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Title

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Permalink

https://escholarship.org/uc/item/2vh621zz

Journal

Journal of palliative medicine, 15(9)

ISSN

1096-6218

Authors

Schenker, Yael
Fernandez, Alicia
Kerr, Kathleen
et al.

Publication Date

2012-09-01

DOI

10.1089/jpm.2012.0032

Peer reviewed

Interpretation for Discussions about End-of-Life Issues: Results from a National Survey of Health Care Interpreters

Yael Schenker, M.D., M.A.S.,[1] Alicia Fernandez, M.D.,[2] Kathleen Kerr,[3]
David O'Riordan, Ph.D.,[3] and Steven Z. Pantilat, M.D., FACP[3]

Abstract

Background: Communication about end-of-life issues is difficult across language barriers. Little is known about the experience of health care interpreters in these discussions.

Objectives: Objectives of this study were to: 1) assess the experiences of healthcare interpreters when interpreting discussions about end-of-life issues; 2) identify interpreter characteristics and experiences that may be associated with improved satisfaction and comfort with interpreting these discussions; and 3) describe interpreter training needs.

Methods: The study utilized an electronically administered survey distributed nationally to health care interpreters in the United States. One hundred and forty-two health care interpreters participated. Measurements included general experiences, attitudes, and perceived training needs when interpreting discussions about end-of-life issues.

Results: Most respondents had received a certificate in interpretation (71%, 101/142), completed more than 40 hours of training (89%, 127/142), and had more than 5 years of interpreting experience (65%, 93/142). Overall, 85% (121/142) of respondents had interpreted discussions about end-of-life issues and most interpreted multiple discussions per week. Of those interpreters who had experience with these discussions, the majority (85%, 103/121) reported feeling comfortable, but only half (48%, 58/121) reported that these discussions usually went well. Interpreters who felt clear about their role were more likely than interpreters who did not feel clear about their role to think that discussions went well (51% [57/112] versus 11% [1/9], $p=0.02$) and to feel comfortable interpreting (88% [98/112] versus 56% [5/9], $p=0.01$). Eighty percent (97/121) of respondents with experience in end-of-life discussions were personally interested in more specific training for these discussions. Attitudes and perceived training needs did not differ by interpreter demographics or qualifications.

Conclusions: The majority of interpreters have experience with end-of-life discussions but, independent of interpreter training and experience, only half report that these discussions usually go well. Interpreters want and may benefit from targeted educational interventions that could improve the quality of care for vulnerable patients and families in these difficult situations. Health systems and interpreter certification programs should incorporate specific training on how to interpret discussion about end-of-life issues.

Introduction

INCREASING MIGRATION WORLDWIDE has led to greater linguistic diversity in a variety of health care settings and a growing need for well-trained health care interpreters. For example, more than 55 million people in the United States, 3 million in Australia, and 2 million in the United Kingdom speak a language other than English at home, and the percentage of the U.S. population with limited English proficiency (LEP) continues to grow.[1–3]

Perhaps nowhere is the need for well-trained interpreters greater than for discussions of palliative care issues. Such conversations, ranging from giving bad news or sharing prognosis to death notifications, are common across a wide variety of practice settings and specialties. Attitudes toward these topics can vary with culture, and concepts and words may not translate easily, making conversations about these topics even more challenging when patients and clinicians do not share a common language.[4–9] Two recent studies of language-discordant family meetings for critically ill patients in

¹Division of General Internal Medicine, Section of Palliative Care and Medical Ethics, University of Pittsburgh, Pennsylvania.
²Division of General Internal Medicine, San Francisco General Hospital, ³Palliative Care Program, University of California, San Francisco.

