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Assessing Latino Caregiver's Knowledge and Understanding of Medication
Management for Children and the Use of Health Technology to Gather
Information

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Submitted in partial completion of the Master of Arts Degree at Sarah Lawrence College
May 2016

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Abstract

For people with low literacy who come from other cultures, accessing, understanding and using the United States healthcare system is challenging. Existing literature states that low parental health literacy among the Latino population is related to poor health outcomes for their children. This project explores Latino caregiver's health practices and the possible uses of technology, specifically Smartphone applications (apps), to provide information about their child's health care. The project included two focus group sessions (one in English, one in Spanish) with a total of 17 caregivers who attend a Head Start Program. The focus groups addressed two aims: (1) to understand caregivers' current knowledge and issues concerning medication management for their children; (2) to assess the current use and effectiveness of existing technology by caregivers to obtain health information. The findings suggest that caregivers are interested and could benefit from a culturally appropriate and linguistically responsive Smartphone health app. While both focus groups discussed features they would like to see in a health app, the Spanish-speaking group emphasized their personal experiences with access, communication with providers, and challenges with navigating the health care system. Caregivers identified a lack of trust that they have with the medical system which suggests the need for education of health care providers to improve their communication skills and understanding of the needs of the Latino population.

Keywords: caregivers, medication management, health, literacy, technology

Introduction

My experience working as an assistant teacher in child care programs, observing, first hand how being sick affects a child and the family, has taught me that when children are healthy, they learn better than when they are sick. My course work and previous experiences have helped me realize that there are many external factors that influence the development of a child. My completion of a double degree in Child Development and Health Advocacy has provided me an opportunity to explore the intersection of education and health. In doing so, this thesis is combined with my Health Advocacy capstone project.

This research project first began during my first year field practicum at a Community Outreach department in one of New York's Metropolitan hospitals. At that time, I was a Health Education and Adult Literacy (HEAL) volunteer. While a volunteer, I conducted a short qualitative assessment about the current medicine management and adherence practices among patients and their caregivers. These assessments indicated that low literacy and low English proficiency (LEP) among Latino caregivers are major factors contributing to medication management challenges and personal health outcomes of their children.

As a HEAL volunteer, I rotated and worked throughout family health clinics where the HEAL curriculum was implemented. The curriculum contains topics like medication administration, home remedies, planning a visit to the doctor, well-child visits and the difference between the cold and the flu. I provided this information and material to families of pediatric patients in the waiting room and discussed ways to improve their visit.

Physicians and health care providers at these clinics are aware that there is a need to better inform patients and their families about health education related topics. From observations and anecdotal reports from physicians, a few challenges related to medication

administration and management emerged. Physicians noted that a major barrier to successful medication administration was the lack of tools in patient's homes and in pharmacies to administer liquid medication. This prevented parents from administering the correct amount of medication to their children. In addition, prescribed medications are often not clearly labeled and prevent all of the liquid medication from being consumed. It was hoped that the plastic syringes provided to parents would help combat this problem, but that relies on parents actually using the syringes they are given when administering medication at home.

Although HEAL volunteers have access to patients and their families in the waiting area of the clinics, they are not qualified to teach medication administration and it would not be feasible or time efficient to train them in this as they don't have the clinical skills or time commitment necessary for working with parents. Further, they are not consistently present in the clinics and therefore could not take on the responsibilities of individualized medication administration review or medication management. The community health workers (CHWs) spend most of their time out in the community and are present in the clinic for two shifts a week. They work specifically with pediatric asthma and diabetic patients and do not complete medication administration and management tasks. An additional barrier to implementing an intervention utilizing the CHWs is that they currently focus on asthma and diabetic patients only and are not qualified to conduct medication administration and management training.

The CHWs do teach medication administration techniques specifically related to asthma and diabetes, but if they become aware of the fact that a parent is not correctly administering other medication, the CHWs refer the patient to their physician. From personal observations and discussions with Latino caregivers (parents and grandparents), a strategy

they use to access and gather health information is by using Smartphones, especially during their wait time in the clinics. A short study (Subramony, Martinez, Bregstein, Zimmerman, Meyer, Stockwell, n.d.) conducted at a Pediatric Emergency Department (PED) assessed how delivering health message using iPads in a low health literacy population could improve fever assessment and medication administration knowledge and care practices among parents. The study concluded that delivering health messages using multimedia applications is feasible and effective in a busy PED setting among low literate caregivers. The recommendations from this study suggested assessing the use of multimedia education on personal handheld devices.

Based on observations and understandings of the barriers of medication administration and management, it was clear that both could not be addressed through one intervention. In relation to medication management, it was obvious that the task falls on the physicians due to their qualifications and access to patient records. There is some flexibility with a medication administration intervention, but it still became clear that an intervention should not include shifting tasks to other staff due to the already overloaded staff responsibilities in the clinics. Therefore, it was determined that an intervention that would allow the patient to work on health literacy techniques independently, would prove to be most feasible and useful. The proposed intervention at the conclusion of this qualitative data is to develop a Smartphone application geared specifically towards medication management.

A larger research project about medication management was being carried out prior to my arrival to the clinic. The overall purpose of the larger research project was to assess the current knowledge and understanding of medication management for Latino caregivers, explore the barriers in communication between Latino caregivers and providers and assess

the feasibility of a Smartphone app to improve the process for parents. As I became more involved in the proposed research to develop a Smartphone app, it became clear that there was a need to assess the major challenges around medication management among the families in pediatrics.

The project took place at a major metropolitan hospital in New York City. The focus groups were held at community based Head Start Program with the target population of Latino caregivers who have Smartphones, speak either English or Spanish fluently and have children under the age of 5 who attend the Head Start program. Since the target population is Latino caregivers who are low-literate and low English proficient, there is the issue, whether or not there is culturally appropriate and linguistically responsive education and tools available regarding medication management. In addition to developing educational tools, it is equally important to assessing whether there is sufficient training for medical physicians and other health care providers about how to support the needs of a low health literate and culturally diverse population of patients. The issue regarding medication management among children is both an issue for the health care providers and the caregivers. Physicians and other health care providers could benefit from an education intervention designed specifically to increase their knowledge and awareness of health literacy. Latino caregivers could benefit from a culturally appropriate, linguistically responsive and interactive Smartphone health app geared towards health management.

Understanding Latino caregiver's use of health technology regarding their child's medication management is rarely researched; therefore the main goals of the project was to understand Latino caregivers current knowledge of medication administration and their use of health technology and health apps to gather information. Overall, this project was

designed as a first step to understanding the needs of the target population and to inform the development of a Smartphone health app.

My role as a lead researcher was to help plan and implement two focus group sessions to assess Latino caregiver's current knowledge and understanding of medication management as well as their use of existing health apps and health technology to gather information. I also transcribed the English-speaking focus group session and analyzed the findings by organically pulling out reoccurring themes from the caregiver's discussions. The project was a beneficial experience in the sense that it allowed me to learn what is required of planning and implementing/analyzing a study.

Literature Review

Accessing, using and understanding the United States healthcare system is difficult for almost everyone. For the people who speak limited English or come from other cultures, these tasks can seem impossible. There is a significant correlation between literacy skills and overall personal health. (Sentell & Halpin, 2006) Literacy skills include five core skills, which are: reading, writing, numeracy, speaking and listening. (Rudd, 2010)

According to the 2003 National Assessment of Adult Literacy (NAAL), which is a national representative assessment of English literacy among American adults age 16 and older, people identified as having literacy skills of a high school reading level or below, are considered to possess inadequate literacy skills. ("National Center for") Literacy influences one's ability to access information and to navigate the highly literate environment of modern society. (Rudd, 2010)

Those with low literacy have more difficulty understanding health information, receive less preventive care, and use emergency services more frequently. (Kutner, 2006)

Limited health literacy affects over 90 million Americans and is especially prevalent in low-income households and amongst minorities and people with limited English proficiency.

