

A case for "little English" in Nurse Notes from the Telehealth Intervention Program for Seniors: Implications for Future Design and Research

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ABSTRACT

Community telehealth programs (CTPs) enable low-income older adults to receive telehealth services in community settings (e.g., retirement homes). The Telehealth Intervention Program for Seniors (TIPS) is a CTP that provides vital sign monitoring services managed by remote nurses. TIPS has successfully recruited and retained Limited English Proficient (LEP) participants, but lack of language services might hinder LEP participants' equitable access to care. We conducted a two-part mixed-methods study. We first qualitatively analyzed 40 nurse notes to identify challenges nurses encounter gathering information due to language barriers and the workarounds they employed to address these. We then tested our qualitative findings on 23,975 nurse notes to quantify and compare how these challenges and workarounds scale between LEP and English-proficient TIPS participants. We present future research implications beyond low-hanging solutions, such as automated translation services, and discuss how novel technological solutions can support and ameliorate nurse workarounds and caregiver burden.

CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in HCI**.

KEYWORDS

older adult, telehealth, community health, remote patient monitoring, information gathering, language barrier

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1 INTRODUCTION

Telehealth is defined as the use of electronic and telecommunication technologies to provide and support health care when distance separates providers and patients [66]. Telehealth used in community settings (e.g., retirement homes, congregated housing, senior community centers), known as community-based telehealth programs (CTPs), can increase healthcare access equity by bringing telehealth services to individuals with limited technical literacy and other resources, such as transportation [17, 23]. CTPs, as an instantiation of community health, have great potential to deliver health programs to underserved individuals in community settings globally. We use the following definition and framing of community health offered by Goodman et al. [34]: "*Community health is a multi-sector and multi-disciplinary collaborative enterprise that uses public health science, evidence-based strategies, and other approaches to engage and work with communities, in a culturally appropriate manner, to optimize the health and quality of life of all persons who live, work, or are otherwise active in a defined community or communities.*". Community health serves an important function in our healthcare system as a way to provide culturally competent, comprehensive primary care that is accessible to all patients, especially for those who would prefer non-English services [77]. For example, individuals with limited English proficiency (LEP) in the United States can experience structural barriers to accessing and utilizing healthcare services, resulting in worse health outcomes [69]. Community health can help bridge this gap in healthcare access for LEP patients.



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While there is limited research on CTP utilization among LEP older adults, the CHI and CSCW community has explored the use of technology in community health settings [22, 24, 28, 32, 49, 52, 62, 92, 93]. These studies highlight the importance of community health workers (CHWs) and nurses (CHNs) in these healthcare systems who act as infomediaries by gathering and disseminating health information [41]. There is also a growing interest in understanding how technology can support individuals who experience language barriers in healthcare settings [1, 91] and in translation support more generally [8, 12, 36, 45, 56, 97]. However, little research has examined how to address LEP populations' challenges in healthcare access beyond translation, such as the lack of information access and communication challenges that lead to an overall burden in accessing healthcare and over-reliance on unpaid caregiver support (e.g., family and/or caregivers).

To examine this gap, in this paper, we present a mixed methods study of the Telehealth Intervention Program for Seniors (TIPS), a community telehealth program that has served over 2,000 older adult participants since 2014. Participants are predominantly 55+ low-income older adults enrolled in Medicare and/or Medicaid in community sites across five states on the East Coast of the United States: New York, New Jersey, Connecticut, Pennsylvania, and Maryland. TIPS monitors participants' vital signs and triggers alerts when vital signs fall out of a pre-defined clinical range. Remote nursing staff respond to incoming alerts by following up with participants and then documenting the details and outcome of the follow-up in a note attached to the incoming alert.

The nurse notes are rich data that captures how nurses gathered information and interacted with participants and potentially their family members related to incoming alerts. Nursing documentation can provide a more holistic picture of the patient's health status as well as care plans in coordination with family and caregivers [78, 81] and can be leveraged for future research efforts [30]. Our aim was to understand how nurses gather information and what challenges they experience trying to complete their alert response protocols as part of their vital sign monitoring workflow, particularly when a language barrier is present. Therefore, we sought to address the following research questions related to nurses addressing LEP participants' alerts in TIPS:

- RQ1 *What challenges do nurses encounter in information gathering and instruction delivery with LEP participants in TIPS*
- RQ2 *What workarounds do these nurses perform to address the challenges?*
- RQ3 *What is the scale of the observed challenges of information gathering and instruction delivery among LEP participants?*

Data on LEP populations' use of CTPs, is rare as they are less likely to utilize these services [74]. By investigating the specific case of TIPS, we contribute to the following novel research directions:

- Identification of challenges the nurses experienced and the workarounds they employed related to establishing contact and gathering information for LEP participants compared to their EP counterparts
- Recognition there may be an over-reliance on caregivers to take on translation and symptom discussion tasks with TIPS nurses and the potential to scale the other workarounds the nurses have already employed

- Implications for technological improvements to CTPs and other similar healthcare delivery systems regarding communication among nurses, LEP participants, and their families/caregivers.

2 THE TELEHEALTH INTERVENTION PROGRAM FOR SENIORS (TIPS)

2.1 Overview of the Telehealth Intervention Program for Seniors (TIPS)

TIPS offers vital signs monitoring for physical health, wrap-around services, and education for seniors to provide quality care and support their independence. There are over twenty-five established sites in common places where seniors convene, such as retirement homes or community centers where participants can go in person. The program employs trained technical assistants, typically student volunteers, who work on-site with the participating seniors to collect their vital signs and nurses who are located remotely to monitor and respond to abnormal vital sign readings that trigger alerts.

The senior participants cite many benefits of the program, such as independence to self-monitor their health and improved socialization when visiting TIPS in person [99]. Earlier research on TIPS has found that participants have reported fewer hospitalizations over time [37] and had a higher likelihood of retention, especially among female participants with limited English proficiency [79].

2.2 Vital Sign Monitoring Workflow

The overall vital sign monitoring workflow of how TIPS operates is illustrated in Figure 1 below. During their first visit, participants complete an initial intake form that collects their demographic information (e.g., age, sex, language preference), history of chronic conditions (e.g., hypertension, diabetes), and hospitalizations before enrollment. During each subsequent visit, participants have their vital signs (blood pressure, pulse oximetry, and weight) measured by the on-site trained technical assistants. Participants also fill out a questionnaire about changes in medication, mood, and falls/hospitalizations. Vital sign and questionnaire data are collected, saved, and uploaded after each visit.