the intensive care unit in the United States found that these discussions were shorter, involved frequent alterations in interpretation, and contained fewer supportive statements by physicians than meetings conducted with English-speaking families.[10,11] A study of oncology consultations in Australia found that doctors spoke less and ignored more patient cues in discussions necessitating an interpreter.[12] Data from qualitative research with interpreters suggest that language-discordant discussions about end-of-life issues require unique skills from physicians and interpreters, including sensitivity to cultural cues related to death and dying and the ability to negotiate perceived tensions in the interpreter's role between providing strict interpretation versus acting as a cultural broker or an advocate for the patient and family.[13,14] Interpreters also report difficulty handling their own emotions and not feeling like a part of the health care team when interpreting for discussions about death and dying or delivering bad news.[13]

The growing awareness of such challenges and the increasing frequency of these situations call for a deeper understanding of the experiences of interpreters in these uniquely difficult conversations in order to improve the quality of interpretation and the quality of care. We therefore conducted a national survey of health care interpreters to assess their attitudes, experiences, and perceived needs when interpreting for discussions about end-of-life issues. The objectives of this study were: to 1) assess the experiences of healthcare interpreters when interpreting discussions about end-of-life issues, 2) to identify interpreter characteristics and experiences that may be associated with improved satisfaction and comfort with interpreting end-of-life discussions, and 3) to inform future interventions targeting interpreters and clinicians to improve the quality of language-discordant communication around end-of-life issues.

Methods

Survey development

A multidisciplinary project team that included palliative care physicians, health services researchers, and health care interpreters developed the interpreter survey. We used a previous qualitative study with interpreters as a basis for survey development and included questions about specific experiences and attitudes toward interpreting discussions about end-of-life issues that were raised by interpreters in focus groups.[13]

Prior to administration, the survey was pilot-tested with a group of interpreters employed at a public hospital in California that serves a large population of LEP patients. The pilot-testers endorsed the survey as being clear and not burdensome to complete.

Survey distribution

The survey was administered anonymously through an electronic survey portal. The survey link, along with a brief description of its purpose (to assess interpreter experiences with end-of-life discussions and to learn how best to support interpreters and other health care professionals caring for patients who are near the end of life and who speak limited English) was distributed to interpreters nationally through listservs (National Council on Interpreting in Healthcare [NCIHC], Texas Association of Healthcare Interpreters and Translators, Nebraska Association of Translators and Inter-

preters), newsletters (California Healthcare Interpreting Association; INTERSECT: A Newsletter About Language, Culture and Interpreting), Facebook (NCIHC), and e-mail (California Healthcare Foundation interpreter training group and Health Care Interpreter Network). The survey was open to responses for 8 weeks. The study was approved by the UCSF Committee on Human Research.

Subjects

Respondents who indicated that they work as health care interpreters, either as a primary job or in addition to other duties, were invited to respond to all survey questions. Individuals who indicated they do not currently work as health care interpreters received a thank you message and were not asked any other questions.

Survey content

The survey utilized skip logic so that respondents were only asked questions appropriate to their health care interpretation experiences. For example, if an individual said he or she had never interpreted a code status discussion, the individual was not asked further questions about experiences or attitudes toward this discussion type. All respondents, even those who indicated they had never interpreted a discussion about end-of-life issues, were asked general questions about their training and experience, such as number of years of interpretation experience, if they had a degree or certificate in interpretation, and the languages for which they interpret. Respondents also provided general demographic data, including their country of origin, how long they had lived in the United States, age, and gender.

Respondents who indicated that they had interpreted a discussion about end-of-life issues, which might include giving bad news, discussing goals of care, or talking about death and dying, were asked about their recent experiences and attitudes when interpreting for these kinds of discussions. Respondents were asked to rate how frequently the following occurred using a 4-point Likert scale (0 = Never, 1 = Sometimes, 2 = Usually, 3 = Always): 1) meeting with the physician or other providers before or 2) after the discussion to share information or discuss expectations; 3) feeling clear about their role; 4) feeling the doctor understood their role; and 5) feeling included as a member of the health care team. Respondents were asked to rate their attitudes regarding the following issues on a 5-point Likert scale (0 = Strongly disagree, 1 = Disagree, 2 = Neither agree nor disagree, 3 = Agree, 4 = Strongly agree): 1) finding interpreting for discussions about end-of-life issues more satisfying or 2) more stressful than interpreting for more routine clinical encounters; and 3) feeling that interpreted discussions about end-of-life issues usually go well. Respondents indicated their overall comfort interpreting for discussions about end-of-life issues on a 4-point Likert scale (0 = Very uncomfortable, 1 = Uncomfortable, 2 = Comfortable, 3 = Very comfortable).

