HHS Public Access

Author manuscript

Patient Educ Couns. Author manuscript; available in PMC 2020 May 04.

Published in final edited form as:

Patient Educ Couns. 2019 May ; 102(5): 895–901. doi:10.1016/j.pec.2018.12.012.

Agents of Empathy: How Medical Interpreters Bridge Sociocultural Gaps in Genomic Sequencing Disclosures with Spanish-Speaking Families

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Abstract

Objectives: To describe how linguistic tools used by interpreters during return of genomic sequencing results may have impacted communication with Spanish-speaking families, and to discuss the implications for the role of medical interpreters.

Methods: Using discourse analysis, we identified and categorized the various ways hospital-based interpreters adapted clinicians' language in 37 audio-recorded sessions in which Spanish-speaking parents participating in a clinical trial received their child's genomic sequencing results from English-speaking clinicians.

Results: We found that interpreters adapted clinicians' statements using five empathic linguistic tools: contextualization, encouragement, checking comprehension, endearment, and softening. Interpreters used an average of four linguistic tools per session, with contextualization and encouragement being the most frequently used.

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Conflict of Interest

Baylor College of Medicine (BCM) and Miraca Holdings Inc. have formed a joint venture with shared ownership and governance of the Baylor Genetics Laboratories which performs exome sequencing. Dr. Plon serves on the Scientific Advisory board of Baylor Miraca Genetic Laboratory. All other co-authors declare no conflict of interest.

Conclusions: Interpreters used empathic linguistic tools to alter clinicians' statements when communicating genomic information to Spanish-speaking families. Our findings demonstrate the critical role of interpreters as cultural mediators and facilitators of understanding for Spanish-speaking families.

Practice Implications: This study expands upon the definition of clinical empathy in interpreter-mediated sessions. Our findings suggest that revisions of standards of medical interpretation practice may be warranted regarding interpreters' ability to adapt clinicians' language in a culturally sensitive manner during interpretation.

Keywords

cultural competency; communication barriers; empathy; genetics; healthcare disparities; limited English proficiency; Spanish-speakers

1. Introduction

Empathy is an important part of the physician-patient relationship, particularly in cancer care [1]. Physicians' expression of empathy has been associated with improved clinical outcomes, decreased patient psychological distress, and increased patient enablement and satisfaction [2,3]. However, compared to interactions with English-speaking patients, physicians have been shown to be less empathic, verbally expressive, and encouraging with limited English proficient (LEP) patients [4–6]. This may be in part due to physician-patient language discordance, which results in cross-cultural encounters that present unique linguistic and sociocultural barriers [7–9] that are difficult for physicians to overcome [10]. Professional medical interpreters may help physicians take the necessary steps [11] to overcome these sociolinguistic barriers to expression of empathy in interactions with LEP patients. Interpreters' shared cultural background with LEP patients enables them to be cognizant of the nuanced sociocultural differences between physicians and patients [12] and ensure that language is conveyed to families in a culturally-sensitive manner [9,13,14].

While studies report improved communication, satisfaction, and quality of care for LEP patients when professional interpreters are used [15–17], few have described how interpreters might add, change, or remove empathic language between physicians and patients [18,19]. One study described how interpreters acted as "epistemic brokers" by re-designing the content and context of information to make it accessible for physicians and LEP families in a pediatric genetic setting [19], but did not outline what linguistic elements interpreters employed to do so.

Empathy is particularly critical when delivering medical information to LEP families that is both highly sensitive and technical, such as in the case of genomic sequencing. In addition to sociolinguistic barriers, the amount and complex nature of genomic sequencing results may further challenge clinicians' ability to express empathy toward LEP patients. As new genomic sequencing technologies extend into clinical care [20], it is important to understand how interpreters might adapt complex genomic language to be accessible and culturally sensitive for LEP families. We previously reported on the accuracy of interpretation of technical genomic terminology during disclosure of genomic sequencing results with

Spanish-speaking families in a pediatric cancer setting [21]. We now seek to discover the specific linguistic tools that interpreters employ to alter the context and content of clinical genetic information. The goals of this manuscript are to describe how the linguistic tools used by interpreters during return of genomic sequencing results may have impacted communication during disclosure of genomic results to Spanish-speaking parents of pediatric cancer patients, and to discuss the implications use of these tools has for the role of medical interpreters.

