved On

_____

(Date)

by the Following Reading and Examination Committee

_____

Hermann B. Frieboes, Thesis Director

_____

Gina E. Bertocci

_____

Patricia S. Soucy

_____

Peter M. Quesada

ACKNOWLEDGEMENTS

ABSTRACT

Dementia care in the United States faces several challenges, many of them associated with managing the information that is associated with patients. Protected patient information about patients is often separated between many sources. For example, a new doctor may have information on patient medicines, but not the document associated with the caregiving goals of the patient and their family. Problems can develop if a patient is treated by a new caregiver, who may not know the patient's treatment and behavior history. There is a strong desire for a system that can collect, organize, and analyze patient information in a user friendly manner. Through interaction with a clinical collaborator, a novel web application has been created that can help to maintain this patient information. This web application provides access to quality indicators which can be accessed via remote communication, summarized in reports, and evaluated in patient data analytics. The system is designed to run on multiple devices that a user would have access to, including a smartphone, tablet, and personal computer. Adoption of this application by clinicians and caregivers longer term could significantly enhance the quality of care for patients with dementia.

TABLE OF CONTENTS   <u>Page</u>

NOMENCLATURE

QI = Quality indicator

GUI = Graphical user interface

PWD = Person with dementia

ICF = Intermediate care facility

ALF = Assisted living facility

LPN = Licensed practical nurse

CNA = Certified nursing assistant

EHR = Electronic health record

PHI = Protected health information

CQUIN = Commissioning for Quality and Innovation

LIST OF TABLES

LIST OF FIGURES

I. INTRODUCTION

1. Background on dementia

Dementia is a rapidly growing problem in most developed countries. This has created an increasing demand for better information management. In the United States, those over seventy one years old have a 13.93% chance of having some form of dementia (Plassman, Langa, & Wallace, 2007). In addition, the average age in the United States is increasing due to enhanced life expectancy (Arias, 2006). Dementia cases are expected to increase somewhat proportionally with life expectancy, leading to an increased burden on caregiving facilities and doctors. "In terms of total costs to society, AD (Alzheimer's Disease) is the third most costly disease in the US after cancer and coronary heart disease" (McKeithan & Schumock, 1998). Average annual costs of caring for patients with AD have been estimated at US$80–100 billion in the US (CDC and NCCDPHP 2000) (Zhu & Sano, 2006). This increase in cost will be felt across all aspects of caring for a patient with dementia, straining existing systems that are currently in place.

2. Caregiving environment for dementia

There are many environments in which caregiving for dementia can take place, ranging from home care to a full time care facility. Each environment has its own requirements that guide the care of dementia patients in order to function effectively. Three primary caregiving environments have been identified: home care, an assisted living facility (ALF) and an intermediate care facility (ICF). Each varies in terms of the independence of the patient and the level of interaction with their caregiver.

<u>a. Home Care</u>

Home care provides the most independence for patients relative to an ICF or ALF. One major advantage of home care is that a number of exercises can be performed without equipment and the patient is able to accomplish daily activities without major supervision or guidance. On the other hand, within home care, there is typically a lack of a trained professional such as a nurse to oversee care as compared to an ICF and ALF. Specifically, an ICF has more caregiver access than an ALF, which has more access to caregivers than in home care with regards to level and number of formally trained caregivers. The primary form of data collected by the caregiver in a home environment would be handwritten notes recorded by the caregiver, but there is a need for these notes to be seen by a trained caregiver consultant or support personnel such as a LPN. It is important to be able to track the progress of dementia in a patient and assist in recommendations when it may be time to transition to another form of care. Abuse monitoring through QI tracking and analysis is important as well; home care is an unsecure environment when compared to an ALF or ICF, so patient abuse can be an issue (Cooper, Selwood, Blanchard, & Walker, 2009).

<u>b. Assisted Living Facility</u>

An assisted living facility is one where a PWD will live long term under direct supervision from a caregiver such as a nurse (Arizona Department of Health Services, 2013). It differs from an ICF in that the patients often live in buildings separate from their caregivers. This setting allows for more independence when compared to an ICF, and is generally suitable for those with early stage dementia or slight functional impairment requiring assistance with only certain activities of daily living, such as driving and

cooking. A large portion of persons living in ALFs have some degree of cognitive impairment. This can lead to resistance on the part of families and PWD to make a move to a residence with a different level of independence. It is not uncommon for patients with fairly severe dementia to still reside in the ALF setting. Unfortunately, the care staff in the ALF setting typically lacks the expertise when compared to the ICF setting in caring for persons with moderate to severe dementia (Arizona Department of Health Services, 2013). Furthermore, the record generation, logging and documentation capabilities of the ALF care staff are not nearly as comprehensive as in the ICF setting. With improved documentation of problems, solutions, and caregiver burdens, the health care team, families, and all care providers would be better able to make informed decisions. It would also be useful for the caregivers to track the progression of the dementia symptoms (memory loss, emotional changes, communication changes, etc.) of the patient to potentially provide the necessary data to assist in the decision of when to transfer a patient to an ICF. Another aspect of care in an ALF is the solitude that can result. Caregiver and dementia care support for persons with early stages of dementia living alone is very important for people facing isolation, as well as meeting the challenge of sustaining appropriate and quality care for a PWD (Schoenmakers, Buntinx, & Delepeleire, 2010).

c. Intermediate Care Facility

An intermediate care facility is the least independent form of dementia care for a patient; they will be in a facility with dedicated caregiving staff that sees them often (Medicaid.gov). Currently, caregivers in ICFs are required to document all of their care and interventions. To do so, they have to leave the patient alone and be at the nursing

station to document the information, either in paper charts or electronically using a PC. In addition, many ICF's will have PC's for office and electronic health records (EHR) work, since there has been a strong movement in recent years to move all health records to an electronic format. Some sort of electronic platform is very likely to exist in almost all ICF's soon, and that platform will need to integrate with the healthcare systems at large to foster patient care continuity.

3. Problems with caregiving of dementia patients

There are a variety of problems presented to those who are exposed to caring for a PWD, including family members, physicians, and full time nurses. Many of these problems center on the interaction between the caregiver and the PWD. Other problems are centered on more psychological aspects of the progression of the disease, such as the goals of the patient and their families. Enabling caregivers to more effectively tackle the challenge associated with managing large amounts of patient data (Quality Indicators, medical records, patient goals, etc.) would greatly assist in the care of a PWD.

Due to the nature of the disease, it can be difficult for a caregiver to provide care in a totally unbiased fashion (Schulz & Martire, 2004) (Schoenmakers, Buntinx, & Delepeleire, 2010) (Bynum, Rabins, & Weller, 2004). Unlike most other diseases, dementia directly affects the ability of the patient to communicate with a caregiver. As a result, a symptom such as anger from a patient can be misinterpreted as actual anger and not an effect of the disease. Dementia affects many areas of the brain responsible for communication and socialization, and it is well known to result in memory problems (Alzheimer's Association, 2014). Dementia changes a patient at the mental level, which can result in a large number of social problems such as interpersonal relationship

breakdown. For example, the relationship of a husband with some form of dementia living with his wife can be dramatically affected by outbursts of anger (Reger & Welsh, 2004). Aggression in dementia can have a negative effect on any interpersonal relationship of the patient (Rapoport, Reekum, Freedman, & Streiner, 2001). Having a system that could allow for data collection (QI's, patient medicines, patient legal documents, patient goals, records of behavioral changes etc.) would provide hard evidence to caregivers that certain activities should be limited or monitored. In another example, a nurse may find a PWD wandering in the halls, and call a doctor at a local hospital (Klein, Steinberg, Elizabeth, & Cynthia, 1999). That doctor only has the information that is given to him by the nurse, so they can only make an informed recommendation based on that information. With this lack of information the doctor may recommend for the PWD to go to the hospital, even if, in reality the wandering is benign and has been occurring for years. This might be something that the PWD's old doctor might know, but it is not necessarily information that is transferred to the new doctor. A system that allows the doctor to have access to all relevant information needed about the patient would dramatically improve the quality of decisions made.

The direct problems associated with poor dementia care are numerous, from increased costs due to increased hospitalizations to increased mortality for patients (Phelan, Borson, & Larson, 2012) (Sachs, 2004). In patients with dementia in addition to other illnesses the existing medical procedures are often lacking when creating a plan of care. Due to a lack of defined visible markers common to other diseases (for example a tumor in cancers), many doctors are conservative in recommending long term care (Sachs, 2004). Patients who have dementia often also tend to have communication

problems, which can lead to a great deal of trouble in planning long term care with a caregiver (Smith & Buckwalter, 2005) (Sachs, 2004). Additionally, other patients may need help with many activities of daily living such as bathing and eating, further deviating from standard care practices. Care practices that have been created for patients who do not have the cognitive and communication issues associated with dementia are not necessarily valid for those that do have dementia (Sachs, 2004). Due to these problems, caregiving decisions require an individualized approach based on a comprehensive understanding by a professional to determine the best plan of care on a patient by patient basis. This approach involves characterizing the stage of dementia as well as how the disease is presenting in any particular patient. The approach must also be periodic in order to ensure that it matches the patient environment to the condition of the patient. This leads to a direct increase in professional time involved and money spent to collect, manage, and analyze the data required.

"If the patient is transferred to the hospital for acute care, the nursing facility not only avoids the cost of the increased staff time, they may be paid a 'bed hold' if the patient's stay is under Medicaid. Hospital transfer also decreases the facility's chance of both liability for 'allowing a patient to die' as it can be perceived by misinformed family members, and for regulatory citations for weight loss or dehydration that occur as death approaches. The treating physician has a financial incentive to transfer the patient because Medicare reimbursement for an admission visit for a hospitalized patient greatly exceeds that for a subsequent nursing home visit." (Sachs, 2004)

The psychological and social problems associated with caring for a PWD can also have a significant impact on the quality of care (Schulz & Martire, 2004; Schoenmakers,

Buntinx, & Delepeleire, 2010). Depression and fatigue are problems that are prevalent in those who care for patients with dementia (Schoenmakers, Buntinx, & Delepeleire, 2010). As a secondary exacerbating issue, many caregivers are not professionally or emotionally prepared to care for a PWD, especially those with comorbidities. These problems directly reduce the quality of life for the caregivers, and may affect their ability to provide adequate care. In the case of home care, family members will often quit their full time jobs to care for family members with dementia (Schulz & Martire, 2004). This career change can drastically increase the economic and psychological burden on both the caregiver and the patient with dementia. "In fact, a recent study found caregivers who were categorized as 'strained' to have a 63% increased mortality rate compared with family members who were not acting as caregivers for an ill relative" (Sachs, 2004). Other problems can occur as a result of lapses in communication in caregiving. As an example, the wishes of the relatives of a PWD can conflict between different sides of their family (Livingston & Leavey, 2010). This can be exacerbated by the fact that the family members of the PWD often live far away from where the caregiving is taking place. Trying to reconcile the wishes of the PWD and their families can be a challenge with dementia care. These problems often arise in the form of documents associated with these wishes, such as an end of life care document created by the PWD in the early stages of their dementia. When this document is only in the possession of one person, such as a legal advisor working with one side of the family, it can complicate caregiving decisions (Livingston & Leavey, 2010). Another example is an end of life document that defines some of the qualities the patient values like the ability to drive or the need for around the clock care. These values may influence how quickly the family and caregivers decide to

7

move into a higher level of care (Bogardus, Bradley, & Tinetti, 1998). The care is slowed down and it often becomes convoluted when they try to assemble the appropriate information in one place. This results in slower and lower quality care, affecting all aspects of caregiving decisions from medicine selection to long term care choices (Bogardus, Bradley, & Tinetti, 1998).

