

Scribe: Improving Older Adults' Access to Medical Instructions from Patient-Physician Conversations

Pegah Karimi, Parishmita Bora, Aqueasha Martin-Hammond

Indiana University Purdue University Indianapolis
Indianapolis, IN, USA

{pkarimi, paribora}@iu.edu, aquamarti@iupui.edu

ABSTRACT

During doctor's visits, the medical conversations shared often contain essential instructions and tailored advice necessary for daily care, particularly among older adults who manage chronic illnesses. However, some older adult patients face barriers and accessibility challenges that limits their access to shared information. Current research to improve access to instructions provided during patient-physician conversations focuses on methods such as one-to-one sessions that can be applied during the visit but are not available after the session ends. Electronic health portals provide access to some information after the visit, but many older patients find it challenging to navigate and access information through portals. To address the limitations of existing methods, this paper introduces a prototype called Scribe that provides older patients with access to the transcripts of medical conversations associated with multiple doctors' visits. Scribe automatically creates notes from doctors' visits that contain key information to assist individuals in navigating through information. In a study with 10 older adults, we examined Scribe's perceived usefulness for improving access to medical conversations. Findings suggest Scribe's potential to help older patients better access shared information from doctors' visits as well as support their relationships with caregivers. We contribute considerations for improving older adults future access to medical instructions using similar technologies.

CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in HCI**; • **Social and professional topics** → **Seniors**.

KEYWORDS

patient-physician communication, recall, AI-assisted tools, older adults

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1 INTRODUCTION

Evan is 75 years old and lives with her husband. She was diagnosed with Type II diabetes at the age of 43 and is currently managing two other chronic illnesses including heart disease and thyroid disease. She visits her primary health-care provider once every three months and several specialists yearly to help manage her diabetes and heart disease. During the visits, her doctor usually provides important medical instructions, detailed prescriptions, and dietary advice to help keep her glucose and cholesterol numbers under control. After the visit, Evan receives printed information about her test results from the front desk. She also has the option to see the results using an online e-health portal; however, both the printouts and the e-health portal do not always include all the information provided during the visit. Therefore, Evan sometimes calls to the doctor's office to get answers to her questions, but she often has to wait for a long time to get an answer. In addition, Evan finds that managing multiple paper leaflets is time consuming and it requires her to search for a long time to find the information she needs.

Patient-physician conversations, such as the ones Evan has with her doctor, contain tailored advice and critical medical instructions that can be difficult to recall at a later time. Studies have shown that older adults experience information access issues due to technical challenges when using e-health portals [47] and encounter accessibility challenges such as difficulty hearing [7] and recalling information [25], which leads them to rely on family caregivers or to schedule additional follow ups. However, support from caregivers may not always be feasible [18].

Research on improving patient-physician communications has introduced interventions, such as audio recordings [35], cognitive methods [23], and written materials [4] that can aid recall of information shared during doctors' visits. However, while methods such as audio recordings can provide access to detailed information, they contain verbatim conversations which can make them inefficient to revisit and navigate. Cognitive methods simplify the language to improve patient-physician conversations, but they are often applied during or right after the visit and are not available once the session ends. While written materials can aid recall after a visit, managing paper notes could be inefficient and time consuming [21]. As a result, there is a gap in knowledge in how we can better support older patients' access to medical conversations during visits.

To address this gap, we developed a medium fidelity prototype called Scribe. The tool enables patients to have access to medical notes from all their doctors in one place. Each note incorporates a transcription of patient-physician conversations, a summary, and an outline of doctor's words. In this paper, we evaluate older adults' experiences using the Scribe prototype and ask them to reflect on

how Scribe compares to their current ways of managing health information from doctors' visits. We conducted a study with 10 older adult patients who interacted with the prototype through a series of five tasks. The results of our study shows that overall participants had a positive opinion of the prototype. Participants shared the advantages of the prototype compared to their current ways of managing information received from doctors' visits and highlighted how it can better support relationships with both formal and informal caregivers. Based on our findings, we discuss design considerations for improving access to medical instructions among older adults that experience different types of barriers and for better supporting interdependence in care.

2 RELATED WORK

2.1 Health Information Management among Older Adults

Information management in the health-context is identified as a potential response to illnesses with uncertainty, such as chronic or acute illnesses. In one study [33], information is defined as "*stimuli from a person's environment that contribute to his or her knowledge or beliefs*". Information management encompasses activities that involve communication and cognition, such as seeking, providing, and interpreting the stimuli [33]. Individuals with chronic illnesses often use different channels to manage their health. Some patients consult health-care providers, family members, or peers, whereas others use media and health services organizations [3]. However, managing health information via multiple resources could be time consuming and inefficient among older patients [37]. For older adults with chronic illness, managing health information can be even more challenging as chronic illnesses require additional management for all stakeholders involved in this process [22].

Among various resources, older adult patients are more likely to trust a person that they can discuss their health condition with frequently, such as their health care providers [6]. This implies that one significant aspect of managing health conditions relies on information communicated during patient-physician conversations. During a visit, physicians provide critical information, such as patient's current condition, prescriptions, assessments, and future plans that help patients to better manage their health conditions at home. However, these verbal conversations introduce accessibility challenges among older adults during and after visits.

