An Intercultural Analysis of Sources of Medical Information in Spanish-Speaking Diabetes Patients

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Abstract

Understanding and improving health literacy have become important goals in health communication. Research has shown that limited health literacy is associated with poor health outcomes and that it is more prevalent in culturally and linguistically diverse populations. The goals of this study are to describe English-speaking (ES) and Spanish-speaking (SS) diabetic patients' perceptions of sources of health information, to identify the actions patients report taking in seeking that information, and to test reading comprehension of medical information among SS patients.

Data for this study were based on semi-structured interviews, life-story narratives, and a reading comprehension test with diabetic patients (43 native ES patients and 22 native SS patients with limited English proficiency) collected at a bilingual clinic and at an English-speaking clinic in the Midwestern United States (Indianapolis, Indiana). The results showed that the three approaches to the assessment of health literacy revealed disparities in access and use of sources of information as well as disparities in reading comprehension of health information. In view of the results, we argue that understanding and assessing health literacy, particularly in the case of ethnic minorities, requires complementary approaches of study. Emphasis should be placed on addressing the disparities SS patients face. Interventions should aim at maximizing the role of oral sources of information, training patients to use a wider variety of sources, and designing

linguistically and culturally appropriate sources of health information for patients with limited English proficiency.

Key words: Health Information, Health Literacy, Latino Health, Diabetes Management.

Introduction

Limited health literacy has been associated with less primary prevention (Scott, Gazmararian, Williams, & Baker, 2002) and poor health outcomes (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004). This study investigates perceptions and practices in health information-seeking behavior among English-speaking (ES) and Spanish-speaking (SS) diabetes patients in the United States.

Diabetes has rapidly become a global health problem. The American Diabetes Association has documented that in the U.S. alone 25.8 million people (8.3% of the population) have been diagnosed with diabetes, seven million have undiagnosed diabetes, and 79 million are in the pre-diabetes phase. Among those 20 years old or older, Hispanics suffer from diabetes at a higher rate than Non-Hispanic whites (11.8% of Hispanics vs. 7.1% NHW) (Centers for Disease Control and Prevention [CDC], 2011). Given that the Hispanic population in the US reached 50.5 million in the 2010 Census, which represents 56% of the total U.S. growth, a better understanding of diabetes management in the Hispanic population is critical.

Based on data from semi-structured interviews conducted with the patients, we illustrate and discuss three approaches to understanding variation in health literacy between English-speaking (ES) and Spanish-speaking (SS) groups.

Health Literacy

The study of health literacy in the U.S. has increased since the publication of the Institute of Medicine (IOM) *2004 Health Literacy Report*, which defined health literacy 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" (p. 32). This is based on an individual's skills to interact with health contexts, the healthcare system, and the education system, as well as social and cultural factors at home, work, and in the community.

In a meta-synthesis of the literature on health literacy, Edwards, Davies and Edwards (2009) propose a model of information seeking/giving that leads to an empowered patient. Their model highlights the importance of other types of literacy beyond functional literacy, namely *interactive health literacy* and *critical health literacy*. Interactive health literacy involves the social and personal skills that enable individuals to derive meaning from different kinds of communication and apply it. Critical health literacy entails advanced skills to analyze information and use it to control life events. According to Edwards et al. (2009), poor health literacy contributes to a decreased ability to participate in shared decision making.

Studies have documented the difficulties caused by low health literacy levels in comprehending labels on pill bottles, patient information leaflets, educational materials, and informed-consent forms (e.g., Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs 1999;

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Doak, Doak, & Root 1996; Gazmararian et al., 1999; Mayeaux et al., 1996). Functional health literacy has also been related to diminished oral comprehension among patients of technical and explanatory dimensions of clinician-patient dialogue (Schillinger, Bindman, Wang, Stewart, & Piette, 2004).

In sumary, recent research has uncovered a clear connection between the ability to obtain information and turning that information into knowledge. Patients who know how to access information about complex health issues should be better able to take care of themselves. Yet research results indicate that additional skills, such as speaking and listening, need to be considered part of health literacy as well.

While the definition of health literacy largely relies on individual capabilities, others have highlighted a *contextual appreciation of health literacy* (Paasche-Orlow & Wolf, 2007) in which individual and system-level factors affect access and actions in health care management. Paasche-Orlow and Wolf's conceptual model of causal pathways, which may explain the association between health literacy and health outcomes, highlights three points where health literacy is most relevant. These are: 1) access and use of health care; 2) patient-provider interaction; and 3) self-care. In accessing and using health care, a patient's ability to navigate the health care system and the patient's self-efficacy interact with system factors such as the overall complexity of rules and regulations for accessing health care. In interacting with health care providers, a patient's knowledge and beliefs about the disease, together with the patient's expectations on being able to participate in health decision-making, interacts with the provider's ability to communicate with patients, the time available to interact with patients, and the provider's orientation to patient care. Finally, in self-care, individual factors such as motivation, self-efficacy, and knowledge about the disease interact with extrinsic factors like health education and other media and technological resources to support patients. Motivation and the ability to take care of oneself must be supported by the knowledge of what to do.

The National Assessment of Adult Literacy survey (NAAL) showed that health literacy ability predicts disparities in access to sources of health information and health outcomes (Kutner, Greenberg, Jin, Paulsen, & White, 2005). In the following section, we discuss previous literature on health literacy and access to health information by ethnic minorities with special emphasis on Latinos.