Resident		Identifier	Date

Section C | **Cognitive Patterns**

C0100. Should Brief Interview for Mental Status (C0200-C0500) be Conducted?
Attempt to conduct interview with all residents

Enter Code [ ]
  0. **No** (resident is rarely/never understood) ➝ Skip to and complete C0700-C1000, Staff Assessment for Mental Status
  1. **Yes** ➝ Continue to C0200, Repetition of Three Words

Brief Interview for Mental Status (BIMS)

C0200. Repetition of Three Words

Enter Code [ ]
Ask resident: *"I am going to say three words for you to remember. Please repeat the words after I have said all three. The words are:* **sock, blue, and bed.** *Now tell me the three words."*
Number of words repeated after first attempt
  0. **None**
  1. **One**
  2. **Two**
  3. **Three**
After the resident's first attempt, repeat the words using cues ("*sock, something to wear; blue, a color; bed, a piece of furniture*"). You may repeat the words up to two more times.

C0300. Temporal Orientation (orientation to year, month, and day)

Enter Code [ ]
Ask resident: *"Please tell me what year it is right now."*
A. Able to report correct year
  0. **Missed by > 5 years** or no answer
  1. **Missed by 2-5 years**
  2. **Missed by 1 year**
  3. **Correct**

Enter Code [ ]
Ask resident: *"What month are we in right now?"*
B. Able to report correct month
  0. **Missed by > 1 month** or no answer
  1. **Missed by 6 days to 1 month**
  2. **Accurate within 5 days**

Enter Code [ ]
Ask resident: *"What day of the week is today?"*
C. Able to report correct day of the week
  0. **Incorrect** or no answer
  1. **Correct**

C0400. Recall

Figure 1 – Patient QI Survey Subset (MDS 3.0)

There are also institutional caregiving problems that are associated with caring for many dementia patients. Caregiving facilities must submit progress reports on facility average quality indicators to various regulatory bodies (such as the Centers for Medicare & Medicaid Services) in order to stay properly qualified as a Medicaid certified long term

care facility (Mor, Orna, Unruh, & Cai, 2011). This certification is covered in detail in the United States regulation 42 CFR 483.20, which specifies what must be submitted to regulatory bodies. The regulation defines how the submitted data must allow for the highest quality of care, covered in 42 CFR 483.25, which describes how care must provide "... the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being". The results of the data collection are also used to give information to consumers as they decide what facilities to select for their family members with dementia (CMS.gov, 2014). The ability of the facility to participate in Medicare and Medicaid (using Medicare and Medicaid as funding) can be a significant source of income for these facilities. The reports typically utilize Quality Indicators (QI), which provide a quantitative measure of progress for a patient. Figure 1 shows a subset of an individual QI survey, provided by the clinical collaborator. These QI's have been standardized across facilities through the use of the MDS (Minimum Data Set) document. There are other forms that can be used, but the MDS 3.0 is the primary form specified by Medicare/Medicaid. By aggregating QI's across patients within an institution, facility managers can see where their facility has improved as well as how it compares to other facilities at the state and national level. One major problem with this method is that these MDS documents are often physical documents in the form of paper surveys which are completed for each patient. These QI surveys are typically scanned into a digital format, and then analyzed as needed. As a result, assembling regular progress reports can be a huge task, since someone has to go through the digital records and manually create a facility-wide statistical snapshot. A subset of a sample facility report submitted to CMS

(Centers for Medicare and Medicaid) is shown in Figure 2, with various metrics being

tracked.

Facility Quality Measure/Indicator Report							Page 1 of 2

Facility Name
City/State
Provider Number
Login/Facility ID
Data was calculated on   07/14/2008

Run Date   07/14/08 10:24:07
Report Period   01/01/08 - 06/30/08
Comparison Group   11/01/07 - 04/30/08
Report Version Number   1.07

Measure ID	Domain/Measure Description	Facility				Comparison Group		
		Num	Denom	Observed Percent	Adjusted Percent	State Average	National Average	State Percentile
Chronic Care Measures								
	Accidents							
1.1	Incidence of new fractures	0	19	0.0%	-	2.1%	1.5%	0
1.2	Prevalence of falls	3	21	14.3%	-	16.7%	13.3%	38
	Behavior/Emotional Patterns							
2.1	Residents who have become more depressed or anxious	7	21	33.3%	-	19.4%	15.0%	90 *
2.2	Prevalence of behavior symptoms affecting others: Overall	3	21	14.3%	-	16.5%	17.2%	47
2.2-HI	Prevalence of behavior symptoms affecting others: High risk	2	14	14.3%	-	19.5%	19.9%	38
2.2-LO	Prevalence of behavior symptoms affecting others: Low risk	1	7	14.3%	-	7.9%	7.2%	82
2.3	Prevalence of symptoms of depression without antidepressant therapy	0	21	0.0%	-	5.0%	4.7%	0
	Clinical Management							
3.1	Use of 9 or more different medications	13	21	61.9%	-	77.1%	67.7%	8
	Cognitive Patterns							
1.1	Incidence of cognitive impairment	2	8	25.0%	-	13.7%	12.2%	85

Figure 2 - Facility Aggregate QI Data

4. Existing solutions to address problems with dementia caregiving

A number of software applications currently exist that focus on dementia care.

Some solutions focus on communication with those who have dementia, others integrate

physical GPS tracking to reduce wandering, such as those developed by Cainson

(Cainson-Global Tracking Solutions, 2012). An entire category of applications exists that

is designed to provide much more functionality to the patient rather than the caregiver,

providing services such as the iReminiscence system from CognitionSys (CognitionSys

Ltd, 2014). Software that combines advanced QI tracking with telehealth systems is novel

in the field of dementia care software, notably so in the United States due to increased legislation surrounding healthcare compared to other countries.

There are numerous applications that exist centering on a concept known as "Reminiscence Therapy" (Spector & Davies, 2009). This therapy involves creating and tracking life stories as a method for dealing with end of life issues. Reminiscence therapy is well suited for use in patients with dementia; it attempts to improve cognitive function and overall wellbeing. To this end, many applications have sprung up that act as digital tools for use in reminiscence therapy (CognitionSys Ltd, 2014) (My Life Software, 2013). These tools allow for digital photo albums with built in timeline features and offer communication features to keep in touch with family and friends. Both the iReminiscence from CognitionSys and the My Life Software focus on making sure patients maximize their happiness and cognitive skills. While they do track specific indicators, these indicators are psychological and not physical. The software is able do this by tracking measures that represent the mental wellbeing of a patient over time. iReminiscence is a very similar software, that has similar functionality. One drawback is that it is designed as an application for Apple devices, specifically the iPad. Since it is an "app" it requires an install on whatever device is used, whereas a web application would only require a modern internet browser to access on any device. Reminiscence therapy based software solutions are common, but they lack advanced features such as physical QI tracking and video/audio recording features.

There are two software applications, IMS Maxims and CoolCare3 (IMS Maxims, 2014) (LNT Software, 2013), which are highly functional applications designed for dementia care. However, both are designed for National Health Service guidelines, and

are targeted at caregivers and facilities in the United Kingdom. CoolCare3 integrates includes payroll management. It can also track various indicators. CoolCare3 is designed to meet a foreign set of standards, namely CQC (Care Quality Commission) and National Health Service (NHS) guidelines. Further, CoolCare3 does not include a telehealth system. It has built in text and email communication, but not currently real time video and audio.

IMS Maxims is another application designed for the market in the United Kingdom, primarily designed around managing electronic patient records. IMS Maxims works on a facility by facility basis to design systems for managing patients and their electronic records. It is sold as a base software plus a number of additional modules that can be added in. IMS Maxims has a dementia care module that functions similarly to the dementia care manager presented here. It has a form of QI tracking built in, conforming to a rule created by the Department of Health (NHS) known as CQUIN. Combined with the base software the dementia module can perform many tasks in a similar fashion to the dementia care manager. It can track indicators for patients, generate shareable reports, access a centralized patient record, and even manage beds within a facility. Ultimately this is primarily differentiated from the dementia care manager by its target, caregivers and facilities in the United Kingdom.

Patients needing medical care are normally treated by clinicians and cared for by caregivers according to established medical guidelines and procedures. However there is a subset of medical patients for whom these guidelines and procedures have been shown to be insufficient; thus, leading to unnecessary costly hospitalizations and catastrophic, often fatal, behaviors, viz., patients who in addition to illness also suffer from dementia (Alzheimer's Association, 2014). Such patients are typically in need of constant watch by caregivers (CGs) because of inability to carry out activities of daily living and atypical, unpredictable reactions to their environment. Due to cognitive impairment, they are often unable to communicate with their caregivers and healthcare providers. As a result, creating plans of care for optimal outcomes is virtually impossible without carefully studying considerable amounts of data for the periodic and one time medical consultant. Furthermore, the care of persons with dementia (PWD) is for most CGs counter-intuitive, yet most CGs are pressed into becoming CGs with inadequate cultural, mental or emotional preparation (Bynum, Rabins, & Weller, 2004). If CGs are not in-home loved ones, they tend to be hired for in-home or in the nursing facility setting and come to the job with minimal training. The challenge is that a course of action for a cognitively-intact patient may be inappropriate for a patient who suffers from dementia. This lack of intuitiveness and complexity hinders provision of appropriate care of PWD and leads to unnecessary and excessive morbidity, mortality, increased use of health care expenditures as well as societal costs (Alzheimer's Association, 2014) (Bynum, Rabins, & Weller, 2004). Hence, there is a critical need to help caregivers to determine appropriate general and medical care for PWD in various situations. Strong evidence suggests that

appropriate dementia care is cost effective, delays institutionalization, and reduces hospitalization (Bynum, Rabins, & Weller, 2004). Collecting patient information in the form of mental and physical quality indicators in a secure and easy-to-access manner would be an important first step to help reduce the time to decision for caregivers.