The remote nurses monitor the incoming vital signs and questionnaire data in their web portal. They are assigned alert tasks if any alerts meet pre-defined clinical range limits (e.g., Systolic blood pressure exceeds 170mmHg). Nurses evaluate alerts and may dismiss them (e.g., due to technical error), continue monitoring, or follow up with the participant to complete an alert response protocol. The alert response protocol comprises reviewing the participant's vital sign history before reaching out, calling the participant by phone to conduct a medical assessment in which they inquire whether participants are experiencing any symptoms related to the alert, and providing care instructions or resources to address the alert or other health concerns that are mentioned in the conversation. Nurses document the following information from the alert response protocol in a nurse note: the conversation details, instruction delivery, participant's feedback, and any additional next steps in a note attached to the alert.

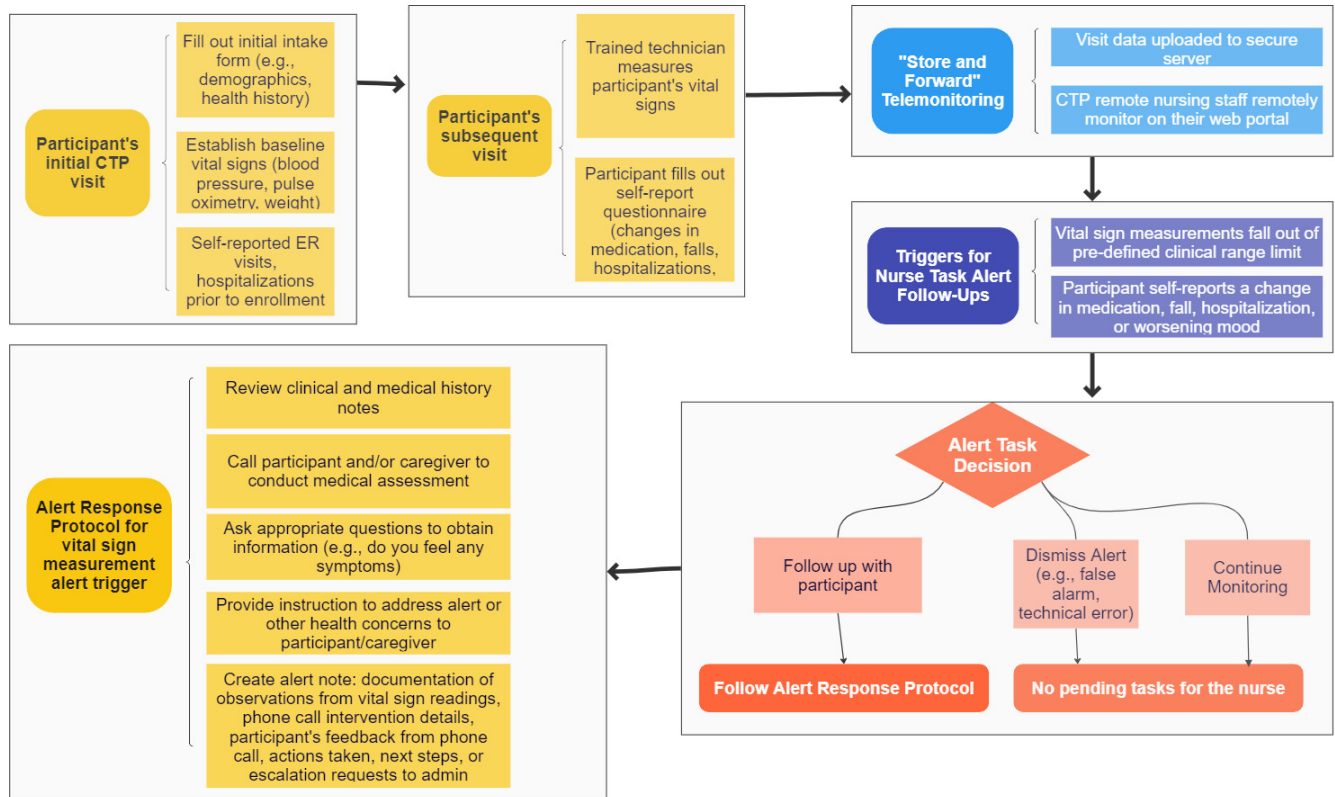


Figure 1: Overview of the TIPS workflow from participant's initial visit to nurses' alert response protocol

3 RELATED WORK

3.1 Supporting Community Health Workers (CHWs) and Nurses (CHNs)

3.1.1 *Understanding the roles and responsibilities of CHWs and CHNs.* Community health workers (CHWs) and community health nurses (CHNs) are on the frontline of providing community health services. They take on diverse responsibilities such as delivering healthcare through disease prevention and management, promoting health and well-being through public education initiatives, collection and maintenance of data records, and acting as a bridge to the communities they are serving [48, 82, 95].

Previous CHI research has examined the roles and responsibilities of CHWs and CHNs in supporting community health initiatives. Studies have found that they are uniquely positioned due to their situated knowledge to act as "infomediaries" or individuals who provide health and wellness information and decision support [41]. This enables them to address the disconnects present in community health stakeholders between healthcare providers, community health workers, and patient groups. CHWs also take on "invisibilized" work, including maintaining community health infrastructure (e.g., maintaining an in-depth understanding of the sociocultural context, local needs, everyday knowledge, practices, and environments) [93].

The CHI community has provided helpful descriptions of the work that CHWs and CHNs take on in their community health

work, which provides helpful context for us to understand the responsibilities related to information gathering and communication the remote nurses of TIPS take on, particularly for their work with LEP participants.

3.1.2 *How CHWs leverage technology to enable their work.* Previous work has also studied how CHWs and CHNs use information and communication technologies to do their work. They have leveraged mobile health technologies, multimedia (e.g., video), and social media to disseminate information to promote health and wellness practices globally [28, 42, 49, 62, 92]. They have also used information and communication technologies to set up secure environments to enable patient and provider interactions [28, 50]. Other studies have shown increased use of technology to track CHW's performance and feedback [24, 25, 32, 94], and support education and training initiatives [5, 21, 40].

There has been limited work specifically examining the challenges CHWs and CHNs experience when leveraging technology in their "infomediary" or information-gathering role or how they have found and leveraged alternative solutions to achieve their work goals. We aimed to build on this growing focus from the CHI community to find appropriate technology interventions to support CHWs and CHNs in their public health initiatives.

3.2 Mediating Communications between Providers and LEP patients

3.2.1 Limited healthcare access for LEP patients in the US. LEP patients in the United States can experience structural barriers to accessing and utilizing healthcare services. LEP patients were less likely to have a usual place to go when sick other than the ER or have access to preventive care [35, 69]. They also were more likely to report having low health literacy impacting healthcare information communication and understanding [53, 96]. Previous studies identified several challenges related to healthcare communication and coordination. For example, while patients needed professional language translators [85, 89], they often had to rely on ad-hoc translators (e.g., family or caregivers) who could not always adequately translate the provider's care instructions or experienced privacy violations [96]. LEP patients were more likely to report worse health outcomes, such as impaired healthcare decision-making [2] and poorer disease management [69].