Older adult patients face accessibility challenges including hearing impairments and recalling information as well as technical challenges when accessing e-health portals [24]. Older patients with hearing impairments often ask caregivers to accompany them for their medical visits and rely on their caregivers to collect and recall information provided during the visit [7, 38]. Alternatively, older adults might ask the doctor for the same information multiple times or to amplify their voice [27]. Older adults also often face challenges recalling information. Ward and colleagues state that as we age, we naturally see declines in our ability to recall previously learned information and establish new routines, such as new medication regimens [44]. This means that older patients may experience more difficulties recalling medical instructions from doctors' visits. Additionally, studies have shown that factors such as high amounts of information, stress, and complex medical terminologies

(e.g., name of medications) can further hinder older patients' ability to recall information after the visit [41]. While e-health portals are becoming popular for exchanging information between doctors and patients, technological challenges when using e-health portals can prevent older adults from accessing lab results and other important information provided by their doctors [24]. Moreover, studies have shown that older patients experience user interaction issues (e.g., lack of content) and usability issues (e.g., difficulty logging in), which hinders their ability to understand and navigate through portals [47].

2.2 Interventions for Recalling Information received from Doctors' Visits

The challenges patients face recalling information during doctors' visits is well-recognized in the medical community. Patient-physician communication is key for supporting patients' understanding of information as well as their role in shared decision making [20]. As such, various interventions both during and after visits exist to help patients recall information shared during their doctors' visits. Among different in-visit interventions, rehearsal [45] and cognitive methods [30] have been shown to enhance recall. Rehearsal involves asking patients to repeat information that is shared with them in real-time, and cognitive methods require physicians to simplify language and emphasize key information by reviewing it directly with the patient. Other interventions, such as visual aids [12, 42] and personalized teaching [8, 39] have shown to improve recall only in some studies. Visual aids provide patients with a video supplement or printed materials to aid with recall of the information received during the visit, and personalized teaching involves one-on-one session with the doctor or nurse to discuss health-related concerns. However, all these methods are implemented during or right after the visit and are not available at a later time. Therefore, some patients might bring caregivers during the visit in order to help collect information [18] but caregivers may not be readily available.

Interventions that help patients recall information shared during doctors' visits at a later time include paper notes [5, 13], audio recordings [15, 34], and video recordings [31]. For example, pamphlets and manual notes provided by the doctor after the visit have been used for years to provide patients with supplemental information and communicate follow-ups. However, keeping track of paper notes can be challenging, especially for patients who visit multiple doctors per year [21]. Providing patients with an audiotape after the visit has shown to help information recall among older adults [35]. In addition to audiotapes, video recordings have also been shown to enhance patients' memories and improve patient-provider communication [31]. However, both audio and video recordings often fail to condense the information in an efficient format and can be difficult to navigate due to lack of audio indexing. Alternative methods that patients might use to recall information after a visit is to call or email the doctor but getting an answer from the doctor may not always be immediate as they are usually provided for non-urgent matters [1, 17]. Online portals are an additional channel to refer to a doctor's notes and can address some challenges for efficient access of information from a visit. However, portals introduce certain barriers for older adults due to limited digital literacy or usability

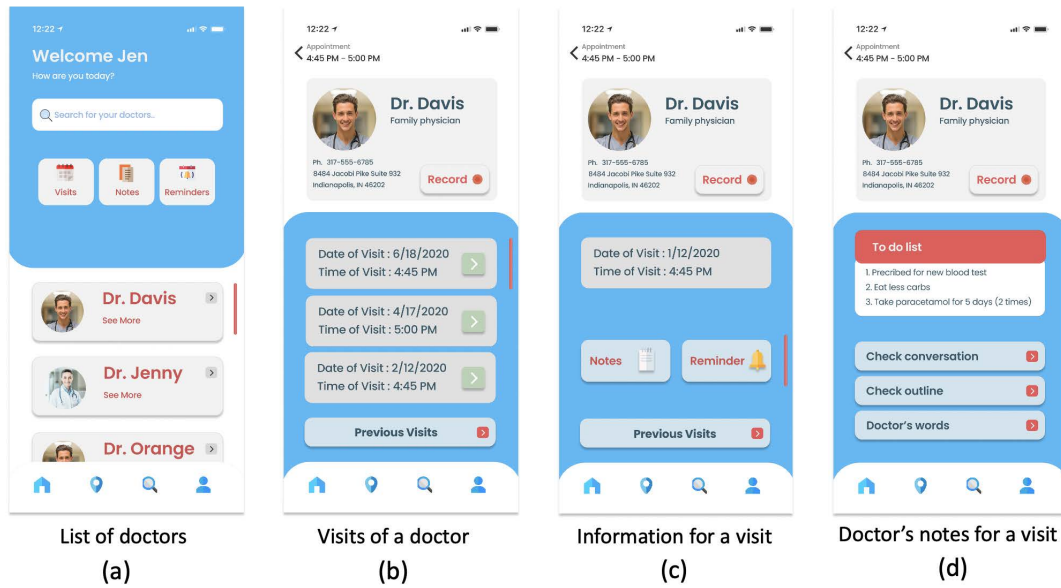


Figure 1: Scribe basic features: a user's list of doctors (a), times and dates associated with a doctor (b), doctor's notes and reminders for a particular visit (c), full conversations, an outline, and summary of doctor's words for a visit (d).

challenges they encounter [43]. Therefore, patients, specifically older patients, can find it challenging to access information from their doctors' visits.

2.3 Interactive Note-Taking Tools to Document Patient-Physician Conversations

As doctors are required to take notes during consultations, interactive tools have been developed to create encounter notes for physicians in order to document information collected and shared during visits. The aim of these interactive tools is to reduce the physician's burden when documenting patients' medical data. For example, activeNotes [46] is a prototype application created for physicians that divides and displays patient's data into two views. On the left side, the doctor can view notes that can be reviewed and edited. On the right side the doctor can view a patient's information which are results retrieved from data queries. The doctor can review and insert the retrieved data and assign them a tag to dynamically add subsequent notes to the existing ones. eNote [19] is another example of a note-taking tool designed for physicians. eNote documents semi-structured clinical notes to record patient's data over time.

