Published in final edited form as:

J Community Health. 2016 June ; 41(3): 526–534. doi:10.1007/s10900-015-0126-x.

Help-Seeking Behavior and Health Care Navigation by Bhutanese Refugees¹

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Introduction

Immigrants to the U.S. navigate a complex health system. Under ideal conditions, they must select and apply for health insurance, find a primary care provider accepting both new patients *and* one's particular insurance, understand automated telephonic menu systems or appointment-scheduling websites, and learn to travel to health care facilities. Individuals seeking specialty care often need referrals and insurance prior authorizations, and they may subsequently need to address medical billing errors. These tasks are rarely trivial for U.S. citizens [1, 2, 3, 4, 5]. They may be all but insurmountable for immigrants with limited literacy, English proficiency, or prior experience with comparable health systems.

¹**Contributions:** All authors conceptualized the study and contributed to the final manuscript. K.Y., P.P., L.K., and P.S. collected data. K.Y., P.P., L.K. analyzed the results. K.Y., P.P., and P.S. drafted the manuscript.

We know relatively little about how new immigrants learn to overcome these barriers [6, 7, 8]. As a result, programs targeting new immigrant communities may rely on incorrect assumptions or ineffective interventions. Many programs assume that the primary barrier is informational and can be addressed by knowledge transfer in the form of lectures, brochures, or handouts. Others offer direct assistance (e.g., case management) with limited educational engagement. Very few programs have been systematically described or evaluated for acceptability, feasibility, or effectiveness. This gap presents a challenge to community organizations and public health programs seeking to improve access to care. The challenge may be greatest for organizations serving refugees and asylum-seekers who, unlike migrants driven by family or economic ties, have typically had little preparation for life in the U.S.

The Bhutanese refugee community is one of the largest recently-arrived refugee groups in the U.S., with over 83,000 individuals arriving in the U.S. from 2008 through the present [9]. Within the Bhutanese refugee community in Philadelphia, many adults are unable to schedule appointments or navigate insurance systems. Others face high levels of medical debt (personal communication, Parangkush Subedi, Feb 1, 2013). Problems are believed to be most acute for individuals with limited English proficiency (~65% of the community) and limited literacy (~35%) [10].

To address these problems, Bhutanese community leaders in Philadelphia proposed a “Health Focal Points” intervention modeled after programs in refugee camps in Nepal. Bhutanese refugees had resided in camps after being expelled from Bhutan in the late 1990s. In the camps, trained community members were often used as health educators or community health workers [11]. Community leaders reasoned that a comparable program in the U.S. could help resettled refugees learn to overcome barriers to health care. Concurrently, we sought to systematically describe health care access problems from the perspective of Bhutanese refugees in Philadelphia, describe help-seeking behaviors within the community, and document program acceptability. Additionally, we documented features of the program likely to require adaptation prior to implementation with other immigrant groups.

Methods

This was a community-based participatory research project conceptualized by Bhutanese community leaders and conducted in partnership with academic partners. A patient navigator model was selected because it was similar to programs in Nepal, would increase the community's capacity for mutual assistance, and had evidence-based antecedents in the community health work (CHW) literature [12, 13]. The program was designed to maximize accessibility: It included an accessible location in the heart of the community and accessible hours (10/week, weekdays and weekends, appointments not required) to accommodate work schedules. Additionally, eligibility criteria were purposefully broad to ensure that the study team developed an emic (insider) rather than etic (outsider, professional) understanding of health care navigation challenges: Refugees were eligible if they had any problem related to health or health care and did not currently have a case manager at another agency. Recruitment was through word of mouth. No incentives or reimbursement were offered (apart from reimbursement for participation in post-intervention interviews) to determine

whether there was inherent demand for these services. Consent for participation was obtained in Nepali.

Patient navigators, called “Health Focal Points,” (HFP) were bilingual adult refugees with >9th grade education and 30 hours of training who agreed to volunteer for at least two hours each week. Training topics (Table 4) were selected by the research team based upon prior experience, review of existing patient navigator curricula [13, 14, 15, 16], consultation with health care providers serving the community, a community needs assessment, and other literature [17, 18]. Resources available to the HFPs comprised an office, telephone, computer, printer/scanner/copier, internet connection, and consultation with program supervisors, as needed. The intervention was delivered over six months in 2013-2014.