(Stockwell et al., 2011)

Culture also impacts how people understand and make sense of health information. (Stockwell et al., 2011) People bring their individual experiences, values, customs and logic to each new situation. Despite cultural and linguistic differences, health providers must communicate in ways all of their patients can understand. This is more than just good patient care. As the U.S. becomes increasingly diverse, health care needs to transform from a reactive situation into a rigorous implementation plan that is culturally sensitive and linguistically appropriate and that has methods and procedures in place to increase new needs of new populations, regardless of how large or small.

Current Medical Training

Physician-patient communication is considered a fundamental aspect of medical care; yet, research shows that patients commonly have difficulty in understanding medical instructions from physicians. (Kripalani & Weiss, 2006). Physicians often use medical jargon, deliver too much information at a time, and do not confirm patients' understanding of what was discussed. Based on an observational study conducted by a former medical resident (O'Niell, 2014), physicians at New York metropolitan community health clinics who prescribed medication to the patient were supposed to teach the patient's parent how to administer the medication using a "teach-back" approach requiring feedback from the caregivers/and or patient. However, this form of a teach-back approach was greatly underutilized and physicians were less likely to discuss medication administration techniques in addition to not checking in with parents for clarifications.

The observation assessed 24 physicians and their process of explaining how to administer and use prescribed medications, such as antibiotics, in addition to their process of checking the parent's understanding of the physician's instructions. (See Table 1 below) The observation was categorized from 'not applicable' to 'well done', which means each physician observed was rated on a scale to determine how well of a job the physician did in terms of instructing and checking in with parents about prescribed medication. Based on the findings from the observations, if looking under the 'not done' category (highlighted), almost 50% of the physicians did not either discuss detailed information about the medication, did not provide clear instructions on how to administer or where to store the medication. When physicians were observed for their explanation on the use of antibiotics, almost 50% or more of the physicians did not provide clear instructions or details about administering the antibiotic. Majority of the physicians did ask the parents if they had any questions at the end of the visit, but over 50% did not follow up with checking the parent's understanding of the medication instructions just provided.

This observation of a small sample of physicians depicts a greater issue in current medical practices. At the end of the medical encounter, patients remember less than half of what the physician tried to explain, and they may be uncertain about what steps to take next. (Kripalani & Weiss, 2006).

Table 1
Observation of Physicians' Communication with Patients

| Prescribed Medicine/Medication Management | Not Applicable | Not Done | Partially Done | Well Done |
|---|----------------|----------|----------------|-----------|
| 1. Tell patients name of medicine including brand and generic | -- | 11 (46%) | 7 (29%) | 6 (25%) |
| 2. Describes why medication is necessary and how it will make patient feel better | -- | 11 (46%) | -- | 13 (54%) |
| 3. Explains how much medication to give, how often it should be given and for how many days | -- | 11 (46%) | 3 (12.5%) | 10 (42%) |
| 4. Describes where in the body the medication is meant to be given- mouth, nose, ears, eyes, rectum | -- | 13 (54%) | -- | 11 (46%) |
| 5. Demonstrates using a syringe how to draw up the medication and how much should be given | 4 (17%) | 17 (71%) | 1 (4%) | 2 (8%) |
| 6. Explains where medication should be stored (refrigerator, or cool dry place) | 2 (8%) | 21 (88%) | 1 (4%) | -- |
| 7. Gives patients tools to keep track of medication administration | 3 (12.5%) | 17 (71%) | -- | 4 (17%) |
| 8. Describes common side effects that patient might experience | 2 (8%) | 22 (92%) | -- | -- |
| 9. Details when the patient should expect to feel better | -- | 12 (50%) | 1 (4%) | 11 (46%) |
| Use of Antibiotics | | | | -- |
| Explains what antibiotics are used for | 10 (42%) | 11 (46%) | -- | 1 (4%) |
| Stresses importance of only using antibiotics when prescribed by physician | 10 (42%) | 13 (54%) | -- | -- |
| Explains some of the side effects the treatment may cause | 10 (42%) | 13 (54%) | -- | 1 (4%) |
| stresses importance of completing full course of treatment | 10 (42%) | 12 (50%) | -- | 1 (4%) |
| Describes what happens when antibiotics are not used correctly | 10 (42%) | 12 (50%) | -- | -- |
| Gives patient brochure on "Use of Antibiotics" | 10 (42%) | 13 (54%) | -- | 1 (4%) |
| Asks if patient has any questions | 10 (42%) | 12 (50%) | -- | -- |
| Uses visual methods of clarifying information | 10 (42%) | 13 (54%) | -- | -- |
| Asks if patient has questions or concerns | 10 (42%) | 1 (4%) | -- | 23 (96%) |
| Checks patients understanding of information given: "teach back" method | 10 (42%) | 14 (58%) | -- | 10 (42%) |

Health Literacy

Limited health literacy affects people's ability to access and utilize health information, and adopt healthy behaviors. (Institute of Medicine, 2012) Health literacy has been defined in many ways and with a inconsistent use. Having no clear definition shows that there is a lack of qualifying standards to incorporate into a medical training program, especially among medical providers who work with low literate and culturally diverse populations.

Under the Affordable Care Act (ACA) health literacy is defined as “the degree to which an individual has the capacity to obtain, communicate, process and understand health information and services in order to make appropriate health decisions”. (ACA, 2012)

The U.S. Department of Health and Human Services defines health literacy as

“...as the ability to read, understand, and act upon related health information. It also refers to the capacity to which professionals and institutions can communicate effectively”. (“America's Health Literacy”, 2008.)

Similarly, the Office of Disease Prevention and Health Promotion provided a definition in the National Action Plan to Improve Health Literacy and defines it as,

“... the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. Limited health literacy affects people of all ages, races, incomes, and education levels, but the impact of limited health literacy disproportionately affects lower socioeconomic and minority groups. It affects people's ability to search for and use health information, adopt healthy behaviors, and act on important public health alerts. Limited health literacy is also associated with worse health outcomes and higher costs”. (“Office of Disease Prevention”, 2010)

A health literacy component of the National Assessment of Adult Literacy (NAAL) measures the health literacy of adults living in the United States. The findings indicated,

based on a below basic, basic, intermediate and proficient performance levels, that majority of adults (53%) had intermediate health literacy, 22% had basic and 14% had below basic health literacy. (Kutner, Greenberg, Jin, & Paulsen, 2006). When other variables such as education level, age, race and ethnicity were factored into health literacy levels, adults with below-basic or basic health literacy were less likely than adults with higher health literacy to get information on health related issues from written sources (newspapers, magazines, and books or the internet); and more likely than adults with higher health literacy to get health related information from radio and televisions. (Kutner, Greenberg, Jin, & Paulsen, 2006).

Low health literacy contributes to the communication gap between health care providers and their patients. Patients with low health literacy may have less familiarity with medical concepts and vocabulary, and they ask fewer questions (S. Kripalani, unpublished data). They may also hide their limited understanding out of shame or embarrassment. (Kripalani & Weiss, 2006). Research shows that physicians commonly overestimate patients' literacy levels, and they rarely consider limited literacy skills in their assessment of whether patients understand what they need to do. (Ali, Ferguson, Mitha, & Hanlon, 2014). In addition, when provided information about patients' literacy levels, physicians appear ill prepared to communicate effectively, use plain language and teach back skills. (Ali, Ferguson, Mitha, & Hanlon, 2014). Furthermore, if health care providers received adequate training on health literacy knowledge and skills required to feel confident in identifying with low health literate patients and providing appropriate resources, future office visits might be shorter or needed less frequently.

What the individual definitions clearly state is that it is an individual's responsibility to acquire the skills necessary to function in a society where accessing and utilizing

information is a requirement. In addition, the individual is responsible to incorporate the skills needed to navigate the health care system. Likewise, individual's health literacy skills and abilities are also a function of the complexity and ease of use of the communication channels and devices that carry health information. In either case, both health care organizations and those who develop communication channels and devices have a responsibility to make health information understandable and easy to use for people all health literacy levels. Overall, health literacy has been described as a juxtaposition (IOM, 2009) of the individuals' skills and abilities with the aggressive demands and complexity of the health care system.

