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Experiences of Medical Interpreters During Palliative Care Encounters With Limited English Proficiency Patients: A Qualitative Study

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Abstract

Background: There are many challenges in communication and cultural barriers for patients with limited English proficiency (LEP) who suffer from serious illnesses. Palliative care utilization among this population remains limited and the experiences of medical interpreters during palliative care encounters remain understudied.

Methods: We conducted semistructured video interviews with interpreters working at an academic medical center. Interview questions explored interpreters' observations and experiences during palliative care encounters with LEP patients. We performed thematic analysis of the interview contents.

Results: Our study included 20 interpreters who interpret in 9 languages with a mean experience of 16.3 years. We identified four themes from the interviews that shed light on the challenges of incorporating palliative care into the care of patients with LEP: (1) lack of a verbatim interpretation for the term "palliative care," (2) poor patient understanding of their treatment goals, (3) suboptimal timing of palliative care involvement, and (4) fears and misconceptions related to palliative care. Owing to challenges in word choice, the timing of palliative care involvement, and poor understanding of palliative care, interpreters observed that many patients with LEP declined palliative care involvement in their treatment plan.

Conclusions: In this study, we identified several actionable barriers interpreters noted to incorporating palliative care into care of patients with LEP. Interventions directed toward providing LEP patients with standardized culturally appropriate information on palliative care are needed.

Keywords: end-of-life discussions; limited English proficiency; medical interpreters; palliative care

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Introduction

IT IS ESTIMATED THAT ANNUALLY ~40 million people in the world need palliative care, but only 14% of those actually receive it.¹ Palliative care availability across the United States has grown exponentially over the past 12 years.² However, significant barriers to expanding access to palliative care remain. One group particularly vulnerable to poor access to palliative care, because of both challenges in communication and cultural differences, is patients with limited English proficiency (LEP).³⁻⁵ Prior studies have demonstrated a growing disparity in access and utilization of palliative care among patients with LEP across different ethnic groups.^{6,7} In addition, patients with LEP have lower utilization of hospice services, family bereavement services, and poor advance care planning discussions.^{8,9}

Interpreters are a critical part of palliative care encounters with LEP patients. In a prior study evaluating Spanish and Chinese interpreters' experiences during end-of-life discussions, interpreters cited language complexity, ineffective communication practices, and lack of standardized training for interpreters in palliative care as some of the challenges they faced during palliative care encounters with LEP patients.¹⁰ In addition to challenges with interpreting the terminology related to palliative care, Kirby et al also showed that interpreters experienced a significant emotional burden managing complex encounters and balancing being sensitive while remaining professional during encounters.¹¹

Examining interpreters' observations, experiences, and attitudes as they relate to palliative care encounters with LEP patients is an important step to understand barriers and highlight the role of communication in such encounters. Therefore, we performed semistructured interviews with medical interpreters from nine different languages to understand the interpreters' experiences in these conversations and explore the interpreters' observations during palliative care encounters with LEP patients.

Methods

Recruitment and study cohort

We recruited interpreters employed at a single academic medical center; all interpreters working fulltime at the medical center were eligible to participate. A recruitment email was sent to all language group supervisors at our institution; we received responses from interpreters for Spanish, Chinese, Vietnamese, Cape Verdean, Russian, and Arabic. Part-time interpreters working at our institution who spoke Italian, Polish, and Hindi were also contacted by email. Interpreters contacted the research team directly to schedule the interviews.

All interpreters interviewed were hospital based and certified as medical interpreters. There are no differences in certification requirements or training requirements between full-time and part-time interpreters at our institution. Interpreters interviewed did not receive any specific training for interpreting palliative care encounters. Medical interpreters at our institution provide interpretation in all areas, thus their experiences with palliative care conversations varied widely depending on their years of experience.