2. Methods

2.1 The BASIC3 Study

The Baylor Advancing Sequencing in Childhood Cancer Care (BASIC3) study evaluated the impact of incorporating exome sequencing (ES) results into the clinical care of pediatric cancer patients with newly-diagnosed solid tumors. The study is a Clinical Sequencing Exploratory Research (CSER) program project supported by the National Institutes of Health and was approved by the Institutional Review Board (IRB) of Baylor College of Medicine. Enrollment started in August 2012 and was completed in June 2016 (n=287 patients and their parent(s)/legal guardians, n=20 pediatric oncologists). Germline and tumor (if available for testing) ES results reports were entered into patients' electronic health records and returned to patients/families by the child's oncologist and a study genetic counselor (GC) [22,23]. All BASIC3 study consent documents were provided in Spanish for Spanish-speaking families; however, ES reports and genetic counseling letters provided to families during the disclosure visit were only available in English.

2.2 Hospital-Based Medical Interpreters

Per standard clinical procedure, medical interpreters employed by the hospital were asked to interpret disclosure sessions per Spanish-speaking families' (53/287, 18%) stated language preference. To be employed by the hospital, all medical interpreters are required to have at least two years' experience interpreting in a clinical setting, and must pass a healthcare interpreter assessment. The interpreters participating in study disclosures did not receive training specific to the BASIC3 study or genetics. Their participation in disclosures was part of their routine clinical care duties and they were not asked to participate in any additional study procedures. As such, we received a waiver of consent from the BCM IRB to analyze their statements during BASIC3 disclosures.

2.3 Procedures

Each family identified a primary parent for provision of informed consent and participation in return of results sessions. All disclosure sessions were audio-recorded, except in the case of deceased patients. Sessions with Spanish-speaking families were then transcribed verbatim. Transcripts were included in analysis if the patient's primary parent/legal guardian, oncologist and/or study GC, and medical interpreter were present. The patient, a second parent, and other family members may have also been present. Because we were interested in exploring how interpreters adapted clinicians' language, we excluded sessions in which a bilingual oncologist served as the interpreter or returned results directly to Spanish-speaking families. We have previously reported on our findings related to the

accuracy of interpretations in those sessions [21]. Coded transcripts were uploaded to ATLAS.ti (v 7.5.11, Scientific Software Development, GmbH, Berlin, Germany), a qualitative data management software program.

2.4 Discourse Analysis

Using discourse analysis [24,25], we identified the various ways interpreters adapted clinicians' language during interpretation. We developed a content analytic coding scheme through an iterative process: we first used a deductive approach to create initial codes based on research questions, which were further refined by inductively identifying emergent tactics from the discourse. We developed categories of the functions of interpretations to capture different linguistic techniques (or tools), and decided that these categories must have at least 10 instances in the sample. Two study investigators, bilingual in English and Spanish, identified and compiled all Spanish statements from interpreters that differed from clinicians' original English statements. The bilingual investigators translated the Spanish phrases into English for two additional study investigators who were not Spanish-speaking. The unit of analysis consisted of a continuous section of dialogue from the clinician in English, the interpretation of that segment into Spanish, and the English translation of the Spanish interpretation. Codes were not mutually exclusive of each other, as more than one code could have been applied to the same unit of analysis. The investigators coded each transcript individually and then met as a group to resolve discrepancies and reach consensus.

All identifying information was removed from the transcripts; any quotation excerpts are referred to exclusively by study identification number noted in parentheses. We provide both the original transcribed Spanish text and the English translation in italics and brackets.

3. Results

3.1 Overview

Of the 53 Spanish-speaking families enrolled in the BASIC3 study, 51 participated in a disclosure session; the remaining two were lost to follow-up. Fourteen disclosures were excluded for the following reasons: a bilingual clinician returned results without the use of an interpreter (n=8); a non-hospital-based contract interpreter conducted session over the phone (n=1); the primary parent was not present at the disclosure (n=2); disclosures were not audio-recorded due to patient death (n=1) or the family declined recording at the time of the disclosure (n=1); and a disclosure was conducted in English at the parent's request (n=1). We analyzed the entirety of the remaining sample of recorded disclosure sessions, which was 37 sessions.

