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Challenges and Opportunities in Design for Older Adult Healthcare Preparation

THESIS

Submitted in partial satisfaction of the requirements
for the degree of

MASTER OF SCIENCE

in Computer Science

by

Sonali Madireddi

Thesis Committee:
Professor Yunan Chen, Chair
Professor Alfred Kobsa, Co-Chair
Professor Ramesh Jain

DEDICATION

To

My grandmother Sree Lakshmi Koka, for her inspiration, constant support, wisdom and kindness for which I will be forever grateful and without which I will not be able to be who I am today. Thank you for making me into who I am and who I will be.

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ABSTRACT OF THE THESIS

Challenges and Opportunities in Design for Older Adult Healthcare Preparation

By

Sonali Madireddi

Master of Science in Computer Sciences

University of California, Irvine, 2015

Professor Yunan Chen, Chair
Professor Alfred Kobsa, Co-Chair
Professor Ramesh Jain

This qualitative study is a result of conducting 6 month long observations and interviews of older patients in the senior health center at the University of California, Irvine medical center. The study revealed three areas within which challenges for older adults were encountered. These areas include 1) Information work management 2) Resource utilization and 3) Caregiver facilitation. The challenges within 1) Information work management include a) Lack of information work organization strategy, b) Caregiver responsibility co-ordination, c) Patient aggregated data exchange limitations, d) Comprehension challenges of specialized information, e) Patient medical history organization and retrieval limitations, f) Health care agenda planning barriers g) Lack of comprehensive analysis of healthcare outcomes. The challenges within 2) Resource utilization include a)

Emotional barriers to resource use b) Lack of direction during resource use c) Lack of resource support for vital sign tracking and reporting. The challenges within 1) Caregiver facilitation include a) Privacy and access challenges and b) Task coordination. These challenges encountered are demonstrated during the “timelines of healthcare preparation” of before, during and after a medical visit.

These challenges present potential technology development and design opportunities for health informatics researchers and healthcare designers. In this work, challenges encountered and opportunities for design have been discussed by considering the three phases of 1) pre-visit information preparation, 2) facilitation of information exchange during the medical visit and 3) assistance during task execution after the visit.

CHAPTER 1: INTRODUCTION

It is shown that the World's population is aging at its fastest rate from the time records began [3,20]. With this movement indicating an increase, it becomes important to consider the implications of the rising aging population as it relates to that of healthcare delivery, management and care processes. This work has focused on the health care preparation process of older adults and their caregiver networks which we term as the "caregiving unit". The caregiving unit comprises of family members who are part of the healthcare preparation process for older adults. This work demonstrates challenges encountered and opportunities for design during the three-phase health care preparation process that we term as "timelines of health care preparation". The three phased timelines include healthcare preparation before, during and after the medical visit.

In light of the requirements for health care management, preparation and recovery process for older adults, researchers in the field of health informatics, cognitive sciences, geriatrics, assistive technology user interface designers and computer scientists have elaborated on the unique requirements for older adult health care needs and technology design to augment and facilitate their needs in the variety of scholarly work [2, 9, 12]. These unique challenges pertain to that of vision,

cognitive abilities, motor skills, and health literacy among others [12]. With regard to vision requirements for technology platforms navigation, older patients face challenges in legibility, navigation, search and feature distractions and recommendations suggested were to include larger font size and contrasting shade of colors. With regard to cognitive abilities, the older adults face information processing challenges and the recommendations were to include sitemaps in systems being developed for older adults. With regard to motor skills, the challenge is the inability for older patients to accustom their hand movements to that of user interface interactions, where the recommendations that were suggested included mouse over technologies in the websites.

During the duration of this study, some of the challenges such as lack of information work organization strategy, caregiver responsibility co-ordination and patient aggregated data exchange limitations were uncovered during the qualitative study of older adult patients in the senior health center of the UCI medical center that were elaborated in the context of the framework of emotional, functional, scalable and temporal levels. These challenges were found in the domains of medical information work, resource use and roles of caregivers in the medical preparation process for older adults.

Based on the findings uncovered, it is highly evident that designing technologies and tools for older adults should be considered from the specific requirements of the older patients and their caregiver units to enable older patients prepare significantly better for their health care management and preparation process and thereby allow older adult patients to play a significant partnership role in health care decision-making along with their health care providers.

CHAPTER 2: RELATED WORK

Introduction

Related work presented in this section consists of scholarly work within the work of CHI, CSCW, UbiComp, gerontology, nursing science and cognitive sciences literature. The focus of related work begins with the understanding of the domain of elderly health care, followed by the necessity of including elders in the health care decision making process. The decision-making principles of elders have been grounded in the self-management theory of health literacy and patient education.

Scholarly work examined for this study is illustrated in the following sections.

Firstly, scholarly work in the domain of older adult patient care in the context of increasing older adult population is studied. *Secondly*, the role of caregivers has been studied in the context of providing care during the healthcare preparation process. *Thirdly* the theory of self – management has been examined as it pertains to that of healthcare literacy, management and prevention for older adults and caregiver networks. This relates to using the theory of self-management into obtaining higher health literacy thereby enabling the older patients to make better health care decisions and collaborate as partners in the health care agenda planning along with primary care providers.

Elder Health Care

Increasing Interest in Elder Care

The concept of elder care has been of significant interest to the CHI and HCI research community, which is also represented, in the number of papers published within this sphere. In John Vines et al paper of “An age old problem: Examining the Discourses of Aging in HCI and Strategies for Future Research” [3]. This paper elaborates on scholarly work that relates to technology design and old age. Based on systemic searches and data gathering conducted, a total of 644 papers were found to have been published in the avenues of ACM SIGCHI between the time period of 1986 and 2012[3]. This systemic search comprised of key search terms such as “aging”, “older people”, “seniors”, “older people” and “elderly”. This represents a distinct growth of interest and popularity in the area of aging within the CHI community.

Based on the scholarly work researched among the 644 papers that appeared in the period between 1986 and 2012, the discussion surrounded the discourse on Health Economics that consisted of technology reducing the risks of growing old. In the work of “Home made methods for managing medication” by Palen et al [21], the work consisted of discourse on how the world’s age old population continues to rise and the “methods in which the technological advances made can defray the

medical costs by maintaining the dignity of older adults who can continue to manage their health care in their homes and communities”.

In the work of Dahl et al [22] of “ value biases of sensor based assistive technology”, it is stated that the multiple chronic conditions and continuous care management is connected to that of the portrayal of old age. Technological advances have been discussed to control the issues that arise with old age by reducing the costs and developing new healthcare tools to meet the changing needs of the older care demographics. These technologies range from monitoring tools for medication intake [23], technologies to allow reflection on medication use by elder patients [24] and reminder systems for medication intake [25].

Additionally it has been presented that traditionally aging has been proposed as a problem and that technology can play a role in destigmatising the problem [3]. However, as the percentage of baby boomer’s generation who are also termed as elders, older adults and seniors who are typically in the age range of above 65 years [4] is increasing, the community of CHI and gerontology researchers have started including the factors such as social, societal, emotional and economic factors along with their reduced capacity of using all their faculties. These factors will play a role in determining how elders utilize health care technology

interventions. In the paper titled “ The ELDer project: social, emotional and environmental factors in the design of eldercare technologies” [9], social, societal and physiological factors play a role in designing healthcare technologies for older adults. Specifically, for the social and physiological factors, design recommendations suggested that the use of specific technology prototypes influences the method in which older adults user populations are viewed by members of the society and the community in which the older adults are a part of. Devices that do not provide clear aesthetic look to the older adult user of the technology system will pose a stigmatizing aesthetic and thereby contribute to older adult depression. Particularly, the aesthetic and usability of the tool will contribute to the social, physiological, emotional and environmental factors in older adults.

Statistics and the uniqueness of the aging population

In the US alone, it is estimated that, the number of the aging population is estimated to increase by 135% and that this would take place between the time period of 2000 and 2050 [5]. With this movement indicating the increase, it becomes important to consider the implications of the rising aging population as it relates to that of healthcare delivery, management and care processes followed across public private medical institutions, organizations delivering health care,

technology-design-services-platforms being developed delivering health care services at the individual level and at the system wide level.

The provisions and systems in place for providing health care for the elderly is distinctly different as compared to other segments of the current population particularly due to the treatment of care plans. For the elderly, the treatment of care corresponds to health care management and long term health care preventative care as the care for adults is based on chronic conditions such as cancer, diabetes and osteoporosis as opposed to acute care conditions such as broken limbs, fracture, ligament surgeries and flu [6]. Firstly, for the management of elder care, the care process is structured to provide long term examination and coping mechanisms and secondly, chronic care comprises of long term care features comprising of caregivers and health care homes. This unique healthcare maintenance process for older adults where both acute conditions and chronic conditions interact with each other can form an opportune platform for developing technology systems, interfaces, design frameworks and processes to aid in healthcare management, prevention, tracking and support continuity of care.

Role of caregivers in elder health care

Caregivers represent a significant component of the health care provision process for the elderly. Marie R. Haug et al [7] terms the caregivers as the “hidden patient” of the provider servicing the elder patients, where the caregivers also receive the level of informational, technical and emotional support as that of the elder patients in the caregiving process of the elderly. Caregivers of the elders usually consist of family and friends of the elder patients. The primary and secondary caregiver of an elderly couple is the wife/husband or the partner within the couple and the first daughter in the family. In the case that the elder is widowed, separated the first daughter becomes the primary caretaker in the family.

It has been stated in gerontology literature that the primary role of caregivers in the elder patient care is used to serve the role of emotional supporter, service provider, connector to official medical providers and the broader medical service sector and provider of financial assistance [8]. The array of duties taken on by the caregiver is dependent on the specific medical conditions faced by the elder patient and the significances might vary based on the condition of care. In addition, the array of duties might be distinctly different for different levels of caregivers. In this study we have encountered multiple caregivers caring for an individual elder patient and the roles and the quality of care provided by each type of caregiver is distinctly

different based on multiple factors such as the personal relation, geographic distance, and economic ability [9]. In the cases that an elder patient is supported via a caregiver/caregivers, the unit of support is termed as the “caregiving unit” in this study.

Need for health care decision making by elder patients

Medical health providers may have the capacity to influence the medical health decisions of the elder patients due to their range of specialized information and this can be offset by the elder patient knowledge and general understanding of the health care decisions and thereby morphing the health care decision making process into a partnership and a thereby into a more collaborative process. Self-management education is a viable source of attaining this collaborative exchange [10].

The paradigm of self-management education can be applied to elder patient health care. This paradigm consists of different phases in which the elder patients can participate more holistically in the health care decision making process in the cycle of care of long time chronic conditions and can be applicable to that of acute conditions also. The phase consists of problem solving, decision making, resource utilization, forming a patient/provider care partnership and taking action. These

phases have been developed and established in Lorig Kate et al's paper on " Self-Management Education" [10]. The paper provides 5 parameters that are unique to older adult health care preparation process in the context of self-management. *Firstly*, for self management and particularly in the case of problem solving, older patients with problem solving abilities are advised to follow the stages of understand the problem, discuss problem parameters with medical personnel and their caregiver network, work on problem and solution implementation and analyze results.

Secondly, in the case of decision-making – decision making is an important quality that needs to be practiced by older adults to manage their healthcare maintainence. As older adults have to maintain continuous care patterns to deal with chronic care conditions, decisions have to be made daily in managing their healthcare conditions. In order to make accurate decisions in healthcare maintainence, older patients would need to have the right information to take the decisions necessary to move their health care outcomes in the right direction.

Thirdly, in the case of resource utilization, sharing resource information with older patients is part of the resource utilization techniques, but far important that providing resources to older adults to maintain their healthcare is to teach and train them to effectively use the resources provided. The teaching can be provided

within the senior clinic environment consisting of medical personnel, primary care providers, in addition the teaching can be provided via home caregiver networks such as family and friends.

Fourthly, in the case relationship development with health care providers, in the case of chronic illnesses, older patients have to constantly interact and develop partnerships with their healthcare providers in order to learn, make decisions and report the signs, symptoms and requirements to their medical health providers in the case of chronic conditions.

Fifthly, in the case of taking action, older patients must be able to devise short term and doable action plans that enable them to perform and complete health related tasks that are part of the health care agenda plan.

Out of the different phases involved in self-management education of elder patients related to elder health care, the phase of decision-making will be explored more holistically in this study.

Decision-making is important criteria while managing care during the chronic illness and in addition acute care problems of elder health care. While elders are

involved in managing their care plan at home, where the maximum implementation of care plans occur, it becomes crucial for elders to make the right decisions regarding any changes in their health patterns and the methods to resolve them at home if and when required. As indicated in the work by Lorig Kate et al on "Self Management Education" [10], there are significant differences in care plans in older adult populations and other younger adult populations. The care plans for younger adults are targeted towards acute conditions, symptom based conditions where the emphasis is on symptom reduction and recovery from specific ailments. Hence the role of medical health providers for acute condition treatment in younger adults is to diagnose and treat. However, in the case of older adults, the conditions such as chronic conditions and acute conditions are all inter related and the care process involves healthcare management, prevention and continuity of care. Additionally decision-making is a skill that can be used during the medical consultation process. For achieving both the goals of 1) making the decisions regarding health care plan at home and 2) effectively collaborating with providers during the patient-provider consultation period, the decision making entails understanding the details of the health care plans, information and documentation provided to them by their medical health network and performing individual research. In this study, the elder patient care preparation process is documented, analyzed and evaluated in order to provide strategies for effective methods of

health care preparation process in order to make better decisions regarding their care plans via the process of self management as detailed in the discussion above.

Information work management by elder patients

Information work organization and technology support

Health information work is a major component of the health care preparation process for elder patients and for the caregiving unit of the elders where the information prepared by the patients results in producing health care decisions and health care agendas in collaboration with the health care provider. Managing information work during the different stages of before, during and after the medical visit by elderly patients is particularly difficult.

