Bridging the Gap: Spanish speaking Hispanic patients’ information preferences during hospitalization.

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Abstract

Background: Self-management of chronic conditions, such as cancer or diabetes, requires coordination of care across multiple care settings. Current patient centered hospital-based care initiatives, including bedside nursing handoff and multidisciplinary rounds, often retain a focus on provider information exchange and roles but fall short of the goals of participatory medicine, which recognize the right of patients to partner in their own care and take an active role in self-management.

Objective: The purpose of this study was to elicit Spanish-speaking Hispanic patients’ perspectives on the exchange and sharing of information during hospitalization.

Methods: This exploratory pilot study incorporated a qualitative descriptive approach through the use of Spanish language focus groups, post hospitalization, to determine patient identified information needs during a hospitalization.

Results: Participants preferred paper instructions in Spanish. Doctors and nurses were the key information providers and communicated with the participant verbally, usually with the assistance of a translator. The participants expressed a desire to be informed about medications and treatments, including side effects and why there were changes in medications during the hospitalization. They expressed interest in knowing about the progress of their condition and when they could expect to go home. Emotional readiness to receive information about their condition and prognosis was identified as an individual barrier to asking questions and seeking additional information about their condition(s).

Conclusions: Overall, participants shared positive experiences with providers during hospitalization and the usefulness of self-care instructions. Language was not recognized as a
barrier by any of the participants. Future research on the influence of emotional readiness on timing of medical information is needed.

**Keywords:** Self-management, chronic disease, diabetes, cancer, patient-provider collaboration, Hispanic
Current patient centered hospital-based care initiatives, including bedside nursing handoff and multidisciplinary rounds, often retain a focus on provider information exchange and roles but fall short of the goals of participatory medicine, which recognize the right of patients to partner in their own care and take an active role in self-management [1, 2]. Yet, research has shown that patients who were more involved with their care had better health outcomes, fewer hospitalizations, and lower health care costs [3]. In the U.S., the Patient-Centered Outcomes Research Initiative (PCORI) was established in 2010 to support the patient-centered care research component of the Patient Protection and Affordable Care Act [4]. The PCORI vision recognizes the importance of patients having “information they can use to make decisions that reflect their desired health outcomes” [5], but little is known about patient identified information needs.

Self-management of chronic conditions, such as cancer or diabetes, requires coordination of care across multiple care settings. For example, in the outpatient environment patients with cancer commonly participate in shared decision making; starting with treatment decisions when first diagnosed, monitoring of laboratory results during chemotherapy and radiation treatments, and monitoring of the efficacy of treatment and progression or remission of the cancer through imaging studies [6]. Online ambulatory personal health record portals commonly include test results and visit summaries. Patients participating in the “Open Notes” project have real time access to their ambulatory medical record, including clinician notes [7]. Participating patients have reported that this access helped them understand their medications and to review and recall treatment decisions [7].

Hospitalization has been described as a disempowering experience [8] that can be particularly challenging for Spanish speaking Hispanic patients as a result of cultural differences.
and language barriers which have been associated with patient safety risks [10, 11] and misunderstandings that lead to adverse events during hospitalization and after discharge [12]. One way to support inpatient access to health information during hospitalization [13-15] is for healthcare providers to share information during interdisciplinary rounds and nursing shift change handoff at the bedside. This behavior supports the exchange of health information such as treatment options, test results, care decisions, and discharge plans. Nonetheless, research has shown that patients may be reluctant to ask questions due to structural barriers, such as the way the care is delivered or organized, perceptions of paternalistic attitudes, and the power imbalance between patients and providers [16, 17]. The purpose of this pilot study was to identify what health information Spanish speaking Hispanic patients want and need during hospitalization and to explore participant’s views on inclusion in nursing shift change bedside handoff and medical rounds held in their hospital room.

Methods

Study Design. This exploratory pilot study incorporated a qualitative descriptive approach through the use of Spanish language focus groups, post hospitalization, to determine patient identified information needs during hospitalization and how hospitalization influences patient self-management of cancer across care transitions.