Ethnicity and health literacy

An important part of managing a chronic disease is having access to–and understanding– necessary and culturally appropriate information. Yet research has demonstrated that poor health literacy is more common among patients who have low educational levels, as well as among immigrants and older patients (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999). Processing of information presents a special challenge to those whose native language is not English. Both general literacy and health literacy (Gazmararian et. al., 2005) are reported as lower among minority groups and non-native speakers. Gazmararian et al. (1999) studied new Medicare enrollees at multiple sites in the U.S. and found that Spanish-Speaking (SS) patients scored lower in health literacy than English-Speaking (ES) patients, with 53.9% of SS patients measured at marginal or inadequate functional health literacy on the short

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Test of Functional Health Literacy as compared to 33.9% of English speakers. The SHINE project (Gordon et al. 2004) examined health communication through focus groups and individual interviews of elderly immigrants (n=101) from nine language groups, including 18 Spanish speakers. Their conclusion was that elderly immigrants lacked competency for effective communication in a health care environment. These and other studies demonstrate that SS patients in the U.S. face challenges in accessing and comprehending information.

A telephone study by Talosig-Garcia and Davis (2005) identified what information sources are accessed and what differences exist between language groups in information access for a specific disease. Other studies (Arora, Marzec, Gates, & Menchine, 2011; Rosal, Borg, Bodenlos, Tellez, & Ockene, 2011) later showed that health information fails to reach Latinos. In a large study sponsored by the National Cancer Institute, the Health Information National Trends Survey (HINTS), data were gathered on different aspects of information related to cancer and how this information is used in the US. The survey included general questions about information use and information seeking trends that are relevant to populations with diabetes as well. Three reports on this survey are of particular interest here. One report from HINTS (Rutten, Moser, Beckjord, Hesse, & Croyle, 2007) summarized phone survey cross-sectional data from 2003 and 2005 on health communication and cancer communication, including media exposure, information seeking, internet use for seeking health information, knowledge of the disease, perception of barriers to information seeking, evaluation of information efficacy and use. The study tracked information seeking behaviors as a function of acculturation and compared those behaviors of Hispanics with those of Non-Hispanic Whites (NHW) based on HINTS 2005 results. Results indicate that ethnicity and language are important predictors of health information seeking and that SS Latinos are overall less likely to seek health information from any source than ES Latinos and NHW.

It is also clear that SS Latinos have different preferences for sources of health information than the other groups. Of particular note, reporting on seeking health information on the internet shows stark differences. Fewer than 8% of SS Latinos reported such use compared to over 40% of ES Latinos and NHW. More SS Latinos reported doctors as their first source of health information compared to ES Latinos and NWH. SS Latinos also reported books as a source of health information at a much higher rate than ES Latinos and NHW. On the other hand, more media (television, radio, internet, newspapers) was used by ES Latinos than SS Latinos. NHW also used television and newspapers more often than SS Latinos.

According to another report, the HINTS Briefs (National Institutes of Health [NIH], 2009), Hispanics are less likely to seek cancer information than non-Hispanics, and among Hispanics, rates differ according to English proficiency. Lack of English fluency is a barrier to health information for SS Latinos. Eighty-three percent of SS Hispanics have never looked for cancer information, and those who did reported dissatisfaction with the experience due to difficulties in comprehension and lack of trust. The report recommends language appropriate information tools, use of interpersonal communication (healthcare providers, family, friends) in addition to translation of printed documents.

Zhao and Cai (2009) noted in a third HINTS report that immigrants have less access to healthcare than their U.S. born counterparts. They are also less likely to seek information, have great difficulty in using that information, have lower trust in health information sources, and have more negative beliefs about cancer. Information seeking, however, is associated with more accurate beliefs among foreign-born individuals. Thackeray et al. (2004) indicate that family members, health beliefs, and healthcare access influence Hispanic diabetes management in ways that differ from non-Hispanic behavior. Differences in information seeking and information access may shape knowledge, attitudes, and behaviors about health, including medical decisions. Thus, such differences may contribute to health disparities in disadvantaged populations.

Most work done to date on health information and information-seeking practices, and particularly of differences among and between Hispanic and non-Hispanic populations, has been survey-based (NIH, 2009; Livingston, Minushkin, & Cohn, 2008; Peña-Purcell, 2008). The results of these studies suggest that interventions are needed in the areas of health beliefs of different immigrant groups, health information needs of immigrants, and evidence-based strategies of health communication.

While surveys provide important information on trends and areas for further study, the need to search deeper to understand what lies behind survey results is evident. Survey-based studies have not addressed how information is turned into knowledge, and how knowledge impacts medical decisions. It is this lack of understanding of the chain of events between information access and application in disease self-management that motivates the use of additional methods of inquiry into health information-seeking behavior. This study was designed to determine what information sources diabetes patients (including Spanish-speakers) access and their preferences and ratings of such sources, and then through interviews to identify their application of this information to disease self-management. In the study presented here, multiple approaches were used to analyze information-seeking preferences and practices. This comparative study of non-Hispanic English speakers (ES) and SS Latinos with diabetes used an open-ended qualitative interview and a patient information leaflet (PIL) reading comprehension test, in conjunction with a survey-based approach, to provide complementary information on health literacy practices among our patient population.

Research goals

The goals of this study were 1) to describe the *perceptions* of ES/SS patients related to various sources of medical information for managing their diabetes, 2) to identify the *actions* patients report taking in seeking medical information, and 3) to gauge the level of reading comprehension of medical information among SS patients.

Methods

This study used a multi-method approach to obtain data to arrive at a thorough understanding of the sources of information that patients use, how well they understand that information, and how their behavior relates to searching and acting on information about the disease.