Latino Population

The strong association between literacy skills and health outcomes has substantial impact on all aspects of healthcare, especially on patient medication knowledge and proper medication administration and management. Existing literature states that Latinos are at high risk for poor health literacy (Stockwell et al., 2010; Stockwell et al., 2011) and low parental health literacy among this population is related to poor health outcomes. (Subramony, n.d.) Nearly half (41%) of the Latino community lacks basic health literacy skills compared to their Black (24%) and White (9%) counterparts. (Lo, Sharif & Ozuah, 2006)

Among the Latino population, there are communication factors that additionally affect medication adherence and management skills. Latinos who spoke only Spanish were less knowledgeable about antibiotic resistance than Latinos who spoke English. (IOM, n.d.) In a metropolitan city, there are many pockets of communities, some of which are the most underserved areas. Many Latinos or foreign-born people reside in some of these communities and approximately one third of the families live below the poverty line. (Stockwell et al.,

2010) A recent study conducted at a community health center, concluded that problems with prescribed medication were the most reported reasons for walk-in visits. Some of the major challenges, among a Latino population, are the misuse of prescribed medication, such as for Asthma, substituting prescribed medications with home remedies or herbal medicines and frequent visits to the Emergency Department (ED).

Role of the Caregiver

A child's health outcome depends on the parent's ability to understand and comprehend their child's health information. Despite an expanding body of literature on health literacy and health outcomes in adult populations, very few studies have assessed the relationship between parental health literacy and pediatric health outcomes with regards to medication administration. (Stockwell, 2010) Yet, recent evidence indicates that a large number of U.S. parents possess limited health literacy skills and that low parental literacy impedes appropriate parental understanding and administration of pediatric medications (Sleath et al., 2006; Yin, Dreyer, Foltin, Van Schaick, & Mendelsohn, 2007). In a study conducted in a community pediatric clinic, at least 50% of parents were reported making dosing liquid medication errors, which is the cause of most adverse drug events in pediatric outpatients. Findings concluded that parent's inability to dose and administer medication correctly was related to limited health literacy. (Yin, Mendelsohn, Wolf, Parker, Fierman, van Schaick, Bazan, Kline, & Dreyer, 2010)

Asthma

Asthma is the most common chronic disease of childhood and adolescence. It affects 4.8 million Americans under 18 years of age and accounts for 2.2 million annual visits to pediatricians (Adams & Marano, 1995). It is the most frequent cause of school absenteeism and pediatric hospitalization (Eggleston, 1994). A study conducted at a university pediatric clinic (Dewalt, D., Dilling, M., Rosenthal, M., & Pignone, M., 2007) determined that children with asthma of parents with low literacy had greater incidence of ED visits, hospitalization and days missed from school. A cross-sectional study sought to determine the association between low health literacy among caregivers and child ED visits and concluded that children of caregivers with low health literacy had more prior ED visits and increase of non-urgent ED visits. (Morrison, Shapira, Gorelick, Hoffman, & Brousseau, 2014). Parents with low literacy had less asthma related knowledge and their children were more likely to have moderate to severe asthma and needed to use fast acting medications more frequently. (Dewalt, D., Dilling, M., Rosenthal, M., & Pignone, M., 2007)

A study conducted among a Dominican-American community, found out that mothers with children with asthma did not use prescribed medication (72%) for the prevention of asthma. Instead, they substituted home remedies, derived from their folk beliefs about health and illness. Over half of the mothers did not think their child had asthma if the episodes were acute. A majority of the mothers felt strongly that prescribed medication are over used in the United States and that physicians deliberately hide alternative treatment options from them. Mothers who do not administer prescribed medication for their child's asthma are considered non-compliant by western medical practices. However, the mothers

believed by using herbal remedies to treat their child's asthma, they were providing the best option for their child. Although the use of herbal remedies or botanical medicines are not considered part of standard medical practice, there is a need to further promote patient-provider communication in order to allow western medical practices and home remedies to coexist and collaborate as intervention options. (Bearison, D., Minian, N., & Granowetter, L., 2002).

Addressing the Problem

The strategic decision in this project was to explore how health technology, specifically a Smartphone health app, for a Latino population, has the potential to improve health literacy and provide a culturally and linguistically appropriate tool for health management.

With increased access to Smartphone technologies, this generation has been coined, a "generation of information" and has transformed the way society communicates. (Bert, Giacometti, Gualano, Sliquini, 2014) Patients who are owners of Smartphones have more opportunity to access health information than patients did just one decade ago. Worldwide, Smartphone ownership has grown from 1 billion in 2002 to over 6 billion in 2012. (Broderick, Jordan et al, 2014; Pop-Eleches, Christian, et al., 2011) In the United States alone, there were 239 million (79%) diverse users of Smartphones in 2007 proving that this device is accessible to all regardless of socio-economic class. With phones becoming more powerful, cheaper and accessible to a greater population, their use in delivering healthcare services and medical information has brought great value. (Patrick, Griswold, Raab, & Intille, 2009)

Among the Latino population, there is a high percentage of those that access the Internet via smart phone rather than computers. (Copenhaver, Ferdandez, Vawdreym, Kotchoubey, Stockwell, 2014) A recent study looked at the usage of Smartphone technology among a predominately female Latino population and showed that 87% owned a Smartphone in which more than half of Smartphone users gathered heath information on their devices and 20-30 percent of them downloaded apps related to health. (Broderick, Devine, Langhans, Lemerise, Lier, Harris, 2014) Additionally, 70% of the study population used the Internet on their Smartphones. Most (83%) of these women were also generally interested in using their Smartphones to access online health information for their child. (Copenhaver, Fernandez, Vawdrey, Kotchoubey, & Stockwell, 2014)

In order to adequately and appropriately evaluate the potential of health technology to address healthcare disparities, adoption and utilization barriers must be understood. Furthermore, because healthcare is increasingly being delivered in community-based settings, barriers and opportunities within these differing delivery settings must be identified. Identification of these barriers and opportunities will enable an evidence-based approach to the design, development, and implementation of appropriate tools.

While Smartphones are able to provide its owners easy Internet access, the flood of information available may not be culturally and linguistically responsive. More specifically, it does not effectively inform patients who have low health literacy skills. Though it is important to have health information that is readily available for parents to access on their smart phones, it is essential to have information that incorporates health literacy elements to ensure readability, understanding, and utilization. There is little evidence on how to implement Smartphone health apps on a community scale.

Effective Smartphone health apps can allow patients to empower themselves with knowledge by providing information and education about medication management and diagnosis; connect patients to their communities and local resources; and allow patients to advocate through interactive technology engagement.

The FDA encourages the development of mobile medical applications that improve health care and provide patients and health care professionals with valuable health information. (U.S., FDA, 2014). Jeff Shuren, Director for the FDA's Center for Devices and Radiological Health was reported stating, "the rapid change pace has prompted the agency to take a more flexible approach in its reviews of the products." (Gard, 2012) Mobile apps for Smartphones and tablets are changing the way doctors and patients approach health care. Many are designed for the doctors themselves, ranging from handy databases about drugs and diseases to sophisticated monitors that read a person's blood pressure, glucose levels or asthma symptoms. Others are for the patients-at their doctor's recommendation-to gather diagnostic data, for example, or simply to help coordinate care, giving patients an easy way to keep track of their conditions and treatments. (Dayer, L. et al., 2013).

The clinical uses of Smartphone Health apps are broad and have expanded rapidly over the past decade. Smartphone health apps allow new and interactive ways to engage patients with medication and health management care. There are countless apps developed for mobile phone users. There's apps for logging fitness workouts; apps for monitoring vital signs; apps for providing health tips; apps for medication reminds; apps for counting calories and nutrition information; apps for pregnancy and menstrual cycle; and apps for keeping personal health records.