As examined by Wanda Pratt et al in the paper on “Barriers to Organizing Information During Cancer Care” [2], it can be examined that patients especially with chronic healthcare issues and especially elders face significant barriers to organizing information work that might be needed to effectively handle health care preparation. These barriers are illustrated as emotional, scalable, temporal and functional. These particular barriers of emotional, scalable, temporal and functional can be found during the function of information work management. In the work of “Barriers to Organizing Information During Cancer Care” [2].

Firstly, the emotional barriers to information work organization is discussed where older patients may tend to receive a negative loop of distress by initially not having a strategy to organize the information work followed by the anxiety of postponing the organization. This negative feedback loop is counterintuitive to effective management of health care information and prevents older patients from participating in their care work. *Secondly*, the scalable barriers were discussed where the managing large quantities of information work becomes problematic. In the case when older patients had to organize a small quantity of information work, it was easier to retrieve this information. However, when the quantity of information collection grew, the process of information organization and retrieval proved to be more difficult. *Thirdly*, temporal barriers consisted of two part problems consisting of Time Compression and Task Fragmentation over time. The case of time compression arises because older adults lack the time required to adequately understand large quantities of information before the medical visit. In the case of task fragmentation over time, particularly in the case of older adult chronic care, the health care information received by patients is fragmented over time and with varying quantity.

For the cases of senior patients managing clinic generated documentation work and self generated documentation, effective organization of the documentation provides proves vital for making health care decisions and choose treatment plans effectively based on the discussion on “Barriers to Organizing Information During Cancer Care” [2]. However due to emergence of emotional, scalable, temporal and functional barriers that get compounded, senior patients and other patients in different age groups dealing with chronic health cases are unable to manage their care work effectively. This work on patients dealing with different types of barriers illustrates the importance of considering these areas while providing recommendations while managing information work by elders.

As indicated in the above discussion on barriers to organizing information during cancer care, the ways in which the emotional, functional, scalable and temporal barriers, where these factors are also used as a framework for analyzing challenges encountered in this study, can be mitigated are in the form of providing technology and interface design recommendations to the development of electronic healthcare records, in the form of 3 ways, where 1) this can be obtained by linking the current information to already existing elder patient information in the PHR as well as electronic personal health information management tools such as personal calendar and other task management utilities, 2) providing functional views of the data

present in the PHR which includes the features of additions of descriptive and procedural information such as what; why, when, where respectively, 3) organizing the information in the form of due date relevant data helps navigate the healthcare agenda timelines. In addition, information work organization is a task that needs to be explained in form of providing health care literacy to the elder patients. Elders would need assistance in the learning curve of managing the information work within the PHR for which the medical practitioners and the medical personnel may have to provide support. Additionally, as illustrated by the emotional barriers to organizing and managing information work in Wanda Pratt et al's work on "Barriers to Organizing Information During Cancer Care" [2], healthcare information management is an emotional process for which the design and interface design should inculcate design recommendations to manage emotions of the patients. Recommendations for design modifications to manage emotions during information work management include the design of calming technologies such as embedding cognitive behavioral techniques that induce mindfulness, relaxation and other stress reducing methods into the PHIM interfaces [2].

General design guidelines for elder care technologies

Usability guidelines for web based online research for health care preparation by elder patients

According to Kathryn Zickuhr et al at the Pew Internet project [11], it has been studied that 53% of all older adults use Internet and email as of April 2012. A study indicated that older adults use the Internet to search for health care conditions and medications [12]. Technology use patterns such as the web based Internet use to research health care plans, options and conditions are distinctly different for younger adults as compared to that of older adults. The specific conditions such as vision, cognition, motor skills and literacy affect the senior adults in obtaining full health information from web-based sources [12].

The U.S National Institute on Aging (NIA) and the National Library of Medicine (NLM) [2002], recommend the following suggestions to the online health resources in order to improve the usability of web-based resources for the elderly. In the context of vision, the aspect that impacts the ability to comprehend the information in health care resources online is the legibility, navigation, search feature and feature distractions. To overcome the above stated barriers, the recommendations suggested are to have a larger font size to avoid highly patterned backgrounds and to have a contrasting shade of colors between the foreground and

the background, with regard to vision. With regard to cognitive abilities, the recommendations were to include site maps in the health care websites. With respect to motor skills, the recommendations were to reduce mouse over technology in the websites. With respect to literacy, it has been suggested that the language used in the health care websites should not be highly specialized but rather should be able to be understood with relative ease and there by the recommendations were to include the text at the grade level of seventh grade.

Mobile based guidelines for health care preparation by elder patients

Mobile health technologies also known as health applications have increased with the adoption of mobile phones being used as a means for obtaining medical health aid. Health technologies are particularly useful for elder care and for the caregiver in different instances. The areas in which health applications can be used are 1) symptom monitoring 2) self-management education 3) automated decision-making [16]. These essential features discussed in the work by Wanda Pratt et al of “Managing Health with Mobile Technology” [16] are discussed in greater detail as below.

For the case of symptom monitoring applied to elder patients, it becomes important to track symptoms and vital signs such as heart rate, blood pressure, glucose levels,

body temperature and more. These levels can be reported by either self-reporting or via sensor input. If and when these symptoms rise above a certain safe level, required actions must be taken. In the case that the mHealth application is connected to an alerting system, medical health care providers and emergency contact persons can be automatically informed about the state of conditions and appropriate actions that would need to be taken. It has been proven that the symptom monitoring process will enable preventative care in long-term management of the chronic and acute conditions in elder patients. This reduces the period of hospitalization of elderly patients for a certain condition.

For the case of self-management education, mHealth applications can be used to provide educational materials and knowledge about the medical information provided by the primary care provider. This will influence the way in which patients learn about their symptoms and participate in monitoring the conditions. The mobility of the mobile phone and the mHealth applications will enable the senior patients to actively continue learning the specifics of the condition at any location. For the case of automated decision support, mHealth applications can consist of automatic decision support use cases that consists of managing the health care plan and advise on health care agenda set with the partnership between the elder patient and the provider.

System wide platform technologies in use by elderly patients

Guidelines for PHR platform design development for elder patients

The personal health record systems also developed, as health organization specific patient portals are a major technology platform for elderly patients to participate in preparing and participating in patient-provider health care agendas. Traditionally, patient data was part of electronic healthcare records that consisted of specialized health care information and in which the content was determined by the medical providers and the medical personnel. With the development of electronic personal health care records, the initial data population within the patient health records was through the electronic health records. The initial release and adoption of the personal health records were directed by medical providers and the medical personnel where the content of the personal health records consisted of diagnosis related documentation, medical records, test results, medication prescription and other longitudinal health information of the patient.

With the focus of electronic personal health records transitioning from provider centric to patient centric it has become increasingly important for the content, architecture, design and source of data entry, presentation and usability features of the current electronic personal health records to reflect the needs of the patient.

This includes data such as patient generated health care agendas, communications log between patient and provider, current medication data among others [13]. PHR systems play a significant role in filling the implementation segment gap in self-management of health care by patients. The role of PHR is to accomplish the 3-fold use of 1) information collection 2) information sharing 3) self-management education.

It has been studied that certain groups of patients are likely to adopt the patient centric electronic patient portal. These patient groups include patients with chronic conditions, patients with disabilities, parents with small children, patients who are interested in maintaining healthy lifestyles, senior patients and their caregivers. For the higher adoption and usability of the PHR systems by the above stated groups, it is particularly important to focus on the specific needs of individual user segment populations [13].

Specifically for the population of elders, significant considerations have to be made for the design, development and adoption of electronic personal health records by elder populations including their caregiving units. There are multiple barriers that need to be overcome during the design and development of new and modified PHR systems for the elderly including health literacy, cognitive barriers

and psychological barriers [14]. Both the cognitive and the psychological barriers in adopting to the personal health records by elder patients can be addressed by modifying the layout, language, usage structure and obtaining increased support from the health care providers and medical personnel respectively. Both the cognitive and the psychological barriers depend on health literacy.

According to the Nutbeam's health literacy model and the usage of PHR's by the elderly population, the stages in health literacy are 1) functional literacy, 2) Interactive literacy and 3) critical literacy [15]. All three phases of health literacy play into the usage and adoption of PHR's by elder patients. For functional literacy of the PHR's for the elderly, it is important for elder patients to understand the complex ways in which the medical health documentation pertains to their health care. However functional literacy can begin by teaching how the resources pertain to the elder patient health in simple terms. For elderly patient understanding of the resources located in the PHR the inclusion of resources such as videos, interactive display and interactive means can be used to convey the information. For the second phase of interactive literacy, the emphasis on using the health care information obtained through the PHR and utilizes the information while acting on the advice provided. This may consist of inserting website links within the PHR systems that can help in providing help from external health groups. The third

phase of critical literacy builds on the functional literacy and the interactive literacy where in elder patient can communicate with healthcare leaders in the community to begin and engage in community wide health support systems.

Role of caregivers in health care preparation

In the context of elder care, the caregiver network if present for the elder is an essential component of providing care to the elder patient. In this context and throughout this study we have termed the caregivers of the elders as the caregiving unit, which would comprise of the primary and peripheral caregivers in the elder patient caregiving network. There are several ways in which the caregiving unit can aid in the health care preparation process of elders. According to this context Consolvo et al [18] has demonstrated the computer supported cooperative care context of providing elder care by the caregiving unit. The areas in which the computer supported cooperative care can be beneficial are 1) providing privacy modes in access to electronic personal health record details of the elder patient 2) systems should consist of introducing similar copies of medical data that can be used by caregivers in addition to elders and 3) systems that allow sharing of responsibilities between the elder patient and the different members in the caregiving network.

This study reveals the challenges encountered by older adults and their caregiver units in the environment of outpatient senior health center, during the process of healthcare preparation identified during the three stages in which healthcare decisions need to be taken by older patients supported by the level of health care preparation performed by older patients during the three phased timeline of before, during and after the medical visit.

The body of scholarly work examined during the study-discussed 1) barriers to organizing information during cancer care as stated in Wanda Pratt et al's paper, 2) social, economic and environmental factors for designing eldercare technologies as stated in the ELDER project by Hirsch Tad et al, 3) self - management education by Lorig Kate et al and more, however the challenges surrounding the areas of information work management, resource utilization and caregiver facilitation needs more examination as it relates to the current method in which older patients in outpatient senior health centers are utilizing methods currently available to them in the form of paper based tools, electronic personal health records and self generated documentation to prepare for the health care agenda. This study examines the challenges as it pertains to the inability of older patients to adequately prepare for their healthcare maintenance and play a stronger role in implementing the healthcare agenda by increasing participation during the three stages stated above. These

challenges studied provide a framework to explore design opportunities that will further enable older patients better prepare for their healthcare maintenance process.

CHAPTER 3: METHODOLOGY

In this study of analyzing the methods in which senior patients, caregivers and providers interact while sharing information with each other and where senior patient's pack and unpack health care management information to better aid in the self health care process, we have conducted a qualitative study spanning between October 2014 to March 2015. This study demonstrated the methods in which the older patients can take control of their health care and give a direction to their health maintenance via self care, self health maintenance with the assistance of caregivers by utilizing already existing health information storage, exchange and communication methods with health care providers in a more structured and efficient manner. This study was conducted at a senior health center.

The senior health care center is a senior patient centric medical home facility, where the care delivery model at the senior health center concentrated on relationship based care and the professional practice model represented the shared governance model. This facility emphasized the use of technology in everyday care process by making use of technology such as ipad's and telemedicine. The work carried on by the senior health center was distributed in the form of teams such as the red, blue and the green teams.

The qualitative study consisted of conducting observations, collecting closed ended demographic questionnaire data and semi-structured interviews. A total of 16 older patient observations and 18 patient interviews were conducted in the senior health center examining the modes of information transfer among the senior patient, caregiver and the health care providers.

Data collection

The data collection site was chosen as the senior health center to examine the ways in which senior patients communicate and share health related information with the provider and receive health care plans and care management methods from the providers.

The data collection process began by shadowing doctors during the process in which they were involved in the care consultation process with the patient and sometimes the caregivers. During the shadowing process, observations of the various kinds of patients were conducted when the patients were involved in the consultation process with the doctor. 16 patient observations and 18 patient interviews were conducted at the senior health center where the flow of patients and events within the senior health center were observed, capturing interactions of patients, caregivers, and healthcare providers while observing the utilization of

artifacts, tools and systems utilized in this setting. The average time period of observations per patient ranged between 30 to 45 mins.

Observations were conducted to understand and learn about the types of patients and types of conditions for which patients visit the senior health center for, to understand the type of interaction between the patient and the health care provider, to observe the participants of the study in their natural setting of healthcare exchange process, to learn about the materials-artifacts transferred to the provider during the doctor's consultation interaction. The observations also included short interviews to clarify questions with patients healthcare providers, note taking and photographic documentation of accompanying artifacts brought by the patients.

After completing a set of observations, based on the interesting learning's and outcome analysis, an interview protocol was developed to gain more in depth knowledge about the interesting key points. This interview protocol consisted of two versions based on whether the senior patient was accompanied by caregivers or not. The interviews consisted of both senior patients and caregivers. Before each interview, each interviewee was given a demographic survey to complete which consisted to questions (such as age, educational background) including questions on higher level medical health care questions such as the patients medical history

conditions and the time frame for which the patient received treatment for the above said health conditions.

Interview Protocol

The interview questions and demographic questionnaires were prepared based on the in situ discussions observed and shadowed during the medical visit of the senior patients and caregivers. Based on the study, it was determined to streamline the interview protocol into three sections of collecting data in the form of 1) before the doctor's medical visit, 2) during the medical visit 3) after the medical visit. Since some of the patients were present with a caregiver, it was determined to have a separate interview protocol asking questions related to how caregivers provided care to the patients.