Data sources comprised 35 intake and 34 post-intervention interviews with clients, 14 intake and 14 post-intervention interviews with patient navigators, and program case notes. Multiple data sources were used to triangulate themes. The interview guide and the intervention itself were informed by social cognitive theory and by ethnographic work within the Bhutanese refugee community [19, 20, 21]. Social cognitive theory posits that health behavior is shaped by and shapes personal characteristics and social conditions, e.g. social networks. Perceived self-efficacy is a key personal characteristic and one that can be promoted through both mastery experiences and social models. Social modeling occurs when one sees someone similar to one's self succeed in the same or similar task and has been used in culturally- and linguistically-adapted interventions for other refugee communities [22].

Client and patient navigator interviews included a demographic survey, questions about health system knowledge and access, the Patient Activation Measure (PAM) [23], the Post-migration Living Difficulties (PMLD) inventory [24], the PROMIS physical and mental health measures [25], and open-ended semi-structured questions about health care access problems, help-seeking, and program acceptability and accessibility. The PAM, a measure of health care self-efficacy, was included because lack of confidence/self-efficacy was believed to be a significant barrier to care. PROMIS measures were used to describe the health status of program participants. All standardized instruments were scored per published guidelines. Open-ended questions for program participants were designed to elicit a narrative of a particular time when the participant had difficulty navigating the U.S. health system, an approach consistent with community storytelling traditions. Interviewer prompts were designed to solicit details about help-seeking, forms of assistance, social relationship between participants and those providing assistance, and expectations for assistance. Open-ended questions for patient navigators focused upon training strengths and weaknesses.

Instruments were translated by a bicultural study team member with expertise in epidemiology and then reviewed by a bicultural certified medical interpreter with attention to semantic and content equivalence [26]. Differences were resolved by consensus [27]. Surveys were administered in Nepali by a bilingual study team member. The REDCap electronic data capture tool at [redacted for peer review] was used to manage survey data [28].

Responses to open-ended questions were interpreted by a bilingual study team member. Analysis was then conducted of the English text. Textual data were coded using the constant comparison method: After reviewing eight interview transcripts, a coding scheme was developed by the investigators and transcripts were coded in NVivo 10.0 by a 3-person team with an inter-rater agreement (kappa) of >0.8 [29]. The coding team comprised two academic partners (redacted) and one bilingual community expert (redacted). Content analysis of patient navigator case notes was used to categorize the type and number of problems identified by program participants, as well as the number of encounters per client.

The project was reviewed by the IRB and found to be exempt.

Results

Thirty-five Nepali-speaking refugees enrolled as clients, and 14 community volunteers served as Health Focal Points. Demographic data are shown in Table 1 and 2.

Health Care Navigation Problems

There were 163 encounters (27/month) with 35 clients. Among these 35 clients, the most common reasons for *initially* seeking assistance were: unpaid medical bills (6 clients), lack of health insurance (5), difficulty scheduling appointments (5), and difficulty using health insurance (4). Unpaid medical bills ranged from \$150 to \$35,000. Most were accrued by chronically-ill, uninsured individuals who did not understand the U.S. health system or by uninsured individuals who had required emergency care for severe, significant health problems.

Uninsured individuals typically had chronic health problems, including physical disabilities and mental illness, or had acute health concerns and did not know where to obtain affordable care. When appropriate, patient navigators guided clients through Medicaid applications for adults with disabilities. Individuals with acute concerns were directed to nearby Federally-Qualified Health Centers (FQHCs). Appointment scheduling concerns were typically due to language barriers, as most secretarial staff were not accustomed to telephonic interpretation. Difficulty using health insurance was typically due to prior authorization requirements.

Most clients had more than one concern at the time of intake: 22 had two concerns and nine had three concerns. Secondary concerns included lack of health insurance, difficulty scheduling appointments, and problems with Supplemental Security Income applications. Fifteen participants required limited support and had 2 encounters. These were most commonly individuals with discrete problems (e.g. assistance submitting a copayment). Twenty participants had multiple visits, including 6 clients who visited the program more than 10 times. These clients typically had complex problems (e.g. bills or insurance). Clients with multiple encounters were somewhat more likely to be uninsured (8/20 versus 4/15) and illiterate (15/20 versus 8/15).