3.2.2 Use of technology to address language barriers. Technologies to support LEP patients in healthcare contexts. There has been an increased focus on how technology can help to address many of these concerns, such as coordinating care through language-appropriate appointment reminders [64], chronic disease self-management [55, 60], multilingual offerings of patient-facing interfaces [91], mental and behavioral treatment and support [20], and interpretations services for nurses [61].

Addressing language barrier-related challenges at CHI. The CHI community has also studied how HCI research and techniques can be leveraged when designing multilingual or translation systems in health contexts. Previous work includes technology needs assessment for mobile translation [52, 57], usability challenges [83], and design and evaluation methodologies [15, 87]. CHI researchers have also proposed using personal health informatics to supplement patient-provider communications [13, 14]. While these solutions show significant promise, there remain barriers to successful implementation for the primarily low-income, older adult LEP population, which may be due to cost, lack of access, or readiness to use the technology [27, 33, 51, 55, 58].

3.3 Addressing Caregiver Burden

3.3.1 Understanding challenges caregivers experience in their caregiving work. Family (or informal) caregivers have a significant role in caring for LEP patients. Caregivers for LEP patients often go beyond traditional caregiving tasks, so in addition to assisting with daily living and coordinating care, they often take on communication and translation with medical providers, filling out forms and documentation, and helping with medical decisions [84]. Caregiver burden is an important topic to address since caregivers of LEP participants have reported taking on more time- and labor-intensive caregiving work [75] and have reported higher levels of stress [84]. The CHI and CSCW community has done extensive work examining the challenges related to caregiver burden and how technology can support caregivers. Previous HCI research has examined the factors contributing to challenges caregivers experience. Interview studies have found that caregivers take on significant work related to coordinating and managing the care of their care

recipient, including handling communications, scheduling, finding care resources, and maintaining relationships between the caregiver, care recipient, their care team, and loved ones [80]. They also contribute directly and indirectly to the healthcare delivery of their care recipients by consulting with doctors to present their care recipients' medical history and medication adherence, participate in medical decision-making, and take on a lot of the medical care at home when necessary [4]. Caregiver burden and challenges can be exacerbated by the caregiver's age, education level, family and support system size, average daily care, and their own language proficiency status duration [9, 84].

3.3.2 Role of technology to mitigate caregiver burden. CHI researchers have also studied the role of technology and design in supporting caregivers, such as understanding their journey to establish new mindsets, adopting more mindful activities to alleviate stress, making them more aware and supporting their physical and emotional selves, encouraging meaningful social interactions among caregivers for strengthening social ties, and supporting the emotion work in caregiving [6, 11, 86, 88].

Despite the promise of these solutions to alleviate the caregiving burden, studies have shown there may be an over-reliance on caregivers altogether [63]. Limited CHI research has examined the need to give respite to caregivers, such as through the use of professional respite caregivers or identifying alternative care resources to take a break [19, 90].

Our work builds upon previous research by examining and quantifying the potential over-reliance on caregivers for LEP participants compared to their English-speaking counterparts. We also identified other workarounds adopted by the TIPS remote nurses for information-gathering and communication tasks in their workflow. While caregivers will remain important in caring for LEP patients, these alternatives are important to empower TIPS remote nurses to address participants' health concerns even when caregivers are unavailable or to find alternative ways to reduce caregiver burden. By understanding a case of nurses' stated challenges in language barriers, our study provides potential implications to the challenges CTPs and their associated healthcare workers and caregivers might experience in exchanging information and effective delivery of care in supporting LEP patients.

4 METHODS

4.1 Data Collection and Processing

4.1.1 Overview of the Data. TIPS supplied data records of program activity from 2014-2019. The dataset comprised four components: (1) participants' baseline demographic (age, sex, and language preference) and history of chronic conditions (e.g., hypertension, diabetes), (2) their vital sign readings (blood pressure, pulse oximetry, and weight), (3) the triggered alerts due to being out of pre-defined clinical ranges, and (4) nurse notes: remote nurses' response notes associated with each alert. Because these data are de-identified data that contain participants' vital and self-reported data, this research was approved as exempt by our university's IRB.

4.1.2 Participant Exclusion Criteria. The dataset consists of N = 2,778 participants enrolled in TIPS and active between May 2015 and October 2019, who triggered 24,934 alerts. Due to our focus

on nurse notes responding to alerts, we only included participants with at least one alert and corresponding response from a nurse in their program history resulting in 1,290 participants who triggered 23,832 alerts. We further excluded participants with missing demographic information in their intake forms since we wanted to focus on participants who have reported their language proficiency. As a result, $n=1,208$ participants with 20,476 unique alerts were included in our analysis, representing 43% of participants and 86% of alerts. This corresponds to 23,975 nurse notes, with some alerts having multiple associated notes. We will only describe the total participants and nurse note counts when describing the data sample throughout the manuscript.

4.1.3 Summary of Participants in the Data. Our data consists of 1,208 participants, of which 23% of participants were LEP and 77% were EP participants (See Appendix Table 1 for full information). Both LEP and EP participants were predominantly over 60 years old, female, and had a history of chronic conditions. Although their demographic profiles were similar, LEP participants had disproportionately fewer nurse notes relative to their population proportion (23% population vs. 19% notes).

4.2 Qualitative Analysis: Nurse notes that mention a language barrier

4.2.1 Nurse note Inclusion Criteria. We qualitatively analyzed notes that mentioned there was a language barrier in the interaction with the participant to identify compelling and relevant themes related to how nurses gather information and the challenges they experience.

We defined the following filtering criteria to help us prioritize which notes to focus on for qualitative content analysis: (1) The participant associated with the notes has indicated their preferred language is not English in their initial intake form; (2) The note contained at least one of the following keywords to indicate there was a language barrier: "language barrier", "little English", "unable/couldn't/not speak English", "Spanish", "translate", and "interpret". (3) The triggered alert was deemed "high risk" according to TIPS. Alerts were classified as high-risk if they were triggered by blood pressure or pulse oximetry vital sign readings, while alerts triggered from weight readings were designated as lower risk. We focused on the remote nurses' priority alert tasks to understand whether there were specific challenges and workarounds for LEP participants.

A hundred total notes remained after applying the filtering criteria. After removing duplicates, we were left with 40 unique notes. Duplicate notes occurred if a participant triggered multiple alerts during a single visit. Nurses typically consolidated responses to each alert in one message and pasted that message into each individual alert in their web portal or had common responses to similar types of alerts that would not result in distinct thematic concepts for analysis. The 40 unique notes corresponded to 30 unique participants. This sample of participants had a similar demographic profile as the overall data, with a majority of them over 60 years old, female, and with a history of chronic conditions.