Interviews and analyses

Our interview guide was designed by an interdisciplinary team composed of an internal medicine resident physician

(Z.L.), a qualitative methods expert (S.L.F.), a palliative care physician (J.A.), and a cardiologist (H.W.). Our interview questions explored the verbatim interpretation of "palliative care" in the various languages of the interpreters interviewed (Supplementary Data S1). We elected to start our interview with a nonstandard close-ended question to gain an objective answer and assess whether a verbatim interpretation for the term "palliative care" is available in the languages interviewed.

We also explored experiences interpreters had with palliative care encounters and end-of-life discussions. Video interviews were conducted by the first author (Z.L.) who is a third-year internal medicine resident physician. The interviewer received guidance regarding qualitative research interviews and methodology from a qualitative methods expert (S.L.F.). The interviews were conducted online using an online platform (Version 4.10.28 [211,991]; Starleaf, Watford, Hertfordshire).

The recordings were then transcribed using speech recognition captions on an online platform provided by Harvard University (Version 11.5.1.00001; Panopto, Seattle, WA). After redacting all identifying information from the transcripts, the scripts were distributed to the coding team that consisted of two internal medicine resident physicians trained by the research team (Z.L. and TM). This study followed the COREQ guidelines and the study was approved by the Beth Israel Deaconess Medical Center Institutional Review Board.

Thematic analysis was used in this study in addition to an inductive coding approach.^{12,13} Two interviews were coded during each session and the coding team met weekly to discuss coding decisions for every two interviews. Any coding disagreements were reconciled through discussions and group consensus. The interviews occurred concurrently with analysis, and interviews continued until thematic saturation was reached.^{12,13} The coding team used line-by-line software-assisted coding (Version 1.5 [4577]; Nvivo, QRS International, Melbourne, Australia) and the emerging codes were organized into a code book that was shared with other members of the research team. The main themes from the interviews were identified and reported in the results. The study was approved by the Beth Israel Deaconess Medical Center Institutional Review Board.

Results

We interviewed 20 interpreters (16 full-time, 4 per-diem) with a mean experience of 16.3 years (standard deviation [SD] 10.6) and a mean age of 48 years (SD 14.3) (Table 1). Our recruitment email was sent to 12 staff languages, and we had participants representing 6 staff languages in this study in addition to 3 per-diem languages. Interpreters interviewed spoke nine languages. Interpreters interviewed conducted encounters in both the inpatient and outpatient settings, their views reflect their experiences and observations from both settings. Four major themes related to challenges of palliative care integration in the treatment plans of patients with LEP were identified (Table 2):

1. Lack of a verbatim interpretation for the term "palliative care"
2. Poor patient understanding of their treatment goals
3. Suboptimal timing of palliative care involvement
4. Fears and misconceptions related to palliative care.

TABLE 1. STUDY DEMOGRAPHIC

Characteristic	Demographics N (%)
N	20
Gender	
Male	8 (40)
Female	12 (60)
Mean age (years)	48 (SD 14.3)
<30	4
30–49	6
>50	10
Mean years of experience	16.3 (SD 10.6)
≤5	4
6–10	4
11–20	7
21–39	3
≥40+	2
Languages	
Spanish	4
Cape verdean/Portuguese	4
Chinese ^a	4
Russian	2
Arabic	2
Other languages (Polish, Italian, Hindi, Vietnamese)	4

^aMandarin and Cantonese.
SD, standard deviation.

Theme 1: Lack of a verbatim interpretation for the term “palliative care”

Interpreters in our study reported that in many languages there was no verbatim interpretation for the term “palliative care.” This was a fundamental challenge for interpreters during palliative care encounters. There was no standard interpreting style that interpreters followed, creating a wide variability in the way they interpreted palliative care encounters. The way interpreters approached this challenge varied widely and was influenced by the interpreters’ knowledge of palliative care, their experience with the patient, and their comfort level with end-of-life discussions. Some interpreters asked clinicians to describe the term “palliative care” since a verbatim interpretation was unavailable, whereas other interpreters provided patients with their own understanding of palliative care that varied widely among interpreters.

