

Cultural and Linguistic Challenges in Palliative Care

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Outline

- Define language and culture; describe US population
- Review drivers of disparities for populations with limited-English proficiency
- Describe communication strategies and best practices for working with interpreters
- Describe additional multi-level solutions informed by our research

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SETTING THE STAGE

- Demographic trends
- Definitions

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Why This Topic?

- Older adult population is becoming increasingly diverse
- Effective clinician-patient-family communication is central to high quality primary care AND is critical in the context of serious illness
- Cross-cultural communication and language barriers amplify challenges for 4Ms and across other aspects of care
- Palliative care can help elucidate **What Matters**, optimize symptom management (Medications), and improve quality of life
 - Needs to be done in a culturally- and linguistically-appropriate way

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Influence of Culture, Language on Health

National Institute on Minority Health and Health Disparities
Research Framework

		Levels of Influence*			
		Individual	Interpersonal	Community	Societal
Domains of Influence (Over the Lifecourse)	Biological	Biological Vulnerability and Mechanisms	Caregiver-Child Interaction Family Microbiome	Community Illness Exposure Herd Immunity	Sanitation Immunization Pathogen Exposure
	Behavioral	Health Behaviors Coping Strategies	Family Functioning School/Work Functioning	Community Functioning	Policies and Laws
	Physical/Built Environment	Personal Environment	Household Environment School/Work Environment	Community Environment Community Resources	Societal Structure
	Sociocultural Environment	Sociodemographics Limited English Cultural Identity Response to Discrimination	Social Networks Family/Peer Norms Interpersonal Discrimination	Community Norms Local Structural Discrimination	Social Norms Societal Structural Discrimination
	Health Care System	Insurance Coverage Health Literacy Treatment Preferences	Patient-Clinician Relationship Medical Decision-Making	Availability of Services Safety Net Services	Quality of Care Health Care Policies
Health Outcomes		 Individual Health	 Family/ Organizational Health	 Community Health	 Population Health

National Institute on Minority Health and Health Disparities, 2025
*High-designated Populations with Health Disparities: Racial and Ethnic Minority Groups (identified by OMB Directive 15), People with Lower Socioeconomic Status, Underserved Rural Populations, People with Disabilities, Sexual Minority Populations

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Key Terms: Assessing Language Use, Proficiency

US Census Bureau Definition

How well does this person speak English?

- Very Well
- Well
- Not Well
- Not at All

LEP

Healthcare Context

In what language do you want to talk to your healthcare team about your care?

- English
- All other languages

LOE

Terminology

LEP – Limited English Proficiency
 (P)LOE – (Preferred) Language Other than English
 NELP – Non-English Language Preference

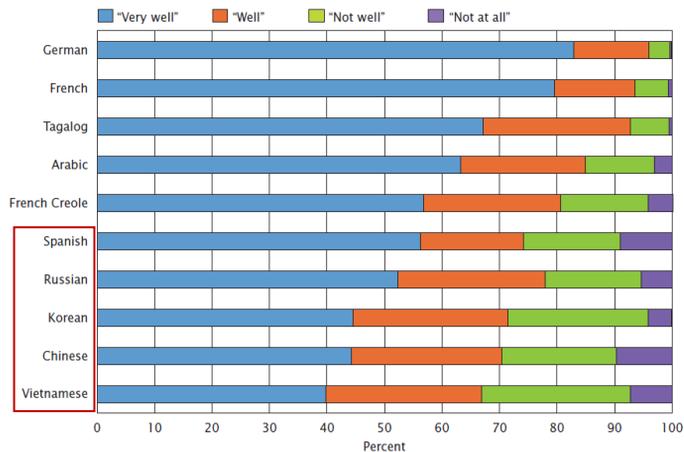
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English Speaking Ability by Language

Top 8 Languages Spoken at Home Other than English (2010)