Twelve oncologists, two study GCs, and 16 hospital-based interpreters participated in these sessions. All of the patients' primary parents self-identified as Hispanic or Latino, and most (84%) were female. Eight (22%) identified as White, three (8%) identified as Native American or Alaska Native, and 26 (70%) declined to specify their race. None of the oncologists identified as Hispanic or Latino, and most (75%) were male. Since interpreters were not enrolled into the BASIC3 study, their demographic information was not collected.

3.2 Interpreters' Use of Empathic Linguistic Tools

We found that interpreters adapted clinicians' language in disclosure sessions with Spanish-speaking families by using five linguistic tools: contextualization, encouragement, checking comprehension, endearment, and softening. We refer to these linguistic tools as "empathic" because they fell under one or more of the dimensions of clinical empathy as defined in the literature [1,26,27] such as building interpersonal relationships, promoting mutual patient-physician understanding, and/or personalizing communication. Definitions of each empathic linguistic tool are provided in Table 1.

There were a total of 151 instances in which at least one empathic linguistic tool was used to adapt a distinct statement across all 37 sessions. Table 2 shows the frequency of use of each empathic linguistic tool, the number of disclosure sessions in which each tool was used as least once, and the number of interpreters who used each tool at least once. The overall average number of empathic linguistic tools used per session was four. Interpreters' use of one linguistic tool was not mutually exclusive of use of another, as interpreters may have used more than one tool to adapt the same statement.

Contextualization (38%) and encouragement (22%) were the most frequently used tools, each occurring in more than half of the sessions (57% and 54%, respectively). The majority of interpreters in this study utilized encouragement (88%), contextualization (81%), and checking comprehension (63%) during their interpretations of clinicians' statements.

3.2.1 Contextualization—Interpreters contextualized complex genomic discussions for families by adding phrases during interpretation that clarified clinicians' statements or restated details that had been mentioned earlier. Contextualization allowed interpreters to simplify complex genomic terminology, such as interpreting "a mutation" as "*a bad change*" in a gene as the clinician had defined it previously (Disclosure 221). Interpreters specified vague objects and demonstrative pronouns, such as changing "the other ones" to "*the other cells*" (Disclosure 222) and interpreting "these" as "*these changes*" (Disclosure 394).

Interpreters seemed to keep track of patients' results during disclosures. This allowed them to add clarifying details, such as specifying that "one other change" was "*the third change*" shown in the child's results (Disclosure 222), and clarifying that vague statements like "those medications" referred to "*those three medications*" (Disclosure 349), or to specific types of medications.

Clinician: If a doctor in the future wants to put him on one of these medications, he can pull [the report] out and show it to them.

Interpreter: Si en algún momento en el futuro, en la edad adulta de él, un médico quiere darle a tomar antidepresivos o adelgazadores de la sangre, usted le muestra el informe. [*If at some point in the future, in his adulthood, a doctor wants to give him antidepressants or blood thinners, you show him/her the report.*] (Disclosure 261)

Interpreters also used contextualization to point out when clinicians were making jokes. For example, a clinician joked while explaining that the session was being audio-recorded for

study purposes: "When they listen to the tapes, they grade me not you. So feel free to say a couple times to the tape what a great job I am doing" (Disclosure 222). After directly interpreting the clinician's joke, the interpreter added clarification to the parents, "*He's joking*" (Disclosure 222).

3.2.2 Encouragement—Interpreters provided encouragement to families by adding phrases like "*it's no problem*" (Disclosure 348) and "don't worry" after interpreting clinicians' statements.

Clinician: We can actually provide you with a handout.

Interpreter: Nosotros podemos darle información escrita, no se preocupe. [*We can give you written information, don't worry.*] (Disclosure 293)

One interpreter added the supportive phrase "*I know it can be overwhelming*" after the clinician mentioned that the results may be difficult to understand (Disclosure 452).

Interpreters also changed clinicians' statements to be more reassuring, for example interpreting "It doesn't matter" as "*It's okay, don't worry*" (Disclosure 348). In one instance, a clinician jokingly stated, "So now, everything makes you worry about cancer," which the interpreter adapted to "*Don't worry*" (Disclosure 409).

3.2.3 Checking Comprehension—Interpreters interjected during clinicians' explanations of results to ask parents if they had any questions or if they understood the information the clinician had just presented.

