Trabajo Fin de Grado
Grado en Trabajo Social

Comparación del papel del trabajador social en cuidados paliativos pediátricos en España y en EEUU

Comparación del abordaje, emociones y sentimientos en los trabajadores sociales y en las familias atendidas.

Alumna: María Sangrador Torres
Tutor: Carlos Hernández
10 de junio de 2022
Convocatoria extraordinaria

Índice

1. Introducción

Para poder entender los cuidados paliativos desde una perspectiva del trabajo social, es importante primero entender de qué se trata este término. Según la RAE, el término cuidados paliativos hace referencia al "conjunto coordinado de intervenciones del ámbito de la salud dirigido desde un enfoque integral a mejorar la calidad de vida de las personas enfermas y sus familias". (Real Academia Española, s. f., definición 1)

Los cuidados paliativos no pretenden alargar la vida del individuo innecesariamente, y tampoco hacerla más corta, simplemente es una forma de acompañar al enfermo o enferma durante el final de la vida, haciendo ésta más digna, disminuyendo el sufrimiento y controlando los síntomas que puedan surgir (E. Pérez Costa, D. Rodríguez Álvarez, M. García Boyano, I. Noriega Echevarría, 2018).

Según un informe del National Institute of Nursing Research (NINR), "los cuidados paliativos reconfortan a su hijo. Los cuidados paliativos pueden ayudar a los niños y los adolescentes que viven con diversas enfermedades graves, entre ellas trastornos genéticos, cáncer, trastornos neurológicos, afecciones cardíacas y pulmonares, y otras" (NINR, 2019).

Los cuidados paliativos son una realidad presente en miles de familias alrededor del mundo. Según la Organización Mundial de la Salud, "se estima que anualmente 40 millones de personas necesitan cuidados paliativos (...) y actualmente, a nivel mundial, tan solo un 14% de las personas que necesitan asistencia paliativa la reciben" (OMS, 2020).

Es por esto que los cuidados paliativos, y más concretamente en niños son considerados un campo de investigación importante, para poder así ampliar el conocimiento sobre los problemas que provocan esa gran laguna de tratamiento a tantas personas necesitadas en el mundo.

Según el documento del Ministerio de Sanidad, Servicios Sociales e Igualdad Cuidados Paliativos Pediátricos en el Sistema Nacional de Salud: Criterios de Atención en 2014, los cuidados paliativos pediátricos son "cuidados activos totales del cuerpo, la mente y el espíritu del niño incluyendo también el apoyo a la familia. Comienzan cuando se diagnostica una enfermedad amenazante para la vida y continúan independientemente de si el niño recibe o no tratamiento de la propia enfermedad". (Ministerio de Sanidad, 2014)

Los cuidados paliativos en personas mayores son una realidad, pero cada vez más lo es también en los niños. El hecho de que un niño tiene que ser tratado con cuidados paliativos tiene un impacto diferente que cuando lo tiene que hacer una persona mayor o adulta (no más fácil ni más difícil, sólo diferente). Es una alteración en el ciclo “natural” de la familia, en el que se preconcibe la idea de “los hijos ven morir y acompañan a sus padres”. En este caso, los roles cambian, y son los padres los que tienen que afrontar esta pérdida de un hijo o hija, o de verlos sufrir durante el proceso. Este es el motivo principal de interés en ahondar en el tema de los cuidados paliativos pediátricos, cómo afecta a la familia el hecho de estar en el momento de fallecimiento del hijo y los efectos en el funcionamiento de la familia en su conjunto. Comprender las intervenciones que reciben de los profesionales psicosociales, entre otras cosas, es esencial.

Así, es importante entender cuál es la diferencia que existe entre los cuidados paliativos pediátricos y los brindados a adultos. Según la fundación Get Palliative Care (2018), existen unas diferencias entre estos dos modelos de cuidados paliativos entre las que destacan el impacto que puede tener una enfermedad terminal en un niño frente a un adulto, en todos los ámbitos de atención (no sólo médico), la toma de decisiones; mientras que en cuidados paliativos pediátricos son los padres o tutores quienes protagonizan esta acción, en los cuidados paliativos de adultos, son los mismos pacientes (en la mayoría de los casos) quienes toman las decisiones en relación a su vida, su tratamiento, etc., y por último, otra de las diferencias es el equipo profesional que interviene en el proceso. El equipo de los cuidados paliativos de adultos es más reducido en personal en comparación al de los cuidados paliativos pediátricos, que, en la mayoría de los casos, se cuenta con una persona especialista en infancia (terapeuta, etc.) además del equipo de profesionales que suelen participar en este proceso.

Además, según el informe de Cuidados paliativos pediátricos en el Sistema Nacional de Salud: Criterios de atención, se expresan los factores de desarrollo como una de las diferencias más importantes entre la atención a pacientes pediátricos en cuidados paliativos en comparación con los adultos, ya que los primeros se encuentran en un constante desarrollo no sólo físico, sino también psicológico y emocional que afecta al tratamiento que pueden recibir los niños en caso de encontrarse en un proceso de cuidados paliativos. según el texto, “esto afecta cada aspecto de sus cuidados, desde la dosis de la medicación, a los métodos de comunicación, educación y apoyo” (Ministerio de Sanidad, Servicios Sociales e Igualdad, 2014).

El tema de los cuidados paliativos en niños, cómo se aborda desde el punto de vista del trabajo social y los sentimientos que rodean a los profesionales en este entorno, es una forma de recoger una realidad cada vez más común en la sociedad mundial. Con la comparación de los cuidados paliativos en dos países completamente distintos, con un sistema sanitario casi opuesto se pretende dar una visión más holística de éstos, de las diversas formas que tiene.

Además de hacer referencia a los trabajadores sociales, a sus sentimientos y emociones en el momento de acompañar a niños y sus familias en el final de la vida, también se va a hacer un estudio de cómo se percibe el trabajo social desde el punto de vista del paciente (en el que se incluye tanto al paciente en cuestión como a la familia del mismo) y desde el punto de vista de la sociedad, para poder conocer lo que se conoce del trabajo social en este ámbito, y así mejorar las futuras intervenciones que se hagan en este ámbito.

Todo ello pretende ser una comparación entre los cuidados paliativos en Madrid (España), y Austin, Texas (EE. UU.)

2. Estado de la cuestión

2.1. Legislación en España y EE. UU.

El primer contacto que se tuvo en España con la legislación en relación con los cuidados paliativos se remonta al año 1999, donde tras varias recomendaciones, el Pleno del Senado, en septiembre de ese año, aprobó una moción en la cual se exhortaba al Gobierno a llevar a cabo un Plan Nacional de Cuidados Paliativos. Más tarde, se aprobó por el Pleno del Congreso Interterritorial del Sistema Nacional de Salud, de 18 de diciembre de 2000, el documento "Bases para su desarrollo. Plan Nacional de Cuidados Paliativos". Las recomendaciones que se exponían en este plan no fueron muy efectivas hasta el año 2003 (Ministerio de Sanidad, Servicios Sociales e Igualdad, 2014).

En España, en el año 2003, se promulgó la Ley 16/2003, de 28 de mayo, de Cohesión y Calidad del Sistema Nacional de Salud. Era la primera vez que quedaba garantizada una atención integral y universal a los pacientes que se encontraban en la etapa terminal de la enfermedad. Se entendería esta atención como una prestación básica de todo ciudadano, brindada tanto desde atención primaria como especializada.

En 2007 se aprobó la Estrategia de Cuidados Paliativos del Sistema Nacional de Salud. Al año siguiente se creó el Comité de Seguimiento y Evaluación de esta estrategia, y en 2010 fue presentado el Informe de Evaluación al Consejo Interterritorial y aprobado por el mismo, elaborando así la Estrategia en Cuidados paliativos del Sistema Nacional de Salud 2010-2014. Según el documento elaborado por el Ministerio de Sanidad, Servicios Sociales e Igualdad en 2014 (Cuidados Paliativos Pediátricos en el Sistema Nacional de Salud: Criterios de Atención), esta estrategia destaca entre sus puntos más importantes la casi completa inexistencia de recursos en relación con los pacientes pediátricos de cuidados paliativos.

Actualmente, existe en España una ley que protege a los pacientes pediátricos que se encuentran en un proceso de cuidados paliativos. Esta es la Ley 4/2017, de 9 de marzo, de Derechos y Garantías de las Personas en el Proceso de Morir. En el Artículo 10 (Derecho de las personas menores de edad a la información asistencial y a la toma de decisiones), es donde se hace alusión a los derechos de los menores que se encuentran en el proceso de morir. Para los datos que nos incumben en esta investigación, cabe destacar los derechos que hacen alusión sobre todo a recibir la información acorde a la madurez del niño, a ser tratados de forma única e individualizada en todo momento, siendo preferible que sean los mismos profesionales en todo el proceso, a ser acompañados por sus padres o tutores el tiempo que debieren estar hospitalizados, y cuando el tratamiento del menor impida acompañamiento, éstos tienen derecho a poder contactar con sus padres o tutores en momentos de tensión o de incertidumbre.

La legislación en Estados Unidos es completamente distinta a la que existe en España, y el principal motivo de esto es el hecho de que el sistema sanitario estadounidense difiere totalmente del de España. El ministerio de sanidad tal y como lo conocemos en España tiene el nombre de "Departamento de Salud y Servicios Humanos de los EE. UU." (Health and Human Services Department) y su misión es "mejorar la salud y el bienestar de todos los estadounidenses, brindando servicios humanos y de salud efectivos y fomentando avances sólidos y sostenidos en las ciencias subyacentes a la medicina, la salud pública y servicios sociales." (Departamento de Salud y Servicios Humanos de los EE. UU., 2021).

Además, la organización territorial de los Estados Unidos es completamente distinta a la que tenemos en España. Se entiende la nación estadounidense como una agrupación federal de 50 estados. Cada estado puede organizar el gobierno de su forma, pero siempre bajo las normas reguladas en la Constitución.

Es por ello que la mayoría de las políticas y legislación que existe en Estados Unidos (y en concreto en relación a nuestro tema de cuidados paliativos pediátricos), se abordan desde la legislación federal, de cada estado. Se sobreentiende que las leyes que emanan de las federaciones están alineadas a las leyes nacionales, de la Constitución.

Uno de los puntos más importantes en materia de legislación sobre el tema y por los que ahora se rigen muchos de los programas de cuidados paliativos pediátricos es la Ley federal de reforma del cuidado de la salud promulgada en 2010, llamada Affordable Care Act (ACA).

Antes de esta ley, el niño o niña que quisiera optar a los cuidados de hospicio no podía recibir también tratamientos para intentar curar la enfermedad. Bajo la ACA, los niños con problemas de salud que amenazan la vida, (problemas que están inscritos en Medicaid) pueden obtener ambos tratamiento curativo y cuidado de hospicio. Se llama cuidado concurrente. Esta parte de la ley *ACA* se llama Concurrent Care for Children (or Section 2302). (Courageous Parents Network, 2020)

Más tarde, en 2016, se presentó un proyecto de ley para sustituir la Ley del Servicio de Salud Pública (Public Health Service Act) llamado Ley de Educación y Capacitación en Cuidados Paliativos y Hospicio (Palliative Care and Hospice Education and Training Act), en el que se pretende modificar dicha ley del Servicio de Salud Pública exigiendo al Departamento de Salud y Servicios Humanos que los centros de cuidados paliativos, y los centros de formación de éstos dispongan de subvenciones y prestaciones para mejorar las competencias de sus profesionales. (New york State Department of Health, 2013)

Actualmente, hay algunos estados que están trabajando para promulgar su propia legislación y así garantizar el acceso a los cuidados paliativos pediátricos. El estado de Illinois es gran ejemplo de esto, ya que según la periodista Vossel (2021), "la Asamblea del Estado de Illinois aprobó un proyecto de ley para crear un beneficio de cuidados paliativos en el hogar para niños que enfrentan condiciones que limitan la vida. La legislación ahora irá al gobernador JB Pritzker (D) para su firma. Las partes interesadas dijeron a Hospice News que la medida podría indicar un avance en el establecimiento de un beneficio nacional de cuidados paliativos." Además, afirmaba que este proyecto de ley, The Pediatric Palliative Care Bill, tiene como objetivo "hacer que los servicios de cuidados paliativos interdisciplinarios basados en la comunidad sean más accesibles para los pacientes y reembolsables para los proveedores. Los pacientes podrían recibir tratamientos curativos junto con estos servicios." (Vossel, 2021).

En otro artículo en 2022, la periodista anteriormente mencionada, explicaba que la Asamblea General de Illinois aprobó otro proyecto de ley en ese año (llamada Bill SB.3819) que "modifica la Ley de Seguros Colectivos de Empleados del Estado (State Employees Group Insurance Act) de 1971, amplía el acceso a los cuidados paliativos y de hospicio pediátricos para los pacientes y proporciona una ruta de reembolso para los proveedores. Según sus parámetros, los pagadores estatales y privados deben proporcionar cobertura para cuidados paliativos y cuidados paliativos pediátricos basados en la comunidad."

2.2. Recorrido histórico de los cuidados paliativos pediátricos en España y en EE. UU.

La historia que ha tenido el término de cuidados paliativos hasta llegar a España y a Estados Unidos tal y como lo conocemos hoy ha sido cambiante y diversa. De hecho, el término de "cuidados paliativos" y su aplicación práctica, nacieron gracias al desarrollo de otro término. Digamos que gracias al desarrollo del movimiento “hospice”, podemos utilizar ahora el de “cuidados paliativos”.

Hospice, según VITAS Healthcare, un proveedor de salud al final de la vida y conocido en gran parte de Estados Unidos, “brinda cuidados de confort sin intención curativa; el paciente ya no tiene opciones de curarse o ha elegido no someterse a ningún tratamiento ya que los efectos secundarios superan los beneficios. El cuidado paliativo es un cuidado de confort con o sin intención curativa.”

Una vez entendida la diferencia entre cuidados paliativos y de hospicio, es más sencillo entender que los paliativos son unos cuidados que nacieron gracias a que ya existieran los de hospicio.

La primera vez que se utiliza el término “hospice” fue, según la Fundación Paliar, en Lyons (Francia) en 1842 por Jeanne Garnier. Pero el movimiento hospice oficial fue inaugurado con la creación del primer centro de cuidados de hospicio en Londres del St. Christopher 's Hospice, en 1967.

El término de cuidados paliativos, según J. Sanz Ortiz (1999), fue “acuñado en el Hospital Royal Victoria de Canadá (Belfor Mount 1977)”. Este nuevo término tiene un carácter más completo, universal, independiente de situaciones culturales concretas, y es capaz de integrar todo tipo de programas. En 1980 el término de cuidados paliativos es integrado oficialmente en la OMS (M. Ignacia del Río et al., 2007).

A continuación, tras haber analizado la evolución del término desde un foco más general, se hará un acercamiento más concreto del concepto de cuidados paliativos en los países en los que se ha centrado la investigación: España y Estados Unidos.

El primer contacto que tuvo España con los cuidados paliativos fue en el año 1991, cuando se puso en marcha la primera unidad de cuidados paliativos pediátricos en el Hospital Sant Joan de Déu, en Barcelona.

Uno de los puntos clave en la historia de los cuidados paliativos en España, es la creación, el 8 de enero de 1992 en Madrid de la Sociedad Española de Cuidados Paliativos (SECPAL) “que reúne a diversos profesionales sanitarios: médicos oncólogos, médicos de cabecera y centros de salud, médicos anestesistas, enfermeras, asistentes sociales, psicólogos, religiosos y bioeticistas. Todos los que en su tarea diaria atienden, cuidan y consuelan a los pacientes que no son curables”. (SECPAL, s.f.)

Más tarde, y según Berga Liarte, L., et al. (2021), en 1997 se crea una unidad en el Hospital materno Infantil de Las Palmas; en 2008 la del Hospital Niño Jesús de Madrid y en 2013 otra en Son Espases (Mallorca).

En 2016, tras la publicación en 2014 de la Estrategia Nacional de Cuidados Paliativos Pediátricos del Sistema Nacional de Salud, se creó la Sociedad Española de Cuidados Paliativos Pediátricos (PEDPAL), de la mano de la Asociación Española de Pediatría, en la que se proponía proveer a los pacientes pediátricos de un equipo multidisciplinar para promover el desarrollo, educación, conciencia social del menor, además de advocar el derecho de éste de una atención adecuada en términos de cuidados paliativos. (Vilarrubí, N. S., 2018)

Actualmente, y según un estudio realizado en 2019 por la PedPal, existen un total de 17 unidades y recursos que atienden a pacientes pediátricos en materia de cuidados paliativos. Sin embargo, no se encuentra esta necesidad cubierta en todas las comunidades autónomas. (Pediatric Paliative Care, 2019)

Hasta el año 1960, no tuvo Estados Unidos su contacto “oficial” con el término de cuidados paliativos. En este año, y según G. Ferrer (2018), “la psiquiatra Elisabeth Kübler-Ross publicó su libro “La muerte: Un amanecer”, que integra las fases emocionales que atraviesa un paciente a lo largo de la enfermedad terminal, hasta la muerte”. Este fue el punto de partida para contemplar las necesidades de las personas al padecer enfermedades terminales.