With advances in artificial intelligence (AI) and speech recognition, doctors have also begun to use automatic speech recognition (ASR) technology to dictate and document their notes associated with a patient's visit. More recently, researchers have attempted to build tools that generate encounter notes based on patient-physician dialogues during a visit. These tools dictate the dialogues in real-time using ASR technology and apply Natural Language Processing (NLP) algorithms on the transcript in order to create encounter notes for the physicians automatically. For

instance, in one study, this process is used to create accurate structured data representing patients' clinical conditions based on the patient-physician conversations [26]. In 2018, Microsoft introduced a project called EmpowerMD [19], in which the system transcribes patient-physician dialogues in real-time and creates a user journey by categorizing the text into different classes. The resulting user journey starts from the beginning of the transcript and categorized it into classes such as a patient history, medication, assessment and plans. Payne and colleagues explored using voice to create inpatient progress notes that could be integrated with a electronic health record to understand if it improved physician satisfaction with taking notes [36]. These studies have therefore identified and helped us understand how interactive technologies can reduce physicians' challenges when documenting patient data during visits. However, no literature discusses the implications of these types of interactive note-taking tools to reduce patient barriers to access and manage information shared during visits.

3 SCRIBE: A NOTE-TAKING TOOL TO SUPPORT PATIENT-PHYSICIAN COMMUNICATION

To enable older adult patients access doctor's advice provided during patient-physician conversations, we developed a prototype called Scribe. The goal of the prototype is to help patients access and organize information provided during their doctors' visits. There are three main features that guide Scribe's design: 1) enabling older adult patients to have access to a full transcript of the conversation with their doctors; 2) providing users with both a summary and key sections highlighting doctor's advice; and 3) enabling users to set reminders associated with a visit. These features were prioritized based on preliminary work examining older adults' experiences

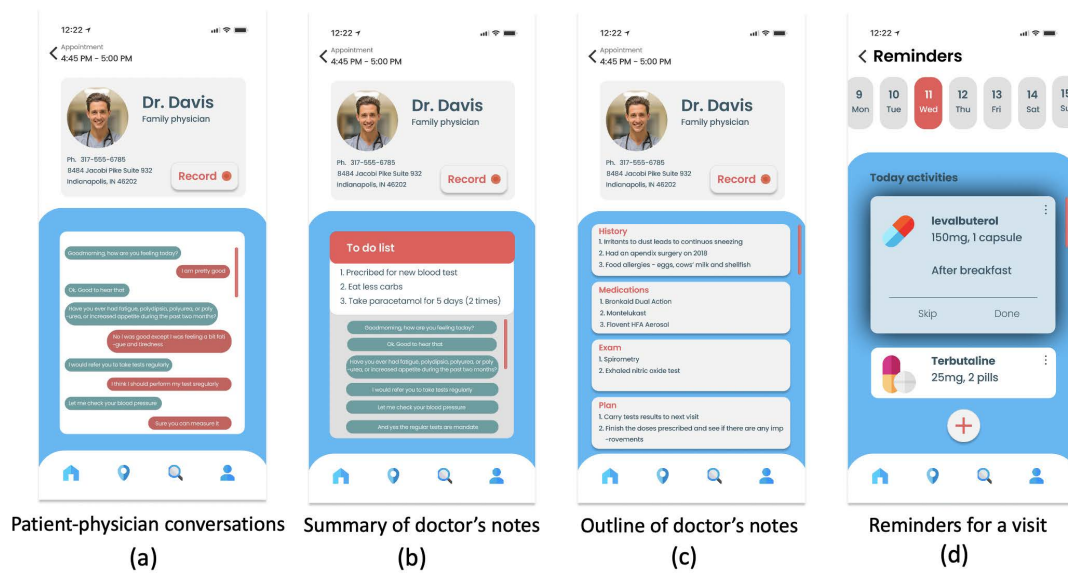


Figure 2: Scribe features that help older adults recall information shared during doctors' visits: full conversations associated with a visit (a), summary of doctor's advice for a visit (b), classification of doctor's notes into different categories (c), manual reminders for a visit (d).

and challenges gathering and organizing information from doctor's visits [24]. In this work, we shared with older adults an example of a transcribed medical conversations and asked their opinions of how the tool may or may not be useful. Findings from this preliminary work was used to guide Scribe's design.

To help patients recognize their doctors, the prototype contains the list of doctors that the patient visits regularly along with their name and a picture (Figure 1-a). When the user selects a doctor, they can see detailed information about them including their phone number and their address; users can also see the dates and times of their last three visits and the option to select previous visits (Figure 1-b). Once a user chooses a specific date, they can then see the note generated for that visit as well as to set reminders associated with that visit (Figure 1-c). Each note includes a key summary of the visit along with options to see a detailed transcript of the conversation they had with their doctor (Figure 1-d). In order to access the full conversation associated with a visit, a user must select the corresponding visit from the list and choose the 'check conversation' option. The full transcript includes the entire patient-physician conversations with the doctor's words displayed on the left and the patient's words on the right (Figure 2-a).

