4-26-2018

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Recommended Citation
Daggett, Alexandria, "Una solución para la continuidad de cuidado médico para los latinos e hispanos" (2018). *Celebrating Scholarship and Creativity Day*. 5.
https://digitalcommons.csbsju.edu/ur_cscday/5

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HISP 371

19 diciembre 2017

Una solución para la continuidad de cuidado médico para los latinos e hispanos

Los Estados Unidos es un crisol de culturas, un lugar donde, supuestamente, todos pueden realizar sus sueños, a pesar de su origen, raza, nacionalidad y más. El país se basa en los derechos de la vida, la libertad y la búsqueda de la felicidad. Para obtener y practicar estos derechos, uno requiere que sus necesidades básicas estén satisfechas. Una de estas necesidades básicas es la salud. Si uno no tiene buena salud y cuidado médico, es mucho más difícil vivir la su vida al máximo. El acceso y uso de los servicios sanitarios son esenciales para proteger los derechos humanos, y deben ser una prioridad para la gente de los EE. UU.

En el sistema médico en los Estados Unidos, hay varias barreras al acceso adecuado, especialmente para la población latina e hispanoparlante. En adición a las barreras que tienen varios grupos minoritarios en acceder el sistema de salud, los latinos e hispanos que no hablan el inglés tienen barreras idiomáticas y culturales. Un dominio limitado del inglés (*LEP*, "*limited English proficiency*") es un factor muy importante en la continuidad y calidad de cuidado médico que uno recibe en el sistema actual. La continuidad es fundamental para proteger la seguridad y bienestar de los pacientes y, corrientemente, esto falta en el sistema. El sistema de intérpretes no es suficiente para atender las necesidades de los latinos e hispanos con dominio limitado del inglés. Es necesario cambiar a un modelo exhaustivo para servir a la población latina e hispana en un sistema sanitario con partidarios y navegantes del sistema para los pacientes con dominio limitado del inglés. En esta obra, voy a discutir la importancia de la continuidad de cuidado sanitario, las barreras que los latinos e hispanos experimentan, y las soluciones para que ellos puedan mejorar su salud y accedan a servicios sanitarios al mismo nivel de calidad como angloparlantes. Voy a explorar el rol del intérprete y defensor de pacientes en una escena clínica u hospital. La investigación viene de la literatura e investigaciones ya existentes en adición a entrevistas informáticas con profesionales médicos de varios puestos en un hospital pediátrico.

La población latina e hispana en los Estados Unidos

Antes de hablar de los cambios grandes en el sistema de salud para beneficiar a la gente latina e hispana, es esencial entender la magnitud de este grupo étnico. La población latina e hispana en los Estados Unidos es un grupo cada vez más grande. Es el grupo minoría más grande del país; los latinos e hispanos son más numerosos que los afroamericanos, y sigue creciendo (Rodríguez Sorriano 50). En 2016, el departamento del censo de los EE. UU. estimó que eran unos 57 millones de personas latinas y hispanas en el país, 17,8% de la población total (U.S. Census Bureau). Desde el año 2000, la población latina e hispano ha crecido un 50%, mientras la población total ha crecido 12%, significando que el crecimiento en los latinos e hispanos ha contribuido la mitad de todo el crecimiento de la población en este país en los últimos dos décadas (Brown). La gente latina e hispana se hace cada vez más un grupo visible e influyente en nuestra sociedad.

Los latinos e hispanos en el país vienen de diferentes países, origines, pasados, clases socioeconómicos y niveles educativos. Algunos inmigraron a los EE. UU. y otros nacieron aquí. Como cualquier grupo, tienen distintos niveles de habilidad con el inglés. De los 57 millones de latinos e hispanos en los EE. UU., es estimado que 16,2 millones tienen dominio limitado en el inglés (Zong y Batalova). Eso constituye el 28% de la población latina e hispana y el 5% de la población total del país. Las tendencias visto en la población total son semejantes a las tendencias vistas en la esfera médica y en los demográficos de los pacientes. Hay una población creciente de pacientes latinos e hispanos que tienen dominio limitado del inglés que requieren asistencia médica y cuidado de alta calidad.

Barreras al acceso de la medicina para los latinos e hispanos

Los latinos e hispanos en los Estados Unidos experimentan grandes barreras al acceso y utilización de los servicios sanitarios. Las barreras enfrentadas no son únicas a la población latina e hispana, representan barreras para varios otros grupos minoritarios en los EE. UU., especialmente para los grupos que hablan una lengua distinta de la lengua dominante del país. Por la gran diversidad del grupo latino e hispano, no es razonable presumir que todos experimenten estas barreras en la misma manera, pero las barreras constituyen la norma para muchos. Los inmigrantes latinos e hispanos típicamente enfrentan barreras con mayor severidad. Los inmigrantes son una población vulnerable que tiene un riesgo aumentado de tener malos resultados físicos, psicológicos y sociales de la salud (Derose et al. 1258).

En un estudio de los factores que influyen a la vulnerabilidad de los inmigrantes latinoamericanos, encontraron varias fuentes de riesgo. Los inmigrantes muchas veces tienen problemas financieros, especialmente si no tienen el estatus inmigratorio legal. Los inmigrantes indocumentados tienen peor probabilidad de tener el seguro; el 65% no tienen el seguro, en contrasto con el 32% de residentes permanentes sin el seguro de salud (Derose et al. 1260). Los inmigrantes indocumentados no pueden acceder a los servicios gubernamentales de asistencia médica como otros residentes de los EE. UU. Las cargas monetarias causan mucho estrés para muchas familias latinas e hispanas en el sistema sanitario y pueden prevenir la búsqueda de ayuda médica cuando realmente sea necesario.

Además, los inmigrantes latinos e hispanos no documentados llevan miedo por ser reportados a la policía por su estatus inmigratorio mientras buscan la asistencia médica. Según un intérprete en un hospital pediátrico en una presentación de "*Grand Rounds*", muchos inmigrantes temen sus visitas al hospital por la presencia de policía y guardias de seguridad. Temen usar sus nombres y presentarse delante de los trabajadores del hospital porque no tienen documentos legales para estar en los EE. UU. Temen la posibilidad de la prosecución y las consecuencias legales mientras buscan ayuda sanitaria para sus hijos (Gil et al.)

Los latinos e hispanos encuentran barreras por su falta de modas de transportación, por bajo alfabetismo y educación, por mal entendimiento de la medicina y la salud, por la discriminación, por baja clase socioeconómica, malas condiciones laborales, falta de cuidado de niños, y barreras adicionales no mencionados aquí. Pero encima de todo esto, muchos latinos e hispanos sufren por una barrera dominante, que añade dificultad a todas las otras: el dominio limitado del inglés. Los inmigrantes con dominio limitado del inglés, y sus hijos, tienen peor probabilidad de tener seguro de salud y un proveedor típico, visitan el doctor con menos frecuencia, reciben menos cuidado preventivo, tienen menos satisfacción con su ayuda médico y salen con peor entendimiento de su situación médica que los pacientes con la fluidez en el inglés (Derose et al. 1260-1261). Los hijos de padres con dominio limitado del inglés tienen tres veces la probabilidad de tener mala salud (Flores et al. 427). Para los niños con necesidades especiales para su salud (por ejemplo, el cáncer, discapacidades físicas, u otras enfermedades crónicas físicas, emocionales, de desarrollo o de comportamiento) hay una asociación con el dominio limitado del inglés en los padres y peor acceso y calidad de cuidado sanitario que los niños con salud normal (Eneriz-Wiemer et al. 128). La dificultad en usar el idioma primario en los Estados Unidos puede causar muchos problemas en la coordinación de su tratamiento y todas formas de la continuidad del cuidado.

La continuidad del cuidado

La continuidad del cuidado es un tópico sustancial en el sistema de salud. Hay mucho debate sobre su significado, pero también hay mucha investigación que apoya su importancia. La continuidad de cuidado se define como la manera en que el paciente individual experimenta la integración de servicios sanitarios y su coordinación (Haggerty et al. 1220). Hay dos componentes esenciales a la continuidad. El primero es el cuidado para el paciente como individual (Haggerty et al. 1220). Cada paciente tiene una historia y experiencia única con su salud. Es importante que los proveedores reconozcan los pacientes como personas únicas. No puede practicar la medicina en un ambiente vacío como si fuera directamente de los textos de medicina, sino cada persona es un caso nuevo con factores distintos y expectativas diferentes para su cuidado y su salud. El segundo es el cuidado sobre el tiempo o cómo el tratamiento se mantiene tras días, semanas, meses, o años, dependiendo de las circunstancias (Haggerty et al. 1220). La continuidad de cuidado no puede existir sin los dos componentes. Sin la continuidad, los pacientes experimentan cuidado fragmentado y sin mucha organización. Para entender mejor la continuidad de cuidado, deben saber de los tres tipos dentro de la medicina.

La primera forma de continuidad de cuidado es la continuidad informática (Haggerty et al. 1220). La información y las historias médicas son una parte esencial a la diagnosis y tratamiento de cualquier enfermedad. La continuidad informática depende del acceso a la historia médica para un paciente y su uso para crear un entendimiento completo de su salud antes de diagnosticar y tratar. La historia médica tiene mucha información sobre un paciente por toda su vida y puede usarla para entender el contexto de su enfermedad, los niveles típicos de pruebas para su cuerpo y saber de los tratamientos y diagnósticos anteriores. La continuidad informática está arriesgada cuando el proveedor no tiene acceso a la historia médica de su paciente por razones variadas. Cuando una persona recibe servicios en dos centros médicos distintos, muchas veces la información no está transmitida de uno al otro. Por eso, el mismo paciente pueda tener muchas historias médicas incompletas para cada hospital y clínica que ha visitado. Cuando esto pasa, los doctores no saben nada sobre el paciente, excepto lo que le dicen por sí mismo. Un ejemplo de una falta de continuidad informático ocurre con los pacientes con cáncer que reciben la radioterapia en un hospital diferente que la quimioterapia. A veces, el centro médico que administra la radioterapia no manda la historia del tratamiento al hospital donde el paciente recibe el resto de su tratamiento. Esto causa problemas cuando los doctores no saben exactamente el tamaño de la dosis (hay límites de la radioterapia que uno no puede superar en su vida) ni el centro de salud de la administración (para buscar la información). Otra circunstancia que amenaza a la continuidad de cuidado es el uso de nombres diferentes. Muchos inmigrantes no documentados usan nombres falsos cuando buscan a la ayuda médica por miedo de las consecuencias por la inmigración. Por eso un paciente puede tener muchas historias médicas incompletas de distintos centros médicos o del mismo, pero sin historia completa, el doctor no tiene toda la información necesaria para diagnosticar y tratar al paciente.

La segunda forma de la continuidad de cuidado es continuidad administrativa o la gestión del tratamiento (Haggerty et al. 1220). Muchas veces en la medicina, un paciente con una enfermedad complicada tiene que recibir tratamiento de muchos doctores y proveedores en varias especialidades. La continuidad administrativa requiere que el tratamiento siga de una manera puntual según el plan adoptado por el paciente y su equipo de tratamiento. Cuando un paciente tiene un plan y todos los proveedores pueden accederlo y seguirlo, el tratamiento es mejor coordinado y organizado. Un plan de tratamiento asegura que los doctores no empiecen distintos métodos de tratamiento, ayuda en eliminar pruebas y tratamientos no necesarios y mantiene un gasto bajo para su tratamiento. La continuidad de cuidado es importantísima en el tratamiento de varias enfermedades complejas. Por ejemplo, el tratamiento del cáncer involucra varias especialidades: la oncología, la radiología, la endocrinología, los trabajadores sociales, la cirugía, la hematología, la farmacología, y más. Para el tratamiento de varios cánceres comunes, usan protocolos según la mejor práctica actual. Los planes incluyen toda la información sobre los medicamentos, las pruebas diagnósticas y los resultados esperados. Todos los proveedores necesitan acceso al plan para que puedan contribuir su parte al plan total. La continuidad de la gestión del tratamiento asegura que haya predictibilidad y constancia en su cuidado. La continuidad tiene que ver con la habilidad de hacer citas y volver según el horario de su tratamiento. Si el paciente tiene problemas en hacer las citas, van a tener una falta de la continuidad de la gestión del tratamiento por no regresar cuando sea necesario.

La tercera forma de la continuidad de cuidado es la continuidad relacional e interpersonal (Haggerty et a. 1220). Esta forma tiene que ver con la relación entre el proveedor y el paciente. Cuando uno tiene un doctor regularmente, empieza una relación que crece con el tiempo. Con más visitas con el mismo doctor viene confianza y honestidad por la parte del paciente. Por la parte del doctor, viene conocimiento del contexto del paciente y una mejor idea sobre sus valores y preferencias en su cuidado. La relación entre proveedor y paciente permite comunicación abierta y honesta que pueda ayudar en la educación sobre su condición y aliviar estrés de tomar decisiones sobre su salud. Esta continuidad facilita las otras dos formas, informática y administrativa, porque involucra un doctor que sirve como una guía por el sistema y refiere el paciente a las especialistas que se requiere. Un paciente puede tener continuidad relacional con especialistas que saben mucho sobre su enfermedad específica. Por ejemplo, un paciente con diabetes puede formar una relación con su endocrinólogo por citas regulares para discutir el mantenimiento de su enfermedad y su progreso en cambiar su estilo de vida para controlar su diabetes. Parecido, un paciente con cáncer puede formar una relación íntima con su oncólogo, la persona quien primero compartió la mala noticia de su enfermedad y quien entonces dirige el método para superar este obstáculo o minimizar el dolor durante el camino. La continuidad de proveedor es la forma más investigada en la medicina.