1. Spanish
2. Chinese
3. French
4. Tagalog
5. Vietnamese
6. Korean
7. German
8. Russian

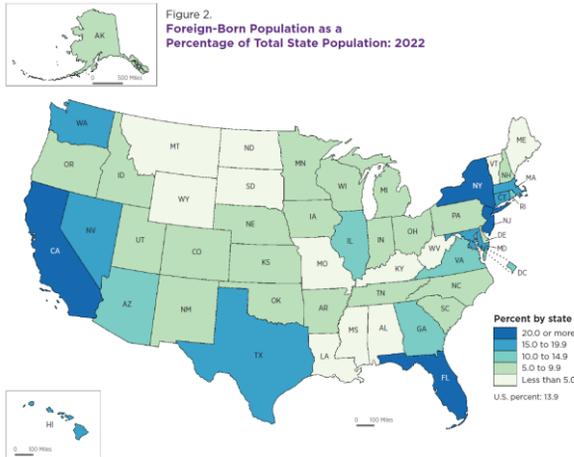
English-Speaking Ability for the Top Ten Languages: 2011
 (Population 5 years and over who spoke a language other than English at home)



Source: U.S. Census Bureau, 2011 American Community Survey.

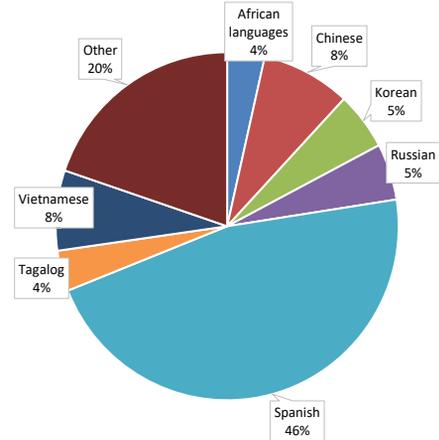
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Foreign born and LEP Demographic Makeup



American Community Survey Foreign Born Population in the US: 2022

Washington - > 580,000 residents with LEP; > 110,000 older adults



American Community Survey 2013

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Culture: What Clinicians Need to Know

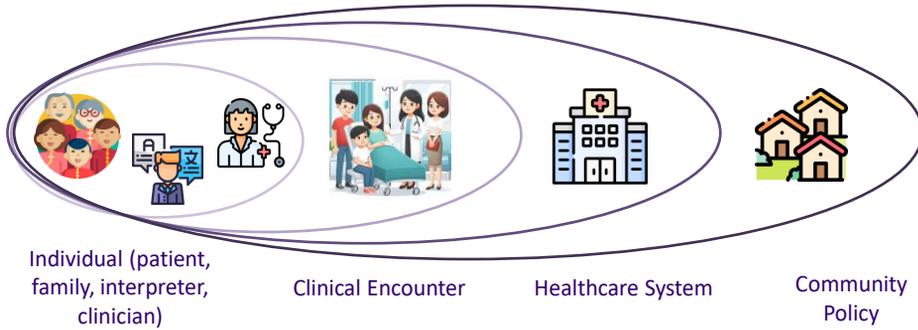
- Culture influences beliefs, communication, decision making, and the meaning of illness
- Not static – continually evolving
- Cultural humility shifts the focus from **Content to Process** and emphasizes self-reflection, appreciating patient's expertise, shared power, and curiosity



Lekas H. Rethinking Cultural Competence: Shifting to Cultural Humility. Health Serv Insights. 2020 Dec 20.

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Culture, Language Affect Multiple Levels



*Icons created by Freepik

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DETECTING DISPARITIES

- Disparities and Why They Occur

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Patients with PLOE Experience Poorer Care

- Patients with PLOE and their families experience disparities in multiple areas
- Sub-optimal assessment and treatment of symptoms
- Unmet informational needs; not informed of or didn't understand diagnosis, prognosis, treatment plans or side effects, or available resources
- Impaired informed decision making
- Feeling vulnerable, disempowered, frustrated, difficulty communicating adverse effects
- Systems lacking interpretation services in key areas (patient registration, pharmacies, operation rooms)

Yeheskal-Rawal et al. 2019. Journal of Immigrant and Minority Health

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Disparities Exist in the Outpatient Setting

Vulnerability of Older Latino and Asian Immigrants with Limited English Proficiency

Giyoon Kim, PhD,*† Courtney B. Worley, MPH,*† Rebecca S. Allen, PhD,*† Latrice Vinson, BA,*†
Martha R. Crouther, PhD,† Patricia Parmelee, PhD,*† and David A. Chiriboga, PhD†

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Table 3. Health Service Use and Barriers to Service Use According to English Proficiency