Furthermore, to enable users to have a quick access to critical information provided by the doctor, the prototype includes a summary of the transcript with key topics associated with that visit (Figure 2-b,c). To access these topics, a user can select 'doctor words' or 'check outline', respectively. The summary distills doctor's words into a bulleted list of to do items, whereas the outline classifies doctor's words into key categories, such as medication, exam, and plan. Based on a doctor's notes, users can also set reminders by selecting the 'reminders' button on the same page (Figure 1-c). This option allows users to set notifications for themselves for specific dates

(Figure 2-d). In order to record the conversation associated with a visit, users can select a doctor from the list and chose the option to record (Figure 1-b). Once the recording starts, users have the option to pause, continue, or save the recording.

4 METHOD

We conducted a user study to understand users' current experiences visiting their doctors and to assess the user experience and acceptance of using the Scribe prototype for collecting and reviewing medical information provided during their doctors' visits. We were especially interested in learning about the perceived usefulness of the tool for organizing the medical information in relation to participants' own experiences.

4.1 Participants

We recruited 10 older adults, age 60 and older (6 females and 4 males) living in Indianapolis, IN. The participants ages ranged from 60 to 78 years old (Avg=66.6, STD=5.44). The number of doctors and family caregivers involved in participants' health-care team ranges from 1-2 to more than 10. All participants specified that they always use smartphone. Among them, five described themselves as very familiar with smartphones and five indicated that they are familiar. More specific demographic information is listed in Table 1.

4.2 Procedure

Based on a preliminary work with older adults [24], we defined three different fictitious scenarios to capture situations in which users visit a doctor and use Scribe during and after the visit: (1)

Table 1: Demographic data

ID	Age	Number of doctor visits in the last 12 months	Chronic illness	Level of difficulty recalling information from doctor's visits	Level of difficulty navigating through online portals	Disability
P1-M	62	1 to 2 times	Hyper cholesterolemia	Somewhat easy	Somewhat difficult	No
P2-F	60	3 to 5 times	No	Somewhat easy	Somewhat difficult	No
P3-F	68	6 to 9 times	No	very easy	No use	Low vision
P4-F	65	10 or more	Hypothyroidism, arthritis vasovagal syncope	Moderately difficult	Somewhat easy	Hearing impairment
P5-F	63	6 to 9 times	Diabetic and Hypothyroidism	Moderately difficult	No use	Hearing impairment
P6-F	78	3 to 5 times	Diabetic and orthopedic surgeon	Somewhat difficult	Somewhat difficult	No
P7-M	64	6 to 9 times	Hypothyroidism and asthma	Somewhat difficult	Somewhat difficult	No
P8-M	64	3 to 5 times	Hyper cholesterolemia and high blood pressure	Somewhat easy	Somewhat easy	No
P9-M	70	3 to 5 times	Diabetic and high blood pressure	Somewhat easy	Moderately difficult	No
P10-F	72	10 or more	Type I diabetics	Very easy	Very difficult	low vision

recording notes from their conversations with the doctor, (2) reviewing the notes from a specific previous visit, (3) forgetting to take a medicine after breakfast. For the first and third scenario, we asked participants to complete one task and for the second scenario, participants were asked to complete three tasks. The tasks associated with the first and third scenario were “recording the conversation” and “checking reminders”, respectively. The tasks associated with the second scenario were “reviewing the full conversation”, “reviewing the outline”, and “reviewing doctor’s words.” Our study utilized a within-subject design where each participant completed these five tasks. The order of the three scenarios were counterbalanced in order to account for ordering effect.

Participants were first introduced to the purpose of the study, the Scribe app and its features. Then they were asked to perform a training task to ensure their ability to interact with the prototype and navigate through different parts of the tool. The entire training session took between 5 to 10 minutes. After training, participants were asked to start the tasks associated with the first scenario, and each scenario was followed by a 5 minutes break. After the last session, we asked participants to complete the technology acceptance model (TAM) questionnaire [11] related to perceived usefulness and ease of use and recorded their answers. Following the completion of the questionnaire, we asked participants a set of semi-structured interview questions. Interview questions focused on situations in which the tool might be useful, advantages and disadvantages of the tool versus current ways of managing information received from doctors’ visits, and how the tool might affect their communication with formal and informal caregivers. The answers to interview questions were audio recorded. The entire session for each participant took approximately 30 to 45 minutes. We provided each participant with a \$20 gift card as a compensation for their involvement.

5 RESULTS

In this section, we describe the result of our TAM analysis, older patients’ opinion about Scribe, and how it might influence their access to information from doctors’ visits and the relationship with their caregivers.

5.1 TAM Analysis: Perceived Usefulness and Ease of Use

We descriptively analyzed the data from participants’ responses to the TAM survey (See Tables 2 and 3). Overall, we found that participants agreed that Scribe is useful and easy to use. We did not have any participant that answered neutral or disagree for any items in the TAM survey; therefore, we have excluded those options from the tables. Most participants (70%) extremely agreed that they believed the tool could help them to accomplish tasks, such as reviewing doctors’ notes or recalling information more quickly and the majority of participants (70%) quite agree that the tool could improve their performance with similar tasks. All participants extremely agreed that the tool is useful except for one participant who slightly agreed.

Most participants (80%) extremely agreed that learning to use Scribe would be easy. However, one participant only slightly agreed that it would be easy to get Scribe to do what they want it to do, while most participants (70%) quite agreed. Moreover, the majority of participants (70%) extremely agreed that their interaction with Scribe would be clear and understandable, while 30% quite agreed. Participants either extremely agreed (80%) or quite agreed (20%) that the tool is easy to use.

Participants’ TAM responses suggest that they perceived tools such as Scribe would be useful for helping them accomplish the task of managing and recalling information from visits with their doctors. In addition, participants perceived SCRIBE as a tool that would be easy to use.