Existing solutions to address problems with dementia caregiving show that there is a need for a system that can provide relevant information to caregivers that will allow them to make an informed decision on the care of a PWD with comorbidities. Creating patient reports manually can be time consuming, but could be automated into a new system. Automation would also allow for more advanced analysis of the statistics to be performed. For instance, one could analyze only patients over a certain age who cannot feed themselves, thereby providing a powerful tool to the caregivers, clinicians and CMS to evaluate the proper level of care needed for a given PWD patient. Development of a system that is portable and provides easier documentation is expected to allow caregivers to spend more time providing interactive and hands on care, which would result in better care quality outcomes.

6. Purpose and scope of thesis

The purpose of this thesis is to develop the first stage of a solution to help caregivers manage dementia patients. This solution is centered on the MDS 3.0 quality indicators and their supporting functions, such as encryption and user interface. The proposed solution is a web application that would only require a modern internet browser to access on any device. The application is designed to meet Center for Medicaid Services guidelines, as well as HIPAA guidelines. The application will track both psychological and physical patient indicators. Unlike IMS Maxims, the application is

deployed as a single function that does not have "add-on" features. The work on the application has been divided so as to be completed in multiple stages over time. This thesis specifically encompasses the first stage of the development, which involves the design, implementation, and testing of the core functions (survey integration (MDS 3.0) and its encryption, analysis, and record generation). By the end of the first stage it is desired that there be a functional prototype with these core features implemented so that it can be further developed upon in later stages.

II. INSTRUMENTATION AND EQUIPMENT

The application will be compatible with many form factors of both stationary and mobile technology, including personal computers, smartphones, tablets, and laptops. Since it is web-based, the application can run on any device that is capable of running a modern internet browser. The devices that have been used are a PC running Windows 7, a smartphone running Android 4.1.2, an up to date 7" tablet (Nexus 7), and an up to date 10"tablet (Nexus 10). The first version of the mobile software has been developed for Chrome Canary, which was chosen due to the built in mobile audio and video features that the application needed. These features are not yet implemented in other mobile browsers such as Chrome and Internet Explorer. On a personal computer, the application will work on any modern browser. Because the application can be run on many devices with many different form factors it is important for the interface to be robust in terms of its GUI (graphical user interface) design and data input. As such the GUI has been designed with visibility in mind, with a high degree of color/luminosity contrast and large buttons when using the mobile version. The standards that were used were the Web Content Accessibility Guidelines 2.0, created by the World Wide Web consortium. The application was also designed with multiple input methods in mind, from a mouse and keyboard to multiple variations on touchscreen devices. One of the proposed end users will be caregivers of a PWD, so the user interface also has to be simple and self-intuitive so that they can use the software easily. The application has been constructed so that it can work in multiple languages, which the software has been built around. This means

that all files associated with the program (PHP, HTML, etc.) have the ability to interact with the language elements, even if they have not yet been implemented fully. The first language that has support is American English, with other languages accessible via a lookup table once created. This was done to allow for the possibility for use by non-English speakers.

III. PROCEDURE

The goal of this project is to create a patient centered software application that can collect, return, and analyze quality indicators (MDS 3.0) on a patient with dementia for the purpose of aiding the caregivers of a PWD. This information is collected and analyzed to provide a personalized care plan for a patient. The software is designed to run on mobile devices as well as traditional PC's. Input from the clinical collaborator based on her experience and analysis of the requirements from the caregiving environment provided the bulk of the information for the design.

1. Input from the clinical collaborator

One of the primary goals was that the application can display the quality of patient care, as well as any positive or negative changes to that quality. These changes in patient care quality may be revealed via the application in a number of ways, all of them centered on the use of the MDS 3.0 and its supporting analytics. In most caregiving settings a mobile platform is viable given that the caregivers are not always in the same location as the patients, often times separated by many floors, or different buildings for most of the day (by contrast, in an ICF the care staff is closely assisting in daily care of PWD in areas such as medications, bathing and so on). A caregiver could bring a tablet or mobile phone rather than a chart to the resident's apartment or cottage in an ALF, which is expected to save time entering the data for the MDS 3.0 later since the caregiver will not have to input the data into another central computer. The MDS data will be accessed

and updated right from the application, rather than going from a physical document to a computer system. Due to the encryption that the application uses, data is secure over the WiFi of a facility (see section 4.1). These environments also allow for a patient to access some of the data in the software. This data includes their goals as well as the Skype features.

The interface for patients is such that patients can only view and submit data, not change existing data. The application allows for a feature that takes the user directly to a video chat system, such as Skype. This link to video chat can be customized with contacts, for example one to call the primary caregiver (spouse or in-home hired helper), one to contact the physician's office or medical help, and one to call distant family. Integration with a video capable device also allows for video/audio recordings that may be useful to future caregivers and medical providers. Video and audio recordings can help document the severity of a visible condition and the progression of the dementia. Rather than simply noting via text or an MDS survey that a patient has difficulty walking, the use of a video is expected to more clearly illustrate the degree and type of impairment. For example, is an injury in the lower leg or the ankle? How much impairment is there as a result? These videos can be stored for future viewing, and are documented such that they are easy to find (time-stamp, user-stamp, etc.). In addition an audio recording might be more useful for notes when the caregiver (in this case a nurse or other healthcare professional) is otherwise occupied and is unable to hold the device running the application. The caregiver's perspective on the documented problem would also offer an indication of the caregiver burden, and could be captured in video or audio notes.

2. Requirements from caregiving environment

A setting with consistent professional caregiver access allows for the most flexibility in the software, since it can exist in both the caregivers and patients hands. These settings lend themselves best to desktop PC's, at least initially. While tablets and smartphones are growing rapidly in popularity they have not overtaken the prevalence of the PC for patient record management in an ICF/ALF. A portable pocket sized device is ideal for the ICF/ALF settings because they may allow the caregivers (i.e. LPNs and CNAs) to be less tethered to the desktop PC, which typically is located at the nursing station in a centralized location. As described, these environments lend themselves more towards mobile devices when they are available. As a result settings like these require that there be a good interface between mobile devices and PC's on site. The data collected and utilized by the software will need to be standardized across devices to ensure that all devices can properly receive and interpret the data that is generated and transmitted.

There are a few other important areas of consideration when looking at dementia care software in an ALF/ICF. Use of software in these settings can allow for more efficient communication, since the necessary information can be communicated between all devices using the software, rather than traveling from caregiver to caregiver with potential miscommunications in between. Typically, the sum total record of problem behaviors is not clearly understood by professionals (including healthcare specialists such as physical therapists) and physicians when reported by the caregiver through chart notes (which are just large quantities of text), or verbally summarized by caregivers (Burgio, Cocoran, Lichstein, & Nichols, 2001). This software creates a tool to log behaviors,

which produces a record of the frequency and severity of the behaviors as the caregiver experiences them. These records exist in the form of generated report files. The resulting report is expected to aid the expert consult team in deciding the best plan of care, which should optimize outcomes. For example the necessity for risky psychoactive medications is something that is a controversial topic from a legal aspect and quality of care aspect for the ICFs (Kales, Valenstein, Kim, & McCarthy, 2007). With an accurate and standard way to log and record behaviors of interest as determined by the caregiver (such as wandering), the justification (or lack thereof) to use these drugs will be more concrete, rather than based on hearsay. The software uses a tabbed GUI system to keep track of information with tabs for drug information, treatments given, recommended activities, family contact information, long term goals, etc. The end result is an application that can securely collect as much of this patient information as it can from an EHR from caregiver daily input, and learn from it to create recommendations and warnings.

As a result of the various settings, electronic health record (EHR) data would be difficult to obtain and update securely, especially in a home care environment. The data would be used in a potentially unsecure home network by someone who does not necessarily know the proper way to access/edit an EHR. The caregiver in these situations is typically a family member, so the software could share functionality with the patient version in an ALF. This limits the access and control that a user has so that they do not accidentally or intentionally edit the EHR. Users will always have access to a suite of certain features, which includes video and audio note taking (submission and viewing only), video chat features, and email features (email an external caregiver such as a nurse who visits occasionally).

3. Request for input from local facilities

An inquiry was made to local caregiving facilities in order to help define the application goals was research into the prevalence of various mobile operating systems. This was done in order to determine if there was a potential market for an application that can operate on mobile devices within caregiving facilities. Facilities that care for those with dementia are starting to use mobile devices like tablets and smartphones in care, but they are still fairly uncommon in caregiving. Data exists for market penetration of mobile devices in the consumer market, but it is harder to find it for the dementia care market (ATKearney, 2013). Several facilities around Louisville were called to ask about their use of mobile technologies. None of the facilities replied however, likely due to the fact that it would involve permission through writing. A report from Lipinncott Williams & Wilkins estimates that seventy one percent of nurses use smartphones while on the job (Dolan, 2012). This represents a significant source of computing power that can be utilized for more effective caregiving. The application has been designed to operate in all three environments on whatever computing device (tablet, PC, or laptop) is available.

4. Design criteria

This system can provide the information collection, management, and analysis of MDS quality indicators that is needed to assist in decision making. Several design criteria were defined for an application that implements such a system while also helping to determine the best plan of care:

1. The proposed system must collect patient-specific data in the form of the MDS 3.0 quality indicators. These indicators allow for easier creation of plans of care

for patients with dementia and comorbidities. The baseline is defined as the current system using existing decision systems, as detailed above. The data will be in the form of standardized surveys such as the MDS 3.0 and doctor created input in the form of behavioral surveys. The data collected will be: QI's, patient goals, patient legal documents, record and logs of patient behaviors, and patient medications.

2. The proposed system must maintain this MDS data after it has been collected and allow access to all relevant parties. This specifies that the data must be accessible and fully usable at least five years after the last data input. End of data life must also be taken into account if a patient dies in order to free up existing systems for other patients. Relevant parties include all the caregivers for a patient as well as family members and legal representatives.

3. The proposed system must adequately secure this MDS data to ensure compliance with the HIPAA security rule. The security rule covers the storage, creation, transport, and maintenance of protected patient information by a covered entity. Using accepted encryption methods and securing all data to the maximum reasonable extent is required. Transfer between devices must also be secure, ensuring it is protected to the maximum reasonable extent.

4. The proposed system must provide analysis of the MDS quality indicators described in criteria 1 that is useful to a medical professional when making a caregiving decision for a PWD with comorbidities. Useful analysis is defined as analysis that facilitates the time to decision, which is expected to reduce problems associated with poor decisions such as excessive cost and patient mortality. Time

to decision is defined as the time to make any major caregiving decision. This includes:

a. The decision to move to a higher or lower level of care (home care to nursing home for example). This also includes the non-critical decisions involved in moving the patient into a hospital.

b. The decision to restrict or allow certain behaviors, for example stopping an individual from driving once the dementia has progressed sufficiently.