Respondents were also asked about their recent experiences interpreting for six different kinds of discussions that involve palliative care issues: giving bad news, discussing code status, prognosis and planning future care, surrogate decision making, withdrawing life-sustaining treatment, and death notifications. A brief vignette was used to illustrate each discussion type. Interpreters who had experience with the

TABLE 1. DEMOGRAPHIC CHARACTERISTICS
OF INTERPRETERS (N=142)

Interpreter characteristics	N (%)
Age (years)	
Mean (SD)	46.2 (11.9)
Gender	
Women	115 (81)
Language	
Spanish	104 (73)
Vietnamese	8 (6)
Mandarin	8 (6)
Cantonese	6 (4)
Russian	5 (4)
French	4 (3)
German	2 (1)
Other	5 (4)
Certificate	
Yes	101 (71)
Training	
≤40 hours	15 (11)
40+ hours–1 year	52 (37)
1+ year	75 (53)
Years experience	
Mean (SD)	10.8 (7.9)
1–5 years	49 (35)
6–10 years	33 (23)
11–20 years	45 (32)
> 20 years	15 (11)
Time spent interpreting per week	
<8 hours	28 (20)
9–32 hours	47 (33)
> 32 hours	67 (47)

SD, standard deviation.

discussion type were asked to respond to the following questions on a 4-point Likert scale (0=Never, 1=Sometimes, 2=Usually, 3=Always): 1) how often the doctors used technical terms that did not translate well; 2) how often the doctor asked them to say things that conflicted with the culture of the patient or family; 3) how often the discussion was so emotional that they felt overwhelmed; and 4) how often the case stayed with them and they found themselves thinking about it afterwards. Respondents also indicated their overall comfort interpreting for each discussion type on a 4-point Likert scale (0=Very uncomfortable, 1=Uncomfortable, 2=Comfortable, 3=Very comfortable).

Finally, respondents who had interpreted a discussion about end-of-life issues were asked to rate how strongly they agreed or disagreed with specific recommendations for improving these discussions and about their perceived need for more training. An open-ended question asked interpreters to make one suggestion for improving discussions about end-of-life issues.

Analysis

Descriptive statistics (frequencies, mean, 95% confidence intervals) were used to examine the distribution of measures. We dichotomized experiences as Never/Sometimes versus Usually/Always and attitudes as Agree/Strongly agree versus Neutral/Disagree/Strongly disagree. We used χ^2 analyses to test for bivariate associations between interpreter experiences and attitudes toward end-of-life discussions. The Statistical Package for the Social Sciences (SPSS) for Mac (version 17; SPSS, Inc., Chicago IL) was used to analyze these data.

Results

Respondents

In total, 142 health care interpreters completed the survey. The majority of interpreters were women (81%), and the most common language interpreted for was Spanish (73%), followed by Vietnamese, Mandarin, Cantonese, and Russian (Table 1). Most interpreters had received a certificate in interpretation (71%) and had completed more than 40 hours of training (89%). Thirty-two percent of respondents worked in California. Forty percent of respondents interpreted only in-person, 5% interpreted only via telephone, and 1% interpreted only via video. The remainder of respondents provided interpretation via multiple modalities.