Sample and Setting. Participant inclusion criteria: Hispanic, Spanish speaking, age 18 years and older, living in the community, diagnosed with cancer or another chronic disease, and have had an inpatient hospitalization after their chronic disease diagnosis. Recruitment flyers with study information and research team contact information were distributed at a local cancer center, community clinics, and through the university Hispanic employee organization. Spanish
speaking team members were available via phone or at designated times at the cancer center to answer questions and sign up participants that met the inclusion criteria.

**Study Procedures.** First, the research team collaborated on the development of culturally appropriate focus group questions and probes. Next, a focus group interview guide was developed by the research team with input from two Spanish language focus group consultants and professional focus group moderators. The guide included an introduction that provided the purpose of the session, including the reason for the focus on Spanish speaking Hispanic patients with chronic diseases, and introduction of the main study concepts. The interview and the demographic question questionnaire were translated into Spanish. The focus group facilitators used the research team developed interview questions and guide. Table 1 contains the English version of the moderator guide.

**Table 1: Focus Group Moderator Guide**

| **INTRODUCTION:** Role of moderator; Independent moderator, not connected to research organization; general description of research; everyone participate – no right or wrong answers; recording audio of session; anonymity |
| **INTRODUCTORY QUESTION:** Tell us your first name, family life, and in which hospital did you most recently receive treatment? |
| **TRANSITION QUESTION 1:** How do you keep track of your health information (medications, appointments, treatments, etc.) as you go from provider to provider and location to location? |
| **Probe:** Personal health record, notebooks, electronic apps, calendars, other family member. What do you like about this method? Explain why some methods have not worked for you. |
| **TRANSITION QUESTION 2:** What about when you are in the hospital during a hospital stay? How do you keep track of your health information (what the providers tell you about your medications, tests, and treatment plan) while you are in the hospital? |
| **Probe:** In-patient portal (Ask if they know what this is. Explain what this is); white board in the room; personal tools – paper and pencil (e.g. notebook; folders); electronic method, family member. What about this method works best for you? What does not work for you? |
| **KEY QUESTION 1:** Tell me about the last time you were hospitalized. Who explained your self-management treatment to you? How did the conversation make you feel? |
| **Probe:** Describe the conversation? Were you invited to participate in the discussion? Did they speak Spanish or did they have a translator? If you asked a question, did you feel that the personnel were responsive? |
| **KEY QUESTION 2:** What kinds of medical information are you interested in knowing about or documenting when you are in the hospital? Explain why this information is important to you? |
| **Probe:** Is there anything you would prefer not to know about when you are in the hospital? What information do you need while hospitalized to prepare you for managing your own care when you go home? |
Focus group procedures followed established guidelines [18] and were facilitated by experienced Spanish language focus group moderators. Spanish speaking members of the research team obtained informed consent and distributed the demographic survey. A research team member also supervised the session recording.

**Measures.** Demographic questions included participant age, education, gender, ethnicity, primary chronic disease, secondary chronic diseases, hospitalization date, and length of stay. During the focus group, participants were also asked to recall hospital characteristics and information sharing processes (e.g. nursing handoff location, patient invitation to participate). Focus group questions included asking about patient beliefs regarding existing self-management practices, the influence of hospitalization on self-management, patient information access during hospitalization, and information needed by patients to resume self-management after discharge (Table 1).

**Data Analysis.** Descriptive statistics were used to analyze the demographic questions. Focus group sessions were conducted in Spanish, audiotaped, transcribed and translated into English by
the Spanish language focus group moderators. The research team members and focus group moderator were debriefed after each session. Analysis of the focus group transcripts followed the steps of conventional content analysis [19, 20].

**Protection of Human Subjects.** The University of Texas at Austin IRB approval and cancer center permission were obtained before the study commenced. Spanish language informed consent was obtained per regulatory guidelines and institution IRB approvals. Participation was voluntary and participant identification information was not collected during the focus groups. A $75 gift card was offered as incentive for participant time and transportation.