Según Marston J (2019), un colaborador del International Children's Palliative Care Network (ICPCN), Florence Wald fue la mujer que introdujo este concepto en los Estado Unidos, gracias a la influencia de la doctora Cicely Saunders, ya que ésta fue una de las fundadoras del St. Christopher´s Hospice, el primer hospital de cuidados de hospicio del mundo. La forma en la que Florence Wald introdujo el concepto y práctica de los cuidados paliativos fue a través de la apertura, en 1971 del Cincinnati Hospice. Justamente la apertura de este centro fue con la ayuda de la previamente mencionada Elisabeth Kübler-Ross, psiquiatra y pediatra.

El primer centro de cuidados paliativos con servicio a domicilio fue inaugurado en 1974 en Connecticut. Con este centro se constituye el inicio del movimiento hospice en EE. UU. (G. Ferrer, 2018)

En 1977 se inauguró en Virginia el Edmar Children 's Hospice por una doctora y una madre cuyo hijo estaba al final de su vida debido a la enfermedad rara que padecía.

Más tarde, Ann Armstrong-Dailey fundó el Children 's Hospice International, en 1983. Este es un sitio en el que se da a los niños y sus familias apoyo emocional, viendo la situación en la que se encuentran como un proceso de mejora de la calidad de vida, y no como mejora de las condiciones que hacen que el niño esté falleciendo. (Marston J, 2019)

Uno de los pacientes de este centro, según este artículo publicado en ICPCN, afirma que "los cuidados paliativos ya no significan ayudar a los niños a morir bien, sino ayudar a los niños y a sus familias a vivir bien y luego, cuando sea el momento seguro, ayudarlos a morir con tranquilidad". (Mattie J. Stepanek, 1990 - 2004)

Actualmente, y según un estudio realizado en 2020 por la Industry of Statistics - United States, en ese año había un total de 1.768 negocios de hospicios y centros de cuidados paliativos en los EE. UU.

2.3. Acompañamiento profesional en el proceso de los cuidados paliativos pediátricos

Existen varios profesionales que intervienen en el proceso que atraviesa un niño en el momento de involucrarse en un programa de cuidados paliativos. Lo importante en esta labor interdisciplinar es determinar concretamente qué rol desempeña cada profesional, para así poder establecer un orden, y que ninguna necesidad tanto de la familia como de los pacientes queden sin cubrir.

Según la Association of Palliative Care Social Workers en Reino Unido (s.f.) afirma que, "junto con el equipo profesional multidisciplinar que rodea al paciente y a sus seres queridos, el trabajador social se asegura de que los servicios y las intervenciones tengan en cuenta a la persona en su totalidad, así como a su familia, sea lo que sea que eso signifique para ella".

Es importante remarcar la idea de que para que la atención recibida por el paciente y su familia sea completa, integral y enriquecedora, tiene que darse dentro de un entorno multidisciplinar.

Como regla general, la mayoría de los hospitales que cuentan con programas de cuidados paliativos pediátricos en España cuentan, para que la atención sea integral, con "médico y enfermera, y todo equipo de atención contará con un equipo interdisciplinar pediátrico de referencia, con formación específica, que incluirá un médico especialista en pediatría, enfermería, psicología, trabajo social, experto o consejero espiritual o, en su defecto, por equipos profesionales multidisciplinarios con formación avanzada en cuidados paliativos pediátricos." (Sanidad, 2014)

De hecho, según el Informe de la Situación Actual en Cuidados Paliativos (2014), "de las 12 CCAA que cuentan con plan específico de cuidados paliativos únicamente son 6 las que contemplan la figura del Trabajador Social y del Psicólogo de forma específica y propia. En el caso del resto de CCAA (6) dos tienen psicólogos y cuatro no especifican. En su mayoría, los profesionales especializados en estas áreas son externos a la sanidad pública, es decir, aportados por una entidad privada". Esto quiere decir que no todos los pacientes pediátricos cuentan con una cobertura social en este aspecto. Si bien es cierto que se ha estado trabajando para cubrir la esfera social del paciente desde la publicación del informe, aún son muchos los centros en España que ofrecen cuidados paliativos pediátricos, pero no cuentan con trabajadores sociales en su equipo multidisciplinar.

En Estados Unidos, y según la organización Get Palliative Care (2018), los profesionales que componen el equipo de cuidados paliativos pediátrico son, en términos generales, un doctor, enfermero o enfermera, trabajador social, y un especialista en vida infantil. Además, algunas de las unidades de cuidados paliativos pediátricos cuentan con terapeutas, psicólogos, capellanes, etc.

2.4. Principios básicos de los cuidados paliativos pediátricos y funciones del trabajador social

En esta sección se pretende hacer una recopilación de los principios más importantes de los cuidados paliativos pediátricos. Haciendo una recopilación de estos, podremos ver y entender la pertinencia que tiene el hecho de que un trabajador social esté dentro del equipo profesional.

Para identificar los principios éticos que se supone que un trabajador social debe desempeñar en el ámbito de los cuidados paliativos pediátricos, es importante primero entender cuáles son los roles que tiene el trabajador social en España en este ámbito. Para ello, se ha hecho una recopilación de literatura a lo largo de los últimos años para abordar esta cuestión.

En primer lugar, y según un estudio realizado por Corrales et al (2012), el trabajador social en cuidados paliativos pediátricos pretende poner en relación a la familia con los distintos recursos a los que puede acceder. Es cierto que una familia que atraviesa una situación tan impactante en todos los ámbitos necesita un profesional de referencia que le oriente e informe de las posibilidades que tiene de recursos tanto a nivel público como privado. En este aspecto, cabe mencionar que no sólo se pretende hacer de informador, sino de conocedor de los recursos en cuestión, junto con la intrínseca responsabilidad que ello conlleva de conocer a fondo los recursos, valorando de forma ética la pertinencia de este en cada caso, estudiado de forma única e individual.

Además, según un artículo de Riquelme (2017), se afirma que "la intervención se basa sobre todo en incorporar los recursos propios de la familia y los de su red de apoyo más cercana, y las comunitarias". De esta forma, respetando las formas de vida de cada familia, se podrá satisfacer una de las necesidades más importantes de la familia en este proceso: promover que la familia pueda ejercer la función cuidadora con el miembro enfermo.

Para que esa función pueda darse, el trabajador social deberá acompañar a la familia en las otras esferas de su día a día, y así poder ejercer la función de cuidador de su hijo.

Actuar de punto de unión entre la familia y el resto del equipo profesional es una función que también desempeña el trabajador social en términos generales. Se trata de una función de coordinación no sólo familiar-profesional, sino también entre los miembros de la propia unidad familiar. (Corrales et al, 2012).

Una vez analizados las funciones más importantes que realiza el trabajador social en los cuidados paliativos pediátricos, podemos afirmar que van de la mano con las funciones que la organización Get Palliative Care afirma que son las más las más importantes: "los trabajadores sociales de cuidados paliativos pediátricos ayudan a los niños y sus familias a sobrellevar el trauma de la enfermedad. Pueden ayudar a acceder a los servicios de salud mental para los pacientes, sus padres y sus hermanos. También suelen estar al tanto de los recursos que los ayudan con cuestiones financieras y de otro tipo".

Dicho esto, se pueden alinear las funciones del trabajador social a los principios universales de los cuidados paliativos pediátricos, que, según un artículo de Salas Arrambide (2004), son 15:

1. El criterio de admisión en un programa de cuidados paliativos pediátricos será que no sea probable que el niño vaya a llegar a ser adulto. No se requiere un pronóstico de supervivencia a corto plazo, porque esto interfiere con que se proporcionen los servicios desde el momento del diagnóstico
2. La unidad objeto de atención es el niño y su familia. Se define a la familia como la persona o personas que se ocupan de los aspectos físicos, psicológicos, espirituales y sociales del niño, independientemente de una relación biológica.
3. Los servicios de cuidados paliativos deben estar disponibles para los niños y sus familias en el lugar que prefieran o sea apropiado para sus necesidades. Puede ser en un hospital, en la unidad de cuidados intensivos, en el hogar, etc.
4. Los cuidados paliativos no tienen como objetivo acortar la vida, sino controlar los síntomas de manera aceptable para el niño y su familia.
5. Los cuidados paliativos se centran en el alivio del dolor físico, social, psicológico y existencial o espiritual del niño y de su familia, independientemente de su elección de continuar con tratamientos que prolonguen la vida del niño.
6. Los niños con enfermedades crónicas y sus familias deben tener acceso a un grupo de cuidadores, o por lo menos a un coordinador.
7. Los cuidados paliativos buscan aumentar la calidad de vida del niño y de su familia; se incluye a los niños y a la familia en la decisión de prioridades, utilizando una información completa respecto a la enfermedad y opciones de tratamiento.
8. El equipo sanitario reconoce la individualidad de cada niño y familia, y acepta sus valores, deseos y creencias, a no ser que puedan provocar un daño significativo.
9. Los cuidados paliativos pediátricos se desarrollan en el marco de un equipo multidisciplinar. La implicación desde el momento del diagnóstico implica que haya un contacto respetuoso con los profesionales que intentan curar o prolongar la vida del niño.
10. El equipo de cuidados paliativos debe estar disponible 24h al día, 365 días al año.
11. La provisión de descanso, sean horas o días en un momento dado, es un servicio esencial para las familias.

12. Las familias deberían poder demandar ellas mismas cuidados paliativos.
13. Los servicios multidisciplinarios de cuidados paliativos pediátricos deberían ser reconocidos como servicios médicos legítimos y valiosos, y deberían financiarse adecuadamente, para permitir su viabilidad y disponibilidad.
14. El apoyo psicológico y el seguimiento del duelo deberían llevarse a cabo tanto tiempo como sea necesario para todas aquellas personas afectadas por la muerte del niño. Este apoyo debería proporcionarlo un equipo profesional formado en cuidados paliativos pediátricos.
15. Los cuidados paliativos pediátricos son un trabajo difícil. Los cuidadores directos deberían recibir apoyo y supervisión psicosocial, formal e informalmente.

Como puede apreciarse, los principios universales de los cuidados paliativos deben abordarse desde una práctica interdisciplinar, donde el personal de lo psicosocial tiene un papel importante. Se remarca la idea de que, para poder cubrir todos estos principios, es necesario que las funciones de los distintos profesionales estén bien definidos.

3. Objetivos y preguntas de investigación

3.1. Preguntas de investigación

Este proyecto de investigación es una forma de profundizar en una realidad como es la de los cuidados paliativos pediátricos. Ante esta situación, tras la revisión de la bibliografía existente, surgen en la investigación una serie de preguntas que van a guiar la investigación.

- ¿Cómo se abordan los cuidados paliativos pediátricos desde el punto de vista del trabajo social en España en comparación con Estados Unidos?
- ¿Cuáles son los retos a los que se enfrentan los profesionales de lo social en cuidados paliativos pediátricos en España en comparación con Estados Unidos?
- ¿Cómo perciben las familias con casos de cuidados paliativos pediátricos la atención recibida por parte del personal psicosocial que les atiende en España en comparación con Estados Unidos??
- ¿Cuáles son los campos de mejora que perciben las familias en la atención proporcionada por parte de los profesionales?

3.2. Objetivos

Objetivo general

Entender las formas en las que se aborda el trabajo social en el ámbito de los cuidados paliativos pediátricos en dos países distintos.

Objetivos específicos

- Entender cómo se abordan las necesidades psicosociales de las familias españolas y estadounidenses en los cuidados paliativos pediátricos desde el punto de vista profesional.
- Descubrir cuáles son las necesidades psicosociales que una familia tanto española como estadounidense implicada en cuidados paliativos pediátricos presenta durante el proceso de hospitalización.
- Establecer una relación lógica y coherente entre la atención brindada por los profesionales y la recibida por las familias en cuidados paliativos pediátricos.
- Descubrir los campos de mejora en la forma en la que se abordan las necesidades psicosociales en cuidados paliativos pediátricos.

4. Metodología

El enfoque que se va a dar en este proyecto de investigación es el cualitativo, ya que se trata de profundizar en la comprensión de una realidad, la de los cuidados paliativos pediátricos. El propósito de la investigación cualitativa, aplicada a este tema en concreto, es la descripción de cómo se llevan a cabo los cuidados paliativos pediátricos en dos países completamente distintos, y con ello entender cómo perciben ambas partes (familias y profesionales) el trato proporcionado y recibido. Este fenómeno ayuda a la descripción de las experiencias de aquellas personas que se enfrentan a ese fenómeno.

Para llevar a cabo este enfoque se va a utilizar el método de la entrevista. La entrevista en profundidad, de tipo semiestructurada. La entrevista semiestructurada es una forma de recolección de datos cualitativos en la que se pretende, teniendo una estructura de preguntas predeterminada, comprender las experiencias de los entrevistados en relación a un tema concreto.

La entrevista semiestructurada permite formular las preguntas en función de cómo se esté desarrollando la entrevista, al contrario que las entrevistas estructuradas. Unas de sus características principales es la combinación que hay de flexibilidad y al mismo tiempo estructura (organización).

El motivo de elección de este tiempo de entrevista para el trabajo de investigación en cuestión es principalmente el tema del que se trata. Debido a la delicadeza del fenómeno, se considera importante el hecho de tener una estructura básica de preguntas para poder formular a los usuarios, así como la posibilidad de cambiar el orden de las mismas en función del desarrollo de la entrevista. Estas características pueden darse en las entrevistas semiestructuradas, y no en otro tipo de entrevista.

Las entrevistas que se van a llevar a cabo son las siguientes. Se van a realizar dos entrevistas a profesionales del trabajo social en cuidados paliativos (o profesional psicosocial), y dos entrevistas a familias/personas que estén en relación con un caso cercano de cuidados paliativos en niños en ambos países (España y Estados Unidos). Se trata de un total de siete entrevistas (cuatro a trabajadores sociales, y tres a familias) para poder llevar a cabo los objetivos de investigación.

Para poder abarcar todos los objetivos en su totalidad y dar respuesta a las preguntas de investigación, se llevará a cabo un estudio bibliográfico del funcionamiento de ambos centros (en España y EE. UU.), y así poder aportar una visión holística a los resultados obtenidos.

A continuación, se presentan las entrevistas realizadas con una contextualización de estas, para comprender el tema de cada una, su procedencia, etc.

	Nombre	Posición /cargo	Historia/situación	Nombramiento
EE. UU.	Rachel	Trabajadora social	Trabaja en el hospital Dell's Children Medical Center en Austin, Texas, EE. UU.	E1
	Emily	Trabajadora social	Trabaja en el hospital Dell's Children Medical Center en Austin, Texas, EE. UU.	E2
	Maria Matts	Madre	Su hija, Nina, falleció en 2019 con 17 años.	E3
	Sabrina Romero	Madre	Su hijo, Dean, falleció hace en 2017 con tan sólo 3 años.	E4
España	Lourdes Díaz del Río y Araceli Parres	Directora de Desarrollo y Espacios y responsable de Desarrollo y Fundraising, respectivamente.	Trabajan en la Fundación Vianorte-Laguna	E5
	Elena Catá del Palacio	Trabajadora social	Trabaja en el Hospital Niño Jesús	E6

	Paula Jiménez	Madre	Su hija, Eugenia, falleció en 2021 con 10 años.	E7

5. Resultados

Una vez realizadas las entrevistas a distintas personas, tanto trabajadores sociales y familias que han estado involucrados en procesos de cuidados paliativos pediátricos, tanto en España como en Estados Unidos, pueden sacarse algunas conclusiones que responden de forma clara a las preguntas de investigación que se planteaban al principio, además de poder abrir nuevos horizontes en este tema. Estas nuevas consideraciones han surgido al descubrir nuevos aspectos de investigación que no estaban contemplados en un primer momento en la investigación.

Se han podido observar varias diferencias (así como similitudes) en el papel que desempeña el trabajador social en cuidados paliativos pediátricos en los dos países. En primer lugar, en EE. UU., el trabajador social tiene unas funciones mayoritariamente psicológicas, de apoyo, de seguimiento en las necesidades más de tipo emocional que pueden acarrear las distintas situaciones del proceso.

Por otro lado, es importante entender el funcionamiento de las dos entidades a las que se hizo las entrevistas en España. Se quiso hacer un estudio de los cuidados paliativos pediátricos en ambas, en primer lugar, por su distinta financiación (público y privado, respectivamente), y además por el tamaño de cada uno, que se pretendía observar las diferencias entre ellos. La gestión de los casos de la Fundación Vianorte-Laguna depende precisamente del Hospital Niño Jesús. En palabras de la responsable de Desarrollo y Fundraising del Hospital Laguna, Araceli Parres: *"pero realmente lo que nos llega a nosotros es que nos enviarán los niños que ellas consideran que su propio equipo del Niño Jesús no llega a atender por dificultades, sobre todo geográficas".* No se tiene en Laguna el papel de trabajador social en el centro de Día de Cuidados Paliativos Pediátricos con el que cuentan, aunque la trabajadora social del Niño Jesús se desplaza cada semana a Laguna para hacer un seguimiento de los pacientes junto con sus familias. (E5)

De todas maneras, las personas entrevistadas, aún sin ser trabajadoras sociales, conocen bien el papel importante que tienen en procesos como este, tal y como lo expresa Araceli: *"Nosotros realmente ponemos un equipo de médicos, enfermeras, auxiliares, fisioterapeutas, musicoterapeutas (...) y no podemos poner más porque en nuestro presupuesto no podemos incluir a un trabajador social".* Afirma de todas formas que, aunque sería lo ideal tener una figura de trabajo social o incluso psicólogo en el centro, esto no sería del todo factible porque "*esa labor, ese acceso a los datos del sistema los tiene que tener el hospital. Claro, por eso nosotros no tenemos trabajadora social, aunque sería buenísimo traerla", "nosotros tenemos presupuesto solamente para ayudar a una labor a la que no llega el Niño Jesús. A la figura del trabajador social sí llega el Niño Jesús".* (E5)

5.1. Funciones del Trabajador Social en EE. UU. y en España.

Como afirma Rachel *"nuestro rol principal es apoyar a pacientes y familias", "haciendo con esos padres duelo anticipado, ayudándoles a reconocer que su hijo tiene una enfermedad seria que hará que tenga una vida corta"* (E1).