Experiences

Eighty-five percent ($n=121$) of interpreters who completed the survey had interpreted a discussion about end-of-life issues. Recent experiences interpreting these discussions are shown in Figure 1. Interpreters more commonly met with
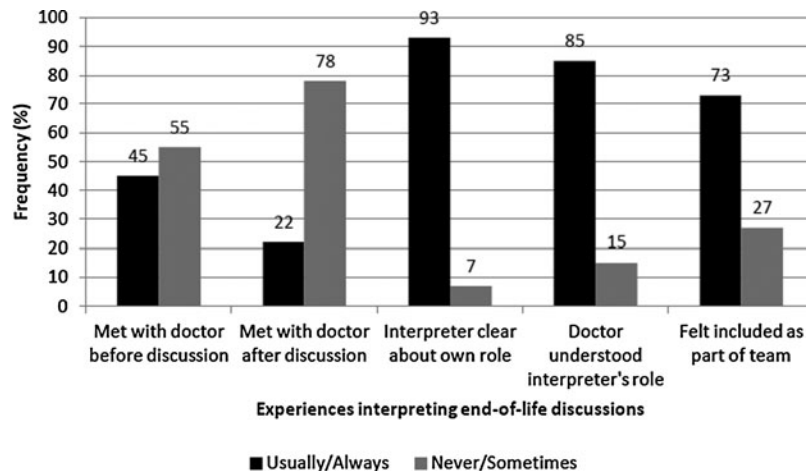

FIG. 1. Experiences interpreting end-of-life discussions ($n=121$).

TABLE 2. INTERPRETER EXPERIENCES IN DIFFERENT END-OF-LIFE DISCUSSION TYPES ($N=121$)

	Bad news N (%)	Prognosis and planning N (%)	Surrogate decision making N (%)	Code status N (%)	Withdrawing treatment N (%)	Death notification N (%)
Ever interpreted this discussion type	117 (97)	114 (94)	98 (81)	95 (79)	87 (72)	82 (68)
How many interpreted per week						
None	18 (15)	19 (17)	5 (15)	19 (20)	17(20)	25 (30)
1–5	83 (71)	82 (72)	75 (77)	67 (71)	69 (79)	57 (70)
6+	16 (14)	13 (12)	8 (8)	9 (9)	1 (1)	0 (0)
Doctors used technical terms	95 (81)	93 (82)	73 (74)	79 (83)	64 (74)	39 (47)
Doctor wanted to say things that conflict with culture of patient or family	79 (68)	73 (63)	64 (65)	60 (64)	50 (58)	34 (41)
Discussion so emotional that felt overwhelmed	77 (66)	59 (52)	52 (53)	46 (48)	51 (59)	57 (70)
Thought about afterward	102 (87)	89 (78)	74 (76)	73 (77)	70 (80)	70 (85)
Felt uncomfortable interpreting	18 (16)	11 (10)	8 (8)	8 (8)	11 (12)	23 (19)

physicians before the discussion than after. The majority felt clear about their role and felt that doctors understood their role. Just under three-quarters usually or always felt included as part of the health care team.

Experiences interpreting different discussion types are shown in Table 2. The most commonly interpreted discussion types were giving bad news, followed by prognosis and planning future care, surrogate decision making, code status, withdrawing treatment, and death notifications. Interpreters reported that doctors often used technical terms and asked them to say things that conflicted with the culture of the patient or family, although these experiences were reported less frequently for death notifications. Most interpreters thought about these discussions afterwards, and a *substantial* percentage felt overwhelmed at least some of the time.

Attitudes

Attitudes toward interpreting end-of-life discussions are shown in Figure 2. Few interpreters found interpreting end-of-life discussions more satisfying than interpreting routine clinical encounters and more than three-quarters found interpreting end-of-life discussions more stressful. Just under half agreed or strongly agreed that these discussions usually go well, and most (85%) reported overall comfort interpreting

for end-of-life discussions. No interpreter characteristics, including age, gender, certification, training, time spent interpreting, language, and years of experience interpreting, were associated with attitudes toward interpreting end-of-life discussions (data not shown).