La continuidad de cuidado ha sido investigada varias veces para ver su relación con los resultados del tratamiento. Hay una asociación significante entre mejor continuidad de proveedor (relacional) y una disminución en el uso de servicios sanitarios (van Walraven et al. 954). La continuidad interpersonal da como resultado un mejor cuidado preventivo y menos hospitalizaciones (Sautz y Lochner 164). La disminución en la utilización de servicios médicos corresponde con una reducción en la necesidad de tratamientos por mejor mantenimiento de altos niveles de salud. También corresponde con un descenso de gastos médicos para el paciente. Mejor salud y bajos gastos de cuidado son dos metas principales para el sistema de salud. Hay una asociación entre mejor continuidad de proveedor y mejor satisfacción del paciente en los resultados de su cuidado (van Walraven et al. 954). Es más fácil estar seguro y feliz con su cuidado cuando lo recibe de una persona en quien tiene mucha confianza. También hay más satisfacción porque la relación permite que el doctor sugiera tratamientos que están de acuerdo con sus valores y creencias porque conoce al paciente en un nivel íntimo. Todavía no existen muchos estudios de la continuidad administrativa e informática, pero uno puede adivinar que un doctor pueda ser riguroso y preciso en su tratamiento del paciente cuando tiene más información sobre la salud e historia de un paciente y sabe el plan de doctores anteriores

El sistema actual

El método dominante en el país para proveer cuidado para las familias latinas e hispanas con dominio limitado del inglés no es suficiente para garantizar la continuidad que necesitan. En muchas circunstancias, cuando no hay concordancia en el idioma, los pacientes reciben cuidado de mala calidad y los proveedores no entienden cómo pedir síntomas, ni diagnosticar, ni educar a los pacientes. Por faltas de entendimiento en la medicina, el gobierno estadounidense creó regulaciones exigiendo que las facultades que cuidan a las personas con dominio limitado del inglés provean intérpretes para sus pacientes. Las regulaciones se llaman CLAS ("*National Standards for Culturally and Linguistically Appropriate Services in Health Care*") e incluyen otros requisitos (MinorityHealth). La ley requiere o un intérprete en persona, o por teléfono, o por video. A pesar de las regulaciones del gobierno, no hay intérpretes en cada interacción que ocurre en una clínica ni hospital con un paciente que no habla inglés (Derose y Baker 78). En un estudio del uso de intérpretes en el hospital de 2011, 60% de los pacientes con dominio limitado del inglés recibieron un intérprete cuando hablaban con el doctor durante su visita y 37% recibieron un intérprete cuando hablaban con una enfermera (Schenker et al. 714). Aun en un hospital con muchos intérpretes disponibles, algunos doctores deciden no llamar a un intérprete porque tienen poco tiempo (véase apéndice C). Los pacientes deben recibir un intérprete en todas las interacciones y no está pasando, un factor grave en la falta de continuidad y entendimiento del cuidado. Si no hay intérprete, no hay comunicación verdadera y no puede ver continuidad en la información recibido y percibido por el paciente.

Cuando el sistema funciona según la ley, utiliza intérpretes de varias formas y ocasionalmente los trabajadores sociales y coordinadores de cuidado para organizar y dar el cuidado sanitario. Según un estudio de pacientes tratados por doctores que no hablan el mismo idioma, las barreras idiomáticas resulten en mal tratamiento y cuidado. Cuando hay un intérprete en la cita, su cuidado se mejora, pero todavía falla lograr la misma calidad de los pacientes que hablan inglés (Ngo-Metzer et al. 327). El intérprete tiene un rol muy específico en el escenario médico. El intérprete tiene que traducir el discurso, palabra por palabra, entre el proveedor y el paciente. Funciona como una persona invisible, objetivo y despersonalizado en el discurso, un rol que es difícil mantener (Hilfinger Messias et al. 132). Tiene la expectativa de no conversar con el paciente personalmente, sino solamente con las palabras del proveedor dentro de la cita (Gil et al. 191). Tiene una habilidad limitada de asegurar de que todos entiendan lo que está pasando porque no pueden añadir al discurso, excepto a veces para preguntar alguna clarificación del proveedor (véase apéndice A).

Su rol debido a la concordancia y respeto cultural es pequeño. No tiene mucho poder para asegurar de que no haya tensión por diferencias en cultura. Solamente puede dar pequeños consejos al doctor sobre cómo pueda preguntar ciertas preguntas o puede sugerir que haya confusión. No puede corregir la confusión ni hablar directamente con el paciente (véase apéndices A y B). Si el proveedor no entiende la cultura de un paciente, puede amenazar su comunicación y su relación. En un estudio de las barreras con dominio limitado del inglés en el sistema sanitario, encontraron que los padres con dominio limitado son cuatro veces menos probables de llevar a sus hijos al doctor porque los proveedores no entienden su cultura (Flores et al. 423). Es probable que el intérprete entienda la cultura del paciente, pero no queda dentro de su trabajo navegar estos discursos en la cultura. Los proveedores tal vez no tengan bastante entrenamiento en culturas distintas y los intérpretes no tienen la capacidad de hacer correcciones y clarificaciones de la cultura.

En muchos lugares, los intérpretes que están no tienen suficiente entrenamiento médico para poder interpretar en ciertas circunstancias. Por ejemplo, en el tratamiento de un niño con cáncer, es muy difícil explicar el diagnóstico a una familia que habla inglés y aun más cuando no habla inglés y requiere un intérprete (véase apéndice C). Si el intérprete no tiene experiencia ni educación específicamente para esta diagnosis y tratamiento, no tiene los talentos o la práctica para explicarlo a la familia y puede causar problemas peligrosos y graves en su tratamiento (véase apéndice B). Por ejemplo, si uno no entiende la gravedad de su enfermedad, es menos probable tomar las medicinas o seguir las recomendaciones del doctor.

Si hay una falta de comprensión, puede causar problemas graves con la salud. Si uno no entiende cuándo ni cómo tomar su medicina, hay miles de problemas que pueden ocurrir que nunca deben pasar en la medicina moderna: tomar demasiada medicina, tomar menos que es recomendado, tomar sin o con comida en contra de las recomendaciones y otros. Mientras estaba trabajando en una clínica gratis para los hispanoparlantes sin seguro sanitario, escuché de una mujer que tomó once pastillas porque no entendía las instrucciones escritos en inglés en su botella que decía "*Once daily*" o "Una vez cada día". Accidentes con la medicina representan un fracaso en la continuidad y seguridad de cuidado. Los pacientes no reciben el cuidado como debe ser recibido, hasta poner sus vidas en peligro.

Otro problema que surge en el sistema actual es la dificultad de navegar el sistema sanitario, especialmente en hacer citas y coordinar con otros. En algunos lugares, hay coordinadores y asesores que pueden asistir a familias en estos procesos, pero eso no es la norma. Aun cuando haya personas para ayudar con el sistema y los detalles, muchas veces solamente ayudan con los casos donde el paciente tiene una historia médica compleja (véase apéndices A y B). El rol simple del intérprete no permite que el intérprete llame a grupos externos para coordinar cuidado para el paciente. En el hospital de mi investigación, el intérprete solamente es permitido ayudar con llamadas a clínicas dentro del sistema del hospital (véase apéndices A y B). Niños de padres con dominio limitado del inglés tienen dos veces la probabilidad de no recibir cuidado porque sus padres tienen dificultad en hacer las citas (Flores et al. 422-423). La existencia de este problema demuestra otro ejemplo de una falta en la continuidad y continuación de cuidado.

Un problema grande surge con la continuidad interpersonal: la continuidad del intérprete. El intérprete en la escena médica tiene un lugar íntimo en el tratamiento del paciente. El intérprete está presente para la cita y aprende mucho sobre el paciente durante la sesión. Además de adquirir confianza en el doctor, el paciente tiene que desarrollar confianza en el intérprete para poder hablar honestamente con el doctor y tener una cita productiva. El doctor necesita tener confianza en las habilidades del intérprete para comunicarse bien con el paciente. El cambio constante de intérpretes, que pasa cuando la clínica usa un servicio telefónico o de video, hace que el paciente y el proveedor tengan que empezar de nuevo aumentando la confianza en el intérprete. Este cambio constante puede prevenir la formación de una relación auténtica entre el proveedor y el paciente. También puede tener el efecto de prolongar las citas porque pueden gastar más tiempo en las partes principales de la cita mientras aumentan la confianza y la relación profesional en el cuarto. Si el intérprete es alguien que el paciente ha visto antes, o frecuentemente, tendrá confianza desde el principio y lograrán mejor comunicación. Aunque el intérprete no es un proveedor directo de servicios médicos, es un proveedor de un servicio esencial para el éxito del tratamiento. Otros modelos de sistemas de intérpretes pueden eliminar este problema con una fuente más regular de los intérpretes.

Soluciones posibles

El primer problema que tiene que ser abordado es el uso regular de los intérpretes en las interacciones médicas. Es problemático que algunos proveedores den tratamiento a los pacientes con dominio limitado del inglés sin la ayuda de un intérprete porque puede causar daño masivo o fatal para los pacientes. La ausencia de intérprete niega los derechos a los pacientes porque no entienden las razones que están recibiendo ciertos medicamentos y pruebas. La ausencia elimina su habilidad de abogar para sí mismo porque no tienen las facultades ni el apoyo que requieren. Para asegurar cuidado de alta calidad, es absolutamente necesario tener un intérprete involucrado en cada cita, examen, llamada, explicación de resultados, y cualquier otra interacción. El intérprete puede dar una voz (y un oído) a los pacientes que ya están en una situación vulnerable. Para lograr eso, los centros de salud deben contratar más intérpretes que trabajan en el hospital para enfatizar y apoyar la humanidad y derechos de los pacientes. Los centros de salud deben tener acceso a intérpretes por Internet cuando nadie esté disponible. Pero esta solución dejará agujeros en el cuidado todavía.

Para mejorar la continuidad relacional en las interacciones, es importante usar el mismo intérprete cuando sea posible y crear un sentimiento de confianza en la cita. Es necesario que los doctores puedan confiar en los intérpretes y que puedan hacer su trabajo sin preocupación sobre el entendimiento y precisión de sus explicaciones e instrucciones. Por eso, es preferible tener intérpretes en persona en lugar de intérpretes por un servicio de Internet o teléfono donde es completamente aleatorio. En adición a los beneficios investigados, las familias prefieren tener el mismo intérprete porque valoran la confianza, las relaciones y la constancia (véase apéndice C). Cuando existe esta relación profesional, puede ser un sentido pequeño de entendimiento de la cultura de la familia, aunque eso normalmente no es suficiente. Tener el mismo intérprete puede hacer que no haya ninguna falta de confianza y que no haya grandes errores en contra de las creencias y prácticas de la familia, pero esa relación es temporal y no provee mucho apoyo fuera de la cita.

El entrenamiento insuficiente de los intérpretes, o no tener intérpretes con entrenamiento especializado para ciertas áreas de la medicina, es difícil para mejorar. Hasta recientemente, no había ningún programa oficial para el entrenamiento de los intérpretes médicos. En los hospitales, muchos intérpretes no tienen credenciales oficiales para hacer su trabajo (véase apéndice A). El programa de credenciales empezó en el 2010 por el *National Board of Certification for Medical Interpreters* y provee un proceso para recibir el título de CMI (*Certified Medical Interpreter* o Intérprete médico certificado) (Martínez-Morales). Ahora mientras existe, muchos intérpretes no pasan por el proceso por falta de tiempo y recursos (véase apéndices A y B). Además, dentro de las especialidades médicas hay vocabulario especializado que debe requerir entrenamiento adicional para los intérpretes. Para solucionar esto, las regulaciones deben ser estrictos para las credenciales y educación de los intérpretes para asegurar su precisión y competencia en la medicina y la seguridad del paciente.

Con respeto a los malentendidos con los medicamentos y otros procedimientos en el cuidado sanitario, es esencial eliminar estos problemas inmediatamente. Las faltas de comunicación ocurren por razones complejas. El idioma distinto es la primera razón, y la más obvia. Un paciente que no entiende las palabras usadas para la instrucción no entenderá el proceso. Ocurren problemas con analfabetismo académico y de la salud. Un paciente que no puede leer, ni el español ni el inglés, probablemente por falta de educación, no puede organizar los medicamentos, ni seguir instrucciones escritas cuando tenga preguntas. El analfabetismo de salud puede causar confusión entre medicamentos y procedimientos que tienen nombres semejantes o procesos complejos. Por ejemplo, alguien sin mucha educación médica tal vez no entenderá la importancia de tomar ciertos medicamentos con comida y otros por la noche, o tal vez no va a entender que la orden en la que preparen para una cirugía es esencial a su éxito. El éxito en la medicina requiere el entendimiento. Para mejorar el entendimiento, es necesario que los pacientes reciban materiales informáticos e instrucciones en su lengua nativa. Es necesario que haya una solución para el analfabetismo, que tal vez pueda ser varias repeticiones de las instrucciones por medio de un intérprete. Una solución beneficiosa es el uso de colores y símbolos para corresponder con distintas medicinas y tiempos del día. Además de mejorar el éxito en seguir las recomendaciones del régimen de tratamiento, los horarios personalizados pueden darle confianza al paciente o a sus cuidadores o parientes (véase apéndice B). Corrientemente, los intérpretes no sirven este rol, especialmente no dentro de sus habilidades profesionales. Los intérpretes pueden ayudar en el momento en el que el doctor escribe la prescripción para un medicamento, pero no tienen contacto con la familia después. No hay ninguna persona en la mayoría de los centros de salud quien dedica su tiempo a la producción de materias en español y el desarrollo de materias al nivel educativo del paciente y su familia. Tal vez podría ser el trabajo de los trabajadores sociales, pero parece un poco fuera de sus roles también. O podría ser la responsabilidad del doctor, pero ya tienen mucho trabajo y tareas de la documentación encima de cuidar a los pacientes. Aunque si fuera la responsabilidad de un proveedor o trabajador social, no hablan el idioma y no tienen la habilidad de averiguar su precisión o calidad. Hay que tener otra persona para hacer este trabajo.