Además de este acompañamiento, Rachel afirma que, en la mayoría de los casos, los trabajadores sociales tienen que ayudar a las familias a afrontar la doble pérdida: *"no es tanto el tipo de duelo de cuando un hijo fallece. Es más, sobre el sentido de pérdida que se tiene en el momento"* (E1). Rachel se refiere al papel que los trabajadores sociales tienen que hacer cuando pierden la idea de ser madres y padres de un niño sano, como pensaban que iban a ser, o la pérdida de la idea de que su hijo o hija vaya a tener una vida normal, larga y feliz. Y con relación a este rol, se añade el de *"ayudándolos a descubrir cómo quieren seguir siendo padres de su hijo de esta manera"* (E1), que tiene que ver con la adaptación de los padres a la nueva circunstancia, habiendo perdido esa idea de ser padres como lo esperaban.

Otro de los roles que desempeñan los trabajadores sociales es: *"ayudar a normalizar las experiencias que las familias están atravesando para ponerles nombre"* (E1), además de lo que se conoce como la "planificación anticipada de la atención", que se da siempre de la mano de un apoyo emocional. Según Rachel, esto implica *"poner límites a las intervenciones que los padres quieren para sus hijos, tal vez eligiendo poner una orden de no resucitar en el cuadro, trabajando en la planificación del funeral, el duelo y el duelo después de la muerte de un niño, etc."* (E1).

Además, la trabajadora social de este hospital afirma que el trabajador social también realiza funciones de provisión e información de recursos: *"por supuesto, hay algún tipo de trabajo relacionado con la provisión de recursos y la conexión de las familias con los recursos de la comunidad, ayudándolos con los problemas de seguros"* (E1), pero también afirma que es su parte menos favorita de este trabajo.

Una de las madres de familia a las que se entrevistó, Maria Matts, afirmaba con relación a esta función de gestión: *“El trabajador social que estaba en la unidad de oncología hizo muchas cosas, como ayudas específicas y físicas, logísticas, financieras, ya sabes, aquí hay alguien a quien llamar. Hicieron que alguien llamara a un enlace escolar que trabaja, que se encargó de llamar a las escuelas y entrar a hacer todas las cosas”* (E3).

Pero estos recursos no son solamente físicos. Según Rachel, *“ayudamos (a la familia) a desarrollar las habilidades y las conexiones y los recursos externos e internos para poder superar el duelo”* (E1), haciendo referencia a sacar potencial a los recursos tanto internos como externos con los que las familias cuentan y así poder superar el duelo y las situaciones a las que se enfrentan éstas de la manera más positiva.

Se ha podido observar que la figura del trabajador social es quien tiene el papel de mantener las conversaciones más difíciles tanto con la familia, como con el paciente. Las conversaciones no en relación con el pronóstico médico, sino más bien a conversaciones que tienen que ver con las implicaciones sociales que las decisiones que tomen a lo largo del proceso entero pueden tener en su vida. Y no sólo proveer a las familias de información en los momentos difíciles, también el trabajador social pretende dar información en cualquier punto de la intervención, facilitando así el camino a la familia, preparándola para lo que pueda venir a continuación. Rachel lo confirmaba así: *“Lo que necesitan las familias es información, información clara y directa, porque la familia al principio de este camino tiene miedo. están buscando recomendaciones sobre qué hacer a continuación”* (E1). Además, otra de las trabajadoras sociales del hospital, Emily, confirmaba esta idea diciendo: *“Rachel y yo definitivamente estamos más involucrados en conversaciones sobre la toma de decisiones médicas y tenemos que tener una comprensión muy profunda, en la mayoría de los casos, del diagnóstico de los niños y me gusta todo lo que tienen que hacer desde el punto de vista médico para poder apoyar ellos bien, desde una perspectiva psicosocial, porque muchas de esas cosas médicas están afectando las necesidades psicosociales de la familia”* (E2), haciendo alusión también al hecho de que el trabajador social también tiene una labor de proveedor de atención psicosocial para las familias y para el paciente en cuestión.

Además, esta idea de proveer de información a las familias es percibida por una de ellas, Maria Matts: *“Y luego, cuando Nina ingresó en el hospital, y el trabajador social de oncología vino y habló con nosotros, y básicamente dijo, estoy aquí para ayudar, ya* *sabes, cualquier cosa que necesites, una especie de ayuda para navegar y todo ese tipo de cosas. Entonces yo estaba como, está bien, ya sabes, entonces, ya sabes, ella dice, aquí hay algunas cosas gratuitas de salud mental y algo así como decir, aquí hay algunas cosas que puedo darte"* (E3).

El tema de los valores es un aspecto muy importante a tener en cuenta en las intervenciones de los trabajadores sociales para con las familias involucradas en procesos de cuidados paliativos. Rachel afirma que, aunque a veces sea algo costoso, *"el rol de nuestro equipo es siempre abogar por los deseos de la familia"* (E1). Además, en relación con este tema, afirmaba que una de las funciones (en este caso ligado a una responsabilidad ética) es intervenir con el paciente, con la familia *"no haciendo suposiciones sobre ellos, invitar a las familias a compartir con nosotros lo que es importante para ellos"* (E1). Esta idea también es apoyada por Emily, cuando afirma *"Miramos a la familia y nos preguntamos qué podemos hacer para escuchar lo que es realmente importante para ellos, cuáles son sus metas para su hijo, cuáles son sus valores, cuál ha sido su experiencia con el sistema médico, cuáles son sus con la esperanza de que la vida de sus hijos pueda verse como en el futuro, y luego proporcionar recomendaciones y orientación personalizadas realmente buenas para ayudar a apoyar esos objetivos"* (E2). Unida a esta labor que desarrollan los trabajadores sociales, está la de intervenir con las familias *"juzgar y tener siempre una consideración positiva incondicional"* (E2).

Otra de las funciones que se han podido observar por parte del trabajador social es facilitar a la familia la toma de decisiones. Cuando una familia tiene que tomar decisiones importantes en su vida, muchas veces suponen una carga, y más cuando esas decisiones son tomadas de manera errónea. Es por ello por lo que los trabajadores sociales en EEUU en este ámbito asumen esas responsabilidades para que las familias, en caso de que esa decisión sea negativa, no tengan que cargar con el peso de la culpa. Rachel lo expresa de la siguiente forma: *"Quite algo de esa carga de la familia, ya sabe, hay decisiones que van a ser realmente difíciles de llevar para esta familia por el resto de su vida que podríamos quitarles"* (E1).

Es importante las aclaraciones que ambas trabajadoras sociales han expresado en relación con la concepción que se tiene de las funciones que tiene un trabajador social en cuidados paliativos pediátricos.

En primer lugar, afirman que el papel del trabajador social no tiene que ver con hacer todo lo posible para que las familias dejen de estar tristes, sino más bien ayudar a éstos a sobrellevar esa tristeza de la mejor forma posible. Rachel lo define así: *"Dejé de sentir que mi trabajo era hacer que la gente no estuviera tan triste, sino descubrir cómo ayudarlos a superar esta tristeza"* (E1).

Además de la relación con las familias, los trabajadores sociales tienen el deber de estar en constante relación con el resto del equipo médico. Emily (E2) lo explicaba de la siguiente forma: *"definitivamente, siempre estoy en conversación con los médicos y la enfermera practicante para comprender mejor lo que significan ciertas cosas para la familia, y también para ser una especie de voz no médica en la sala para la familia".* Esto evidencia la importancia que se le da al trabajador social como nexo entre la familia y el resto del equipo médico. Implica el hecho de estar en contacto con el personal médico para poder entender de una mejor forma las cosas que el niño está viviendo y cómo eso afecta a la familia.

Muchas veces los trabajadores sociales en EEUU tienen que hacer una labor de, como afirma Emily, *"trabajadora social tonta"* (E2), que significa hacer preguntas al personal médico que pueden ayudar a la familia, que parece que no van a ser hechas por la familia. Se basan en experiencias previas que han tenido los trabajadores sociales, preguntas que han tenido otras familias, etc.

Por otro lado, y en contraposición a algunos aspectos que tienen las intervenciones del trabajo social en EEUU, se ha podido investigar sobre los roles que desempeñan los trabajadores sociales en España, entrevistando a una trabajadora social del Hospital Niño Jesús de Madrid, Elena Catá del Palacio (E6), y a la responsable de Desarrollo y Fundraising (Araceli Parres) y a la directora de Desarrollo y Espacios (Lourdes Díaz del Río) de la Fundación Vianorte-Laguna (E5), también en Madrid.

Según Paula, una madre que tuvo a su hija en la unidad de cuidados paliativos del Hospital Niño Jesús afirma que *"la trabajadora social ha sido la persona más importante de mi vida, (...) porque gracias a ella me enteré de que yo podía acogerme a la ley esta, que ahí he cuidado de la hija por enfermedad grave y que no tenía que trabajar y que yo seguía cobrando mi vida"* (E7).

Una vez dicho esto, se pueden recopilar las funciones de los trabajadores sociales en cuidados paliativos en España de forma sintética y conjunta con los dos centros a los que se ha entrevistado, ya que es el mismo personal de trabajo social del Hospital Niño Jesús quien atiende a los pacientes de la Fundación Vianorte-Laguna.

Según la trabajadora social del hospital Niño Jesús de Madrid, Elena Catá (E6), existen varias funciones que se realizan para con las familias que están involucradas en procesos de cuidados paliativos pediátricos. Lo expresa así: *"pues hay veces que lo que hacemos es para valorar la atención en el domicilio, hacemos incluso una valoración en domicilio previa antes de que vaya el equipo sanitario".*

Además, las funciones de los trabajadores sociales en este hospital varían en función de la modalidad de atención del paciente, que ésta varía en función de la situación concreta de la familia. Según Elena, *"se les puede ver en forma de consulta externa si es una situación en la que todavía no está muy avanzada su situación y no se espera una muerte a corto plazo, es más una situación de cronicidad y se le conoce en consulta externa o se puede hacer alguna atención en un hospital de día si necesita alguna cura de alguna úlcera con el personal de enfermería o algo así. Y luego los pacientes que están peor son los pacientes que se valoran para la atención en domicilio, porque los que vienen a consulta no se le garantiza la atención 24 horas en el domicilio, a no ser que estén hospitalizados a domicilio. Entonces, los pacientes que están hospitalizados a domicilio llevan el pack completo de atención de todo el equipo"* (E5).

La función de valoración es otra de las más importantes de los trabajadores en España según Elena (E5): *"Y el trabajador social lo que hace es valorar primero las necesidades sociales de los niños, (...) asegurar que todos los niños están escolarizados o que reciben una atención en las mismas condiciones que un niño que no tenga una enfermedad en cuidados paliativos y si puede ir al colegio, pretendemos que los niños mantengan la normalidad yendo al colegio".* Se trata de una función de asegurar que el niño esté protegido en todos sus aspectos. Relacionado con esta función de valoración: *"es acompañamos haciendo un poco una detección de indicadores de riesgo social o de factores de desprotección."*

Otra de las funciones que expresaba Elena (E5), tiene que ver con el hecho de poner en contacto a la familia con los demás recursos para que puedan cubrirse necesidades de la vida de cada uno: "*y si ellos no tienen esa interacción, pues les ponemos en contacto con alguna entidad que pueda hacer actividades de ocio y colaboramos con muchísimas* *asociaciones para para poder conseguirlo".*

Y no sólo poner en contacto con los recursos, sino también darles un alivio en cuanto a la gestión por parte del trabajador social de los mismos: *"anticipar los trámites funerarios para dar herramientas a la familia de cómo organizarse, como estar preparados, como hacerlo, con qué recursos disponemos, si quieren que avisemos a alguna o alguien."* (E5)

Las funciones del trabajador social en España no se acatan sólo a lo que es la familia. También, según Elena (E5), se atienden a los niños que se encuentran en alguna medida de protección. Las funciones que se desempeñan con estos pacientes son distintas, y tienen que ver con: *"nos coordinamos con la Comisión de Tutela del Menor y con los directores de los Centros para organizar la asistencia y asegurar también que el niño tenga todas sus necesidades cubiertas y garantizando que al ser un niño en cuidados paliativos, que también pueda tener el contacto con la familia de origen, si así la familia quiere. Entonces vamos a centros donde hay niños que están con tutela o con alguna medida de guarda. Y cada familia es distinta, claro, y hay pocos recursos y cada uno pues cuenta con lo que tienen."*

Informar a las familias y ponerlas en contacto con los recursos es otra de las funciones más importantes de los trabajadores sociales en España según Elena (E5): *"también hago de asesora de la familia sobre los recursos en función de la situación."*

Los recursos con los que cuenta el Hospital Niño Jesús son limitados, ya que se trata de un centro de financiación pública. Para poder abarcar todas las funciones y necesidades tanto de los profesionales como de los pacientes, se crean iniciativas privadas, como extensión de los recursos a los que éste no puede llegar: *"es un hospital público, no podemos tener una delegación de un vehículo. Esto se tiene que hacer a través de la beneficencia"* (E5).

5.2. Comparación de las necesidades expresadas por las familias españolas y estadounidenses

Otra de las líneas de investigación que se han llevado a cabo y que se pueden observar diferencias es en las necesidades que expresan las familias españolas y estadounidenses en relación con los cuidados paliativos pediátricos. Son necesidades de todo tipo, pero las que son oportunas para la investigación se resumen en las necesidades sociales que demandaba la familia al encontrarse en un proceso completamente nuevo.

Cabe destacar que las entrevistas que se han realizado (dos en EE. UU. y una en España) tratan de familias cuyos hijos han fallecido tras haber pasado por los cuidados paliativos de sus respectivos hospitales. Es por ello que las necesidades expresadas son en su mayoría necesidades que ahora ya no tienen, expresándose en pasado y en base a un recuerdo.

Las necesidades además que expresan los pacientes (las familias) han sido también preguntadas a los propios trabajadores sociales. De esta forma, queda un cuadro de necesidades expresadas tanto por los profesionales que atienden esas necesidades como por las familias, que son las demandantes.

Dicho esto, se comienza haciendo un recorrido por las necesidades expresadas por las personas de EE. UU., tanto profesionales como familias.

En la perspectiva de las propias familias, existen necesidades que tienen al atravesar un proceso como este la familia en su conjunto. En EE. UU. se realizó la entrevista a dos madres de familia; Maria Matts (E3) y Sabrina Romero (E4).

Por otro lado, la perspectiva profesional es importante para esclarecer cuáles son las necesidades de las familias que los profesionales perciben.

Rachel (E1), afirma que *"la familia es la que dice que nos gustaría que nuestro hijo acabara con su vida de la mejor manera posible".* Esto se dice que es la principal necesidad que tienen las familias, la de asegurarse de que su niño o niña vaya a acabar su vida de la mejor forma, aunque eso suponga no alargar más ésta. En esta línea, Rachel afirma *"tenemos que asegurarnos de que el niño está cómodo hasta que fallezca",* haciendo alusión a la mejor forma de morir que se comentaba previamente.

Otra de las necesidades que se ha descubierto es el hecho de hacer frente a todas las pérdidas que tienen a lo largo del proceso. Si bien es cierto que la pérdida más importante es la del niño o niña, existen otras más que tienen que ver con la pérdida de relación con el personal sanitario, que se han convertido en una familia, compartiendo mucho de lo que se ha vivido, si no todo.