Associations between experiences and attitudes

Associations between experiences and attitudes are shown in Table 3. Interpreters who felt clear about their role were more likely than interpreters who did not feel clear about their role to think that discussions went well (51% [57/112] versus 11% [1/9], $p=0.02$) and to feel comfortable interpreting (88% [98/112] versus 56% [5/9], $p=0.01$). Interpreters who felt that the doctor understood their role were more likely than those who did not feel that the doctor understood their role to think that discussions went well (52% [54/103] versus 22% [4/18], $p=0.02$). Experiences were not associated with satisfaction or stress when interpreting discussions about end-of-life issues.

Interpreter recommendations

Interpreter recommendations to improve discussions about end-of-life issues are shown in Table 4. Eighty-one percent of respondents felt that doctors needed more training on how to
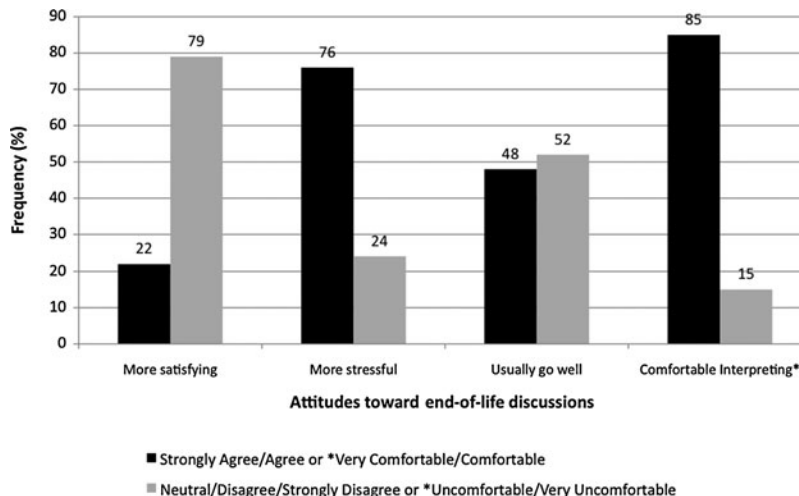

FIG. 2. Attitudes toward interpreting end-of-life discussions ($n=121$).

TABLE 3. ASSOCIATIONS BETWEEN RECENT INTERPRETER EXPERIENCES AND ATTITUDES TOWARD INTERPRETING DISCUSSIONS ABOUT END-OF-LIFE ISSUES ($N=121$)

Interpreter experiences	More satisfying than interpreting routine clinical encounters			Usually go well			More stressful than interpreting routine clinical encounters			Overall comfort level interpreting		
	Agree (n=26) N (%)	Neutral/Disagree (n=95) N (%)	P value	Agree (n=58) N (%)	Neutral/Disagree (n=63) N (%)	P value	Agree (n=92) N (%)	Neutral/Disagree (n=29) N (%)	P value	Comfortable (n=103) N (%)	Uncomfortable (n=18) N (%)	P value
Met before discussion												
Usually/always	15 (27)	40 (73)	0.2	28 (51)	27 (49)	0.6	43 (78)	12 (22)	0.6	49 (89)	6 (11)	0.3
Never/sometimes	11 (17)	55 (83)		30 (45)	36 (55)		49 (74)	17 (26)		54 (82)	12 (18)	
Felt clear about role												
Usually/always	23 (21)	89 (79)	0.4	57 (51)	55 (49)	0.02	87 (78)	25 (22)	0.1	98 (88)	14 (12)	**0.01**
Never/sometimes	3 (33)	6 (67)		1 (11)	8 (89)		5 (56)	4 (44)		5 (56)	4 (44)	
Felt doctor understood my role												
Usually/always	22 (21)	81 (79)	0.9	54 (52)	49 (48)	0.02	78 (76)	25 (24)	0.9	90 (87)	13 (13)	0.1
Never/sometimes	4 (22)	14 (78)		4 (22)	14 (78)		14 (78)	4 (22)		13 (72)	5 (28)	
Felt included as part of team												
Usually/always	20 (23)	68 (77)	0.6	45 (51)	43 (49)	0.3	68 (77)	20 (23)	0.6	78 (89)	10 (11)	0.08
Never/sometimes	6 (18)	27 (82)		13 (39)	20 (61)		24 (73)	9 (27)		25 (76)	8 (24)	
Met after discussion												
Usually/always	9 (33)	18 (67)	0.1	15 (56)	12 (44)	0.4	22 (81)	5 (19)	0.5	26 (96)	1 (4)	0.06
Never/sometimes	17 (18)	77 (82)		43 (46)	51 (54)		70 (74)	24 (26)		77 (82)	17 (18)	