4.2.2 Grounded Theory Analysis. Guided by a grounded theory approach [16], two authors conducted a joint open coding session on the first 10% of the notes data. They iteratively reviewed and

incorporated feedback from the other authors until alignment was reached. The first two authors then open-coded the remaining notes. Afterward, three of the authors applied affinity diagramming in which we grouped open codes by common themes to form axial codes [3]. We compared and contrasted themes against our current knowledge of the TIPS workflow outlined in section 2.2 to form our selective codes and derive our working theories according to what the nurses documented in the notes. The results informed salient themes and elements in the nurse notes for answering RQ1 and RQ2.

4.3 Quantitative Analysis: Chi-Square analysis to quantify Nurse Note Content Differences by Language Proficiency

Since our sample of nurse notes for the qualitative analysis was relatively small (40 notes), we wanted to observe how these challenges and workarounds may scale in a larger sample. Therefore, we analyzed and compared the nurse note content by participant's language proficiency over the total 23,975 eligible nurse notes in TIPS.

4.3.1 Applying a codebook to the nurse notes. Codebook Selection. To systematically determine the content of the nurse notes, we applied the codebook developed by Nguyen et al. [67] to classify the content of the nurse notes in TIPS. We selected this codebook as it was trained on the same nurse note data from TIPS to provide a scalable approach to classify and describe the content of nurse notes. We leveraged their existing classifications related to nurses' workflow, including alert task decisions and alert response protocol, as illustrated in Figure 1. The codebook consists of 17 nurse note content codes and the most common regular expression-based keywords to identify which codes apply to a given note.

Mapping the codebook to the qualitative themes. 5 of the 17 codes could be mapped back to the codes and themes identified in our qualitative analysis of the remote nurses' challenges and workarounds related to information gathering and alert response for LEP participants in which a language barrier was present. We observed some codes in the codebook that were not applicable and qualitative themes that were not present in the codebook. This was likely due to the codebook being trained on the entire population without factoring in differences in nurse notes according to participants' language proficiency. Despite these differences, we determined the codebook was still relevant to our goals of analyzing the frequency of the qualitative themes between EP and LEP participants, given the codebook was still based on the same TIPS nurse note data and adequately described the nurses's alert task decisions and response protocol.

Table 1 below provides definitions of nurse note content codes from the codebook, example notes, and how they map to our qualitative themes and subject areas regarding nurses' challenges and workarounds.

4.3.2 Chi Square Analysis. We conducted a chi-square analysis to compare the frequency of nurse note content codes between LEP and EP participants. A chi-square analysis is a robust statistical testing methodology best suited to examine differences in thematic

content frequencies in nurse notes by participants' language proficiency. This analysis would inform how the qualitative themes scaled in a larger sample and examine the prevalence of these challenges among the LEP participant population compared to their EP counterparts within the context of the larger sample of nurse notes present in TIPS.

Data and Analysis Setup. We applied the regular-expression keywords curated by Nguyen et al. to determine which of the 5 codes applied to each nurse note. Nurse notes could contain multiple code concepts. So, we flagged the presence or absence of each code for a given nurse note and used that to calculate a contingency table for each code that broke down the number of nurse notes with the presence or absence of that code delineated by the participant language proficiency status. Note that unlike the qualitative analysis, we did not remove duplicate notes in this chi-square analysis because we wanted to include the full volume of nurse notes to assess the scalability of observed content themes, and we could not clearly discern the reason for duplicates at a larger scale in the complete TIPS dataset.

Statistical Testing. We leveraged the chi-square statistical test implementation in Base R to conduct our hypothesis testing. The inputs were the contingency tables, referred to as "observed counts." Base R's chi-square test function then computed the "expected counts," or projected frequencies of each cell in the contingency table, if the null hypothesis were true. In this case, the null hypothesis is there is no difference in nurse note counts for each code between LEP and EP participants. The alternative hypothesis is that there is a difference in the number of nurse notes for each code between the two participant groups. The expected counts are based on what proportion of the population is LEP or EP. Then, the R function computes the chi-square statistic and p-value.

Statistical Analysis Interpretation. We first examined the chi-square statistic and p-value to determine whether there was a statistically significant difference in the observed and expected nurse note counts for LEP vs. EP participants for each code that corresponded to our qualitative theme, based on an $\alpha = 0.05$. If there was a significant difference, we then compared the observed vs. expected nurse note counts of the LEP population to determine in which direction the observed counts of nurse note content codes deviated from the expected distributions. If the observed count was higher for LEP participants, we concluded the nurse note content was more prominent among LEP participants, indicating how much the challenges or workarounds observed in the qualitative analysis scaled within TIPS.

5 RESULTS

In this section, we first report how nurses encountered challenges with information gathering with LEP participants due to language barriers (RQ1) and how they worked around those challenges (RQ2). We then investigate the prevalence of the problem to gain insights for future implications (RQ3).

5.1 Challenges with Information Gathering and Instruction with LEP Participants (RQ1)

5.1.1 The inability to establish contact with participant. Nurses could not effectively address alerts if they could not establish contact with the participants. In their notes, nurses expressed three major reasons for this: (1) Wrong or invalid number, (2) Hard of hearing, and (3) Unavailability to speak.

Wrong or invalid number. Participants' phone numbers are listed next to the alert information in the nurses' web portal. If that phone number is wrong or invalid, nurses cannot communicate with participants. Note 21031 below is an example of how a nurse attempted to find alternate methods to reach the participant by calling the TIPS site directly and then stating the next steps to take to escalate to TIPS administration.

"Attempted to contact client, phone number listed [phone number] gives a busy signal, attempted to call twice. Contacted the [anonymized TIPS site] who stated client has gone home at this time, the [anonymized TIPS site] has the same phone number listed for client...Escalated this issue to management, will keep alerts open at this time, will attempt another connection within the next week, and will speak to management again." (Note 21031)

We also observed that wrong and invalid numbers were not always addressed quickly. The participant from this sample nurse note was first flagged as having an invalid number in September 2015, and the problem persisted until July 2019, the last note documenting attempted contact.

Hard of Hearing. While not frequent, there was an incident in which a nurse documented a participant did not speak English and may be hard of hearing (HOH). The nurse attempted to discuss the alert and instruct the participant to follow up with his doctor but could not complete this process with the participant or the participant's wife due to the stated language barrier before the participant ended the call. The nurse did not document any next steps or escalations to TIPS administration:

"Telephone call to Pt regarding low BP and HR at times. Pt may be HOH; states "no escucha". Pt repeats throughout call that he doesn't speak english. Attempted to recommend Pt see his Dr to check BP and HR. Unable to speak with Pt or wife due to language barriers and Pt hung up." (Note 20426)

Unavailability to speak. The last reason nurses could not establish contact with the participant was when the participant or designated caregiver could not speak on the phone. In these situations, nurses left a brief message stating who they are, where they're from, and their message. Note 11925 shows the nurse left a voicemail directly with the participant. There was no record in the nurse notes data afterward indicating any follow-up phone call in Spanish to complete the alert response protocol:

"The pt is attempted to contact via home phone with no answer. A VM was left on the phone regarding high blood pressure reading on the 13th. However, the pt appears to be Spanish speaking only and may require follow up phone call in Spanish in the future." (Note 11925)

Table 1: Codebook of Nurse Note Codes relevant to alert response protocol.