Patient specific interview protocol

The categories of questions for before the doctor's visit consisted of questions pertaining to the ways in which elder patients prepared for the medical visit by keeping track of healthcare specific data, about what specific tools or information sources they used to prepare for said medical visit and in what ways and methods did patients use to contact the medical provider or others in case of questions about their specific care process. The category of questions that were asked of the

patients during the medical visit consisted of questions pertaining to their communications with the doctor during the medical visit, the methods they use to remember the information they obtain from the doctor during the doctor's visit and the strategies that they would use to ask questions to the doctor in the case they have questions. The categories of questions for after a doctor's visit consists of questions about the resources received by the patient after the medical visit and how the patients utilize this information after the medical visit.

Caregiver-caregiving unit specific interview protocol

In addition, to the interview focus on the senior patient, a specific interview protocol was used for senior patients that visited the senior center with their caregivers. The health care process would significantly differ due to the aid of the caregiver and in some cases the presence of multiple caregivers. The interview questions targeted towards the caregivers consisted of how the caregivers would care for the patient before the medical visit and what methods would the caregivers use to help the elder patients prepare for the medical visit. For the duration during the doctor's visit, the questions were surrounding the type of questions that the elder patients and the caregivers have during the medical visit along with the kind of responses provided by the caregiving entity of caregivers to the medical provider's questions and what ways in which the caregiving unit would present the

information to the medical provider. The questions after the medical visit pertained to how the caregiving unit would unpack the information shared and provided during the medical visit. Specific focus was provided to the case in which the caregiving unit for the elder patient consisted of more than one caregiver. The interview questions centered around how multiple caregivers would manage caregiving in the context of helping the elder patients prepare for the medical visit, collect, store and share specific health care pertinent information during and after the medical visit with other caregivers in the caregiving unit in the family.

Format of interview and material collection

The interviews lasted at an average 15 minutes in length and were audio recorded. During the duration of the interview, visual information was also captured with the permission of the patient and caregiver such as the photographs of the note taking paper based forms and condition specific folders. Other clinic specific sources of information such as the patient's intake forms completed by the nurse during the nurse triage section consultation of the patient before the doctor's consultation process and the end of visit summary visit sheet have also been used as data sources to understand and learn about the medical health data received by the patient and provided to the patient before and after a medical health visit respectively.

Survey Data Analysis

The average age of the sample data of 18 patients is 75, with 15 female patients and 3 male patients that represent a 83% female sample size representation and 17% male sample size representation. 13 out of the 18 patients interviewed had at least 1 caregiver, with 4 out of the 18 patients having more than 1 caregiver. The conditions being faced by the patients and the frequency of their doctor's consultation is as follows:

Table 3.1: Patient conditions specific care time periods

Patient #	Medical Health Condition	Time period of caring for these conditions
P1	Arthritis	4 years
P2	Geriatric Conditions	3 years
P3	Geriatric Conditions	10 years
P4	Geriatric conditions	10 years
P5	High Blood Pressure	4 years
P6	Cough, Liver conditions, cancer	2 years
P7	Thyroid Conditions, Stomach Conditions, General Check Ups	10 years
P8	Cancer, high blood pressure	Cancer - 2 years, High Blood Pressure - 38 years
P9	Knee & Hip Problems, Heart Valve replacement	10-15 years

P10	Breathing problems, hip replacement, cataract problems	> 4years
P11	General Check Ups	10 years
P12	Breast Cancer, Flu - current visit	4 years
P13	Brain Tumor Surgery, Knee Problems, Diabetes, High Cholesterol	3 years
P14	Diabetes, prostate cancer	10 years
P15	Thyroid	25 years
P16	Cancer, blood pressure	15 years
P17	Cough, High Cholesterol	1 years
P18	Bone density, physical therapy, weight management	1 year

Description of patient specific data collected via demographic questionnaire

In the 18 interviews that were conducted the average age of the patients was identified as 75 years, with the range of ages varying from 44 to 92. On the criteria of gender, there were 3 males and 15 females. Regarding the criteria of ethnic background the majority of the interviewed elders identified themselves as Caucasian which included 10 interviewed elders, with 2 elders identifying themselves as Asians, with 4 identifying themselves as Hispanic, with 2 being identified as Asians and 1 of them identifying themselves as mixed heritage.

Regarding the criteria of marital status, 10 of the 18 senior patients interviewed were married, with 3 of the senior patients widowed, with 4 of the senior patients never married and with 1 senior patient separated. On the criteria of academic education, 3 of the senior patients have graduate level master's degrees, with 5 of the senior patient's college graduates, with 6 of the senior patients having equal to or more than 1 year of college education but less than 4 years of a college degree, with 3 of the senior patients graduating high school and with one senior patient graduating 8th grade. On the criteria of annual household income 10 of the 18 senior patients released their household income out of whom, 7 have an annual household income in the range of \$40,000-60,000, with 2 of the senior patients in the range of \$20,000-\$40,000 and with 1 patient in the range of above \$80,000.

Out of the 18 senior patients interviewed, 17 out of 18 patients interviewed informed that they stayed at home and 1 of them stayed at a senior health apartment. Out of the 18 senior patients, more than 1 caregiver at home cared 13 of the senior patients. The maximum number of caregivers per senior patient was 4. In addition, on the criteria of frequency of medical provider visits, 10 of the 18 patients visited the senior health center at least once in 3 months, with 3 patients visiting once every month and 5 senior patients at least once a year.

Demographic Questionnaire Data Representation

Table 3.2 Older Patient Age Distributions

Age Distribution	Number of Patients	Percentage of Patients(%)
40-50	1	5.55
50-60	1	5.55
60-70	5	27.77
70-80	5	27.77
>80	6	33.33

Table 3.3 Gender Distributions

Gender	Number	Percentage
Female	15	83.33
Male	3	16.67

Table 3.4 Ethnic Backgrounds

Ethnic Background	Number of Patients	Percentage of Patients(%)
African American	1	5.55
Asian	1	5.55
Caucasian	10	55.55

Chinese Asian	1	5.55
Hispanic	4	22.22
Mixed Heritage	1	5.55

Table 3.5 Educational levels

Education Level	Number of Patients	Percentage of Patients(%)
Less than 8 th Grade	1	5.55
Some High School	1	5.55
High School Graduate	2	11.11
Some college or technical school	7	38.88
College Graduate	5	27.77
Masters/Doctoral	2	11.11

Table 3.6 Annual Household Incomes

Income	Number of Patients	Percentage of Patients(%)
No Reports	8	44.44
\$20,000-\$40,000	1	27.77
\$40,000-\$60,000	7	38.88

\$60,000-\$80-000	0	0
>\$80,000	1	5.55

Overall Data Analysis

The primary analysis method used is grounded theory [1]. With the range of qualitative data collected through observations, shadowing and interviewing of the senior patients and their caregivers, a qualitative interpretation framework was used to obtain a theoretical meaning of the information gathered while continuing to ground the analyses in factual meaning of the data.

We used the process of affinity diagramming to analyze the qualitative data we received via interviewing and observing senior patients at the senior health center. The data including the patient comments, observations, questions, design ideas and any topographical data from individual patients were examined to gain insight into the health maintenance process of elder adults along with the care provided by caregivers. By collating information on individual patients and consequently all patients, similar findings and concepts were grouped together to identify different themes or trends in the data.

The initial analysis of the data by using affinity diagramming gave rise to a series of three themes which included patient information work during the three phases of patient's interaction with health data before the doctor's visit, during the doctor's visit and after the doctor's visit; the usage of technology tools to handle health care preparation process including patient portals and other tools; the role of caregivers in the health care maintenance process of older adults. After analyzing the data from the interviews, the themes were compared and analyzed with the whole data set to ensure that the themes and the coding process was consistent with the interview and observation data set of the elder patients. With the emergence of the following themes, the recommendations for health care technology tool redesign and system feature updates are being suggested as illustrated in future sections of this thesis.

CHAPTER 4: FINDINGS

Study Details

The qualitative data collection approach of utilizing observation study data and interview data together yielded a richer collection of results as each step enabled us to refine the interesting themes while studying senior patients, caregivers and healthcare providers in the senior healthcare setting of the UCI medical senior health center.

Elder Patient and Caregiver Observations

The study began with conducting observations of elder patients while their visits to the health care providers at the senior health care center. The age range of the older patients being observed was in the range of 50 to 90 years of age. The location of the study proved to be a rich source of information as the senior patients and the caregivers were observed in the environment of receiving active and direct care from the health care providers. Out of the 16 patient observations that were conducted during the span of the data collection process, 8 patients had caregivers along with them during the doctor's visit. The observation process began when a new senior patient and caregiver checks in for the appointment after which the nurse in the respective team treating the patient collects vital sign information from the patient including heart rate, cholesterol level, weight, height and the conditions

for which the patient is visiting the senior health center. After the vital sign health information exchange the patient and the caregiver if present are taken to the clinic room in which the doctor will be consulting with the patient.

During the doctor's visit, the elder patients and caregivers explained the reasons for the doctor's visit which comprised of three different conditions comprising of *firstly*, regular scheduled appointment to manage chronic care conditions such as specific forms of cancer, diabetes, bone density problems and other age related conditions; *secondly*, appointments to discuss temporary health deterioration conditions and symptoms such as flu symptoms, body muscular pain symptoms, fractures due to accidents among others and *thirdly*, new patients being on boarded into the senior health center from other clinics due to transfer of residence and change of primary health care providers.

Out of the 16 elder patients observed, 13 of the elder patients served as the primary spokesperson even when the caregiver was present wherein the elder patients answered condition specific questions asked by the doctor; presented medical documentations such as lab test results, vital sign information and other documentations requested by the doctor; asked questions about the health care process including medication requirements. The remaining 3 senior patients relied

on the caregivers present to relay information to the health care providers, as the age group of these elder patients was over 80 years of age. The reasons for the remaining three elder patients from not being as participatory as the other patients can be attributed to communication-language barriers and knowledge-education level differences.

Elder Patient and Caregiver Interviews

Based on the interactions among the elder patients, caregivers and the health care providers in the senior health care center setting, the interview direction was determined. This resulted in the development of the interview protocol, which consisted of the list of questions to ask the elder patients and their caregivers. The interviews were conducted after an elder patients visit to the doctor in the same examination room as that of the doctor's consultation. As the interviews were conducted after the observation of the elder patient and caregiver-provider interaction during the medical visit, the interaction elements that appeared interesting during the observation session were asked as questions within the interview protocol.

The interviews consisted of a range of questions to help understand the medical health history of the elder patient, the methods in which the elder patient manages

his/her healthcare process, prepares for the health care visits and maintains associated health care information work. In the cases that the caregiver was present along with the patient, additional caregiver specific questions were asked such as the methods in which the caregiver provides care to the elder patient, the ways in which the caregiver helps the caregiver prepare for health care management process and other ways in which the caregiver plays a role in the care of the elder patient.

In the below explanation of the ways in which senior patients prepare to conduct and execute their health care agenda shared by the medical health provider by making the appropriate health care decisions, the term “caregiving unit” is used for one or more caregivers who are caring for a senior patient.

Elder patient's unique role in health care

Senior patient's care receiving and care giving process is very unique within the healthcare ecosystem. The senior patients spend significantly more time and resources in understanding and managing their health care. In comparison to treatments received by young adults, treatment of senior patients is distinctly different as that for young adults, the health care provider treats a particular symptom to reduce an existing condition. As illustrated in the paper by Lorig Kate

et al of “ Self-Management Education” [10], the primary reason that younger adults would seek medical treatment is for acute illness in the form of flu, injury, surgery, fractures and more. In this system, the role of health care providers was primarily to provide diagnosis and provide treatment via prescription medications. However, in the case of older adults, the treatment pattern is long term healthcare maintainance and management, where rather than symptom reduction healthcare agendas, symptom checking, monitoring and controlling are followed. Hence, most often the conditions for which the younger patients receive treatment for is for non-chronic conditions and other singular incident treatments. However for senior patients, as patient’s age, the health problems interact with each other and thereby affects the entire health care machinery and hence treating one symptom does not necessarily solve all the problems.

Since for senior patients the conditions for which they receive care is more complex, interrelated and most often chronic conditions for which the patients have managed the care process for extended lengths of time, the senior patients want additional information and detailed answers to their questions from their care providers and health care centers. This detailed information facilitates the elder patients manage their health care process by making informed decisions about next steps in their health care process. Being informed about the conditions and the care

plans, allows the senior patients make the right decision for improved functioning of their body and choosing a care plan that best fits their needs. This is shown through the observation of patient 10 as follows:

Patient 10: "I think you look at your life and how you are able to continue doing what you do or need to do and if you find that the suggested option would improve your ability to keep functioning, then you go with the option that will help you improve your functioning."

As illustrated in the above patient remarks, the patient would like to make the right decision about their care plan based on the information they already have about the status of the conditions that are being faced by them. The knowledge of these conditions can be obtained by the elders and by their individual care giving units by reviewing their longitudinal health history that would include clinic generated health data such as lab reports, MRI's, test results, medications prescriptions and recommended health care plans including self care generated elder specific information such as questions for the doctor, recommendations from friends, relatives and other caregiving units and personally conducted research via different information sources individually or with the help of other caregiving units and thereby make the right decision about their individual care plans.

In addition to being able to make informed data driven decisions, the senior patients receiving additional information from their healthcare providers allows them to be more invested in the healthcare process by raising their interest levels in their own healthcare decisions and allows them to play an equal role in the direction in which the healthcare process is headed along with that of the clinical physicians, nurses and other health care providers. This allows the health care plan to evolve as a partnership between the senior patients and their health care providers rather than as health care plans suggested by the health provider individually. The older patients want to know about the conditions being faced by them in order to make decisions on healthcare agenda. This is illustrated by patient 1's comment of:

Patient 1: "That is now that you are older they don't think that they (primary care providers) have to answer all the questions but I have all my facilities intact so I still want to know all the answers and understand the conditions."

