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Title	InfoSAGE Information Sharing Across Generations and Environments
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Abstract

Purpose

We built a “living laboratory” of aging older adults and their adult caregivers called InfoSAGE (Information Sharing Across Generations and Environments) to assess the informational needs and collaboration patterns of families undertaking the challenging aging process.

Scope

Families, friends, and other community-based supporters often assist aging patients with their health and social needs. To do so effectively, elderly patients often share control of their personal health information and decision-making. It can be difficult to balance this sharing while fully respecting elders’ autonomy. Health systems implementing patient portals would benefit from guidance about how to manage proxy access.

Methods

Through the online platform, InfoSAGE, we first identified the needs of this population through focus groups with stakeholders, families, and elders themselves, informing the design of the beta website. We then longitudinally studied a dyad cohort of elders and informal care partners, tracking use and informational patterns through the website and periodic surveys over the course of two years.

Results

Our study shows that it is feasible to establish an online platform for elders over the age of 75 and their families and caregivers for information exchange and care coordination. Although adoption of new technology is challenging within this population, especially in competition with entrenched forms of communication, health-IT systems such as InfoSAGE have the potential to address difficulties in communication and collaboration within families and will become increasingly important in the face of shifting demographic trends.

Key Words

Health information technology, Informal caregiving, mHealth, Frail older adults, Health literacy

Purpose

Objectives of Study

We proposed to study the information needs of elders and their adult children who are involved in their care and home needs. We built a “living laboratory” which we called InfoSAGE (Information Sharing Across Generations and Environments) to study real-life situations of elders and the challenges for families of communicating, coordinating, and collaborating with complex and costly care environments. Our study puts elders and their family at the center of information and communication.

Scope

Background

We proposed to study the information needs of elders and their adult children who are involved in their care by building a “living laboratory” which we are calling InfoSAGE (Information Sharing Across Generations and Environments). InfoSAGE allows us to study real-life situations of elders and the challenges for families of communicating, coordinating, and collaborating with complex and costly care environments.

Elder patients may face diminishing cognitive function and may need to transfer aspects of control of their personal health information and decision making to one or more family members. We hypothesize that these elders will still want to retain governance over some of their healthcare information and decision-making, but will also want to gradually transition to a shared model.

Our broad goal was to gain a deep understanding of the healthcare information ‘ecosystem’ that can support the special needs of the independent elder, yet also be capable of supporting an incremental transition to shared management of information, decision making and communication. Based upon our extensive experience

studying IT-enabled collaborative care we know that one of the most effective ways to understand a person's information needs is to learn through direct observation of behavior.

Our aims were to:

1. Identify the information needs and decision-making dynamics of elders and those helping to care for them, with a particular focus on how needs evolve as they transition from full independence to family-supported care.
2. Create a "living laboratory" – InfoSAGE, a novel, family-centered information management and collaborative environment that is based on the requirements and needs identified in Specific Aim 1.
3. Longitudinally study elder and family collaborative interactions and information management behaviors within InfoSAGE in the context of real healthcare decision-making and care transitions.
4. Evaluate the extent to which InfoSAGE improves Communication, Coordination, and Collaboration for elders and their family.

Context

Recent census information indicates that the population over the age of 75 is increasing at a faster rate than any other age group. Families will likely need to play an increasingly important role in the caretaking and well being of the elderly. Greenberger (2002), Burrows (1997), and others, for example, have emphasized the increasingly important health 'facilitating' role that family members assume. [1,2] This 'facilitating' role includes such things as helping to maintain independence and autonomy, administering care, directing the elder to healthy behaviors and providing health-related information. As important, the role also involves "positively manipulating the environment, recruiting other individuals to assist, negotiating [healthcare system] bureaucracy, and optimally rearranging the care-recipient's living accommodations".[1] Even with the increasing need for familial support, each year a larger proportion of individuals will live alone (spouseless), and at a distance from immediate family members. More often than not, neither the elder nor their family knows how to readily access and share information.

As described by Agarwal and Khuntia (2009),[3] consumer health information technologies (IT) could play a role in reducing this vulnerability. In order to successfully do so for this unique population, special considerations need to be given to the design and functionality of these tools and resources. First, the concept of the 'user' must be flexible, and the underlying design of the technology must be capable of accounting for a variety of 'user' models. In some cases, the 'user' will be the independent elder, whose physical capabilities can diminish over time. In other cases, the 'user' may be a network of elder and family caregivers. In still other cases, the 'user' may be a designated healthcare proxy. Second, we need to increase our understanding of the information needs, information management practices, preferences, and priorities for any of these 'user' models – a topic about which we know very little. Some studies have examined the elder use of information technology and the Internet to support their health information needs. However, as a group, these elders perceived the value of the information retrieved to be low, and they continued to prefer direct contact with a traditional healthcare provider as their primary source of health information. The major limitation of these studies, however, is that they have not examined in detail how the information needs of the elder evolve over time, how information acquired from consumer sources shapes decision-making, and how needs and behaviors change in response to specific health events.[4-8] Additionally, these studies under-represented the 'oldest old age group.' In the Kaiser Foundation report, for example, only 9% of the respondents were age over 75. Finally, these studies do not differentiate between the needs of a fully independent elder and one who has chosen to or needs to share governance over personal health information with an extended family.[9]

With respect to the information management practices, preferences, and priorities for the *informal caregiver or proxy*, our understanding was also patchy. A number of earlier studies had identified that for a family member who is engaged in day-to-day care for an elder, access to healthcare related information can be an important mediator of stress, and can measurably influence the effectiveness of the caregiver. Few studies, however, had elaborated on specific types of information, specific use cases or other detailed requirements. For example, Bakas, et al (2002) found that caregivers of stroke victims for whom they were providing long-term in-home care consistently expressed a need for better access to information, as well as informal social outreach,[10] but the study did not elaborate on how and in what specific contexts this information, might be most useful. Buckley, et al. (2002) evaluated a specific health-IT intervention, telehealth, and found that the technology was embraced by in-home, family caregivers of stroke survivors to seek informational and emotional support not only for the patient, but also for themselves.[11] Clearly, when considering the features and functionality of consumer

health IT for the elderly population, one must consider not only the elder, but also the informal caregivers within their family.