Variable	Latino Immigrants (n = 783)			Asian Immigrants (n = 962)		
	LEP (n = 503)	EP (n = 242)	EO (n = 38)	LEP (n = 484)	EP (n = 405)	EO (n = 73)
Service use						
Saw a doctor in past 12 months, %	83.9	86.4	92.1	81.6***.a,b	90.6	93.2
Number of doctor visits in past 12 months, mean ± standard deviation	5.09 ± 7.17	5.06 ± 10.97	3.47 ± 3.87	5.73 ± 5.97***.a,b	3.92 ± 3.92	2.85 ± 2.46
Barriers to service use, %						
Difficulty understanding doctor [†]	10.1***.a	1.2	5.3	13.6***.a,b	4.9	1.4
Needed someone to help understand doctor [†]	24.3***.a,b	2.1	2.6	11.8***.a,b	3.0	0
Difficulty understanding doctor because doctor spoke different language [†]	9.3***.a	0.4	2.6	6.6***.a,b	2.7	1.4
Difficulty understanding written information at doctor's office	33.9***.a,b	13.5	16.2	42.1***.a,b	8.9	11.9
Difficulty reading instruction on prescription bottle	18.7***.a	4.7	10.8	31.4***.a,b	9.1	2.9

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LEP Older Adults Have Higher EOL Utilization

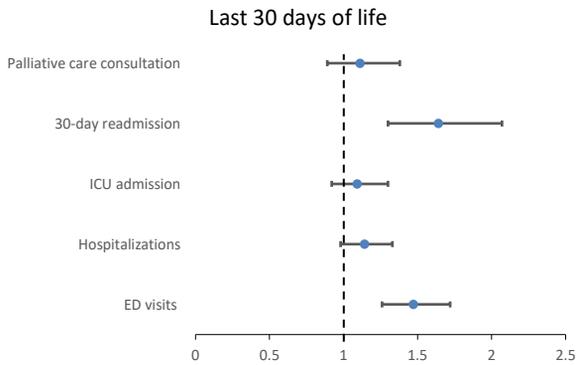
Received: 15 November 2021 | Revised: 2 May 2022 | Accepted: 6 May 2022
DOI: 10.1111/jgs.17913

CLINICAL INVESTIGATION

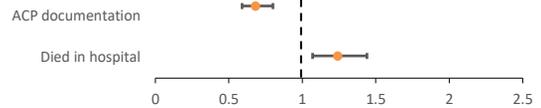
Journal of the
American Geriatrics Society

End-of-life healthcare utilization and palliative care use among older adults with limited English proficiency

Nauzley C. Abedini MD, MSc^{1,2} | Lois Downey MA³ | Ruth A. Engelberg PhD^{2,3} | J. Randall Curtis MD, MPH^{2,3} | Rashmi K. Sharma MD, MHS^{2,4}



Other outcomes



* Models adjusted for race-ethnicity, age, # diagnoses, education

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Interpreters are Underused



Patterns of Interpreter Use for Hospitalized Patients with Limited English Proficiency

Yael Schenker, MD, MAS¹, Eliseo J. Pérez-Stable, MD¹, Dana Nickleach, MS¹, and Leah S. Karliner, MD, MAS¹

Table 2. Patterns of Interpreter use for Three Types of Clinical Encounters Among Patients (N=234) of Two Hospitals in the San Francisco Bay Area, 2005-2008

	With physician at admission N (%)	With physicians since admission N (%)	With nurses since admission N (%)
Interpreter present	130 (57)	137 (60)	85 (37)
Hospital interpreter	57 (17)	30 (14)	10 (4)
Family member, friend or other patient	63 (26)	50 (23)	42 (18)
Nurse, clerk or physician	26 (12)	52 (23)	31 (14)
Interpreter not present	100 (43)	90 (40)	146 (63)
Preferred to speak English	10 (4)	13 (6)	20 (9)
Physician or nurse spoke your native language well	42 (19)	26 (12)	14 (6)
Too long to wait or none available	15 (7)	17 (8)	26 (11)
"Got by" or the physician/nurse barely spoke to you at all	31 (14)	34 (15)	86 (38)

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Getting By: Underuse of Interpreters by Resident Physicians

Lisa C. Diamond, MD, MPH^{1,2,5}, Yael Schenker, MD³, Leslie Curry, PhD, MPH⁴, Elizabeth H. Bradley, PhD⁴, and Alicia Fernandez, MD²

"I know that when people are very pushed for time, they may or may not call an interpreter. They may just 'get by' on the few words they know in different languages for like 'pain' and 'take a deep breath' and just fumble through."