En relación a las necesidades de los hermanos del paciente, cabe destacar en EEUU la figura del profesional *"experto en la vida del niño"* (Child Life Specialist) que tiene como labor principal, según Rachel, *"Y su trabajo es realmente, ya sabes, también su* *capacitación es muy similar al trabajo social, pero está muy enfocada en el desarrollo infantil. Entonces, son realmente expertos en apoyar a los pacientes en hermanos, les gusta hacer mucho trabajo para normalizar el entorno hospitalario, ayudan con los procedimientos dolorosos, ayudan a sobrellevar la situación".*

Se trata de una necesidad que ni siquiera se contempla al comienzo de las intervenciones, pero que son en realidad una gran ayuda para el lograr el bienestar de la familia en su conjunto. Esta necesidad estaba soportada por una de las madres, Sabrina (E4), que afirmaba: "P*ero ee, eso fue de gran ayuda, porque el especialista en vida infantil y, a veces, la propia Rachel hacían esto: sacaban a Ellen de la habitación del hospital para que le gustara la sala de juegos de los hermanos, y simplemente iban a jugar con ella por separado. Mientras lidiábamos con eso, estábamos lidiando con Dean en la habitación del hospital. Y eso fue muy, muy beneficioso para nosotros no tener que preocuparnos por los dos niños, Ellen fue manejada, fue cuidada".*

Según Maria Matts (E3), afirma que lo más importante para ella fue el hecho de no tener que preocuparse de nada desde el principio, y eso era algo que le abrumaba al tratarse de una experiencia completamente nueva. La mayoría de sus necesidades se basaban, principalmente, en recibir información clara, concreta, indicaciones de lo que debía esperar: *"el equipo comenzó a hablar con todo el mundo, yo no tuve que hacer nada".* Además de información, Maria necesitaba un acompañamiento, una seguridad de que estaba haciendo las cosas bien *"Al menos una persona en el equipo se aseguraría de estar allí para cada cita solo para saber lo que estaba pasando. Porque una cosa que dijeron fue una vez que me convierto en parte de ellos, y ellos se vuelven parte de mí, que nunca me desharé de ellos".*

Maria afirmaba que una de las necesidades más importantes que demandaba del trabajador social era el hecho de pensar que estaría ahí cuando ni siquiera supiera qué necesitaba. Cuando falleció Nina, la trabajadora social apareció. *"Ella dice, ¿qué, ¿qué necesitas de mí? Y sí, lo cual no sé, ella se disculpa por preguntar eso. Y ella dice: "Está bien, esto es lo que puedo hacer por ti". Y ella comenzó a hablar y creo que dije algo en el sentido de que era como, no sé, como, no sé qué hacer. No sé qué hacer. Y ella dice: ¿Qué quieres decir? Estaba como, logísticamente, no sé, no sé lo que se supone que debo hacer. Entonces ella lo hizo todo. Llamó a las enfermeras, hizo la llamada. Ella dijo que hiciera las preguntas".*

Además, una de las necesidades que las dos familias (E3 y E4) han reportado es el hecho de que alguien le explique (en este caso el trabajador social) la diferencia que existe entre el término *"hospice"* y *"palliative care"*. Según Maria Matts, *"Porque al menos aquí, los cuidados paliativos no significan que sea una sentencia a la vida"*. Sin perder de vista esta consideración, Maria afirmaba la importancia y necesidad de conocer esta diferencia ya que la gente suele confundirla mucho. *"Entonces, el equipo de cuidados paliativos en St. Louis, Missouri, no se llaman así. (...). Pero la razón por la que lo son es porque la gente escucha paliativos y se asusta. Sí. Entonces, en realidad tuve una larga conversación con otra mamá sobre esta panelista que es ella, ella está en mi breve grupo de bar de padres. Y cuando murió su hija, hace como siete u ocho años, volvió a la escuela, se hizo enfermera y ahora trabaja en el hospital infantil. Pero lo que hace es hablar con los padres, muy específico, lo que sea, pero cuando habla con ellos, les dice que saben, hay una organización que vendrá y ayudará con el dolor y la calidad de vida y venderá lo que los cuidados paliativos son. Antes dice el nombre porque el nombre asusta a la gente porque piensan que es un hospicio. Y el hospicio es el final de la vida"* (E3).

En relación con este término, otra madre, Sabrina Romero (E4), afirmaba que una de sus necesidades era el poder tener una conversación franca, de las opciones que tenían: *"Necesitábamos tener conversaciones francas y saber cuáles eran las posibilidades reales, y comprender cuánto tiempo podríamos tener con nuestro hijo".*

Según Maria Matts: *"Para ser honesta, muchas de mis necesidades específicas eran emocionales. (...) Y yo quería saber que Nina estaba siendo cuidada por cualquiera que estuviera dispuesto a cuidarla",* y *"lo que necesitaba de esa trabajadora social era que se sentara en el sofá una hora y hablara conmigo"* (E4).

Por el contrario, la otra madre entrevistada, Sabrina (E3), afirmaba *"no estábamos tan interesados en, ya sabes, desnudar nuestra alma a un extraño al azar en el hospital. Como si eso no fuera algo que tuviéramos ganas de hacer. Y por lo que pude ver, ese era su único uso",* refiriéndose a que eso no era algo que necesitara al principio.

Sabrina (E4) nombraba también necesidades de tipo económico, cuando un trabajador social les propuso la idea de entrar en un programa de una especie de programa de becas para financiar todo el proceso o gran parte de él: *"La trabajadora social de allí se acercó a nosotros con un programa que ellos llamaban Seguro Social (...) era básicamente como,* *financiación (...). Este programa pagará esas facturas astronómicas",* refiriéndose a los costes relacionados con el hecho de estar durante mucho tiempo hospitalizado en la Unidad de Cuidados Paliativos Pediátricos. Y cuando el niño (Dean) salió de la UCI Pediátrica, *"Rachel, me explicó esta noción de estos programas federales, uno de ellos es MDCP. (...) MDCP significa Programa para Niños Médicamente Dependientes. Es un programa de financiación para niños que están, ya sabes, muy enfermos".*

La continuidad en el trato es otra de las necesidades que se ha podido observar. Cuando las familias pasan la mayor parte del tiempo en casa, pero tienen que ir a hacer revisiones semanales al hospital, es una gran ayuda cuando al llegar todos los médicos conocen el caso, no hay que estar actualizando información continuamente del niño o niña. Sabrina lo defiende así: *"Y entonces fue como si alguien que ya conocía a su hijo ya supiera su situación, que podría ayudar a ayudar a esa pieza de continuidad de la atención con cada hospitalización".* (E4)

Como señala Sabrina (E4) con relación al tema de la comunicación entre profesionales, se trata de un tema muy importante para tener en cuenta. Por ejemplo, su hijo (Dean), tenía que acudir a múltiples servicios del hospital debido a su enfermedad, y por eso señala la importancia que tiene el equipo de cuidados paliativos pediátricos como nexo entre todos los servicios: *"Entonces, cada vez que algo sucedía en un sistema, e inevitablemente afectaba a todos los sistemas, y necesitábamos algo de todas estas malditas personas, y el equipo de cuidados paliativos, a menudo eran los que organizaban estas conferencias de atención con todos. de estos médicos juntos para que todos podamos sentarnos en una habitación y conversar con todos. Entonces todos estamos en la misma página y hacemos un plan y averiguamos qué hacer. Creo que ellos encabezaron eso. Creo que fueron ellos. Y eso fue enorme. Necesitábamos eso".*

Cambiando de perspectiva, en esta sección se procede a plasmar los resultados obtenidos al haber identificado las necesidades de las familias, pero en España. Según Paula Jiménez, (E7) la madre entrevistada aquí en España, las necesidades más importantes que tenía eran más de tipo médico, eran necesidades de falta de conocimientos que su hija Eugenia necesitaba. Al principio entró en el nivel 1, donde la asistencia era en casa mayoritariamente excepto en casos donde se complicara la situación: *"tienes un servicio de 24 horas los 365 días al año de médico, enfermeras, psicólogos, trabajador social y todo ese acompañamiento y todo que te vienen a tu casa sí que está mal Eugenia. ¿Pero* *qué tiene? Tiene fiebre, tiene tal cual el oxígeno. Súbele más el oxígeno y de tal manera en una hora estaremos allí"* (E7). Cuando se encontraba en momentos de crisis, que la niña no estaba en el hospital, podía contar con este servicio 24h. Además, apoyaba esta idea diciendo: *"Es que yo siempre decía qué descanso para mí porque yo no soy médico, pero es que tengo a este equipo que viene aquí a casa a cuidar a Eugenia y sé lo que tengo que hacer. Claro, para mí es que era un lujazo"* (E7). Hacía referencia a la importancia que tiene el equipo de cuidados paliativos en los momentos difíciles para que ella pudiera hacer de madre, no de enfermera.

Otra de las necesidades expresada por esta familia es la de la gestión de informes sociales para poder dedicar el 100% de tiempo a su hija *"como yo estaba con una reducción de jornada del 99.9% para no trabajar y poder cuidar a Eugenia, pues me tenían que hacer informes, pues ese informe me lo hacían trabajadores sociales, o sea eso fenomenal de papeleo, de gestión y todo eso que simplifica mucho la vida"* (E7).

Al contrario que en EE. UU., las personas que tienen las conversaciones más difíciles con los hermanos y con los padres, son sobre todo los psicólogos: *"para eso está la psicóloga, que sobre todo al final pues nos decían, oye, ¿vosotros habéis hablado alguna vez con vuestras hijas de que Eugenia pues se puede morir mañana?"* (E7), mientras que, en EE. UU., es el trabajador social quien se hace cargo de esa labor.

Según la trabajadora social del Niño Jesús, las familias españolas que tienen hijos en cuidados paliativos pediátricos expresan unas necesitades determinadas, y en la entrevista realizada se concluyeron que las más importantes son: *"una necesidad es la interacción con sus hermanos, con su grupo de iguales, con sus amigos"*. (E5)

Según la trabajadora social del Hospital Niño Jesús (E5), las necesidades más importantes del niño es que sus circunstancias de vida tengan la menor alteración posible. Que los distintos ámbitos de su vida, a pesar de la situación en la que se encuentran, se vean lo menos afectados posible. Es por eso que la valoración de las necesidades del paciente que se hace como trabajadores sociales es atendiendo a los distintos ámbitos de la vida de éste: *"actividades de ocio, actividades educativas, pues por ejemplo, si se pueden ir de vacaciones si quiere ir al cine, si, pues que tenga una vida social activa, asegurar que todos los niños están escolarizados o que reciben una atención en las mismas condiciones que un niño que no tenga una enfermedad en cuidados paliativos y si puede ir al colegio, pretendemos que los niños mantengan la normalidad yendo al colegio"*.

5.3. Campos de mejora en la intervención en ambos países

Aparte de las funciones que tienen los trabajadores sociales en ambos países, así como las necesidades de las familias, se ha podido observar unas líneas de campo de mejora en la intervención desde el trabajo social.

En primer lugar, al preguntar a las familias sobre cuáles serían las líneas de mejora que les gustaría haber recibido por parte del trabajador o trabajadora social, las dos familias estadounidenses afirmaron no tener ningún aspecto que mejorar en la intervención, pero, por otro lado, la familia española (Paula), señaló que le hubiera gustado *"que Eugenia pasara al nivel de graves antes, pero que a lo mejor no estaba pasaba porque estaban un poco saturados. Entonces que bueno, también pienso que las cosas han sido así, pero que a lo mejor a mí me hubiera dado muchísimo más descanso que Eugenia en vez de hace 6 meses, haber entrado al nivel grave hace un año. Entonces el trabajador social podría haber dicho, oye, que esta niña pues tiene pinta de que, si no es dentro de un mes, va a ser dentro de seis, pues vamos a adelantar para que sea también descanso para esta familia"* (E7).

5.4. Retos a los que se enfrentan los profesionales

Otra de las líneas de investigación que se han descubierto al realizar la investigación, es el hecho de ahondar más en los retos a los que se enfrentan los profesionales en el ámbito de los cuidados paliativos pediátricos en ambos países.

Para empezar, las trabajadoras sociales de EE. UU. tienen que ver con el hecho de intervenir respetando completamente los valores culturales de las familias, con la humildad en el equipo interdisciplinar, dejando que cada profesional sea experto en su área, afrontando las competitividades que surgen en el desempeño profesional. Concretamente, Emily (E2) afirmaba *"Y eso puede ser muy, muy difícil para mí, porque hay mucha evidencia que respalda que cuando los niños tienen la oportunidad de tener conversaciones abiertas y honestas sobre su muerte, eso reduce el sufrimiento general para la familia y para el niño como incluso aunque es realmente difícil de hacer en este momento, por ejemplo, las familias reportan experiencias más positivas al final de la vida cuando han tenido la oportunidad de hablar como familia sobre lo que significará para ellos la muerte de su hijo y de incluir a su hijo en esa conversación, así que hago lo que puedo".*

También se expresa el poco valor que tiene el trabajo social en EE. UU., *"También puede llegar a que la gente no entienda realmente cómo es tu trabajo, tal vez no entiendan todas las cosas diferentes que estás haciendo. Como proveedor de cuidados paliativos para niños y familias, y eso puede causar que sea como el sistema médico, puede hacer que sea muy similar, infravalorado tanto desde una perspectiva cultural como desde una perspectiva de financiación o un recurso, ya sabes, en comparación con otras disciplinas"* (E2). Sin un reconocimiento como se da en el resto de las disciplinas, no puede hacer una atención integral, ya que la pata de los recursos está muy limitada.

La desinformación acerca de la realidad que hay muchos niños que se ponen enfermos y mueren, es otro de los retos que hace que quede esta área de la medicina sin tantos recursos.

La trabajadora social de España, por otro lado, afirma que lo difícil es hacer frente a los prejuicios que se tiene de los trabajadores sociales, que su labor se entiende, según ella, como *"venir a casa y nos van a hablar y no piensan que les estamos examinando. Incluso hay situaciones en los que previamente ya están amenazando con quitarle la custodia de su hijo y tenemos que ganarnos la confianza para que vean que nosotros lo que queremos es que el niño viva con ellos y ayudarles en esa tarea tan difícil que es cuidar a un niño en una situación clínica tan compleja"* (E5). Esto supone un reto importante en la intervención ya que se trata de una barrera a la que hacer frente que viene dada de muchos años atrás.

6. Conclusiones

La diferencia más importante que se ha podido ver con relación al abordaje de los cuidados paliativos tanto en España como en EE. UU. por parte del trabajo social es en relación con los roles que se ejercen. Si bien es cierto que la línea horizontal del profesional es facilitar el proceso de muerte del menor y acompañar a la familia en todo momento, la forma en que esto se lleva a cabo es distinta en los dos países. Mientras que en EE. UU. se desempeña más una labor de atención psicopedagógica, dejando a un lado la gestión de recursos, en España se puede observar lo contrario: primero está la gestión de recursos y en un segundo plano estaría la atención psicológica.

Es cierto que esto en parte se debe a que en los equipos de cuidados paliativos de EE. UU. no está tan presente la figura del psicólogo como lo está la del trabajador social, y es por eso por lo que los trabajadores sociales tienen esa labor tal vez más psicológica-emocional.

Con relación a la coherencia entre las necesidades percibidas por los trabajadores sociales, y las expresadas por las familias, se puede ver que éstas coinciden, no quedando ninguna de ellas sin cubrir por el hecho de que no se perciban o se expresen de la mejor forma.

Lo mismo ocurre en relación con los roles que se desempeñan como trabajadores sociales. Las familias esperan de los trabajadores sociales de manera precisa lo que realmente desempeñan los trabajadores sociales.

Gracias a esta investigación se ha podido ahondar en este mundo tan poco conocido y que tiene tanto impacto en la vida de las familias. Es por ello por lo que se precisan intervenciones concretas en ambos países para hacer frente a los retos observados y por descubrir.

7. Anexos (transcripción entrevistas)

7.1. Entrevista a trabajadora social en EE. UU. (Rachel → E1)

SUMMARY KEYWORDS: hospital, patients, family, child, psychosocial, people, medical, helpful, team, life, important, job, support, grief, question, child life specialist, helping, called, providing, insurance

Maria: Hey, nice. Okay, thank you. It was great. Yeah. Thank you. So how was the COVID with the children and everything? Was it hard?

Rachel: It hasn't been, there have been a lot of challenges with COVID, mostly around visitation restrictions in the hospital. So there was a portion of time, like probably six months or something where we were only letting one parent be at the bedside at a time. Which is just really hard. You know, in palliative care, we're having lots of difficult conversations with families. And so it was really hard to do that without the full family present. We have had a couple of patients who have died of COVID, which has been challenging, but for the most part, the patients that we've had who have gotten COVID or been exposed have gotten better. We have we have had a couple.

Maria: Well, okay, so, um, you want you want us to start?

Rachel: Yeah, sure.

Maria: Can you hear me with this?

Rachel: A little bit. It's better with the microphone. Okay, I can hear you good enough. And yeah, don't worry.

Maria: So. Okay, so in my research, I want to compare from a Social Work view, how are the actions and activities that a social worker does in pediatric palliative care ? You understand? Please let me know.

Rachel: Oh, yeah. No, that's, I got you.

Maria: So what are the actions that our social worker does for children that are in palliative care? And what is the difference? Not different, but like how you contrast? Like taking care of the family? I'm taking care of the kid like, but not medically, like, you know, not? Not all of that, you know, like the necessities? Or, you know what I mean?

Rachel: Yeah, I do. Now, that's a really good question. And, you know, so I think, in general, the types of kids that we work with in palliative care are kids with really serious illnesses. And most of those patients have some kind of genetic or chromosomal abnormality, some kind of underlying illness, that for the majority of them, I would say, like maybe 80% of our patients have pretty significant cognitive deficits, and so may not communicate in a way that we're used to have a very, you know, are kind of a developmentally are, are, like the age of an infant or a toddler.

And so really, you know, when I think of the work that I do, and in supporting patients and families, really, I'm working primarily with parents. So I would say like, my main, the main client, for me, is a parent. And, and occasionally, you know, sometimes we have patients who have cancer or other types of illness that haven't affected them neurologically. And I certainly do work with the, the patient themselves as well. And but a lot of my work is done with parents. And so you know, I'm doing a lot of work with those those parents around anticipatory grief. And so kind of recognizing that their child has a serious illness who may have a short life and, and the experience of grief that they're having kind of an on an ongoing basis.

There's also another idea related to that called ambiguous loss. And it's not as much about grieving something that you know, is coming, like the, like the death of your child that you know, is coming. But it's really about the sense of loss that you have in the moment. So for example, for a family who maybe was expecting a healthy baby, and then their baby is born and has a lot of medical problems, you know, there's a lot of grief in that there's a lot of loss in that. But it's but it's not like you're grieving a death. It's this ambiguous, kind of lost. So it's this idea called ambiguous loss. It's really It's great.