Themes Analysis

Based on the observations and interviews conducted three unique themes were identified to illustrate the methods in which senior patients can take control of their health care and give a direction to their health maintenance via self care, self health maintenance with the assistance of caregivers by utilizing already existing health

information storage, exchange and communication methods with health care providers in a more structured and efficient manner.

The findings in this section are also accompanied with the breakdowns and challenges observed for the specific target population of senior adults and the caregiving unit in the healthcare process. The breakdowns indicated are the result of senior patient and in some specific cases the caregiving unit that was observed and interviewed in the senior health center. These breakdowns and challenges then form the foundation for further elaboration in the discussion section. These challenges are portrayed in the form of potential technological design, interface, platform and service recommendations that may be used by health care technology designers, developers, elder care technology designers who design and develop technologies for self care management and in this context self care of elders, develop ways in which the health care organizations supported health care platforms such as existing electronic healthcare records, patient monitoring recording systems can be support and enhance the use of self care technologies being used by elders and the caregiving units of elders.

Senior Patient's information work

Patient's information storage and preparation methods before medical visit

In this study, the health care preparation process for senior patients has been segmented as a 3 part process that we shall term as “timelines of health care preparation” consisting of preparation before the doctor's visit is scheduled, during the doctor's visit and after the doctor's visit thereby the primary event around which the health care preparation process is centered around is in the context of the doctor's visit. We believe that the senior patients health care visits with the doctor which include the primary care provider and the specialist are rich with data points because the frequency with which senior patients visit their healthcare providers is much higher because of the type of conditions being faced by the senior patients that include preventative care, chronic care management and general health maintenance.

The senior patients have a system that they have developed to store information about their health care conditions in an accessible manner. This information includes current medical condition information from their current health care provider including information from all prior health care providers. This information is being stored in physical paper based format, audio recording and CD's. The system consists of patients storing their health related documents in

condition specific folders. Each condition specific folder consists of documents such as lab reports, MRI reports, discharge sheets, medication lists. A particular patient - patient 18 among the patients that store information using this system specified in detail the way in which she manages this system:

Patient 18: "I note everything down with a paper and pencil. I maintain the folders in such a way that all the results, forms, vital signs for a particular condition that I am facing is in a separate folder and all of them will be part of different sections of the same folder, that is the same folder but different sections of the folder"

As is represented by the patient 18, the patient has developed a very unique system of storing all pertinent health related items in a folder-based system at home. This particular patient has previously worked as a registered nurse and also as a certified case manager and hence has additional knowledge, interest and expertise in the format of storing her health care related documentation. The system that has been developed by the patient relies on maintaining a separate folder for each of the conditions faced by her. The folder includes 3 different kinds of information in different sections, 1) the hospital generated documents including the lab results, x-rays, test results, medication prescriptions 2) patient generated self documentation including questions to ask the provider; the vital sign information including self

noted and measured blood pressure, weight, heart rate, glucose level; medication levels; directions to the hospital 3) online documentation materials such as email communications between the medical health provider through followMyHealth provided at the University of California and the patient, online research materials conducted by the patient regarding the health conditions which consisted of self generated health materials and other documentations that pertain to the health care of the patient.

Some patients such as patient 13 store the notes taken during the doctor's visit and the to do list required to be completed before the next doctor's visit also as part of the condition specific folders, as illustrated by the following quote:

Patient 13: "I write all my questions and notes down. Mostly during all my visits I write them down. They also give me the printouts after the medical visit is completed, but I like to write them down to have the information on my terms. I keep the notes in a notebook at home. The notebook is in the form of a folder. For example, when I had brain surgery, I had a thick folder to keep all the information related to brain surgery"

As illustrated by the above patient 13, the self generated to do list along with the questions that the patient records regarding their health care plan are also part of the folders that are maintained by the patient as their preparation materials.

The patient's use the information stored in the condition specific folders to prepare for their medical visit before the next doctor's appointment. As the patient's store the notes taken during the doctor's visit and the to-do list in the form of their own notes or in the summary discharge sheets in the folders, it becomes relatively easy for the patients to refer back to the folders based on the conditions for which they are visiting the doctor and complete the tasks as suggested and provide follow up information to the doctor and the nurse during the next doctor's visit.

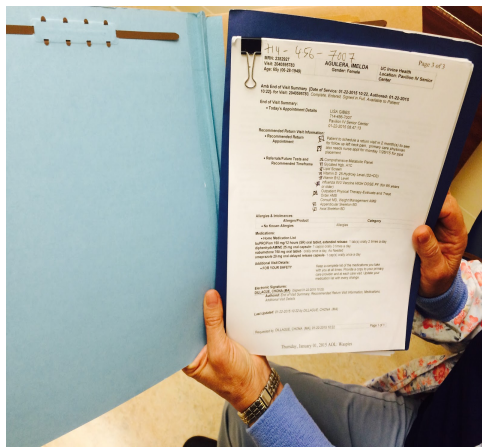


Figure 4.1: Patient Checklist of Items

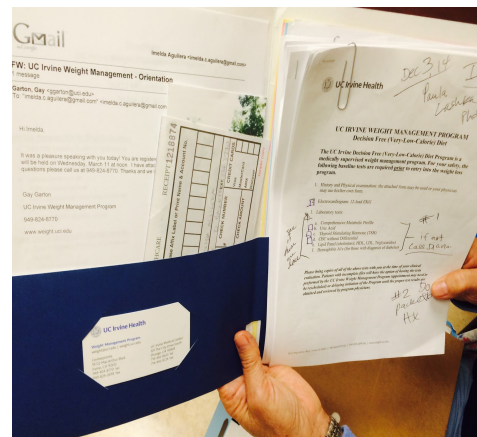


Figure 4.2: Doctor Email Correspondence

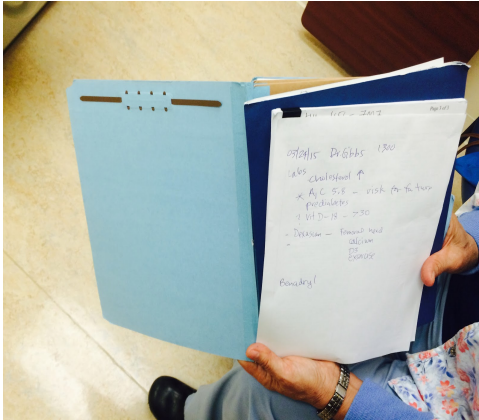


Figure 4.3: Patient handwritten to do list

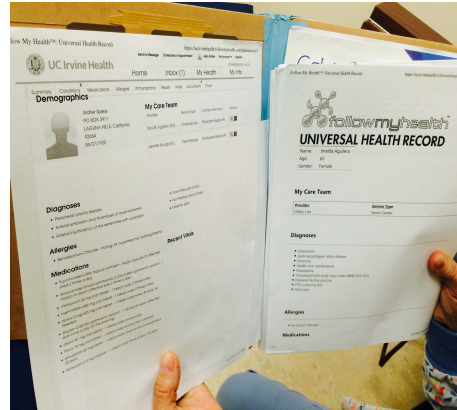


Figure 4.4: Online Healthcare Portal

Images: Pictorial representation of patients storing information such as checklist of items, doctor's email correspondence, to do lists and online healthcare information.

Challenges and Breakdowns before the medical visit

Lack of information work organization strategy

As previously described it has been observed that older patients observed and interviewed during the study were found to have 3 different kinds of healthcare information preparation work that included 1) hospital or clinic generated lab results, test results, MRI documents, medical prescriptions, x-rays 2) elders self care generated documentation including questions for the doctor, to-do notes maintained by the elders and the caregiving units, the vital sign preparations including readings that include the heart rate, glucose level, weight, blood pressure

3) online materials including the email communications from the health care provider and individual research conducted by the patient online among more.

It can be observed that most senior patient's file away their information work without a coherent organizing strategy as illustrated by the patient 13 who claimed that all information is in the form of a folder without a specific strategy based on which this organizing is taking place.

Patient 13: I keep the notes in a notebook at home. The notebook is in the form of a folder. For example, when I had brain surgery, I had a thick folder to keep all the information related to brain surgery.

This lack of information work organization strategy is due to the lack of process knowledge and guidance from the health care providers, nurses and other health care staff. For elders to have efficient systems of organization of information work, it is essential to 1) understand the content of the information 2) know the importance of the information work and the context in which it applies to the care plans and 3) learn how to form conclusions from the information gathered. The location within which most of the information work is studied, understood and acted upon is in the home setting and this is the setting in which the elders and the

caregiving unit of the elders are away from the medical personnel, medical providers and other medical staff. Hence having different forms of access to the medical professionals with regard to organization of the information work forms the first step in managing healthcare information and thereby making health care decisions that are critical to elder care.

Caregiver Responsibility co-ordination

One of the ways in which the elder patients manage to receive feedback on the information work preparation before the medical visit is by contacting the medical clinic via a phone call. During the interview Patient 1 discussed some of her concerns about the method of contacting the senior health center to clarify questions regarding her health care work. When the patient contacted the senior health care center, she was kept on hold for a long period of time and her questions was routed to 3 nurses where she had to repeat her concern each time with the nurse before the specific concern was met. The patient expressed her concern that as she is elderly, she would want immediate answers to her questions that would support the information preparation work conducted by her at home. Due to physiological, emotional anxiety associated with the process of preparing for a medical visit, the medical personnel and medical providers would need to provide immediate, consistent attention to senior patients questions regarding preparation

for information work before a medical visit. Before a medical visit, one of the ways that older patients prepare for the medical visit, is by inquiring the kind of information work that has to be brought to the medical visit and this form of information can be requested by contacting the medical health personnel via phone. In the event that older patients receive care from the caregiver unit consisting of family members, caregivers may also contact the medical health personnel over the phone.

Accurate representation and consist presentation of information work is essential to a successful consultation with the medical providers. As it has been observed through the observations and interviews that senior patients and the caregiving units of the elders meet with the medical provider once in every 3 months to discuss the status of health maintenance and preventative care in the case of chronic health conditions and each consultation lasts for an approximate time frame of 45 mins. This limited time frame needs to be accurately used in which case the information work presentation forms a crucial component of the consultation and health outcome decision-making process.

To prepare for the medical visit, senior patients and their caregiving units have to prepare different kinds of information for the medical provider that includes but

not limited to 1) vital sign presentation that includes daily, weekly readings and monthly readings summary of the vital signs such as blood pressure, heart rate, glucose level, weight, and diet intake 2) contacting third party vendors for ordering medical equipment needed to maintain health care 3) information gathered from different sources such as caregivers, friends, relatives and family physicians. In our observations and our interviews, we have observed multiple challenges and breakdowns faced by their senior patients and their caregiving units in the process of preparing effective information work before the medical visit.

In our patient observations, it has been particularly observed that for observed patient 5, who was being treated for the conditions of leg problems, high blood pressure, high heart rate and mental health problems, and who was accompanied by a caregiver during the consultation session, the primary care provider during a previous consultation process requested for vital sign readings such as the blood pressure and the glucose level to make accurate medical health care plan strategy during the current session. However, as the elder was being provided care via 2 caregivers representing her 2 daughters, it was found out that the caregiver that tabulated the vital sign readings at home was not present during the doctor's medical visit and thereby the current treatment plan was unable to be decided upon until the current caregiver within the medical visit was able to contact the other

caregiver. In this scenario, it can be clearly observed that in the cases where the elder patient is being cared by multiple caregivers, the communication between the multiple caregivers in sharing information work that was conducted before the medical visit is vital to a successful doctor's visit. Hence, information work such as the vital sign information should be recorded, shared, communicated, stored and organized before the medical visit among caregivers of the elder patient, in ways that will facilitate transfer of prepared home related health information to the medical provider.

Additionally, in the case of observed patient 10, the caregiver and the elder patient during a previous doctor's visit were requested to place an order of a medical equipment with a third party vendor whose contact information was provided to the elder patient and the caregiver after the previous medical visit, however, during the observation of the elder patient and the caregiver, it was found out that the elder patient and the caregiver were unable to place an order with the third party vendor as the patient and the caregiver were not reminded about the medical visit preparation work from the clinic and thereby missed the action item of contacting the third party vendor. This example illustrates that information preparation work before medical visit consists of completing action items of contacting third party vendors for medical needs fulfillment to continue health plans. In the specific case

of elder patients, due to physiological, emotional and situational barriers for caring for geriatric conditions themselves or through a caregiver, it is inherently challenging to remember critical information during a medical visit and follow up on medical provider's action items after the medical visit. This area is ripe with potential ways of providing technology design and process improvements and interventions that can be recommended in self care resources and health care organization's existing healthcare platforms and processes.

Patient aggregated data exchange

In addition, a significant aspect of elder patient information preparation work consists of collecting information about the health care plan and health care status from friends, relatives, caregivers and other support network individuals. Many of the senior patients who interviewed consulted with different support networks including friends, relatives and caregivers for support in terms of help finding specialists, aid in managing health care plans and in preparing the information work.

In the case of patient 3, the patient brings up the narrative on contacting their family physician with regards to consultation advice.

Patient 3: We refer to a family physician for most of our cases and he better than most other doctors. He generally will bring up things and I will add things to that conversation. For example he will ask about a particular condition which we never talked about and he will bring it up and ask me about it and I will respond accordingly.

Additionally in the case of Patient 9, the patient and caregivers conduct additional research on the specialists that they would like to visit before they visit with their primary care provider.

Patient 9: Sometimes we call different specialists and other sources to know which doctor we have to choose.

As indicated by patient 3 and patient 9, the senior patients contact additional contacts for support on the health care plans including advice from family physicians and different specialists. The challenge noticed in receiving additional advice from support networks of the senior patients, is that it has been observed that the conversations from the support networks are not being documented and communicated with the primary care physician to maintain a partnership based approach on making the choices on the health care plans based on the combination

of the advice received from the senior patient's support network and the medical expertise and judgment of the primary care provider.