For the prototype (first stage) phase, the testing of this criterion involves checking that the application is capable of performing such an analysis. The first user survey that was created is detailed in section 3.8, which asked a number of yes/no questions relating to some of these criteria. These design criteria were key in the creation of the high level design for the application, and were evaluated at the end of the project.

5. Process flow design

After the initial design criteria had been defined (see section 3.4), the student worked to define more concrete engineering design requirements for the application. These cover the inner workings of the application as well as the design for the interface. This thesis will not cover the inner workings of the software in detail, but will cover the functions as they work at a high level. Figure 3 shows a flowchart indicating how information flows within the software. Orange lines show an interaction with the report generation feature. Since the report generation can collect data from many different blocks it has many systems it can interact with. Figure 4 shows a block diagram of various functions within the application, and how they interact. The MDS block is the

24

core of the application. The surveys involved are the MDS 3.0 (all sections. The design requirements can be broken down into several categories as described in the next section.
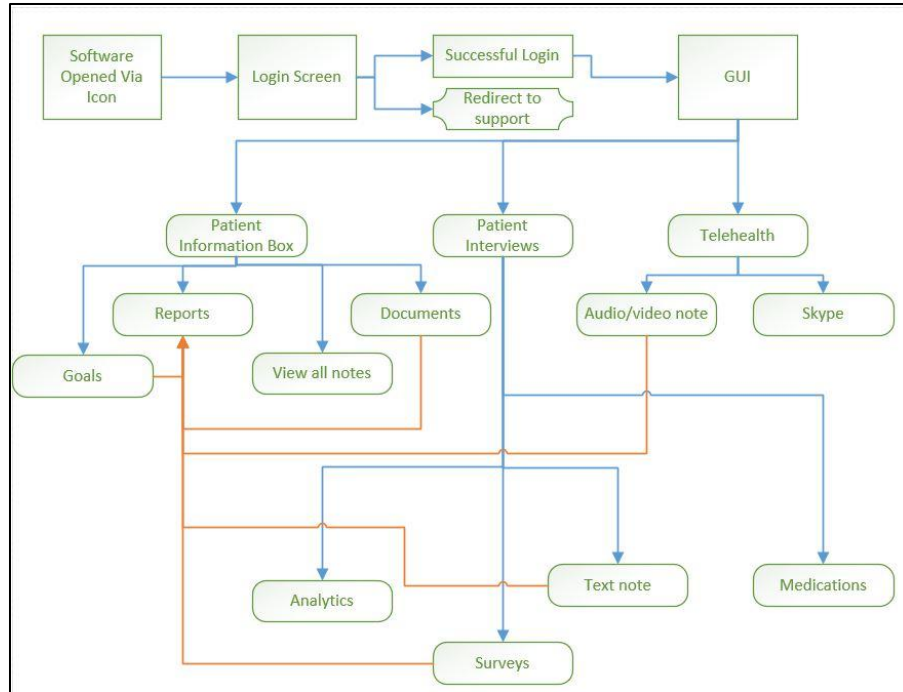

Figure 3 – Data Flow in the Application

6. Functions

The design requirements were first described in detail in a document provided by the clinical collaborator. This document detailed the GUI and how the different functions would interact. The student worked with this document to create a second document which detailed the engineering design requirements. For example, the ability for a PWD to use the interface was translated into engineering requirements covering the color contrast for the interface. The application specifically meets the WCAG (Web Content Accessibility Guidelines) for color contrast at an AAA level (World Wide Web Consortium, 2008). An online tool was used to test color schemes against the WCAG

standards in order to maximize readability (Snook, 2009). Buttons are made large with standard fonts to allow those with poor vision to more easily use the interface.

The functions were organized into several categories: information for the user, information from the user, report generation, and real time connection features. Information for the user detailed how the survey system would work, for example a behavior survey that can log certain behaviors and build a record of them. This section also detailed how the application should analyze the information it receives, for instance
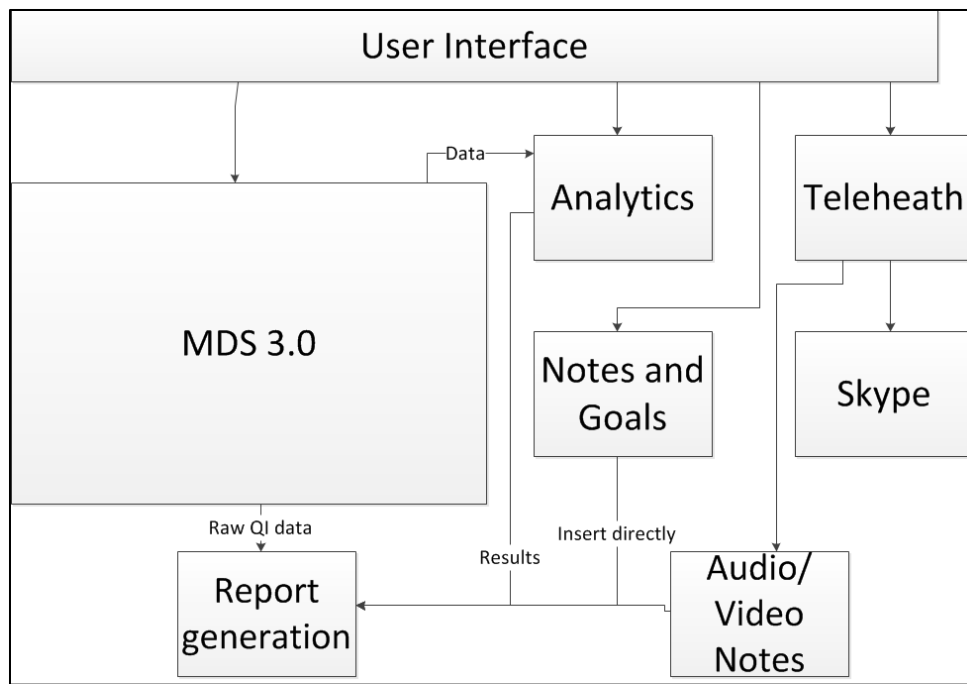

Figure 4 – Function Block Diagram

providing potential reasons for a particular behavior (e.g., wandering) when presented with the results of a behavioral survey. These analyses also need to be able to be integrated into a report. The collaborator detailed the integration of the note features with report generation, specifying how video/audio/text notes could be integrated into the report.

26

The next section that was detailed by the clinical collaborator was information from the user. In this section a user was defined as a caregiver directly caring for a person with dementia. Users include professional caregivers such as registered nurses as well as informal caregivers such as family members in home care. This section detailed how data should be collected to prepare it for the analytics, and how data is collected when using mobile devices as a collection tool. Survey information from behavioral or MDS surveys should be collected and plotted versus time as an "intensity" bar graph. For the MDS surveys this is simply ordering responses by desired response. For example, tracking sleep quality over time and displaying it with low sleep quality as a small response and high sleep quality as a large response. The section also described how these analytics and surveys should have the ability to have written logs associated with them in order to provide qualitative insight into their meaning. The last thing that was described was how these graphs could have qualitative text notes associated with them when they were in the reports, which is described in the next section.

The report generation section went into detail about what should be included in a report. The primary components included in a report are logs of behavior (video/audio/text), analytics results, and legal documentation. This section further expanded on how to collect and manage stored data as detailed in other sections. It built on other sections describing the reports by adding in desired functions for document management, time-stamping, multiple graph plotting, and saving. The document management centers on creating a record of legal documents such as power of attorney and documenting changes to the documents in reports. Time-stamping refers to putting a date on every piece of information in a report so that it can be more easily tracked. The

final item was the ability to display multiple graphs from analytics at once so that a user could visually look for interactions between survey questions, such as a sudden drop in sleep quality that occurs at the same time as an increase in daily activity. Saving is detailed in the communication features.

The final section went into detail regarding the communication features that should be included. This section mainly described who would be communicated with, not necessarily the fine details of how. It also detailed the email features of the report generation. Email features refer to the desired ability for the application to save a created report as a file that can be emailed to persons of interest. This saving feature is explicitly for emailing, since the application already has built in saving for reports. The contacts listed for Skype integration are family, advisors, support groups, physicians, and social workers. Skype is chosen as the software to use since it is widespread and usable on many different devices. This section also described how it could be possible to consult with a "professional" (a doctor for example), which would not necessarily be free, whereas the connections to authorized family and friends would be free. This was described so that in the future if a patient wishes to get insight into a problem they could quickly connect to and chat to a professional even if the professional is not the patient's doctor. This is described as a potential feature by the clinical collaborator, and may change depending on future phases of the project and legal advice that may be acquired.

This thesis encompasses the work done to create a first functional prototype. This prototype must have the ability to create and interact with MDS 3.0 surveys, as well as all the secondary functions described above at a functional level. The application must perform these functions on all described devices, including a personal computer, tablets,

and smartphones. Lastly, the application must be designed to be upgradeable and changeable, depending on the changes that are made based on user input.

7. Testing

Once the functions of the first prototype had been finished, it was tested by the student to ensure that it worked as intended. The student's testing can be summarized as follows:

1. Tested login and logout on all devices using all devices (smartphone, PC, and 7" and 10" tablets) and multiple categories of users. Included registering new users. Done with each category of user (patient, caregiver, and administrator).

2. Tested secondary inputs including audio/video/text note submission. Also tested the primary input of the MDS 3.0 quality indicators. Again this was done with each device with each category of user.

3. Tested outputs including analytics, report generation, and note list. Done with each category of user on each device.

4. Tested interface layout and usability by primarily looking for interface layout/usability issues caused by changes in screen size / aspect ratio between devices.

A large amount of testing was done to ensure that the GUI formatting worked correctly across multiple devices. The testing was done in several steps to fully test each aspect of the application. First, the login screen was evaluated on all devices. This testing involved attempting to log into the application as multiple different users, to see if any parts of the interface had errors or if the main page did not load correctly. After testing

login, the student went through each function in detail, testing the inputs and outputs of each. Inputs are text boxes, video/audio recording windows, survey submission, etc. Inputs are any location where data is being created and submitted into the device. The testing had to ensure that any data that was input was stored correctly and was accessible where and when it was needed. For instance, a video note had to be available to the report generation function fairly rapidly to allow for a report to be created. Rapidly was defined as within thirty seconds, the estimated maximum amount of time to navigate to the report generation window if a user went directly to that section after recording a video note. The same timing testing was done is on survey results and medication lists. It was found that all the inputs were available immediately after submission with the correct access that needed to be applied to them.

After testing the inputs the student went through the application testing the outputs. The outputs are any function that takes one or more inputs and reorganizes, analyzes, communicates, or displays them. These included the report generation, analytics, and view all notes. Testing was done to ensure that any data that was handled by these functions was not changed in the process, and that the data was still accessible at its original location. For example, a student created a video note, saved it, and then immediately went to the various outputs that read this input. A processing lag was discovered due to technical limitations with processing the video, but several minutes later the video was available to report generation and was visible in the notes list. After this the student tested this piece of data to ensure it had not been changed. In this case this meant playing the video inside of a newly created report and then inside of the note list. This process was continued for all combinations of inputs and outputs on all devices.