Finalmente, hay el problema de la navegación del sistema. Con todas las compañías de seguro, los cambios recientes en el programa nacional, los requisitos para recibir ayuda médica del gobierno, y tantos otros componentes, es casi imposible navegar el sistema estadounidense sin la barrera del idioma. Los pacientes con dominio limitado del inglés necesitan acceso a una guía por el sistema complicado. Pueden poner un énfasis en su salud cuando tengan los recursos y la asistencia para buscar ayuda. Una guía por el sistema ayudará con hacer las citas, ayudará con acceder a otros proveedores médicos cuando sea necesario, abogará por ellos en el sistema de seguro, y los ayudará con coordinar la transportación a sus citas, y cuidado para niños. Podría ayudar con cosas donde no existe una persona dedicada a su asistencia. Debe existir ayuda en coordinar entre especialidades para tener citas en días que minimicen el trabajo perdido y el transporte requerido, y también en coordinar con otros programas sociales fuera del centro de salud. Para estar saludable, una persona requiere que todas sus necesidades básicas estén realizadas.

Un intérprete me contó la historia de cómo ayudó a una familia, fuera de su rol como intérprete, porque no había nadie para ayudarlos. Tenían muchas barreras para abordar: a) tenían un bebé que recientemente tuvo una cirugía; b) el hospital era dos horas y media de su casa; c) eran inmigrantes guatemaltecos indocumentados; d) el español era su segundo idioma (su primero era un idioma indígena); e) tenían baja alfabetización en leer y en la salud; f) tenían problemas en conseguir la fórmula para bebés correcta cerca de ellos y en la cantidad que necesitaban; g) tenían miedo de conducir tan larga una distancia sin licencia; h) tenían ansiedad de conducir en una ciudad grande; i) no podían regresar al hospital varios días porque el padre perdía pago por no estar allí. El intérprete vio tantos problemas y decidió ayudarlos, aunque pudiera causar problemas con su propio trabajo. Los llevó a la farmacia, algo dentro de su rol, y ofreció usar colores para hacer los medicamentos más comprensibles. Llamó al programa de WIC (un programa para mujeres y niños con poco dinero) para pedirles ayuda a esta familia en poner un orden específico con el supermercado cerca de su casa. Insistió en que las citas de consulta sucedieron en el mismo día. Y condujo al lugar donde tenían suficiente fórmula para bebés con la familia siguiéndole (véase apéndice A). Esta historia ejemplifica la necesidad de tener alguien para hacer estos trabajos. Las familias con dominio limitado del inglés necesitan ayuda en muchos aspectos de la vida para mantener buena salud, y debe ser la responsabilidad del sistema de salud para proveerlo y cuidarlos. Los coordinadores y trabajadores sociales tienen mucho trabajo para hacer, o debe ser una responsabilidad que añaden a su trabajo, o debe ser la responsabilidad de otra persona dedicada a la continuidad y provisión de cuidado en muchos aspectos de la vida para las familias con dominio limitado del inglés, aun si los problemas médicos no son tan complejos.

Es ciertamente posible crear un sistema que satisface todas las necesidades y grietas en la continuidad de cuidado para pacientes y familias con dominio limitado del inglés. En Washington, el hospital Harborview junto con un programa llamado *“Community House Calls”* ha creado el puesto de *“Interpreter Cultural Mediator”* o “Intérprete y mediador cultural” para cuidar de las necesidades de los pacientes (Miyagawa). Su rol incluye: asistencia en entender su diagnosis y opciones para el tratamiento, la continuidad de la interpretación, defensa y apoyo en circunstancias con distintas agencias, navegación por el sistema, ayuda con formas y suplicaciones, educación de salud, y coordinación con citas y el transporte (Miyagawa). La única cosa que no incluye es el entrenamiento especializado para una especialidad. Un rol aun más completo existe en un hospital pediátrico.

El rol de intérprete y defensor de pacientes con dominio limitado del inglés

El rol de intérprete y defensor de pacientes con dominio limitado del inglés es un rol único en el hospital, y por la investigación, en todo el país. El puesto integra tres puestos en uno: el intérprete médico especializado, el intermediario cultural, y el defensor de sistemas de salud/gestión de casos (Gil et al. 192). El rol existe únicamente en la clínica de la hematología y la oncología. Los proveedores y otros miembros del equipo sanitario en la clínica reconocieron que los pacientes con domino limitado del inglés tenían riesgo de recibir cuidado fragmentado y crearon un puesto para luchar en contra de las barreras (Gil et al. 194). El uso de este rol en el hospital pediátrico ha sido exitoso según los padres de los pacientes, los proveedores, los otros intérpretes en el hospital y el defensor sí mismo.

Su rol como intérprete médico especializado es un componente que diferencia el rol de intérprete y defensor de pacientes del rol de “intérprete y mediador cultural” descrito. Tiene la educación necesaria para tener éxito, no solamente como intérprete, sino como intérprete médico y oncológico. El defensor tiene un título en el español con una subespecialización en estudios étnicos y tiene su certificación de CMI (véase apéndice B). Los proveedores notaron que antes no siempre tenían un intérprete con el conocimiento necesario de los procedimientos y protocolos en la oncología. Con el sistema nuevo, los pacientes siempre tendrán un intérprete (el defensor) con la capacidad fuerte y congruente para interpretar en las citas para el cáncer (véase apéndice D). El intérprete y defensor sabe mucho sobre los protocolos, medicamentos, pruebas, resultados esperados (véase apéndices D y E). En adición, tiene una buena idea de que significa la diagnosis de cáncer para la familia y cómo es la locura de la vida con cáncer que no entiende la mayoría de las personas (véase apéndice B).

Como mediante cultural, ha sido un recurso sustancial en la clínica. Es cómodo con la cultura latinoamericana, y más específica, la cultura y experiencia de los inmigrantes, algo esencial a su trabajo como guía dentro de las culturas de los proveedores y los pacientes (véase apéndice B). Tiene experiencia y comprensión de varias rituales y creencias, por ejemplo, remedios alternativos que las familias pueden intentar (véase apéndice B). Aun educa a los proveedores en las circunstancias de conflicto o confusión cultural. Una practicante de enfermería certificada dijo que el defensor le ayudó entender varias diferencias en la cultura latinoamericana, por ejemplo, los significados del bienestar y la enfermedad y la importancia de la familia (véase apéndice C). El intérprete y defensor analiza las necesidades de la familia en forma individual para asegurar de que todas sus necesidades culturales estén realizadas de manera respetuosa (véase apéndice B).

El sistema de salud en los Estados Unidos es fragmentado y confuso, y para las familias, el trabajo del defensor como navegante del sistema es esencial a su bienestar como pacientes y como seres humanos. Los pacientes que utilicen los servicios del intérprete y defensor tienen varias barreras que enfrentan cada día. El sistema sanitario tiene la potencia de ser un obstáculo encima de todo, pero el defensor elimina el estrés y dificultad de navegar el sistema (véase apéndice B). Su rol y la continuidad de cuidado acompañante mejoró la comunicación y simultáneamente disminuyó el estrés de los padres en la situación (Gil et al. 194). Dirige la navegación de los horarios complejos de la administración de los medicamentos, haciendo calendarios con codificación de colores o palabras sencillas cuando sea necesario (véase apéndice B). Los padres tienen buena confianza en que pueden administrar los medicamentos a sus hijos y los proveedores creen que sus pacientes reciben los medicamentos como deben cuando haya intérprete y defensor de pacientes (Gil et al. 195-196). Según un doctor, parece que, en adición a coordinar el cuidado de los pacientes, el defensor sirve como coordinadora de la vida para las familias (véase apéndice D).

Una manera para mejorar la continuidad de cuidado en la clínica y hospital es mejorar la comunicación. El rol del intérprete y defensor de pacientes aumenta la calidad de la comunicación entre los proveedores y el paciente y su familia, pero también dentro del equipo de tratamiento. Los proveedores tienen confianza que toda la información necesaria está transmitida al paciente (Gil et al. 195, y véase apéndice D). Los pacientes y sus familias sienten que puedan expresarse como si están hablando personalmente con el doctor, y que el defensor es interesado en su entendimiento de todo (Gil et al. 195). La comunicación es abierta y eficaz cuando existe este tipo de relación en el cuarto. La sinceridad en la comunicación viene de la confianza que tienen las familias en el defensor, y por asociación, en los proveedores (véase apéndice E). Un doctor dijo que, con el intérprete y defensor de pacientes presente, no hay barreras en comunicar con los pacientes, un gran testimonio a sus capacidades y su buen trabajo (véase apéndice E).

El intérprete y defensor de pacientes provee un alto nivel de la continuidad de cuidado para los pacientes con dominio limitado del inglés. Desarrolla una relación fuerte con los pacientes y su familia por estar con ellos durante todas las partes de su travesía con el cáncer. Su relación cultiva altos niveles de confianza, no solamente en sus habilidades profesionales, sino confianza personal y de una amistad por su consistencia (véase apéndices B y C). El defensor es parte del equipo de cuidado durante la experiencia completa, desde diagnosis hasta sus visitas de remisión, o desafortunadamente, hasta la muerte (Gil et al. 192, y véase apéndice E). Es el miembro más constante del equipo de cuidado, y según una enfermera, es el miembro más valorado del equipo (véase apéndices B y C). Es parte de las consultas con los oncólogos, la terapia física, estancias de hospitalario, visitas por otras especialidades, etcétera (véase apéndice

B). Los proveedores lo tratan con respeto y una estima alta porque reconocen su valor (véase apéndice B). Le consultan con preguntas como, “¿Cuándo vamos a ver a nuestra paciente, X?” y “¿Cómo debemos presentar esta información?” (véase apéndice B). Todo funciona como una gran colaboración con la meta compartida de un paciente saludable y una familia estable.

La presencia de una persona en cada interacción médica ayuda en la continuidad de cuidado entre proveedores. Por estar con el paciente frecuentemente, puede mejorar las transiciones entre los proveedores, por ejemplo, cuando hay un cambio temporario en la enfermera trabajando en un caso, hay mejor comunicación y continuidad en el cuidado dado al paciente (Gil et al. 194). El tiempo entre citas es una época de problemas posibles, es la hora cuando los pacientes con dominio limitado del inglés están perdidos en el sistema, y eso se cuida y vigila el intérprete y defensor de pacientes (véase apéndice A). El intérprete y defensor de pacientes ha notado diferencias o equivocaciones en la dosis de un medicamento o el plan que presenta un doctor cuando otro doctor dijo algo distinto; son problemas donde la aumenta en la continuidad de cuidado puede prevenir una herida peligrosa al paciente, y aun puede salvar la vida (véase apéndice B).

Es claro que el rol tiene muchos bienes generales, pero es especialmente beneficioso en la especialidad de la hematología y oncología. Hay estudios que encontraron enlaces entre la supervivencia y éxito de tratamiento de cáncer en pacientes pediátricos y su etnicidad y raza (Bhatia et al. 1961 y Worch, J. et al. 986). Si las diferencias existen por la discriminación, racismo, o falta de acceso a los servicios sanitarios, presenta un problema gravísimo en el sistema de salud. Hay que hacer lo posible para eliminar diferencias en el cuidado disponible; el defensor hace justo eso para los pacientes latinos e hispanos con dominio limitado del inglés. Este rol es importante en la hematología y oncología porque los diagnósticos constituyen una amenaza para la vida y son complejos (véase apéndice B). El tratamiento de cáncer requiere conocimiento profundo y la coordinación de medicamentos y citas en que el defensor puede ayudar. Con el cáncer, los pacientes y las familias necesitan entender lo que está pasando en cada momento, algo que no es posible si no tienen defensor e intérprete disponible y listo para explicar todo a ellos de una manera que pueden entender (véase apéndice E). La oncología no es única en sus demandas en el paciente y los proveedores de cuidado, pues no debe ser el único lugar donde se utiliza este puesto.

La expansión del rol

Hay muchas especialidades en la medicina donde hay necesidades únicas y barreras numerosas para los pacientes y familias con dominio limitado del inglés. Al pedirlos cuales especialidades podrían beneficiar de tener un defensor así dentro de su práctica, y cuales no recibirían muchos beneficios, todos los participantes respondieron que todas las áreas de la medicina beneficiarían de tener intérpretes y defensores de pacientes (véase apéndices A, B, C, D y E). Los dos oncólogos pediátricos respondieron que el cuidado primario recibiría mucho del puesto (véase apéndices D y E). En el cuidado primario hay mucho espacio y tiempo para el cuidado preventivo que mejora la salud en general y disminuya la incidencia de problemas de salud agudos (véase apéndice D). Es valioso tener un puesto relacional como el defensor en una especialidad donde su meta es desarrollar relaciones que duran muchos años (véase apéndice E).

La segunda prioridad es tener intérpretes y defensores de pacientes en las áreas donde tratan a enfermedades que amenazan a la vida. Deben existir este puesto en las Unidades de Cuidado Intensivo Neonatal y Pediátrico. En las dos unidades, hay enfermedades y heridas graves y normalmente el paciente tiene una estancia larga. Durante su estancia, hay visitas de doctores de varias especialidades y puede ser un ambiente estresante y confuso para las familias. Las familias, similar a la oncología, tienen que recibir información frecuentemente sobre el estatus de su hijo y el plan de tratamiento (véase apéndices B, D y E).