**Findings**

**Characteristics of the Focus Group Participants**

The two focus groups were conducted at the School of Nursing on the campus of the University of Texas at Austin. Focus group participants (n=8) were Hispanic women with an average age of 55 years (range 47-66). Primary chronic disease diagnoses included cancer and diabetes. Secondary chronic diseases included hypertension, arthritis, idiopathic thrombocytopenia purpura, and heart or liver disease. Participants reported having been hospitalized within the last 2-8 months and were hospitalized for 2-14 days (µ=6).

**Tracking Health Information**

Participants were asked about how they kept track of their health information (medications, appointments, treatments, etc.) across multiple care settings and providers. Most participants did not have a specific method for keeping track but some relied on “papers” handed to them by providers and on reminder calls initiated by the providers. Most did not have home computers or internet access but did have the ability to text using their mobile phones. When discharged from the hospital, participants reported receiving a folder or a bag with information about their
condition and upcoming treatments. This information was commonly provided in both English and Spanish. When asked about reading the information, the participants indicated preference for Spanish language information but one participant reported purposely not reading any of the information because she preferred not to know about her condition.

Next, the participants were asked how they kept track of their health information while they were hospitalized. Results of tests, information on treatments, and medications were provided to the patient, family members or relatives, almost exclusively in verbal format by nurses or other health care providers. Some participants reported receiving lab results and information about their treatment from their doctor in English, but always having a translator available either in person or via telephone to assist. Also, participants mentioned that they occasionally had a Spanish speaking nurse or they relied on family members who spoke English to translate.

Participants reported that they did not actively keep track of test results, medications or treatments in any written format or use any specific tracking system. Only one participant mentioned a family member taking notes. None of the participants reported having access to an inpatient portal during their hospitalization. Some participants mentioned a whiteboard in their room that provided the name of the doctor, nurse, nurse assistant, and medication administration times; others reported not having access to any of their health information while hospitalized.

**Opportunities to Participate in Information Exchange**

Of specific interest were opportunities for the participants to obtain health information during nursing bedside shift change handoff and medical rounds in the patient’s room. During shift change handoff, most participants reported that both outgoing and incoming nurses were present in their room. Commonly, the nurse that was leaving introduced the new nurse and discussed the patient’s treatment plan for the upcoming shift. Most participants reported they were able to
participate in these conversations. In some instances, only an introduction of the new nurse took place without much treatment discussion and, at times, no introduction took place before a shift change. In contrast, the participants reported that the doctor(s) visited them after surgery and during rounds when they would explain the treatments the patients were receiving. All doctors made a point to introduce themselves. The participants felt doctors were respectful and as patients they were able to understand and ask questions through in person translators or via telephone. Doctors also shared information with families if they were present.

**Information Desires/Needs**

Some participants in the focus group identified information that they would like to receive from practitioners including: explanations regarding tests they are to undergo, test results, reasons for receiving certain medications or treatments, side effects of medications, and why there is a change in medications or the reason medications are not working. In addition, participants wanted to be informed about the progress of their condition and be informed regarding when they could expect to leave the hospital. Other participants want more information on the consequences of their condition (diabetes) when it is not controlled. Avoiding negative emotions and “sinking into depression after her cancer diagnosis” were concerns but the solutions varied. One patient indicated she wanted more information and another did not want to know more soon after the cancer diagnosis due to feeling overwhelmed and depressed. Contact with social workers and counseling in Spanish were reported to have been helpful for some after leaving the hospital.

**Information Shared by Providers During Hospitalization**

When asked to recall the last time they were hospitalized and information they received about managing their medical conditions after they went home, the participants reported
receiving good information from a doctor or nurse and that there was always access to a
translator in person or by telephone. Participants shared that the information was well explained,
they were able to ask questions through the translator, and they knew who to call if they had
further questions or concerns once they got home. On discharge, they were provided with paper
information in English and Spanish to take home and refer to for their self-care and follow-up
treatment.