Semi-structured, in-depth interviews, including open-ended questions as well as closed Likert-scale survey questions were conducted with 65 patients with diabetes. The interview was

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structured into nine sections that elicited data about medical and personal aspects of living with a chronic disease. Open-ended questions were included in Part I of the interview, thus allowing for qualitative information on the patients' perspectives about living with diabetes. Other sections inquired about the patients' outlook on life, medicines, information sources about diabetes, literacy practices, quality of care, and knowledge about diabetes.

- Part I: Diabetes and Patient
  Eliciting narrative on diagnosis and aspects of living with and managing diabetes
- Part II: Outlook on Life
  Includes Locus of Control, Life Orientation, and Beliefs About Your Health questions
- Part III: Medicines
  Includes adherence rates and reasons for non-adherence
- Part IV: Information Sources for Understanding & Managing Your Diabetes
  Identifying all sources used
- Part V: Literacy Practices
  Includes brief questions about health literacy
- Part VI: Using Medication Information
  Includes PIL comprehension testing
- Part VII: Quality of Care
- Part VIII: Diabetes Knowledge
- Part IX: Background Includes demographic info and request to contact for follow-up study in future.

Bilingual interviewers conducted Spanish-language interviews in an urban bilingual clinic. The interviews were videotaped and transcribed.

Various sources of data were used to address three main components of health literacy. Survey data elicited information about access to health information; patients' narratives revealed their intentional use of information sources and how the information is processed at the individual level; finally, a reading comprehension test provided a good measure of the degree of understanding of written health information. Thus, the combination of data sources allows for a holistic approach to the study of health literacy.

First, we present quantitative comparative survey results on the perceived value of information sources for understanding and managing diabetes by ES and SS patients. Second, we present results of the qualitative analysis of the patients' life-story narratives where they discussed their actions regarding their search for medical information and support. Qualitative analysis and descriptive quantification of the patients' talk provide a different perspective on patients' agency with regard to their use of sources of information. Finally, we present quantitative results from a third method of investigating health information sources that was used. Patients' reading comprehension of a *patient information leaflet* (PIL) for a common medicine prescribed to patients with diabetes was tested.

Participants in the study included 43 ES and 22 SS subjects (Total n = 65). The age range was 25-69 years (mean age: 51) for ES and 28-65 years (mean age: 44) for SS. Both groups of participants were predominantly of low socioeconomic and educational levels, although SS were overall lower in both categories than ES. The average household income for SS was $17,000 and for ES was $27,000. Average years of schooling for SS was 8 and 13 for ES subjects.

Table 1
Participants' profile.

English Speakers	Spanish Speakers
Subjects in the Study	**Subjects in the Study**
Native English speakers (n=43)	Native Spanish speakers (n=22)
Days with Diabetes	**Days with Diabetes**
Average: 2724, Std. dev: 2820	Average: 1730, Std. dev: 1553
Range: 66 to 14,308	Range: 39 to 5519
Age	**Age**
Average: 52, Std. dev: 10	Average: 44, Std. dev: 10
Range: 25 to 69	Range: 28 to 65
Race	**Ethnicity**
Non-Hispanic White: 48%	Mexican, Mexican American, or Chicano: 91%
Non-Hispanic Black: 38%	Central or South American: 9%
Other Race: 14%	Other Race: 0%
Gender	**Gender**
Male: 49%	Male: 59%
Female: 51%	Female: 41%
Education Completed	**Education Completed**
Not a High School Graduate: 26%	Not a High School Graduate: 65%
High School Graduate/GED: 32%	High School Graduate/GED: 20%
Some College/Post-Secondary Education: 28%	Some College/Post-Secondary Education: 15%
College Graduate (4-year degree) or Above: 14%	College Graduate (4-year degree) or Above: 0%
Total Household Income	**Total Household Income**
Less then $30,000: 62.5%	Less then $30,000: 82%
$30,000 to $50,000: 22.5%	$30,000 to $50,000: 13%
$50,000 to $100,000: 15%	

According to self-reported language ability, English proficiency among the pool of SS participants was not high. Seventy three percent (73%) of the SS patients reported that they speak English not well" or "not at all." Ninety percent (90%) reported that they write English "not well" or "not at all," 82% indicated that they read English "not well" or "not at all," and 55% claimed that they understand English "not well" or "not at all." The profile that emerged from these responses highlights the need to address limited English proficiency in sources of information on medical care and disease management.
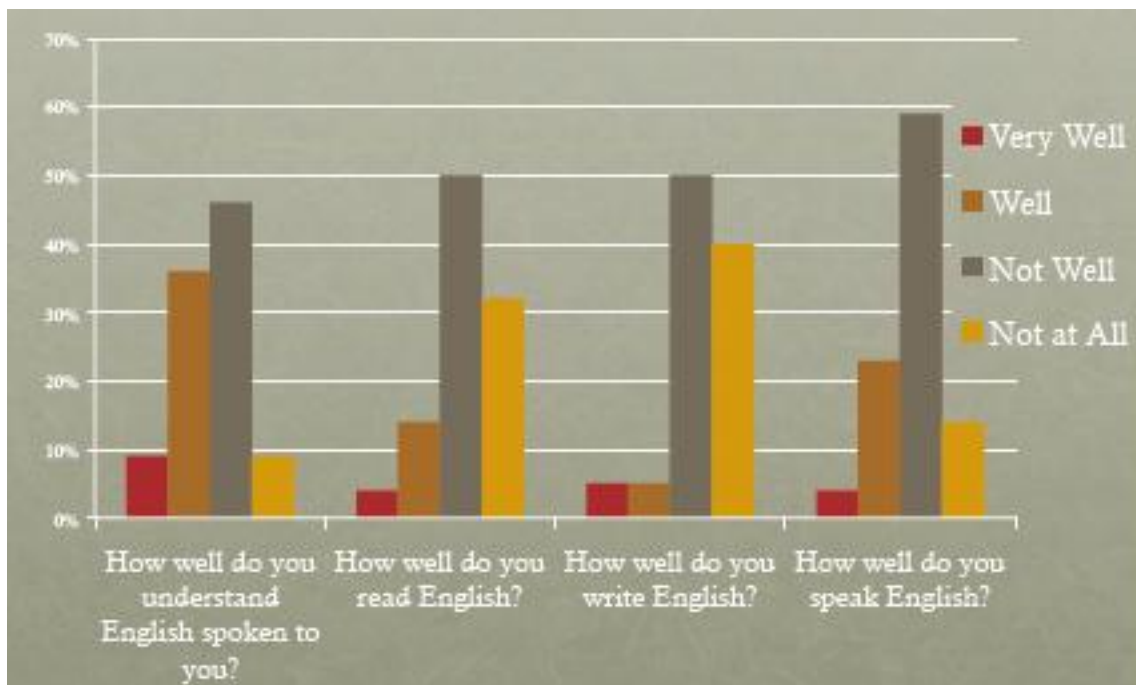
Figure 1. Self-reported English language proficiency of Spanish-speaking participants