La tercera prioridad es implementar el rol en las clínicas de especialistas. Como la oncología, otras especialidades en la medicina tienen su vocabulario completamente único. Tienen enfermedades complejas con mucho tratamiento y poco entendimiento por la parte de las familias con dominio limitado del inglés y poca comprensión del intérprete sin entrenamiento específico para esta especialidad. Muchas especialidades trabajan con pacientes con condiciones crónicas que requieren una relación larga con los proveedores para manejar la enfermedad y su progreso (véase apéndice B). Sería importante en las clínicas de la endocrinología y con pacientes con diabetes por su duración de toda la vida y los cambios grandes en el estilo de vida que exige de los pacientes (véase apéndices A y B). Sería valioso en las clínicas donde trabajan con niños o adultos con necesidades especiales. Los pacientes tienen tratamiento y cuidado personalizado y su éxito depende mucho en el apoyo de la familia; una familia que tiene que ser bien educada en sus circunstancias (véase apéndice B).

Para implementar este rol en otras especialidades, clínicas y hospitales, hay que tener un método para pagar por los servicios. Corrientemente, el rol recibe sus fondos de dinero filantrópico de una colecta organizado por el hospital (véase apéndice B). No es posible, ni sostenible, pagar este rol exclusivamente por fondos donados. Es importante analizar las prioridades del cuidado sanitario y crear un sistema para apoyar un trabajo y ministerio tan requerido. El programa gasta mucho dinero al principio, pero es una inversión en el futuro de los pacientes latinos e hispanos con dominio limitado del inglés que proveerá grandes beneficios al país en total por el futuro (véase apéndice B).

Conclusiones

La expansión e implementación del rol del intérprete y defensor de pacientes con dominio limitado del inglés es una tarea expansiva, pero vale la pena. Los pacientes con dominio limitado del inglés son la gente más vulnerable en nuestro sistema sanitario. Tienen barreras sociales, económicas, idiomáticas y culturales. La salud no debe ser algo que un ser humano no reciba solamente porque viene de otro lugar y tiene diferente herencia idiomática. Este país es el campeón de la libertad, es nuestro derecho asegurar de que todos tengan la libertad de recibir la ayuda que necesitan para estar saludables. Es nuestra responsabilidad proveer la oportunidad de vivir, la oportunidad de perseguir la felicidad con cuerpos capaces de continuar. Para lograr esta meta, es necesario combatir las barreras que enfrentan los latinos e hispanos en los Estados Unidos. Es esencial proveer cuidado sanitario adecuado y servicios culturales y de intérprete para la gente que los necesitan. El rol del intérprete y defensor de pacientes supera muchas barreras y crea la posibilidad de un futuro sano y feliz para los latinos e hispanos en el sistema de salud. En la medicina, la prioridad es el paciente. La implementación de este rol permite su continuación como la prioridad y la historia de éxito en nuestro sistema de salud.

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Apéndice A

Entrevista anónima con un intérprete profesional
Entrevistador: Alexandria Daggett
Método: Llamada por video
11 noviembre 2017

Daggett: What is your job title and your certification?

Participante 1: Ok, so I am just a staff, not just…I am a staff Spanish medical interpreter. So, I do not have a role like [Participante 2].

D: Is CMI (Certified Medical Interpreter) the credential for that? Or is that a different certification?

P1: I don't have the certification but there are two different certifications offered right now for Spanish, I think…I believe for Somali. They don't have it for many languages yet. Unfortunately, I went through a certificate program through [a college] in [location]. We have the [State university] and I was of the first group that went through the [college] program for translators and interpreters. It was brand new when I did it there. It was more economical, so I did it there instead of the [State university], which is right by my house, which would have been really convenient, but it was just more expensive.

And so, that's a certificate program. But in addition to the certificate program, I could take the tests - the oral and written tests - to get the certification, which is more at this point a personal goal for many people. And I do believe that it would be a good idea to require that. I wholeheartedly believe that. I haven't done it myself more just out of life realities and not having the money and the time right now to put towards that. But there isn't any direct benefit to us in our profession right now. That's the other thing. Our profession is so much in its infancy, there is no financial benefit, or even employment benefit, although it probably will be moving there. Which again, I think is a really good thing.

D: Okay, awesome. So, as a medical interpreter then, what does your normal interaction in an appointment look like?

P1: Well it depends. I would say there is a difference between…I am a staff interpreter who has been here at [hospital] for ten years. So as a staff interpreter, we tend to, in some ways…Not in every department, as we were just coming out of a staff interpreter meeting saying that we don't feel like our role is completely understood, but that we're treated as professionals in some cases. But generally speaking, I think as a staff interpreter, when you're in one place, there's much more of a sense of teamwork. Not just among us interpreters, because we are a part of a department, but we wear two hats. That is we wear the [hospital] employee hat and try to live out the values of going above and beyond and listen, really listen, and all these values that [the hospital] has, then we wear these two hats. And so that can impact our role versus somebody who is working with an agency, you're not an employee of the place, you're not connected to the staff at the facility necessarily.

And so I think there is a dynamic that plays out a little differently there, in that we, perhaps, tend to do maybe more than what strictly, theoretically, in a class you would be told is part of an interpreters role. So, in other words, in your training, and in your ethics, and in your guidelines, they're pretty…it's pretty…even though those of us that have practiced know that it's kind of a gray area. You are trained to be constantly evaluating yourself, that you are not going outside of your role, for example, as an advocate, or interfering in any way in the encounter beyond what your role is.

You wouldn't…obviously it would be unethical to be offering any sort of advice to the family. Or, we're not even to…Let's say, if a nurse says, "Oh, can you hold the child for me while I'm doing this?" or "Can you help me hold down the child?" or something, those are things we are not supposed to do. Or, like, we don't stay in the room when a provider leaves, we step outside. So we have those general guidelines of our profession and our ethics. Some that are very similar to lots of professions, you know, confidentiality, impartiality. Obviously, accuracy in our interpretation is our main standard, we don't add, we don't delete.

But, again, there is a gray area when you are more in situations like… Like for example, myself, who has worked in the system for 10 years. We understand the system. We understand processes. We also understand clearly how families fall through cracks. And so, we might offer to do things like…So in our hospital, if somebody is referred down to our financial counseling services in our family resource center on [hospital location], we might offer, or even be asked by the provider, to show them where it is. Or we just, naturally those of us who have worked here, might automatically ask the parent, "Do you know where the family resource is?" We might initiate that question. That's beyond our strict theoretical role, because we don't initiate, necessarily, dialogue. But we might be in that case, because of the hat we wear as a [hospital] employee, that we'll offer to take them. And so maybe those have been…now become expectations for patients because, "Oh well, the staff interpreters they offer to do that." We might offer to, say, "Oh, I can help make that referral call," especially if it's internal within [the hospital].

So that happened to me today in an appointment. Now the provider didn't say to me, "Could you help Mom make that appointment?" although some providers do. And we're allowed to. As part of our department we made that rule, that we're not supposed to interpret for, let's say, a parent calls us and says, "Can you help me make this appointment at this neurology clinic outside of [the hospital]?" No, we can't do that. But if we are in the appointment and the provider says, "Can you help Mom make this call to this neurology clinic?" and we're at [hospital], we could do something like that. But these are just examples of how we can go a little beyond what would be strictly the interpretation of dialogue.

D: Thank you. Alright, what are some of the largest challenges or barriers for families and patients with limited English proficiency?

P1: I think health literacy for many of our families is a big issue. I don't know if they recognize it as an issue, but I think from our end, I see that as one of the big issues. So, health literacy, a mistrust and lack of understanding of how our healthcare system works. I think other barriers…I mean I think of all the social determinants of health. So, things like issues with transportation.

You know, just being able to navigate, well navigate internally the system, but then access the system as well. There are things outside the scope of, you know, an education level or whatever, it just has to do with social determinants.

I also think that the navigation piece, of navigating the system, both within and outside. So, if you didn't have an interpreter who really said something, or a provider who said, "Oh, let's make sure we're helping you make that appointment," …So that type of hand-offs and follow through with helping them, especially with continuation of care kind of things outside of our building.

I think sometimes those can fall through the cracks because you're just given a number on a paper and told to call and make this appointment, but you call and you get this long voicemail in English that goes on and gives you five options of what you're supposed to press to get to this, to this, to this, to that, and somebody might just say, "I don't understand what they're saying. I give up." And they hang up. And then, maybe they try it two times, but then they give up on it. You know, those kinds of things.

D: So, you discussed this a little bit, but how does your job as an interpreter contribute to continuity and quality of care? And then, are there any instances where your capabilities and your position are not sufficient to ensure continuity of care?

P1: Oh boy, this could be a long answer. Well, if you don't have… obviously the interpreter is needed in terms of, if you're talking about continuative care and treatment, if there isn't an understanding of treatment, or there isn't a clear understanding, you need to follow-up in three months, or, you know, that's just a basic level. We contribute by just making sure that there is this…that the message is getting through, right, to the family.

As well as, we also can act as cultural brokers. So, if there is an issue where a provider might feel like, "I just don't understand why this family...I'm asking them this. They say they are, but it doesn't seem like they're really taking the medication or not." We can consult. The provider can have a pre- or post-encounter kind of session with us to discuss or ask us if we are detecting anything cultural. Maybe cultural, or something that is upsetting this family, or a reason why they don't seem willing to take this medication, or to go back to this doctor, something like that. So we sometimes can provide insight as to what may be a barrier that's not…doesn't involve the communication, it might be a cultural belief or practice. And we can sometimes help to clarify that. So I think our role can at times catch something like that.

We also sometimes can intervene to say, I think if we have a clear sense of the literacy and cultural beliefs of a family, we might say, "You might want to ask the question this way." Or, "I think…Excuse me, the interpreter would like a clarification," or "…Would like to clarify, I think mom/parent is misunderstanding what you're...." So, we at times can intervene as long as we are transparent about our intervention. We can intervene and catch some of those things.

And so, on that end, in the moment of the encounter with us, the limitations to our role I see as many. And that's why I'm a passionate advocate of these roles that go beyond just the communication piece. Because I think the barriers have so much to do with literacy, have so much to do with understanding, again, the healthcare system, understanding the processes, navigating. And for all those things, you need more a navigator/advocate role. So, I think there is a lot of education that needs to be done. There's a lot of work that needs to be done with health literacy. The tools, I mean, we are discharging families with discharge instructions all in English.

So, I'm going to give you an example of how I completely, one time, completely stepped outside of my role as an interpreter. And I let my supervisor know. I said, "This is a case where we have this couple with a baby who had a problem with their liver and had this major liver surgery and they were being discharged." And I happened to have been the same interpreter who had been with them for the surgery and for one other encounter, I believe. So, I kind of understood a little bit the background of this family. A young couple, Spanish was their second language although they were pretty fluent, it was their second language. So, mom, which is…the Guatemalan indigenous language was her first language. And with this baby. And I knew that their level of health literacy and literacy in general was very low. Mom, in fact, could not read or write well in Spanish or her own native language. So, when it came time to discharge this family.

…Oh, and another thing was that I knew that this family came from two and a half hours away, from a very small town. And they also were undocumented, so immigration is also a social determinant of health. It can impact, we know it impacts, health. And not only access to health because of the fear of driving, because they are driving without a driver's license. For this dad, it was the fear of I am driving two and a half hours without a license, but I am also driving in the big city which I am not used to driving in. I drive normally in a small town.

So, I am giving you this background because, because I knew these things is when I intervened at the time of the discharge in a way that was beyond my role. Which could get me fired actually, if somebody wanted to. But I was transparent that I was doing it, and I use this case to say that this is why I passionately believe, and strongly believe we need, for in-patients, an LEP advocate role. Because I see a lot of things falling through the cracks for our in-patients.

So, on this particular day, then, they were discharging the patient and I was…I think I ended spending pretty much the entire day with this family on the floor for their discharge. It was, whether I went beyond my role or not, it was going to be a long discharge anyway. There was a lot to do. So, there were providers who were doing their final rounding with them. It involved gastroenterology. It involved a specialty doctor doing a consult. So, we did all the final consults, the nurse started doing the discharge, going over all the instructions. I accompanied the family to the pharmacy to get the medications. There were three medications. One of them was a very important medication that they needed to have for the liver. And, so that is within our norm to accompany a family down to the pharmacy to get their medications, but I was even more adamant that, yes, I'll make sure that I accompany them.

So, we went through that whole process. But it also became clear to me that if this mom wasn't…she's the one home with the baby, and she's not fluent or literate in reading or writing in Spanish, that we needed to do something about these discharge instructions written out in English. And, making sure she understood what were the three different medications…what they each were for. I took it upon myself to offer them, and work together with the nurse to say, "I think we need to get color coded these medications and have something written out and make sure that it's clear what medication is what and how they are taken. Make sure that we carefully and as clear as possible explain it."

So, because I have been trained to do [Participante 2]'s role when [he or she] is gone and sub for [him or her], I knew that [he or she] does color coded calendars. So, I went down to [Participante 2] that day and said, "Hey, I have this family. I am doing this outside of my role, but I just cannot get myself to see this family leave without this being done." So, I went down and [he or she] helped me. I went to the pharmacy with the dad. I had…and then we color-coded everything.

And that took time because I was waiting until [Participante 2] was free and calling [him or her] and going down and coming up. I had asked my supervisor if I could be freed up to spend this time because of the nature of the case and the help that I thought this family needed. So together with the nurse, we got that together.

But then I also played an advocate role in insisting that we try to make their follow-up appointments on the same day as much as possible when we could. So this family wouldn't have to be driving back and forth, to and from, and save them several trips. And that was very tricky, but the gastroenterology person, and you know, the provider that was there present, also agreed and was helping. I explained it that I helped this family not come back and forth as many times. Dad is also taking off of work and mom doesn't work, so that's a loss of income. So, we worked on that. And then I also offered to help and call and actually make those appointments. And that was very time consuming to try to get all these appointments, as much as we could, scheduled and explained to them. "You know, this one isn't going to be in [hospital], it's in this other place in [location]. And this, you're coming here for the blood work first and then you're going to go to gastroenterology and then you're going to come back later for these two appointments in genetics," and I forget what the other one was. So, it involved a lot for a family who was new to understanding the healthcare system and who was coming from two and a half hours away.