Finally the student tested the interface layout and Skype features, as well as ensuring data input on one device was available at the output of another device. The student had to ensure that the interface of the device was usable on all form factors from a smartphone to a monitor with a PC. Since different devices (such as a PC or smartphone) have different screen sizes and aspect ratios, it was extremely important that GUI elements like buttons did not overlap other elements. Testing was done by attempting to utilize all the screen elements that could be interacted with, in both horizontal and landscape views when applicable. Screen elements include things like buttons, pop up/out windows, selectable text boxes, etc. Any page element that can be interacted with was tested. The testing revolved around making sure each element was accessible on the first try without other parts of the interface getting in the way. Problems arose on the smartphone where elements would small enough that they would inadvertently be covered by other screen elements, which were corrected in a later fix. For the Skype testing the student made sure that the Skype window would add contacts correctly and that it would minimize the browser window and open Skype when used. If Skype is not installed the program will display an error when attempting to access the Skype button, since it is integral to the functioning of that feature. The final tests involved taking inputs from one device and reading them as outputs on another device. For example recording a video on a smartphone and attempting to view it on a tablet and a PC. This was done to ensure differences between input characteristics (screen size, camera quality, etc.) did not affect usability of the functions. After each round of testing had been completed a document listing the problems was created and John and Andrew corrected them.

<u>8. Caregiver testing</u>

A user survey was created and presented to the clinical collaborator and her team for testing. This survey is shown below in Figure 5. Initial surveying revolved around assessing a user's opinion of the primary functions of the application. The survey had ten questions, each with a yes/no response. The survey was made simple in order to maximize completion and survey speed. This was considered to be important for this first round of surveys to get a general sense of how users view the prototype application. The results are shown in section 4.2e.

User Survey for Dementia Care Manager Prototype

4/16/14

Please answer yes or no to the questions about the Dementia Care Manager. Please answer honestly.

Do not put your name on this form

Q1: Did the application allow for mobile real time data entry?

Q2: Did the application improve patient data accuracy?

Q3: Did the application allow for patient-centric transition of care?

Q4: Did the application help to track and document care?

Q5: Did the application allow for behavior monitoring and recording?

Q6: Did the application allow for real time video communication and audio recording?

Q7: Did the application perform well on pocket sized devices?

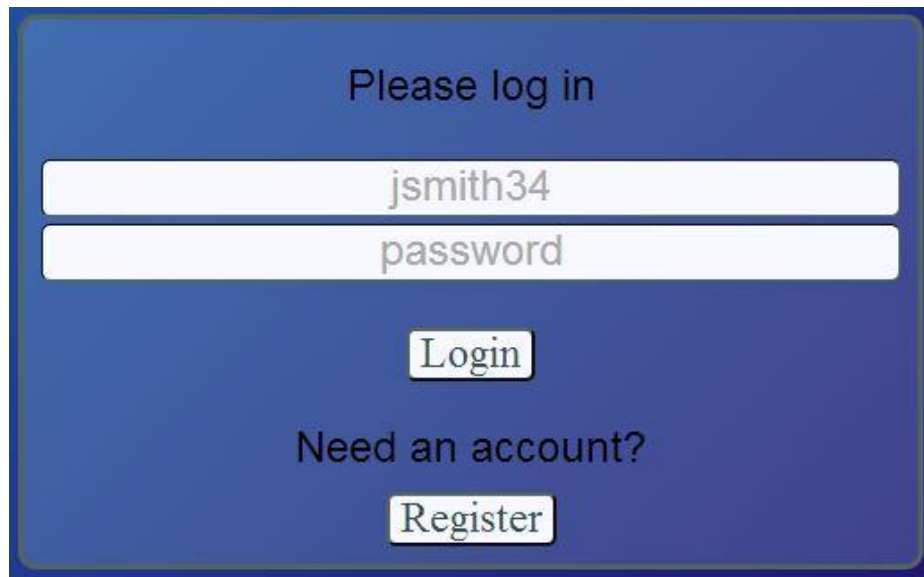Q8: Did the application assist in providing intra-facility consistent documentation?

Q9: Did the application help with facility surveying?

Q10: Was the application synchronized well with the MDS report?

Figure 5 – User Survey

IV. RESULTS AND DISCUSSION

In this study, a prototype application design has been fully specified in terms of potential features and implemented features. The application can be broken down into several key functions: login/logout and security, analytics and report generation, and interface usability. All of these secondary functions are designed to support the primary function of MDS quality indicator submission. The results obtained from the initial verification process are described below in section 4.2.
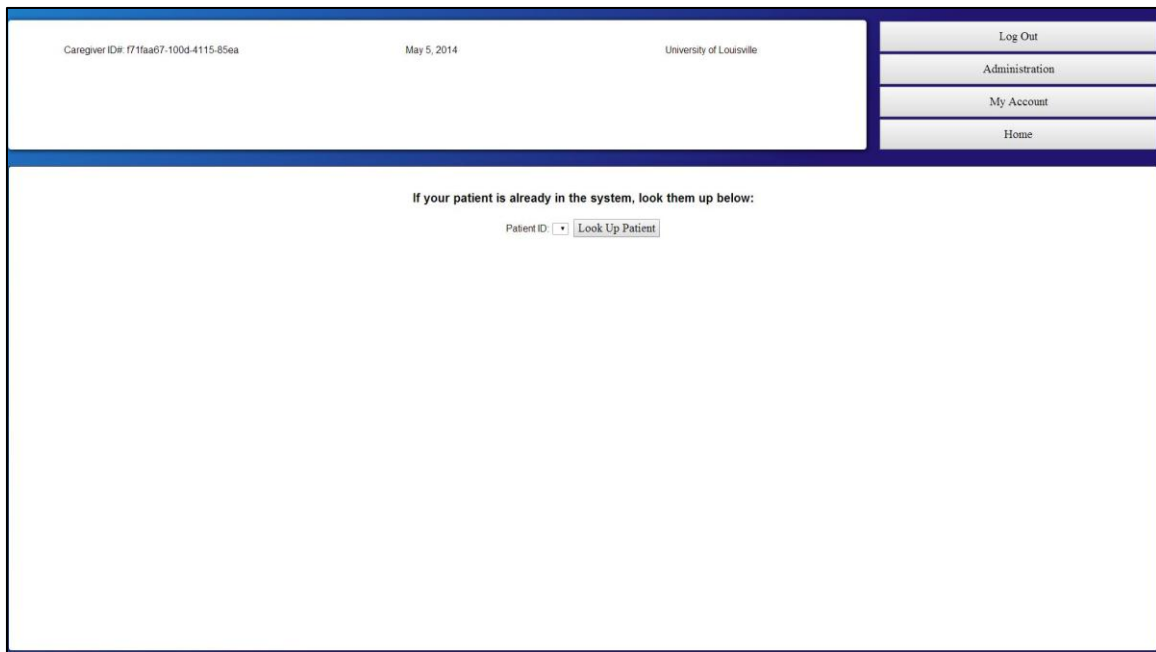

Figure 6 – Login page

Figure 7 – Administrator Main Page

1. Current functionality

The first element of the application is the user login page, which has the ability to allow a caregiver to access the application and register a new patient (Figure 6). The application runs a fairly stringent encryption in the form of AES-256. AES-256, or the Advanced Encryption Standard with a 256 bit key length, is a standard encryption across many medical fields, and is the standard encryption specified by NIST for Protected Health Information (PHI) (NIST, 2001).

After login, there are a number of potential interfaces that can show depending on the type of user. There are three potential interfaces depending on which user is accessing the application: a patient, a caregiver, and an administrator. Figure 7 shows the main page that is displayed for an administrator. Figure 8 shows the main page that is displayed for a caregiver. These figures show that the screen elements are slightly different depending on the type of user. For instance, an administrator has controls for patient management

and survey creation. An administrator has the highest level of access, and can directly edit many aspects of the program setup. This includes things like creating a new building section in the software, uploading new surveys, and editing caregivers and their assigned patients. Creating a new building section would be done to keep the software up to date with the facility, for instance if a facility added a new wing and had patients in that wing. A caregiver (defined as a certified healthcare professional such as a LPN, CAN or doctor) has the ability to look up patients and edit data associated with them, but cannot create new building sections or upload new surveys.
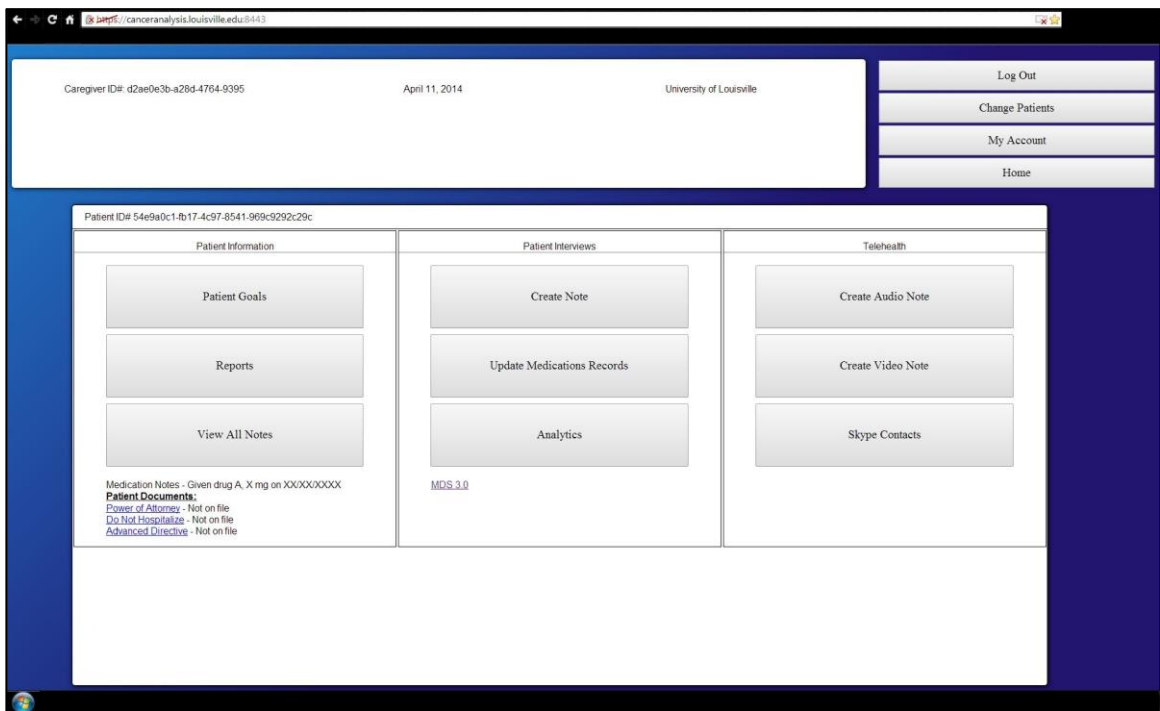