However, there has been little research on how useful these tools are across patient populations. The ubiquity of cell phones and touch screen technology presents the opportunity to use Smartphone Health apps to bridge gaps in health disparities if underserved communities accept and can easily use such tools. There are concerns that non-English speaking, low-income, and older patients will be isolated from the benefits of Smartphone health apps or will not be accepting of its adoption in clinical practices.

Based on the literature presented thus far, a user-friendly Smartphone health app could improve the current knowledge of Latino caregivers about medication management and their trust in the healthcare system therefore, reduce medication management related issues among children. This might contribute to an increase of effective response to medication treatment by children.

Methodology

The purpose of the research project was to assess pediatric caregiver's experience with medication management and the possible usefulness of a Smartphone app to improve the process. Focus groups were the best option to allow individuals to express attitudes and beliefs, to listen to other's opinions and share their understandings in order to form their own. Focus groups allowed the flexibility to explore unanticipated issues as they were mentioned in the discussion and was relatively low in cost. The study received institutional review board (IRB) approval from an accredited NYC metropolitan medical university.

Recruitment

A community based Head Start Program allocated their family advocates to help facilitate the recruitment by informing potential participants during their monthly meetings. These family advocates approached participants using a pre-approved informational handout developed by the research team that explained the project. If attendance was low at the meetings, the family advocates placed phone calls to parents. The telephone script asked potential participants if they were willing to attend a focus group about their current practices regarding medication management, adherence and the use of smart phone apps.

Participants received a light meal, a \$5.50 metro card and a small collection of brand new children's books valued at \$40 each in addition to a subsequent workshop regarding appropriate care of upper respiratory infections as compensation for participating.

Research Design

The two focus group sessions (1 in English, 1 in Spanish) were held on Monday, March 30, 2015 and Wednesday, April 1, 2015 from 7am until 10am at a community-based Head Start facility. There were two research assistants and one research coordinator present that day.

The study design consisted of two focus groups with 7 caregivers in the English focus group and 10 caregivers in the Spanish focus group. Originally, the study design anticipated 10 caregivers in each English and Spanish focus group. However, there were challenges with the recruitment process for the English focus group, which impacted how many participants could participate.

As part of the research team, a trained and experienced moderator conducted the two focus groups (one in English, one in Spanish) in order to help the research team identify

features needed for the development and design of the smart phone health app that can assist Latino caregiver's medication adherence and management. The moderator focused on facilitating the discussions and the research assistants were responsible for audio-recording and making supplementary notes. The moderator informed participants that the session would be recorded and all information was strictly confidential, explained the purpose of the discussion, and had each participant sign the appropriate consent forms. The focus group questions were designed to accomplish the two aims of the research study.

During the English focus group, two participants dismissed themselves because they did not have a Smartphone. During the session, one participant said very little and later mentioned that was not in charge of administering medication to his child. For that reason, he did not feel he had much to add to the conversation. The expectation was 9 participants but because two participants left, there were 7 participants, two of which were male fathers and one grandmother. At this time, the research team had to meet again with the family advocates and reiterate the importance of using the informational sheets and telephone script to recruit participants.

The Spanish focus group consisted of 10 participants. There were no recruitment issues and all the participants had Smartphones. There was one participant in the Spanish-speaking group stating she was a pharmacist and provided her knowledge and professional experiences with the group.

The focus group questions were designed to explore the two aims of the research study. The first aim was to understand Latino caregivers' current knowledge and issues concerning medication administration and management for children. The research team

included probes as well, which explained the initial question or suggested ideas for further exploration.

Aim 1: Questions

1. Describe any challenges you had in giving prescribed medicine to your child?
2. Tell us what steps you take to give your child medication? What do you do to remember when you have to give the medication to your child?
3. What do you use to give the medication to your child? For example if it is a liquid, how do you give it? Spoon, cup?
4. What would you like a doctor to give you to help you give the medicine to your child and to remember to manage your child's medication?
Probe: A log for medication schedule, tools to measure, etc.)

The second aim was to assess the current use and effectiveness of existing technology and Smartphone health apps by Latino caregivers to obtain health information. Probing questions were included, as previously explained.

Aim 2: Questions

1. What kind of apps do you currently have on your phone?
Probe: Social media, news, health?
2. Describe some of the smart phone apps you currently use to help manage your child's health?
3. What kind of features would you like to see in a smart phone health app that will help you manage your child's medicine?
Probe: example: measuring tools
4. What kind of features would you like to see in a smart phone health app that will help you follow your doctor's instructions?
Probe: features such as reminder to take medication, a schedule, etc
5. What has been your experience in finding health information through the Internet on your smart phone?
6. Sometimes medications are to be given for a set number of days, what do you do to complete the treatment?
7. Tell me what steps do you take to remind yourself to give medication to your child?

Results

The results include the demographics of the focus group participants and an analysis of the themes developed based on the participants' responses to the questions asked in regards to the two aims of the study.

Demographics

The first table provides the demographics of the seven participants in the English-speaking focus group (See Appendix 1). The second table provides the demographics of the 10 participants in the Spanish-speaking focus group (See Appendix 2).

Emerging Themes

In analyzing the transcripts, themes were developed in relation to the two specific aims. The first aim was to understand Latino caregivers' current knowledge and issues concerning medication management. The second aim was to understand Latino caregivers' current use of technology to gather health information. The five most common themes that emerged included (1) caregivers' experiences with medication administration, (2) techniques for administering medication, (3) relations with health care providers, (4) types of health resources caregivers use, and (5) the use of Smartphone apps. Based on the first aim of the study, caregivers' experiences with medication administration, techniques for administering medication and relations with health care providers were discussed. Based on the second aim, types of health resources caregivers use and Smartphone apps were discussed.

Aim 1: To understand Latino caregivers' current knowledge and issues concerning medication administration and management for children

Theme 1: Caregiver's overall personal experiences with medication administration

The caregivers discussed their overall personal experiences with medication administration. A caregiver from the English-Speaking focus group (FGE) responded to the moderator as she asked the question whether the caregivers ever miss any doses of medication for their child. The caregiver says,

I do, and um, before, when I first came out of the hospital, he was diagnosed with um complex partial seizures in July. I...I was so scared about it, so... I would give him medicine every single day, same time and um, then the medicine, it would, I thought it caused him to be overly hyper. So I spoke to the neurology, they said that's rare, that never happens, they usually like go to sleep and are calm, he's never calm. (FGE)

English-speaking focus group participants concluded that missing a dose or multiple doses of medication was worrisome. There was also a sense of fear among caregivers from the English-speaking focus group of the side effects of over dosing when administering medication. One caregiver says,

yah cause you know like, sometimes, if you give them, ourselves, when we drink something to much in our stomach, upsets our stomach and causes something else. Then it'll give you the runs, go do #2 to go to the bathroom to do number two or makes you throw up. Its always something so I was always scared. I didn't want to him to go back to the hospital so I was like, being on top of everything. (FGE)

There was mention of positive experiences among the caregivers in both the English and Spanish-speaking focus group (FGS) about being reminding by family members to administering medication to their child. They mentioned numerous times that being reminded from other family members, helped them administer medication; family members including the child taking the medication, siblings, husbands, grandparents, and other relatives.

I, for example tell my girl, to my big girl I say, "remind me that your brother should take medicine", then she comes and tell me, "Mami, it's time to give him his medicine", if not he himself comes and tells me, "It's time for my medicine" and looks at the clock. (FGS)

Grandparents...yes, they will call you at five o' clock in the morning. Literally. That's cultural. They're calling, and also they visit their grandparents, so we're working as a team and its, and as, and my daughter is like a big team. She is like the only granddaughter on her father's side. My sister calls, my mother calls, all the grandmothers. "La medicina! Now!" So everybody, the other grand mother calls, my mother, they call me, everybody is calling, the grandfather, its like, teamwork. (FGE)

Moderator asks: Umm, do you share the responsibility with someone else?...