Results

Results will be discussed in terms of the three goals: A) to describe the *perceptions* of ES/SS patients related to various sources of medical information for managing their diabetes; B) to identify the *actions* patients report in seeking medical information; and C) to gauge the level of reading comprehension of medical information among SS patients.

**A. Survey results on sources of information**
In order to describe the perception of patients related to various sources of medical information for managing diabetes, participants' ratings of the value of a variety of sources of information for understanding and managing diabetes on a six-point scale going from "excellent" to "poor" were examined. Figure 2 below presents the percentages of how participants rated "sources of information for managing diabetes."

Percentage of Respondents Who Rate Various Sources of Information for Managing Diabetes as "Poor" or "Don't use"
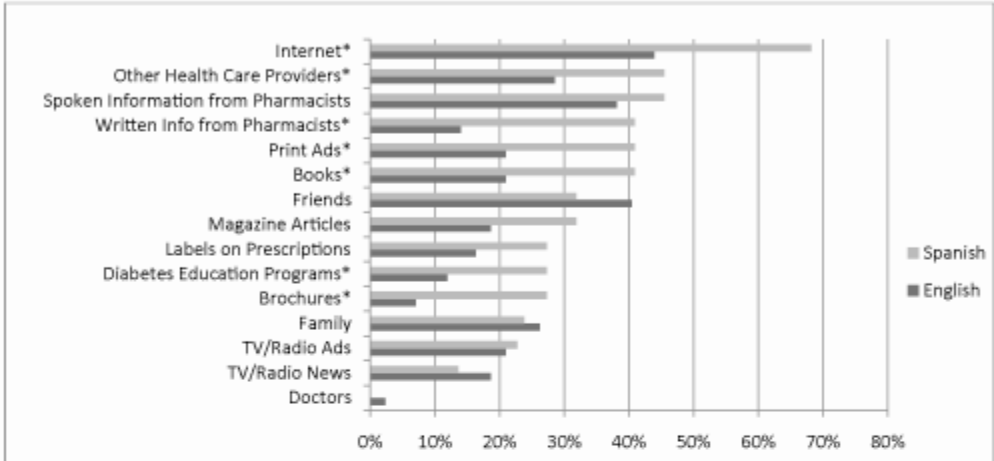
* Statistically significant differences between Spanish-speakers and English-speakers at least at the 0.10 level or better

Percentage of Respondents Who Rate Various Sources of Information for Managing Diabetes as "Excellent" or "Very Good"
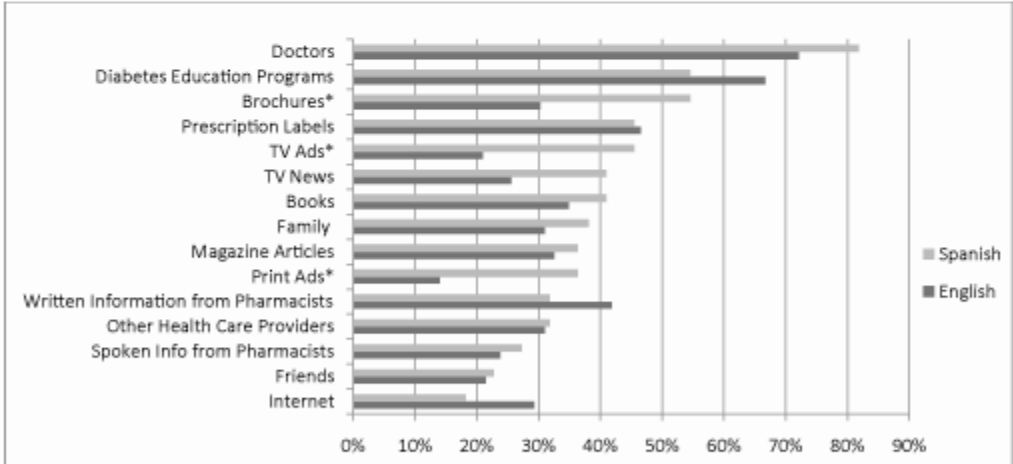
* Statistically significant differences between Spanish-speakers and English-speakers at least at the 0.10 level or better

Figure 2: Ratings of sources of information for managing diabetes

For those rated "excellent" or "very good," three information sources were differently rated at statistically significant levels: brochures, TV advertisements, and print advertisements. Brochures were rated as a valuable source of information by 55% of SS, but only by 30% of ES. TV and radio information sources were also rated differently by both groups. Advertisements on TV or radio were considered "excellent" or "very good" sources of information by 45% of SS, but only by 21% of ES, while news reports on TV or radio were valued as sources of information by 41% of SS, but only by 26% of ES. There were also differences in the perception of print advertisements: 36% of SS patients rated this source highly, while only 14% of ES patients gave a high rating to this type of source.