Table 2: Perceived ease of use

Survey items	Extremely agree	Quite agree	Slightly agree
Learning to use Scribe would be easy for me.	80%	20%	
I find it easy to get Scribe to do what I want it to do.	20%	70%	10%
My interaction with Scribe would be clear and understandable.	70%	30%	
I would find Scribe to be flexible to interact with.	40%	50%	10%
It would be easy for me to become skillful at using Scribe.	40%	60%	
I would find Scribe easy to use.	80%		20%

Table 3: Perceived usefulness

Survey items	Extremely agree	Quite agree	Slightly agree
Using Scribe would enable me to accomplish tasks more quickly.	70%	30%	
Using Scribe would improve my performance.	30%	70%	
Using Scribe would increase my productivity.	40%	30%	30%
Using Scribe would enhance my effectiveness.	40%	60%	
Using Scribe would make it easier to complete tasks.	40%	60%	
I would find Scribe useful.	90%		10%

5.2 Experiential Themes

We performed an open coding thematic analysis from participants' responses to interview questions to extract experiential themes regarding participating thoughts about the usefulness of Scribe. Overall, we found that participants had a positive opinion about Scribe and how a similar tool might improve their access to information from their doctors' visits. Participants also provided broad array of insights regarding their thoughts about Scribe and how it might support them which are presented below.

5.2.1 Initial thoughts about Scribe. To better understand participants mental models about Scribe and the features it provides, we asked participants to share their initial thoughts about Scribe and the features it provides. A common theme that emerged from participants' reflection on their experiences with Scribe is that they believed the tool would enable easy access to conversations with their doctors after visits. For example, P3 stated: *"it is a device that helps me to keep cheap track of my doctors' appointments and what happened during the appointments and medications that I need to take."* In a similar vein, P2 commented: *"it's a device that records all the conversations with my doctor. In addition, it takes notes from important parts of the conversation with my doctor."* This statement is in reference to Scribe's features that extract key topics and summarize the transcript of the conversation. Participants also emphasized Scribe's ability to streamline all the medical advice from different doctors in one place which is one of the goals of Scribe's design. P10 stated: *"I would say you can have access to all the information in one spot in an app...Because all the information is right there, I could even imagine for my referral situation I can go back and see what he said or how he spells that to me. So, it makes the life a lot easier, especially when you visit several doctors."* Our findings suggest that participants' mental models of what Scribe could do are aligned with our conceptual model for Scribe's design. As such,

participants had a good understanding of the system and features when addressing interview questions.

5.2.2 Enhanced organization and navigation. When reflecting on existing ways of managing information received from doctors' visits, participants mentioned that one of the main advantages of Scribe was its potential to improve organization and navigation of medical information. For instance, participants who used online portals described the usefulness of Scribe's ability to potentially organize all their medical information in one place. P8 commented: *"Everything is in one place, but you know with Mychart [a type of patient portal] every hospital has its own network and you have to use a different system for each."* Another participant P5 stated, *"if I go to a private doctor like a dentist or plastic surgeon, they are not in the network to put the information in online portals, but I can use Scribe for every doctor I visit. So, this tool can be useful for any medical conversation even with a pharmacist."* Participants who relied on paper notes to collect information received from doctors' visits also saw value in Scribe to help them better organize medical information. P8 shared that *"managing paper notes or the hard copies that the doctor gives are difficult, and this system eliminates that concern... because your phone is always in your hand and you can have access to the information faster."* Therefore, participants saw Scribe's ability to collect verbatim conversations as advantageous to minimizing some of the existing difficulties they encountered organizing and keeping track of information from doctors' visits including managing and accessing information from different mediums such as paper and electronic health records.

Participants also believed that Scribe could potentially improve their ability to navigate information from doctor's visits. P10 said, *"With online portals I have to login and sign-in all the time and scroll and try to find where those notes might be hidden on the page. But the app is more condensed and user friendly and it is easier to read notes."* Similarly, P2 commented, *"If I want to search for the information that*

I received during a visit it is a faster way to find the information related to that specific visit. With online portals I have more difficulty navigating and finding the information related to a visit." Another participant, P1, who collects data in Microsoft Word documents stated, *"it is easy for me to use Word but with this system since all the conversations are recorded it is easier to review and see what happened between me and the doctor."* For some participants, they felt that Scribe presented information in ways that could remove some of the barriers they faced searching for and finding specific information compared to online portals which they implied to be difficult to navigate. For other participants, such as those that created custom approaches for keeping up with information, they felt that their system worked but Scribe could better help them to review and recall the interactions occurred in the doctor's office.

5.2.3 Supporting Recall. Our results show that participants believed a tool such as Scribe could support recall in two different ways. First, participants shared that having access to the transcript of the doctor's conversation could improve their note taking efforts. Second, participants felt that having access to the transcript could improve their ability to create reminders. Moreover, participants described how doctors' notes could support recall in various circumstances. For instance, P6 stated, *"people like me due to age cannot memorize everything, so definitely the application is useful because after a while we can refer to the application to remember doctor's instructions and name of medications."* Additionally, P9 stated, *"Later after the visit if you get occupied with other life responsibilities and you forget some of the things the doctor said you can refer to the app."* Participants shared that it is often difficult to memorize and recall all the information shared in their visits such as medications and information they would like to refer to later. Thus, participants saw having access to transcripts of the visit they could refer to at a later time as an opportunity to remove some of the burden of having to memorize those details. When pondering specific situations where the tool could assist recall, P6 stated, *"For example, when I go to my orthopedic doctor, she says to me to use specific machines to exercise on, but I might forget the name of the machine."* Therefore, the tool can enhance recall when age-related memory problems, other life responsibilities, and complicated terminology may hinder older patients' ability to recall doctor's advice.