Figure 8 – Caregiver/Patient Main Page

A patient has the least amount of control over the software, and is only able to view and submit data. A patient does not have control over which caregiver they are assigned to or medicines that they are taking (edited by a caregiver or administrator). If

they attempt to edit their medicines for example, the software will present an error and not allow it to happen. There are a number of other functions that are limited, all to prevent unwanted changes to patient data and the application as a whole. Figure 8 shows the main page for a caregiver, showing information on a patient known as "Test Patient". The mobile interface contains the same buttons and functionality in a slightly different layout compared to the PC interface; however, this effort was beyond the scope of this thesis. As a result, all remaining GUI images shown will be from the PC version of the application unless otherwise specified.

a. MDS quality indicator submission and analytics

One of the primary functions built into this application is the survey submission and analytics component. This formed the core of the application, initially centering on integration and analytics surrounding the MDS 3.0. Any category of user may submit a survey by clicking on the MDS 3.0 button. Due to the time and user-stamping on all surveys, users can easily sort through surveys submitted by the patient or caregiver. When clicked, this button leads to a screen which has a digital version of certain sections of the MDS 3.0 (Figure 9). The user fills out the survey as desired, and also can create a text note that is associated with that survey submission. The user (if a caregiver or administrator) also has the ability to update the medication list if needed in the same window, since these surveys are often done in front of the patient where medication changes can take place. The user may decide to change the patients' medications as a result of the meeting, and this feature allows them to easily update them right from the survey page. Users can also update medications via a button on the main page if desired. There is another button called "behaviors" which will contain a survey to track and

quantify certain behaviors. This survey is currently unfinished as the information needed to complete these surveys has not been submitted by the clinical collaborator and her team. However, once the content for the survey is available it is uploaded by creating it in a markup language known as YAML (Yet Another Markup Language) and uploading it as an administrator. These surveys are also tagged with a date, allowing the application to analyze the responses over time.

Figure 9 – MDS within the application

On the main page (see Figure 8), a user can click another button to go to the analytics page. This page displays a number of individual questions from the MDS 3.0.
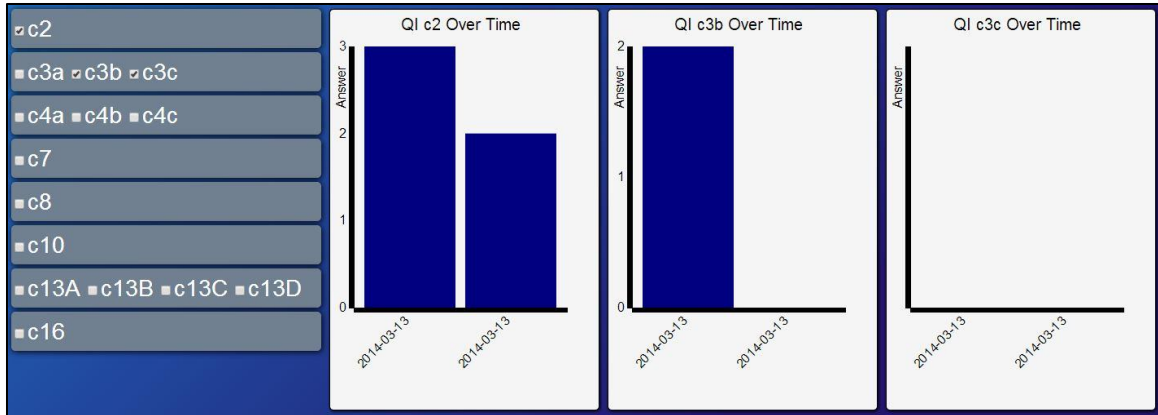

Figure 10 – Analytics window

By selecting one or more questions, the user sees the response to the question over time in the form of a bar graph. The question identifier is shown (C2 for example), which reflects the nomenclature of the MDS 3.0. The analytics section is shown in Figure 10, where the response is plotted versus the date of the survey in which question was asked. In addition to these analytics, the user may also record video and audio, and create a report to document a meeting.

b. Report generation

A report is a file created to document a meeting with a caregiver, or to highlight a particular problem such as a sudden change in QI results or behavior survey answers (new wandering for instance). When a user clicks on the reports button, they are redirected to the page shown in Figure 11. In this window, a user may select from videos, audio, and text notes (goals or notes) to insert into a new report. The final result is a report that appears under the reports window, and can be accessed by anyone who has access to this patient's reports. This means that a doctor who is treating a dementia

patient for the first time could bring up the list of reports, and look through for information of interest. This report can be printed directly, or saved as a PDF to allow its transfer through email (a desire of the clinical collaborator).
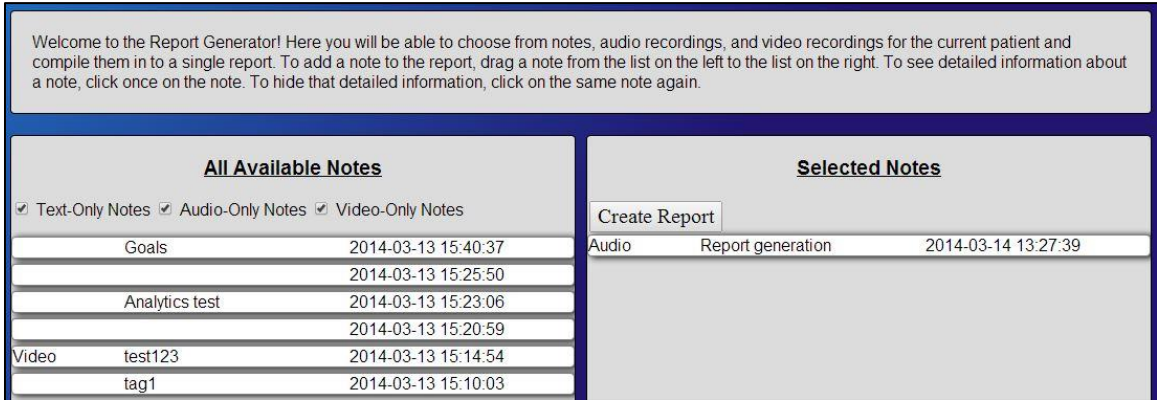

Figure 11 – Report Generation Window

c. Audio and video features

Audio and video recording are important parts of the application, allowing users to record events to improve the quality of the notes. If a caregiver needs to provide physical support to the patient, being forced to submit a report via text would be undesirable. The audio recording (in combination with the video recording) allows for hands free note generation, which can later be incorporated into a report. Figure 12 shows the window for video recording on a PC, which currently only allows up to five minutes per recording. This time limit is currently in place due technical limitations with storing large files directly on a single server. There is a similar limit for audio recording. Via a text box users can also directly create a note associated with the audio, and give that note a tag to make it easier to find later. Video recording has similar functionality to audio, but is accessed via a separate button. Recording a video will automatically record audio as

well, but requires an attached camera on whatever device is being used. Figure 13 shows

the window for audio recording, showing the similarities to video recording. The

integration of video and audio allows for more descriptive notes that are expected to be
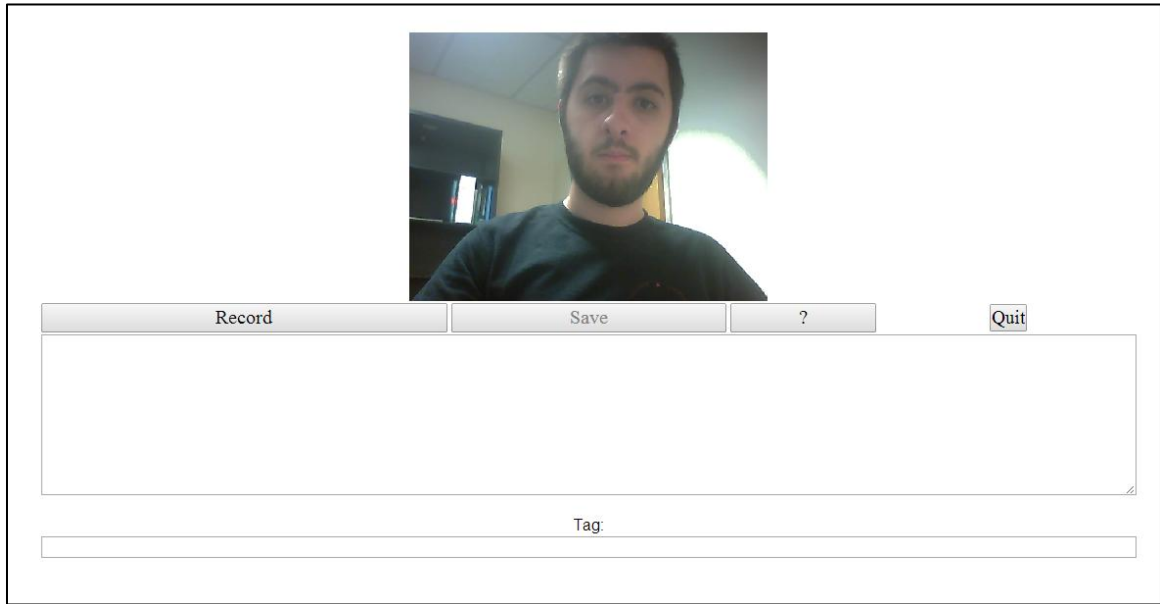
Figure 12 – Video Recording Window

more useful to caregivers.