Other differences, although not statistically significant, point to interesting trends. Both groups rated doctors as a valued source of information, followed by diabetes education programs, but a higher percentage of the SS chose doctors as valuable sources of information than did the ES patients. Inversely, a higher percentage of ES patients designated diabetes education programs as valuable sources of information. Both groups considered family as an "excellent" or "very good" source of information, but the SS participants rated them slightly higher. Written information from pharmacists was rated positively by a higher percentage of the ES than the SS patients. Finally, a lower percentage of the SS patients rated the internet highly as a source of information.

Looking at the data from the other end of the spectrum, Figure 2 illustrates the percentage of participants that rated the given sources of information as "poor" or "don't use." In both groups, a large number of participants regarded the internet as a poor source of information or simply reported not using it. However, the percentage of the participants who rate the internet negatively as a source of information was higher among the SS group (68%) than among the ES group (47%). Other sources of information that were rated as "poor" or "don't use" by a larger percentage of SS participants were written information from pharmacists (41% SS vs. 14% ES), print advertisements (41% SS vs. 21% ES), books (41% SS vs. 21% ES), brochures (27% SS vs. 7% ES), and diabetes education programs (27% SS vs. 14% ES).

Other health care providers were also rated significantly lower by more of the SS than the ES subjects. Friends, family, doctors and TV or radio news are the only variables that were rated poorly by a slightly larger percentage of the ES participants than by the SS participants (although differences do not reach statistically significant levels). These results suggest that among those who regarded sources of information as "poor" or "don't use," a larger percentage of SS participants compared to ES participants did not value or did not use written sources of information. On the other hand, a lower percentage of the SS participants rated oral sources of information (friends, family, TV and radio) negatively.

In conclusion, the survey results on sources of information suggest that there are similar tendencies in both groups, but there are also relevant differences. Overall, while SS rated brochures and other printed materials highly, the picture that emerges suggests that SS regard oral sources of information (TV, radio, doctors, family and friends) somewhat higher than ES. It also suggests that written sources of information are generally rated poorly or not used by a higher percentage of the SS than the ES participants.

The survey results provide a first approximation to the potential value of these sources of information for modifying behaviors leading to better health outcomes. Differences found among Hispanics and other groups have important implications for health care personnel and health educators. For example, doctors, as the highest rated source of information by both groups of participants in this study, could be trained to help influence patients' perceptions of sources of information. Health personnel could also design interventions to train patients to use sources of information that patients perceived as poor, such as the internet. As a first approximation to patients' views on sources of information, surveys are helpful in pointing at areas of need for further research, for example, the need to identify why patients poorly regard some sources and what socio-cultural factors affect these views.

B. Qualitative analysis of text narratives
To identify the *actions* patients report in seeking medical information, a second approach to understanding patients' use of sources of health information (the qualitative analysis of patients' talk) was used. Some researchers (Mishler, 1984; Hamilton, 2001) have begun to focus on the patients' own experience. In regard to Spanish-speaking patients, Solomon et al. (2005) interviewed cancer survivors to determine information preferences for development of an appropriate booklet for Spanish speakers

During our interviews, life story narratives were collected from patients. Some questions elicited information on the patients' use of sources of information. For example, patients were asked:

> Who told you information about the disease? Can you tell me about that?
> What do you do to manage your diabetes?

Responses to these questions were analyzed qualitatively for information on agency on the part of the patient in managing the disease. Agency has been defined as the "capacity to make a difference" (Castor & Cooren, 2006, p. 573). Several researchers (e.g. Glasgow, Toobert & Gillette, 2001; Hadjistavropoulous & Shymkiw, 2007) have studied the factors affecting individuals' health-related agency, or their ability to take actions towards the self-management of chronic health conditions. Our use of the term agency, based on an individual's actual actions, is related, but not identical to self-efficacy, which is based on one's *belief* in the ability to do what is needed to attain an outcome (Bandura, 1977). Both agency and self-efficacy are concerned with a person acting positively in order to improve his or her health. Surveys have been common measures of self-efficacy and agency (e.g. Anderson, Winett & Wojcik, 2000; Bandura, 1997). However, we suggest that the actual words of patients may contain more accurate indicators of their actions. Agency in our study was operationalized as the degree of action the patient reports taking vis-à-vis adherence to current diabetes regimen recommendations.