Changes in Patient Activation

Thirty-four program participants completed follow-up interviews. There were no significant differences in post-migration living difficulties or PROMIS health scores following the

intervention, yet more clients reported being in “poor” health after the intervention (Table 1). There was no change in a simple measure of health system knowledge (“number to call for emergency services”; Table 3). Nonetheless, after participating in the program clients were less likely to miss or forgo care due to language and navigation barriers, and they were significantly more likely to report high levels of patient activation (Table 3). Prior to entering the program, most clients reported the lowest level of patient activation (68.6%) and very few were highly activated (5.7%). Subsequently, only one-third reported the lowest level of activation (35.3%) and one-third were highly activated (32.4%).

Help-Seeking Behavior

All program participants had sought assistance prior to engaging with the HFP program, and most participants sought help recurrently. Male and female family members (e.g., adolescent or adult children) were the most common source of help, followed by neighbors. Less frequently, participants sought help from nonprofit or governmental organizations outside the Bhutanese community. When seeking help, participants preferred individuals who were familiar to them (“at the doorstep”), bilingual, literate, and who had experience or perceived experience with “the system” in the U.S. Participants were comfortable receiving help from laypeople, provided that helpers had other qualifications, e.g. English proficiency:

“I don't mind getting help from younger people, because they know the system and then they know English and they know how it works in the United States. So I don't mind getting help from those people.... In general, I made a point to contact other people who came here earlier, and somebody who didn't have insurance. And especially who could speak a little bit of English.” 50-64 year-old female, reads poorly, does not speak English and was uninsured

“We were not the first family here from my husband's side. There were some other family members already here that are uncles, that are his sisters, and we went to them to seek help when there were problems.” 35-49 year-old female, illiterate, does not speak English

“[Community elder] has been here for some time. And whenever new people come, he already knows everything about the system here.” 35-49 year-old male, reads poorly, does not speak English

“There are people who are educated who know the system to some extent. And we do not know.” 35-49 year-old female, literate, speaks English poorly

Help-seeking was rarely simple or linear. Participants noted that even seemingly-simple tasks could be quite complex:

“How do I pay my [medical] bills when they are sent to me? So it is not simply paying bills, but it's all about which company to call, how to call, all that stuff, like make a big difference.” 18-34 year-old female, literate, does not speak English

They described following a chain of helpers until finally being referred to the person or agency that could solve their problem. Additionally, they sought help in parallel, going to multiple people or agencies for the same problem, particularly for complex problems like

insurance applications. Participants were often unsure which person or agency had ultimately solved their problem.

Program participants typically sought assistance in the form of proxies, meaning someone who would do something in their place. Specifically, participants sought to avoid tasks that required communicating with unfamiliar individuals who did not speak Nepali, such as secretaries, and tasks that required English literacy, e.g., applications:

“My daughter-in-law calls [the doctor] – she manages everything, so I really don't know how she does that all... My daughter-in-law takes me [to the doctor]. I cannot make it there, so my daughter-in-law takes me.” 35-49 year-old female, illiterate, does not speak English

“I think I'm too old to get help [from the doctor] by myself. And then I can't speak any other languages and then I can't go outside and go meet people, so [my granddaughter] helps me... she takes me to hospital every time. She brings me the medicines. I don't know how to do that.” 65 year-old female, illiterate, does not speak English

“Whenever we had any appointment, at the end we were always given an appointment, the follow-up appointment. So we're never required to make our own appointment through phone” 65 year-old male, literate, does not speak English

“When I visit [hospital name], they also give me the next appointment. Or in other cases, my son makes it.... Somebody else takes me [to the doctor]. I cannot read the bus [signs] and it's not possible for me to figure where to get off.” 65 year-old male, literate, does not speak English

Social modeling was less common. Repeated practice was required before most participants attained confidence and mastery, if ever. Knowledge alone was not sufficient for most participants to gain competency with these activities:

“I am still scared of doing it [asking for an interpreter on the telephone] and I still feel that they might not do it for me, but I speak when somebody speaks Nepali.... [Health Focal Point name] used to tell me that I cannot make calls for you all the time, so you have to learn to make calls by yourself. And I'll dial the phone and then you have to speak and ask for the interpreter. That's what she told me and I spoke.... She was there. I was safe, secure. I feel good about that. And she had told me what to do beforehand, so that helped me a lot and we could make the appointment.” 50-64 year-old female, illiterate, does not speak English