Research Question	Nurse note Code	Code description	Example note
RQ1: Challenges	Leave Message	Nurse left voice mail or note writes "Voicemail left, LVM"	Call placed to client. Left voice message with contact information
	Wrong Number	Nurse could not reach the patient because the phone number was incorrect	@4:47pm Called participant d/t weight increase of 3 Lbs. Wrong number. Caller verified [phone number] is not participant PH#.
RQ2: Workarounds	Discuss Symptoms	Nurse called patients to discuss or talk or make the patient aware about medication or health issue	Pt reports she gained a few pounds on vacation and is back on a healthy diet. Pt walks daily. Pt is eating more vegetables and cutting back on sugar.
	Review History	Note that compares vital signs with patient's "trend" or note that contains the previous status of the patients (trends, medication, or any disease issues)	Previous hx of low BP readings. No reports of related s/s associated with reading CTM
	Within Normal Limit	Note that writes "WNR, WNL/within trend for consumer/within the parameters/fluctuate within the normal baseline/ Diastolic within the trend/in line with recent trend". Or, data is normal.	Diastolic reading was 91 which did alert for being over 90. Diastolic mean is 92 and trend is 88-96. Will continue to monitor.

On the other hand, Notes 16269 and 16394 demonstrate the protocol could be completed asynchronously via voicemail. In Note 16269, the nurse documented leaving a voicemail with the participant's daughter and explained this was due to a stated language barrier if the participant is directly called. The participant's daughter called back and left another voicemail, which was captured in Note 16394:

"LM for Dtr. [participant's daughter] to return phone call. Pt unable to understand d/t language barrier when she is called directly." (Note 16269)

"VMM - Dtr [participant's daughter] returned call to report Pt has an appointment with the MD on Monday... Family aware BP is high at times. Fluids encouraged." (Note 16394)

5.1.2 *The lack of available, effective translators.* There were 7/40 nurse notes where an interpreter was requested to translate the conversation between the nurse and the participant, expressed by either the nurse or the participant. We distinguish this from when the participant's family or caregiver took on the responsibility of communicating with the nurses on behalf of the participant, which we discuss later in this paper. We found several instances where translators were either unavailable, ad-hoc, or ineffective.

Unavailable translators. If translators were unavailable when requested, we found three possible scenarios. In the first scenario, nurses left the alert task unaddressed in their portal and escalated to TIPS administration, as shown in Note 19923:

"Contacted client in regards to tachycardia from 10/24/18 of 113 BPM, client is primarily Spanish speaking and did not understand RN, interpreter was not available. Will leave alert open and contact management as far as what to do. Please let it be noted HR from today 10/31/18 is 78 bpm." (Note 19923)

In the second scenario, nurses tried using Google Translate to translate the conversation in lieu of a third-person translator, but the nurse reported that the client still did not understand:

"Contacted client about SBP...client speaks Spanish only. RN knows minimal Spanish..attempted to state "I am RN, how do you feel, do you have a headache" in Spanish using google translator. Error with language barrier, client did not understand. Will mark as complete and refer to management." (Note 17548)

In the last scenario, nurses attempted to converse with the participant. We found that this happened in a little over half of the notes in our sample. In these cases, nurses indicated that the participant spoke little or some English. In one-third of this set of notes, the participant only stated that they felt "fine" or "okay" and no other discussion about the participant's symptoms related to the alert took place:

"HR taken x3 (109, 114, 116). SpO2 74. Pt called. Pt only spanish speaking, but was able to say she 'feels okay.' CTM" (Note 3318)

As a result, nurses did not get all the contextual information they sought. For example, one nurse wanted additional information about a recent fall a participant shared in their self-report questionnaire, but the nurse could not get adequate information to complete the alert response protocol:

Pt called regarding recent fall and elevated HR. Her BP is also slightly high CTM. Pt spanish speaking, asked if anyone could translate for her and she said no. She said she can speak a little english. She was able to say she had a recent fall, but couldn't explain it. She also stated she felt okay. CTM" (Note 2066)

Adhoc or ineffective translators. However, even if a translator was available for the conversation, we found they were often ad-hoc

translators or not professionally trained. For instance, participants would sometimes have their neighbors volunteer to translate the conversation:

"Telephone call to Pt; speaks only spanish. Pt asked next door neighbor to translate. Pt fell on Sunday while she was vomiting. Pt reports she was in "la-la land". Pt notified dtr and dtr drove Pt to the hospital. Pt reports she feels fine now and denies any injury. Encouraged fluids and eating at regular intervals. Neighbor states Pt can ask her to translate as needed." (Note 22255)

The participant's neighbor could share details of a recent health emergency that the participant experienced with the nurse, translate the nurse's instructions to the participant, and volunteer to translate future conversations when they were available.

We also saw that some of the TIPS sites tried to provide on-site interpreters, but nurses complained they were not effective at translating since they were not always fluent in both English and the participant's preferred language:

"...the [[anonymized TIPS site]] usually tries to assist in finding an interpreter, but for the most part, the interpreter is not fluent in both English and Spanish..." (Note 21031)

Here, the nurses are expressing their concerns about not having a reliable translator consistently available, which affects how well nurses are able to complete their alert response protocols and how LEP participants are cared for at TIPS.

5.2 Nurses' Workarounds in Information Gathering and Instruction Delivery Despite Language Barriers (RQ2)

So far, we have observed the challenges nurses experienced when gathering information and delivering instructions to participants as part of their alert response protocol. We found two common workarounds to circumvent these challenges: (1) Reaching out to participants' families or caregivers for more rich and contextual information and (2) supplementing any information with an offline review of the participant's vital sign history.

5.2.1 Participant's family/caregivers provide rich contextual information. Participants had the option of specifying a family or caregiver to speak with nurses on their behalf. The participant would provide verbal consent or authorization for nurses to speak with their family/caregiver, prompting nurses to update the contact information in the web portal to reach out to the caregiver first in the future.