Patient narratives in response to questions such as the ones identified above were analyzed using grounded theory methodology (Strauss & Corbin, 1990), which has been used extensively in the qualitative analysis of health communication. Initially coders used *open coding* to identify linguistic behaviors relevant to their target variable in a sample of patient narratives. Using the *constant-comparative approach*, which is a key feature of grounded theory, coders compared

each piece of data or *token* (i.e., a particular linguistic instantiation of agency) with other similar tokens to develop a conceptualization of relevant relationships vis-à-vis their target variable. This open coding process resulted in preliminary rubrics of relevant themes describing the linguistic realizations of each of the three variables. The next stage in the coding process was *axial coding* in which the additional narratives were coded using the same rubrics to make gestalt assessments of the variable (i.e., high, medium, or low agency).   Agency was coded across six domains, one of which was *Information and Support Seeking Behavior.*

A patient's agency level was determined by the particular linguistic cues they used to describe their action or inaction with regards to seeking and using health information. These linguistic indicators of agency are delineated below. First, the propositional content (i.e., the unembellished reporting of actual action or inaction) of a patient's agentive talk was considered In addition to communicating action or inaction through propositional content, patients expressed stance (i.e. personal feelings, attitudes, value judgment and assessments) toward their action. According to Biber et al. (1999), stance may be expressed in several ways, including word choice, grammatical and paralinguistic devices. Because we were interested in identifying the linguistic features for agency, we only took into account the grammatical and lexical markings of stance. In our data, the grammatical devices used to express stance were adverbials, further categorized as single adverbs, hedges, adverbial clauses, complement clauses, and pre-modifying stance adverbs, which usually preceded an adjective or noun phrase. The full linguistic coding system has been presented elsewhere (Lauten et al., 2010).

Briefly, high agency was signaled in the talk by particular linguistic cues such as propositions encoding the performance of many actions or some salient actions in searching for information, by the use of intensifiers (adverbs) and categorical assertions, by expressions of certainty and high precision, and by lexical adverbs expressing positive evaluation of actions. Medium agency manifested itself in linguistic expressions of attempts rather than action, expressions of medium certainty and precision, comments and hedges. Finally, low agency was signaled by propositions that indicate detrimental actions, few actions, adverbs that intensify detrimental behavior, predicate adjectives of adversity, expressions of low certainty and precision, and idiomatic expressions explaining lack of action.

The following quotes (Table 2) from patients' talk exemplify the linguistic realizations of agency with respect to searching for information and information support:

Table 2
Linguistic Indicators of Agency

High Agency

ES	SS
I read all the side effects	Folletos [leo]
I went to a series of classes	(*I read brochures*)
My doctor wanted me to go to **a series of** classes so I went	Pláticas que **he ido** (*I have gone to talks*)
I joined the American Diabetes Association	**Vine** con la nutricionista
I'm on the web **all the time**	(*I have come to see a nutricionist*)
I started **tearing through** Web Md	El doctor me dio libros y yo los **leí**
I wanted to find out more about it so I I read **a lot of** stuff about it	(*The doctor gave me some books and I read them*)

Medium Agency

ES	SS
I **try to** learn as much as I can	Cada vez que hay talleres aquí, yo **trato de** asistir
Usually any article that I see that talks about diabetes I read it	(*Whenever there are workshops here, I try to attend*)
I **try** and keep abreast of what's going on with the medicine and different things	Folletos yo leo, **hay veces** que leo (*I read brochures, sometimes I read them*)
It **took awhile** to learn the different foods that I can and cannot eat	La diabetes, **casi no** la conozco **realmente** (*I know hardly anything about diabetes*)

Low Agency

ES	SS
Over the years it's just something **I picked up**	**Casi** me quedo yo con las preguntas, **no las hago**
I picked it (information) up from different people over the years	(*I keep the questions to myself, I don't ask them*)
I didn't really get into talking about it (diabetes management with doctor)	**No sé** yo qué era la diabetes ni cómo tratarla
I haven't been to class on dietician you know the diabetic or + in really know a whole lot about it	(*I don't know what diabetes was nor how to treat it*)

Almost half of the ES patients (49%) exhibited highly agentive talk about their use of sources of information and seeking support for managing diabetes (see Figure 3 next). By contrast, only 24% of the SS patients said that they actively search for sources of information and support. This indicates that, overall, ES patients are more likely to actively seek information about their disease. The sources of information about which highly agentive SS patients talked are those

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identified in the survey results (Section A) as most useful: doctors, family and friends, other diabetics, diabetes education meetings, brochures, and, in only one case, books. The patient who mentioned having read books about diabetes added that the doctor had given that patient some books. As mentioned above, it would be worth exploring the power of doctors and other health care providers in advising patients to seek information about their disease.
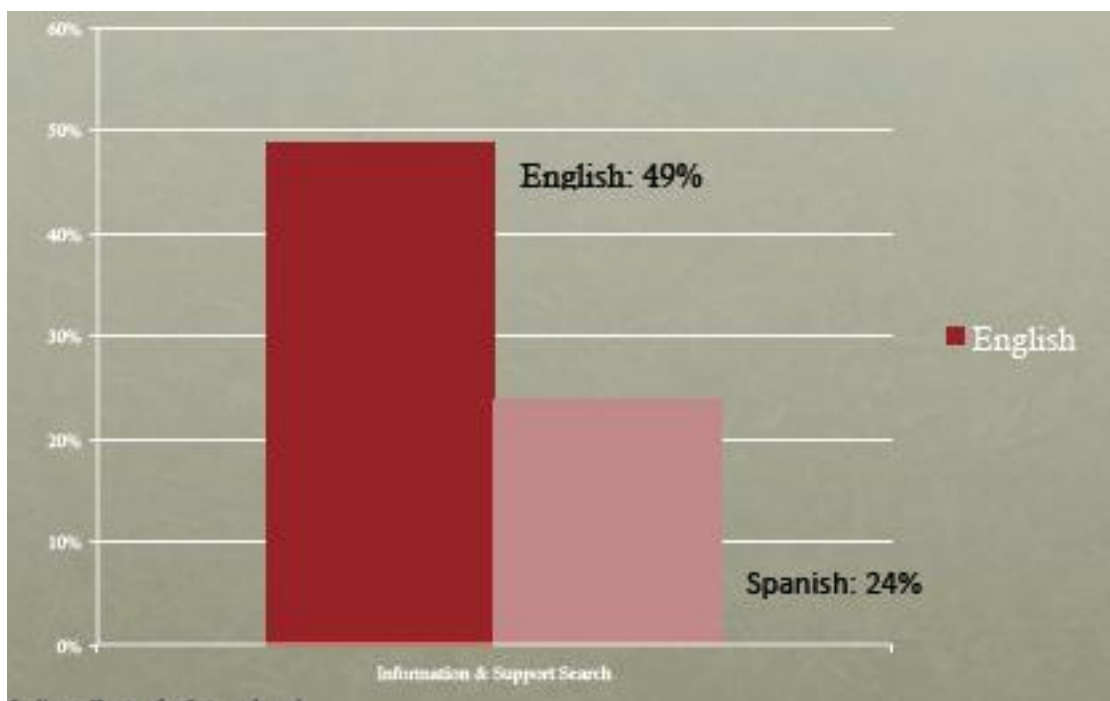