Hence, these challenges and breakdowns allow for the development of technological system, interface, platform recommendations for modifying current personal health systems, for developing design prototypes of new self care tool kits and for modifying health care organization specific patient portals to respond to the specific needs and challenges of elder patient population.

3.1.3 Elder patients information work exchange during the medical visit

During the patient provider communication within the doctor's visit, there is a lot of information exchange that transpires and this period of time is ripe with potential sources of information to learn about different kinds of patient provider interactions that take place and with what artifacts. Based on the interview and observation data collected on how patients prepare in different ways before a medical visit, we can see by the discourse provided how the prepared information will be shared with the health care providers during the medical visit.

The patients prepare for the conversation with their healthcare providers, primary care physicians and specialists based on the conditions for which they are visiting

the health care center. *Firstly*, in the case of senior patients with chronic care management of conditions, patients tend to have more questions on the process of continuous care, the medications, follow up care and preventative care that needs to be taken. The senior patients facing chronic conditions provide information on the types of follow up work that the patients and caregivers (if present) have completed after their previous visit with the doctor and also discuss about potential medication bottles refills. The questions that the senior patients and the caregivers would like to ask is written down as a list of questions in either paper based form or in a notebook specifically used for the purposes of writing down questions. In most cases, the information that is being shared by the provider during the health care visit is also written down in the same paper based form of document or the notebook. In the cases where the patients bring the medication bottles to show the provider, the nurses would have instructed the patients to bring the medication bottles if they need refilling. Some patients write down the names of the medication bottles in the notebooks rather than bringing the medication bottles to the doctor's visit. Some patients write down the questions in the form of a to-do list or a checklist of items to complete as they speak with the doctor.

In the case during which patients have to discuss their vital sign information with the medical provider in the case of chronic care patients, older patients who use

vital sign recording tools bring them along to share the information. For example, during the observation sessions,

“Observation for patient 2: brought in a blood pressure arm cuff medical monitor to show the readings to the doctor. The conditions being discussed was blood pressure and hence the arm cuff was brought in”.

Secondly, In the case of singular incident conditions, senior patients have questions on the medications that need to be taken and the kind of specialist that needs to be referred to. During the interviews and observations conducted of the patients, it has been observed that patients with singular incident conditions such as an accident, surgery, flu and others do not write down specific questions for the doctor but talk about how they are feeling and how they got into the conditions that they did. Of specific interest to these patients are the medications that are going to be prescribed and the specialist or the test center that they will be referred to.

Thirdly, In the case of new patient who are being on boarded to the senior health center, the senior patients in this case bring along with themselves all the previous medical documents from all former clinics that the patient was part of, these documentations include paper based form of lab reports, MRI reports, doctor-patient communication forms, medication reports, and other associated reports.

These paper based form of reports will be transferred to an online version of the reports at the senior health center. The center either accepts these reports from previous clinics either in paper-based form or in the form of faxed documents. During the communication with the doctor during the new patient onboarding process, the senior patient and the caregiver (if present) explain all the conditions faced by the patient in the past and the types of medications that the patient has taken. Recommendations provided by the previous doctors are also discussed during the visit.

For example, for patient 3 during the observation process, the patient represented a new patient and had to discuss information work relating to all previous conditions.

A vignette from the observation notes for the patient is as follows:

“Observation notes for Patient 3: New patient and hence had to explain all her previous conditions and consultation details from her medical history.”



Figure 4.5: Patient Notebook

Breakdowns and challenges during the medical visit

Comprehension Challenges of Specialized Information

Firstly, challenges faced by senior patients with chronic problems during the medical visit are distinctly different as compared to senior patients with singular incident conditions. For example patient 7 mentioned that during the medical visit, her information preparation work consists of questions to ask the doctor which she brings in a written format. During the duration of the consultation with the doctor, the patient manages to transcribe the information provided by the primary care provider, however in a few instances the patient forgets to ask the questions prepared before the medical visit because of the overflow of information received by the primary care provider. This is demonstrated by the following quote from the patient:

Patient 7: Sometimes I might forget to ask the questions. Sometimes I wait until the next time I have to visit the doctor, it depends on the conditions.

Senior patients need significantly more time to assimilate all the information received from the primary care provider during the medical visit and to ask the questions that were prepared as part of the senior patient's information work. In addition, during the patient consultation process the primary care providers and

specialist's communication techniques consist of highly specialized technical and medical jargon that senior patients find challenging to understand and comprehend. This is represented by the remarks of patient 3 who states the following:

Patient 3: I prefer the interactive kind of conversation with the doctor. The biggest problem I see is the language. Doctor want to talk in their very specialized language and I want to say that my stomach hurts. For example, with our family doctor I call him out on that, I say that I don't know what the name of the muscle means and what it does.

The technical and specialized form of communication during the medical visit is a barrier to the senior patients as they are unaccustomed to the medical terminology and thereby during the process of making notes during the medical visit, senior patients miss recording the important action items as they are unaccustomed to the terminology. This is detrimental to the process of maintaining and following up on health care plans by the senior patients.

This is illustrated by patient 18's observation session of the medical visit consultation process during which time it was observed that the senior patient forgot to follow a specific medication plan provided by the primary care provider

because the patient didn't fully comprehend the information provided by the doctor because of the complexity of the specialized information shared.

During the case when, multiple caregivers are present during the older patient consultation process, co-ordination between the information work exchange among the medical health care providers, caregivers and older patients proves vital to carry on the healthcare agenda setting for the older patient. For example, a vignette from the observation of older patient 5 illustrates that having multiple caregivers with differing specialized information may prove to be a barrier in coordinating health care outcomes effectively among the medical providers, caregivers and the older patients.

“Observation notes for patient 5: Patient had multiple caregivers (her three daughters). One daughter was a nurse at a different UCI medical center unit and had specialized medical information knowledge. Different communication levels between caregivers, medical information knowledge varied between caregivers.”

Secondly, while the medical providers communicate with the singular incident elder patients who face conditions such as surgery, flu and other vaccine related conditions, it has been observed that the medical providers discuss issues related

with other specialists and different referred health care centers that portrays as specialized information to elder patients. It was noted that during observations and interviews, the elder patients didn't not note down the information shared by the medical provider, which resulted in the elder patients unable to make an appointment with the specialists recommended by the patient and thereby pushing back the timeline of health care plan completion. Hence, regarding the process of recommending specialists and off site health care centers, additional follow up and consistent information flow is required between the medical personnel, primary health care providers and the senior patients.

Patient medical history organization and retrieval

Thirdly, for the case of new senior patients being on boarded into the senior health care center, the observed patient 6 demonstrates the challenges faced by elder patients who transition from different health care providers to the current health care facility where the only form of information exchange of the longitudinal history of information work of the elder patient, is to bring in extensive medical history documentation during the patient consultation to discuss the past medical history with the doctor. In the case of observed patient 6, the patient presented a large single folder consisting of a wide range of different information types including previous doctor's consultation notes, lab reports, test results, diagnostic

results, medical prescriptions among others. The information presented did not contain a certain organizational strategy. When asked by the medical provider about a particular health condition, both the medical provider and the senior patient had to go through the process of leafing through all the documents in the folder which resulted in a significant amount of time being spent on the process of finding information.

This demonstrates that during the patient consultation process, new senior patients being on boarded into the senior health center need support and guidance into the process of arranging their medical health information work and presenting this information to the medical provider and the health clinic.

Elder Patients information work after the medical visit

After the health care visit with the provider, the senior patients and their caregivers are provided with an end of visit summary sheet that consists of 1) tests to be completed 2) health maintenance schedule consisting of when to take the medications 3) upcoming appointments 4) summary of the doctor's visit. The end of summary sheet will be provided at the end of every patient visit and helps the patient understand the next steps in the care process. During the interview and observation process, most patients responded that they store the end of summary

sheet in the condition specific folders that they maintain at home. The end of visit summary sheet specifically consists of follow up items to be carried out by the patients before the next medical visit. These instructions are part of the health maintenance schedule and the within the tests that have to be completed.

Breakdowns and challenges after a medical visit

Senior patients after the completion of a medical visit face significant challenges. These challenges after a medical visit can be grouped into 2 categories of 1) Barriers in health care agenda planning 2) Issues in information work management.

Healthcare agenda planning barriers

Firstly, all senior patients receive an end of visit summary sheet after the medical visit at the senior health center where the listed items on the end of summary sheet represent a) To-do list, b) Health maintenance schedule, c) Referrals and upcoming appointments, d) Patient education, instructions and goals among other items. The challenges faced by the senior patients in following and understanding the end of summary visit sheet was that, the end of summary sheet included highly technical and specialized information that is not easy for the senior patients to follow. These included the tests that have to be included sections, health maintenance schedule, referrals and the education section where the information regarding how, where

and when to complete the tests was not indicated; similarly the health maintenance schedule did not include information regarding the process of completing the tests and lacked the reasoning behind why these tests were required; the upcoming appointments section lacked the health information work preparation work that would be required for the senior patient to better understand the agenda of discussion during the next appointment; and the patient education section consisted of highly specialized information which consisted of highly medical terminology.

As an example, an excerpt from the end of visit summary sheet is as follows:

End of visit summary sheet:

1. Tests to be completed

Thumb Left AP + Lateral XR

2. Health Maintenance Schedule

Due: 09/01/2015 - Influenza

Due: 11/03/2014 - Pneumococcal (PPSV)

3. Upcoming Appointments

Patient to schedule a return visit in 1-2 months to see as me previously scheduled.

4. Patient Education, Instructions and Goals

Left thumb pain - most likely a tendon problem but symptoms of crepitus exist.

The above excerpt of the end of summary discharge sheet proves that there is a lack of contextualized information and follow up information including the details such as how, when and where as illustrated in the cases of tests to be completed, health maintenance schedule and upcoming appointments. In addition the use of specialized information can be noted in the case of patient education, instructions and goals.

Due to the lack of specific and contextualized follow up instructions, missing data on future health care agenda set by the health care provider and the role played by the senior patient, and due to the presence of highly specialized information, the senior patients face barriers in playing a larger involved role in the healthcare agenda setting performed by the primary care provider. This pattern can be illustrated by the comments provided by patient 3 and by patient 1.

Patient 1: That is now that you are older they don't think that they have to answer all the questions but I have all my facilities intact so I still want to know all the answers and understand the conditions.

Patient 3: I prefer the interactive kind of conversation with the doctor. The biggest problem I see is the language. Doctor want to talk in their very specialized language and I want to say that my stomach hurts. For example, with our family doctor I call him out on that, I say that I don't know what the name of the muscle means and what does it do and the family doctor is ready to provide that information in a more simplified manner.

From both of these examples, it can be noticed that the senior patients would like to receive more information more their health care providers to participate in the health care decision making process and planning the health care agenda, however the senior patients would prefer receiving information in non specialized terms.

Lack of procedural and descriptive information support

Secondly, an additional challenge in maintaining information work after the medical visit is that of issues that arise with information work management and how it relates to tasks that need to be completed immediately after the medical visit. The senior patients are provided with follow up information which will include the end of summary discharge sheet, additional informational pamphlets consisting of specialized and detailed information about the condition being faced by the senior patient. This information portfolio provided by the health center is in

addition to the senior patient's and caregiver's personal notes and lists transcribed by the patient during the doctor's consultation. Hence, the senior patient has a wide array of documentation present with them after the doctor's consultation has concluded. However, the patients are not provided adequate process and information support on how to organize and manage these documentations including how these documentations may be useful to prepare for the next medical visit. Clear instructions and suggestions on the functional and contextual use of the gathered information is not provided by the medical personnel and the medical health provider, thereby resulting in breakdowns of information work management and usage by the senior patients after the medical visit.

Resource Use during medical health care preparation

Senior patients and their caregiver units use a variety of resources to enter their health care data, track their changing health care patterns, consult with their healthcare providers and their medical personnel, maintain a repository of personal health data. The usage of these resources by elder patients will be termed as resource use. The resources will comprise of technology tools such as mobile phones, including iPhone, android; health clinic specific health care reporting platforms such as followMyHealth which a patient and provider centric healthcare

portal is used by the University of California medical system which includes the senior health system.

Methods of resource use before the medical visit

Some interviewed patients conducted online research before the doctor's visit. This online research consisted of cases of the following 1) Online health groups - Patient 17 would regularly conduct online research before visiting the doctor to conduct research using online health groups where the patient would review the kind of medications and care process that the patients with similar conditions would undergo when the patient is facing a particular condition. For example, patient 17 discusses the process in which she looks for information:

“Patient 17: Sometimes I type what it is that I am looking for. For example my spouse's rods broke 3 times, so I typed in cobal rods. She had titanium before, just because I want to know what it is that is going on. I dont look out for the sites so much, but I look and see who is giving out the information and who is going through similar conditions.”

2) Specialists search - patient 7, patient 3 and patient 4 research online to find out about specialists that they would like to consult with. According to patient 3, the following is the statement made with regards to finding specialists online:

“Patient 3: The amount of information I search for entirely driven by the medical needs at the time. I will tell you one thing that can be improved online is finding a doctor, locating a doctor and finding a specialist. Understanding what the specialties are, and most often the subspecialties that many people don’t even realize its there. I mean there are a lot of cardiologists out there who might practice differently and who have different credentials for performance. Sometimes, it depends on the primary care physician. Because most often the doctors you go to is based on the doctors that are picked by your own primary care doctor, so the most knowledgeable person to make that decision is your own family care doctor, but for a lot of reasons you would want to have some degree of say in that process or control it completely.”

Patient 3 specifically talks about how the specialists prescribed by the primary care provider depends on the knowledge and information already present with the primary care provider but if the patient is also involved and invested in specialists selection process, this ensures a specialist who is more suited to the requirements of the patient will be referred to by the primary care provider.