There's a woman who did a lot of research about that. Her name is Pauline boss, and she's like her work is really amazing and But so as you know, so I think a lot of my job is helping to normalize the experiences that families are going through helping to name some of that for them like that. This is grief, this is loss. We do a lot of help with medical decision making. So as kids are offered new interventions or treatments, kind of helping families decide does this make sense? Is this what we want to do? We do work around advanced care planning. So kind of putting limits in place on the interventions that they want for their children, maybe choosing to put a do not resuscitate order in the chart, they do work with around funeral planning, kind of grief and bereavement after the death of a child. And then, you know, of course, there's some level of kind of resource providing and, and connecting families with community resources, helping them with insurance problems, which is my least favorite part of this job. But yeah, we do that too. So you know, some of that kind of stuff as

Maria: Well, more administrative, maybe?

Rachel: Yeah, but I would say, you know, compared to other social workers who work in a hospital setting, specifically in our hospital here at Dell Children's, and I think I do more of kind of clinical work, like around emotional support. Like, they tend to focus much more on like, helping families get ready to go home, like discharge planning, and in resources and things like that. And my role really does tend to be kind of having these hard conversations with families with the rest of the medical team, and it's a lot more political work.

Maria: Yeah. Right. Okay. That's interesting. Yeah, um, for example, in terms of, okay, like a family is with their child. And, like, I've seen in your website, that is something called, outpatient care or care at home. So who decides, like, okay this is my situation, but then you have to, like, is there something that suggests the doctor or the social worker or the family? Or, you know, what I mean? Like, what are the things that make someone a better profile to stay at the hospital? Or to go home to care?

Rachel: Yeah, that's a great question. And it can be all of the things that you said. So sometimes, it's really based on what kinds of medical interventions that patients need. And so sometimes those interventions can't be done outside of the hospital. So the doctors kind of say, if your goal is to prolong your child's life, then they have to stay in the hospital until they can get more stable, or we can figure out a way to replicate like do some of this care at home.

But sometimes it is the family just saying like, we don't want to be at the hospital anymore. And we would like to receive as much care as possible at home, even if that means our child won't live as long. And I would say most of the time, it's something in between where the hospital is able to get the patient to a place where they are stable, and safe to be at home. And so most of the patients that we work with are these really medically complex kids and who have, you know, lots of different treatments at home, maybe have a feeding tube, because they can't eat by mouth, maybe they have a tracheostomy, because they need assistance with breathing. But they aren't, like, near the end of their life. They could live for years and years and years at home. And in those situations, you know, it's really up to the hospital to decide when a patient is safe to go home.

Maria: Alright. Yeah,

Rachel: And sometimes we work, you know, kind of there's two different parts of palliative care, right? Like there's the one where we're just working with families for years and years and years, their kids are really complicated. And then there's another subset where we're working with families whose kids are closer to the end of their life. And that really is the time where we may make different decisions, where maybe the child could live longer in the hospital. But the family has decided that that's not their goal, that they don't want their child to die in the hospital or that they really just want to be home as much as possible. And so then families kind of change their goals and focus more on how do we have as much good time as possible outside of the hospital. And so they're kind of two separate situations.

Maria: Okay, gotcha. Yeah. And for example, in Spain, in this hospital, I told you it was not pediatric, pediatric that it was like, yeah, for adults like, and when we like, when we went to, like, we used to go to visit her, right. Like they had, like, specific, like, as you said, like the family was, I would say, maybe it's not that much, but family, the family was like, the important thing. So, like, in your hospital? How is it? Like, concretely, how can you say that? Because we had like, spaces for the family, like living rooms, you know, like, tv? Or, you know, and there was like, always someone to say, Hey, do you need something like, like dining rooms? Like, right, so what, how do you specify that in your hospital? And why do you think it is important?

Rachel: Yeah, I think especially in a pediatric hospital, you know, that you're really, it's almost impossible to just treat the patient, you really have to treat the whole family, because sometimes these are tiny babies, but even if they're older, you know, the parents are the main caregivers, they're the ones making the decisions. So yeah, I think our hospital does a really good job of including the whole family. You know, we have kind of patient waiting areas where families can leave the room and take a break where there's coffee, and you know, we have a beautiful outside garden space where families can walk around every room in our hospitals, a private room. And so it's one patient and there and there is a little couch thing that pulls out into a bed so parents can spend the night with their kids, they can stay at the bedside. And we have a cafeteria in the hospital, so families don't have to leave to go get food if they don't want to, they can order it to their room, almost like room service. Yeah, I think, you know, we do the kind of medical rounds when the doctors come by, and it is standard practice in the hospital to invite the families out of the room to participate in those rounds every day so to get all the medical updates on their child. And if the child is old enough and interested, then they can also participate in those rounds. And yeah, I think the care, I think at many children's hospitals, but I think especially here is very family oriented.

Maria: Wow. Okay. Yeah. So it's kind of the same. While I like, when I go back in January to Spain, I'm gonna, like, try to do this kind of interview with someone there. So I'm excited to see the differences. But yeah, it's for what I've seen, it's mostly the same. But yeah, so in the website, you said something like, the importance of providing emotional and social support? Respecting the family's cultural values? And I guess that means that is related, like maybe to more ethical issues. Right. So what is it like? Did you hear that? I think you froze?

Rachel: No, you got frozen for a second.

Maria: Okay. Yeah. So I guess that respecting cultural values of the family implies some ethical issues. Right. So I don't know if that is what it's related to, but like, what does it mean to respect family cultural values? And up to what point like what is the limit? You know what I mean? Like, yeah,

Rachel: Yeah, that's such a good question. And that's something that comes up a lot in our hospital, I think, you know, when I think of respecting people's cultural values, and, you know, practicing cultural humility, to me, that really looks like not making assumptions about people, really, based on anything and inviting families to share with us what is important to them. You know, I have definitely seen things backfire on providers when they go and say, Oh, this is a Muslim family. So, you know, this is the way that they're going to react to this or oh, this family is from Mexico. This is how they will receive this information. And, and people just aren't like that, right? It's not like oh, hi, I'm from Mexico. This is exactly how I will behave now. And so I think our you know, I certainly practice and I think our team practices much more from a every family is different in the way they like to receive information and the way they make decisions together in what is important to them. And it's our job to find out for this specific family's culture, like the little culture of this family, like how do we best serve them? I can think though, kind of thinking about ethical issues. twice now in our hospital, we have had patients who were close to the end of their life, and the family was interested in trying kind of supplemental medication, or not even medication, like vitamin supplements or special teas kind of that I think both of these families were from Mexico. And so I think that our, you know, part of the practice and in the Mexican culture of providing kind of these different teas to help rid the body of toxins. And in both cases, the medical team was kind of uncomfortable with that they were worried, you know, this hasn't been studied, and they don't know what the potential side effects are, and how that might interact with the other medications we're providing. But in both situations, you know, I think our team's role was really to advocate for the family's wishes. And this is something that felt really important to the family. Yeah. And in both families, you know, they were very reasonable. And, and had agreed, you know, if they started to see bad side effects, or if they, if it wasn't helping, or, you know, certainly if it was harmful to their child, they would not want to continue that, that treatment. And so with the help of our team, and the ethics team, who, you know, we have a whole team at the hospital to kind of help us sort out when, when there are these ethical questions. And in both situations, the families were able to use these kinds of teas and supplements that felt really important and meaningful to them. But I do think, you know, those those kinds of cultural considerations, I think, kind of coming at it from this very, like, Americanized view of health care. It can feel hard for some of the doctors to accept like, okay, maybe there, maybe there are other things that we could pull in that would be meaningful for the family.

Maria: Right, right. Yeah. So you have like, kind of a limit, like to say, our goal here is to, okay, I know, well, I don't know, but I'm gonna say like something random, we can be like, our goal here is to extend the life as much as possible, even though the law, you know what I mean? Like, what it is just to take care of the patient and family, until what you know, like, when he's,

Rachel: you know, yeah, I mean, and I think a lot of our goals come from the family. So in both of these situations, you know, the family's goals really were to try to extend their child's life, they were they were not comfort director, they were not saying things like, we just want to make sure he's comfortable till he dies, like it was, they were still trying to extend their life. And so the medical team, you know, joins in on a goal, then that becomes their goal as well. But you're right, that the medical team does put limits on that.

So there are certain times where we will say, like, for these two cases, you know, we will try these supplements and these these things that you have brought. But if we start to see that it is harming this patient, then we will stop them, we won't do that. And the same thing like with doing CPR at the end of life. So for some patients, it feels really important for the families that they have tried everything, and they want to do CPR, like chest compressions, at the end of life, and sometimes our medical teams will do that. But sometimes they feel like that would cause harm and suffering. And so sometimes the medical teams will say like, this is not going to change the outcome. And in fact, will cause suffering and cause harm to this child. And we won't we won't do things that we know will cause harm. And I would say 99% of the time. The families understand that and are accepting of them. Yeah,

Maria: yeah. I think if you focus on each family, it's difficult to understand, because you're not okay, I'm following these terms. I have these policies and like everyone has to, it's not like that. It's not like you as a family have your own kind of phones. You know, I think that is this year for our family.

Rachel: Yeah, yeah. And I think the other thing we talk a lot about is like, you know, No, we, this is our job, like, we're here for a job. And then we go home at the end of the day, and we don't have to live with these decisions, like these families will relive these moments for the rest of their lives. And they have to carry the burden of did they do enough? Are there things they regret? Are they good parents, like they have to hold that burden for the rest of their lives? And so we talk a lot as a hospital about what are the ways that we can take some of that burden away from the family, you know, are there are there decisions that are going to be really hard for this family to carry for the rest of their life that we could take from them? You know? Because I do think, you know, it's easy at a job to say like, well, this is the way it is here. Here's the policy, but when it's your kid, but like, Nope, none of that matters. Yeah. And I think I think most of the time, we do a good job of understanding that and trying to balance that.

Maria: Yeah. And they do, like, the families perceive that. Like, for example, when a child dies, or whatever, and they have to leave the hospital, like, you know, or, or maybe doesn't, that he or she doesn't die, but you know, like, when they leave, do they perceive that? Like singularity or like personnel for cues of like, how, like, I don't know, exactly the kind of satisfaction surveys or whatever about? I don't know, but what do you feel the family feels like, receiving all those efforts you put to make them feel unique? You know, what, like,

Rachel: I hope I hope they feel that I don't we, you know, we the hospital does do satisfaction and surveys, I'm not sure that they're that specific. But you know, I, I really hope that they do feel that especially because a lot of the patients that we work with with palliative care, we know for so long. That I think the I hope that the families can look back to lots of examples that they have in their mind of when we we joined the family in a step towards a goal together, like when it felt like we were all working together. Even if sometimes there are conflict, I hope that the families can remember those other times. You know, and I do we do some support groups after patients have died. So I'm we're in the middle of one right now I do them twice a year for our palliative patients. And the families talk a lot about how hard it is to to leave the hospital after their child dies, like kind of the experience of feeling like they've built another family here at the hospital. And then that's an additional loss that they're experiencing losing this hospital family that they've built. So I do think that most families do feel very connected to the hospital.

Maria: Wow. Yeah. So I think I guess that the difference between when they come and when they leave, it's like really different, right? Because like a family like the first touch, I guess it's like to arrive. I don't know if they have any idea of anything like they are like, I guess they are scared, they do not know what are they going to find? What do you think are the first like necessities a family need when they first come in, like the first like, you know, like, how is that precedes your particular question?

Rachel: I think you're right, you know, when families are kind of starting this journey, they are scared. I think what families need is information, clear and direct information. I think they, you know, especially at the beginning, they're looking for guidance from the medical team. And so, you know, looking for recommendations about what to do next. I think families need to feel like they're supported by the medical team but also the psychosocial team that they're not alone. You know, I think this is kind of these are often the moments we actually just this week met two patients who are kind of like this like right at the beginning of their journey one has a dislike an underlying disorder and the other patient drowned in a pool. I've had almost drowning. And they're both at the very beginning of this journey. And the other thing that I think specifically our team can do to be helpful is to kind of shine a light down the road of what is coming next. And sometimes we call that anticipatory guidance of like, here are some of the things. Here's some of the conversations you might expect, in the coming days, here are some of the things we'll be looking for and thinking about in the next few days or the next few weeks. I think a lot of time in the hospital, people are really nervous to do that, because there's so much that we don't know, and they don't want the families to like, get an idea, you know, they don't want to be wrong. So they try not to do any of that. But, like, personally, I'm a person who really likes to know a plan, who likes to be able to know what's coming next. Yeah. And so we say to families all the time, like we are here to help, if that feels helpful to you, we can draw on all of this experience that we've had to help you guess what's coming next and kind of what to be expecting next, so that you're not surprised by it.

Maria: Okay, that's great. Yeah, I think that it's like much more. Like, okay, yeah, this is a plan bla bla bla.

Rachel: Yeah, yeah. And I, you know, we often will say to families, like, even if we can't answer all the questions that you have right now about the future, like for some families, it's helpful to know that we will be there like we, right now, we may not have all the answers, but we'll be there when we get to the next point. And will will, will have more information for a like, sometimes that's enough to just know that, like, okay, these people are going to be with me for the rest of this journey. And I can lean on them when I need something.

Maria: Yeah, that's great. Yeah. That's great. Yep. Okay, so I have three more questions. So one of them is that you said some, like, you have like this psychosocial team, like, how? How much do you think it is important to work? Like, kind of on like, contributing with another professionals like psychologists or I don't know, like, like in the psychosocial team who is there and like, what things you think that it's important that you can not do without them? You know?

Rachel: Yeah. Yeah. So I think on our kind of standard psychosocial team, we have a social worker, a chaplain, who does like spiritual support, religious and spiritual support. And then another person called a child life specialist. And their job is really, you know, they also their training is very similar to social work, but it's very focused on child development. And so they're really experts in supporting patients in siblings, they like do lots of work to normalize the hospital environment, they help with painful procedures, they help with coping. You know, they they help with education of the patient. So in a developmentally appropriate way, like how do you tell a five year old what cancer is, you know, they, they have that information, they know how to do that. So those are kind of the three main psychosocial players. We also in the hospital have psychology, we have psychiatry, we have music therapy and art therapy. That problem, that's all I think, but but I would say like every patient really is receiving support from a social worker, a chaplain and a child life specialist. And I think I'm sorry, oh, go ahead.

Maria: No, sorry that you have this kind of meeting like you do really work and, like, think about it procedures. I don't know another word for that. But yeah interventions. Yeah, interventions, right? Yeah, yeah.

Rachel: Yeah, definitely. So the way our palliative care team works, we see kids all over the hospital. So we don't have like, one unit that we see patients in there all over the hospital. So every unit has their own chaplain and Child Life specialist. So when we're starting to work with a family, yes, I absolutely have meetings and collaborations with the chaplain and the child life specialists to talk about kind of what we're all seeing as the needs of the family like what our assessment is, and kind of talk about who will handle what needs I think, you know, I think it's super helpful to have a team approach like that. For a lot of reasons, you know, just personality fits with different families like some families fit naturally with with some of the riders and not the others. And I also think, you know, I am not a religious person. And so providing spiritual support would be very challenging to me. And I have to just kind of default back to validating the the experience and the emotions underneath any kind of spiritual distress. But I, like I'm not in a position to provide spiritual guidance. So I really leaned heavily on the chaplain team for that. And I think I think having a team like that allows you to really grow your expertise and what you're good at, and like letting other people be the experts in their area. And, yeah, it it, it feels really hard to work with a family if you're the only psychosocial provider it I find it incredibly valuable to have other team members to be able to pull in.

Maria: Yeah, that's so cool. Yeah. Like, and there's no like competition, because you… Well, I mean, the idea is not learn like, because you want less you say like the best thing, you're a part of them know, your limits, like.

Rachel: And I think that's, you know, that that is where it can get tricky is if if where there is a right for lap and people's skill set. And I'm really lucky to have good relationships with most of the other psychosocial providers. But there have certainly been times where people have felt like, Oh, you're, you're in mind space, you go back to your job, and which I think is a natural part of wanting to do a good job. But I think we, you know, with a lot of honest and vulnerable communication between the providers, like you can move past that and get to a place where you really are focused on providing the best kind of care to the patient and the family. But sometimes people get a little competitive and territorial.

Maria: Yeah, that's, that's right. I guess like, yeah, okay, so this question is, like, kind of, for me, like worrying, but I think I need to, like, know how, like, because here in the United States, you have, like, medical insurances and everything, but it's been, it's different, right? But because we have like the private where you have to pay and everything, but then we have the public, which like the government pays not basically but you know, so here what, like, what are the not not like requirements, but if a family that has a lower socio economic level? Like, how can you help them? Like, how are the facilities they have?

Rachel: Yeah, so, so it was like this a little bit in Australia as well. And like some of the hospitals, I can't remember the language that they use, but some of the hospitals were like, for people who paid for private insurance, and some of the hospitals were for just regular people who had insurance to the government. And that's not like that here. And, you know, especially for children's hospitals. So there's only one kind of standalone Children's Hospital in Austin. So we work with families who have private insurance, maybe through their jobs, as well as families who are poor enough to qualify for our state funded insurance called Medicaid. And so all of those kids are all treated here in the hospital. And I will say I, I don't see a discrepancy in the care inside the hospital that people are receiving based on what insurance they have. And I think you know, our hospitals good at not paying attention to that. And our doctor, like most of the time, the doctors don't even know what kind of insurance people have. But there is a huge discrepancy outside of the hospital. And specifically for the types of patients that we work with who have really serious medical needs. And you may think that having private insurance that you pay for through an employer or through your job would be better. But for our patients, it is not. For our patients having Medicaid, the state insurance is easier for them to get the services that they need it outside of the hospital like therapies like physical therapy and speech therapy like nurses to come to the house like medications. You know, in fact, we work really hard to try Try to get all of our patients access to that state Medicaid, because it is, it's a lot better. But there are a lot of limits like you. There's financial eligibility. So you have to have a pretty low income in order to qualify. There are some really crazy, it would sound so crazy if I tried to explain to you these like loopholes. If your kid is complex enough, you can do these loopholes, where you have to be on a waiting list for a certain number of time and go to a nursing home and all it's crazy to try to get Medicaid. That yeah, so I think less so in the hospital, but in the community, it is a really, it's a really big difference. All of our patients really need Medicaid, everyone really?