Figure 3. ES and SS Patients' High Agency in Seeking Information and Support Sources

By listening to the patients' actual voices, we are able to gain insight into important cross-cultural and cross-linguistic differences in their behavior, and not just their preferences, with respect to access and use of sources of information on diabetes and diabetes management. Not only are ES patients more active in seeking and using sources of information, but they also report a wider variety of sources as shown in Table 3.

Table 3
Sources of Health Information from Life-Story Narratives

SS	ES
Doctors	Diabetes Education classes
Family and friends	Support group
Other diabetics	Brochures, pamphlets
Diabetes education meetings	Readings, articles, booklets
Brochures	Books
Book	ADA Journal, magazines
	Medical encyclopedia
	Reader's Digest
	Library
	Drug studies
	PIL
	Doctors
	Diabetes specialist
	Nutritionist
	Nurses
	Family
	Web MD
	Weight Watchers
	TV ads
	Conferences

The qualitative analysis of patients' talk provided clear evidence that ES patients are actually accessing and using a wider variety of health information sources with more frequency than SS patients. Patients' talk on their actual actions may provide a more faithful picture of what patients really do than the use of a survey alone in which the patients rate the usefulness of a particular source of information. Thus, it is important to complement results from surveys with methods of investigation that allow researchers to delve deeper into the questions.

C. Reading comprehension test of the Patient Information Leaflet (PIL)
The third goal was to gauge the level of reading comprehension of medical information among SS patients. For this, a third measure of the usefulness of sources of information came from a reading comprehension test administered to both groups of patients. With this test, we sought to understand the depth of processing of medical information by our patients and to explore if there were differences in the degree of comprehension between these two groups.

Patients were given a PIL for Lisinopril, a common blood pressure medication, in their native language. They were asked to locate two items: 1) how to store the medicine; and 2) the side effects of the medication. The rating scale measured no comprehension (operationalized as inability to locate any of the two items requested); average comprehension (ability to locate one

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piece of information); and advanced comprehension (ability to locate both pieces of information).
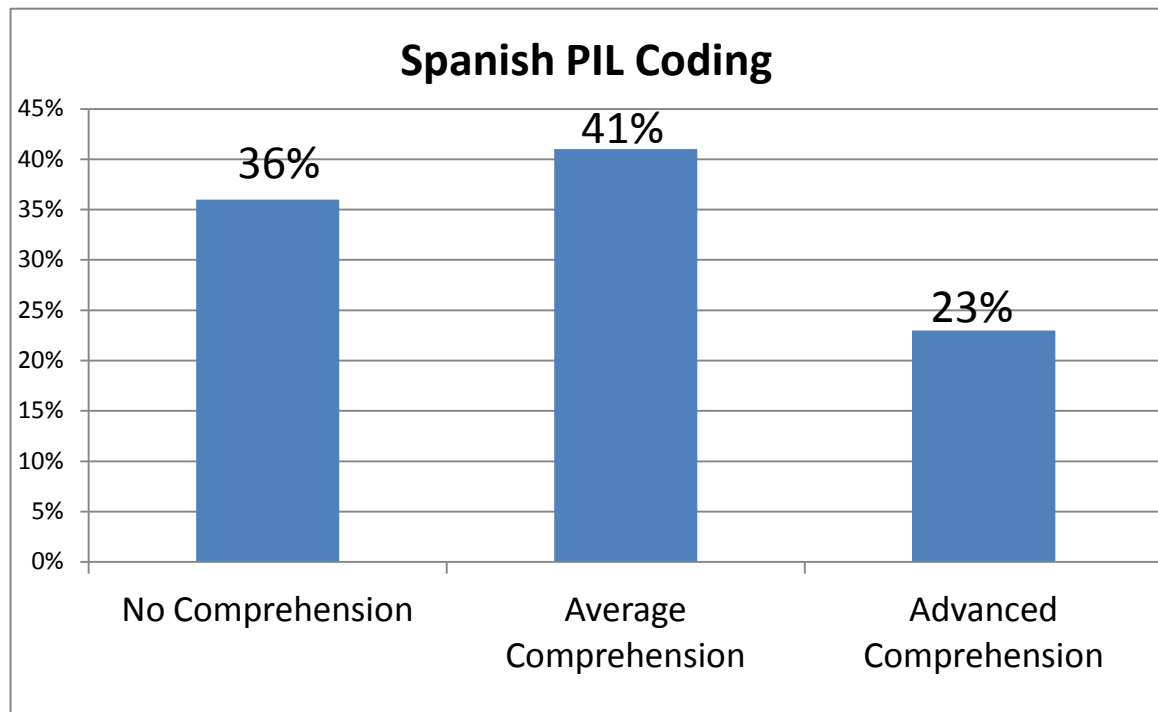