Specifically patient 9 and patient 3 visits various accredited websites such as university affiliated websites, government research funded websites, professional health care service websites to conduct preliminary research on the kind of

procedures offered by the specialists and discuss this research about the specialists with their primary care providers in order to finally choose the primary care provider together with the their primary care providers. For example, patient 3 discusses the following about conducting online research and the type of resources used:

“Patient 3: Primarily through the sponsorship such as if its coming from a government agency or from a medical facility, or information from a health agency. I put way more credence on these sources as compared to any other sources. The amount of information I search for entirely driven by the medical needs at the time.”

Breakdowns and Challenges in resource use before the medical visit

Emotional Barriers to Resource Use

It has been observed the senior patients and their caregiving units perform research before the medical visit by using online resources on their computers. The challenges and breakdowns in utilizing online resources by seniors can be categorized into 2 categories of 1) emotional anxiety caused during online research, 2) performing undirected and unfocused online research.

Firstly, the process of performing online research for a particular condition can primarily be an anxiety filled process where senior patients are reluctant to engage in research due to the implications of the data they would find. This prevents the senior patients from understanding and playing a wider role in the shared health care planning process along with their health care provider. As illustrated by the statements by patient 13:

Patient 13: My eyes went bad, so I had to visit the doctor quickly so they did an MRI and found a tumor on my optic nerve and they had to perform the brain surgery. I didnt look for any information online in this case, because I didn't want to get scared.

In the above statements it can be shown that patients although adept at performing online research on the conditions, might not be able to carry on their regular functions due to the anxiety associated with the conditions that they are facing. This opens up possibilities for technology design recommendations that enables patients to refer to information without causing emotional anxiety and trauma.

Lack of direction during resource use

Secondly, for those patients who do perform online health care research prior to visiting the doctor, the breakdowns for senior patients in this category is the undirected and unfocused form of research online and the lack of process guidelines that would help conduct a targeted search online for the conditions that the senior patients are facing. Currently, senior patients who are interested in conducting online research use sources such as online health groups, university medical websites, government funded research clinic websites, private health care facilities research, specialist's research among others. During the observations and interview process, the patient's informed that when they conduct the research, they either remember this information or write it down in a document and store it. However, there represents no constant format in which patients perform this research and use the research conducted by them during future senior patient-provider consultation processes.

In addition, the amount of information that can be found online can be overbearing for senior patients wanting condition specific and understandable information. This represents an additional criteria based on which online research can prove to be undirected and unfocused. This can be represented by the patient comment of:

Patient 13: Yeah, I would like to look up for more information but there is so much information out there that it is confusing to me and then I just ask the doctor if I have any questions.

Hence, a technology-mediated process in which patients can conduct directed and focused research will facilitate the process of discerning health outcomes individually by the senior patients.

Methods of resource use during a medical visit

During the doctor's appointment, the first stage of the patient interaction with the health care provider is with the triage nurses. The triage nurses complete the intake notes where they request for vital sign information such as blood pressure, heart rate, and weight. In order to complete the intake notes, the nurses and the doctors request the senior patients to note down a regular reading of the vital signs so it can be used to measure the average rating of the vital sign information during the health care visit. Hence patients have to regularly record the vital sign information at home before visiting the doctor.

During the interviews patients have responded that they record the vital sign information such as blood pressure, cholesterol level, heart rate and weight in

different ways. Some patients note down the regular readings in the same document that they note down the questions to ask the doctor and some senior patients who use technology platforms such as smartphones have reported to note down the readings in the “notes” app section of their smartphones. In reference the patient 17 said the following regarding noting down the cholesterol level on a smartphone app:

Patient 17: “I have the iPhone and I use the notes features on the phone to come up with a list of questions to ask the doctor. Also I keep track of the information I ask the doctor including appointments, schedules etc in my calendar which is easier. I also keep a track of my vital sign information such as cholesterol and blood pressure on the phone”

During the observation of patients and caregivers, it was observed that caregivers play a significant role in providing the information required during the doctor’s visit such as the vital sign information being a case in point. The caregivers will have to prepare this information before the doctor’s visit and track the recording to report this information to the doctors. As an example: during an observation session, a caregiver of a patient read out the tracked vital sign information such as blood pressure and heart rate information that was saved on her smartphone when

the doctor asked for the vital sign readings of the patient during a certain duration of time.

Challenges and breakdowns in resource use during a medical visit

Lack of resource support to track vital sign entry, analysis and reporting

The primary technology resource use that has been observed during the observations and interviews in the study has been mobile phones for recording vital sign data such as blood pressure, weight, glucose level, heart rate, cholesterol level among others. While reporting vital signs information to the provider during the primary care physician consultation, it has been observed that the caregiving unit consisting of several caregivers of the senior patient are more likely to present this information to the primary health care provider during the visit.

The senior patients are required to tabulate their vital sign information weekly and monthly to report to the health care provider during the consultation process. On an average senior patients meet with their providers every 3 months and this presents a situation of collecting extremely large volumes of vital sign information for the provider.

During observation patient 5, the primary care physician asked the caregiver of the patient about the vital sign information collected so far and the caregiver could present the information collected on blood pressure of the senior patient and noted in her mobile phone for the past week, but was unable to provide this information for all prior weeks as the information was noted in a different location. Hence the challenge while using mobile phones to collect and store vital sign information is that there is currently no streamlined way of collecting and storing all vital sign information at the same location for convenient storage and retrieval. Hence, technology interventions recommended for senior self care platforms should consider features to streamline the process of vital sign information entry and retrieval. For example, the observation notes for observed patient 5 indicate the following:

“Observation notes for Patient 5: Streamlining information flow such as vital sign information of blood pressure between multiple caregivers for a single patient proves to be difficult.”

Methods of resource use after a medical visit

Senior patients and their caregivers also responded that they would like to go paperless and would like to access all the end of summary information and their health related information online via the online patient portal.

Patient 2: "They give you a list of suggestions and instructions on what to do and information on a particular condition that you are facing. If an online version of the information is present, it will definitely be very useful to see a history of all the conditions that I have"

The senior health center centric followMyHealth online patient portal provides different features such as 1) storing an online version of the patient health documents including all previous doctor visit information 2) online lab reports 3) MRI reports 4) medication prescription 5) vital sign summary 6) ability to email the doctor directly. All these online versions of the health history documents are very useful for the patient to review a historical perspective of the conditions and the medications prescribed for the conditions.

Online patient portal used to communicate with the doctor. Some senior patients use the patient portal to leave comments and email the doctor directly after the doctor's visit. For example for patient 14 if after the specific doctor's visit, if the

patient has additional questions to ask the doctor, the patient leaves comments and emails the doctor directly and gets a response from the doctor in less than a day. This ability to directly contact the doctor is advantageous while using the online patient portal. The lab reports and MRI reports are uploaded to the patient portal after every patient visit.

Patient 14: "I use the patient portal to leave comments and questions that I want to ask the next time I am at the senior health center. This means that every time I visit the health center, it doesn't take as much preparation because the doctor can view the questions and comments that I have noted down in the portal."

Online patient portal is also being used to compare health conditions based on historical data.

In some cases the patient and caregiver prefer to consult the online portal because if the information is in paper form it is very easy to lose this information, but if the information is in an online form, it is very easy to view past history of the patient conditions including lab reports. The patients use online information present in the patient portal because it allows the patients to compare their conditions and see if they are getting better

Caregiver of Patient 6: “She has a sugar and liver problem. Every time you do chemo, you need to check these levels to confirm the white blood cells count. These levels are present in the online patient portal and you need to check. Also she has special condition, the liver condition especially. When you compare, you will know if she is getting better or worse. If she is getting better, we can inform the doctor about her conditions so they know that she is getting better. So online information is very important”

To discuss a use case of a PHR being currently used at the senior health center FollowMyHealth portal needs discussion. FollowMyHealth is the patient portal currently in use at the senior health center and the patient portal in use by elders and caregivers observed and interviewed in our study. FollowMyHealth represents an integrated patient management system that allows patients to participate in their health care process and thereby enhance their patient care process [19]. The current features of followMyHealth are 1) viewing test results 2) refill prescription medications 3) communicate with physicians 4) request appointments 4) complete forms prior to visit 5) pay bills. The user interface of followMyHealth is attached as follows:

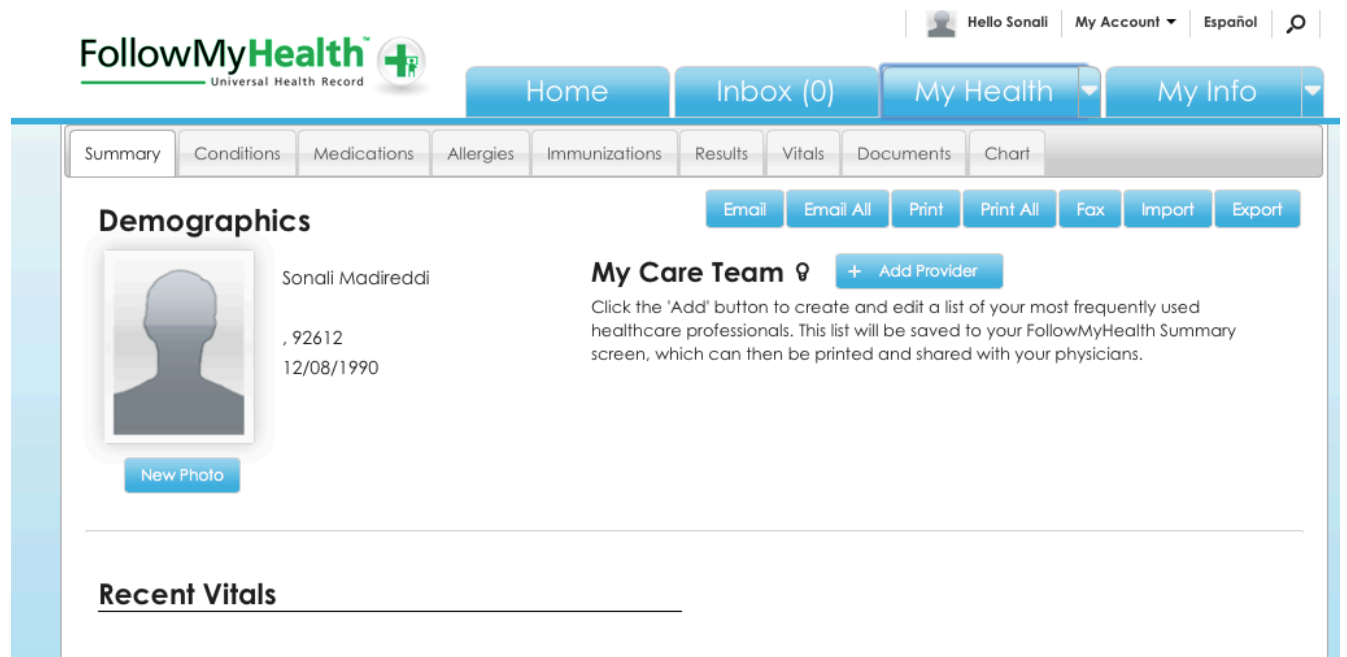


Figure 4.6: User Profile on followMyHealth

As can be observed in the above user design for followMyHealth, the interface and the workflow requirements are in need of specific requirements to be beneficial to the elder patient and caregiver unit population. The design recommendations being suggested are in line with the findings and themes established from the study.

From initial observation and analysis of the followmyHealth interface, it is evident that the design, workflow and user interaction within the followMyHealth user interface does not support the needs of elder patients as stated in the scholarly work of gerontology, cognitive sciences and nursing sciences [12], parameters that are essential to the design of web based technologies and in this case personal electronic record systems such as followMyHealth are vision capabilities,

cognitive capabilities and health literacy parameters. In terms of the challenges that can be identified with the current state of followMyHealth patient portal are 1) vision capability limitations that are highlighted by the use of pastel colors as the theme color for the website which is a color choice that is not in line with the requirement of bright colors for viewing and processing capabilities by elder patients and their caregivers. 2) cognitive capabilities limitations include unavailability of a sitemap to represent the content of the site and thereby preventing cognitive guidance to be provided to the elders 3) health literacy limitations include the use of highly specialized information being shared in the form of hospital generated documents and test results without explanation made in simpler terms.

In addition, based on the framework provided by Wanda Pratt et al in [2] in considering technology design for elder patients, the factors of emotional, functional, scalable and temporal are being used as framework factors to evaluate the design choices of followMyHealth, based on which the recommendations for new designs for personal health records will be provided. The current format of followMyHealth does not include emotional support such as connections to medical personnel, caregivers and other online community reference material. In addition, based on the functional needs, the specifications of the current version of

the followMyHealth, does not include the specifics of the contextual information behind the collection of the elder patient data in certain specific areas. In the context of temporal needs, the items within the portal are arranged based on the timeline of when the action item is due. Based on the scalable metrics, the information present within the portal is not consistent with how the information can be used by caregivers and what unique roles can the caregivers play in the healthcare process of elder care.

Challenges and Breakdowns in resource use after a medical visit

The challenges and breakdowns for resource use can be divided into 2 categories
1) Barriers in onboarding into patient online portal 2) difficulty discerning health comparator data in patient portals.

Privacy and access challenges in resource use

Firstly, regarding the barriers of onboarding into the patient online portal, one of the challenges discussed by the patients regarding the usage of the online patient portal is the difficulty accessing online patient portal by caregivers. The login format for the online patient portal is provided to the senior patients and a common theme of complaint among caregivers during the interview and observation process was that the caregivers do not receive automatic access to the patient portal of the

senior patients that they care for. In the case that some senior patients are also caregivers to other patients in the senior health center, getting access to the online portal has proven to be quite difficult. The case that patients are also caregivers, there should be a unique way of handling the cases of patient provider confidentiality online on the patient portals while giving access to caregivers to participate in the care process via the online portal.

Health Outcome Comparison Challenges

Secondly, regarding the difficulty of discerning health comparator data, the senior patients who access their online patient portals should have an easy method of understanding how the health information illustrated within the patient portal plays into representing information which portrays whether the senior patient is recovering or deteriorating based on the documentation stored in the online portal. This feature will aid the senior patients in comprehending and consolidating all the different types of information with varying contexts into a coherent whole by understanding their state of health.