“When we first came here, my sister helped us to take to different offices, and that's when she taught us how to use SEPTA [Philadelphia public transportation].” 18-34 year-old female, literate, speaks English poorly

“These days, I can go to [hospital 1] and [hospital 2] by myself.... So my reference is when I board the train, when it stops for seven times, the seventh stop is [hospital 1] and the tenth stop is [hospital 2].... My son taught me that, because my son and daughter are not available all the time. So he told me to count the stops and then get off in the particular count.” 35-49 year-old, illiterate, does not speak English

Difficulty Learning

Not all program participants felt capable of learning health care navigation. Some had memory problems secondary to injury, mental illness, or older age. Others felt that illiteracy made it difficult for them to learn and retain new information:

“So I have a problem of forgetting things. I had a problem sometime back, maybe 12 or 14 years back. I had terrible headaches, and then I have a problem with my eyes also. So I took a lot of medications. I don't know. Maybe because of that, I forget things.” 35-49 year-old female, illiterate, does not speak English

“When I came to America, I was already 68. So at that age, so – and compared with having taking so much of medication, I will – easy to forget things. And I always forget things. So I was always scared to postpone things, thinking that I might totally forget things and then mess up everything.” 65 year-old male, reads poorly, does not speak English

Other program participants were highly motivated to gain health care navigation skills. However, they were not motivated by a desire for independence, as there was no stigma associated with help-seeking. Instead, they viewed greater self-sufficiency as a necessity of their current social setting. As families became better established in the U.S., children became less accessible as sources of help, either because of responsibilities at work or responsibilities to in-laws:

“My daughter took us a couple of times to [refugee agency] and a different hospital and she taught us how to use that [bus]. So she told us this is [Name] Street and this is where the hospital is, [Name2] Street. And after that we learned it by ourselves because my daughter also started working right after the couple times she has helped us.” 65 year-old male, literate, does not speak English

“People are not available to help you all the time, so that's what made me learn.... I collected the courage in me and because I have to go [to the hospital].” 35-49 year-old male, reads poorly, does not speak English

Mutual Assistance

Both program participants and patient navigators described altruism and mutual assistance as cultural and social norms. One participant attributed this to religious beliefs, but most participants simply described this as the correct way to behave in society.

“I think this is because anybody is like my own people. Relatives, in a way. And if you help one member of the community, it is like helping yourself.... In Nepal, also, it was mutual assistance.” 65 year-old female, illiterate, does not speak English

“It's one Nepali suffering, and then the other Nepali just cannot see somebody, you know, suffering there. So that's how, you know, people help.” 18-34 year-old female, literate, speaks English poorly

“I cannot speak for most people, but for all of them, for most people, it might be the case.... It's helping each other. Somebody helps me, I help them....” 18-34 year-old male Health Focal Point, literate, speaks English

“When I came to the United States, right, nobody can help us, just like [refugee] agency people, nobody Nepali right here. They have too many problem at home, they don't know how to read their paper at home and medical system, nobody knows. That's why I need to volunteer for my community people.” 18-34 year-old female Health Focal Point, literate, speaks English

Patient Navigation

Providing health care navigation assistance was described as challenging but rewarding. The HFPs did not have prior experience with case management and required time, experience, and supervision in order to gain confidence assisting others.

“It was the beginning, I was kind of nervous. But it was fun. I enjoyed helping.”
18-34 year-old female Health Focal Point, literate, speaks English

The program structure, which relied on a cohort of 14 volunteers each working for at least two hours per week, was sometimes challenging. Some HFPs had few clients and remained uncomfortable working independently. Those working on weekends often had to hand over tasks to weekday volunteers, as most clinics and insurance companies did not have weekend hours:

“I didn't do it that much, right? We do it together. I didn't think – I didn't do it that much.” 18-34 year-old female Health Focal Point, literate, speaks English

“One lady came here and she showed me the medical bills. We had to call the bill company for the hospital, but they weren't available on the weekend. So I told her to come on the weekday to see [weekday Health Focal Point].” 18-34 year-old male Health Focal Point, literate, speaks English