Figure 4. SS Patients' Levels of Comprehension of Spanish PILs

Comprehension test results (Figure 4) revealed average comprehension by 41% of the SS patients, with 23% showing advanced comprehension by locating information for both questions. The 36% who were unable to respond to the questions included a small number of patients who could not read (1) or could not see the print (4), and in one case a participant who was given the PIL in English. It is important to note that most patients indicated that they could not read English. Therefore, the ability to process written medical information is dependent on providing access to native language written materials for those who do not have high reading proficiency in English, or 80% of our SS patient population according to self-report.

The results allowing for a comparison of ES and SS patients in this group are not available, but a comparison of these results with those of 21 ES patients in an earlier study (Connor et al., 2010) shows that the level of comprehension of Lisinopril PIL is higher for the ES patients than for SS patients who were given the leaflet in their native language. The authors found that 23.8% of the participants in their study showed no comprehension of the leaflet and 76% showed adequate comprehension. Qualitative comments elicited by open-ended questions about the PIL indicated that ES patients found the language of the PIL difficult and the layout of the text inaccessible. SS patients in this study also complained that the small font size and the layout made it difficult to find information.

Discussion and Conclusion

Non-English speakers face special challenges in achieving functional health literacy in the US health care system. Hispanics in the U.S. are disadvantaged in terms of quality of care and medical outcome compared to non-minority demographic groups. Survey research and a limited number of interview and focus group studies suggest that Hispanics access health information in distinct ways, and that health beliefs impact their transfer of knowledge into health action. However, we know less about how SS patients in the U.S. access and process information to inform their health care decisions, and it is not clear how health beliefs impact patient agency and self-efficacy in disease self-management. In order to create effective interventions to improve self-management of diabetes among Spanish speakers, we must take into account the distinctive ways they access, process, and act upon health information.

Health literacy is an important component of any health outcomes model that interacts with and affects access and use of health care, interaction with health care providers, and self-care (Paasche-Orlow & Wolf, 2007; Von Wagner, Steptoe, Wolf, & Wardle, 2009). This study has contributed to the goal of identifying the relationships among health literacy, information source access, and processing patterns of patients. In the study of health literacy and their effects on health outcomes, it is important to complement survey-based results with other methods (Paasche-Orlow et al., 2006). The results from the present study show that a multi-method approach to understanding which information sources patients value and use and how they process and act on the information can lead to a deeper understanding of the role of health information among different ethnic groups. In particular, survey results are useful in providing categorical preferences for the delivery of health information, while life-story narratives reveal patients' actual behaviors in seeking health information.

However, accessing and using information is different from understanding and processing that information. A comprehension test lets us know the degree of patients' understanding of health information, and their potential ability to use it. Considering Paasche-Orlow & Wolfe's (2007) conceptual model of causal pathways linking health literacy to health outcomes, access to health care and self-care emerge as two areas where the use and comprehension of sources of health information are especially crucial. It is, therefore, important to consider a triangulation of methods to arrive at a deeper understanding of issues involved in health literacy, particularly when addressing the disparities in accessing and understanding health information, as in this study.

The results of the study indicate that preferences for health information sources differ according to ethnicity. SS Latino patients in this study preferred oral sources of information, while ES patients rated printed sources higher, which is consistent with results of other survey-based studies (Rutten et al., 2007; Livingston et al., 2008; Cheong, 2007). HINTS (NIH, 2009) reports that SS Latinos looking for health information feel dissatisfaction caused by effort, difficulty in understanding, and distrust of the information. Relying less on printed health information due to low health literacy may be associated with health beliefs based on personal experience rather than sound educational advice (Von Wagner et al., 2009).

Life-story narratives provide a different kind of information. While in the survey portion of the interviews participants in this study expressed their preferences for sources of information, life-narratives gave voice to the patients to express what sources of information they actually used and why, thus adding a contextual layer to their actions. The results of the narratives' analysis revealed that a higher percentage of the ES patients talked about seeking and using a wider range of information sources than did SS patients. A relevant result was that SS patients reported using fewer sources of information than the ones they had reported as valuable in the survey section of the interview. Finally, our comprehension test explored another dimension of health literacy, the processing and understanding of health information. The results of the test demonstrated that 36% of the SS patients were not able to extract basic information from a PIL in Spanish, a common source of information about medications. Other comparative studies have also found lower comprehension of health reading materials among SS than among ES patients, particularly in the case of minority, low-income, low-educated patients (Gazmararian et al., 1999).

This multi-method approach to the study of different aspects of health literacy (obtaining, processing and understanding health information) concludes that there are disadvantages for SS patients in accessing and understanding sources of health information. These must be addressed through informed interventions to maximize the role of oral sources of information (doctors, TV, family and friends, etc.) (Rothman, 2004; Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005); to train patients in accessing and understanding other sources such as health-related webpages (Campbell & Nolfi, 2005); and to modify existing information sources, such as PILs, so that they are more informative to patients with lower levels of comprehension (Askehave & Zehtsen, 2003; Clerehan, Buchbinder, & Moodie, 2005).

This study has drawn on the patients' own voices to identify their preferences for accessing information, the use of sources of information in processing information into knowledge, and the application of that knowledge in diabetes self-management. Patients' voices provide a sound basis for solid interventions that can lead to improved health outcomes.

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