And, I'll tell you though, here's the thing too. I want to tell you this whole story, because this is what I told leadership when I went to tell them about the advocating for this in-patient role. The baby had to have this very specialized formula. It is pretty new on the market and the nurse said "Ok, here is this formula" and right away we were like...I was like, "Well, can you print something out so this family can take this to someone that can see exactly." So they did. They printed out a picture of the can with the name on it so that they could take that with somewhere when they went to the pharmacy.

But this was on a Friday, right? And they are supposed to be getting their formula through WIC. It's very expensive, it's almost 40 bucks or more a can. So they said, "Well, you'll have to go to your WIC office on Monday and, you know, get this formula." So, the nurse said, "Well, I can send..." So I said, "Well, do you…are you sending them home with any formula from the hospital?" Because I had seen that they'd done that before. And she said, "Well this is all we have. This is all I can send. It's enough for Saturday." And had I been an advocate, but I had done so much that day and I didn't want to push anymore, I would have said, "Find a way to get them enough to hold them off until Monday." Because I knew that they were in this little, teeny town and the nearest city is [location], which is still like an hour from them, or an hour and a half. She said, “Nope. We don't have anymore.” There was nothing done. I didn't hear anybody say, “Well let's check if there was any.” And they were sent home.

Well, you wouldn't believe what happens to this family. And I find out because when they had to come back, the day that they had to come back to [location] for one of their Gastroenterology appointments to meet with the hepatic doctor, they had to come here to [hospital] first, to get their blood work done and then go to the appointment. Well, it was a big mess up when they came. Nobody knew why they were coming, what the blood work was, because Gastro somehow didn't send the order for the blood work and all they could see in the [hospital] chart was that they had an appointment with Genetics coming up.

So, they send down a consult. And it was this big huge mess and there wasn't an interpreter there with them. And I happened to be going down to the lab and saw them. Come to find out that that Sunday when they…or that Friday when they get home…or they got discharged at 4 and at 9:30 the dad was driving around [location] trying to find formula. Going from a Walgreens to CVS and finally the last Walgreens he went to had a couple cans. Okay?

So, skip to Monday. When they go to the WIC office on Monday, they're given these vouchers now that say they…it's a voucher and you can get seven cans of this formula. Well when the dad comes to the…I'm interpreting for them down by the blood work, and we're trying to figure it out. I'm the one, because I had been a part of the whole discharge, who made the staff at [hospital] aware of it. It was a gastro that requested the order.

We called gastroenterology and by now they're going to be late for that gastro appointment. So, then gastro says, “Oh, okay,” so they figure, “yep, it's our mistake. We didn't put the order in. Sorry. And nope, we can't see them now, because they're going to be late for the appointment.” Even though we're saying, “They were stuck here in the lab trying to figure this out because you guys messed up the order.” Right?

So, this family's stuck here. The genetic counselor is down there. The genetic counselor decides that, “Oh, since I'm here, I'm going to sit down and give these parents these results of something else. And I'm going to ask for blood work from the parents.” So, then they're going to have to go register in the lab. They go and so this family was here from 2 'till like 5, just to get blood work from the baby and the two parents. And I interpreted…interpreting for the Genetics appointment that should never have kept the family here all that time.

And then during that whole three hours, the biggest thing that the dad kept saying, and the mom…but their biggest concern was, “Can you please help us figure out how to get this formula for the baby? Because I have to drive an hour and a half every time I need some more formula to [location] and no place has more than two or three cans.” So, this dad was giving his seven can voucher every time and only getting two in return. There is no change given.

So, I stepped completely outside of my role once again, and I said to the dad, “What's the WIC...who is your contact at WIC?” And I called the WIC nurse and I say, “I am a Spanish interpreter at [hospital], I am with such and such family and this dad is having trouble getting their formula.” This WIC nurse says, “Oh, well I told them that they're supposed to go to the local supermarket, ask to speak to the supervisor, and tell the supervisor at that local supermarket that they are to now start to order this formula for them here so that they can fill it here…their WIC prescription here.” And I said to her, “Excuse me, do you...does your local supermarket have an interpreter?” Right there is a barrier, right? This family is told that they can advocate for themselves. That's assuming that they know to advocate, understand that supermarkets have these supervisors, and these supervisors if you just tell them...Which they do. They will order special or special order things in. But I knew that this family probably never, whether…I don't know if they just never understood it. And she insisted, “Well, we told them this.” And when I said, “Well do you have an interpreter?” She said, “Uh, no. Could you call for them and set this up?” And I said, “I'm sorry, I'm an interpreter at [hospital]. That is not my role. It is your role as WIC to ensure that this child is getting the formula that they need. I need you to make that call and then I need you, with an interpreter at their next WIC appointment, or call them and let them know that you set this up. And then you should follow up with them in a week and ask them if they've started getting their formula the way they should. There are seven cans with each voucher.” And that's what I left it at.

In the meantime, the dad says to me, “I only have one can left.” And the nurse, well I told the nurse that, “the family only has one can and they're down here right now.” And she said, “Oh great! You're in [location], well they can easily find it in [location].”

Well the two phlebotomists down in the lab overheard this phone conversation and they join in. And three of us are all on the phone, calling all the Walgreens and CVS stuff in [location]. We could not find one that had more than one or two cans or any. Finally, we located one that had four cans. Then we had to tell this dad, “You're going to go somewhere in [location] where you've never been and go pick up these four cans of formula.”

So I, again, did something that I, again, could probably easily get fired for. When I clocked out, I was already in over my time. I clocked out at 5 and I told these phlebotomists, “I will, on my own time, have the dad follow me and try to find this.” Because I didn't even know where it was and he is already paranoid about driving in the city. And I got him there and I went in and made sure that the four cans were waiting there and they picked them up and I left.

D: It's so important that there is someone to do that.

P1: It's so important, but people don't, you know, don't...it's...it comes down to money. And because it’s not a role that is reimbursable, the hospital doesn't see it as a role that should come out of their operational budget. Because I don't think there's an understanding of the importance of it. So if child life is paid through, or if chaplaincy is paid through, how much more important would it be for...if we really believe that we talk about equitable health care, and we know of these social determinants of health, we know that health literacy…we know that all of these things are barriers, then why aren't we creating roles that help address those barriers?

But everybody…I think another fallacy is that they believe that, “Oh, well that, the nurse should've been doing that,” or, “the case manager on the floor should have caught that.” But they don't catch it because they don't have the cultural competency. Maybe they haven't...maybe it's not the same social worker who went up. It's not the same case manager. Or the case managers that I've seen, they come in and want to make sure, “Do you have a pharmacy?” and “Do you have a primary clinic to follow up with afterward?” If it's a kid that has home equipment and home health care nurses, they'll help set all that up. But if it's a case like this one, where there wasn't...she just came in and I was there when she came in. All she wanted to know was, “Oh, do they have a pharmacy set up? And do they have a health care? Home health care clinic?” That was it. And she was out of the room.

And so, that's...I see it as complementary to all those roles. I see someone working with the social worker, working with the nurse, working with the providers to make sure they're not falling through the cracks. I don't see it as doing their role, but that's the belief and the fear that some have that, “Oh, that person will end up doing what the nurse should be doing” or whatever. But I see it as complementary and as part of the team, a whole team that is ensuring that these things don't fall through the cracks.

D: Wow. Alright, so I want to be respectful of your time, so I just want to ask one more question. So, the LEP advocate is currently in effect in the hematology and oncology clinic. Where else should it be in effect? Where would it be most important to implement this in other places? And then, is there anywhere where it wouldn't necessarily be needed?

P1: Well you're talking to a very biased person. So, I feel it is needed all over the hospital. But I especially feel…that's why I started with the in-patient. I really feel it is needed on the in-patient floors because that's where I see so many needs not being met. And because I feel that our LEP families when they are in-patient are at a disadvantage. They are less likely to have conversation. They're more likely to feel isolated, to not understand the whole in-patient process, and not to understand who are all these people coming in and out of my room. They're less likely to know what medications are being administered to their child, when are they being administered, and why are they getting them. Because they are not having that conversation, you know. They're not having the informal or the formal conversations that those of us who can speak the language or have a health literacy education and advocate for our children when they're in-patient can ask those questions. I see that they don't. And so, I see a lot of those needs going unmet in the in-patient.

I also believe that specialty clinics…every specialty clinic should have this. It's hard to justify if you don't have a high LEP population, perhaps, in those clinics. But I had a case with a diabetes patient where there's...they came into the diabetes clinic and this child's blood sugar was off the charts. And they were supposed to have done follow up and they weren't do...they didn't. And I thought, oh my gosh, they couldn't...and their mom didn't understand all of the...how to…you know, she just needed so much more education and help to understand and navigate the whole diabetes, you know, process, treatment and follow-up and all of that. So, I do believe that specialty clinics.

We do have these care coordinators in our ambulatory...it's only in our peds clinic now. And they have certain criteria. It has to be kids with complex medical needs. And I do feel like there's families who might not fall into that category of complex medical needs. A lot of specialty type of appointments…and yet they could use advocates, but they don't, they don't qualify for that case or care coordinator role. So, we do have a care coordinator role that does meet that need for the families that have their real complex healthcare needs.

But I think of specialty clinics, I think of...And I don't know the role has to always be advocate, I just think we need more, call it what you want, community health care workers, patient navigators, educators. I even see a need for that in the emergency room, to help educate and help families understand when and when not to use the emergency room. Or, you know, how...just even...so, I see a need for it maybe not all to the extent to a role like [Participante 2], maybe not that involved, but some type of education patient navigating advocating role. I see a need in almost every area.

D: Awesome. Well this has been very helpful. Thank you so much for your time. Do you mind if I reach out if I have any follow up questions?

P1: Oh not at all, not at all. I am for any little grains of sand that we can add to, you know, to educate and to advocate and to just start the conversation and engage people on how…on these kind of needs. And it's interesting because I was at a...last year…was it last year or the year before?...At the International Medical Interpreters Association conference. And it was interesting to me that a lot of, there was a lot of talk about these added roles that I think we're getting to a point, I hope, that we're realizing that it's just not the communication. That there's always other barriers and that it's requiring these additional roles. And in that conference that was talked about a lot and I thought that was really interesting. Because I think if we, maybe we're getting there, like it took us a long time to get to the understanding the need for interpretation all the time. And we still battle that, believe me. We're still battling training people on why it's so important to have an interpreter, not use family members, all these different things. But, maybe we're starting to move into understanding more the need for these, you know, added roles. Yeah. So, good for you that you chose this as a topic.

D: Yeah, I mean, I am a Hispanic Studies major, Premed, and I think that it's something that is a huge issue. And seeing [Participante 2]'s role and hearing about how that has changed the clinic was inspiring to me and I think that's something that we need to be implementing across the [hospital] and across all of our hospitals and healthcare systems.

P1: Right, and it's important to realize too, I think, that that type of role is needed not just for LEP. As you know [hospital] has a community...Native American community liaison, and [he or she] has been tremendous in...And I really believe that [he or she] is an advocate too. And [he or she] is helping to raise the level of cultural competency in our hospital around working with Native American populations. And you know as well that we have the Sickle Cell advocate role now in hematology. Were you aware of that?

D: I wasn't

P1: Yeah, so those aren't language-based. They more are ethnic, cultural-based advocate kind of roles, or community liaison roles. And that's because we've seen such…like with the Sickle Cell, we've seen such like an issue of disparity in even the treatment of Sickle Cell patients, which are primarily African American. But we've, you know, created that advocate role for Sickle Cell, for

African Americans. So, I think it's important to note too that it's beyond just the limited English proficient, the need for minority or disenfranchised communities. Which, I hate to use minority anymore because they're coming the majority in our healthcare facilities. Especially in urban, you know, pockets or areas. So, you know, that's an important…I think, you know, thing to acknowledge as well, that we see the need beyond just the language groups.

D: Well thank you so much for your time.

P1: You're welcome. Send us your final paper!

D: Okay, it'll be in Spanish, so that's exciting.

P1: Hay, ¡Qué bien!

D: Sí, sí, have a great rest of your day!

Apéndice B

Entrevista anónima con un intérprete y defensor de pacientes con dominio limitado del inglés
Entrevistador: Alexandria Daggett
Método: Llamada por teléfono
16 noviembre 2017

Daggett: Thank you so much again for agreeing to talk with me.

Participante 2: Of course.

D: It's very helpful. So first off, let's start with...Can you describe your position? And then, well I suppose before that even, what certifications or titles do you have?

P2: Sure. So, I guess I can start with my educational background and certifications or titles. The title is Limited English Proficiency Patient Family Advocate, so LEP for short. And I got my bachelor's in Spanish language and literature and a minor in ethnic studies, which I think is worth mentioning because I think that that kind of world view kind of shifted me a bit, and made…it's quite important. Having that foundation is quite important for the work that I do.

I hold...the certification for medical interpreters is fairly new. I think it has only been around for maybe four or five years and I've been here at [hospital] interpreting for almost 14, and there have been other, you know, other interpreters have been around much longer. So really, it's a really new certification program. I did get certified in 2015, I believe, so I hold what's called a CMI, which is just Certified Medical Interpreter, and there are a couple different certifying bodies, but that's the one that I went through. And that is crucial to this role as well.

So, the LEP patient family advocate role is really kind of an integration of three roles, I would say. And they're separate, but they're also mutually beneficial while we're working over long periods of time with patients. And I guess I'd point out right upfront too, before I describe each of those roles, that there has...like with any dual or multi-role position, you have to be very transparent to avoid...like which role am I doing right now?...to avoid confusion that could affect interactions either with the advocate or with the team or confused staff. Families could expect that every interpreter they have is going to take on these other tasks as well, even though it's not listed in their job description or their code of ethics really. And so, what this role does is take…take the medical interpreter and take that out of the title and place it as one of my three job descriptions, kind of roles.