"I feel guilty... because I feel like I'm not doing my job, and it also makes me feel very frustrated and upset at how our hospitals and clinics are run - that we allow this to happen... There is a lot of sentiment that 'well maybe [patients with LEP] shouldn't be getting healthcare.' I think the reason that I feel badly is because I know that I am not giving equal care to my patients."

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Inadequate Interpreter Use = Poorer Outcomes

- Providers frequently rely on family, including minors, to interpret information about diagnosis and prognosis
- When professional interpreters are not used:
 - Patients and families had inadequate understanding of diagnosis, prognosis
 - Patients had worse end-of-life symptom management
 - Families experienced emotional conflict and distress

Silva MD, Interpreting at the end of life. JPSM 2016 March

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Inequities in the Presence of Interpreters



Patient Education and Counseling 92 (2013) 246–252

Should culture affect practice? A comparison of prognostic discussions in consultations with immigrant versus native-born cancer patients¹

Phyllis N. Butow^{2,3*}, Ming Sze^{2,4}, Maurice Eisenbruch⁵, Melaine L. Bell⁶, Lynley J. Aldridge^{2,5}, Sarah Abdo^{2,5}, Michelle Taniou^{2,5}, Skye Dong⁷, Rick Iedema⁸, Janette Vardy^{2,5}, Rina Hui⁹, Francis Boyle¹⁰, Winston Liaw¹, David Goldstein¹

- **23% of MD prognostic statements were not interpreted**
- **27% of interpreted MD statements were not interpreted accurately**
- **59% of patient/family prognostic statements were not interpreted**

Oncologists used more jargon with immigrants with interpreters, made fewer statements of hope

Topics discussed	Anglo-Australian (n=31)	Immigrants with interpreters (n=32)	Immigrants without interpreters (n=15)	p-Value ^b
Doctor conveyed hope	30 (97)	18 (62)	14 (100)	0.0004
Doctor suggested coping strategies	13 (42)	12 (38)	3 (20)	0.3
Section B: Overall behavior				
Doctor used medical jargon	22 (71)	28 (88)	7 (47)	0.009
Ceasing disease specific treatment	18 (58)	20 (63)	4 (27)	0.06

Dr: We think there is a 40% chance that the treatment will prolong your life

Int: The treatment will prolong your life^c.

Dr: But you have a reasonably good chance to respond to the chemo-therapy and therefore I should be able to control this cancer for...you know, for months and months

Int: But you have a great chance that if the chemotherapy works...the disease should be under control and it (your life) should be able to be prolonged and prolonged.

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Interpreter-Reported Missed Opportunities

- Interpreters report multiple missed opportunities:
 - Infrequent pre-meetings
 - Rarely receiving feedback or being able to debrief with team
 - Often don't feel they are treated as a part of the medical team
- Other challenges:
 - Conflicts between strict interpretation and cultural brokering
 - Palliative care jargon is hard to translate (DNR, hospice)

Howard J. JPSM 2025 Mar; Slusarz C. Pall and Supportive Care. 2023 Oct; Latif Z. JPM 2023 June; Silva MD. JPSM, 2020 Mar

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EFFECTIVE COMMUNICATION

- Clinical Encounters: Working with Interpreters

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Assessing the Need for an Interpreter

- Check the medical chart to see the patient's preferred language for medical care
- Ask the patient/family their preferred language for medical care
- Being conversational in English may not be enough to understand medical jargon -> **normalize the need for an interpreter to help with complex conversations, reduce burden on the family member**
- Family members may want to act as interpreters or resist having a "stranger" -> **reassure HIPAA protections, confidentiality**

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Negotiating with Family

There is also a group that, they feel that they are independent and they don't need an interpreter. So, you have to negotiate with them. Most of the time, when I talk to them, I tell them, "Okay, all of us, we speak English." The problem is, the medical lingo is difficult to understand. My concern is that you are listening to a conversation with the doctor; there is a word that you don't know. You start to wonder, "What is this?" When you come back, you lose track of the conversation. **So, let me help you and you do your part, which is taking care of your loved one and listening, so you can take any decision and do whatever is needed. That usually puts the people at ease. People then don't get offended.** They work with us and they do really participate in a better way, to do the treatment of the patient. (CCM_Interview_01)