I share it with my husband...Yes, he takes care of him at night and I in the daytime. I jot it down that I have done it in the daytime. He does it at nighttime because I don't in the night time. (FGS)

There were many caregivers who either preferred not to give their child medication as the first option or agreed that they often considered non-prescribed options to administer to their child. Both the English and Spanish-speaking focus group were very verbal about this. An example from a caregiver in the English-Speaking focus group says,

I think its really healthy to find a good balance because at some point you may need something but yeah, its always to try other things first because kids can build up immunity and or yeah, when they are kids, they don't necessarily really like it so you talked about cold clothes, doing temped tubs, getting them in a tub if they have a fever. (FGE)

The Spanish-speaking focus group also stated that because the school does not administer medication for their children, they have to come to the school in order to administer medication.

Head Start does not administer meds, parents must do so...

(Moderator asks) Ah-huh, ok, what do you do when your child has to take the medicine during the school day?

That's a problem because the school does not permit medications. One has to come to give it to them... it depends on what type of medication. (FGS)

The Spanish focus group also made it clear that while administering medication, they identify side effects based on reactions as opposed to reading the medication label or instructions.

Clearly, I will not use a large quantity, but I try small amounts to see what happens, to see if it works... (FG2)

When you get a reaction...Asking the doctors, if there are secondary reactions you should not give to them. " (FG2)

In addition to the caregivers' experience with administering medication to their child, they discussed types of measuring tools used for administration. From both the English and Spanish-speaking focus group, it was a clear consensus that the use of a plastic syringe and a dining spoon to measure and administer liquid medication were the most frequently used.

(moderator shows a picture of the syringe)

yah that's the best. (FGE)

that's...best thing that's ever made...its just like the measuring, he can take it himself. um, there be less spills. (FGE)

(Moderator) okay, so less spills, the measurement is clear on the syringe. um, he can take it himself so he can administer it. (FGE)

That is more for toddlers. I used it to give Tylenol since the did not open their mouths wide it is easier to give with the oral syringe. But also, it is not easy to give the child medicine when they are sleeping, you can place the quantity of medication in it and you place it on a spoon the exact amount, "open your mouth". (FGS)

(Moderator shows a picture of a dining spoon)

This is the one for us. (FGE)

That's what I do...easier and there's times he just wants the spoon like take away the syringe and give him the spoon. (FGE)

Some of the caregivers present for the English-speaking focus group had children with chronic bronchial illness or Asthma and described their experience with the inhaler and nebulizer, yet not pleased with the product usability. Some of the caregivers said,

*(Moderator shows a picture of an inhaler and nebulizer)
It has helped my daughter. It takes too long for it to work. It has to be the other one, the electric one, that one takes too long. (FGE)*

Mine cannot use, because she is little, and it is with a spacer. (FGE)

oh in, at the beginning, it was generic, it wasn't...okay. they had to hold them, tie it up like this, here.. it was a problem. (FGE)

I remember when he use to get congested when he was a baby still, I gave him the machine, that didn't work. I was like, I'm like, he was like fighting with me, I'm trying to put the cup. I'm like you know what...(FGE)

Theme 2: Techniques for Administering Mediations

Different techniques for administering medication were discussed by both focus groups, which included administering with a chaser, such as juice, using either physical restraint or scare tactics with the child and modeling the behavior of taking the medication.

An example used to describe a chaser was:

I give him cold glass of water or juice (FGE)

I always have the gummy vitamins at home, so when I buy him the other vitamin so that he can eat more, because he eats everything, but but only a little bit. (FGS)

An example of a scare tactic used by the caregiver was:

With the father he takes it easily, well, I will tell him drink it, drink it, drink it and if he does not want to drink it, then I will tell the father and I start telling him you will get better if you drink it. And he drinks it little by little. Because I just to hold him

and give it to him but not anymore. Now he takes the dosage cup and he drinks it. (FGS)

An example of a time the caregiver used physical restraint was:

My niece is the worse. You have to like tie her down, grab her and give her the medicine and she will spit it out. It's a hot mess (FGE)

An example used to describe modeling the behavior for the child was:

I drink it first... I taste everything first... (FGS)

Me too, I taste everything before giving it to the kids. I say look, it tastes sweet...or anything else I say first. (FGS)

I say, "it's delicious!" ... (FGS)

The Spanish-speaking focus group heavily emphasized grandparents and other family members as being active agents as a technique for reminding the caregivers to administer medication. They will either call, text, or leave a voicemail as a way to remind. Having family members as reminders was identified as a cultural aspect to the Latin community.

[grandparents] will call you at five o' clock in the morning. Literally...That's cultural. (FGE)

They're calling, and also they visit their grandparents, so we're working as a team and its, and as, and my daughter is like a big team. She is like the only granddaughter on her father's side. However, ...its favoritism...my sister calls, my mother calls, all the grandmothers. "La medicina! Now!" So everybody, the other grand mother calls, my mother, they call me, everybody is calling, the grandfather, its like, teamwork. (FGE)

I, for example tell my girl, to my big girl I say, "remind me that your brother should take medicine". Then she comes and tell me, "Mami, it's time to give him his medicine", if not he himself comes and tells me, "It's time for my medicine" and looks at the clock. (FGS)

Other reminder techniques included phone alarms and visual alarms (written on the fridge).

I kinda had remembered that, it was nice but I didn't have a phone with my children and I would set the phone, I would always have the phone with me. I set the alarm for the, I think it was 12 hours a part that he had to take it, you know, one of them ends up with he's sleeping, but you know, it was, it was pretty good. (FGE)

Sometimes I place a chart like on my fridge; I place and say, oh! For example, my daughter's name is Sara, Sara should use things because she got pneumonia. Then I constantly had to be on top of the medicine to take the phlegm out of her chest. (FGS)

Another technique mentioned by the caregivers was to use treatment or intervention options without seeking medical care; this is called self-care techniques because it is without seeking medical services by a health care provider in the U.S. This includes home remedies, over the counter medications and using medications brought back from the DR, which was very common among the Spanish-speaking focus group.

The Spanish-speaking focus group mentioned, on multiple occasions, using home remedies or botanical medicine as a technique. A few examples of what was said include:

...oregano tea, El-itzer, anti-parasite remedies, chamomile tea with algusema, star anise, miel de aveja. (FGS)

Yes, cause my grandmother use to make... for my little girl tea with two types of oregano. At night, in my house you can't miss out ... One at day, and another at night. (FGS)

Chamomile tea with algusema, star anise, things like that, and I give him a Little tea at night. Not everyday, but at least two to three times per week, you know. And I'm always there check his ears, checking his throat, his eyes. I'm always there, you know, it good to be on top of it. That's why he doesn't get sick. (FGS)

Caregivers from the English-speaking focus group mentioned using over-the-counter medications (OTC) and saline water as examples of self-care techniques. OTC medications include Tylenol, Motrin, Ibuprofen and suppositories)

· The name of the child has been changed in order to protect the identity.

First thing I have is, Ibuprofen and then the saline water...yeah that's like, all year round. Everywhere, I take it everywhere (FGE)

My son suffers form very high fevers and Tylenol, ibuprofen, nothing works, [Spanish]. I'll be up for like days and his fever goes up to 105 so its like those are things that doesn't even work. At first, when he first got it. my mom was like, get him, how you call this again-Feverall is the name of the box but um, basically its rectal... the medicine....supositorio [suppository in Spanish] ...so its that. It's the only thing that will calm his fever down, that's it. (FGE)

In addition to using home remedies and OTC medications, the Spanish-speaking focus group highlighted the use of medications from the DR as a self-care technique.