Palliative care is roughly translated as they are just waiting for people to die, that you cannot do anything about it... There’s no such idea [in my language] actually, so there is no word. You have to come up with something like joint words where it’s usually a full sentence to express that. *Interpreter 16 (Hindi)*

Another interpreter commented,

That’s one of the things that are challenging because it depends on the way the interpreter understands palliative care. *Interpreter 4 (Cape Verdean)*

Palliative care was interpreted in multiple ways in some languages. Interpreters often chose the meaning based on the overall theme of the encounter.

TABLE 2. THEMES AND REPRESENTATIVE QUOTES

Themes	Representative quotes
Theme 1: Lack of a verbatim interpretation for the term “PALLIATIVE CARE”	“We don’t have that part of medicine in our country, so we don’t have anything in our country close to it. But we just interpret it the best way we can. We just tell them exactly as I told you, this department is for patients when there is no more treatment, and it can take care of your quality of life” “There are at least three, if not more than three ways [palliative care] translate to. It all depends on how much you want to focus on the issue of death.”
Theme 2: Poor patient understanding of their treatment goals	“Sometimes they just get so angry and so frustrated and a lot of times they’re like, ‘why didn’t anyone tell me this sooner?’ I get that a lot of times it’s because the kids or the wife didn’t tell him he’s dying”
Theme 3: Suboptimal timing of palliative care involvement	“I think once the person knows that they have cancer or a terminal issue, right away palliative care should be approached just to say, ‘we’re an option. Reach out to us if you need us. This is what we can provide for you.’ But if the guy is already dying and you offer palliative care, he just looks at you and he’s like ‘where were you three months ago?’”
Theme 4: Fears and misconceptions related to palliative care	“When we say ‘since you are gravely ill, we should involve palliative care.’ For Russians, this doesn’t go well, it’s like you are saying there’s no hope for you, but they want to always have hope. And that’s why palliative is a bad word for them. Let me first say, they are scared of the word. They want to have hope until the last day they breathe. It’s like taking the hope away for them.”

There is one way where it means you are dying, this is going to be the end, but we use the other way, another word and symbol, like comforting you and making you better. *Interpreter 14 (Chinese)*

Theme 2: Poor patient understanding of their treatment goals

Interpreters observed that the attitudes of patients with LEP toward palliative care were heavily influenced by the patient’s knowledge of the disease stage and goals of treatment. Interpreters noted that when patients lacked insight into the stage of their illness, introducing palliative care created anger and frustration. Interpreters also felt that one of the few

times the care team communicated prognosis and treatment goals clearly to patients with LEP was when the care team introduced the patient to palliative care.

Interpreters also observed that during some palliative care encounters, LEP patients were surprised about their prognosis and treatment plans. Interpreters interviewed speculated that the utilization of *ad hoc* interpreters such as family members to conduct these encounters could explain the patients' gap in knowledge regarding their care.

A lot of times, [patients say] 'what do you mean I have cancer? What do you mean it's that bad? How come no one told me this earlier?' that's because they've refused interpreters, or the patient has not refused an interpreter, but the elected family member has refused interpreters. *Interpreter 10 (Polish)*

Theme 3: Suboptimal timing of palliative care involvement

The timing of involving palliative care in the treatment plan for patients with LEP was highlighted by many interpreters during the interviews. Interpreters observed that palliative care was often offered late in the course of a patient's illness or close to a patient's time of death, which created confusion for patients and families in addition to limiting the benefits of palliative care.

Most of the time, they get involved at the end of life. All of a sudden, there is a doctor who comes suddenly and says 'what do you value in life and how would you like to live the rest of the time you have left?' This is shocking for patients *Interpreter 2 (Arabic)*

Interpreters emphasized the importance of discussing with patients the meaning of palliative care in a granular manner and the ways the palliative care team can help the patient before the patient's meeting with the palliative care team. Interpreters observed that many clinicians only introduced palliative care to patients during family meetings when other family members were present. In these situations, if families dominated the discussion and declined palliative care involvement, the patient was left with minimal input.