Moreover, participants mentioned that referring to doctors' notes can clarify any confusion that might have happened during the visit. For instance, P7 commented, *"I don't have to be in doubt of what the doctor said because the app can confirm everything."* The participants' comments suggest that in addition to helping with memory and recall, they felt Scribe could support their decision making efforts at home by helping them to confirm details regarding the doctor's instructions and assessment of their health. Participants also pointed to the reminder feature included in the tool and how it could further support recall after the visit. P9 stated, *"The reminder is the main advantage. To have somebody to remind you. It is like having a friend or a partner to tell you that it is time for this medicine or tomorrow you have an appointment at this time, especially for elderly who live alone."* Therefore participants appreciated features that allowed them to create reminders based on their doctors' notes.

5.2.4 Supporting Accessible Doctor's Visits. The result of our study indicates that Scribe also has the potential to support older

adults with various disabilities, such as hearing impairment and low vision. Participants with hearing impairments mentioned that the tool could support them both during and after doctors' visits. For example, P4 commented: *"Usually when I go to doctor due to my hearing impairment it is difficult for me to understand all the information and I have to ask the doctor to repeat what he just said but with this application I can record the conversation and after that if I didn't understand something I can come back home and read the information."* P5 also described how they felt the tool could support people with hearing impairments after the visit: *"For me reading is better than listening and this tool challenges me to read more and learn more. Because if I am hearing something, I forget about it very soon but if I read it 2 or 3 times I can see what is going on."* Both P4 and P5 self-reported a hearing impairment and therefore saw Scribe's potential to support their interactions with doctors and their engagement with the information shared once they returned home.

Participants with low vision additionally described how the tool can help them overcome accessibility barriers compared to existing ways of managing information received from doctors' visits. P10 stated, *"I know that every time I leave the hospital, they give me a big piece of paper that has all the notes and summary and everything, but I can't read all of it due to my poor vision and I have to throw it away. But with an app I can read my notes from the visit and I can refer to my visits because if it will be voice-over friendly it will be very easy to have access to all [the] information."* Another participant with low vision also described how the tool relieves the need to rely on caregivers to read the information for them. They stated, *"it could help me to be more independent. You can take care of your medications by yourself."* [P3] Therefore, older adults with low vision suggested that Scribe could additionally improve their experiences accessing paper notes shared during doctors' visits and for engaging with this information independently.

5.2.5 Supporting Relationships with Caregivers. In addition to supporting individual information tasks, participants also shared their perceptions of how Scribe might influence relationships with caregivers. When asked how Scribe might influence communication with caregivers, participants mentioned that they felt the tool could have a positive impact on their relationships with both formal and informal caregivers. Participants mentioned that they believe the tool could enhance communication with their informal caregivers (e.g., family members) by allowing them to easily share doctor's notes associated with a visit. For example, P6 commented, *"It is useful to review and show to family members what the visit was about. If they ask questions and you can't answer you can show them the transcript. And maybe after reviewing the transcript we might understand that I forgot to ask a question from the doctor."* Another participant, P7, stated, *"For older patients, we have to explain everything to our family caregivers but when I show them the information on this app, they can get accurate information."* This suggests that participants saw the app as a way to remove some of the burden of updating family caregivers about their visits and for providing a source to continuously track and share what happened during the visits. Additionally, some participants emphasized that the tool could help them to rely less on informal caregivers when they need to be supported during the visit. P5 stated, *"not always you have*

your caregivers with you during visits, so the tool helps you to be more independent and rely less on your caregivers.” Therefore, in addition to sharing information with caregivers, some participants saw Scribe as a tool to help them be more independent.

When discussing how the tool might influence the relationship with formal caregivers, participants pointed to enhancing communication, enabling trust, and saving time. P8 commented on how the tool could help their communication with the doctor before the visit, *“You are more ready to ask questions in your upcoming visits with your doctor. Also, it would make the communication with your doctor more clear because you know what you want to ask...what has been talked about.”* Similarly, P4 stated, *“I think this way I can have a note to ask the doctor if I have any questions or problems. For example, I can show in the app that this medication that you mentioned is not working for me what do you suggest.”* Some participants therefore saw Scribe as a way to enhance their interactions with doctors by helping them prepare for visit and more clearly communicate questions and concerns.

Participants also described how Scribe can help them be more efficient during doctors’ visits. P2 said, *“During the visit, I can focus on what the doctor says about my situation without being worried to memorize everything.”* In addition, P7 commented, *“During the visit I don’t have to ask the doctor to repeat some information and later, when I get home, I can refer to the app.”* This implies that Scribe could partially relieve the need to commit to memory information provided during the visit, allowing patients to focus on their conversations with their doctors. Another advantage participants mentioned was saving time after the visit. P9 stated, *“If I forget some information, it is useful because it saves time both for me and the doctor as I can refer to the app instead of calling the doctor again.”*

Finally, participants emphasized enabling trust as another area where a tool such as Scribe might enhance their relationships with their formal caregivers. For instance, P6 stated, *“Because sometimes we as older adults forget the things that doctors told us and we forget to do what we were told to do and so with this app your doctors are confident that what they told you is written there.”* Another participant, P3, shared a similar opinion, *“I think they [my doctors] would be impressed with something like that [Scribe] and also, maybe feel confident that I could use this tool and I didn’t make a mess with my medications.”* Thus, in addition to individual support, participants also envisioned ways in which tools such as Scribe might support their relationships with those involved in their care.