Normally the child when he has an infection it's either the throat or ears. I always have in my house, when I go to Santo Domingo (Dominican Republic); I always bring the antibiotics in powder. I don't prepare it, I always have it there. I also bring anti-parasite remedies (laughter in group). It's true, I give to my child twice a year. Because, you know why? We neglect a lot here (referring to the states), I know why I say this. It's true, that's why my child doesn't get sick. (FGS)

Theme 3: Relations with Health Care Providers

Among both focus groups, it was clear that their experience with health care providers, whether their own or their child, was instrumental in the process of being able to administer medication to their child successfully. In addition, they vividly expressed their expectations with their health care providers. A caregiver from the Spanish-speaking focus group provided a detailed experience with a health care provider when her daughter became ill and how she felt the health care providers in the DR were much more responsive. The caregiver said,

Draw blood, take an x-ray, who care that Medicaid or I have to pay and I have to work for a salary, but I want my daughter to be well...But there in Santo Domingo, the girl said (referring to another participant) that they don't care about the license

as much there, that's a lie. I take my child to a clinic when she's there, obviously not everyone can pay a clinic in Santo Domingo. But thank God-what happens- it's like about \$400 that about \$16,000 or \$18,000 Dominican Pesos. My daughter got sick with pneumonia; she had an accumulation of phlegm in her chest. What happened here... I went to the emergency and spent 7 to 8 hours with my mother. "Ah no it's because of a virus, it's a cold. They did not do lab work nor take x-rays and my little girl with pain in her chest. So we went to Santo Domingo. Three days later, I had to fly back because of college and I had to leave my daughter there with my grandmother, may she rest in peace. She had them draw blood and take x-rays. When they saw it her lungs were full of phlegm. They don't none of that here. All they do here is prescribe. (FGS)

Apart from having a healthy and communicative relationship with health care providers, caregivers in both focus groups discussed their expectations of the specific providers they believed to be the most qualified to provide medical advice. Among the Spanish-speaking focus group, doctors were the only professionals that should be able to provide medical advice.

NO residents...maybe a doctor...I just don't like students. Ya I've had bad experience with the student. (FGS)

Among the English-speaking focus group, it was clear the pharmacist was not the most qualified to provide medical advice.

Not a pharmacists, [they] are the ones who want to get their money. (FGE)

The caregivers from both focus groups explained their reasoning for having high expectations with their health care provider. They want to be diagnosed by their doctor and when they are not, they become frustrated with the medical system. A caregiver from the English-speaking focus group said,

Yes, because, look hospital (referring to community hospital); I was born there and my daughter too. And I say it, I don't like it. The system there is a joke. All they have

there are novices. The kids – it's alright you have give all an opportunity, because just like they studied, the doctors of today, obviously they have to go through school and there you have to understand, you have to see, you have to examine with your hand of experience. But I don't think it's right or just that you have to spend 6,7,and 8 hours in the emergency department. (FGE)

One caregiver from the Spanish-speaking focus group tries to explain why she thinks the general doctors do not provide a clear diagnosis on the first visit.

What happens is that doctors from here bases themselves more on what they have learned here in medicine. For example, when I interpret for the doctors whom I work for, the patients are like, "but he hasn't examined me". ... Anyhow, the doctor is the back and I am interpreting and patient says oh this hurts me and he's (the doctor) only there in the back saying, "okay, I am going send this to the pharmacy, this and that, and that's it. Usually the patient gets better. Until they don't do analysis (blood work) or they send you to a referral or specialist, a neurologist or gastroenterologist, you're not going to know what you have. You know, because the medical doctors only give you the general. If your stomach hurts, they send you to a gastroenterologist. That's why I think they are like that, you understand? (FGS)

A caregiver from the Spanish-speaking focus group provides a unique perspective of how elderly people are a reflection of the type of medical care they receive in the U.S.

Here it's Medicaid...Don't you see that when people ask me where do I live. I say in the country of the canes and diabetes. (a few giggle loudly) Really! In Santo Domingo they ask me where do you live, and I say in the country of the canes. Because here you got Medicaid, here, here...they don't think, oh let's give them something that will work. If you go to the doctor...You work, you take a day off to go to the doctor. You can't take off tomorrow because you have to work, you have to pay the house. (FGS)

Aim 2: To assess the current use and effectiveness of existing technology and Smartphone health apps by Latino caregivers to obtain health information

Theme 4: The Use of Health Resources

When discussing health resources, both focus groups discussed their use of conventional resources (Google, Wikipedia, WebMD) and their interest in chat rooms (peer-to-peer, professional interaction). A caregiver in the English-speaking focus group mentioned an example of using a conventional online data resource. She said,

(Moderator asks): lets go back to the conversation about looking up medical information on phones. Um, so there was mention that the use of Goggle, right?

yeah or Wikipedia...Wed MD tells you exactly what you need to know. (FGE)

During a conversation among the Spanish-speaking focus group, one caregiver shared a personal experience with using online resources to collect health information for his daughter. He also mentions how using a chat room with other parents having a similar issue with their child is beneficial.

Sometimes I have used ah, to ask for example, to Google something about situation I have with my daughter and Google give me some answers of people that have asked the same and people had answered that question but people. Google give me an address that for example, Univision.com, but its like a chat room that you check. I ask something in many people have had answered that possible that give a possible answer to that situation that someone ask. But its like, it's not professional. Its people answering something, cause of the experience that she has. (FGS)

Theme 5: Smartphone Apps

Among the focus groups, Smartphone Apps currently being used for health information were discussed. There was a consensus among the English-speaking focus group that an app that is specifically health related would be a good idea to develop. However, it was conclusive that they did not use an app to track medication. It was asked by one of the caregivers if an app that provided a tracking function existed.

(Moderator asks): How about do you have any apps on your phone? Have you downloaded any apps on to the phone that are health related?

Na...No...(FGE)

Well that's a good idea...now I feel like doing it. (FGE)

(Moderator asks): any apps that help you track medicine?

Haven't even...Na...I really haven't... I've never tried... I've never looked into see if there is one...is there? (FGE)

Current apps both focus groups discussed using included fitness apps and female/pregnancy apps. For caregivers with children with asthma, there was some discussion about using an app to inform them about asthma. Some of the social apps both focus groups discussed using included Pinterest, Facebook, Instagram. Findings suggest all participants are familiar and aware of these apps.

Both focus groups discussed what they would like to see in a health app and what some of the features may entail. It was clear that the function of the app, such as usability and contain no links to advertisements, was important. There was also mention of the app being all-inclusive, which means it would need to have multiple functions in one place and easily accessible information.

The most, most I would want, is simple. Simple is that like a Smartphone that be a smart. Because there are apps that are not smart are complicate, are stupid. (FGE)

Host app has many links and give you links and you continue. It's a host. (FGE)

...so that I can do it as I am walking to a train or to school. I mean, I don't want to sit there for 10 minutes trying to get my information.... (FGE)

Both focus groups discussed the need for a health app to include specific features. These features include:

To be offered in multiple languages:

Bilingual (Spanish); all agreed...in this place of course, Spanish first. (FGE)

For it to be in different languages, because there are people who do not speak Spanish, nor English. For example, there are people who speak Mandarin, French, or Portuguese, and they don't only talk in Spanish. (FGS)

To include chat options for peer-to-peer exchanges and to talk with health professionals:

An app that has like a doctor, like you can conversate with, like...have a conversation. That's a new update for the iPhones that there's gonna be a doctor. Like, I don't know if its connected, like which hospital it is, but you ask the doctor what you have and it tells you what you have to do and if its something that you can't do, they'll tell you to go to a hospital. That's something new their gonna come out with. (FGE)

About...let's say the child is for example...There are times that doctor may say if your child has a fever of 102.5, you can go to the emergency, but there are times that the fever can be controlled at home with medicines. So, therefore, if you had a live chat one can ask like... "look my child has a fever of 102.5, do you recommend that I go to the Emergency or give him Tylenol at home and if in 6 or 4 hours it does not work, well then take him to the emergency.(FGS)

To have visuals, including interactive photo sharing and videos:

Let say you have a rash, and I take a picture and send it. That will be good too...Visuals would be good. Like a small video. (FGE)

To include educational information for the local community for caregivers to access:

The application would be for local... taking that into consideration that it is for our community...Ummm, they can add things like activities for kids in the neighborhoods. Ummm, recommendations, for example about food. Well, things like that. Am I asking for too much?...Like for example, how to make a basic snack or a basic quick meal...they bring you the dip chips... (FGS)

If I have an app that can give me everything, it is even better yet and what is there in the neighborhood, because there are not a lot of activities for the kids. (FGS)

Well it should have every sickness out there that a child could get. How to cure it, what to give him or her. It should have everything. (FGE)

To include a space for patient and provider profiles for caregivers to use and view:

As for as the doctors, if we speak directly to a doctor, umm, or a resident, however, just for us to have their IDs and their information also. (FGE)

It seems that would be another good thing to have in a medical app though, a place to put all of your medical information and your insurance. Again, if you are with your child or someone else is going for the weekend... (FGE)

To have the immunization card inside too. Yeah, this will all be elective, you can either add the information to the app or... (interrupted)

There's a lot of parents that loses a lot of important things, but if you have it there, you know that you not gonna lose it. (FGE)

To include features to help prepare for medical visits to the doctor:

That app should have in consideration that always ask the time that our children have a feeling, specific symptom. I ask that because, I say that because, depending the time, that they, our children have a feeling that way, depends of the importance that we take the children to the emergency or not. For example, if you're asking something about how my child, my daughter has feelings this, for 4 days, it must be intelligent and give the answer, oh 4 days? that is a long time or it is a short time, depending on what you're asking. You see? (FGE)

To have a medication management component, including medication reminders, notifications, and dosing instructions based on the child's age and weight.

It's like the Do List, you know, its called the DO list, who ever has the iPhone, its called the DO list. Until you don't click on it that saying you did do it, it keeps on reminding you, reminding you (participant laughs). (FGE)

Maybe, see how, um, some things when you see a notification that comes up at the top of your phone, maybe something like ""time for medicine"". Everyone looks at the phone when it, when you have notifications, everyone goes through it. I just clear it out but I read it. So if basically a little reminder when it's ""time for medicine". (FGE)

Normally its by, you know when you look at a medicine in the back it tells you age or the weight. Like I noticed, when I was going to the hospital, they told me, no your child weighs more and he needs this amount and that's why its not working. and I'm like, how am I suppose to know if they never told me this. (FGE)

Caregivers from both focus groups were asked about the marketing strategy for this health app. They discussed the cost of the app and how they would promote it and specifically who should or should not promote the app.

A trial... Yeah exactly, I don't want to pay for something that is not going to be worth my money. You never know when it comes out, how it works. (FGE)

so there's at least like a trial and you have after two weeks. Even after...if I have try it for two weeks, I don't care how much it cost...\$10 or \$20, who cares as long as it does work. So I feel we should get a little taste into it. (FGE)

Yeah, like a year free subscription...(FGE)

The first 100 people who download the application should get it for free (all laugh loudly). (FGS)

Marketing strategy and promotion would best be accomplished through social media for those in the English-speaking group. The Spanish-speaking group related more to commercials, newspapers and radio as best option for promotion. Interestingly, it was made clear that using the doctors to promote this app would not be the best option.

Instagram, word of mouth, community meetings like at schools, Facebook, Twitter, commercials, public schools. (FGE)

One of them would be to make a lot of TV commercials in Hispanic channels. For example, in 41 is usually involved in (inaudible). For example, like I have heard them promote a lot of things about cancer for the women to go...So when they give a lot of promotion, people say "wait, let's download, let's get that. (FGS)

(Moderator ass): What if you heard from a doctor or medical professional, would you be more apt to download it?

It depends what doctor tells me...If my neurologist told me, I definitely be like go ahead and do it. It just depends where you take the child to... I just feel like um doctors, pediatrics, and hospitals; there should be flyers, word of mouth. (FGS)

Discussion

Discussion of Aim 1

The study demonstrated that for the Latino population with low literacy and English proficiency, there is a need to improve the understanding about administering and managing their child's medication in order to decrease the errors that many physicians report experiencing with their patients and their families. This perspective implies that the parents are the ones who need to change. It becomes clear from conducting both focus groups, that health literacy is a juxtaposition of individual skills and the demands and expectations of a health care system. This means that there needs to be an effort from both the population and the health care system to find a way to communicate better in order to receive the optimal care. The Spanish-speaking focus group expressed their distrust in the health care system when it comes to receiving the optimal care. There was also a sense of feeling dismissed by the health care providers or that their child's health issue "was no big deal".

Health literacy issues need to first be addressed by changing the demands and expectations of those working with patients with low literacy skills and low English proficiency. In addition, barriers in the system need to be removed in order to provide this population a shame-free and blame-free environment.

In order to create a shame-free environment, health care providers need improved training in health literacy and how to have a conversation with their patients and families. They need to explore ways to encourage families to ask questions and share their concerns and problems. In addition, health care providers should be more transparent about the fact that most people have difficulty understanding medical advice, not just those that are low

literate or low English proficient. Medical instructions need to be relevant to caretakers' culture and experiences.

The Spanish-speaking group provided a fruitful discussion about their experiences with the health care providers and their challenges with the system. Among the Spanish-speaking group, it was clear that their experience communicating with health care providers was instrumental in the process of being able to administer medication to their child successfully. In addition, they vividly expressed their expectations with their health care providers.

Majority of these participants have Medicaid insurance, and as they described in their discussion, they use their insurance to cover the cost of visits and prescribed medication; for instance, prescribed Tylenol. Although Tylenol is considered an over-the-counter (OTC) medication, by having it prescribed, Medicaid recipients do not have to pay out of pocket for this. Another strategy many of the caregivers discussed was using services in the Dominican Republic (DR). Although some of the caregivers mentioned some people could not afford to pay out of pocket costs for health services in the DR, they would continue to go in order to get faster service and faster treatment options such as antibiotic injections, a full blood work and x-rays-services.

The Spanish-speaking participants stated that using both services in the U.S. and in the DR was also a way to receive a second opinion. This means that by receiving services from both countries, the caregivers believed they could choose which treatment option they believed would work best for them and reject the option from the original diagnosis. The Spanish-speaking participants expected the "right" treatment whether it was in the DR or in

the U.S., meaning that fast appointments and prescribed medication is a way of knowing that they received the care and services they were expecting.

The demands and expectations of the health care system need to conform to what patients already know, and compliance with medication management needs to be a two-way process. The findings are clear- Latino caregivers want to feel included in their child's health decision-making process, but they also have their own expectations as to what they should receive from their providers. This is critical for health care providers to understand.

Discussion of Aim 2

Providing a child with medication is not always an easy task, which means that understanding the caregiver's challenges helps us, as researchers, understand the needs of this population. The focus groups provided important information about the need for clear, useful instructions and the need for reminders.

Some of the social apps both groups discussed using included Pinterest, Facebook, Instagram. Findings suggest all participants are familiar and aware of these apps. Both groups discussed currently using apps for fitness and pregnancy. For caregivers with children with asthma, there was some discussion about using an app to inform them about asthma. Apps currently being used by the caregivers are for health information but not for tracking medication management.

The English-speaking group was very informative in the development of a health app and specific features they would like to see included. They did not mention having the app available to be shared among family members as patients in addition to pediatric patients. This group seemed very excited about the app to use for their child alone. There was a

consensus among the English-speaking focus group that an app that is specifically health related would be a good idea but their main concerns were the use of links or ads. They wanted an all-inclusive app, which means the app should provide videos, pictures, chat rooms with parents and health care providers and easily accessible. Interestingly, the English-speaking group wants to be informed about the development of the app and consented to being contacted for further information in regards to the study and the development of the app.