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Working with Interpreters (In-person/video)

- **Before**

- Pre-meet with the interpreter: review purpose of the discussion (heads up), basics of patient's condition, ask about any relevant cultural norms, linguistic nuance

- **During**

- Avoid medical jargon; break sentences into shorter segments
- Focus on underlying concepts for complex terms (DNR, hospice)
- Use empathic statements as you normally would
- Check for patient/family member understanding (teach back)

- **After**

- Debrief: chance for emotional support, consider providing/asking for feedback

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Why Pre-Meetings Matter (Interpreters Voices)

"Some says 'Oh I'll give you some background and here is where we are at.' That's help a lot . . . some information so that they [interpreter] feel connected, . . . they're more confident. So I interpret but . . . I don't feel like I completely understand the whole picture." (Vietnamese)

"on the pre-session, give us a little bit insight, but not all the providers do that . . . So the provider said, ' . . . Here's the patient and that's her name. But just so that you know, she has memory issues.' So right away, I know it's a dementia session." (Chinese)

"It's like we get dunked in ice water every single patient, because we don't know what we're going to talk about." (Spanish)

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MULTI-LEVEL APPROACHES

- Innovative approaches
- Intervention targets

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Moving Beyond Interpretation

Understanding the Role of Caseworker-Cultural Mediators in Addressing Healthcare Inequities for Patients with Limited-English Proficiency: a Qualitative Study

Rashmi K. Sharma, MD MHS¹, Anna Cowan, MPH², Harimrat Gill, BS³, and Lea Ann Miyagawa, MN RN⁴

[Journal of General Internal Medicine](#) volume 38, pages1190–1199 (2023)

- Program started in 1994 as a 2-year grant; 5-6 CCMs
- In 1996, HMC took on program funding and hired nurse manager
- Team has grown to 10 representing Ethiopian Amharic, Cambodian, Vietnamese, Somali, Spanish, Pashto and Dari languages

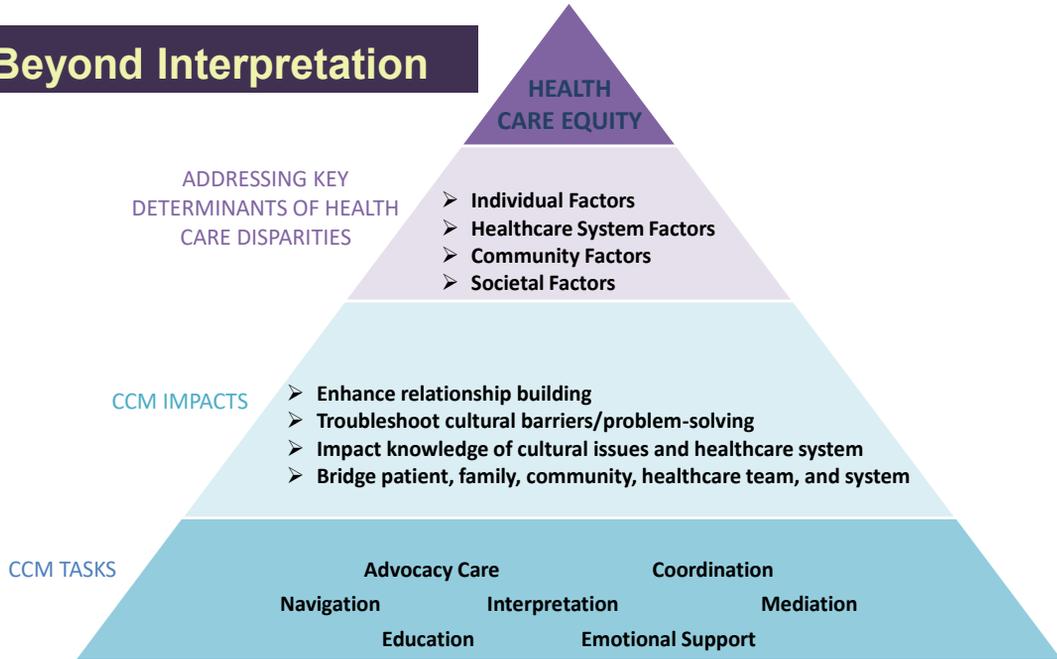
<https://ethnomed.org/about/community-house-calls-program/>



Mission: To contribute to the health of refugee and immigrant patients, families, and communities through partnerships that promote culturally sensitive and health equitable care.