New technologies provide great opportunity to enhance the quality and safety of healthcare. However, consumer healthcare IT is biased to the young, relatively independent user. It is rare to see underlying designs capable of simultaneously supporting specific physical and cognitive limitations of the user, or more general needs of an elderly population, despite published guidelines relating to readability, presentation of information, ease of navigation and incorporation of other media.[12-16] It is even rarer to see designs that can accommodate evolving models of the user, such as are required when family members begin to share decision-making and management of care with their elderly parents or grandparents.

Our project's broad goals were to close the gap in knowledge, and precisely define the needs of the independent elder as well as his or her extended family care network. Using a variety of strategies, we systematically studied the individuals as well as their roles, preferences and the diverse and evolving contexts in which personal healthcare information is used.

Settings

The primary locations of recruitment were the local collaborating senior care facilities and senior living communities, Hebrew Senior Life (Boston, Massachusetts, USA) and Lasell Village (Newton, Massachusetts, USA) in addition to recruitment at the grantee hospital, Beth Israel Deaconess Medical Center (Boston, Massachusetts, USA). These sites participated in the longitudinal study recruitment, and provided venues for dissemination of the study material and results to community members. InfoSAGE is also available to the general public through an online signup process and was not limited geographically. Study participation was an optional component to the use of the platform.

Participants

Dyads were enrolled based on the following eligibility criteria. The senior is our keystone participant, and must be ≥ 75 years of age, and the native English speaker. Elders were community dwelling, meaning that they live in a private residence, a continuing care retirement community such as Hebrew SeniorLife, subsidized senior housing, or assisted-living. We did not include those seniors who live in skilled nursing facilities permanently. The keystone or index senior was required to have a family member who was willing to participate in this project. Family members were required to be native English speaking, and to be involved in the Keystone elders' life and care, though not necessarily local to the area. Enrollment began March 2015 and finished March 2017 for the longitudinal portion of the study.

Methods

Study Design

The tool and platform are public and available for anyone to use on the Internet. To answer the questions set forth in the specific aims, we employed a prospective observational cohort of patients over the age of 75 (keystone) and their family members (proxy/caregiver). The study was designed as a limited technology evaluation/assessment to assess feasibility, usability, and to assess for early impact on our outcome measures. We recruited 26 dyads into the longitudinal cohort.

At the time of website enrollment, users who met the inclusion criteria and none of the exclusion criteria were asked to opt-in to the cohort/study. Users read information about the study and what it means to "opt-in" on the website, and completed a short form to verify eligibility.

Participants were based in the United States. Each study participant was asked to designate one key family member to participate in the InfoSAGE project. The purpose of defining a 'primary' InfoSAGE care network participant was to establish a family member or proxy who coordinates care, and could interact with the senior and other family members as needed on the InfoSAGE platform.

All study participants were asked to fill out a study questionnaire/survey at the time of enrollment. This was delivered through the Internet using RedCap, an electronic data capture (EDC) software. Participants were

invited to use InfoSAGE and we planned to be in touch with them every 6 months for brief telephone surveys, and every 12 months for a longer follow up survey. We contacted them by phone or email, and/or regular mail to remind them of scheduled questionnaires, unless they have opted out of the study. We followed this cohort for two years.

Research Methods and Procedures By Specific Aim

1. Create a novel, family-centered information management and collaborative environment that is based on the requirements and needs identified through our ongoing research.

To achieve our first specific aim, we developed a secure, web-based platform where patients and their family members can connect with one another, communicate, collaborate, and search for curated information and local resources pertaining to aging. It is public-facing, and available on the Internet for families to use.

Our 'beta' version has the following components:

- Search function (a search engine with curated links designed to be helpful for seniors)
- Resource guide of curated local resources with help from Hebrew SeniorLife and Beth Israel Deaconess Medical Center (BIDMC) social workers
- Calendar function
- Shared task list
- Medication list (as entered by the senior or their proxy)
- Networking function (connect with family members/friends)
- Microblog function (short posts or status updates secure to the user's network)

By default, no user can see any other users information unless there is an explicit linkage made by the user who wishes to share information. For example, a family member looking to use the calendaring function and microblog function of a senior can only do so if the senior (or their proxy) explicitly invites the family member into their network. One can think of this as a very private social network designed around micro-networks and families.

Any user can create an account and use our platform. However, for our research purposes, we assessed the experience only of study participants enrolled in the prospective cohort.

2. Identify the information needs and decision-making dynamics of elders and those helping to care for them, with a particular focus on how needs evolve as elders transition from full independence to family-supported care

In order to establish a baseline assessment of users' a) information needs; b) information management practices, preferences and priorities; and c) the specific context of use, we conducted a series of focus groups with potential stakeholders, including elders, family members of elders and informal caregivers. These discussions informed the preliminary design, features, and functionality of the electronic family-centered information management and collaborative environment that we later developed into the 'beta' site of InfoSAGE.

Between October 2013 and February 2014, we conducted 10 facilitated focus groups: 5 with elders living in senior housing facilities, and 5 with family members. We planned separate elder and family member groups in order to encourage free expression from each group's particular perspective. We recruited elders at least 75 years of age and care partners of residents. They were recruited independently; a resident did not need to participate in a group for his/her care partner to participate.

At the start of each 90-min group, investigators reviewed the study consent form and answered participants' questions about their consent. Written informed consent was obtained from all participants. At least two investigators attended each group. Then, using a discussion guide developed by the research team, a professional moderator experienced in health care and with elderly populations facilitated the session. At the end of the group, participants received \$50 as compensation for their time. Each meeting was audiotaped and transcribed verbatim.