We found that the participant's family/caregiver was more likely to provide more detailed context and information regarding the participant's health status and concerns, both related to the alert and otherwise, as shown in Note 15635:

"Telephone call to client regarding elevated BP readings ... Client gave verbal consent to speak with her dtr [Participant's daughter] ... Dtr denies client has any edema and states BP fluctuates between "'low to 154/'... Dtr reports Pt has back pain d/t arthritis and sciatica and can only take Tylenol prn d/t kidney problems. Encouraged Pt to use pillows and positioning for comfort and

try deep breathing exercises and creative visualization to help manage back pain... Dtr requests we call her or her sister as her mother does not speak/understand english and has an interpretator when at the [[anonymized TIPS site]]." (Note 15635)

The nurse initially called to discuss the participant's elevated blood pressure. The participant's daughter shared the participant did not experience symptoms related to the alert. The participant's daughter went on to discuss her mother's other health concerns, to which the nurse provided additional care instructions beyond the initial alert response protocol.

The notes also captured the toll caregivers experienced taking on these additional responsibilities while trying to balance their other life commitments, such as work, friendships, and relationships, as seen in Note 22933:

"...[participant's] Son appeared to get frustrated during the conversation because it is difficult for him to go to work and see his girlfriend and friends because Pt always asks to go too or cries when he leaves." (Note 22933)

5.2.2 Nurses supplement conversations with review history. When nurses were unable to contact either the participant or their caregivers, or if they could not get all the information from the phone call, they would use the review history as a supplemental information source. The TIPS administration trained nurses to review the participant's medical and vital sign history prior to initial contact attempts at the start of the alert response protocol. We saw that nurses would document trends or their most recent vital signs when they could not conduct the medical assessment as per their protocol, as shown in Note 19923:

"...Please let it be noted HR from today 10/31/18 is 78 bpm." (Note 19923)

As such, nurses used review history to assess the participant's health status as supplementary information they would have gathered had they completed their alert response protocol.

Next, with the insights gained about the challenges nurses encountered in gathering information and delivering instructions for LEP participants, we step back and show how prevalent identified challenges are at a larger scale within TIPS.

5.3 Disproportionate nurse notes related to contact and information gathering among LEP participants (RQ3)

5.3.1 Expected Proportion of Nurse Notes by Language Proficiency. From 1,208 participants with 23,975 nurse note responses, LEP participants had disproportionately fewer notes (19% out of 23,975 notes) relative to their population proportion (23% out of 1,208 participants). And 19,552 of the 23,975 nurse notes (82% of notes) were responses to high-risk alerts. LEP participants had similarly disproportionately fewer nurse notes relative to their EP counterparts, with 77% of LEP nurse notes responding to high-risk alerts compared to 83% of EP nurse notes. Given that LEP participants triggered 19% of nurse notes, we expect a similar breakdown of nurse note content - (e.g., we expect that 19% of nurse notes related to 'Discuss Symptoms' should be for LEP participants and 81% for

EP ones). Table 2. shows the comparison of observed and expected counts of nurse note content related to the qualitative stratified by participant language proficiency and whether the frequency differs from the expected distribution based on the chi-square analysis.

5.3.2 Chi-Square Analysis Findings. We observed statistically significant differences in nurse note content related to the challenges nurses face between LEP and EP participants and their workarounds between LEP and EP participants.

Frequency differences in documented communication challenges. Among codes related to challenges due to the inability to establish contact, we found that the "Wrong or Invalid Number" code occurred 2.5x more often LEP participants than expected (48% observed vs. 19% expected) and was statistically significant ($p < 0.001$). On the other hand, the theme, "Unavailability to Speak", approximated by the code "Leave Message", occurred statistically significantly less than expected among LEP participants, or 2.7x less often than expected (7% observed vs. 19% expected).

Frequency differences in documented workarounds. Families/caregivers providing rich, contextual information was one of the workarounds to challenges in alert response protocol completion, which we mapped to the "Discuss Symptoms" code in the codebook. "Discuss Symptoms" was statistically significantly more likely among LEP participants, 1.5x more than expected among LEP participants (28% vs. 19%). However, the other workarounds regarding how nurses supplement information through offline vital sign history review, investigated using the content codes "Review History" and "Within Normal Limit", both occurred significantly less often than expected (16% vs. 19%).

We could not examine the prevalence of the themes related to HOH and the lack of effective translators, given that we did not have these themes in the code book.

6 DISCUSSION

6.1 Content of Nurse Notes for LEP participants is more focused on contact and communication

6.1.1 Challenges in outreach to LEP Participants. The presence of wrong or invalid phone numbers in the TIPS web portal system was one of the contributing factors to disrupting nurses' alert response workflow. Regardless of how often nurses encountered this case, we observed that it was an issue that persisted for several years. Similarly, the unavailability of participants and/or caregivers came up in the nurse notes as a disruption to the alert response protocol. Despite some nurse notes indicating it was possible to complete intervention protocols asynchronously via voicemail messages, we found statistically significantly fewer alerts containing content about leaving voicemail messages for LEP participants or their caregivers when examined across the whole program dataset.

Prior work [65] similarly reported a higher incidence of wrong phone numbers of LEP caregivers of children in a children's hospital EMR system. Our study confirms this phenomenon in a different healthcare setting, geography, and age population. More broadly, this fits into research studying "unreadiness" for telehealth. Despite significant advances in the adoption of telehealth, largely accelerated because of the COVID-19 pandemic, many older adults

may not be prepared for this shift in healthcare delivery. Lam et al. [51] found that nearly 20% of older adults in the United States were unready for telehealth services via telephone due to difficulty hearing or communicating. These challenges were documented in the nurse notes, including participants being hard of hearing. Our study shows that these challenges can be layered and compounded and can affect the ability of nurses to deliver healthcare to LEP participants.

6.1.2 Inadequate substitutes for professionally trained interpreters. There were no systematic methods to find effective translators when they were requested who could adequately mediate conversations about alerts between participants and nurses. Nurses would either ask the participant if anyone was available on their end. If participants did not have a dedicated family member or caregiver, they would rely on their neighbors or try to find an interpreter through the TIPS site services. This approach is constrained by the availability of neighbors or staff members, which can lead to a lack of consistency in finding a reliable translator in a timely manner.

When interpreters were unavailable, nurses sometimes tried to use technology solutions like Google Translate to communicate in the participant's primary language but reported unsuccessful outcomes. This aligns with existing research evaluating tools like Google Translate and other translation apps to provide language translation services in healthcare [10, 46, 59, 73]. These studies have found inconsistent translation capabilities to deliver care instructions to LEP participants, with some finding translation quality similar to humans, particularly during everyday communication in healthcare settings, while others concluded these technology solutions were still inferior to professional interpreters.

Even if interpreters were available, there was still concern about the quality of translation services. Nurses complained they were not fluent in English and/or the participant's primary language. Previous studies have found that ad-hoc translators do not always capture nuances of health practitioners' recommendations [69, 96]. A lack of consistent and reliable translators who can adequately translate the nuanced details of care instructions is critical to overcome, especially given that most nurse notes in TIPS are responses to higher-risk alerts.