Under another section there is a button for using Skype. The integration with

Skype allows for users to directly call contacts through the Skype program. AES-256 was

strategically selected as our encryption code since Skype already uses this encryption

format, so no additional changes were required to encrypt the video and audio stream that

Skype generates. This further ensures that the PHI is protected in a way that is both

secure and standardized across the medical field. Users have the ability to add contacts

into the Skype function, which will then appear as a link for one click calling. This is

designed to be used for direct contact with a doctor or family who live far away. It does

require Skype to be installed, as clicking a contact button will open Skype and prompt a login. The proposed application has been created to comply with HIPAA and the HIPAA security rule, as well as regulations surrounding the submission of reports to Medicare/Medicaid. (American Medical Association, 2013). The HIPAA security rule covers the creation, transport, use, and maintenance of PHI (protected health information) in the United States. Core design decisions like the method of encryption and transmission were directly influenced by the security rule for the dementia care manager.
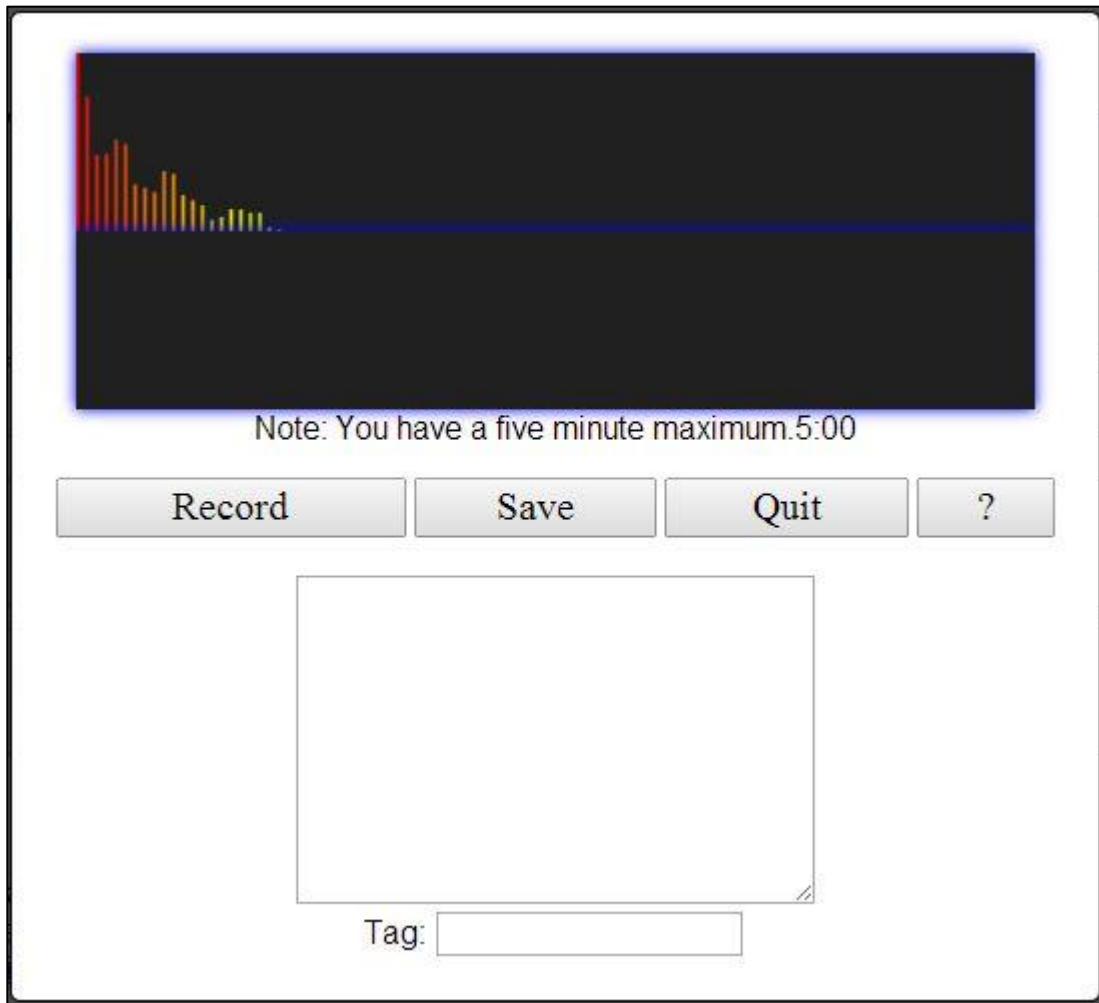

Figure 13 – Audio Recording Window

2. Assessment of testing

Each major application function was evaluated through the testing described in section 3.4, the results of which are shown below:

a. Login/ logout

Type of Test	Result/Output
Encryption	AES – 128 rejected, sent to error page
Form Factor	No errors resulted

Table 1 – Testing for login/logout

Testing of the login and logout functions centered on usability and security (Figure 6). The testing that was done showed that the login was secure; no-one without a login could get access due to the lack of account. The login was also determined to be secure by attempting to access the website using a weaker form of AES (AES-128) in an older browser. The application rejected the attempt to access the login page, showing that only by using a modern browser with proper encryption can a user access the login page. The testing surrounding usability evaluated the different device form factors as well as ease of registration. Testing by the student showed that it was usable, not displaying errors and working the first time. Usability will be covered more in section 4.2d.

b. Data submission

Type of Test	Result/Output
Video	Result; No errors resulted
Time for video to be available for reports after recording	Takes longer for longer videos
Time for text/medication records to update	Took less than 10s

Table 2 – Data submission testing

Data submission covers the submission of any data to the application. This includes video/audio/text notes and MDS survey results, as well as updates to the medications list. Testing surrounded usability and functionality. The functionality describes how well the function works: does it meet the initial goals the student and clinical collaborator had for it? Functionality was tested to ensure that data was delivered to where it needed to go, as well as how long this movement took. For instance, recording a video on a mobile device and then timing how long until that video was available to the other functions that could use it (report generation). Due to technical limitations a longer (1 minute+) video can take several minutes to be available. This is due to the fact that there is no database for the system, and there is only one desktop computer for operations. Storing and processing the video takes processing time that is otherwise used to run the application when in use. As a result, it can take several minutes to process a video if the application is being used while waiting. Text notes and medication updates were available almost instantly due to their data size, and would be tested with the report generation to ensure a complete data path (input data → report generation). By the time the student exited the window for the text and medication notes, they were available where they needed to be. Usability for data submission is covered in section 4.2d.

<u>c. Analytics and report generation</u>

Test	Result
Formatting the same on PC and mobile	Correct apart from initially on mobile device
Time for survey data to be available to analytics function	Available in under 10s

Table 3- Analytics and report generation table

The testing for analytics and report generation centered entirely on function, since usability was tested as part of 4.2d. The student first tested that data was delivered to where it was needed. This meant that the data from surveys was correctly available for analytics and was organized correctly. The results from this testing showed that analytics was working correctly, where the data from the surveys was rapidly (within 10 seconds) available to the analytics once submitted. The visibility of the analytics section was determined to meet the standards set by the guidelines.

<u>d. Interface usability</u>

Test	Result
Mobile interface formatting comparison to PC formatting	Initial errors with formatting; errors have been corrected
PC interface formatting (no overlapping boxes or buttons)	No errors resulted

Table 4- Interface usability testing

The administrator and caregiver interfaces are shown in Figures 7 and 8 respectively. The testing was performed to ensure the application was usable to the same level as the baseline, which was defined as operating the application on a desktop

computer. It was found that using a very small device such as a smartphone can be cumbersome compared to the desktop PC when accessing the surveys. This is a result of the form factor of the device and the input method (touch screen), not the application itself. The student determined that the application was still usable, as the only problems with the usability encountered were due to the input method. For example, the student encountered a problem where a button could accidentally be clicked when attempting to pinch zoom on a smartphone. This was a rare occurrence during testing however, and the application has built-in back and home buttons on every page to allow a user to easily recover from such an error.

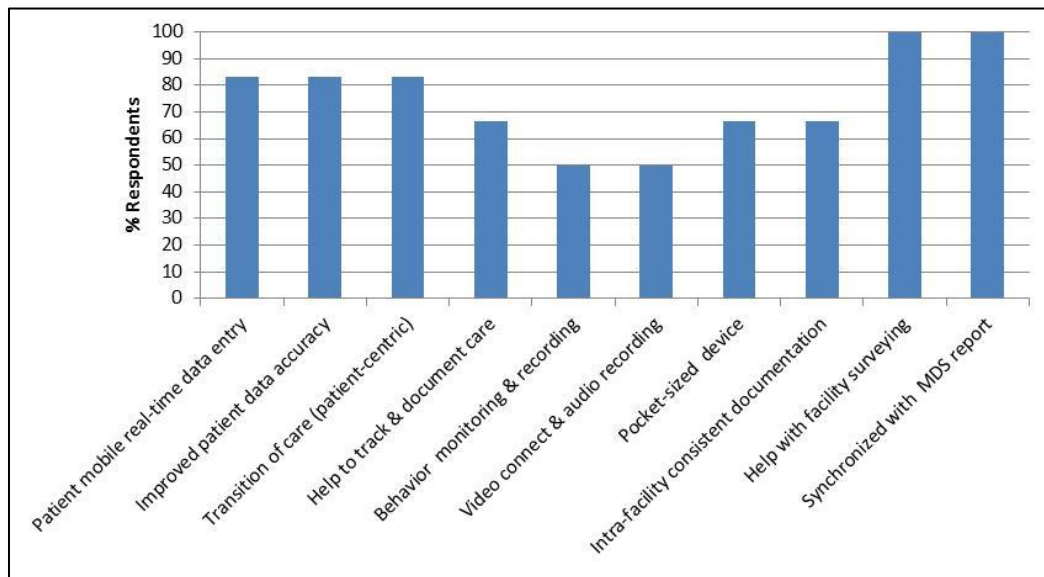e. User survey results

Figure 14 – User survey results

The questions in the survey shown in Figure 5 were answered by six users at the request of the clinical collaborator, including institutional and home-based caregivers. Their aggregate responses denoting approval for particular aspects of the application are shown in Figure 14. These responses are organized from left to right, with question 1 on

the left, question 10 on the right. Answering in favor (or yes) to a question counted towards the total percentage, while answering no or not applicable was counted as a subtraction from the percentage. The last four questions were only from institutional users, rather than a mix of institutional users and home-based users. An average 75% of caregivers approved of the aspects described in the questions.

The first design criterion was that the proposed system must collect patient specific data that allows for creation of plans of care. Responses to questions 9 and 10 show that the application performed well in these areas. Institutional users agreed overwhelmingly (90%) that the application helped with facility surveying and was synchronized with the MDS. The second criterion covered the maintenance and access of the data. This criterion is covered in questions 3 and 8. These also had a majority approval from the users surveyed, with percentage approvals of 80% and 65% respectively. The third criterion covered the security and compliance with the HIPAA security rule, which is a technical feature that was confirmed during the initial testing to work properly with industry-standard encryption (Section 4.1). The last criterion described how the data analysis that is provided must be useful in aiding in decision making for caregivers. This was evaluated as part of questions 2, 4, and 9. The responses to these questions were positive (80%, 80%, and 90%), showing that the application met this criterion according to both institutional and non-professional users. Questions 5 and 6 had lower results (50% for both) than other responses. From comments provided by the clinical collaborator, this is due to the fact that some users did not need or were not interested in the features described in the questions. The responses from the institutional users show that the designed application has met the initial goals that were defined for the

project in terms of access to quality indicators accessible via remote communication, summarized in reports, and evaluated in patient data analytics.