The study was conducted within a large regional network of senior housing in the Boston metropolitan area, where InfoSAGE would be pilot tested. Hebrew SeniorLife (HSL) is a senior health care organization that manages five senior living communities: two are continuing care retirement communities, and three are independent living apartment complexes that include low-income housing. Though HSL is a nonsectarian organization and offers services to all elders, it has traditionally supported Boston's Jewish community. Residents may receive care from HSL clinicians, and many also see other area providers. Although HSL does not have a patient portal, many of the external providers host secure portals for their patients.

All groups were held at the facilities where the elders lived. The study was designed and conducted with the approval of the institutional review boards of Beth Israel Deaconess Medical Center and HSL.

Participants in the study opted-in to having their searches analyzed, though in analysis we protected the security of their identities. Where possible, we deidentified any of the search queries and browsing habits. We retained some linking to develop understanding of their context, such as where they are living (at home, at a retirement community, or assisted living), and their health trajectory.

Qualitative analysis of the coded themes established through the focus groups was analyzed to inform the later design of the InfoSAGE platform. The full results of the focus group segment of the study have been published.[17]

To collect data about health, family, and social context, we contacted our study participants every six months. This included a brief RedCap or telephone-based survey. Additionally, for those study participants who preferred to complete hardcopy surveys, a pre-addressed, self-stamped envelope and survey was delivered.

We did not formally enroll other family members, though our user agreement for the platform stipulated our purpose and our use of data to help inform our elder network analysis and information needs. The study team had no direct contact with these family users.

3. Using our laboratory developed platform, we will longitudinally study patient and family collaborative interactions and information management behaviors in the context of real healthcare decision-making and care tasks.

In order to longitudinally analyze health information utilization in the InfoSAGE 'Living Laboratory,' we used a combination of strategies that are collectively referred to as process mining. The process mining analytic tools enabled us to perform the following high-level analytic tasks:

- a) Analyze information sharing and interaction between patient-family-providers in the collaborative environment around specific tasks, and in relation to specific events. Examples of representative events include ambulatory office visits or discharges after acute inpatient hospitalizations (assessed by telephone interviews).
- b) Analyze the specific type of information that is exchanged within the network after a specific event, or in conjunction with specific tasks. Examples of information include resources retrieved from Internet searches, calendar entries, task entries, and microblog entries.

4. Evaluate the extent to which our platform improves communication, coordination, and collaboration for elders and their family members through surveys.

For our beta phase, we assessed the usability, satisfaction, and caregiver burnout, and assessed the impact of our InfoSAGE platform on the above outcomes. Where possible, we used standardized instruments, though in some cases shortened the instruments to decrease participant burden. We surveyed both the keystone elders and the family members. We conducted our analysis for these outcomes with predictors including utilization of the platform, utilization of the search functionality, utilization of the peer coordination component such as calendar, task list, and microblog, and size and shape of the network.

Data Collection

This study was designed as a limited technology evaluation/assessment (as opposed to a fully-powered clinical trial) for several reasons. First, we needed to obtain preliminary information on the feasibility of recruiting and retaining this population of elders and their caregivers to a study of this type of intervention. Second, the InfoSAGE platform rapidly evolved during the study period. Third, some of the instruments for measuring outcomes are novel and will need to be validated. Therefore, we conducted this evaluation study to determine the feasibility of conducting a trial of InfoSAGE, to refine our outcome measures, and to obtain preliminary estimates of effect sizes to inform our design and sample size necessary for a definitive clinical trial.

The basic approach to analysis of the trial involves the use of longitudinal repeated measures methods. We recognize that we are considering multiple outcome measures in the study, but since this is a technology evaluation/assessment study, we will not explicitly adjust for multiple comparisons.

Patient, family and provider assessments of communication, coordination, collaboration and care are measured 3 times (baseline, year 1 and year 2). To better understand our data, we conducted a variety of exploratory analyses. We attempted to identify correlates of the outcome measures. We also examined any correlations between patient and family assessments and between patient and provider assessments.

Results

Principal Findings

Preliminary results of the focus group sessions led to the development of the beta-version of the InfoSAGE website. The 30 elders and 23 family caregivers enrolled in the focus groups were instrumental in guiding our principles of design. Based on these groups and thematic analysis, we found that elderly patients expressed a wish to remain in control of their healthcare information and autonomy for as long as possible, but are open to an incremental transition to a shared model as they age and become more dependent on informal and formal caregivers. We developed a framework based on these lessons that formed the basis of InfoSAGE (figure 1).

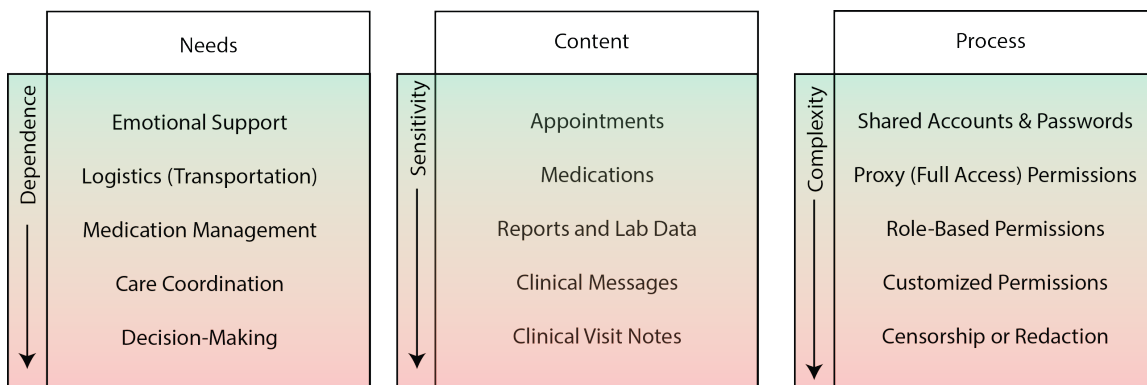


Figure 1 - Domains of Information Sharing For Patient Portal Access. Three core domains are representing, including the elder's level of needs, the content to be accessed by a supporter, and the process for interacting with that content.