I think there should be a way that we could approach the patient without the family and have the patient decide [about palliative care]. I think that the patient's family are thinking he's going to die anyway, why stress him out? But the thing is that he needs to know about other options that are available in the future. *Interpreter 10 (Polish)*

Theme 4: Fears and misconceptions related to palliative care

Interpreters stressed on the importance of identifying and addressing patients' fears and misconceptions about palliative care as that often formed an important factor in patients' acceptance of palliative care. Some patients had prior misconceptions of palliative care that heavily influenced their decisions. Interpreters felt that it was their job to address these fears and misconception about palliative care that ranged from the patient's fear of being sent to hospice to fears of the medical team discontinuing potentially curative treatments in favor of end-of-life care. Interpreters observed that when patients' misconceptions were not addressed properly by the primary care team, patients often firmly declined palliative care.

Most people when they meet [a]palliative care doctor they think 'This is the end.' Like they are just going to give them morphine to make them comfortable. And most of them, they do not accept it. *Interpreter 2 (Arabic)*

In addition, interpreters addressed the consequences when team members did not clearly stress the ongoing role of the primary team after palliative care involvement. Interpreters observed when such conversations did not take place, patients felt abandoned by their primary team when palliative care was involved.

If we say palliative care [will] help relief symptoms then they ask 'what does my doctor do then?' They say 'my doctor has been doing that for me, why now introduce me to palliative care?' *Interpreter 7 (Spanish)*

Interpreters also noted that having the patients' primary clinicians/team play an active role in end-of-life care and discussions even when palliative care is involved was important to patients with LEP.

Some providers when the patient has palliative care involved, they don't even come to see the patient. They let palliative care manage all the discussions. I had a patient say 'where is my doctor who knows me? Why is there a new team handling these conversations?' They get very anxious about that. They feel like the provider doesn't give them the time when they are that sick. *Interpreter 2 (Arabic)*

Discussion

In this study, we explored interpreters' viewpoints on the challenges related to incorporating palliative care into treatment plans of patients with LEP. Interpreters in our study had difficulty describing palliative care to patients with LEP due to the lack of verbatim interpretation of "palliative care" in many languages. Although some interpreters focused on symptom management when describing palliative care, others focused on imminent end-of-life care. Interpreters highlighted this challenge as a potential contributor to the difficulty of incorporating palliative care in the treatment plan for patients with LEP.

Interpreters interviewed also observed from prior encounters that patients with LEP seemed to have poor understanding of their prognosis and treatment goals that created a challenge when interpreters discussed palliative care. Misconceptions related to palliative care were also observed by interpreters during palliative care encounters with LEP patients. The influence of all these barriers likely affect palliative care accessibility to patients with LEP and may help explain the reported disparities in palliative care utilization among this patient population.⁷

This study builds on previous research exploring barriers faced by LEP and culturally diverse patients with serious illnesses in incorporating palliative care teams into their care. In a study by Kirby et al, culturally and linguistically diverse patients demonstrated variable or a complete lack of understanding of palliative care.¹⁴ The authors also found, as we did, the lack of an equivalent term for "palliative care" in other languages to be a major contributor to the patients' poor understanding. In our study, we observed that interpreters varied in the ways they explained palliative care to patients with some interpreters focusing on symptom management and others focusing on imminent end-of-life care.