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Beyond Interpretation



W CAMBIA PALLIATIVE CARE CENTER OF EXCELLENCE
UNIVERSITY of WASHINGTON

ImPaCT - Improving Palliative Care Together

- Study Goals: Identify targets for multi-level interventions to improve palliative care for populations with preferred language other than English (PLOE)



ImPaCT Dementia (Older adults with dementia)

- Mandarin & Cantonese
- Spanish
- Vietnamese



ImPaCT Cancer (Patients with advanced cancer)

- Spanish
- Vietnamese
- Somali



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Framing Palliative Care to Help Support Goals

“The great thing that I like the palliative care is they do the communication better because they can communicate to the other care teams. **They can lessen the burden of the family . . . and give them ideas of their goal of care. It is the right time to maybe to go and visit to Somalia or to see some family members.** Am I okay? And what can I have if I've been there? So to make sure that these patients to get the refills of the medication they need. And . . . towards going to end of life or talking about it, **how to make the persons, the disease, they have to live better.**” (Somali CCM)

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Palliative Care Bridging Info Gaps

“That day, I remember her always asking, ‘am I going to get better?’ The definition of getting better was tricky and I always, with palliative care... talk to her about what getting better really means . . . **‘Are you asking if your cancer is going to be cured or are you asking if you're going to feel better even though the cancer is not gone?’** We were very specific about that.”

“Palliative care does that very well. Not targeting the disease itself, but seeing the human being as what are the cultural characteristics of this individual that make this patient who this person is . . . **she understood what was going to be done, because we were very clear, and we explained to her how far the cancer had gone and what could be expected in the future for her, honest and transparent. That's what we were for her. I'm very proud of working with palliative care with this patient and others.**” (Spanish CCM)

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Healthcare System Navigation Needs

“People have to deal with new cultural challenges being in the US and they need more hand holding. This is hard because the focus here is on empowering people. **But people need help, even if they are capable**, they feel reassured when someone is providing that extra help even if it takes time and then they can feel more confident in the future. Providers need to be mindful of this.” (*Spanish Interpreter*)

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Limited Community Resources

“So the physician offers some community resources, but . . . the resources is also in English and that's why the daughter was looking at me to say, "I don't understand these resources. How do I seek help from this paperwork, this website?" (*Vietnamese interpreter*)

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Implications – Intervention Targets



- Communication skills training
 - Clinicians: working with interpreters; re-frame pall care
 - Interpreters: interpreting serious illness conversations



- Structured approaches for clinician-interpreter partnership – pre-meetings



- Developing culturally- & linguistically-appropriate resources



- Programs that combine interpretation and navigation

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Summary

- Patients with PLOE and serious illness experience disparities in multiple domains including symptom management, information needs, decision making
- Interpretation is a fundamental part of any intervention aimed at providing equitable care to this population **AND** it isn't enough to address the multi-level drivers of inequities for this population
 - **Best Practices: PRE-MEET WITH THE INTERPRETER**
- The CCM program is an example of an intervention that seeks to address multi-level barriers to equitable care by providing advocacy, care coordination, navigation, education, mediation, interpretation, and emotional support to patients and their families
- Multi-level interventions are needed to improve palliative care for populations with LEP

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Final Takeaway

“See me as a human, see me as just somebody like you . . . see me like I'm someone without disease and then let's talk about the disease. . . And so when you walk in that door know that this person had a life before immigrating here . . . I remember one of the doctors, I told him he was shocked. I said, ‘she used to be our best basketball player of national team, this woman. Do you know that?’ (Somali CCM)

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Questions or comments?

SEATTLE-BASED ARTIST MICHELLE KUMATA

你好 HALLO 안녕하세요
CIAO HOLA नमस्ते
γεια HELLO
こんにちは привет
BONJOUR مرحبا OLÁ



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