The HFPs reported individual-, family-, and community-oriented reasons for joining the program. They were motivated by a desire to help others and to develop a positive reputation within the community. They also perceived that skills and experiences gained while helping others would allow them to assist their own family members. Finally, these experiences were believed to contribute to professional development by improving their English language skills or giving them practical experience relevant to planned careers in social work, nursing, or medicine:

“I love to help my community out, and I have a lot of chance to learn a lot of things from this program.... So the first thing is I'm happy when I volunteer. And second thing is when I help the other person and help them to get the things done, they're happy too. And the third thing is I want to go into this field so I can help people out. It helps me a lot to get there....” 18-34 year-old female Health Focal Point, literate, speaks English

“I did this because the people in my community, they don't speak too much. So in order to help them like go to the hospital, make appointment, and for example, my

parents, they don't know how to do that stuff. So in order for them, to help them, I volunteered, but as well as for my own experience.” 18-34 year-old female Health Focal Point, literate, speaks English

“I started feeling like I have to volunteer for the community people.... And one more thing is like even for my parents, they're like – they only speak their own language, so if I volunteer, and if I encourage them to come here, that would be more help for them.” 18-34 year-old female Health Focal Point, literate, speaks English

Discussion

Health care access problems for Bhutanese refugees in Philadelphia were often logistically complex and required a high degree of health system literacy. Given that most clients sought help from family and friends prior to seeking formal assistance, it is likely that immigrants living within established co-ethnic communities use informal assistance to address straightforward problems and that more complex issues rise to the attention of formal services like the HFP program [6]. For this reason, health care navigators serving Bhutanese and other refugee communities are likely to require a high level of training and support.

Refugees' reliance upon proxies and social models contributes to our growing understanding of health care navigation. Navigation is one dimension of health literacy and often defined as the “level of skill to navigate in society and in health systems to manage one's health needs” [30]. This study suggests that, for highly disadvantaged individuals, the ability to navigate in society—specifically the ability to seek help from peers with greater experience accessing U.S. health systems—is a key competency and one that compensates for the absence of other navigation skills. Additionally, basic life skills (e.g., using public transportation) should be included in the taxonomy of health care navigation competencies, as these are likely to be substantive challenges for immigrants from extremely poor, rural regions.

The predominantly older, infirm, and illiterate Bhutanese refugees who participated in this program had very low levels of patient activation at the time of enrollment. They described themselves as lacking in confidence and required on-going exposure and social modeling before achieving mastery. Some individuals also felt that their age, lack of education, or health problems made it difficult or impossible for them to become self-sufficient. This suggests that interventions limited to knowledge transfer are unlikely to improve health access for older, infirm, and illiterate refugees unless targeted at younger family members who are able to serve as proxies. However, the proxy role is not always compatible with full-time employment, so it should not be assumed that educating younger community members is sufficient. Similarly, knowledge transfer alone is unlikely to be sufficient in populations with high rates of depression and other health conditions that impair memory and cognition.

Patient activation rose dramatically over the study period. This may have been due to the support and social modeling provided by HFPs. Alternatively, this may be unrelated to the HFP program, as patient activation may naturally rise over time with increasing exposure to the health system.

Nonetheless, results suggest that the PAM captures meaningful changes in attitudes among Bhutanese refugees and should be used in future controlled trials evaluating comparable interventions.

There was no formal outreach or recruitment for this program, and participants did not receive incentives or reimbursement for participation in the intervention. Nonetheless, the program met its enrollment target and served a multiply-disadvantaged population. Simple program design choices guided by community leaders (e.g., community location, variable hours, and open scheduling) were sufficient to ensure that the program was accessible, and this approach is recommended for other groups seeking to implement comparable programs. The program was feasible with a limited budget but required substantial in-kind support in the form of donated supervisory hours. Following the pilot period, we have continued the program with just three Health Focal Points working 10-20 hours/week, and this has simplified supervision.

Some aspects of the HFP program may require adaption prior to implementation in other communities: (1) The Bhutanese community in Philadelphia comprises approximately 2,500 individuals clustered within two neighborhoods, making it easy to select an accessible location. A center-based model may not be feasible for refugees dispersed across suburban or rural areas where telephone or home visiting programs may be necessary. (2) The Bhutanese community— while diverse with respect to ethnicity, religion, and caste— nonetheless has one lingua franca (Nepali) and has shared expectations for mutual assistance [31]. Additionally, volunteering and altruism are important adaptive strategies within the community, creating ideal conditions for community health worker-led interventions [21]. Programs seeking to promote health system navigation skills among immigrant (and non-immigrant) groups lacking a lingua franca or expectation for mutual assistance are likely to require formal outreach efforts and multi-lingual staff.