We evaluated the platform based on the: (1) adoption and usage of the system by elders and families; (2) network structures; and (3) feedback from user surveys. The population of users represents people drawn from early partnerships with local continuing care retirement communities. We asked users to provide their year of birth during enrollment, and calculated ages using December 31 as the anchor date. Participants additionally self-reported gender and those opting into the longitudinal survey-based study were also asked to self-report race, ethnicity, and educational information. For site usage, we recorded user logins. We more broadly measured site usage and behavior using Google Analytics, which included information about user location, flow through the site, and search terms, although these data were not linked to individual users. We created a geographic representation of Keystone networks based on the location of each users' logins. The study team met regularly to reflect on barriers to enrollment and use, based on solicited early user feedback and meetings with prospective users.

The longitudinal cohort included 26 dyad pairs, enrolled from 03/2015 to 03/2017. User surveys indicated that, when asked 'how frequently have you looked up information about health or medical topics from the Internet?', Keystones and Caregivers both showed an increase between baseline and the six-month follow-up. We observed that the rate of skipped or unanswered survey questions decreased from baseline to six months. This may suggest that Keystones, in particular, were hesitant to engage with a new system, but became more familiar and comfortable after a period of use (Figure 2). Keystones also reported having between two and six healthcare providers. Surprisingly, most keystones expressed some level of comfort with using the Internet, with 18% reporting “very comfortable” when asked about Internet use.

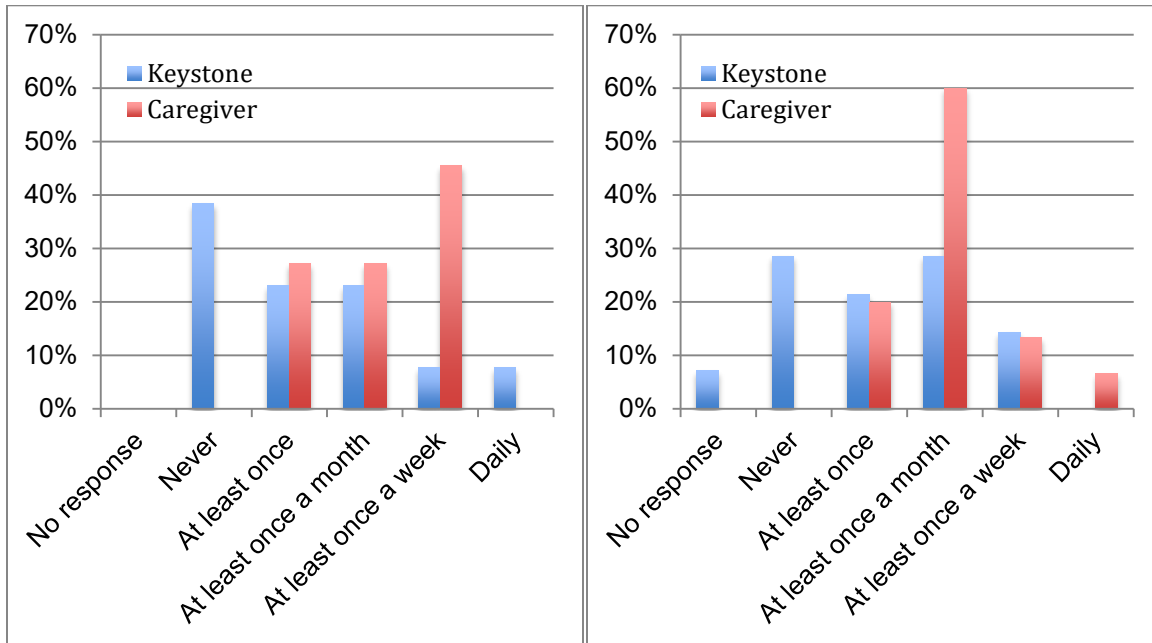


Figure 2 - Frequency of Internet based health searches in the previous 6 months, at enrollment (left, n = 29) and six months (right, n = 24)

Beyond the longitudinal cohort, InfoSAGE is open to the public at large and has experienced wide use across the United States and abroad. From January 1, 2014, to January 8, 2019, there were 356 registered users and 32,434 page views. One-hundred-and-fifty-five users provided their year of birth, and 201 did not. Based on those who did report their year of birth, the average age of the Keystone users was 86.01 years after removing outliers, and the average age of the caregiver users was 63.1 years. Keystones also reported having between two and six healthcare providers that may reflect their need for healthcare for multiple conditions. The keystone or proxy can manage roles within each network. Of the 356 InfoSAGE users, 202 are keystones, 140 are proxies, 20 are caregivers, and 5 are participants, with 24 users having more than one role due to membership in more than one network. One example of a multirole user is in the case of married elders who are often keystones in their own network and proxy to their spouse. Figure 3 shows a family network that has more than one keystone and users can have different relationships to each keystone.

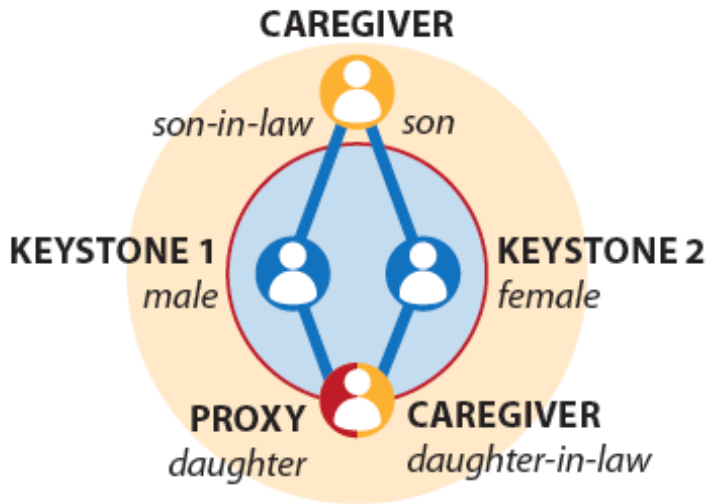


Figure 3 - An example, two elder (keystone) network and network connections.