There are also further concerns about the right to participant's privacy when using ad-hoc translators who are often members of the participant's neighborhood or community [33, 69, 89]. Participants may face a difficult choice of keeping health events or concerns private at the expense of getting help or giving up their right to privacy to have their concerns addressed.

6.1.3 Trading off between rich, contextual information and exacerbating caregiver burden. Our findings demonstrate that when participants' families or caregivers took on the responsibility of directly communicating with nurses on their behalf, nurses could have more in-depth conversations regarding the participant's overall health and not just address the incoming alerts. This was the primary workaround solution nurses relied on for LEP participants since nurses did not rely on supplemental reviews of participants' vital sign history to fill in the gaps with missing information as often for LEP participants compared to their EP counterparts. Nurses expressed wanting more context behind health events related to the alert but could not always get the information they sought without

Table 2: Chi-Square Analysis of nurse note content frequency comparison between LEP and EP participants.

Qualitative Themes Subject	Qualitative Themes	Relevant Code from Nurse Note Codebook (Table 1)	LEP Notes		EP Notes		Chi-Square Analysis
			Total Observed Notes [N, (%)]	Total Expected Notes [N, (%)]	Total Observed Notes [N, (%)]	Total Expected Notes [N, (%)]	
RQ1: Challenges	Inability to establish content: Wrong or invalid number	Wrong Number	70 (48%)	27.32 (19%)	77 (52%)	119.68 (81%)	Higher than expected (p <0.001)
	Inability to establish contact: Unavailability to speak	Leave Message	124 (7%)	319.98 (19%)	1,598 (93%)	1,402.02 (81%)	Lower than expected (p <0.001)
RQ2: Workarounds	Participants' family/ caregivers provide rich contextual information	Discuss Symptoms	1,148 (28%)	761.3 (19%)	2,949 (72%)	3,335.7 (81%)	Higher than expected (p <0.001)
	Nurses supplement conversations with review history	Review History	1926 (16%)	2,259.18 (19%)	10,232 (84%)	9,898.82 (81%)	Lower than expected (p <0.001)
		Within Normal Limit	1,282 (16%)	1,464.25 (19%)	6,598 (84%)	6,415.75 (81%)	Lower than expected (p <0.001)

an interpreter. When the participant's family was involved in the communication, they shared richer contextual details about all the health concerns a participant may be experiencing. In turn, nurses could provide more comprehensive care instructions to support the participant's overall health, fulfilling the objectives of TIPS. Harvath et al. [39] discuss the value of the partnership between family caregivers and healthcare providers as a way to bring together the healthcare professional's expertise with the caregiver's knowledge of the family member.

However, nurses documented how caregiver responsibilities can take a toll, as shared by one participant's son, who expressed frustration balancing caring for his mother with his other commitments to work, friends, and romantic relationships. Caregiver burden, particularly when caring for LEP older adults, is an ongoing research subject [75, 84]. Caregivers take on multiple caregiving roles (e.g., helping at home, helping with medical decisions, helping with medical forms, helping communicate with medical staff, and talking with doctors about medical care) and reported higher levels of moderate/high stress. Schiaffino et al. [79] found that LEP participants at TIPS reported higher rates of having a caregiver. There is a need for more investment in culturally aware home- and community-based care options.

6.2 Design Implications

Implementation solutions. The first step to addressing challenges around language proficiency would include understanding the needs, interests, and technology capabilities of embedding translation services so communication with LEP participants and how that process could be mediated and supported by more nuanced,

socially and culturally appropriate methods. It is important to ensure that future improvement efforts are framed appropriately such that LEP individuals do not feel like a burden to overcome. For example, we should recognize differences between the following two questions: (1) "Do you need an interpreter?" and (2) "What is your preferred language?" as the former indicates a focus on the patient's ability to understand and interpret medical information, whereas the latter encompasses the needs of both the patient and provider to communicate effectively [70]. Furthermore, any proposed solution should support cultural competence in care to promote positive interactions and trust between patients and their healthcare providers [2, 85, 96]. CHI researchers have also argued the need for culturally-informed technology design [29, 31, 76].

With this framing in mind, we can look to studies that examine the use of technology-supported interpretation services between nurses and patients to guide future improvement efforts. We should be mindful not to introduce high-cost, overly complex technical systems that will be inaccessible or challenging for LEP participants and their caregivers to adopt, particularly if initial setup and training prove to be difficult. Furthermore, the reported shortcomings and limitations around how well voice detection works for LEP users [72], older adults [68], and minoritized user populations [38] show that AI-enabled translation services need extensive future effort to work inclusively and successfully. We suggest future research areas that should be prioritized below including the need to invest in multimodal support and solutions that appropriately include caregivers without exacerbating caregiver burden.

Multimodal Support. There are simple methods that can be quickly adapted to make targeted improvements to establishing

contact with LEP participants, such as routine audits of participants' contact information to ensure participants have valid and up-to-date phone numbers in the web portal. At the same time, we see the need for novel, creative solutions to address the challenges noted in the findings while augmenting and assisting the existing workarounds nurses have created. We must go beyond low-hanging fruit solutions of inherent challenges noted in connecting with LEP participants learned from the literature and in our data. For instance, if participants are harder to reach by telephone calls, CTPs can consider adopting multiple diverse communication methods incorporating audio and text-based messaging. Numerous evidence exists around how multi-modal interfaces improve usability and perceived subjective experience for older adults with various impairments, including visual, cognitive, auditory, and motor abilities [43, 44, 54, 98]. These multi-modal interfaces should support interaction modalities that are natural to people, such as speech or touch, for improved adoption [26]. Providing multiple modalities for nurses to reach out to participants may help promote accessibility and improve digital inclusion, especially for individuals who are hard of hearing.

Balancing trade-off between effective information gathering and privacy concerns while minimizing caregiver burden. Also, it would be critical to find novel solutions to alleviate the burden caregivers experience taking over the responsibility of communicating directly with nurses and subsequently translating back to the participant. Note 15635 showed how caregivers took on the responsibility of remembering health history changes and reporting them back to the nurses to discuss the participant's status. Such health history instead can be captured through everyday monitoring devices that also capture context around participants' personalized readings of what is considered "normal". Nurses, as needed, can access such information to understand the recent health status of the participant when they cannot reach the participant immediately or if there is a language barrier to communicating those issues. If there is further situated information that's needed with the monitoring results, such information can be asynchronously exchanged between the nurse staff and the participants and their family members with the monitoring information.