Conclusions

Immigrants face complex problems related to insurance access, insurance coverage, and health care financing. New immigrants from less developed regions also face life skills challenges that are simple to conceptualize (e.g., scheduling an appointment). However, sustained and repeated social modeling is required to promote self-efficacy, particularly for community members with very limited literacy or cognitive challenges caused by age or illness. The HFP model fits into a complex tapestry of help-seeking that begins within refugees' social networks and then gradually moves outwards to formal social services. Adaptation is recommended for similar programs serving immigrant populations with different cultural and demographic characteristics.

Acknowledgments

This program was funded in part by the Center for Public Health Initiatives at the University of Pennsylvania and the Hindu American Foundation. Dr. Yun's time and effort were supported by a grant from the Agency for Healthcare Research and Quality (K12HS021706-02). The NORC at the University of Chicago and the Philadelphia Department of Public Health were not involved in this study. The authors wish to thank the following organizations for sharing information about their community health worker programs: Access Alliance, Toronto, CA; MGH

Chelsea Healthcare Center, Chelsea, MA; the Penn Center for Community Health Workers, Philadelphia, PA; and Puentes de Salud, Philadelphia, PA.

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Table 1
Demographic and Social Characteristics of Clients (Bhutanese Refugees)

	Baseline	Post-Intervention
N	35	34
Female, %	62.9	62.9
Limited English proficiency (poor or not at all), %	97.1	94.1
Limited Nepali literacy (poor or not at all), %	65.7	NA *
Age group, %		
18-34	11.8	11.8
35-49	44.1	41.2
50-64	26.5	29.4
>=65	17.7	17.7
U.S. residency, months %		
<9	22.6	8.6
9 to <12	19.4	2.9
12 to <19	32.3	37.1
>=19	25.8	51.4
Uninsured, %	34.3	27.3
No primary care doctor, %	8.6	6.5
Poor or fair health, %	5.7	23.5
PROMIS Physical Health Score, mean (SD)	14.2 (1.6)	13.4 (2.4)
PROMIS Mental Health Score, mean (SD)	13.6 (1.6)	13.2 (2.2)
Post-Migration Living Difficulty Score, mean (SD)	29.2 (6.1)	28.6 (6.9)

* Not re-assessed, as it is uncommon for adults to study Nepali after arrival in the U.S.

Table 2
Baseline Demographic and Social Characteristics of Bhutanese Refugee “Health Focal Points”

N	14
Female	10
Age in years, mean (SD)	20.6 (3.2)
Years of education, mean (SD)	13.1 (1.8)
Limited English proficiency (poor or not at all)	0
Limited English literacy (poor or not at all)	0
U.S. residency in months	
<9	2
9 to <12	1
12 to <19	2
>=19	9
Uninsured	6
No primary care doctor	2
Excellent or good health	12
Patient Activation Level	
1	1
2	2
3	1
4	10

Table 3
Healthcare Navigation Knowledge, Experiences, and Patient Activation Level (Bhutanese Refugees)

	Baseline (N=35)	Post-Intervention (N=34)
Avoided calling the doctor due to language barriers, %	31.3	2.9
Missed an appointment due to language barriers, %	25.8	8.8
Missed an appointment because did not know how to use public transportation, %	22.6	0
Doesn't know the number to call for emergency services (911), %	26.5	29.4
Patient Activation Level, %		
1 (low)	68.6	35.3
2	17.1	14.7
3	8.6	17.7
4 (high)	5.7	32.4

Table 4
Health Focal Points Curriculum (30 hours)

1	Making Telephone Calls and Appointments
2	Taking Public Transportation
3	Low-cost Pharmacies and Over-The-Counter Medications
4	Medicaid Eligibility
5	Safety Net Services (e.g., Federally Qualified Health Centers)
6	Reading Medical Bills
7	Assistance Paying Medical Bills
8	Rights to Language Services
9	Preventive Care and Cancer Screening
10	Professional Roles & Responsibilities.