Interpreter: (to clinician) Can we give her a chance to ask questions if she needs to?

Clinician: Oh, of course.

Interpreter: (to parent) Le estoy pidiendo un poquito de tiempo en caso de que tú, cuando ella está hablando, quieras hacer alguna pregunta, ¿tienes alguna? [*I'm asking for a little time in case you, when she is talking, want to ask a question. Do you have any?*] (Disclosure 326)

Interpreters checked parents' comprehension even when the clinicians did not, by adding questions after interpretation such as "*You don't have questions for the doctor?*" (Disclosure 364). Interpreters also turned clinicians' statements assuming understanding into questions, such as interpreting "You remember there's a couple of genes related to how we process drugs" as "*Do you remember also that [the clinician] mentioned that there are a couple of genes which are responsible for processing certain medications?*" (Disclosure 261).

3.2.4 Endearment—Interpreters used terms of endearment to personalize the genomic information by making clinicians' language more familiar and informal. For example, in instances where clinicians used the child's name or the pronouns "he" or "she," interpreters used the term "la nena," meaning 'the baby girl' or 'the little girl.' Interpreters used diminutive terms like "hijito/a," meaning 'little boy/girl,' to refer to the child and

"hermanitos" to refer to the child's siblings (Disclosure 293). Diminutive suffixes like "ito/a" meaning 'small or little' are often used in the Spanish language to show affection.

Clinician: His body processes it a little different, so it would be good to let the doctors know this information.

Interpreter: El cuerpecito de él procesa ese medicamente de una forma diferente, así es que sería muy bueno que ustedes le dejaran saber al doctor de él y que siempre lo deje saber que tiene ese problema. [*His little body processes that medication in a different way, so it would be very good that you let the doctor know about him and always let him know he has that problem.*] (Disclosure 227)

3.2.5 Softening—Interpreters softened statements from clinicians to be more polite and less direct. Interpreters made clinicians' commands more polite by adding the word "please," for example interpreting "But just keep—hold onto this" as "*Keep this, save it, please*" (Disclosure 466). In addition to being used to show affection, diminutive suffixes are used in Spanish to convey politeness. Interpreters used diminutive phrases to soften imperative phrases like adapting "It's very complicated—does that make sense?" to "*This topic is a little complicated, he says, but you understand, right?*" (Disclosure 222).

Interpreters used softening to make clinicians' questions less direct and to elicit more of a response from parents.

Clinician: Okay, so do you understand?

Interpreter: ¿Me expliqué señora? ¿Sí entendió? ¿Me expliqué bien al respecto? [*Did I explain myself, ma'am? Did you understand? Did I explain myself well in that regard?*] (Disclosure 277)

Interpreters also used softening to adapt clinicians' statements in a way that may have given parents more agency. For example, the clinician's statement "And what is most important to us…is that you have your questions answered" was interpreted as "*And the most important thing here for them…is that whatever question you all might have deserves a response*" (Disclosure 288).

4. Discussion and Conclusion

4.1 Discussion

To our knowledge, this is the first study to identify how interpreters adapted clinicians' language to provide empathic communication with Spanish-speaking families during sessions where genomic sequencing results were disclosed. When communicating specialized complex results to Spanish-speaking parents of pediatric cancer patients, professional medical interpreters used five empathic linguistic tools: (1) contextualization, (2) encouragement, (3) checking comprehension, (4) endearment, and (5) softening. All interpreters used at least one empathic linguistic tool, and contextualization and encouragement were the most frequently used tools. By using empathic linguistic tools, interpreters were able to situate clinicians' statements within the context of the larger

interaction and make communication of results more accessible, personalized, and supportive for families.

This investigation expands upon previous research that introduced interpreters' role as "epistemic brokers" [19] as our study highlights the strategies interpreters used to provide social framing for clinical information. Our results illustrate how interpreters use their knowledge of the cultural aspects of clinical communication to act as bicultural resources for both families and clinicians to overcome sociolinguistic barriers. This supports findings from another study conducted in a pediatric cancer setting [12] where interpreters reported feeling that pediatric oncologists understood very little about the sociocultural barriers that affect communication with Spanish-speaking families and described a desire to use their shared cultural knowledge to earn families' trust.