The majority of InfoSAGE networks exist as dyad pairs or networks containing only one user (43.2%), a non-paired keystone, which may have resulted from the study design, although 24 family networks consist of three or more users. Network sizes range from one (50.3%), in networks with a single keystone, to seven users, with more than one keystone. The largest networks on InfoSAGE are multi-keystone clusters, encompassing multiple family networks joined by single or multiple users common to each individual network. These extended networks comprise 6.3% of all networks, and no network currently exists that contains three or more keystones.

Although keystones and non-keystones were similarly likely to login and view network information, non-keystones were responsible for most of the actionable events recorded, such as tasks created, modified, or marked complete., as shown in Figure 4. Additionally, non-keystones were more frequent users of the mobile apps, which could suggest that elders are more comfortable with the large-scale format and input that a computer system offers over the smaller screens and touch-enabled navigation of mobile phones.

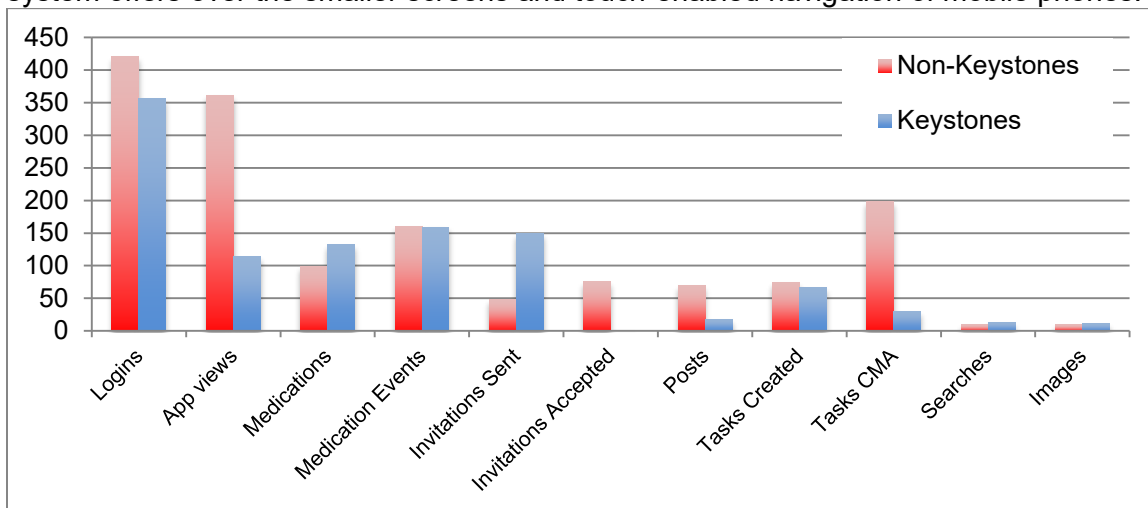


Figure 4 - Distribution of user activities from 03/2015 - 01/2019, all users (n = 356). CMA: Created/Modified/Assigned

Time series activity over each network was also analyzed. We examined the distribution of activity over the normalized over time and found that usage was predominantly in the first half of the life span of the network, as shown in Figure 5.

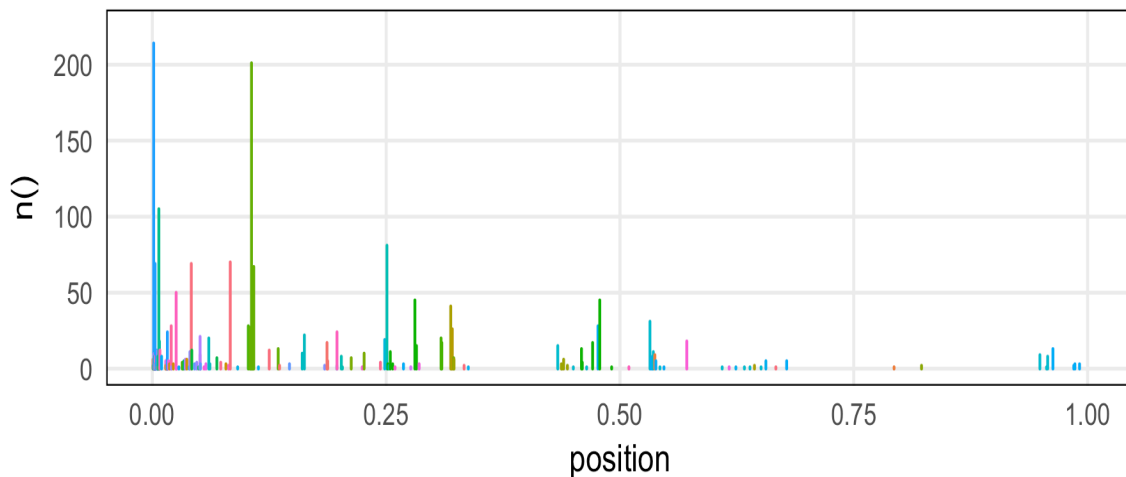


Figure 5 - All networks, normalized activity over time

Discussion

Adoption of Use

Our study has shown that it is feasible to recruit elders over the age of 75 and their families to use online and mobile technologies for information sharing and care coordination. Keystones were more likely to be the driver of network growth, sending more than three times the number of invitations than non-keystones. The system design is based on the belief that older users should be empowered to engage in their coordination of care and be able to invite and delegate to families over time. The engagement seen in the study shows a diverse range of approaches that families take to care coordination.