Maria: Well, I wasn't expecting that. But yeah,

Rachel: I know, every time I like, even when I'm providing that education to families, they're like, Oh, well, I have, you know, we have private insurance. We have, you know, good insurance to our job. Okay. It's not gonna be good for this. Like, I know, you think that I know, you think and it's probably good for like going to the doctor and the dentist and things. Yeah, but we're in a whole different world now. And it's not going anywhere.

Maria: Yeah, well, that's funny. Yeah. Okay, now, this is my last question. And this is like, if you please answer as far as you want to. But, um, so the second part of my project is like, how do not not only how families feel when they receive this treatment, but how do you as a social worker, like, assume those like, I guess that at the beginning was completely different. And you start learning, like, emotionally? How do you cope with every, like, loss or every unexpected, like, you know, like, emotionally how you, like, welcome that in your life? You leave, like, go home that afternoon, knowing that a lot of people like, you know, like, How can you live your life? Yeah, separated from the professional one. Yeah.

Rachel: Yeah, it's, it's hard to it was really hard for me. In the beginning, when I first started this job, like you said, like, it was, I was sad, or more often than I thought that I would be. And I think I got this idea, some, at some point in my social work, education, that if you had good boundaries, and if you were doing good self care, then that meant you would not be sad. Like, that's how you knew, Oh, I have good boundaries, because I'm not having emotions about this. And so that was like, my goal was not to have feelings about the things that were happening around me, which is a terrible, that's a terrible goal. That's not a possible goal. And so I was really, I was sad a lot. And, and I think, you know, within the first like, six months or so, there were a couple of shifts that happened just internally, that really helped. And I think one was recognizing that every patient I met was going to die. And just knowing that at the very beginning, which sounds so depressing, right, like, that sounds worse. But it actually, I found it really helpful, because then when they did die, that stopped feeling like a, like a punch in the gut, like that stop feeling like a surprise, or, or, you know, overwhelming, it became expected and just part of the job. The other thing was really shifting my idea of what my job was, because sometimes I would work with families, and they would be so devastated and so sad. And it would be really hard to not walk away from that feeling like I made them better. Like I wanted them to not be so sad anymore, which is impossible, like their kid is going to die. Like that's impossible. And so I started really thinking about my job being to help these families have the healthiest grief process possible, to help them build the skills and the connections and the external and internal resources to be able to move through the grief process and not be destroyed by that. And once I started thinking of that, and and could identify you like, yes, this mom is so sad and devastated. But she called me and she said, can you come and talk to me because I'm feeling really awesome. That's great. Or I hear her reframing some of these experiences to already be meaningful like, oh my gosh, she's doing this is going to serve her well in the future. And it stopped feeling like my job was to make people not so sad. In it, then my job became how do I help them live through this sadness. And I think that when I made those two internal shifts that helped a lot, I also was in therapy, which was super helpful to have a place to go and talk to my therapist and, you know, talk through I was, I had been in therapy when I was in grad school, and was with the same therapist, probably for the first. I don't know, three or four years of this job. And it was really helpful just to have a space to go and share stories that were really hard for me and have her assistance and processing through that. I think also sorry, I'll just say one more thing I'd like to say about this. I think also having a team or colleagues that work that understand the work that you're doing that you can process with them has been incredibly helpful. Because like my friends and my partner, like they just, they can't, I'll try to tell my husband something and like, Oh, can I tell you that story? And he's like, okay, and it's like, okay, I had this kid who died today. And he's like, okay, okay. I was like, okay, yeah, that was it. That was the whole story. He's like, he can't he just like can't hold. Yes, he's so tender hearted. That that's not helpful. Like he can't provide support to me, then I end up telling him a story and having to provide support to him. So that's not helpful. Hello? pre processing with your exes, or being? Hi.

Maria: Sorry, I don't know what happened. This okay. Okay, yeah. You're telling you're like, Yeah, you're not you're not receiving support from your husband.

Rachel: So yeah. So I think having having a team who kind of is sharing some of those same experiences and who can really understand and like has the emotional capacity to hear your stories? I think that's super important.

Maria: Yeah. I know. Yeah. Well, Rachel, I cannot thank you enough. Like, really?

Rachel: I was also thinking Maria there. So I was on a podcast a couple of years ago talking about pediatric palliative care. And I would be happy to send you the link to that. Yeah. Because I think it's a really good overview of what Pediatric Palliative Care looks like. And that might be helpful for you as well.

Maria: Yeah, for sure. Okay. Yeah. Thank you so much. Yeah. And then when I, when I can, like, have these whole, like, at least pictures of, I would love to send it to you. So you can see, like, what our search was, and yeah, so I'm really thankful. Like, really,

Rachel: Of course, and save my email. So if other questions come up as you're working on your research, or in your future career as a pediatric palliative care specialist, or anything. Yeah, I'm so happy to be a resource for you.

Maria: So thank you so much. Really? Thank you. So let's, uh, yeah, and anything you need just, I don't know if I can help you. But yeah, let me know. Let me know. Thank you so much, Rachel. Okay, bye.

7.2.Entrevista a trabajadora social en EE. UU. (Emily → E2)

SUMMARY KEYWORDS: child, people, family, social worker, medical, hospice, home, life, dying, kids, palliative care, support, psychosocial, team, medical care, questions, role, hospital, care, talk

María: Alright.

Emily: Let me make sure it actually starts recording. I'll tell you it's thinking about it still.

María Sangrador Torres: Okay

Emily: There we go. Now it's recording. Okay, María Sangrador Torres: nice. Okay, so here's like a few questions. Okay. They're like, I have to do the same questions I did to Rachel. Because they have to be like, yeah, the same questions and well, obviously, it's not going to be the same interview, but um, yeah. Okay. So, um, please be like, feel free to talk about anything. You You think it's related to the question or anything like really do like, like, do whatever you want.

Emily: Okay. Yeah, yeah, but you gotta, you gotta have that standardized questions for research purposes, right? Yep, we got.

María Sangrador Torres: Okay. Okay. So, um, the first question is, like, I would like to know, like, How did you arrive to that job on why palliative like a pediatric palliative care for like you, Emily?

Emily: Yeah, I think for me, specifically, I definitely did not start off envisioning that this would be a job that I was super passionate about and wanted to do. So. For me, I arrived at the decision to become a social worker after I had spent several years volunteering with victims of sexual assault. So I was a sexual assault medical advocate. And I would get called out kind of in these crisis situations, or shortly after to help walk people through the process of getting medical care for for themselves after experiencing a sexual assault, or if they wanted to report the sexual assault to the police, walking them through everything they needed to do for that. And in that time, you know, it's it's very acute, you're often dealing with people who are like really high up in crisis brain, and kind of providing counseling and support in that moment. But I also was really surprised by like, especially the people that were in acute crisis, yes, but especially the people that I was seeing, maybe a few days after it had happened, or a little bit later in the process, they were all almost all of them were dealing with a feeling of loss or some kind of grief, like they might have even been in the situation that they're in when they were assaulted, because they had just experienced some kind of loss or grief in their life. And we talked a lot about like loss of safety, loss of connection to other people in their life. And it really just got me interested in grief and loss work, which kind of got me interested in working with older adults who were at end of life and experiencing dementia and other thing and other like terminal diagnosis. So when I started social work school, my focus was actually I was planning on becoming either a long term care social worker working with older adults with dementia or a hospice social worker working with adults. And so that's what I did my first internship in and then whenever it came time to interview for my second one, I interviewed with Rachel because of it being a palliative care position and was offered the internship. And just, as soon as I got here, just realized how much I loved working with the pediatric population, because so much of it as family work. And that was something that I had also really love to do when working with older adults. And it just stuck, I love the hospital environment, I love being able to kind of do this blend of inpatient and outpatient work with pediatrics. And I also really appreciate the some of the legislation in the United States that allows pediatric palliative care to give people like maybe continue to give them a little more access to treatment than adults are able to have access to when they're on palliative care, because I think it makes our role as a team even more important when people are trying to make those really difficult medical decisions for their family. Wow.

María Sangrador Torres: Yeah. Thank you so much. I could just like a little bit more about the differences between like those legal things being the differences between pediatric and adult.

Emily: Sure. Yeah, it's really on the hospice side of things. So like once people get closer to the end of life and we're talking about hospice benefits for that family, for adults 18 and older in the United States. Once you are qualifying for hospice and you enroll in hospice benefits, your insurance will no longer cover any kind of life prolonging Are life sustaining treatment or medication at that point. So everything in your care has to really be focused on comfort and supporting your comfort and quality of life at the end of life. Whereas with children, the concurrent Care Act was passed, I think it's like 12 or 13 years ago at this point, that basically makes it to where all of the state funded and federal funded. Insurances are required by law to continue to cover life prolonging and life sustaining treatments that are clinically indicated by the team, even when children are enrolled in hospice benefits. So this has really made a lot more families a lot more open and receptive to hospice, because they, you know, a lot of times, they're still clinical benefit to those things for their children, or, you know, they, they don't want to have to give up like their kids being on chemo, while they're on hospice, for instance, they still want to be able to hold out some of that hope that there might be a cure, or at least give them a longer period of time with their child. So that's really the big difference and something that I really enjoy helping families navigate once they get to that point.

María Sangrador Torres: Well, yeah, it 's like a big difference. Yeah, Emily: it is. It's a huge difference. And a lot of times when we're talking to families, they are only familiar with hospice and palliative care through the adult lens. So they really can't a lot of times be very resistant, because they are like, well, I don't want to give up on my kid. I don't want to give up on a lot of these treatments. So getting to explain to them like well, you know, that it's not that straightforward. Like there is some difference with, with what children qualify for compared to adults?

María Sangrador Torres: Yeah, sure. Yeah. Okay. So, um, related to what you were talking about, like? So, the children arrive at the hospital and then Okay, wait, I'm like, what are the the necessities that they demand maybe, like, when they arrive? It's like, like, besides the medical ones and all of that, you know, like, it's all about like information to the families like okay, these are the possibilities you have a different like, this is the situation or it's just information or whatever, like psychosocial necessities Do you have or children or you know, they are first time?

Emily: And are you are you seeking maybe like specifically from like the palliative care team has been consulted to meet them for the first time, like, what are some of their psychosocial needs and things that we help support them with? Yeah, yeah, absolutely. So from a psychosocial perspective, I think that that initial palliative care consult, and we get consulted in so many different scenarios. I mean, sometimes, sometimes we get consulted when a kid is pretty close to end of life, right? Like they've they're the team is really worried that they have started kind of the act of dying process. And we're really being consulted for the first time with the family when we're looking at their kids end of life pretty soon. And so we might start talking to them about hospice almost right away. In other instances, we're getting consulted to talk with a family when maybe they've gotten a new diagnosis, or maybe prenatally, the genetics testing for their baby in utero is indicating that they have some kind of very complicated or potentially life shortening diagnosis. And so we're really meeting them right at the beginning of that journey and starting to talk to them about some, you know, what are they hoping for their child's life? What have they heard so far from the medical team, giving them a lot of space, to process, anger, frustration, guilt, fear, sadness, I mean, these kinds of diagnoses can completely change the course of someone's life and what they thought it was going to be like for them to be a parent. And also just like helping them figure out how they want to still be a parent to their child in this way, that is maybe very different than they ever thought they would have to be a parent for their kid and navigating those choices for their child and helping

helping them process like the cognitive dissonance that can happen when we're talking about not pursuing an intervention that might help keep your child alive because maybe their quality of life would be so poor or removing some technology that we think is causing a lot of suffering, but might also cause them to die more quickly, because most parents they're at their base level instinct is keep my kid alive. You know, that's like kind of like basic, instinctual role of parenting. And so it can create a lot of cognitive dissonance. and guilt and shame and frustration for them whenever they're starting to have some of these conversations with our team.

María Sangrador Torres: Yeah. Wow. All right. And, um, so in the website that you have, I've read the like, like, literally, it says, like children are cared for with a family centered approach. Like, how, like, from the side of Social Work? How do you How would you explain that? Like, why is it important to like, what is the role that the family takes? In like, you know, the process like? Well, obviously, like, it's like, children, and they need their parents. Right. But like, what are the things that make? Like the family so important on? Yeah, like, it's family centered?

Emily: Yeah, I think that, why the idea of being family centered is something that gets called out is that you know, medical care isn't inherently family centered, like I think in in a, historically a lot of medical care has been this very paternalistic model, where the doctor is kind of just telling you what to do, or telling you what they see, or, you know, they might not necessarily really be listening to what you think is best for your child, you know, it's more of like, I'm the professional, this is what I'm seeing, this is what I know, I'm the one who went to medical school and have the lessons, this is what you should do. And then there was also like a very big swing, whenever we realized how harmful that kind of medicine can be, and how it can actually cause kind of poor medical care, especially for like more marginalized people. There was almost like this sort of like, reactionary swing towards the other way, where medical care now starts with, well, what do you think we should do? Or a lot of times, they're putting their responsibility almost entirely back on the family of like, well, we can do XYZ, ABC for your kid, what do you think and kind of really looking to the family to drive those decisions. And while that might work, in some scenarios, especially in these scenarios, where children are extremely medically complex, or the interventions are extremely big and scary, and will affect that family's life and like their, it will change how they live and how they interact with their child. That's, that's a lot to put on people to say, hey, we can do whatever you think is best, you know, within the within the realm of like, what is like an ethical like standard of care, right. And asking people to make those decisions without really good recommendations or like thoughtful guidance from the medical team can also be really unfair and lead families to make decisions that might not actually be the best for them, because they don't have all the knowledge that they need. And they don't have the guidance that they really need either. So to me a family centered approach. And the reason why our team really looks at that is we look at the family and we say what can we do to listen to what is really important to them, what their goals for their child are, what their values are, what their experience with the medical system has been, what they're hoping their kids life can look like in the future, and then provide really good tailored recommendations and guidance around that to help support those goals. So we're not necessarily asking parents to make these decisions with no context, but we're really looking to the family to give us the rest of the context that we need in order to provide really good recommendations for their care. And also being able to do it in a really non judgmental way of like, we've seen families make all sorts of decisions. And we've seen you know, them do it for a variety of reasons. And we can really meet you where you're at, and kind of walk that path with you, no matter what you choose. But we're not going to we're not going to put the roadmap down in front of you and say, All right, we can do any of these routes. Which one do you want to do? Because that's not really fair to them either.

María Sangrador Torres: Yeah, okay. So they have, yeah, but like, I put, like, I put myself in the situation, and he's like, okay, you can do whatever, but I, like DuPont always know, what can they do? Because he's like, yeah, you can do whatever, but I don't know what to do. Like, like, between, do whatever you want, but I help you like, so like, you know, because yeah.

Emily: And usually what I feel like that ends up looking like with our team is, you know, families kind of get the different ways forward laid out for them. And then or, if there's a path that the team just know really does not make sense for that family based on that. Maybe like resource limitations that they have, or maybe they have many, many other children in the home. Or maybe there's only one caregiver, there's like extreme financial strain. You know, the team can very strongly say, you may have heard about this, we may have talked about this at some point. But this is why we really don't think that this makes sense, both clinically for your child. And like the goal that you have of keeping them comfortable or not, you know, not extending their suffering, things like that. And because this might also like, fundamentally change the way that you're able to spend time with them as a family, or it might limit your ability to do some of these things as a family that have been really important to you to do. A lot of the times that looks like medical technology, so things like tricky ostomies, that, you know, they add a lot of technological dependence to the child's life and require a lot of caregiving and can also just like change that child's ability to do certain things that they might have still been able to do, just with a shortened lifespan if they hadn't gotten the tracheostomy, so those are some things that we we try to make sure that people always have a really good understanding of all of the different ways forward that clinically would make sense for their child's body. And then we add the context of, and we've heard this from you, we've heard that this is a really important goal or an important value for you. And we don't think that pursuing this intervention would help you meet that goal. Are we based on what we've seen in what we know, or we don't think that this aligns with your values? Or your child based on what we've seen for other families and what we know. So that's a lot of the context that we've tried to provide as a team.

María Sangrador Torres: Okay, cool. Yeah. Okay, um, when you talk about team, like, what, like, Who is that team? Who's the team?