In line with previous research [14,18,19,28,29], our study shows that interpreters actively intervened during the encounter to make real-time changes to clinicians' language, ultimately making language more accessible and culturally-sensitive. However these actions may be considered controversial as current standards for medical interpretation [30] do not allow alteration of clinicians' utterances. In addition, despite feeling that interpreters helped them communicate with patients in a culturally sensitive way, some physicians' have expressed concerns that interpreters' adaptations may add cultural bias [31] and interfere with physicians' ability to provide their own empathic responses [18]. There may be instances where certain empathic linguistic tools may have unintended negative consequences. For example, use of softening of language may remove the emotional gravity necessary to accept diagnoses and treatment implications. Future research should determine if use of empathic linguistic tools affects the integrity of medical information and assess how adaptations resulting from use of these tools may affect the patient-physician relationship, patient understanding, and satisfaction with interpreters.

In order to balance cultural mediation with accuracy, we recommend that, instead of changing the content of clinicians' statements, interpreters first mirror clinicians' speech in their initial interpretations and then use empathic linguistic tools to add clarification, context, or sensitive phrases. While English-speaking clinicians are limited in their ability to understand every LEP patient's culture and how to personalize language, small changes can be made on the part of clinicians' to lessen the need for interpreters to clarify language. Best practices for clinicians include speaking in short clauses [32,33], avoiding jargon [32], using specific words and clear language [32], asking comprehension questions [32], and being cognizant of families' nonverbal cues [28]. In addition, empathy training may be beneficial for clinicians, as studies have shown that it can increase physicians' expression of empathy toward patients [18,34].

4.1.1 Expanding the Definition of Empathy in Interpreter-Mediated Sessions

—Clinical empathy is a nuanced concept, which includes cognitive, affective, and behavioral components [1,26,27]. This multi-dimensional definition suggests that in order to develop empathy, clinicians must move beyond simply understanding patients' perspective; they must also act upon that understanding to individualize their talk according to patients' needs. Our results suggest that interpreters may help clinicians express empathy toward LEP

patients by using their shared background to aid in building interpersonal relationships and promoting mutual patient-physician understanding and personalized communication [1]. While clinical empathy in interpreter-mediated sessions still includes cognitive, affective, and behavioral components, it is distinguished from language-concordant physician-patient interactions in that there is also a cooperative component in which clinicians and interpreters work together to achieve all components of clinical empathy. We recommend future work explore whether the definition of empathy in interpreter-mediated sessions should be expanded to include this cooperative aspect.

4.1.2 Implications for the Role of Professional Medical Interpreters—

Interpreters' tendency to use empathic linguistic tools to improve the accessibility and cultural sensitivity of complex medical information demonstrates their ability to adopt additional roles as facilitators of understanding and cultural mediators, while also fulfilling their primary role as facilitators of information exchange. Even though many interpreters view their duties as multi-faceted [9,13,14,35], existing standards of interpretation practice [30] do not allow interpreters much flexibility in extending their role outside of being invisible conduits of information [29,36,37]. As there are currently no guidelines for how interpreters can adequately adopt multiple roles at once, interpreters have expressed uncertainty regarding the limitations of their clinical role [13,14,28,38,39] and difficulty navigating multiple roles at once [13,28]. There is also disagreement amongst medical professionals regarding the boundaries of an interpreter's role in the clinic [37,39,40]. Our findings suggest that revisions of standards of medical interpretation practice may be warranted regarding interpreters' ability to adapt clinicians' language in a culturally sensitive manner during interpretation. Word-for-word passive interpretation outlined by current standards of practice may not be enough to achieve culturally-sensitive information exchange [36,37], especially in the era of genomic and personalized medicine which involves discussion of particularly sensitive and complex results. If future research finds interpreters' use of empathic linguistic tools provides significant benefits and no harm, this would signal that current standards of interpretation practice should be restructured to provide guidance for how interpreters can assume roles as cultural mediators and facilitators of understanding.