Recruitment proved to be more difficult than anticipated. We hypothesized that the main barrier to participation was overcoming the use of preexisting methods of communication, such as email, phone, or text message, or in-person visits. Potential participants had to be open and flexible to learning and using a new system for communication, made doubly difficult by a dyad-based study design. Additionally, in the elder communities, a sense of reticence and mild distrust was exhibited in sharing medical information online, despite the privacy and security controls that constitute the backbone of InfoSAGE. Other studies have experienced similar difficulties with recruiting from this population.[18-22]

Other studies have experienced similar difficulties with recruiting from this population, speaking to the importance of user engagement and the utilization of continual feedback.[22,23]

One barrier to the adoption of InfoSAGE in this context is the family's perception, structure, and support for using the tools. The perception of 'no-need', alternate forms of contact, or if there are no family caregivers, are reasons for non-use. One possible gap here is the difficulty of incorporating formal caregivers (home health aides, visiting nurses, social workers) and informal caregivers within one network. Future research may explore these barriers in more depth.

Usage Patterns

The InfoSAGE platform is more useful if the user (elder or family) is already registered and familiar with the system before having an acute or subacute medical need. InfoSAGE, or other technologies like it that are designed to support elders in their homes, have many functions and potential uses, such as medication lists, calendars, to-do lists, microblogs, personal stories, etc., that may play a role at different points in care. From a family's perspective, these tools are most useful during the transitions of care. For example, the system may be more valuable during a visit to the emergency room, or a discharge from hospital to home. However, the family needs to be familiar with and using the tools before these transitions occur in order to make information available at the time they are needed.

We have also observed that information and support needs vary over time and are not monotonic. Needs increase and decrease, depending on the care trajectory of the elder. Further investigation is needed to

understand online usage patterns, how they relate to changes in health status, and how the system could be more useful in emergent care needs.

Privacy

In our focus groups elders and families indicated that privacy controls were important. We do not know the optimal balance of privacy vs. information sharing/cascading to family members. We believe that, with changes over time and the care trajectory, the privacy needs and information sharing needs will change. Hence, having a system that allows control of the privacy level to an increasing number of family members may be more valuable over time.

The literature has also reported that among the common barriers to adoption, as expressed by the elders, are issues of trust and privacy.[24] Mistrust is regularly experienced by older online users, expressed as a feeling of being on constant guard against perceived threats to privacy and security.[25] Studies have observed that trust is significantly associated with Internet use among those aged 65 or above, and that, of those with Internet experience, trust is a significant factor of behavior change due to information found online.[26]

In our focus groups elders and families indicated that privacy controls were important. The literature has also reported that among the common barriers to adoption, as expressed by the elders, are issues of trust and privacy. InfoSAGE usage showed that there was a wide variety of family network and roles, indicating that the flexible controls we developed allowed for a wide range of networks. We do not know the optimal balance of privacy vs. information sharing/cascading to family members. We believe that, with changes over time and the care trajectory, the privacy needs and information sharing needs may change. Further work is needed to understand how to create additional privacy controls without complicating the usability of the system.

Apps like InfoSAGE compete for attention as the communication channel of choice. Some families are in the habit of making many phone calls to support care coordination and to update family members. Regular email is also used to update families at a distance. The usage of the system will then need to have a higher value than existing communication channels. We added medication management and interaction alerts based on user feedback, and we have noticed some higher usage since this feature was launched.

Data Integration

The effort expended on data entry by/for the users needs to be minimized to make this tool easier to use. Integration with the existing healthcare environment is difficult but important. There is a significant cost to setting up Internet data connections to import or export medication lists between a consumer-controlled website or app and a healthcare-provider system. Interoperability standards could help, but there is still a cost justification that needs to occur. Clinicians do not necessarily want another communication channel with patients, given the data overload that already exists, and time pressures.

There are many fragmented sources of information, each with their focus and associated politics. For instance, most community resources that have websites are designed to capture the user to their site. However, each website uses a different design. It would be useful to have a community resource information standard that would define an information package that could plug-in to apps like InfoSAGE to make resources more widely discoverable and easily integrated into other systems.

Design for Elders

Difficulties exist in the design of an information system intended for a broad range of ages. This is particularly problematic when the intended users are older may have low computer or internet literacy, physical or age-related impairment, movement disorders, or health literacy challenges.[27,28] Internet search results are not regularly examined by users for accuracy, with users often assuming the results are true and up to date. One study found that, among those seeking health information, only 14% checked the relevancy of the source.[23]

Although the proportion of older Americans who regularly use the Internet continues to rise, there exist barriers to further adoption of technology that are unique to this segment of the population. For example, an estimated 20% of adults in North America aged 75 or older self-reported as having eyesight conditions.[29] Increasing age has been linked to the inability to accurately and precisely use a computer mouse or track-pad.[30,31] Beyond

physical barriers, the design of websites and computer programs often assume a certain level of familiarity, with regards to computer interfaces, that puts late adopters, such as the elderly, at a disadvantage. The design of the user interface and user experience can cause indecision and frustration in this population, especially with elements of web navigation, such as hyperlinks.[32,33] Our design was improved by iterative feedback, but we found through usability studies that adding functionality made it more difficult for elder users. Existing user interface guidelines from international organizations such as The World Wide Web Consortium, The European Commission, and the US Government have focused on web-based interfaces and are out of date.[27,28,34-36] Future research is needed on user interface guidelines for elder care applications.

Perceived Need

A user (elder or family) need to know how to use technology like InfoSAGE before the user needs it. Meaning that InfoSAGE, or technology like it designed to support elders in their homes, have many functions and potential uses such as medication lists, calendars, To-Do lists, microblogs, personal stories, etc. From a family's perspective, these tools are most useful at the transitions of care. For example, the system may be more valuable during a visit to the emergency room or discharge from hospital to home. But the family needs to be using the tools before these transitions to make it useful and available at the time they are needed.

Isolation

Reduction in isolation requires greater family support and communication. One barrier to adoption of InfoSAGE in this context is the family itself. The perception of "no-need", alternate forms of contact, or if there are no family caregivers are all excuses for non-use. One possible gap here is the difficulty of incorporating formal caregivers (home health aids, visiting nurses, social work) and informal caregivers within one network. As mentioned physicians have been reluctant to participate.