Similar to the English-speaking group, the Spanish-speaking group was also interested in the development of the app. However, it was not conclusive whether to have a shared app among the family and for the family's use only or whether the app should include primary caregivers. One participant recommended the app be called "live chat" implying that the app should have a focus on the interactions among the families, patients and health care providers.

Caregivers from both focus groups were asked how they would market this all-inclusive health app. They discussed the cost of the app and how they would promote it and specifically who should or should not promote the app. The conclusion was that they would prefer credible sources to promote the app (news, community meetings, social media) and would not prefer to be told about the app by their doctor.

Limitations of the current study

Time was a critical factor in the accomplishment of specific activities. The time it took to get Institutional Review Board (IRB) approval had an impact on the recruiting, scheduling and conducting of two focus group sessions. In addition, due to the overlapping

conversations between the participants, repeated group laughter, and loud external noises, the audio recording of this discussion was challenging to transcribe and translate. However, there were sections with comprehensible dialogue.

Conclusion

This thesis and capstone project explored Latino caregiver's understanding and current knowledge of medication administration and their use of health technology to gather information. Two focus group sessions were conducted (one in English, one in Spanish) with 17 participants in total at a community based Head Start Program.

The major findings from the focus groups were that there is a distrust of the healthcare system by Latino caregivers, who want to feel included in the conversation about their child's health decision making. In addition, current medical training practices and curriculum should re-define the issue of health compliance and see it as an issue of accurate and appropriate education and communication.

The main recommendations for a community-based outreach program are to work with physicians, pharmacist and other health care providers to develop improved communication skills that are culturally relevant and geared towards diverse populations. In addition, it was recommended to develop a Smartphone health app including the findings from the focus group discussions. If a Smartphone health app were to be created, it would need to have interactive features, be provided in multiple languages, simple to use and include various educational resources. Future research should be conducted on how to create improved medical training programs for health care providers as well as for those working with a culturally diverse and low literate population.

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Appendix 1: Focus Group Demographics: English-Speaking (FGE)

| ID# | Sex | Age | Latino Ethnicity | Race | What language do you feel most comfortable speaking with your doctor or nurse? | How would you rate your ability to speak and understand English? | In which language would you feel most comfortable reading medical or health care instructions? | Education Level | Born | Length of time in U.S. | Insurance |
|-----------------|----------|------|---------------------------------------|---|--|---|--|--|--|---|--|
| | | | 1. Yes 2. No 8/ Prefer not to respond | 1. White 2. Black/ African American 3. Asian 4. Native Hawaiian/ Pacific Islander 5. American Indian/ Alaskan Native 6. Multiracial 7. Other 8. Prefer not to respond | 1. Spanish 2. English 3. Other 8. Declined 9. Unavailable | 1. Excellent 2. Good 3. Fair 4. Poor 5. Not at all 8. Declined 9. Unavailable | 1. Spanish 2. English 3. Other 8. Declined 9. Unavailable | 1. Less than H.S. 2. HS diploma or GED 3. Some College 4. College Grad 8. Don't know | 1. Inside the U.S. 2. Outside the U.S. 8. Don't know | 1. Less than 5 years 2. 5-10 years 3. 10-15 years 4. more than 15 years 8. Don't know | 1. Private 2. Medicaid 3. Uninsured 4. Other 8. Don't know |
| FGE-1 | M | 38 | 1 | 1 | 2 | 2 | 2 | 4 | 2 | 1 | 2 |
| FGE-2 | F | 34 | 1 | 8 | 2 | 1 | 2 | 1 | 1 | / | 2 |
| FGE-3 | M | 30 | 1 | 7 | 2 | 1 | / | 1 | 1 | / | 2 |
| FGE-4 | F | 23 | 1 | 8 | 2 | 1 | 2 | 3 | 1 | / | 3 |
| FGE-5 | F | 27 | 1 | 7 | 2 | 1 | 2 | 4 | 1 | / | 3 |
| FGE-6 | F | 55 | 0 | 1 | 2 | 1 | 2 | 4 | 1 | / | 2 |
| FGE-7 | F | 29 | 1 | / | 1,2 | 1 | 3 | 3 | 1 | 4 | 1 |
| Total FGE (n=7) | 2 M, 5 F | 33.7 | 6 Latino, 1 not Latino | 2 White, 2 Other, 2 Preferred to not respond | 6 English, 1 both E&S | 6 Excellent, 1 Good | 5 English, 1 both, 1 did not answer | 2 HS/ GED, 2 some college, 3 college graduate | 6 inside the U.S., 1 outside the U.S | 1 less than 5 years, 1 more than 15 years, 5 did not answer | 1 private, 4 Medicaid, 2 uninsured |

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Appendix 2: Focus Group Demographics: Spanish-Speaking (FGS)

| ID# | Sex | Age | Latino Ethnicity | Race | What language do you feel most comfortable speaking with your doctor or nurse? | How would you rate your ability to speak and understand English? | In which language would you feel most comfortable reading medical or health care instructions? | Education Level | Born | Length of time in U.S. | Insurance |
|------------------|------|------|---------------------------------------|---|--|---|--|--|--|---|--|
| | | | 1. Yes 2. No 8/ Prefer not to respond | 1. White 2. Black/ African American 3. Asian 4. Native Hawaiian/ Pacific Islander 5. American Indian/ Alaskan Native 6. Multiracial 7. Other 8. Prefer not to respond | 1. Spanish 2. English 3. Other 8. Declined 9. Unavailable | 1. Excellent 2. Good 3. Fair 4. Poor 5. Not at all 8. Declined 9. Unavailable | 1. Spanish 2. English 3. Other 8. Declined 9. Unavailable | 1. Less than H.S. 2. HS diploma or GED 3. Some College 4. College Grad 8. Don't know | 1. Inside the U.S. 2. Outside the U.S. 8. Don't know | 1. Less than 5 years 2. 5-10 years 3. 10-15 years 4. more than 15 years 8. Don't know | 1. Private 2. Medicaid 3. Uninsured 4. Other 8. Don't know |
| FGS-1 | F | 24 | 1 | 1 | 1 | 4 | 1 | 1 | 2 | 2 | 3 |
| FGS-2 | F | 29 | 1 | 7 | 1,2 | 1 | 2 | 4 | 2 | 4 | 1 |
| FGS-3 | F | 36 | 1 | 7 | 1 | 2 | 1,2 | 3 | 2 | 3 | 2 |
| FGS-4 | F | 29 | 1 | 8 | 1, 2 | 1 | 1 | 4 | 2 | 4 | 2 |
| FGS-5 | F | 45 | 7 | 1 | 1,2 | 4 | 1 | 2 | 2 | 2 | 2 |
| FGS-6 | F | 52 | 1 | 6 | 1 | 5 | 1 | 8 | 2 | 2 | 2 |
| FGS-7 | F | 29 | 1 | 7 | 1 | 5 | 1 | 2 | 2 | 1 | 2 |
| FGS-8 | F | 21 | 1 | 7 | 1, 2 | 1 | 1,2 | 3 | 1 | 4 | 2 |
| FGS-9 | F | 42 | 1 | 8 | 1 | 8 | 1 | 8 | 1 | 2 | 3 |
| FGS-10 | F | 25 | 1 | 8 | 1 | 3 | 1 | 2 | 2 | 3 | 2 |
| Total FGS (n=10) | 10 F | 33.2 | 9 Latino, 1 Other | 2 White, 1 Multiracial, 4 Other, 3 Prefer not to respond | 6 Spanish, 4 both English and Spanish | 3 Excellent, 1 Fair, 1 Good, 2 Not at all, 1 Prefer not to respond | 7 Spanish, 1 English, 2 Both Spanish and English | 1 Less than H.S., 3 H.S./GED, 2 Some College, 1 Graduated College, 2 Don't Know | 8 Outside of the U.S., 2 In the U.S. | 1 Less than 5 years, 4 5-10 years, 2 10-15 years, 3 more than 15 years | 1 Private, 7 Medicaid, 2 Uninsured |