5.2.6 Envisioned Use in Additional Scenarios. Participants described additional scenarios in which they felt Scribe could be useful for them. Potential uses included in follow up visits, lengthy visits, complex medical conditions, and taking personal notes. For instance, P1 commented, *“it helps to save money because if I use other ways to communicate with the doctor after a visit, I have to pay more to go by car to the doctor or call.”* This implies that the tool could benefit users by helping them avoid extra costs associated with follow up trips or phone calls to their doctor. P7 emphasized the potential usefulness of the tool when visits are long and information-heavy: *“For visits that are very lengthy the tool is very useful because I can refer to it throughout the year in order to remind myself of the advice that I got from the doctor.”* Participants who were not visiting the doctor regularly during the past year mentioned that the tool could

also benefit them in the future if their condition requires more regular visits to multiple doctors. For instance, P3 stated, *“It might be useful if by chance I lived alone and also if my medical conditions change and worsen to the point where I take a lot of medications and have multiple doctor’s appointments.”* Participants who take notes during or after visits also felt Scribe might be easier to use than their personal note-taking tools, such as papers or calendars. When compared with taking notes using their calendar, P4 commented, *“It [Scribe] would be faster and easier to use. Also, the recording feature is very good.”* These findings suggest that beyond the description of Scribe’s main uses, participants felt that Scribe had many more potential opportunities to assist older adults with information tasks.

5.2.7 Envisioned Future Improvements. Findings suggest that participants saw Scribe as useful for organizing information in one place and improving access to information shared from their visits. However, some participants also discussed how Scribe could be improved to better aid their search for information within the transcripts. While Scribe included several features to highlight key information from transcripts through extracted summary notes and bullets, participants suggested additional features to enhance their ability to search for information independently. For example, one participant mentioned a desire for a chat bot that would allow them to ask medical questions and respond based on the doctors’ notes as well as the ability to connect directly with their health-care providers. Another participant suggested including visualizations or a dashboard that allowed easier access and interpretation of lab results. Participants with low-vision shared that it would also be necessary for Scribe to integrate additional accessibility features to help them navigate the device in addition to the current features. While participants with low vision could interact with the prototype using their magnifiers in the study, they still mentioned that adding the voice-over feature could be more useful and allow faster navigation through information. Participants also suggested including the ability to increase and decrease the font size to adapt it to varied preferences.

In addition to aiding navigation, participants discussed the need for features to ensure the transcripts’ privacy and accuracy. Participants shared that it would be essential for any tool that stores personal health information to be secure and have proper access control. Several participants felt it would be vital for them to ensure that only those they approve (i.e., doctor) would have access to their doctors’ notes. Participants also noted that the accuracy of the transcript would be crucial for genuinely making the tool useful to improve access as well as support their decisions.

6 DISCUSSION AND LIMITATIONS

For some older adults who manage multiple chronic illnesses, recalling, organizing, and navigating information from doctor’s visits can be challenging. These challenges are increased for those that have low vision or hearing impairments. Our findings suggest that participants believed the Scribe prototype and its features could better support older patients in accessing information shared during doctors’ visits and enhance their relationship with their caregivers. This aligns with prior work that suggests patients see the ability to record their encounters as beneficial for health management tasks at home [14]. However, our findings also indicate that similar

to physicians [32], to further improve older adults' experiences, we must also consider features that improve patients' workflows when conducting information task individually and with caregivers. Below, we discuss potential design implications for tools such as Scribe based on our findings.

6.1 Considerations for Addressing Stratified Information Access Barriers

Our findings are aligned with healthcare and accessibility literature that suggests older adults can experience information access issues due to hearing impairments [7] in doctor's visits or technical and usability challenges when using e-health portals to access information at a later time [47]. Therefore, our findings suggest the need to consider how to address different types of access barriers to medical information shared during doctors' visits in our design. Figure 3 summarizes the types of access barriers shared by our participants. We note that while access is a challenge more broadly, each participant shared different types of access barriers. Some of our participants used online health portals to help them revisit information from doctor's visits. However, they admitted that this process could be challenging because the portal often did not include information from multiple doctors and hospitals tended to use different systems. Other participants used paper notes and pamphlets to recall information from their doctors' visits, but they faced other challenges such as difficulty finding specific information associated with a visit. The use of paper notes was particularly challenging for people with low vision as they mentioned they would need to rely on a caregiver to find and read the information for them. Some participants relied on their memory to recall information and faced challenges remembering what was shared. Therefore, our findings emphasize that participants believe it is vital to access medical instructions from their doctors. Still, it is not always easy to access that information. Participants thus viewed our approach of providing individuals with direct access to transcripts of patient-physician conversations as useful for eliminating some of the barriers they encounter and providing a way to access information in one place easily.

We know that this type of technology is being used by physicians [32], so it is technically feasible to provide patients with access to information talked about during their doctors' visits. However, while participants felt Scribe could address access and accessibility barriers of gathering, recalling, and organizing information from doctors, other access barriers emerged. First, findings suggest that in addition to making the transcript available, we also need to consider ways of helping participants easily search and find the specific types of information they need. For example, one participant shared the idea of including a chat feature for this purpose. Participants with low vision suggested additional accessibility features that could improve search within the app. These findings indicate that access to the transcript alone may not be sufficient. While providing features to assist with automatically transcribing conversations are perceived to address some challenges related to gathering, recalling, and organizing data, new potential challenges emerge and other concerns about accessibility and digital literacy take on new forms. Therefore, we need to consider how to support

users with navigating information in the app as well. Second, findings indicate the need to consider ways to help participants quickly interpret and synthesize information, including features such as dashboards or providing easy follow up with their providers (See Figure 4). Scribe included some of these features, including bullets and summaries automatically extracted from the text. However, our findings suggest that in the future, we as designers need to consider more closely the types of organization, navigation, and interpretation aids that support users' access needs within the app.