TABLE 4. RECOMMENDATIONS TO IMPROVE DISCUSSIONS ABOUT END-OF-LIFE ISSUES (*N*=121)

Recommendations for physicians	Strongly agree N (%)	Agree N (%)	Neither/Disagree/Strongly disagree N (%)
Should meet with interpreter before discussions	95 (79)	20 (17)	6 (5)
Should meet with interpreter after discussions	65 (54)	32 (26)	24 (20)
Should discuss expectations regarding strict interpretation versus adding clarification	29 (40)	35 (29)	38 (32)
Should use nonverbal forms of communication	42 (35)	39 (32)	40 (34)
Should avoid using jokes or humor	71 (59)	35 (29)	15 (13)
Need more training about how to conduct discussions	55 (45)	43 (36)	23 (19)
Recommendations for interpreters			
Should be clear when providing strict interpretation and when adding own clarifications	87 (72)	27 (22)	7 (5)
Need more training on how to interpret discussions	59 (49)	48 (40)	14 (12)
I would personally like more training	59 (49)	38 (31)	24 (20)

conduct end-of-life discussions through an interpreter, 89% agreed that interpreters needed more training, and 80% were personally interested in more training on how to interpret these discussion types. Personal interest in more training did not differ by interpreter certification (*p*=0.1), training (*p*=0.4), language (*p*=0.2), or experience (*p*=0.8).

In response to the open-ended question about improving discussions about end-of-life issues, many interpreters recommended avoiding the use of vague language, metaphors, or complex medical terms that do not translate well. For example, one interpreter noted that "hospice" was often mistranslated into Spanish as "hospicio," which also means orphanage or poorhouse. Many interpreters also emphasized the importance of allowing only one person to speak at once and minimizing interruptions. As one respondent noted, "to promote one person speaking at a time can be especially challenging with a room full of upset family members." Improving knowledge about common cultural differences in end-of-life care and preparing the interpreter for the nature of the discussion before entering the room were also recommended frequently. As one respondent wrote, "Going in cold is the biggest detriment. A short briefing prior to meeting the patient and family, in cases such as end of life, is central in allowing the interpreter to be at his/her best."

Discussion

In this national survey of trained health care interpreters, the vast majority reported experience interpreting a wide variety of discussions about end-of-life issues, and most reported participating in these conversations at least weekly. Whereas 85% of respondents felt comfortable interpreting these discussions, less than half reported that discussions about end-of-life issues usually went well, and the majority found interpreting these discussions more stressful than interpreting routine clinical encounters. Almost all interpreters agreed that physicians and interpreters would benefit from additional training in how to conduct language-discordant discussions about end-of-life issues and were personally interested in more instruction in this area.