However, we must consider the participant's right to privacy and autonomy. Crotty et al. [18] argued that there is no "one-size-fits-all" approach to appropriate levels of information sharing between older adult patients, caregivers, and their healthcare providers. They found that some older adults reported feeling comfortable sharing data with their doctors, families, and caregivers, while others preferred to have more granular control regarding sharing their health information with caregivers. There has been a growing trend in privacy-by-design research, which encourages embedding controls to restrict information access when requested by participants to empower participants to exercise their right to privacy [7, 47]. Future solutions should allow for flexible user controls that allow for direct information sharing between older adults and their caregivers or caregiver proxy access when participants provide consent while allowing information restriction when requested.

Applying Design For All to Supporting LEP. These suggested design implications should not merely be considered for supporting LEP participants and associated language barriers as an additional, specialized effort. Rather, we should approach support for LEP

participants with the same philosophy that disability studies perspectives undertake, namely the Design For All movement [71]. The goal would be to design products that would be suitable for most of the potential users without modifications, be easily adaptable, and be built with standardized interfaces where specialized interfaces can be integrated as necessary. Future research should prioritize identifying novel design solutions that can support language barriers and support a wider range of users with various needs, impairments, and diverse strengths.

6.3 Study Limitations and Future Work

Due to our focus on comparing nurse note content for participants with and without English proficiency, our inclusion criteria requiring participants who have shared their language proficiency with a history of alerts with responses from the TIPS remote nurses information resulted in 46% of participants getting filtered out from our dataset. There may be selection bias present if participants enrolled in the program but could not visit the TIPS sites regularly, especially if participants experienced barriers to access (e.g., inability to afford TIPS sites in retirement homes, or lack of access to adequate transportation to visit TIPS sites in-person). Correspondingly, this study did not explore separate but very important socioeconomic and policy implications that could affect how participants, particularly LEP participants, could access healthcare services like the ones offered in TIPS. As a result, the profile of participants included in our analysis may not reflect the broader population of TIPS participants.

Additionally, we did not consider alerts that were triggered but never received a response in our analysis. There may be biases in alert non-response that could affect the generalizability of our findings. Furthermore, we observed that LEP participants had disproportionately fewer nurse notes relative to their population counts. This implies that LEP participants are under-represented in the nurse notes data even among LEP participants who accessed and leveraged the TIPS services.

Our qualitative analysis was conducted on a small sample of 40 nurse notes. Although we could quantify the prevalence of some of these themes within TIPS for EP and LEP participants in our chi-square analysis, we could not do this for themes not present in the code book. However, we employed the same method to code nurse notes that included language barrier-related codes, and we could only discover 40 notes in the end. For the codes that existed, it would be an approximate mapping of codes. For instance, approximating the qualitative theme "unavailability to speak" identified as a "challenge" for nurses to gather information with the "leave message" code is not a direct mapping since "leaving a message" can be potentially interpreted as a workaround by the nurse to reach out to the participant but was the closest semantically to the theme of interest. Furthermore, as with any classification tasks, Nguyen et al. [67] reported imperfect precision and recall scores on nurse note classification, so there may be errors or misclassified nurse notes.

Finally, practice variations by sites and individual nurses were not controlled for in this analysis. Future work should focus on understanding the unique dynamics of each TIPS site and the potential relationship between individual nurses and the content of nurse

notes through interviews or diary studies. We are interested in continuing this body of research in the future. Our team is currently in the process of getting IRB approval to conduct an interview study with the nurses and LEP participants to understand better their daily work experience with LEP participants across the various TIPS sites, discuss these challenges and workarounds from their perspective, and gather their perceptions of the potential technology solutions we explored in this paper.

7 CONCLUSION

Community telehealth is a vital part of healthcare access for diverse and low-income older adults. Our study demonstrates how nurses gathered information with LEP participants, their families/caregivers, and other peripheral information, such as health history, in the community telehealth context. We identified disruptive factors that limited the TIPS nurses' ability to follow their alert response protocol to address LEP participants' alerts, particularly in establishing contact with participants and finding effective interpreters for the observed language barrier. We also quantified at a larger scale, comparing how often these themes of disruptions of information-gathering occurred in LEP versus EP participants. We found significant challenges in establishing contact with LEP participants and delivering needed instructions. Finally, we explored future design implications for addressing challenges around equitable access delivery for LEP populations, contributing to continued efforts to improve healthcare delivery to this vulnerable and underserved population.

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A COMPLETE DEMOGRAPHIC AND ALERTS DATA SUMMARY

Appendix Table below provides a complete demographic and alert data summary in TIPS aggregated from May 2015 - October 2019.

Table 1: Demographic Attributes of Participants and Vital Sign Reading Alerts

		Participant Counts		Alert Counts	
		LEP	EP	LEP	EP
		N = 276 (23%)	N = 932 (77%)	N = 4,455 (19%)	N = 19,520 (81%)
		n (row%)	n (row%)	n (row%)	n (row%)
Participant Demographics					
Age	<59	11 (9%)	108 (91%)	129 (6%)	2,108 (94%)
	60-74	85 (24%)	275 (76%)	790 (13%)	5,469 (87%)
	75-84	107 (28%)	281 (72%)	1,832 (24%)	5,726 (76%)
	>=85	73 (21%)	268 (79%)	1,704 (22%)	6,217 (78%)
Sex	Female	206 (22%)	728 (78%)	3,349 (18%)	15,012 (82%)
	Male	70 (26%)	204 (74%)	1,106 (20%)	4,508 (80%)
Chronic Conditions	Yes	213 (23%)	709 (77%)	3,504 (19%)	15,130 (81%)
	No	63 (22%)	223 (78%)	951 (18%)	4,390 (82%)
Vital Sign Readings & Alert Triggers					
Blood Pressure*	Systolic BP >170mmHg	93 (22%)	330 (78%)	508 (21%)	1,910 (79%)
	Systolic BP <90mmHg	19 (18%)	88 (82%)	98 (26%)	275 (74%)
	Diastolic BP >90mmHg	170 (21%)	641 (79%)	1,001 (14%)	6,079 (86%)
	Diastolic BP <60mmHg	92 (25%)	270 (75%)	986 (29%)	2,362 (71%)
Pulse Oximetry*	Heart Rate >100 bpm	73 (16%)	372 (84%)	334 (17%)	1,612 (83%)
	Heart Rate <50 bpm for 1 consecutive reading(s)	40 (13%)	263(87%)	149 (10%)	1,402 (90%)
	SpO2 <90 %	61 (15%)	345 (85%)	345 (13%)	2,392 (87%)
Weight	Decrease of 5 Lbs. over 7 days	52 (20%)	204 (80%)	117 (19%)	484 (81%)
	Increase of 3 Lbs.	171 (22%)	600 (78%)	735 (23%)	2,474 (77%)
	Increase of 5 Lbs. over 7 days	63 (23%)	211 (77%)	177 (29%)	436 (71%)

*High Risk Alert

% may not add to 100% given participants could trigger multiple of the same types of alerts