Emily: Yeah. So we have a really great interdisciplinary team. So the the palliative care team, before we started expanding, the team to grow bigger to support our hospice program that we'll be launching at some point in the next few months. So kind of Originally, the palliative care interdisciplinary team was the physicians. So there's two physicians, there is a nurse practitioner. Before I was hired, it was Rachel was the only social worker. Now there's two social workers. And then we will be we at one point had a dedicated full time chaplain for the team or a dedicated chaplain for the team, and we will again in the future. And then as we're growing the team to offer hospice services to our clients, we will also be adding a child life specialist. Do you know what that is? Or have you heard of child life specialists? So they are, I would say they are like, their psychosocial provider. And I'd say that they are like, social work adjacent and that they, they get a lot of training on Child Child Development. So they're kind of experts in child development, and how children process trauma how children process death, and medical complexity at different life stages. So they're often called in to help support the families with siblings, like help them figure out like how to talk to the siblings about what's going on with their child who's dying or is very medically complex. They also tend to help with a lot of like, enrichment activities for kids, whenever they're in the hospital, really focused on like, their, you know, social and emotional well being outside of just medical care. So they're a super important part of our team, and are really the go to support people for like children, like, specifically the children, whether that be the patient's like, kind of social and emotional well being or the siblings. And then obviously, you know, the social workers work very closely with them, because that's a big focus of what we do as well. But they've got like, a lot more specific training in terms of like child development, in kind of developmental milestones and stages. So yeah, so it's a really interdisciplinary team, you know, it's nursing, it's physicians, it's like a variety of psychosocial providers, spiritual support. And we all work really closely in tandem to support families and you know, maybe a family doesn't need a lot from us medically for a while maybe they primarily have a relationship with a social worker, maybe it's opposite and maybe they have a lot of medical needs, but they don't necessarily get value from psychosocial support. So they might mostly no are physicians or nurse practitioner. So yeah,

María Sangrador Torres: yeah. So um, you have your, like, each one of you as professionals, you have your own roles, like the We'd always just like, well, obviously, I know you do. But like you said, so straight kind of,

Emily: I'd say, I would say we're proud. We're very collaborative as a team. But we all definitely kind of have our own roles within the team, like, you know, like our physicians are the ones really driving conversations around pain, symptom management, maybe helping, like more from that, like medical management standpoint, our, our NP ER nurse practitioner also drives a lot of those conversations, and then also has a lot of that really good, like, boots on the ground nursing knowledge of like, helping families navigate, like getting more out of their home health, or really talking practically, like, what does it look like to take care of a trach day to day because like they have a lot, she has a lot of that experience. And then the psychosocial providers, I'd say that I probably like, me and Rachel are definitely more like we're very engaged in conversations around medical decision making and like, have to have a really deep understanding, in most cases of like the kids diagnosis and like everything medically that they have going on in order to support them well, from a psychosocial perspective, because a lot of that medical stuff is affecting the family's psychosocial needs on such a deep level. So I definitely, you know, like, even though I'm not the one, medically managing the kid, I definitely am always in conversation with the physicians and the nurse practitioner to get a better understanding of what certain things mean for the family, and also to kind of be that like nonmedical voice in the room for the family, like maybe asking questions that I've heard a lot of families ask that maybe this family is asking it, but I feel like maybe they do have that question like asking that question and getting the answer while we're in the room or kind of playing the dumb social worker and being like, Oh, Dr. So and so could you know, could you tell me like if they got this, would that help improve this? Even though I maybe, ya know, I know the answer. I think maybe the family doesn't, so I'll kind of pose that questions, the family can get that information. So that's a lot of what maybe how our roles kind of intersect with each other.

María Sangrador Torres: Well, cool. So, okay, here's, the next question is like a Well, I think, well, I took it from your website, too. And it did, like, provide emotional and social support, that's, that respects your feminist cultural values. So it's like, um, and you've talked about it? Sorry, you've talked about it a little bit, but like, um, I think this is like more personal like, you have you ever like experienced some like, someone a case or like a family or whatever, that you do not share the, like, ethical things. But like, you have to, you have to respect that cultural belief or something that is like completely the opposite as something you will do. Like how I think it's like, much more difficult to say, like to do it than saying it is like, No, I respect everyone, you know, but then we have that situation, like, how do you manage it?

Emily: Totally. So it's a great question. And it's definitely something that we come up against a lot. I mean, our, like, our whole team's role is to approach things with non judgement and to always have unconditional positive regard for our our families, I will say that it's something that comes up pretty frequently, that can be difficult, because it's just not something that I would do personally is there, there are quite a few families that we work with who even with their children who are quite a bit older, like in their teens, or like middle school age, they don't want their kid to know that they're going to die. And they don't want providers to to tell their children that they are dying or that they are going to die at some point in the potentially near future. And that can be really, really difficult for me, because there's a lot of evidence that supports that when children have the opportunity to kind of have open and honest discussions about their death that that reduces overall suffering for the family and for the child like even though it's really hard to do in the moment, like families report more positive end of life experiences when they've had the opportunity to talk as a family about what their child's death will mean for them and to bring their child into that conversation, so that I do what I can. How I deal with that is I do what I can to find opportunities to try to explain or to make space for, for families to know that like, you know, I hear, like, I hear you, I 100% understand the reasoning behind that, and I hear you. But I do also want to offer this perspective that like, we've seen on wider scales, and many studies that this can actually be really beneficial for most families that choose to engage in this really hard work, that doing, doing the really hard thing in that moment actually ends up being very helpful and can create opportunities for beautiful connection. So if they're open to hearing me on that, I tried to share that perspective. It doesn't always change their minds, I'd say kind of infrequent, very infrequently changes their perspective. But and, and that maybe over time, they open up a little bit of space, or they start talking where they're like, of course, he knows, like, he knows like, he's smart, like he hears things like that they still don't want to talk openly with their child about it. So that's certainly been like a kind of, like, it's a cultural difference in the sense that it's like the family's culture is different than like, what my culture like my family culture would be like. And it often can kind of intersect with religious beliefs that are different than mine, as well. So that's definitely a big one that comes up. Yeah, wow. It can be really hard because like some kids, and it really the kids differ, like, some kids are asking a lot of questions and like, you know, they're really wanting to know, and like, They that can be really difficult to navigate other kids, like, you get the sense that like, they don't really want to talk about it either. So like, you know, they're not really putting a lot of pressure on their parents to talk about it. So navigating those situations might be a little different. But yeah, that can be a really tricky one.

María Sangrador Torres: Yeah, I know. Okay, um, okay. Yeah, at the beginning, you were saying that there's like a kind of a service that service, I don't know how to say it, but like, could you tell me about like, the outpatient care, like, or the care home? Like, how, how is it? Like, who decides to go home? Like the family? Or is that the team that says, Okay, I think it's better, it's better to go home or, and then what are the care that the family they're at their home?

Emily: So, with outpatient, like, if we're talking specifically about children that are getting closer to end of life, and we're talking about them going home with hospice, we really, it gets broached in a pretty big variety of ways. Like, sometimes the family is like, you know, we've been, we've been going through this for so long, like, our child is really tired.

Like, they're telling us that they want to go home, like we're ready to go home, like, what does that look like? And so then that sets us up to talk to them about going home with hospice and the kinds of benefits that they can access through hospice in their home. Other times, you know, the team is approaching us and saying, Hey, like, maybe we already know this family, maybe we don't, but they're like, Hey, we think this kid is acutely dying. Can you help us talk to this family about what that means? And kind of get a sense of like, do they want the like, would they want to go home like do they want to try to get home to the end of life can happen at home? Because that's not a that's not necessarily important to everybody. I think a lot of people imagine that if people have the choice, they would rather die at home or they would rather have their child died at home. And that's, that's actually not the case for everybody. There's plenty there's quite a few families who would rather end of life happened in the hospital because when you're home with hospice, you you do get support from a medical team. You know, there's a hospice nurse that will come out once a week to do an assessment and kind of check in or you know, if there's like acute uncontrolled symptoms that the parents are not able to manage at home, the nurse can come out and help with that. There's also like a 24 hour call number so that if you're seeing a lot of changes in your kid or you're not sure what meds to give, you can call that and get some guidance. There are social workers and chaplains available for psychosocial support as well. But a lot of the day to day care of that dying person or their you know, in these parents cases, their dying child is going to be on the parents, the parents are doing a lot of that hands on medical care and for their dying kid and watching their child's body go through a lot of changes and you know, watching them kind of go through that end of life process. And while that can be a really beautiful, meaningful experience for a lot of families, and a lot of there's a lot of parents who want to do that work. Um, some people just want to really focus on being mom and dad and like, not also being nurse, you know, in that moment, so maybe, maybe dying in the hospital makes more sense for them, they might also really know that team and feel really comfortable with that team and feel better supported in that environment than they would at home. So we really see end of life happen for our families in a lot of different ways. And we have teams that can offer support wherever they are, but it you know, it is still like the care of dying. With hospice, outpatient hospice, the care, the families are still very much kind of in charge of that dying process and caring for their dying child. Which can feel like a really big change whenever their child has been very medically complex for a long time. And maybe they've had a lot of our kids have home nurses still at home, when they're on hospice, because of concurrent care. But some kids don't have and are saying, or maybe they don't have 24 hour nursing. And their parents are used to whenever they get really sick, they bring them into the hospital. And that can be a really big change. Like you see your kids getting sicker and sicker at home. And that's where they're supposed to be like they're supposed to be there until they die. So it can be a really big adjustment for families. Yeah.

María Sangrador Torres: Well, okay. Okay, here's the last one. Um, so, um, the last question. So as a social worker, what would you say that are the, like, maybe one or two things that are like the positive about palliative palliative palliative care? Like, maybe you can, you can talk about like, personally, like, how does it help you like to, like, be a better person like to reach your goals? Maybe or, you know, and then one or two negative things that say, like, I would think this, like, maybe I'm like, in the system? Or maybe you know what I mean? Like? Yeah, I really like Ideally, I'd

Emily: like to do like

María Sangrador Torres: to prove your like environment,

Emily: you know, when prove it. Sure. So the things that I think that are great about it as it is medical, social work, like if people are interested in medical, social work, there's medical social workers, a lot of the times if you're in an inpatient setting, especially very quick relationships, you know, like you're meeting people that are coming into the hospital for a short amount of time, and you're helping them get home safely, or even in an outpatient setting, maybe you just have a huge caseload. And, you know, you might only see people, maybe once a month, like maybe once every few months, so you might not build as much of a relationship. What I love about pediatric palliative care is that you can get all those things that a lot of people love about medical, social work, the inpatient hospital setting, working on an interdisciplinary team, and having those resources at your disposal, but you also typically are building longer term relationships with people like, you know, some of our clients or people that we know, for a year before their child dies, and we see them frequently, you know, we build a close relationship. During that time, are we there are people that Rachel, you know, she's been here for 10 years with people that she's known for years and years, five or six years. So if you're, if you're somebody who really loves that long term relationship building, palliative care is so wonderful for that, because a lot of times you meet kids, you don't, you don't necessarily meet them, right, when they're dying, you meet them at time of diagnosis, or you meet them like earlier in their lives, just knowing that they're going to have a lot of medical complexity and issues over their life course. So I love that. And it's a much more clinical role than a lot of other medical, social work jobs, a lot of other medical, social work, jobs are very focused on discharge planning, or they are meaning a lot more of those case management needs. Whereas like, a lot of what I'm doing is more like direct psychosocial support for the family, or counseling or, you know, helping to facilitate conversations around these medical decisions, with with the family and with the whole team. So that part about it, I think is is incredible, and is a really great fit for people who have interests in both of those things that can be hard to find in other disciplines. And then some things about it that are hard. People don't like to talk about dying children, surprise, surprise, be shocking to you that people don't, you know, want to talk about children and death. But I think just that that cultural kind of fear and resistance to thinking about bad things happening to kids can make communication really hard. It can also make it to where people don't really understand what your job is like they don't maybe understand all of the different things that you're doing. As a palliative care provider for for children and families, and that can cause it within like the medical system, it can cause it to be very like, undervalued both from like kind of a cultural perspective and also from like a funding perspective or a resource perspective, you know, compared to other disciplines that are more focused on curing or kids don't, you know, maybe they have a very high survival rate or they're, they're, you're constantly hearing about these, like heroic stories about transplant, or chemotherapy, or these kinds of, I don't honestly feel good stories, because the families are still having a rough go of it, but like, ultimately, the child is cured and survives. So I think that that's something that can be tough about it. And also that there's just, I think people think that there's not a lot of kids that get really sick and die. So they, they don't necessarily understand how under resourced, this area of medicine for children is. And so, you know, like, there's just not like, there's not a lot of home nurses that feel comfortable taking care of extremely medically complex children. So like, a lot of our kids, even if they qualify for nursing, they might not get a nurse for months, or even a year or multiple years because of staffing issues. So and you know, of course, home nurses are not paid very well either. So I think some of those systemic things, where it's like we are resistant to talk about children going through these really hard things, because we don't want to think about it, we don't want to imagine it makes it harder for us to be included in conversations around how to be properly resourced and funded. And I would just really like to see that change. I'd like to see an expansion of concurrent care to include private insurance, private insurance is exempt from concurrent care, they don't have to do it if they don't want to. There's waiver programs and like, like they can do it like they can and often do continue to pay for things, but it's just not as easy and quick of a process as with like Medicaid or Medicare. So I think just those are some of the things that I think would really help in terms of like expanding resources for children who need to access palliative care and hospice service services.

María Sangrador Torres: Well, there's not, it's not I mean, it's like, not easy.

Emily: Yeah. Perfect. Yeah, yeah. And it's, it is really interesting, because you will, like, I think one of the other things about the job that can make me uncomfortable is that people when when you tell them what you do, they're like, Oh, my God, I could never do that you must be such a special person. And I'm like, not really, like I don't, I don't think there's like, we were very skilled, right, like, we've learned a lot, and we're very skilled in what we do. But there's, there wasn't something that just sort of made me good at this job from birth. You know, like I, maybe there's certain personality traits, or like certain life experiences that make people better able to cope with like, the emotional side of working in this kind of a job. But, you know, it's a very skilled job. And just like hearing people kind of, it can feel a little uncomfortable to just kind of be like, you don't always know how to take it, right. Because you're like, Well, no, maybe not really. And also, like, I wish you would think a little harder about what it means to be this kind of, to have this kind of job instead of just being like, Oh, I could never do that. You're just so special and great, and blah, blah, you know, like, that part can be a little uncomfortable.

María Sangrador Torres: Like, oh, wow, that's amazing that you're doing this research project about this. And it's like, I mean, yes, but um, yeah. Like, I never like my team, like, classmates are like, wow. And it's like, well, you don't Yes, but No, and it's like the people that are studying the same as I am, right. So it's like, I can learn anything, how would be like to like the people outside, you know, when I'm worrying about like, you know,

Emily: because I tell people all the time, I'm like, I because I've done like a little bit of like, as needed PRN work in the emergency departments and stuff in the hospitals like on the weekends and stuff, and I was like, I could literally never be an IDI social worker like I could never work in the emergency room like it is too stressful. It is to like, that kind of stuff to me. feels impossible. So I think it's just like that idea of like, there always going to be people that are like, just because I am maybe well suited to this kind of role. doesn't mean that I am just an inherently amazingly good person who could do any kind of really hard work like hard work means different things to a bunch of different people. So yeah, I don't always really know how to respond when people say stuff like.

María Sangrador Torres: Okay, I think that's all I take. But yeah, I think you've covered all the questions somehow. Awesome. So I really cannot thank you enough.

Emily: Oh, you're so welcome. I'm so glad you're doing a project like this. Because I think it's a really cool part of social work like that. I don't think we always talk about a whole lot in grad school or like people might even not know it's an option. So I think it's a really cool project to take on. And also to see like, how it's different here versus in your country and just like seeing kind of how different legislation different health care systems like different attitudes towards death and dying in children can affect care. So that's really cool.

María Sangrador Torres: I'm gonna send it to you too.

Emily: Yeah, I'd love that. I know, both of us would.

María Sangrador Torres: Yeah, because I can't like I am seeing like the differences. I didn't really know how to like, Put like, all the information like okay, but it's like, I'm like so excited to like, have the project like finished. But yeah, yeah.

Emily: Cool. Well, I we will be very excited to read it and see it whenever that happens.

María Sangrador Torres: Thank you so much. I'm really pleased. So I pushed her yeah,

Emily: yes, it was a pleasure to meet you too. And good luck with school and working and living life and make sure you sleep and drink water and do all those things to your will welcome I'm ready. I'll send you the file as soon as it downloads okay.

María Sangrador Torres: Okay, thank you so much. Bye

7.3. Entrevista familia en EE. UU. (Maria Matts → E3)

SUMMARY KEYWORDS: social worker, Nina, palliative care, hospital, palliative care team, palliative, child, life, talk, pain management, rachel, care, oncology, conversation, pediatric palliative care, called, people, hospice, thought, team

María Sangrador Torres: Okay, now, got it. Cool. Now, I think the recording is in progress, right?

Maria Matts: Yes. Yes. I just proved that. Yeah.

María Sangrador Torres: Okay. Nice. Nice. Thank you so much. And sorry.

Maria Matts: That's okay. I'm terrible at all of this kind of stuff. So which one has problems and like, I will sit here forever and patiently.

María Sangrador Torres: Okay, thank you so much. All right. So, yeah, um, so there are some questions. So first of all, thank you so much. Then second, please let me know. Like, if you don't want to answer any of these questions, or like, you know, you don't want to go through some topics or whatever. Like, feel free to say, Okay, I prefer not to talk about this, like, really feel completely free. And at the same time, yeah. If you don't understand anything, please let me know to. Absolutely. But yeah, like, thank you so much for helping me like, it's a really big help.

Maria Matts: Okay, so I hope that I answer. I hope my answers are what you're looking for. And it shouldn't be anything I'm not willing to answer because I've gone through this with some other things. Rachel, the social worker that set us up, she's asked me to speak at UT panels for the nursing school. So yes, I'm a big believer. For pediatric palliative care. I'm a big advocate. So I will tell anybody anything. So some of it's not pretty. So that's a warning to you. Okay, if we get into something that it makes you uncomfortable, you tell me?