Conclusions

In conclusion, we found that elderly and caregiving participants supported information sharing, even in light of the possibility of unintended consequences. For many families, access to information elements will unlikely be controlled statically, but instead will be determined by a negotiation between caregivers and their elders as needs evolve over time. To help with this negotiation, patient portals should anticipate the need for different levels of information sharing during times of relative wellness and illness.

Our study shows that it is feasible to establish an online platform for elders over the age of 75 and their families and caregivers for information exchange and care coordination. This advances our understanding of some of the technological and adoption challenges in the use of online technologies by elders for information and healthcare coordination. The survey participants reported higher usage of the Internet for healthcare needs after one year. Applications such as InfoSAGE have the potential to increase the quality of life by improving access to high-quality education, improving communication and reducing isolation by connecting elders to their families and support networks. We also need to do more analysis on the structure and demographics of families and informal caregivers, to see which family networks are more likely to benefit from this system. Future work needs to focus on interoperability, improving privacy controls and the usability of interfaces, supporting rural users, and appropriate ways to introduce these technologies to older adults and their families.

Future Model for Family-centered Care coordination

Future models for healthcare systems for elders should take into consideration that more elders will need support from families given the rising number of elders and limited capacity of geriatricians and existing healthcare provider services. Online family-centric healthcare coordination systems rather than hospital-centric models may be more beneficial given that most elders have more than one healthcare provider. There is an opportunity for clinicians and home healthcare aids to be invited into such online networks, and this may reduce the need to have frail elders visit health facilities through telemedicine visits. Financial and regulatory issues will need to be addressed. In 2007, in the e-patient book by Tom Ferguson, Charles Safran said "[When patients] participate more actively in the process of medical care, we can create a new healthcare system with higher quality services, better outcomes, lower costs, fewer medical mistakes, and happier, healthier patients. We must make this the new gold standard of healthcare quality and the ultimate goal of all our improvement efforts: Not better hospitals. Not better physician practices. Not more sophisticated electronic medical systems. Happier, healthier patients".[37] That vision is still a work in progress.

Citations

1. Greenberger H, Litwin H. Can burdened caregivers be effective facilitators of elder care-recipient healthcare? *J Adv Nurs*. 2002; 41: 332-341
2. Burrows D, Kendall S. Focus groups: what are they and how can they be used in nursing and health care research?. *Social Sciences in Health*. 1997;3:244-53.
3. Agarwal R, Khuntia J. Personal health information management and the design of consumer health information technology: background report. HHS A290200710072T. 2009;72:09-075.
4. Hughes LC, Hodgson NA, Muller P, Robinson LA, McCorkle R. Information needs of elderly postsurgical cancer patients during the transition from hospital to home. *Journal of Nursing Scholarship*. 2000 Mar 1;32(1):25-30.
5. Schwartz DG, Mosher E, Wilson S, Lipkus C, Collins R. Seniors connect: a partnership for training between health care and public libraries. *Medical Reference Services Quarterly*. 2002 Mar 1;21(3):1-9.
6. Macias W, McMillan S. The return of the house call: The role of Internet-based interactivity in bringing health information home to older adults. *Health communication*. 2008 Jan 25;23(1):34-44.
7. Cresci MK, Jarosz PA. Bridging the digital divide for urban seniors: community partnership. *Geriatric Nurs*. 2010;31:455-463
8. Kontos EZ, Emmons KM, Puleo E, Viswanath K. Communication inequalities and public health implications of adult social networking site use in the United States. *Journal of health communication*. 2010 Dec 13;15(sup3):216-35.
9. Rideout V, Neuman T, Kitchman M, Brodie M. e-Health and the elderly: How seniors use the Internet for health information: Key findings from a national survey of older Americans. Kaiser Family Foundation 2005.
10. Bakas T, Austin JK, Okonkwo KF, Lewis RR, Chadwick L. Needs, concerns, strategies, and advice of stroke caregivers the first 6 months after discharge. *Journal of Neuroscience Nursing*. 2002 Oct 1;34(5):242.
11. Buckley KM, Tran BQ, Prandoni CM. Receptiveness, use and acceptance of telehealth by caregivers of stroke patients in the home. *Online J Issues Nurs*. 2004 Sep 1;9(3):9.
12. National Institute on Aging Guidelines. Making your website senior friendly: Tips from the National Institute on Aging and the National Library of Medicine. URL: <http://www.nia.nih.gov/HealthInformation/Publications/website.htm>. Accessed May 14, 2011.
13. Grahame M, Laberge J, Scialfa CT. Age differences in search of Web pages: The effects of link size, link number, and clutter. *Human Factors*. 2004 Sep;46(3):385-98.
14. Nahm ES, Preece J, Resnick B, Mills ME. Usability of health Web sites for older adults: a preliminary study. *CIN: Computers, Informatics, Nursing*. 2004 Nov 1;22(6):326-34.
15. Becker SA. A study of web usability for older adults seeking online health resources. *ACM Transactions on Computer-Human Interaction (TOCHI)*. 2004 Dec 1;11(4):387-406.
16. Given LM, Ruecker S, Simpson H, Sadler E, Ruskin A. Inclusive interface design for seniors: Image-browsing for a health information context. *Journal of the American Society for Information Science and Technology*. 2007 Sep;58(11):1610-7.
17. Walker J, Crotty BH, O'Brien J, Dierks MM, Lipsitz L, Safran C. Addressing the challenges of aging: how elders and their care partners seek information. *The Gerontologist*. 2016 Apr 6;57(5):955-62.