**Self-Care and Self-Efficacy**

Most of the participants felt confident about their self-care at home once released from the
hospital. They reported receiving the necessary information needed to take care of themselves
after their discharge and what symptoms or signs to watch for to identify problems. Specific
information that helped them with self-management after going home included; limiting activity
and other instructions to reduce bleeding and infections, learning about diet to control their
diabetes, learning how to use a pillow as a coughing aid after surgery to extract sputum, and
learning about a new prescription and its side effects for a chronic condition.

None of the participants felt they had encountered problems due to not being able speak
English well nor did they feel they had been treated better or worse because of it. One participant
with diabetes expressed being very hesitant and uncomfortable about having to inject herself at
home, but a family member was able to help using information and video instructions provided
by the hospital. Health care providers who were friendly, polite, and who made the patients
comfortable and at ease were identified as contributing to patient willingness to ask and learn
about self-management. Once at home many of the participants noted that they received
important self-management instructions (verbal and paper) from their pharmacists when picking
up medications after treatments or hospitalization.
Discussion

Participants did not hesitate to share their stories of diagnosis and treatment with the group, and in fact seemed eager to share their experiences. For some of the participants, it was clearly the first time they had shared their story publicly. While the emotional consequences of undergoing diagnosis and hospitalization were not part of this study, the topic of depression came up in both focus groups. Participants shared their difficulties in coping emotionally with their medical condition. Research has shown that religious beliefs are an important coping mechanism for this population [21]. The focus group conversations were filled with religious references, such as “I prayed a lot” or “put it in God’s hands” suggesting a strong faith belief among the participants as a way of accepting or coping with their medical conditions.

Research has shown that psychosocial stress [22] and fear of cancer [23] and other chronic diseases, such as diabetes, impact readiness for learning and information seeking behaviors. This study revealed that, for some participants, a major barrier to asking questions was their own reluctance to learn more about their condition, which some linked to their emotional response to dealing with their chronic disease.

Although language barriers have been associated with patient safety risks [14, 15] and misunderstandings that lead to adverse events during hospitalization and after discharge [16] these Spanish-dominant patients did not believe that their inability to communicate in English acted as a barrier in understanding and implementing self-care because translators were always present or available either in person or on the phone. In the outpatient environment, participants identified that pharmacists often provided self-management information which is consistent with previous research findings [24].
These findings stand in sharp contrast to earlier work that revealed patient frustration with lack of access to information [25, 26], provider behaviors that inhibited patient participation in bedside handoff [26], and desire for electronic access to medical records. While differences in patient demographics between the studies may explain some of the differences, there is a possibility that our findings reveal that healthcare initiatives to be culturally inclusive [27] and break down language barriers by provide translators [28] are improving the health care experience of Spanish speaking Hispanic patients.

An important lesson learned during this study was how federal initiatives and resulting news stories may influence recruitment and participation in focus groups. Twenty four people were scheduled to participate in the focus groups but multiple people unexpectedly dropped out. Reminder phone calls revealed hesitancy to attend due to fear of government “representatives” and a perceived threat of deportation. Research is needed to learn more about perceived threat of deportation influences participation in research studies and willingness to access health care services.

Limitations

Although this study revealed important information it is also important to acknowledge study limitations when interpreting the results. The final pilot study sample was smaller than planned and included only women. In addition, participants were recruited from a limited geographic area within the city of Austin. Future research will focus on increasing the number of participants and expanding the recruitment area. This will include holding focus groups at multiple locations, on different days, and increasing efforts to recruit men.

Conclusion
This study supports the need for research to elicit Spanish speaking Hispanic patient perspectives on facilitators and barriers to obtaining the information they need during hospitalization and participation in traditional provider focused information sharing activities, such as handoffs and rounds. Overall, participants shared positive experiences with providers during hospitalization and the usefulness of Spanish language self-care instructions. Surprisingly, language was not recognized as a barrier by any of the participants. Future research on the influence of emotional readiness on the timing of medical information access and the pharmacists’ role in patient self-management in the outpatient setting is needed.

**Acknowledgement:** This research was supported by a grant from St. David’s Center for Health Promotion and Disease Prevention Research in Underserved Populations (CHPR) at the University of Texas, School of Nursing.
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