And so the first, and I would go so far as to say a specialized medical interpreter, even though that doesn't really exist, per se, officially. You can't help but become specialized in something like oncology and blood disorders, having been immersed in it over years and years. And so, everything from the treatment protocols for oncology to all the different lab values that are relevant, medications that have two different names that, first off, should know by heart, so even if the team is saying the generic but the family knows it by the brand name, you kind of know what, you know, can resolve that confusion quite quickly. Research study consents and all the common tests and procedures that are associated with cancer and blood disorders. You just end up with a really unique kind of fluency in those concepts.

And really if you think about it, I've always thought about an interpreter and the field itself as…like if you have, like, an orthopedic surgeon, right, and they've studied a long time and specialized down to that, and yes they had general medicine at some point as an education, but they might be able to tell you about every single bone in the body, but they might not be as well-versed in autism, for example, right? So, if you think about an interpreter, the traditional role is kind of somehow expected to go from a trauma in the ED, to the Down's Syndrome clinic, to the heart clinic, to, you know, a surgery, to endocrine, to epilepsy, and somehow have all of that terminology filed away. And that's really daunting.

So, I'll be honest with you. I'm very confident in my interpreting skills, I'm certified, I know I do a good job. When I end up being sent randomly to help out, like in the cardiovascular unit, it's a struggle. It takes a lot of additional preparation and I have to really think for those terms because it's not something I use. So, that's just my little pitch for, first of all, for having medical interpreters be more specialized in the first place and they can give a better service.

But, aside from the fluency in the concepts and terminologies, it's a, kind of a fluency in the, in what it is for a family to have cancer and what their outlook is and what the situation...what the care is going to look like over time. Kind of the roller coaster that families go on. One thing that families have expressed in the past, kind of anecdotally, but, you know, in the very beginning families would come to a waiting room and there's an interpreter and they have to tell their story over again, you know. And so, the families I work with, being able to come in and see me, and I already know that their child has cancer. And I already know that...to what level they're struggling with that. And it is just a, kind of an additional quality and comfort for the family.

And then the second role is like a cultural liaison. And so, you know, there's no such thing as, like, an expert in the culture, right? I'm working with these families over a long period of time…I want to be very specific in that these are families with limited English proficiency, because obviously I am not working with families who speak English and are Latino, and their level of barrier both culturally and otherwise is very different.

So, I'd say that I've become very comfortable in my personal and professional life with the, kind of, you know, loosely said culture of limited English proficient Latin American immigrants in their...their journeys here, in healthcare, it’s kind of the different...the different things that can affect their care that I'll get into later as well.

So, in the role as a cultural liaison, I can personalize and give some guidance to the healthcare team in terms of little things about the culture or the specific family that we're dealing with that might, kind of, go over the head of someone who's thinking from their own dominant worldview.

And…and also having to do with, you know, alternative remedies that they have maybe expressed to me that they're looking at or things of that nature. And having that close contact with the families over time and having kind of a perspective of like a fly on the wall almost allows for, I think, a level of cultural mediation that is more specific to the family than is possible with a traditional interpreter role. Because we're talking about individual families. We're not talking about, “Oh, this family must think that because they're this,” right? And when I, when you're an interpreter and you're in these kinds of transient roles where you're coming in, meeting the family, interpreting for them, saying only what is said and then leaving, about the most cultural mediation you're really able to do, or cultural liaison work you're able to do is these very general things about general beliefs that some people have.

So if a...if a family...if I was interpreting for a family I didn't know in the traditional interpreting role and a family starts talking about, like, *mal de ojo*, or talking about, that, you know, that...that somebody looked at their child admiringly and they think that's why they're sick. There may be some degree of general knowledge that any interpreter should have, should be able to kind of guide that conversation in a way that the physician understands, that the provider understands, where they're coming from. But that's about to the extent that I feel like, without knowing the family and without knowing the specifics of the family over time…so getting to your point about continuity, it's really hard to mediate or be a liaison on a much deeper level than that.

So then, the third role is what I would call, like, a healthcare systems advocate or kind of has like the coordination aspect to it. So, our healthcare system is so fragmented, I think probably even for you and I for...to...as English-speaking, educated individuals to, you know, follow a path of referrals and understand billing and do all of those things is...it's a challenge. And so, for a family with the additional barriers, language being the first one, but other barriers as well, that's a real challenge.

And it's not just like, “Oh bummer, it's really hard for them to do it,” it's affecting outcomes. If you're not able to follow-up appropriately because of barriers that are placed in your path, not because of a lack of desire to follow-up. And likewise, with medication adherence. I always feel like no parent is trying to give their child medications wrong, right? So, it's a barrier that exists. It's not that this is a non-compliant population, or whatever. It's a barrier like this.

And so, within that, I can assist with coordination, both within the [hospital] system, but also externally across the continuum of care. And so, if we are, as part of the Neuro-Onc clinic, asking the families to have an eye exam yearly or more often, we don't have an eye specialist within [hospital]. And our interpreter services…and each interpreter, I think, follows or breaks this rule to their own extent, but we are not supposed to interpret over the phone for outside clinics, even if it is a [hospitals] patient. Because our expectation is that that other clinic should have interpreter services available. The problem is, big hospital systems tend to have interpreter services available. Smaller clinics might have interpreters offered for the appointment itself, but not over the phone for making appointments. And so, you get into this problem of being able to even take the step to follow-up. And, you know, a million other issues to that extent. And so, that...so that is, as far as appointment coordination-type things go.

And so, what I kind of do over time, not with an explicit evaluation or assessment, because I have the time to get to know the families. But also because I think that we should be using more, kind of universal precautions in terms of health literacy, and not assuming that everybody needs the extra help, but kind of making our systems work in a way that they would work for anyone, regardless of their level of education, regardless of their level of literacy or health literacy, regardless of their language, really, if possible. But, so, over time I kind of evaluate them for, you know, one thing could be the first consent they sign in my presence. Did they kind of scratch out their name in print? Or did they sign it and then print it underneath? That is one very small clue and then just getting to know the families and knowing what their...kind of just through small talk, also, which is also something that interpreters aren't really encouraged or allowed to do, but really becoming part of their team and building that rapport and trust have a lot to do with just listening to them and talking to them and sharing about myself as well. It's a very relational aspect.

And so, once I can kind of figure out who needs what and what can I offer to each of those families. So, the barriers and everything really depend on the family itself, obviously, just like culture does. Some need more, kind of, advocacy help, and others have quite high self-advocacy skills and really just need the language assistance. So I, what I do in terms of that, is collaborate with nursing and with providers and social workers and whoever else is here to make sure that the education materials that we're providing are appropriate linguistically and culturally and really, more than anything, from the health literacy perspective.

And then...and then also coming up with interventions that might be more sensitive to individual families' needs, such as, like, a color-coded medication system or even just a word-based calendar system for the folks that might have a higher literacy level but still...it's...it's hard to organize the ridiculous amount of medications that patients are going home on with this, with these conditions. But also in other areas, like, you know, post-transplant, or cardio, any of those areas have kids that are on a ton of medications that need to be given correctly.

And then, also, kind of as a function of the cultural liaison as well, though it's not culture in the traditional sense of culture, but in terms of the barriers, kind of helping identify cultural and situational barriers that might affect adherence to the education, adherence to treatment schedules and getting here, work schedules, and, you know, things of that nature and then helping the healthcare team and the families trying to overcome those just to be able to get to the best care that they can. That was a super long answer to your question, half hour here to that question, but I have a feeling it touched on a couple of the other questions.

D: Yeah, it definitely did. Very cool. So yeah, you, I think, covered pretty much the next question. So how does your position differ from a staff interpreter? A lot with your ability to interact with patients and go that extra step and go a little deeper. Is there anything more you wanted to say on that one?

P2: Yeah, I think, also just the extent to which my position is integrated into the care team. I'm housed as one of the primary members of their team and I'm consulted as such. I'm constantly astonished at the amount of, kind of, esteem and respect that I'm given from people with titles much larger than mine, especially in the context of a hierarchy of the healthcare system, right?

So, I think, even if you're a staff interpreter…because your question says staff interpreter, there are also agency interpreters which are even, I think, you know, on a different level in the sense that maybe the provider and the family have never even seen them before. Whereas staff interpreters, people are coming here often, the providers know them, et cetera, so that's kind of an in between for me. But I still think a lot of times they're seen as kind of this peripheral service that I have to go grab in order to do my work. And talking from the provider perspective, right, as opposed to, like, “When are we going to go see this patient?” And, “How should we approach this?” Right?

So, I feel like it's important to point out the level of trust and rapport and mutual respect that comes along with being integrated into a team of providers as opposed to this team of interpreters that then is shuffled off individually to different appointments. And then, yeah, I touched on a little bit, like just the constraints of, kind of the hospital rules itself, so it's not interpreting for outside clinics and...what else...there's probably something else and if I think of it I'll come back to it.

D: Okay, sounds good. Alright, so you had mentioned then, that with your families, each family is facing a different barrier and has different levels of need, but what are some of the main barriers that you see with these LEP patients and their families?

P2: So, I'm gonna talk aside from language because that's kind of the most obvious one and the one that the traditional interpreting role is meant to...to take care of. But I will say that for families that are in-patient for a long time, for example, I have a patient who's recently diagnosed who is going to be here for probably the better part of six months, but more like three or four weeks at a time, go home for a week, come back kind of thing. And a barrier there that would be that we can't be...no one can be by their side 24 hours a day. So, even just the little things, like I got a call from her bedside nurse yesterday saying, “Do you have time to come up here real quick? Because I just walked into the room and mom is on the couch crying and if this were an English-speaking patient, I would be able to talk to her and comfort her and I can't do that. And I don't know how to do that.” And that's the kind of thing that it's not that a staff interpreter couldn't do that, but they're often seen...because they're not seen as much as part of the team, I feel like it's less likely that they would be called for something like that. If that makes sense. Unfortunately, because it would be great if that were the case. But also consider the nurse's next best option was getting a phone interpreter, which is great, but it's also like you're trying to comfort a mom through an interpreter on the phone, which is just, like, uncomfortable.

So, the main barrier I would say are...I think there is one main barrier that a good majority of my patients face that kind of informs a lot of their other barriers and that's documentation status. So, it's not across the board, but a good many of the patients that I see and that we see here at [hospital] who are limited English proficient and Latino are undocumented. And, the kinds of things that that affects are really...it exacerbates all the things that we consider as a social determinant of health, right?

So, if you had trouble as a....documented or not, getting a job because of your level of education or getting a job that provides enough for your family, then throw on top of that that you're working kind of in the shadows, or you're using a name that's not yours, or you're getting paid cash, or your employer knows to some extent what your status is and knows that they would have no problem cutting off your employment if they needed and wouldn't face much consequence for it if you were to miss, right? So, there's kind of the job stability that comes with that.

There's housing instability that comes with that a lot of times. Once people get into a good housing situation they don't tend to want to move around a lot because in order to rent, you need to have a background checks a lot of times. To have a background check, you need a Social Security number. And so, it's hard to get into a lot of housing that isn't kind of slum lords, to be honest. Or, like, subletting a room from someone else who's renting an apartment. And so, most of the families, both that I work with, but also that I know in my personal life through my [spouse] and [his or her] family and friends, it has to be either a really understanding landlord that's willing to forego that kind of stuff, or, I don't know, this just came a little off topic, but the main point is just the instability of housing, and...and sometimes the quality of housing that folks are able to obtain.

The...I...I would also say that insurance is a barrier for undocumented folks. A lot of times the kids were born here and have insurance but parents' inability to access medical care for themselves is difficult too. They may need psychological services because of what they're going through and their child's diagnosis. They may need it because of other issues going on in their life and they are unable to kind of reach that optimal health for themselves because of their barriers and then...so that...that obviously trickles down as well. Let's see...I'm going to pull something up because I am drawing a little bit of a blank and there are so many more. But, I would...And cut me off whenever you need to, it's 9 o'clock. We could pick back up, I know I've probably talked way more than you were probably hoping for.

D: No worries.

P2: One second...Okay, so some other things are obviously cultural differences and misunderstandings. I hate to call those barriers, I think it's more a barrier to communication than it is some kind of deficit that they have. So that's an important barrier. That, again, I feel like, this position is able to help overcome a little more because I get to know the particular family's culture, not just the overall assumptions about it.

Level of education...I...you know, a lot of things are written, in English at least, around, they're recommended to be written around a 6th to 8th grade, and that includes newspapers and things like that even, are supposed to be written around a 6th to 8th grade reading level. A lot of the folks that I work with have come from Mexico or from Ecuador and just come because of a lack of opportunity and really to get their kids an education and everything that they never were able to get, so I do have a couple families who have studied through high school and a bit of college in Mexico, or whatever they're coming from before coming here, but the great majority, I would say, has around...even anywhere from, like, 5th and 6th grade is a pretty standard answer when we start talking about that if it ever comes up. And sometimes it does on the questionnaires for different studies and sometimes just in talking about life and what life was like back home and things like that. So, thinking about a 6th to 8th grade reading level, it's really meant for people who probably graduated high school but are reading at that level, it's not, especially in our country where you can't really stop school at 6th grade, right?

So, that can be a big barrier as well as well as numeracy, which is, you know, using numbers, and that becomes really important with dosing and things like that. In terms of if you are supposed to take 75 milligrams and the tablets you're giving them are 150 milligrams, that's super intuitive to you and I that you would take half of a tablet, but how intuitive is it to someone with limited numeracy skills? That, or, you know, if it's...the simple calculations that there are still patients that are being told their liquid doses in milligrams. “Oh, you're supposed to give 45 milligrams of this medication” and it's a 100 milligrams per 5 milliliters. “Okay, go home and give that.” You know what I mean? Like, add those calculations and then even just things like decimals.