Role of caregivers in the context of providing information knowledge & aid in health care preparation to the elder patient

Caregivers are an essential component of the caregiving process of senior patients. Caregivers may comprise of family members such as husband, wife, son, daughter or extended family members who are involved in the healthcare process of the senior patients. Caregivers aid the senior patients during all the segments of the caregiving process of 1) before the doctor's visit, 2) during the doctor's visit and 3) after the doctor's visit. The following are the ways in which caregivers aid in the caregiving process:

Firstly, before the doctor's visit the caregivers in the cases of patient cases of patient 14, patient 9 caregivers perform preliminary research on the conditions being faced by the patient to answer any and all questions the doctor may have during the doctor's visit. The patients are also driven to the senior health center, with the help of the caregivers. Caregivers also help in tracking the range of vital signs for the patient such as blood pressure, cholesterol and heart rate and other vital signs.

Secondly, during the doctor's visit, if the caregivers are present, they most often answer doctor's questions on the health care management process of the patient

based on the level of involvement of the patient. Some caregivers also take down notes during the doctor's visit to keep track of the information shared by the doctor such as next steps, medications and lab tests that have to be taken. As an example the caregiver of patient 14 transcribes the notes during the doctor's visit and emails the information to other caregivers in the family so that all the caregivers are on the same page.

Caregiver of patient 14: "I take notes of the doctors visit and transcribe everything during the doctor's visit and email the notes to my dad and my sister".

Thirdly, after the doctor's visit, the caregiver aids the senior patient in receiving follow up care as suggested by the doctor such as helping the senior patient get the require medications, getting the lab tests completed, transferring that information back to the senior health center and keeping track of the daily health maintenance of the patient as suggested by the health care provider.

The unique case of multiple caregivers for a single patient is particularly interesting to study.

In the cases patients having multiple caregivers, it becomes important for each of the caregiver to be on the same page about the caregiving state of the patient. In the

case of patient 14, the caregiver transfers the notes she takes during the doctor's visit to other caregivers in the family so that when she is unable to attend the doctor's visit at any time or is unable to complete a caregiving process for the patient, the other caregivers in the family can step up and help out in the process rather than leaving a gap in the caregiving process.

Caregiver of patient 14: I take notes of the doctors visit and transcribe everything during the doctor's visit and email the notes to my dad and my sister. So that when I am unable to attend

Hence, it becomes very important to streamline the information flow between the multiple caregivers in the family.

Breakdowns and challenges in caregiving by caregivers

Role of caregivers as facilitators

The most significant challenges and barriers observed during this study is the information flow between multiple caregivers. In the case of health maintenance there needs to be consistency and with different levels of interest, involvement and commitment between caregivers, it is difficult to achieve success in health care plan confirmed by the partnership between the senior patient and the provider.

This shows that caregivers play an important role of caregiving facilitators in the health care preparation process for elder patients.

CHAPTER 5: DISCUSSION

In this study of conducting observations and interviews with the elder patients and caregiver units at the senior health center, we have encountered three specific themes of 1) Medical information work management undertaken by elder patients 2) Resource utilization 3) Caregivers as elder health care facilitators. To reiterate the challenges and barriers faced by the elder patients when dealing with preparation for health care resources can be grounded based on the themes that have been established. The following discussion comprises of the themes in relation to the challenges and breakdowns observed during the timelines of the phases observed during the medical work preparation by elder patients, which consist of a) before the medical visit, during the medical visit and after the medical visit.

The following discussion will highlight the challenges found during information work management, resource utilization and caregiver facilitation discussed in the findings section during the three-phased timeline of the health care preparation process undertaken by older adults of 1) Before the medical visit 2) During the medical visit and 3) After the medical visit.

Challenges faced by elder patients before the medical visit

Medical Information Work Management

Elder patients have significant barriers in preparing for their medical visit before the visit due to 1) lack of information work organization strategy 2) Caregiver responsibility co-ordination and 3) Patient aggregated data exchange limitations.

Lack of information work organization strategy

For the case of lack of information work organization strategy, it is observed that older patients have different types of information work, which needs to be collected, stored, analyzed and reported by the elder patients, and their caregiving networks. For the cases of elder patient the types of information work includes 1) vital sign information such as blood pressure, glucose levels and more 2) hospital and clinic generated medical documentation that includes x-rays, MRI's and other test results 3) online research information gathered by the elder patients. Due to the huge variety of information consisting of varying contexts, uses and application areas, it becomes important for elder patients to be understand the organization strategy of information work at home, which is the primary location of health care preparation work before the medical visit.

The organizational strategy of the information work can be used by the elder patients to 1) understand the content of the information 2) know the importance of the information work and the context in which it applies to the care plans and 3)

learn how to form conclusions from the information gathered. From the related work analysis on the work regarding elder patient information work [2,10] where different factors such as emotional, scalable, temporal and functional factors have to be considered while designing technology interventions and design prototypes to support the information work organization strategy of the senior patients. In addition to considering these above factors, the information work organization strategy in this study is being examined from the theoretical framework of self management education thereby providing decision making capacities to elder patients.

As the data of the information work for medical visits can be of two forms, 1) electronic form and in 2) paper based form, from the perspective of this study technology design recommendations will be made to electronic personal health record systems for the electronic form of documentations and to the current state of the paper based tools such as end of visit summary form that is used within the senior health center at the University of California medical systems. The above factors discussed such as the emotional, scalable, temporal and functional factors within information work management can be applied to technology interventions within the PHR system and the factors of temporal and functional can be applicable to the paper based prototypes.

As per the discussions in this study regarding the challenges faced by older patients while using the PHR system of followMyHealth used at the senior health center the design recommendations considered in this study can be applicable to various other kinds of PHR systems particularly for the populations of older adults and their caregiving units.

Caregiver responsibility co-ordination

In the case that caregivers provide healthcare support to older patients, the caregiver responsibility co-ordination will be centered around tasks that have to be completed to achieve maximum success and completion of diagnosis during the medical visit. Hence, this can be termed as task coordination. The tasks that have been observed to require co-ordination in the case that there are multiple caregivers or a single caregiver in the caregiving unit are the tasks of holistic symptom tracking and market research for third party medical supplies for elder patients. These activities can be streamlined by providing modifications to the current method in which personal health records are designed.

Patient aggregated data exchange limitations

Before the medical visit both the elder patients and the caregivers may perform extensive research on the conditions by performing online searches, interacting with family physicians, relatives and past providers. This information collected may be shared with providers during the medical visits and thereby fostering a partnership model to making healthcare decisions and setting the health care agendas along with the providers. To provide a framework for collection, analysis and future documentation of the information work, technology developments can be introduced to allow the elder patients and the caregivers to collate the work within electronic personal health records specific to the health care clinic in order for this information can be viewable by the provider before and during the medical visit.

Resource Utilization

Older patients face the following challenges before the medical visit with regard to resource utilization, 1) Emotional barriers to resource use and Lack of direction during resource use.

Emotional barriers to resource use

In the design of electronic personal health records and in the case of this specific health care clinic, the personal healthcare record that is being used is the followMyHealth, where emotional factors in designing interfaces for the elder health care has been considered. During the times of long term care plans, elder patients emotional state needs to be considered as an important element in that of defining the requirements for technical modifications to that of PHR use. To overcome emotional barriers in designing technology recommendations, the need to include support mechanisms from provider and caregivers should be inherently included.

Lack of direction of resource use

For the streamlined process of conducting online research before the doctor's visit, resources such as the Internet tools, PHR tools and the mobile phone tool usage should be clearly explained to the patients. For patients there is an enormous amount of information available and to receive the maximum benefit, elder patients and their caregivers would need direction and focus to conduct very targeted research in the case that the elder patients and the caregivers would want to conduct such a targeted research. These mechanisms can also be inbuilt into technology and design modifications of both the PHR and the paper based tools.

Caregiver Facilitation

With regard to how older patients and the caregiver units interact before the medical visit, the challenges observed are in the area of 1) Lack of co-ordination in symptom tracking.

Lack of symptom tracking co-ordination

Elder patients need to maintain consistent, approved and safe level symptoms such as 1) blood pressure, 2) blood glucose level and 3) heart rate, 4) weight and more. For the consistent care to be received by elder patients, it becomes important for elder patients to report all home recorded symptoms. When the providers are unable to receive information on symptoms, a complete care process can not be prescribed. To facilitate the process of effectively tracking symptoms, reminder systems and calendaring systems have to be in place in order to manage the tracking and reporting process to the health care provider. These can be represented in the form of inclusions to that of current PHR systems.

Challenges faced by elder patients during the medical visit

Information work management challenges during the medical visit, include the 1) Comprehension challenges of specialized information and 2) Older patient medical history organization and retrieval.

Comprehension Challenges of Specialized Information

Recognizing that older patients conditions such as cognitive decline; physiological state and content capture, recognition, retention capacity are highly important factors while discussing and sharing highly specialized and technical information. Medical personnel and primary care providers should specifically be aware of these factors while sharing highly specialized instructions. This simplification can be represented in the recap of the meeting agenda discussion within the end of visit summary discharge paper forms provided to the elder patients. In addition to aid in longitudinal review of these conversations, the paper based form specific information can also be included within the elder patient specific information within the personal health record of the specific care unit.

Patient medical history organization and retrieval

The process in which new elder patients are on boarded into the systems should be made as transparent and streamlined as possible. Many older patients bring their entire paper based longitudinal medical health history forms. While in conversation

with the medical provider, the newly on-boarded patients are unsure and unaware of the arrangement of the medical health history documents and thereby losing significant time during the patient consultation process. This can be modified by introducing improved methods of introducing ways in which the newly on boarded elder patients are informed about the medical history information work organization prior to the visit.

Resource Utilization

Challenges in resource utilization during the medical visit include 1) Lack of resource support to report vital sign entry.

During the medical visit, caregivers and older adults lack resource support to track vital sign information such as blood pressure, glucose, heart rate, cholesterol and more. With the inability to track vital sign information, reporting out vital sign statistics to the medical health primary care provider during the medical visit is not streamlined which adversely affects the health care agenda setting process by the care giver and health care maintenance process by the elder patient and caregiver unit.

Challenges faced by older patients after medical visit

Information work management challenges after the medical visit include 1) Healthcare agenda planning barriers and 2) Lack of procedural and descriptive information support.

Health care agenda planning barriers

After the completion of the medical visit, the senior patients and their caregiving unit is provided with an end of visit summary form. Due to the lack of specific and contextualized follow up instructions, missing data on future health care agenda set by the health care provider and the role played by the senior patient, and due to the presence of highly specialized information, the senior patients face barriers in playing a larger involved role in the healthcare agenda setting performed by the primary care provider, which represent the challenges that can be overcome by enhancing these above stated aspects of the end of visit summary discharge forms. Specifically, the areas within which the end of visit summary form can be modified consists of 1) Tests to be completed information section should illustrate context, potential contacts-locations of tests 2) Health maintenance schedule section should consist of description simplified information 3) Upcoming appointments would potentially highlight the health care preparation work that has to be carried out before the next visit, 4) Patient education should one of the most important criteria

under consideration when finalizing health care agenda planning. Hence, one of the forms in which currently, health care agenda planning is performed is via the paper-based tools such as end of visit summary form.

The end of visit summary form has a unique opportunity for improvement in terms of being adapted to the needs of the elder patients and the caregivers. The first stage to modifying the process flow in terms of providing elder specific health care planning process is creating change at the paper based tool level where every single elder patient in a senior center clinic or in a hospital setting will be provided with that of a paper based form at the end of the visit. Currently, the features provided as part of the paper based form do not contain functional and temporal features. By providing extensive content and presentation modification, the health care agenda will be followed by the elder patients. These include functional information of procedural questions such as where, when and how can be explained for the health maintenance section of the paper based tool, in addition older patients would benefit from the patient education section if it is explained in simpler terms.

Lack of procedural and descriptive information support

In the phase after the medical visit, the information that elder patients and their caregiving units receive adequate procedural and descriptive support in order for the older patients to understand the activity that needs to be performed, use the resource information provided in order to complete the tasks and implement the task required of them to complete the healthcare agenda set by the health care provider. In the event of when these components cannot be established, there is the possibility of being unable to complete the healthcare agenda as set by the healthcare provider.

The design and recommendations for technology improvements may be suggested for the features that would provide contextual, temporal and functional information about the health care agenda items within the electronic personal health records. For elder patients for whom the patient education can be conducted via using paper based tools such as the end of summary discharge forms, these above stated factors should be taken into consideration while formatting the discharge forms.

Resource Utilization

Challenges faced by older adults during resource utilization consists of after the medical visit consists of 1) Lack of comprehensive analysis of healthcare outcomes.

Lack of comprehensive analysis of healthcare outcomes

Elder patients as are being treated for long term medical conditions are more likely to consider health comparator data and information useful, in terms of understanding their health care growth or deterioration as per the case. Health comparator data may produce results based on the symptoms monitored, test results and elder patient current conditions. These information sources can help produce visual health comparator health information that may be useful to the patients in evaluating and planning their health care plans with their providers.

In summary, for the effective management of information work by the elder patients and by their caregivers, it becomes very crucial to introduce both electronic personal health records and paper based tool design recommendations and development guidelines to allow for the effective management of information work by elder patients. These design decisions begin with organizational strategy of the information work based on the factors of emotional, scalable, temporal and functional factors for the recommended modification of the electronic personal health record systems and the factors of temporal and functional can be used for the paper-based prototypes. In terms of the caregiver care coordination, task coordination has been identified as the main criteria around which design decisions of including such a feature within electronic personal health records will need to be

made. Additionally, for the basis of patient aggregated data exchange limitations, processes need to be built into the current PHR's where elder patients individual work can be used to aid in making health care plans.