Although there has been increasing attention paid to the perspectives of health care interpreters in a variety of clinical settings,[2,15–17] to our knowledge this is the largest and only national survey of interpreter experiences in health care to

date. Interestingly, attitudes toward interpreting end-of-life discussions among this cohort did not differ by interpreter demographics or qualifications. Although we had hypothesized that older interpreters and those with more experience or training might feel more comfortable and less stressed when interpreting these discussions, we found no difference in attitudes by these interpreter characteristics. We did find that when interpreters felt clear about their role and felt that the physician understood their role, they were more likely to feel comfortable and to think that discussions went well. These findings suggest that factors that are amenable to change, such as specific physician and interpreter behaviors, are important determinants of how interpreters view these interactions. These recommendations could be incorporated into training programs for clinicians.[18] Future research should examine the effect of specific training elements and different interpreter roles on patient, clinician, and interpreter understanding and satisfaction and patient outcomes in language-discordant discussions about end-of-life issues.

Participants also strongly endorsed the need for more interpreter training and almost universally felt that they would *personally* benefit from additional focused training in how to interpret discussions about end-of-life issues. Interestingly, whereas more than half of participants had received at least a year of training, and most had more than 5 years of interpreting experience, more experienced and highly trained interpreters were no more likely to feel that discussions about end-of-life issues usually went well and equally endorsed the need for more training. Formal training opportunities for health care interpreters have grown significantly in recent years, with increasing attention being paid to improving interpretation quality through the implementation of national standards and the goal of establishing a national certification process in the United States.[19–21] Our study suggests that existing training programs in the United States may fall short in preparing interpreters for commonly encountered discussions regarding palliative care issues such as giving bad news, discussing code status, or notifying a family that their loved one has died. Such discussions are more likely to involve unique vocabulary (such as "hospice," "palliative care," or "life support"), clinically important cultural differences (such as how bad news should be conveyed and who should be told), complex family dynamics (one or more family members present may speak English fluently, whereas others may be

limited in their English proficiency and require interpretation), and emotional distress than is commonly seen in more routine clinical encounters. Our findings also speak to the need for improved emotional support of interpreters involved in end-of-life care. Opportunities to observe and practice interpreting end-of-life discussions, to discuss cases that were particularly difficult or emotionally challenging, and to reflect on the emotional aspects of providing care for seriously ill patients and their families could form a cornerstone of a national interpreter certification program, given how common it is for interpreters to be involved in such discussions. The California Healthcare Foundation has recently developed a free online curriculum for interpreters in palliative care.[22]

Our study had several limitations. To target the largest number of interpreters, we used a national convenience sample. We do not have a response rate. Nonetheless, with 142 respondents nationally this is the largest survey of its kind. It is possible that respondents differed in significant ways from nonrespondents, and our findings may not generalize to all heath care interpreters. However, demographic characteristics of participants with respect to gender and primary language were similar to a previous web-based marketing survey of interpreters in North America.[23] Given our recruitment approach targeting professional interpreter organizations, it is likely that respondents were more highly trained and more likely to be certified than the general interpreter population. In this sense, our findings may represent a "best case scenario" in that respondents may have more experience and comfort with interpreting discussions about end-of-life issues than nonrespondents. We were unable to verify experiences or certification. However, the range of responses suggests there was no bias in reporting. We also do not have information on whether respondents worked primarily in an inpatient or outpatient setting or whether experiences differed by the modality of interpretation (i.e., in-person versus over the phone), as has been suggested in previous research.[24] Finally, results represent the views of interpreters and may not be shared by clinicians, patients, or families involved in these discussions.

Interpreted discussions about end-of-life issues present common challenges for interpreters independent of training and experience. Interpreters may benefit from targeted educational interventions that could improve the quality of care for vulnerable patients and families in these difficult situations. Health systems and interpreter certification programs should incorporate specific training on how to interpret discussion about end-of-life issues.

Acknowledgments

Author Disclosure Statement

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Address correspondence to:
Yael Schenker, M.D., M.A.S.
Department of Medicine
University of Pittsburgh
230 McKee Place, Suite 600
Pittsburgh, PA 15213

E-mail: schenkery@upmc.edu