I've had a family once, we were weaning from medication, tapering the dose down, and it went from 0.3 to 0.15 and that was confusing to the mom when she got home she called and told me that her syringe didn't go up to 15. And so, she was picturing, she wasn't familiar with like the trailing 0 and the fact that 0.3 is actually 0.30. And so, “I was giving three before and now I'm supposed to give 15 and I don't have a syringe that goes up that high, mine goes up to five and I'm supposed to give three of those syringes.” And in that particular case, once I kind of explained it to her, I think, I think it might have just been a momentary lapse because she was like, oh my gosh, duh, right?. But I think that that was an illustrative example for me because I was like, “Woah, that is something that we take for granted that we know from our schooling, not from some intuitive knowledge,” right?

Another hardship can play in in many many ways, but part of it can even be working with coordination of appointments. And that's something that is not just because the interpreter can't do it, the traditional interpreter, but because our healthcare system is not set up in a way that makes this easy. I could have a patient who needs...has physical therapy appointments every Thursday at such and such a time and needs to come in for a consult in our same building but with a different provider, sometime in the next month and there isn't much of a way for a family to coordinate that for it to be on the same day that they're already coming. Actually, that's a bad example because in that case they do know their upcoming appointments and can say “I am here on Thursday, can I have an appointment on a Thursday?” But it happens often where they'll need two appointments where they're due for a follow-up here in oncology and also a follow-up with endocrine. And maybe they're supposed to come here in the last week in November and to endocrine in the first half of December, and there's no real way to get both of those scheduling lines on the phone and coordinate something for the same day.

And the reason I'm bringing this up under economic hardship is because folks cannot miss work. And if they do, they're not getting paid. And so, even if their job is secure and they're not going to get fired because they missed work too many times for appointments, they're still not getting paid for those missed days. And when your economic situation is precarious, every day of wages is super important.

And a couple of other things I have from a presentation I have given in the past about my role and about this are prior experiences with racism. Those are all things that come...that families are coming to appointments with beyond just the visible barrier or the audible barrier of lack of English proficiency. And, so, yeah...that's I think, that's probably the majority of the barriers that I can think of at this point.

D: Okay, awesome. Thank you. Let's, okay, I'll just keep going in order. What does your position...or how does your position relate to the continuity of care for Latino patients and their families?

P2: This is a really big one. So, you know, beyond the obvious, trust that's built. The same kind of trust that's built with the primary nurse when you're in the hospital for a long time and you have the same nurse for several days in a row. And it can be similar to that, but more than that, even if you have a primary oncologist, a primary nurse practitioner, a primary nurse, in our program the schedules are such that you're not going to always see that person. And so...and then inevitably there is little bit of what this person said versus what this person said. Or even with just the amount of detailed information that is being passed back and forth in every single visit.

Even if, you know...it's often the case that I'm the most, what's the word I'm looking for, I'm the most constant member of their team. I am the, kind of, the...this role is what binds, kind of, the rest of the team together, around these patients at least. I don't mean to make it sound that I'm the most important piece of the team, but I am the one who is most constantly with them. I'm with them not just from one chemo visit to the next, but also for physical therapy needs, for their scans, and in-patient and out-patient, where there is usually quite fragmented. In the in-patient situation, I am there if the ENT comes and consults. I'm there, you know, for each piece of that and then over time as well.

So, the continuity of care has a lot to do, I would say, with trust and respect and relationship-building that I think that, you know, unfortunately, the traditional interpreter role and the way that most places are set up, you could technically...you could conceivably be in an in-patient situation for a week and have ten different interpreters during that time. And that, as good an interpreter as you can be, that presence is just an added factor into the, kind of, dynamic of that care, if that makes sense.

And so, it's...and interpreters...I want to make sure that it comes across in my answers too that interpreting is a very, very, very important and dignified profession. And so, this role is not meant to like, cut down that, but it's to ask the question if that's enough. If the constraints of that role are really serving the...the different barriers outside of language that a lot of our patients face.

So, to go back to the continuity thing, there are, I think, safety issues that come along with it as well. I can't tell you the number of times that because it is me every time, I have caught things that obviously were misunderstood in the prior appointment, or caught doses, or caught, “That is not what the other doctor said. And I'm confused so the family, must be really confused.” Do you know what I mean? So, kind of having that fly on the wall to see everything that's going on and trying to make sure that it's all cohesive and that there is a continuity. I feel like I'm missing something there, but I'll come back to it again if I think of it.

D: Okay, alright, I think that you've basically answered the next question on the benefits of having a position like yours in the clinic. So, we've talked a little bit about the barriers that traditional interpreters face in their ability to provide care across different barriers and beyond just the language. Are there any instances where your position is not sufficient to

ensure that continuity of care? And where your abilities are not able to help these families with their needs?

P2: I...I don't feel like I'm ever, like, profesionally or institutionally held back from helping to whatever degree I need to help. Does that make sense? So, it's not that the role is so perfect that I can always achieve continuity of care, but rather, I can flex with what's needed in the moment a lot more. Whereas...so, you know...I...it's a lot of thinking on my feet and it's a lot of coming up with a solution right now for this family in front of me to be able to go home and take these ten medications correctly, right? And luckily over the years I've been here, I've come up with a system so that I'm not reinventing the wheel every time that I'm faced with that or the family is faced with that.

But...so, you know...is the continuity always perfect? No. But I do have the ability to, because of the nature of my role, if something seems unclear or...because I...How do I describe this? I have the working relationship with both the team and the family that I can just call and check in. You know, I can just call the family and say, “Hey, how is that going?” And like, “How is that thing we talked about in the clinic, how is that going?” You know, “Last time you were here, you had a ton of nausea and we put you on this, this and this. Like, is that helping?” So that kind of thing that in the traditional set-up I think you would be kind of stuck just appointment to appointment, and this is continuity in the sense of the family can reach out directly to me and have someone who speaks Spanish and understands their disease and understands their treatment and understands their situation and knows their family answer the phone. Whereas, you know, in another situation...I guess that's enough for that piece. I don't know where I was going with that next part.

But, so, I...there always are going to be incidents that go beyond what I can help ameliorate, right? Like it's not perfect, but I feel like at least me and this role, within the leadership of this clinic and, you know, so the people I directly report to and the physicians I work with and whatnot, it's such a team approach and I have a level of respect with the team and trust from them, that I am transparent with things and work closely with whoever else in the traditional team needs to be involved. But I'm able to really think on my feet and do whatever is possible to ensure the continuity of care. I'm trying to think of an example that illustrates that well. I'll think of one. I keep saying that, but I will.

D: No problem at all. Why is your position so important, specifically in the Hematology and Oncology clinic and then on the [in-patient] floor?

P2: So, I can give a specific example just of...just to give an idea of how...I mean, the simple answer is because, especially the oncology diagnoses ,are life-threatening and complex. And so, having patients and families that are already facing enormous barriers, probably even just to get good primary care, are now in a situation where the...any misunderstanding could be, like, devastating.

So, I can give an example of...so I mentioned that I've started a system of color-coded calendars, which is currently in the process of hopefully being a little more streamlined so that other folks besides myself can do something similar. But, I had a patient…the way that those calendars came up was I had a patient a long time ago who was diagnosed with leukemia. He was three and his mother had one of the first things that she disclosed to us was that she had never had the opportunity to go to school a single day in her life. She couldn't recognize letters necessarily, other than the ones she used to write her name, or at least she didn't feel comfortable doing so. And even, like, over the phone, if I were to dictate a phone number to her, instead of the typical way in Spanish, which would be to break it up into double digit numbers, I would be like, digit by digit with a significant pause after each one for her to write it down. She...they lived a couple hours away from the hospital. Didn't have a reliable source of transportation. And a host of other barriers.

But specifically related to this to this question, the type of cancer that the child had was going to require treatment that is very long and three and a half years and the last approximately two years would be...or two and a half years would be a really complicated medication regimen that is given entirely at home. And there actually was a...and then they'd come to clinic once a month to get some IV chemo and for check-up and sometimes a spinal tap.

But moving forward, and then I'll go back again to this, there was a study recently of this that showed that one of those drugs that fits into that complex routine regimen that I was just describing that this mom was going to have to administer at home, one of the medicines is called 6-MP and it was found that if you...this is something that you take for two or three years every night...if you miss an average of one dose per week, your risk for relapse goes up 400%, four-fold. And when you think about, like a ten-day course of antibiotics, first off, you know missing one dose a week, or in a two week course of antibiotics, that's a pretty low compliance percentage, right? Like out of fourteen doses, you miss two. But if you look at it over a long period of time that folks are taking it, one missed dose per week still calculates to 95% compliance. And so, you know, you could be 95% compliant and still have a four-fold increased risk of relapse.

And so, keeping that in mind, this mom was going to need to...she was, I mean, really going to be largely responsible for the success or not of her son's treatment based on these medications she was going to need to give at home accurately. And the regimen is something that I have memorized because I have given a lot of presentations to show this very need and the danger or not having this system in place that make this doable for folks coming from all different levels of barrier and education and language, et cetera. So, it's an antibiotic every Monday and Tuesday for the duration of the treatment. A steroid the first five days of every 28-day cycle, two times a day with food and with an antacid. And it's a one chemotherapy med is given one day a week, so let's say every Wednesday, seven pills, all at the same time. So once a week, except the week that you have a spinal tap. And then another chemotherapy which is the one that I was just describing in the study that needs to be taken every single day. The old recommendation that we'd been doing for years and years that just actually got lifted so that it makes it a little more simple, but before you had to take it at bedtime on an empty stomach without milk-product. And the way that the dosing goes, it would often be, like, one pill Monday, Tuesday and Wednesday, and one and a half pills Thursday through Sunday.

And so that...and that's only the core medications of that regimen. It doesn't include any other things that folks might be taking for symptom control for nausea, which actually is not that bad in that phase of treatment, but still, for constipation, for pain, for any other thing, or if the...an antibiotic course, or if the kid is on asthma meds on top of it all, or allergy, or whatever the case may be. And it is just a really extraordinary burden for families that aren't able to read the medication label. And so actually that particular family, with it being that many years ago, did need to follow the, you know, at that time the empty stomach thing, the other ones with food, the other ones five days a week but not...five days, the other ones only Mondays and Tuesdays, et cetera.

So, I think that is one example of many, but kind of sums up the importance in a specialty that really is life or death. And when the, you know, our hospital and other hospitals, I think especially pediatric, really need to make an incredible effort to help them be successful. It is not a lack of will or a lack of effort to come up with solutions that work for everything, I think sometimes it’s a lack of exposure. It's very surprising for people to know that folks have only studied through 5th grade. It's very surprising to...for people to grasp that the table that they've, the chart that they've been using with the days of the week down the side and the medications along the top and the doses in like a nursing chart format is actually a really high level literacy skill, or at least way higher or that it's a big cognitive burden for folks. And that's not even just for limited English proficient, or for immigrant populations, that across the board is, I think...so, I think it's, you know what I mean?

It's kind of, yeah, in all of this I've become much more interested in health literacy as kind of a big part of the solution for everyone, not just the families that I've worked with, but in working with these families that are kind of at the intersection of all these different barriers, and then on top of it with a cancer diagnosis. For so many years I feel like it has almost been, like, in some ways, my own little lab. That sounds awful, but it's like, if you can solve for the patient that is at the intersection of all of these barriers and help them achieve success, then have you kind of solved for everybody? Do you know what I'm saying? And there are things that can be carried over from what I've learned in working with and helping the population that faces so many barriers have success in our healthcare system and the way that the complicated nature of their treatments and et cetera.

D: Awesome. Okay, final question and then I'll let you go. Are there other clinics or areas of the hospital that would benefit from having an LEP advocate on staff? And then which do you think would need it most? Which would need it least?

P2: I think that there definitely are, I think there are barriers to achieving that, but the areas I think would be great are really anything that is chronic condition or that requires a very long in-patient stay that is going to require...So, I'm thinking even of things like neonatal intensive care unit. The amount of specialists rounding, the amount of things that could be going on, the amount of follow-up that is needed, I think could benefit from something like that. And just the trust that could be built with those families that are there for so long.

I think things like diabetes and endocrine, partially because of how complex those concepts are as well. And the extent to which, especially in diabetes, the families play a role at home in overcoming or in improving outcomes for that. So, having someone with similar qualities to my role would be able to serve as that member of that team I think would be really helpful.

Let's see, and I think, which would need it the least? That's hard. I think that probably things like primary care, just because although I do think within primary care, we have a special needs clinic for example, and I think that that would actually be the number one on my list of who would need it the most. Because I'm also...so, you know, we see...our clinic for oncology sees, we strive to see our patients and families as like we are not just treating this disease and this child, like we have the whole family and every aspect of your life that it impacts in mind as well. And so, apart from being able to coordinate outside clinic appointments and get things on the same day that wouldn't have otherwise been on the same day, I'm also able to help with the families and their access to language access or otherwise to call the county, to speak with HR at their place of employment, to make sure that their communication at school is going okay with the teachers, you know what I mean? So I can step kind of outside of that and I think that for special education that would...sorry, not special education, special needs that would be incredibly important as well. Things like, you know, having a clear idea of all the different specialists that are seeing your child, who they are, what their name is, what they're seeing your child for, what the follow-up schedule is, those kind of things I think would be incredibly helpful.

And then, you could say, “Well, that exists in roles like care coordination and things like that,” but this role's uniqueness I think comes from the fact that you are also their primary interpreter and so you're in their room interpreting and have that first-hand knowledge of why that appointment is needed in the first place. And so that just kind of, that goes back to the continuity as well, I guess. And I think it's important, your question about how does it differ from a staff interpreter, but also how does it differ from a community health worker? How does it differ from a care coordinator? How does it differ...right? It's that integration of the interpreter who is present for the actual visits as well.

D: Okay, I just thought of one final question and then I'll let you be on your way. Do you know, does this position exist in other hospitals, or does it have a different name, or are you guys one of the first to develop this?