Kirby et al observed a similar finding in their study when they interviewed interpreters to understand the interpreters' experiences when patients transition from oncology to palliative care citing that interpreters used a wide spectrum of practices to explain palliative care to patients with LEP.¹¹ Such variability in practice can result in patients having different understanding, attitudes, and preferences toward palliative care. Implementing training programs to address interpreters' questions about palliative care in a mutually respectful training environment has been shown to significantly improve interpreters' confidence in conducting palliative care encounters.¹⁵ Prior studies have documented that patients with language barriers often lack accurate understanding of their diagnosis and prognosis. In addition, investigators of other studies have found that non-English speakers have suboptimal end-of-life and goals-of-care discussions.^{8,16–18} Interpreters in our study noted that palliative care was often incorporated late in the course of a patient's treatment. Although late involvement of palliative care in the treatment course is not unique to LEP patients, we suspect that it plays an important role in understanding the disparities that have been reported among critically ill LEP patients.

In a study by Barwise et al, the authors found that patients with LEP who died in the intensive care unit were less likely to receive a comfort measures order set, took 19.1 days longer to transition to comfort measures only, were less likely to have an advance directive, more likely to receive mechanical ventilation, and more likely to have restraints used.¹⁶ We suspect that such disparities in end-of-life care are likely due to poor communication strategies used by the medical teams and implicit bias resulting in patients' and families' poor understanding of the disease stage, treatment goals, and options available at the end of life.

In a study by De Graaff et al, the authors demonstrated that families of Turkish and Moroccan patients often did not understand the patient's diagnosis and prognosis blaming physicians for poor communication.¹⁹ Partnering with interpreters to conduct encounters for patients with LEP can help enhance our communication strategies with LEP patients and medical interpreters.²⁰ Studies have recommended increasing interpreters' participation and potentially incorporating interpreters as part of the clinical team to allow for better communication and understanding.²¹

Medical interpreters in our interviews highlighted some of the observed misconceptions about palliative care. Challenges such as fear of abandonment by the primary care team when palliative care is involved and lack of discussion about the role of palliative care in a patient's treatment plan are not unique to LEP patients.^{22–24} Previous studies have highlighted the profound impact such factors play in patients' acceptance of palliative care. Although English-speaking patients can be provided with resources to enhance their understanding of palliative care, such resources rarely exist for patients with LEP, making the clinical encounters with LEP patients and interpreters of paramount importance.

This study had several limitations. We interviewed 20 interpreters who chose to participate in the study so self-selection bias should be considered. Interpreters in our study may have more familiarity with palliative care relative to interpreters from those medical centers and community hospitals that have fewer palliative care clinicians. Additional studies are needed to explore these interpreters' ex-

periences with palliative care to gain a more comprehensive understanding of the issue. The interviews in our study were conducted by a physician that could have impacted the responses from the interpreters during the interviews.

In addition, interpreters in this study highlighted their observations while conducting palliative care encounters with LEP patients, we did not interview LEP patients directly to assess and further explore these challenges. Given the qualitative nature of the work, lack of generalizability and transferability of our findings should be considered. Also, there is a lack of objective variables measuring the effectiveness of interpretation and patient understanding of encounters. Lastly, language and culture are often intertwined making it challenging to separate the two.

Conclusion

There are growing disparities regarding end-of-life care and palliative care utilization among patients with LEP seeking care in our medical system. In this study, we show that palliative care interpretation was challenging as there was no verbatim interpretation for the term “palliative care”; patients often lacked understanding of their disease stage and treatment goals when they were introduced to palliative care; and confusion regarding the role of the palliative care team existed. Training interpreters in the terms used during palliative care and investigating the effect of educational programs for clinicians who teach them to explain palliative care correctly to patients with LEP are needed to better address the current disparities patients with LEP face at the end of life.

Authors' Contributions

Z.L. contributed to conceptualization, methodology, data analysis, and article preparation—original draft, review, and editing; T.M. was involved in data analysis and article preparation—review and editing; S.F. carried out methodology, data analysis, and article preparation—review and editing; J.A. was involved in methodology and article preparation—review and editing; P.Q. was in charge of methodology and article preparation—review and editing; and H.W. was in charge of conceptualization, data analysis, and article preparation—original draft, review, and editing.

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Author Disclosure Statement

No competing financial interests exist.

Supplementary Material

Supplementary Data S1

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