V. FUTURE WORK AND CONCLUSION

1. Future work

Although the current prototype has all the core features implemented, there are a number of potential features that are not yet implemented. Advice from experts on the EHR integration would be necessary to further refine the application and ensure compliance with the rule. With proper advice available, future work could extend various aspects of the application, including creating non-Skype video and audio chat, advanced analytics, text mining of notes and other submitted text, and drug lookup.

Integrating with the EHR of the patient is one of the additions that may be needed for a institutional setting. This addition involves accessing and collecting data from a patient EHR as part of the application. Accessing the EHR allows the application to link with information such as patient comorbidities and previous medicines, which could improve the usability of the application by allowing the software to automatically have access to information that can improve the decision making of caregivers.

Another change that could be useful is advanced analytics. Currently the analytics that are implemented are for tracking quality indicators over time for a single patient. The feature can be extended to collect data from multiple patients to generate a facility-wide report. Advanced analytics could allow for significantly more control of the data, for instance showing all male patients for a particular QI, or looking at one wing of a building under one QI. It could also incorporate a detection algorithm that can throw flags to warn or communicate with the leadership of an institution; for instance, if the QI

questions show a significant decrease in quality of care for one particular caregiver. This could be flagged as a potential issue for this caregiver, and an email could be sent to the administration of the building. This would involve significant testing if implemented, since setting a threshold for a flag would need to be done on a per facility basis.

Another possibility would be to change the telehealth system to use in-house code. The current application uses Skype, which is 3rd party software. Having direct control over these features may avoid potential copyright issues in the future. It would also provide complete control over the application, since Skype is the only 3rd party application that is used. New features could also be included, such as voice recognition for calling certain contacts. Implementation of voice-to-text could further improve the functionality of the audio recording, as it could be used for notes as well as potentially accessing the video call software ("Trigger word"→"Call Julie"). By not using Skype, the need for a separate login would be removed.

2. User input

The next phase of the application will incorporate further input based on experience with using the application (see sections 3.7 and 4.2e). This testing will take place in phase 2 of the project, which is expected to last from one to two years, and is beyond the scope of this thesis. Once this testing is complete and changes have been made based on the first round of user input, a second round of user input will take place to evaluate the subsequent (third) iteration of the application. This will involve surveys that will solicit more detail on specific portions such as how well the presentation of the data and analytics improves the quality and speed of care.

In order to test the time to decision, surveys will be created that assess the use of the application by caregivers. An example question on future surveys might be: "How long does it typically take to decide to move a patient to a different level of care facility? Starting from when it becomes physically necessary (for the patient) to do so and ending once the paperwork has been submitted to move the patient." The next questions will ask what information was most useful in that decision, and how well the application performed in reducing the time associated with collecting this information and making the final decision. The application can then be updated to incorporate this new information.

3. Conclusion

The application has met the main goals set for the project. The individual elements of the software were tested and verified using procedures defined in section 3.6. The additional work that is required to further develop the application is centered on user testing that will take place in phase 2 and beyond. Currently, the application has the ability to operate on any device, regardless of form factor or input type. It offers caregivers and facility managers the ability to track quality indicators over time for patients through the MDS integration, providing a means to collect, organize, and analyze patient information in a user friendly manner. By organizing disparate data, the application may be able to reduce confusion when important caregiving decisions need to be made. Having one application that can track patient goals, analyze behaviors, list medications, and allow for real time communication is expected to significantly increase the quality of care for many patients by directly reducing the time to decision for caregivers. It is also expected to be easier to use than other applications, since it does not

require installation on separate computers. With further enhancements, this application could become a valuable tool for more efficient care for patients with dementia.

REFERENCES CITED

Alagiakrishnan, K. (2013). *Vascular Dementia Treatment & Management*. Retrieved August 8, 2013, from Medscape Reference: http://emedicine.medscape.com/article/292105-treatment

Alzheimer's Association. (2014, March). *Alzheimer's Disease Facts and Figures*. Retrieved from http://www.alz.org/alzheimers_disease_facts_and_figures.asp#quickFacts

American Medical Association. (2013). *HIPPA Security Rule - American Medical Association.* Retrieved September 12, 2013, from AMA Web Site: http://www.ama-assn.org/resources/doc/psa/hipaa-phi-encryption.pdf

Arias, E. (2006). United States Life Tables. *National Vital Statistics Reports, 54*(14).

Arizona Department of Health Services. (2013, June 7). *Assisted Living Provider Type Definitions*. Retrieved September 9, 2013, from http://hsapps.azdhs.gov/ls/sod/ALProvTypes.aspx

ATKearney. (2013). *GSMA - The Mobile Economy 2013.* London: GSMA.

Bogardus, S. T., Bradley, E. H., & Tinetti, M. E. (1998). A taxonomy for goal setting in the care of persons with dementia. *Journal of general internal medicine*, 675-680.

Brookmeyer, R., Gray, S., & Kawas, C. (1998, September). Projections of Alzheimer's Disease in the United States and the Public Health Impact of Delaying Disease Onset. *American Journal of Public Health, 88*(9), 1337-1342. Retrieved July 23, 2013, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1509089/pdf/amjph00021-0049.pdf

Buchanan, B. G. (2005). A (Very) Brief History of Artificial Intelligence. *AI Magazine*, 53-60.

Burgio, L., Cocoran, M., Lichstein, K. L., & Nichols, L. (2001). Judging Outcomes in Psychosocial Interventions for Dementia Caregivers: The Problem of Treatment Implementation. *Gerontologist*, 481-489.

Bynum, J., Rabins, P., & Weller, W. (2004). The relationship between a dementia diagnosis, chronic illness, medicare expenditures and hospital use. *Journal of American Geriatric Society, 52*, 187-194.

Cainson-Global Tracking Solutions. (2012). Retrieved September 29, 2013, from http://www.cainson.com/tracking/?page_id=1430

CMS.gov. (2014). Nursing Home Quality Initiative. Baltimore, Maryland, United States of America. Retrieved from http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/index.html

CognitionSys Ltd. (2014). iReminiscence therapy. Retrieved from http://ireminisce.co.uk/

Cooper, C., Selwood, A., Blanchard, M., & Walker, Z. (2009). Abuse of People with Dementia by Family Carers: Representative Cross Sectional Survey. *British Medical Journal*, 583-586.

Dolan, B. (2012, May 1). *Survey: 71 percent of US nurses use smartphones*. Retrieved from Mobihealthnews: http://mobihealthnews.com/17172/survey-71-percent-of-us-nurses-use-smartphones/

IMS Maxims. (2014). Retrieved from http://www.imsmaxims.com/

Kales, C. H., Valenstein, M., Kim, H. M., & McCarthy, J. F. (2007). Mortality Risk in Patients With Dementia Treated With Antipsychotics Versus Other Psychiatric Medications. *American Journal of Psychiatry*, 1568-1576.

Klein, D. A., Steinberg, M., Elizabeth, G., & Cynthia, S. (1999). Wandering Behavior in Community-Residing Persons With Dementia. *International Journal of Geriatric Psychiatry*, 272-279.

Livingston, G., & Leavey, G. (2010). Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK. *British Medical Journal*.

LNT Software. (2013). *VIPS Dementia Toolkit*. Retrieved July 29, 2013, from http://lntsoftware.com/vips-dementia-toolkit/

McKeithan, M. P., & Schumock, G. (1998). Economic considerations in Alzheimer's disease Pharmacotherapy. *Pharmacotherapy*, 79-82.

Medicaid.gov. (n.d.). *Intermediate Care Facilities for Individuals with Mental Retardation (ICF/MR)*. Retrieved September 9, 2013, from http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Institutional-Care/Intermediate-Care-Facilities-for-Individuals-with-Mental-Retardation-ICFMR.html

Mor, V., Orna, I., Unruh, M. A., & Cai, S. (2011). Temporal and Geographic Cariation in the validity and internal consistency of the Nursing Home Resident Assessment Minimum Data Set 2.0. *BMC Health Services Research*.

My Life Software. (2013). *Products*. Retrieved September 29, 2013, from http://mylifesoftware.com/products

NIST. (2001, November 26). Announcing the ADVANCED ENCRYPTION STANDARD (AES) - Federal Information Processing Standards Publication 197. *Federal Information Processing Standards Publications*. United States of

America. Retrieved January 9, 2014, from
http://csrc.nist.gov/publications/fips/fips197/fips-197.pdf

Phelan, E. A., Borson, S., & Larson, E. B. (2012). Association Between Incident
Dementia and Risk of Hospitalization. *The Journal of the American Medical
Association (JAMA)*, 165-172.

Planitz, B., Sanderson, P., Kipps, T., & Driver, C. (2013). Nurses' self-reported
smartphone use during clinical care. *Proceedings of the Human Factors and
Ergonomics Society Annual Meeting, 57*, 738-742.

Plassman, B., Langa, K., & Wallace, R. (2007, November). Prevalence of Dementia in
the United States: The Aging, Demographics, and Memory Study.
Neuroepidemiology, 125-132. Retrieved August 1, 2013, from
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2705925/

Rapoport, M. J., Reekum, R. V., Freedman, M., & Streiner, D. (2001). Relationship of
psychosis to agression, apathy, and function in dementia. *International Journal of
Geriatric Psychiatry*, 123-130.

Reger, M. A., & Welsh, R. K. (2004). The Relationship between neuropsychological
functioning and driving ability in dementia : A Meta-Analysis. *Neuropsychology*,
85-93.

Sachs, G. A. (2004). Barriers to Excellent End-of-life care for Patients with Dementia.
Journal of General Internal Medicine, 1057-1063.

Schoenmakers, B., Buntinx, F., & Delepeleire, J. (2010). Factors determining the impact
of care-giving on caregivers of elderly patients with dementia. A systematic
literature review. *Maturitas*, 192-199.

Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia.
American Journal of Geriatric Phychiatry, 240-249.

Smith, M., & Buckwalter, K. (2005). Behaviors Associated with Dementia. *The
American Journal of Nursing*, 40-52.

Snook, J. (2009, March 30). *Colour Contrast Check*. Retrieved from Snook.ca:
http://snook.ca/technical/colour_contrast/colour.html

Spector, W. B., & Davies, O. M. (2009). Reminiscence therapy for dementia (Review).
The Cochrane Library(1).

Witten, I. H. (2005). Text Mining. In M. Singh, *Practical handbook of internet
computing* (pp. 14-1 - 14-22). Boca Raton, New Zealand: Chapman & Hall/CRC
Press.

World Wide Web Consortium. (2008, December 11). *Web Content Accessibility
Guidelines (WCAG) 2.0*. Retrieved from W3C.org:

http://www.w3.org/TR/2008/REC-WCAG20-20081211/#visual-audio-contrast-contrast

Zhu, C. W., & Sano, M. (2006, June). Economic considerations in the management of Alzheimer's disease. *Journal of Clinical Interventions in Aging*, 143-154. Retrieved July 23, 2013, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2695165/