18. Palmas W, Teresi J, Morin P, Wolff LT, Field L, Eimicke JP et al. (2006). Recruitment and enrollment of rural and urban medically underserved elderly into a randomized trial of telemedicine case management for diabetes care. *Telemedicine Journal & e-Health* 12(5): 601-7.
19. Levine DM, Lipsitz SR, Linder JA. Changes in Everyday and Digital Health Technology Use Among Seniors in Declining Health. *J Gerontol A Biol Sci Med Sci*. 2018 Mar 14;73(4):552-559.
20. Heart T, Kalderon E (2013). Older adults: Are they ready to adopt health-related ICT? *International Journal of Medical Informatics*, 82(11), e209–e231.
21. Hoque R, Sorwar G. Understanding factors influencing the adoption of mHealth by the elderly: An extension of the UTAUT model. *Int J Med Inform*. 2017 May;101:75-84.
22. McCloskey R, Jarrett P, Stewart C, Keeping-Burke L (2015). Recruitment and Retention Challenges in a Technology-Based Study with Older Adults Discharged from a Geriatric Rehabilitation Unit. *Rehabilitation Nursing* 40(4): 249-59.
23. Marshall LA, Williams D (2006). Health information: Does quality count for the consumer? How consumers evaluate the quality of health information materials across a variety of media. *Journal of Librarianship and Information Science* 38(3): 141-156.
24. Castilla D et al. (2016). Effect of Web navigation style in elderly users. *Computers in Human Behavior* 55: 909-920.
25. Yusif S et al. (2016). Older people, assistive technologies, and the barriers to adoption: A systematic review. *International Journal of Medical Informatics* 94: 112-116.
26. Gatto SL, Tak SH (2008). Computer, Internet, and e-mail use among older adults: Benefits and barriers. *Educational Gerontology* 34(9): 800-811.
27. Bailey B. Age-Related Research-Based Usability Guidelines. Available at URL: <https://www.usability.gov/get-involved/blog/2005/11/age-related-guidelines.html> November 1, 2005, [Last Accessed 9 January 2019].
28. Sibley C. Web Usability and Aging, December 1 2008, Available at URL: <https://www.usability.gov/get-involved/blog/2008/12/aging-and-usability.html> [Last Accessed 9 January 2019].
29. United States Department of Health and Human Services. Understanding and Improving Health. November 2000. Washington, DC: US Government Printing Office. Available at URL: <https://files.eric.ed.gov/fulltext/ED443794.pdf> [Last Accessed 9 January 2019].
30. Riviere CN, Thakor NV. Effects of age and disability on tracking tasks with a computer mouse: accuracy and linearity. *J Rehabil Res Dev*. 1996 Feb;33(1):6-15.
31. Dickinson, A., Newell AF, Smith, MJ, Hill, RL. Introducing the Internet to the over-60s: Developing an email system for older novice computer users. *Interact. Comput*. 17, 6 (December 2005), 621-642.
32. Lin D-YM. Hypertext for the aged: Effects of text topologies. *Computers in Human Behavior*. 2003; 19(2): 201-209.
33. Castilla D, Garcia-Palacios A, Miralles I, Breton-Lopez J, Parra E, Rodriguez-Berges S, Botella C. 2016. Effect of Web navigation style in elderly users. *Comput. Hum. Behav*. 55, PB (February 2016), 909-920.

34. World Wide Web Consortium (W3C). Older Users Online - WAI Guidelines Address Older Users' Web Experience. User Experience Magazine, Vol 8, Issue 1, 2009, Available at URL: <https://www.w3.org/WAI/posts/2009/older-users-online>, Last Accessed Sept. 17, 2018
35. World Wide Web Consortium (W3C). Older Users and Web Accessibility: Meeting the Needs of Ageing Web Users. Available at URL: <https://www.w3.org/WAI/older-users/> [Last Accessed 9 January 2019].
36. European Commission. Web Accessibility Initiative: Ageing Education and Harmonisation (WAI-AGE), European Commission Project, 6th Framework, IST 035015, 30 September 2010, Available at URL: www.w3.org/WAI/WAI-AGE/ Last Accessed Sept. 17, 2018 [Last Accessed 9 January 2019].
37. Ferguson, T, and e-Patients Scholars Working Group. e-patients: how they can help us heal healthcare. 2007. Available at URL: https://participatorymedicine.org/e-Patient_White_Paper_with_Afterword.pdf [Last Accessed 9 January 2019].

List of publications and products

- Crotty BH, Mostaghimi A, O'Brien J, Bajracharya A, Safran C, Landon BE. Prevalence and Risk Profile of Unread Messages to Patients in a Patient Web Portal. *Appl Clin Inform.* 2015 June 12;;6(2):375-82. PMID: 26171082.
- Crotty BH, Walker J, Lpstitz L, O'Brien J, Fischer S, Slack WV, Safran C. Information Sharing Preferences of Older Patients and their Families. *JAMA Intern Med.* 2015, Sep;175(9):1492-7. PMID 2617401.
- Bajracharya AS, Crotty BH, Kowaloff HB, Safran C, Slack WV. Improving Health Care Proxy Documentation Using a Web-based Interview through a Patient Portal. *J AM Med Inform Assoc.* 2015 Nov. 13. PMID: 26568608.
- Jan Walker, RN, MBA, Bradley H. Crotty, MD, MPH, Jacqueline O'Brien, BS, Meghan M. Dierks, MD, Lewis Lipsitz, MD, and Charles Safran, MD. Addressing the Challenges of Aging: How Elders and Their Care Partners Seek Information. The Gerontological Society of America. April 6, 2016.
- Croty B, Slack WV. Designing online health services for patients. *Journal: Israel Journal of Health Policy Research.* 2016, 5:22DOI: 10.1186/s13584-016-0082-7.
- Bajracharya AS, Crotty BH, Kowaloff HB, Safran C, Slack WV. Improving health care proxy documentation using a web-based interview through a patient portal. *J Am Med Inform Assoc.* 2016 May;23(3):580-7. doi: 10.1093/jamia/ocv133. Epub 2015 Nov 13.
- Walker J, Crotty BH, O'Brien J, Dierks MM, Lipsitz L, Safran C. Addressing the Challenges of Aging: How Elders and Their Care Partners Seek Information. *Gerontologist.* 2016 Apr 6. pii: gnw060
- Quintana Y. InfoSAGE: Use of Online Technologies for Communication and Elder Care. *Information Technology and Communications in Health (ITCH) 2017*