Additionally, modifications can be introduced into the design of future updates to the personal health records based in the need to reduce the specialized knowledge distribution within the patient-provider communication and within the paper based tools. Regarding the health care agenda planning and analysis of healthcare outcomes- functional, temporal and scalable modifications have to be introduced in order to provide additional context to the information and agenda plan.

Caregiver Facilitation

Challenge encountered by elder patients after the medical visit with regard to caregiver facilitation is privacy and access challenge.

Privacy and Access Challenges

During the elder care health delivery, the concept of caregivers as the "hidden patient" introduced in [7] is consistent with the notion that in the case that caregivers are available to provide care for the elderly population, there should be scalable and redundant ways in which information can be shared and exchanged to the caregiving unit with the consent of the elder patient. This information exchange

is particularly important in terms of introducing privacy protocols during the access of confidential medical health information within the elder patient account within the PHR used by the health care clinic. These privacy and access policies can be integrated into the development of PHR's as user profiles with varying accessibility based on the permission levels of access. Different members of the caregiving unit can obtain access to the health care profile of the elder patient based on the level of caregiving involvement.

Caregiver facilitation of elder care

Caregivers are a significant component of the caregiving process and health care preparation process for elder patients. In order for the elder patients to receive full health care planning and organizing support from the caregivers, caregiving can not only be part of an endeavor conducted at home via physical and emotional support activities but should also be reflected in the support that the caregivers can provide electronically in terms of ways in which caregivers can participate in the caregiving process within PHR systems being used within the health center. As part of this study, we have observed caregivers and elder patients participate in the care process together offline, and that they had difficulties in maintaining similar care patterns online within the PHR echo sphere.

The areas within which caregivers can play a significant role in the care process within the PHR system includes online elder patient information work preparation, aggregation and reporting; symptom tracking and reporting and follow up on the health care agenda plan set by the provider.

In summary, based on the findings of the observations and interviews conducted and the themes obtained, potential recommendations for technical, design and platform updates and modifications can be made for the current in market PHR systems that are in use today by health care clinics. In addition, for the unique segment of the user populations of elder patients, in addition to providing technical design recommendations to PHR systems, it is also important to evaluate the design guidelines for end of summary discharge paper based tools for the continuous care that older patients require. In the following section on design implications the themes will be further explored in the context of technical, design and platform recommendations for PHR's and design recommendations for health care organization specific paper based tools such as end of summary discharge forms.

CHAPTER 6: DESIGN IMPLICATIONS

As discussed within the discussion section, the themes identified within the study as illustrated in the findings section pertain to the focus areas of 1) information work management 2) resources utilization 3) caregiver facilitation of elder care. These themes are embedded within the specific paradigm of elder health care, wherein specific focus must be attached to the qualities of elder care including cognitive, physiological, ambulatory and processing capacities. Considering the specific requirements of the elders and their caregiving units, recommendations to technical, design and platform recommendations are being made with respect to emotional, functional, scalable and temporal metrics of needs. Recommendations will be provided based on the challenges observed during the three phased timelines of before the medical visit, during the medical visit and after the medical visit, in terms of how elder patients can effectively prepare for healthcare maintenance and management by engaging in preparation for pre-visit preparation work, facilitation of information exchange during the visit and providing assistance in task execution after the visit.

Design Opportunities for Pre-Visit Preparation Work

In line with the challenges and breakdowns identified for maintaining health care strategies for elder care and aid them in the health care preparation process, the following are the recommendations for technical systems and process redesigns.

Firstly, with respect to information work organization strategy, as elder patients have to collect, analysis and organize information work such as 1) symptom tracking information 2) online reference material collected and 3) clinic generated documentation, elder patients and their caregivers need guidance into how to organize this information at home and provide this information to the medical provider during the medical visit. This information can be provided in the form of a summary of information work organization guide on the patient portal and for the specific case of assistance can be displayed as a video supported demonstration. This features thus adheres to the elder specific needs of visual, cognitive and literacy provision requirements and also complies with the framework of providing emotional and functional information to the elder patient and the caregivers.

Secondly, if and when the caregivers are present for the elder patients, in terms of caregiver responsibility co-ordination, the focus area is the task coordination, which involves coordinating the tasks such as symptom tracking and contacting

third party vendors. The factors that influence the task co-ordination are functional and temporal. With tasks being represented temporally, it is relatively easier to determine the end date by which the task has to be completed and by whom. The functional use of the task represents the need for the task to occur in the caregiving process. Both the temporal and functional functions of task coordination can occur by if the interface reflects the tasks that need to be completed before the next doctor's appointment with contextual and functional knowledge of the task. The task co-ordination can also be guided by inbuilt reminder systems that notify the elder patient and the caregiver of the upcoming task.

Thirdly, in terms of patient aggregated data exchange limitations to be included as part of the patient portal and other electronic patient health records, the framework feature of functional can be applied, where the elder patients and caregivers can be provided with means to aggregate the information collected from different sources such as friends, family, other providers and other online sources can be collected and shared with the health care providers in the form of the notes section within the patient portal. In addition, for the challenge consisting of lack of direction during resource use, summary of arranging the online resource can be provided along with the case of the video demonstration of the collection, analysis and reporting of the aggregated data. The challenge of direction and focus to resource use can also be

linked to that of providing services to the patients that will allow functional and temporal aggregation of data from different sources.

Fourthly, to include features that support emotional barriers for the elder patients, it would be important to consider features those provide the 1) ability to connect with resources that provide online health case specific support 2) broader caregiving organizations and 3) support from medical care personnel in terms of monthly care health care specific care guides. These features will be provided for the feature of functional and scalable support.

Design opportunities for facilitating information exchange during the visit

Firstly, for the cases of challenges during the medical visit, which includes the comprehension challenges and patient medical history organization and retrieval, the recommendations for these cases can be provided. To deal with comprehension challenges, the medical personnel should attach the use of specialized information within the patient portal with that of simplified language additions. In addition, for the case of patient medical history organization, the platform should provide features that include folder based interface in which all medical information pertaining to each condition can be stored in the form of 1) notes 2) clinic generated documents. This facilitates both the functional and temporal features.

Secondly, during the health care visit the process of reporting out on the symptoms of the elder patient tracked is important for the provider to establish a patient health care plan and will enable consistent care to take place. The challenge observed in symptom tracking is the reminder mechanism to enable the elder patient and the caregiver help record the symptoms accurately in the right area and consistently. These reminder features can enable caregivers and elder patients to track, analyze and report symptoms.

In addition, symptom tracking can be directly inbuilt into the patient portal via patient health data tracking sensors. The range of sensors available to track elder patient symptoms include that of heart rate monitors, blood pressure monitors, glucose monitors and weight monitors. Based on the capacity of the sensors, the data from these may be directly entered to the patient portal to manage continuous tracking of the symptoms.

Design opportunities for assisting in task execution after the visit

Firstly, for the phase of after the medical visit, the comparative analysis of the health outcomes can be accomplished by providing design features within the personal health records which would include graphs in terms of features such as

symptoms and recovery statistics gathered from clinic generated data. The comparative analysis provides functional view into elder patient recovery process and will enable future health care preparation process. This feature also supports the feature for health outcome comparison, with the ability to compare the health data seamlessly with features such as graph based data presentation; the health outcome comparison feature is greatly simplified.

Secondly, for the case of privacy and access, maintaining user profiles and permissions for all caregivers in the caregiving unit will enable every member of the caregiving team has access to similar data in order to provide medical support when needed the most by that particular caregiving unit.

CHAPTER 7: CONCLUSION

In order to develop older adult specific technologies and tools, it is of utmost importance to design around challenges faced by older adults. Due to chronic care condition preparation and treatment, it becomes especially crucial to develop mechanisms in built in existing technology and tools such as personal health records and clinic specific paper based tools, in order to facilitate a richer health care preparation process for the older adult populations.

In this work, we focus on the framework of challenges such as emotional, functional, scalable and temporal in order to target challenges in the three domains of information work, resource use and role of caregivers. Within these challenges, this work highlight potential opportunities for future technology design recommendations for personal health records and paper based tools.

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APPENDIX A INTERVIEW PROTOCOL

Warm up questions

1. For what conditions do you visit the doctor?
2. For how long have you been visiting the doctor for this particular health issue?
3. How many times do you visit the doctor at the Senior Health Center in a year?

Before the Doctor's Visit

1. How do you prepare for a doctor's appointment? Can you illustrate the process of preparations? For example, please explain how you have prepared for this particular doctor's appointment or for other previous doctor's appointments.
 1. During your preparation how do you track information?
 1. Please describe the way in which you keep track of this information. For example: in physical notes or other technology platforms such as computers, phones etc.
 2. Are there any things/tools that you prepare to show the doctor such as prescription bottles and other medical supplies?
 2. (If new patient) Do you bring the information from your previous doctors to your new doctor?

1. If so, in what forms do you bring this information.

2. Does someone help you prepare for the hospital visit with the doctor? For example: a caregiver at home or a family member.

3. If you have questions before your next doctor's appointment, how do you get the questions answered?
 1. Can you give an example of a time when you had a question and had it answered before the next doctor's visit?
 2. Can you please explain how you prepare any information that has been requested by the doctor from a previous doctor's visit?

4. What other sources of information do you use to get medical information about your condition, in addition to obtaining information from your doctor?

During the Doctor's Visit

1. Can you please describe the health related issues for which you seek treatment for at the Senior Health Center?

2. Do you visit the doctor on your own or does someone else accompany you during your hospital visits.

3. If someone else accompanies you, does the same person accompany you every time you visit the doctor?
4. Do you prepare questions to ask the doctor during your visit? How do you know that you have to prepare them?
5. How do you remember the information being discussed by the doctor during your medical visit?
6. Do you get a chance to ask all your prepared questions to the doctor? If not, please explain.
7. If there are any additional questions that you would have missed to ask the doctor, what ways do you use to get answers from the clinic.

After the Doctor's Visit

1. After the doctor's visit, what kind of information is provided to you by the doctor -nurse or the clinic for follow up.
 1. How does the clinic present information to you after the doctor's visit
 1. How do you carry or remember the information provided to you after the doctor's visit.
 2. Can you please describe how you use the information that has been provided to you?

1.2 How often do you refer to the information provided to you by the clinic after the doctor's visit?

1.3 What in specific in the follow up information do you most frequently refer to.

1.4 What information would you have found useful in the follow up information.

2. Can you describe the activities you undertake related to your health care pertaining to the information provided to you after the doctor's visit.

1. Do you use the help of a caregiver to carry on these activities

Follow Up

1. Is there anything else you would like to add?
2. Are there any questions?
3. Do you mind if we follow up with you to ask more questions.

Caregiver interview protocol

Warm Up Questions

1. How often do you accompany the patient to the doctor's visit?

Before the Doctor's Visit

1. Can you please describe the relationship with the patient?
 1. For how long have you been caring for the patient?
 2. Can you please describe the process in which you care for the patient?
 3. How many caregivers are there for the patient in your family?

2. What materials do you consult with before the doctor's visit.
 1. Do you help the patient prepare for the medical visits before the doctor's appointment or just accompany the patient during the medical visit

3. What kinds of information will be useful to refer to before you visit the doctor.

4. Do you consult with the patient while preparing for the doctor's visit.

During the Doctor's Visit

1. Do you help the patient prepare for the medical visit with the doctor? If you do help, please explain why do you think you take a primary role in helping the patient prepare for the visit, rather than the patient preparing on his or her own.

2. Why does the patient take on the role that they take on during the doctor's visit?
 1. During the doctor's visit, do you communicate with the doctor directly or does the patient communicate with the doctor more.
 2. In case the patient does not cover all the questions to ask the doctor, do you help cover some of the questions that were missed?

3. What are the most common questions asked by the doctor?
 1. Where do you note down the observations recorded at home to report on to the doctor.
 2. What kinds of questions do you or the patient have during the consultation process?
 3. If you or the patient forgot to ask a question to the doctor or the nurse during the consultation process, how do you follow up with the doctor to follow up on a question?

4. Are there multiple caregivers for the patients?
 1. If there are multiple caregivers, do all the caregivers/family members visit the doctor along with the patient

2. How do you share the information discussed during the patient consultation time with the doctor with the other caregivers.
3. Can you describe the process in which you ask a question to the other caregivers if they are not present during the consultation process

After the Doctor's Visit

1. What information do you and the patient receive at the end of the doctor's consultation?
2. If there are multiple caregivers for the patient, do you share any follow up information provided by the clinic after the doctor's visit with the other caregivers.
3. Please describe the process you use to discuss with the patient about the next steps after the doctor's visit.

Follow Up

1. Is there anything else you would like to add?
2. Are there any questions?
3. Do you mind if we follow up with you to ask more questions.

APPENDIX B: DEMOGRAPHIC QUESTIONNAIRE

Please answer each of the following questions by writing down or choosing the single best answer.

1. Your age:
2. Your gender: Male _____ Female _____
3. Your ethnic background:
4. What is your marital status? Never married _____ Married _____
Separated/Divorced _____ Widowed _____
5. How many people live with you now? _____ Adults (18 years or over) _____ Children _____
6. How much schooling have you completed? Less than 8th grade _____ Some high school _____ High school graduate _____ Some college of technical school _____ College graduate _____ Some postgraduate education _____ Masters/Doctoral degree _____
7. What is your annual household income?
<20,000 _____ 20,000 – 40,000 _____ 40,000 – 60,000 _____
60,000 – 80,000 _____ >80,000 _____
8. Do you live at home or in an assisted living facility? _____
9. Do you have caretakers/caregivers at home or helping you in the assisted living facility? _____ If Yes, how many caregivers do you have? _____

8. For what conditions do you visit the doctor often for ? _____

9. How long have you had these conditions ? _____

10. How often do you visit the doctor ? _____

11. Does anyone else in your family have similar conditions ? _____

13. How would you rate your understanding of the conditions that you discuss to the doctor for and its treatment?

Poor

Excellent

1 2 3 4 5