In addition to access barriers related to navigating and interpreting information, participants also discussed the need to ensure information was secure with appropriate data access. Therefore, including features to allow participants to manage their data in ways they see fit will be crucial to the potential adoption of the tool. However, our findings suggest that understanding access will likely extend beyond providing binary controls (e.g., share data or not) to more broadly understanding the relationship dynamic between older adults and their caregivers and how this influences the design of control features.

6.2 Considerations for Supporting Interdependence in Care

Findings suggest that the tool could improve older patients' relationships with their caregivers and help them be more independent. It is well known in healthcare literature that formal and informal caregivers can play a crucial role in helping older adults manage information tasks related to their daily health management [16]. As such informal caregivers often face burdens to their health while providing care [28]. Our findings are aligned with prior work that suggests older adults see value in intelligent assistant that can support caregiver relationships [29]. There are tools that have examined how to improve communication between an individual and their informal caregivers [48]. However, our findings suggest a



Figure 3: Summary of access barriers participants encountered accessing information from doctor's visits.

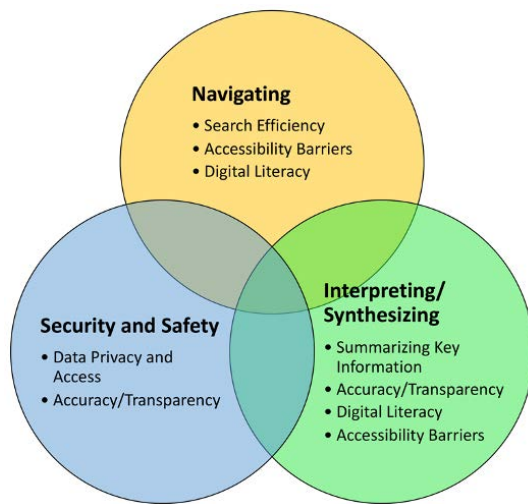


Figure 4: Summary of potential open access barriers after the introduction of tools similar to Scribe.

need to further consider the role of interdependence in caregiving relationships [2] when designing tools such as Scribe. Our findings highlight the need to examine participants' desires for formal and informal caregivers to be involved in the information tasks they complete at home. Participants with and without disabilities described different ways; both formal and informal caregivers helped them with information tasks. Several participants discussed that they viewed Scribe's ability to automatically collect information from their doctors' visits as advantageous because it enabled them to share this information with family caregivers. Findings suggest that in addition to supporting older adults' information tasks, we also need to understand better and consider how informal caregivers are involved in managing and interpreting information from doctors' visits.

Similarly, participants brought up concerns about the privacy and accuracy of health data. For example, one participant mentioned their desire for their doctor to be the only one with access to their information. Other participants suggested features to be able to contact the doctor directly. Like other adult caregiver relationships [10], the relationship dynamics among older adults and caregivers can vary. It would be useful to consider how power dynamics, necessity, and other factors impact relationships between older adults and their caregivers and their influence on older adults' data privacy preferences. For example, for those who appreciate informal caregiver involvement in informational tasks, what features might support this dynamic, and how do they differ from those who prefer no involvement? For older adults with disabilities that rely on informal caregivers for support, does introducing a tool such as Scribe change the relationship dynamic for better or worse, and how might we account for these changes through design? While our study does not provide direct insight into addressing these open issues, it does suggest a need to further explore these topics given participants' recurring discussion of caregivers' roles.

Participants also mentioned concerns about accuracy of the transcript. One potential approach to address these concerns is to include doctors in this process to verify the accuracy of the transcripts. However, given evidence that doctors spend quite a bit of time on clerical tasks such as summarizing and updating electronic resources and therefore have low satisfaction with such systems [40], it might be useful to understand their perceptions for ensuring content accuracy. By doing so, we can better understand if there are ways to automate corrections or, on the other hand, provide better transparency so users can identify issues easily and make better decisions about acting on the information. It will also be important to gauge physicians and other healthcare providers' potential involvement in the task and how that might be translated to features that improve transparency and decision making regarding a transcript. For example, we suggest identifying the strengths and limitations of the proposed design ideas to obtain insights about how doctor's intentions within medical instructions are preserved and to advance the design principles related to intelligent note-taking tools.

6.3 Limitations

One limitation of our current study design is the number of participants. Although we were able to reach saturation [9] of our themes with 10 participants, future work will involve more participants, including other stakeholders such as doctors or informal caregivers to better understand the implications of such a tool on their work and relationships with patients. In addition, we will involve more older patients with disabilities to further explore accessibility needs while interacting with the tool. Moreover, while TAM is a validated tool to capture perceived usefulness and ease of use, we acknowledge that TAM mainly phrases questions positively, which might create bias. Future work will include examining other aspects of usability other than TAM to provide a more balanced view of benefits and concerns.

7 CONCLUSION

This paper presents a prototype called Scribe to aid older patients review their conversations with their doctors at a later time. The tool enables access to patient-physician conversations, a summary, and an outline of doctors' words in one place. Patients' can review the transcript and the notes associated with a visit and set reminders. The findings demonstrate that Scribe can support older adults to recall, navigate, and access information shared during doctors' visits. Moreover, it enhances the relationship with both formal and informal caregivers by allowing them to be more independent and save time for additional follow ups. In the future, we plan to explore more of these ideas with both formal and informal caregivers to better understand how technology such as Scribe might support or hinder older adults' relationships with their caregivers and how to support caregivers through the design.

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