4.1.3 Limitations—

There are limitations to this analysis. Our conclusions were made based on coders' observations of the linguistic content of transcripts and knowledge of the aspects of cultural and empathic communication. We did not verify these findings with clinicians, interpreters, or parents in this study. Future studies should interview all parties to understand their perspectives and experiences regarding use of empathic linguistic tools. Though clinicians were unaware of interpreters' linguistic actions, this discourse analysis may help them become more aware by shedding light on interpreters' adaptations to clinical conversation. As the BASIC3 study did not survey parents' understanding of the information presented at disclosure nor their satisfaction with interpretation services, we were unable to determine the impact of any adaptations that resulted from interpreters' use of empathic linguistic tools. Without verification from parents, we cannot be certain that interpreters' use of linguistic tools altered parents' perceptions of clinicians' empathic expression or cultural communication. As our study population consisted exclusively of parents of pediatric cancer

patients at a single large academic center, our results are limited to this context and may not apply in other contexts. We did not collect demographic data on the parents' country of origin so the Spanish variant/dialect spoken by families could not be inferred. The Migration Policy Institute, however, reports that Latinos in Houston, Texas primarily originate from Mexico and Central America [41]. Interpretation in other clinical settings with patient populations of different linguistic and cultural backgrounds should be explored. Such research could assess the impact of linguistically appropriate educational materials on the level of families' participation in physician-patient communication. As these are qualitative results, they are subjective and may not be generalizable to other populations.

4.2 Conclusion

This is the first study to describe the nature of the empathic linguistic tools used by interpreters during disclosure of genomic sequencing information for Spanish-speaking families. Interpreters' use of these linguistic tools was vital to the culturally sensitive disclosure of information as they streamlined complex genomic information and reduced cultural distance between clinicians and LEP families. Our findings highlight interpreters' ability to bridge sociocultural gaps between language discordant patients and physicians. Our study adds to the growing body of research showing that interpreters serve multiple important roles for both LEP families and clinicians, and highlights the importance of viewing medical interpreters as more than invisible conduits of information. With proper training and concrete guidelines, medical interpreters can serve as bicultural resources for both clinicians and Spanish-speaking families during disclosure of complex genomic test results.

4.3 Practical Implications

We expand upon the definition of clinical empathy in interpreter-mediated sessions through addition of a cooperative component. Our study suggests there may be benefits to expanding interpreters' role to encompass their ability to act as cultural mediators and facilitators of understanding for LEP patients. Current standards of practice for medical interpretation should be revisited to determine if they should be restructured to further define and incorporate these additional roles. In order to lessen the burden on and added responsibilities for interpreters, clinicians should gain familiarity with common sociocultural communication barriers that LEP patients face and aim to make complex medical language generally more clear and accessible.

Acknowledgments

We would like to thank Robin Raesz-Martinez, Stephanie A. Gutierrez, Laurence B. McCullough, Jacob D. Hofstetter, and Uma Ramamurthy and her team at the Baylor College of Medicine Institute for Clinical and Translational Research. We would like to especially thank the oncologists and parents who participated in this study and all hospital interpreters for playing a crucial clinical role for limited English proficient patients and their families.

Funding

The BASIC3 study is a Clinical Sequencing Exploratory Research program project supported by the National Human Genome Research Institute and the National Cancer Institute (U01HG006485).

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Table 1.

Definitions of the empathic linguistic tools observed in genomic disclosure sessions.

Empathic Linguistic Tool	Definition
Contextualization	Addition of phrases that reiterate or clarify clinicians' statements.
Encouragement	Addition of reassuring or supportive phrases.
Checking Comprehension	Insertion of questions inquiring about parents' understanding.
Endearment	Use of terms of endearment to refer to the child/patient.
Softening	Adaptation of clinicians' statements to be less direct and more polite.

Table 2.

Interpreters' use of empathic linguistic tools in genomic disclosure sessions.

Empathic Linguistic Tool	Total Frequency of Use* (%) (N=151)	Use in Disclosure Sessions (%) (N=37)	Use by Interpreters (%) (N=16)
Contextualization	58 (38)	21 (57)	13 (81)
Encouragement	33 (22)	20 (54)	14 (88)
Checking Comprehension	26 (17)	15 (41)	10 (63)
Endearment	21 (14)	5 (14)	5 (31)
Softening	13 (9)	9 (24)	8 (50)

*Total frequency of use refers to the total number of instances across all disclosure sessions in which each empathic linguistic tool was used to adapt a distinct statement. Use of one linguistic tool was not mutually exclusive of use of another.