P2: We have not found anyone else that has this particular position. I mean, we came up with it and named it and made the job description so no one else would have it exactly this way. But we have looked to see if there's something similar anywhere else and it's hard to find. I mean, my position has been around for so long and other folks don't know about it either, you know?

I'm looking something up right now because there is something that's been around for a long time that my role was not modeled after because I didn't know about it, but I did come in contact with the person who runs it many years ago. It's at Harborview Medical Center in Seattle and...I'm going to look up right now, what were they called? It's called CHC and it stands for Community House Calls. And I'm seeing something online on Ethnomed right now if you just google that, you'll see it. But, so their...so I do know of that, and interestingly I haven't really looked back into that over the years to see how it's evolved. They were set up a little differently, I believe it's with an adult program, but they describe it as like a bilingual, bicultural caseworker cultural mediator. Provide the same language services and serve as liaisons to their respective communities. So that would be something, I think interesting to look into, I don't know...

You know the big issue for all of these things, it would be interesting to find out how they're funded, but is funding. So, would it be great to have this position in the other areas? Absolutely, but I'm funded through philanthropic dollars that, so it's not a grant, it's not the hospital actually paying me, it's a fund that is called [fund name] that is through our foundation and through the hospital, but that all of the money in that fund comes from donors and fundraising events.

And so, a big thing is budget. A big thing, especially now with every hospital system trying to pare down everything because they're nervous about ACA going away, or for whatever other reason. It's really difficult to get something approved that provides a tremendous amount of value but how to quantify that is difficult. And it's an upfront investment in, that, you know what I mean? So, we are working on some measures, doing some kind of chart digging to take a look at different measures and see if we can now, after this many years, go back and say, "Look, with this position, X, Y, Z about no-show rates. X, Y, Z about, like, follow-up, do our patients still come for follow-up as compared to other populations or as compared to similar populations in other areas of the country." Or whatever the case may be but just trying to show something significant other than just the gushing of all of the providers and families that I work with that I think would anecdotally have a lot to say about the benefits, but really showing that in a way that then an organization is going to take it on budget-wise as well is tough.

D: Alright. Well thank you very much for all of this information. It'll be very helpful.

P2: Awesome.

D: And [Participante 1] had asked that I forward her the finished product, so if you would like, I could do the same.

P2: I would love that!

D: And then, is it alright if I contact you with follow-up questions?

P2: Absolutely.

D: Well thank you so much again for your time.

P2: Good luck! I'm excited to see what you come up with.

Apéndice C

Entrevista anónima con un CNP (Una practicante de enfermería certificada)
Entrevistador: Alexandria Daggett
Método: Correo electrónico
21 noviembre 2017

Daggett: What are some of the barriers that you face as a provider when providing care to families with limited English proficiency? Specifically, with Hispanic families?

Participante 3: We are very fortunate to have our own service line Hispanic LEP advocate who gets to know our families and makes herself available. Her position is valued and considered extremely vital to providing care.
One of the barriers is when she is not available. When rounding on the floor we are often seeing 6-10 patients. Timing the interpreter visit can be challenging if we have other priorities For example is the interpreter is scheduled to come at 1000am and we are busy with a sick patient or trying to discharge or admit a pt, this can be problematic for both the provider and the LEP interpreter. Another barrier is that usually the LEP interpreter comes once a day when in reality there can be many times during the day when we might need to communicate with the patient and family. I hear families report that is is difficult when they have a different interpreter every day as they value trust, relationships and consistency.

D: What are some of the barriers you see your LEP patients facing?

P3: Consistency of care as mentioned above. Not being able to develop relationships with the interpreter. Not having someone available if a crisis arises or a patient’s condition worsens. Some of our physician groups opt out of using an interpreter if they are rushed and have limited time.

D: How do you perceive the continuity of care given to your Latino patients and their families with an LEP in the clinic?

P3: It is wonderful. The relationships are strong and built on trust and consistency of care. For Hispanic families I truly believe that our LEP is the most valued member of the team able to communicate past cultural barriers. She has helped me understand different cultural values that affect behaviors. Just being able to help me understand the meaning of illness and wellness and the importance of family in the Hispanic culture has made me a better provider.

D: How does the care given now differ from before the LEP family and patient advocate position was added?

P3: Families are more willing to trust the decisions regarding treatment plans. They know they having an advocate looking out for their needs and interests and world view.

D: What gaps does an LEP advocate fill in the care equation?

P3: Trusting a different health care system, adherence to the treatment plans, understanding the treatment plans and the importance of certain aspects of care, for example taking oral chemo when they don’t feel sick.

D: Are there other clinics or areas of the hospital that would benefit from having an LEP on staff? Which would need this the most? Which would need this the least?

P3: Certainly the emergency room, the preop and post op areas, surgery. I think anywhere where a family and patient need to know what is happening and in area where informed consent takes place. All areas would benefit.

Apéndice D

Entrevista anónima con un oncólogo pediátrico
Entrevistador: Alexandria Daggett
Método: Llamada por teléfono
29 noviembre 2017

Daggett: What are some of the barriers that you, as a provider, face when providing care to families and patients with limited English proficiency, and specifically Hispanic or Latino families?

Participante 4: In general, not when they have the opportunity to have [Participante 2] there, right?

D: Correct.

P4: Okay. So, I think that it's incredibly complicated to explain a diagnosis of cancer and to explain a treatment plan to patients and families that are proficient in English. And so, because it's such a unique sub-specialty, it's really hard to just use general interpreters to communicate, you know, word for word. So, I would say, the skill set of the interpreter is tremendously variable and I think can directly impact, you know, patient safety for example, if you are trying to explain chemotherapy and them being compliant with chemotherapy. So, I think the biggest challenge for me in my field is that because it is such a specialized part of medicine, that just being proficient as an interpreter, word for word interpreting, is not adequate for our patient population.

D: What are some of the barriers that you see the limited English proficiency patients and families coming in with, in addition to language?

P4: Transportation. Poverty. The ability to, you know, reliably have transportation to and from medical appointments. Sometimes the difficulty with getting care for their other children, so oftentimes needing to bring, you know, other young children along with and try to keep them entertained and fed. Yeah, I think that those are probably the biggest things.

D: So how did you perceive the ability to give continuous care to Latinos before the LEP position was implemented? And then how do you perceive continuity of care in the clinic now that it is implemented?

P4: It's a night and day difference. So, when I first started here, which was before we had [Participante 2]'s position, it would just be, you know, whatever interpreter was available that day. So there was not consistent continuity. There was not consistent pediatric oncology knowledge among the interpreters. It was more, you could almost think of it more as shift work, whereas now, since we have had [Participante 2], you know, I mean, we kind of joke sometimes that I think our Spanish-speaking, primarily Spanish-speaking families may get better care even than our English proficient families because [he or she] has done such an amazing job providing continuity, providing patients and families with things like color-coded symbols on calendars or bottles for those that can't read English. [He or she] helps coordinate their appointments in our department and then also throughout the hospital. [He or she] helps coordinate their transportation. And [he or she]...I call [him or her], I think a life-coordinator is probably a better description of [his or her] position and certainly way above and beyond the simple interpreter.

D: Are there other case coordinators in the Hematology/Oncology clinic?

P4: We did have a temporary pilot with a Hmong family liaison that...it was similar to [Participante 2]'s position. We didn't have as great of an experience with just how [he or she] didn't work full time and our Hmong population is much less, so I think there also wasn't a lot of work to keep [him or her] busy for a full-time position, so that no longer exists.

D: What is [Participante 2] able to offer that is above and beyond, you sort of touched on this, but above and beyond interpreters and does [he or she] cross into the realm of social work at all do you think?

P4: [He or she] kind of does if you think about it from a, you know, helping with coordination of appointments and coordination of transportation. That is a little bit more kind of what you would expect a social worker as opposed to an interpreter. But I know [he or she] works very closely with our social workers. So, every patient has a social worker assigned to them as well.

D: One part of my research, I am interested in seeing where else could we use this in our healthcare system? And so [Participante 2] works also on the [in-patient] floor, right?

P4: Yes. That's basically our patient population. [He or she] will either be with them here in clinic or [he or she] will be with them on the [in-patient] floor.

D: Okay. So, with your experience with [Participante2]'s role, where else do you think someone like [him or her] could be implemented in the healthcare system? Or should be implemented?

P4: Well, it would be really ideal if you had unlimited resources to have a position like [his or hers], you know, in every clinic, in, you know, in every in-patient care area. You know, I'm thinking even for all the other supportive care services that patients need, so like physical rehabilitation centers, you know, you could conceptualize if you had unlimited resources, in every contact point with the healthcare system a position like [his or hers] would be valuable.

D: So, let's shift a little bit and say we don't have unlimited resources because that's very much the reality. Where do you think the priorities should be for adding extra support for Spanish-speaking patients? Where do you think the top, let's say, top three clinics or specialties or locations we should add those, and then maybe the bottom three that need it a little less than others?

P4: Well, I guess, I would say primary care is huge because the more preventative and primary care access patients have, hopefully will prevent acute care incidents.

I would also think that the next most important, in my mind, would be anything life-threatening. So, the emergency department, the critical care units, you know, so NICU, PICU, I think those would be the most important.

I can't really think of an area where it wouldn't be important, because I mean you can use any example. You could say, “Well, how about an asthma clinic?” Yep, in an asthma clinic, if you don't understand well what your asthma care plan is, you could become critically ill and die from an asthma exacerbation. You know? Endocrine clinic they're dealing with diabetics. That's also life-threatening and incredibly important that you have a clear understanding of your care plan.

But if you had to prioritize, I guess my first would be primary care because it's preventative, and then next would be any sort of acute, life-threatening areas.

D: Alright, one other question. How does the relationship you're able to build with your patient differ when you have [Participante 2] in the room or when you have another interpreter in the room? Does that affect your relationship with the patient?

P4: Yes, it sort of does because I can't guarantee, particularly involving interactions that don't include [Participante 2], I've worked with [him or her] for years so I have a really good working relationship with [him or her] and I trust [him or her] and I trust that everything that I'm saying is going to be portrayed to the families. With other interpreters that I don't know, it can impact my relationship with patients and families because I don't always have the sense that they have a clear understanding of what I'm saying. So, I am not sure that they are relaying that information accurately to the patients and families.

D: Awesome. That's actually all the questions I have for you.

P4: That's great! You'll have to let us know when you have completed.

D: Yeah, I will certainly. I'll send you some summaries in English.

P4: That would be great!

D: Thank you so much for all of your help with this.

P4: Good luck with all of your finals!

Apéndice E

Entrevista anónima con un oncólogo pediátrico
Entrevistador: Alexandria Daggett
Método: Correo electrónico
15 diciembre 2017

Daggett: What are some of the barriers that you face as a provider when providing care to families with limited English proficiency? Specifically, with Hispanic families?

Participante 5: It depends on what language you are talking about it in out department.
There are no barriers with our Spanish speaking patients due to the work of [Participante 2] in our department.

Hmong, Karen and Somali are much more variable depending on who is translating for me. With these groups, there is variability in their medical knowledge, variability in their understanding of what I'm trying to convey, and sometimes I'm not sure if the families are understanding the nuances of their complex medical care.

D: What are some of the barriers you see your LEP patients facing?

P5: Often they, like non-LEP patients face financial challenges and barriers. Often the adults are working long hours, and have challenges getting to appointments. Their lives are often stressful, and they are often tired.

Again, I worry less about our Hispanic families. They trust [Participante 2], and the other people [he or she] has trained, so I know they can work with [him or her] to understand their complex care, details of their care, medications they need and details of their treatment.

There are unique issues with Hmong, Karen, Somali families. They may have older grandparents who don't believe in our medical care/recommendations. They may have women in charge at home, but without a voice in our clinic. They may have interpreters who don't understand the nuances of their care. They may have paternalistic male interpreters who have biases against the female mothers they are interpreting for/to. They may see a different interpreter every time they come to our clinic.

D: How do you perceive the continuity of care given to your Latino patients and their families with an LEP in the clinic?

P5: I think the care of our Latino patients is better than the care to our non-Latino patients. I have said that to [Participante 2] and [his or her group] for years. It's true. [Participante 2] is part of their team for their entire journey. If their disease returns, [he or she] is there. If the patient dies, [he or she] is there to support the family. If the patient is dying, [he or she] is there to translate this to the parents.

D: How does the care given now differ from before the LEP family and patient advocate position was added?

P5: I can't speak to that, because [Participante 2] has been part of the team since I've been here. I imagine it would be more like what it is like for the non-Latino families.

D: What gaps does an LEP patient family advocate fill in the care equation?

P5: In addition to translating the conversations, there is a small group of them. This group:

1. Understands leukemia care. [Participante 2] could give the new patient leukemia talk.
2. Understand the linear narrative. [Participante 2] has been with them on their journey since diagnosis. When the patient is dying or another family member is sick, or dad has lost his job, [he or she] knows this.
3. The families TRUST [him or her].
4. [He or she] is like a social worker, [he or she] champions their needs, [he or she] cares about them. I have worked with [him or her] to prevent deportation for family members.
5. [He or she] makes calendars, and writes their meds in a color-coded way so they know which drug, how often, and proper dosing.

D: Are there other clinics or areas of the hospital that would benefit from having an LEP on staff? Which would need this the most? Which would need this the least?

P5: PICU, CVCC and NICU would benefit. These are places where kids are really sick, and can be hospitalized for weeks to months, and may die.

Primary care clinics would benefit as well -- places where people establish relationships and come for years.

I think every department would benefit in having “their [Participante 2]”.

D: Has your ability to have a relationship with the patient and family changed since the implementation of the LEP advocate position? How?

P5: I give better care. [Participante 2] and I partner together. Families trust me more because of [him or her]. [Participante 2] makes sure they understand everything. [He or she] remains their constant advocate for the entire course of treatment.