María Sangrador Torres: Of course. Yeah. Don't worry, okay. Until the the like the aim of this study is like to find out what is the paper that the social worker takes place like in this whole palliative pediatric palliative care system, like kind of, and I want to do like a comparative between the US and Spain. So I'm doing like, some interviews, like two people here, like there, and then here, like to see the difference. So this is like kind of the general like, okay, so, um, yeah, so first of all, like, I don't know, would you tell me a little bit about like your story with like, Nina was her name, right? Okay. Yeah. Like, how did you find out like about this palliative care system or program? What were the other options you have? Like, why did you decide to get enrolled in this process and everything?

Maria Matts: Okay, so I'll just kind of tell my story. Yeah. Okay. And that's why I'm glad we're recording. So you can stop me ask questions. So horse in November of 2019. So two and a half years ago, my daughter who's 17 was diagnosed with acute myeloid leukemia. And I, I don't know, say in Spain, but here I think, for pediatrics, that's an inpatient treatment. So we were told, okay, you live in the hospital now. And that's what we did. Within two or three weeks, it became clear that vocabulary is different when you're talking about this after the fact. So it became clear, it wasn't going to be easy, as if chemotherapy is easy, but it became clear, she got multiple secondary infections. She had a chest infection had to get a tube to drain it, she had other infections, things were terrible. And there was a lot of pain. And so our oncologist, and the oncology social worker for the children's, the unit came to me and said, Hey, we haven't proposition for you. We want to get our palliative care team to help. But I did not know what that was. Okay, because, at least for in America, when you hear palliative care, you associate that with hospice care, do you know what? Okay. I mean, literally, so this was two and a half, three weeks into everything. And so they're telling me that we need palliative care. So well, tears, lots of, you know, whatever, you know, and they're like, it's not what you think it's not what you think. We want you to meet them. The team is, we have a doctor, a nurse practitioner, a social worker, and the chaplain was also part of this team. So I was very open to anything so I said, Okay, We all agreed to meet them, because why not? And so we met. And they're very kind and very open. They met me where I was. And they understood my why was hesitating. And then they explained what they did that that palliative does and can have a hospice option. But that is not what they're about. They're about quality of life. For me specifically for what was becoming a medically complex child pain management. And at that point, we had gotten visits from almost every specialty in the hospital for one thing or another, you know, pulmonary. You know, a&p like everybody, everybody had come infectious disease team, that's all fun. And so what our palliative care doctor says is that their team would be an umbrella up here, keeping an eye out on all of the other teams that were taking care of it. And what they would be able to do is make it all work together for our family, and they said, specifically, our family, and not just my daughter, because the other thing is they do whole family here. Yeah. Well, all of this sounded like, great to me just kind of what I do in my line of work.

I was like, Yeah, that sounds good. Because who doesn't want someone else on their team for their child? And so I was very, very open with that. And immediately they, they started talking to all the people, I didn't have to do anything. You know, they were certainly no strangers to the oncology floor. So they had other people. So I alternated. I was there a couple of nights a week that my daughter's father stayed over. We are had been divorced since she was a baby. So. So when I was there, there wasn't a day go by that I didn't see at least one person from the team, usually to, even if it was checking in, say hi. But what they did was they got to know us. They got to know us as a family. They got to know me and they got to know my daughter. Now her dad was resistant, because he couldn't get past the hospice, he just couldn't accept it very well, not that he was telling them to go away. But what they did was they made sure they were coming when I was there, you know, that kind of thing to make sure that we could really talk and there were times that Rachel the social worker, she just come in and didn't hang out. Tara thing, do you need anything, just talk, talking to her talking to me, and all of that, and took care of took over pain management, which is very helpful. And then we were there about eight weeks. Nina came home for a couple of weeks, you know on a chemo break. A couple of times we went to the blood in cancer clinic that's part of the hospital. And when we went there for bloodwork or whatever, chemo, well, we didn't have chemo there. But we have blood work and stuff. At least one person on the team would make sure that they were there for every appointment just so they knew what was going on. Because one thing that they said was once once I become part of them, and they become part of me that I'll never get rid of them. Even if there's not a need anymore. Yeah, they will always be there. And that was the case. When we went back to the second chemo round and treatment, you know, the came in, checked in how are things going things seemed well, they went south, they went bad very quickly. And so they came in again, for pain management, what do we need? The palliative care doctor had a very holistic view and a lot of things which made sense to me because they were there to take care of the family. And so she would do different things. And this went on. And again, they did pain management because something happened again, another infection. And when we left that time, Nina had been on Dilaudid, which is morphine basically. And so they had to wean her off. And so they worked with me and talked to me and did a schedule and helped me do that. Again, every time we went back to the clinic for whatever they were there. And the third time we went in was right before it was March 2020 which in nine states. We literally went in the Friday before everything shut down for COVID Okay, and which was hard. That's the timing here. And things seemed okay. And again until they weren't. And so it was harder for all of that to happen. But we I never, I never thought that they still weren't there. You know? Yeah, phone call away, but they were still coming in all of them. And then by April, things had gotten so bad that we had to have an end of life conversation. And that's a palliative took over for that. That was their job. Honestly, if we hadn't accepted palliative, I don't know who would have done that. I really don't know, because this is absolutely a choice that people make. And so they came in. And because my daughter was 17, she was about to turn 18. But she was old enough to know what she wanted. And through them getting to know her, they absolutely trusted. She knew what she wanted. She was that kind of kid. So they had those very difficult conversations with us, with us as a family. And then they talked to her alone. And I was fine with them talking to her alone, because I wanted her to be very honest, what she wanted. Yes. And they had, and they went through all the things with her. And then another family meeting, and this is kind of what we want, what's going to happen. And things turned around for a while, but again, they never went away. Because you know, once you haven't, they're there for life. Things turned around for a while. And she stayed in the hospital just for lots of reasons. And then they thought, Okay, we're ready for bone marrow transplant. Okay. And so we went, and they don't do bone marrow transplant at the hospital in Austin. But we are going to drive to the hospital in San Antonio, which is an hour south of Austin. Yeah, I went there met a palliative team. They're just hey, this is us. How are you just want to say hi. Because Rachel had called. We ended up not going there. Because once we need to have radiation and all the things and then the radiation killed the leukemia that was in her spinal fluid. But then it all came back in her bone marrow. So there was never a time that she was clear. And so this was in June of 2020. And we had to have a second end of life conversation. And this one was much I don't even know the word I'm straightforward. Because this time before, the first conversation was, they weren't sure what to do. Nina was very refractory. And they were looking into trying to find things out. And so it was kind of a pre emptive individualized conversation. This one that we had was more unless there's unless there's a miracle. This is, you know, so she went through it, again, is pretty much all of the same thing. Rachel was wonderful, they were wonderful. And then we got our the oncology team never stopped trying. And they found a clinical trial. There's lots of clinical trials all the time, but either very specific, you know, there, and they found one that they thought okay, this might work. It was in St. Louis, Missouri, three states away, like a 16 hour drive. And there was no guarantee that was going to work. It was only in phase two, but it there was not for Nina. By then she was 18. And she was like, there's not I don't have another choice. Like, what's the choice and at least this way, if I go, someone might learn something. And so we decided to do that very frank conversation again before we left from our palliative care here, plain speaking, you know, they looked at her and they said, you know that you might die there. I mean, this is but they'd had this conversation. Nina was very comfortable talking about her own mortality with this team. You know, so we went and mainly got sick on the way there so we came like flying into the emergency room at two o'clock in the morning, they got us in a room, all of this, you know, we were finally got in a room at five in the morning. I hadn't slept in, like 27 hours and all the things. But by that afternoon, someone sticks their head in the door, like it's okay to talk. And it was the palliative care team at St. Louis Children's Hospital. Because Rachel had called them and they had all the information. That mean, they were ready. It's wasn't, do you want us to come in. But hey, we're here. Because again, you can't get rid of us. And it was wonderful. And they were wonderful. And so we had a moment, I had a moment in the next couple of days, I could go and really talk to them. You know, they had been given a lot of information, but they're like, tell us about her as a person, not as a patient. And so I did, and the social worker, and one of the doctors would come in quite frequently, she was never quite her when she was there. And she was on medication a lot. So there was only a couple of times they could really, really talk to her. The clinical trial, it worked. It did exactly what it needed to do. But while that was happening, we communicate back and her spinal fluid, that radiation and killed so there was, I mean, this time it was there was nothing. So that was our third end of life conversation that they had to come in. And they were they're constantly waiting for her to be Nina enough to be able to really talk to them. And even though they had her Advanced Directive and all of that stuff from from the Austin hospital, they wanted to, for her to have knowledge and be able to say it again. And they talked when I was not in the room. And then I was brought back in. And then they talked to me very thorough, very, you know, we're here for you and all of that kind of stuff. After it, things went very quickly. And she passed on August 17 of 2020. Like at 1030 1030 at 11 o'clock at night. And at midnight, there's a knock on the door. They cleaned her body and I was just in there with her is knocking on the door. And they had called the the palliative team and their homes and the doctor left his house and came and sat with me for quite a few hours. Just doing what they do and talking to me and being there for me not trying to fix it just sitting with me in my space. And then the next day, I was waiting for her dad to fly up to Austin. And I'm sitting in the empty room. And the another of the doctors came in palliative care. And she's like, what, what do you need from me? And yeah, which I don't know, which she apologize for asking that. And she's like, Okay, here's what I can do for you. And she started talking and I think I said something to the effect that was like, I don't know, like, I don't know what to do. I don't know what to do. And she's like, What do you mean, I was like, logistically, I don't, I don't know what I'm supposed to do. So then she just did it all. She got the nurses, she made the call. She said ask the questions. And, you know, how are you what were her wishes, because if she wanted, she wanted me to take the body back to Texas, and we need to make arrangements and you know, and just did all the things and that was me. And then the social work that came in and they were just there. For me. It took about a week for her ashes that I could pick up and then I drove home. But in that time, Rachel from had called me What can I do? You know? And pretty much I got communication from the palliative care team in St. Louis. For almost a year after I came back to Texas checking on you what can we do still thinking is Mina you know, and then I never stopped getting communication from the one here from the doctor and Rachel force and then when she had set up some bereaved parents support groups that were specific for the parents of children who'd received palliative care, like very specific. And she called me sick I think I want you to do this. And I was like, no, because I don't do people. I don't like people. I don't do groups. I don't want to. And she's like, No. And you worked with Rachel. Right. So you know, I know. Okay. You wouldn't think she could be firmed. But she was like, no. Yeah, yeah. I think you need to come to this, because I think, I think you will get something out of it. And she's like, as far as the people, you will like these people, like, she went so far as to know that the people that she had selected for this group would be, we'd all get along. And so for her, I went, and it was held, of course at the hospital. And it's the first time I walked up to the hospital since we had left because Nina had gotten sick. And so when we went to St. Louis, she had spent the night in the hospital. So we literally left from their car was loaded. So it's been almost a year since I've been there. And I had a panic attack things I don't know, started crying. I mean, just walking in the sound of the doors opening and all of that kind of stuff. So of course, she came out, she got me, she took care of me. And she was she was right, that support group was the best thing that could have happened to me. And she kept in contact and say, Hey, do you want to speak on this panel at UT about pediatric palliative care? I said yes, did that she said there's another support group, then another panel, and she's still just checking in occasionally, because I'm never gonna get rid of her. I think the amount that they said, right, once you're in, they never do. But I feel so strongly about what they did for me and my family, that I advocate for them, and I will talk about them. And I tell people, because a lot of people think palliative is hospice, and they're scared of it. And anytime I hear that for children or adults, I'm like, hold up on the I've Stuart, let me talk to you. So. Yeah.

María Sangrador Torres: Okay, could you tell me a little bit more about hospice? Because it's like, I've read something about it. But I didn't really like imagine. I don't know the difference.

Maria Matts: Okay. So hospice, is I don't know the definition. But that is actual end of life care. All right. So when someone goes on hospice, that's it. And it is. So you can do in hospice in a hospital. Or if you choose to die at home, there's teams that will come to your home. And that is absolutely their number one job is to make you comfortable while you die. And then presumably, kind of take care of things. So when someone talks about hospice, hospice, it's not a bad thing. It's a very good thing. But that is actual end of life. Whereas palliative care, as I learned, it is to take care of the whole family, and quality of life. And it does not mean a death sentence. There are people who use palliative care for years and years and years, if they are medically complex, or their child's medically complex. They come in and they do pain management, they organize other services, and everything like that. And that's just a difference that I didn't know about. So the palliative care team in St. Louis, Missouri, they don't call themselves that. They're the pack and it's Pediatric Advanced Care Team. But the reason they are is because people hear palliative, and they get scared. Yeah. And so I actually had a long conversation with another mama as on the this panelist that is she, she's in my brief parents bar group. And she when her daughter died, like seven or eight years ago, she went back to school, came in nurse and now works in the children's hospital. But what she does is she speaks to parents, very specific, whatever, but when she talks to them, she tells them you know, there is an organization that will come in and help with pain and quality of life and she'll sell what palliative care is. Before she says the name because the name scares people because they think it's hospice. And hospice is this is end of life.

María Sangrador Torres: Okay, nice. So I guess hospice needs to need to have like, a specific prognosis of time, right? Yeah, okay. Yeah. Short term palliative care, I guess. us like incident like to go to hospice, like will not go. But you have to have like a specific time left, if it's good to say that way. But yes, that is shorter than palliative care. Right?

Maria Matts: Correct. For at least here, palliative care does not mean that it is a life sentence. Like when they came when, when they were brought to me. Because that's exactly what happened. I was not taking them, they were brought to me. This was just a few weeks into my daughter's diagnosis. At that time, they thought things would still, you know, because it could have been three or four chemo treatments. And then she would be going off to University in the fall. Yeah. They're about to me, because there were complications and all kinds of areas, and she was in a lot of pain, and they were there to help manage the pain and help do all the things kind of thing. They were not brought in. Because, you know, yeah, they thought Nina at that time was terminal. Yeah, okay. Yeah. And so that was the distinction is it doesn't have to be that. And I know some people who've had the palliative team for six or seven years, their child is alive. They're just extremely medically complex, and they need that extra assistance. But because they they come with the view that it is to take care of the whole family. And that is a difference out. Because they always have asked about Nina's brother, my son, who at the time was 22, he is now 24. But they got to know him in the hospital until the hospital shut down for COVID. And then they were only letting a parent in. But they got to know him. And there's never a time that they don't ask about him. How's Connor doing? Because as far as they're concerned, their job was to take care of all of us.

María Sangrador Torres: Okay, nice. Yeah, no, I got it. Okay. Could you tell me like more specifically, like, how did you feel like taking care? Like the family, like a by the social worker or the palliative care team? Like, what were the needs? You had old covered when Nina was in this, like, program or process?

Maria Matts: Yes. So for me. To be honest, my a lot of my specific needs were emotional. And don't worry about this. And I wanted to know that Nina was being taken care of by anybody who was willing to take care of her. So for me, them coming in was just another layer. And they worked very well with the oncology team. Like Ben Collins, your team, they were like, Yeah, bring, bring them on in, bring them in for every family that wants it. Like they're very open. Because again, as many people as possible, right to take care of this child. The social worker that was on the ecology unit, did a lot of things like specific and physical like logistically, like financial helps, you know, here's someone to call. They had somebody called a school liaison that works, that they took care of calling the schools and getting in doing all the things. So I didn't have to do anything like they bring in the children's hospital already. So much was lifted off me so many burdens were lifted off me. Like day to day life burden so I could concentrate on my child. But palliative care when they they came in the social worker, again, she you know, there were conversations about do you need phone calls to insurance? Or do I need to get together with the other social worker and talk about it, or money or you know, things like that. But a lot of it was, I would say mental health from the social worker, how are you doing what needs to be done and then doing the same with Nina although Nina had a psychiatrist and a psychologist assigned to her because that's the big thing for them. So she had all the help. And again, same thing with my son if they knew he was there, someone would slip in how are you doing just literally checking in on us as people and not as patients. And I think that's a bit big distinction. We did not get a lot of that. I think because we were in a children's hospital. I think for adults, it's probably very different. But never once did any of them make us feel like Nina was just a patient or she was a kid with cancer. She was Nina. And they knew everything about her. They knew her hobby. They knew her like they brought stuff in for her. Her birthday I had baked, made some guava guava hand pies because she loved guava. And like three days later, one of them comes in with a bag of guavas because we'd never had fresh flowers. And it was that kind of thing. When I think the doctor brought some movies from home, that she knew that Nina, they loved Studio Ghibli movies. And she's like, I have those set. Let me bring them so you can watch them near, you know, because they got to know us. So I would say the biggest thing we got from them. The main thing was was emotional, if that makes sense. Like yeah, of course. Just just come in and sit and talk to us. You know, but then there was the whole, they helped us navigate those three, end of life conversations. And my 17 year old daughter. This was her senior year of high school, she had just gotten all of her college acceptance and scholarship letters literally the day that she was diagnosed. The original plan if things had gone well, she would be done with chemo at May. And possibly going to college in the fall like this could have been a very terrible just part of her life. Yeah, that. And so there was a lot and she was very high achieving had a lot of stuff. And so they were very careful to very interesting. Speak very plain, and very straightforward about this is what's happening. And we need to talk about, you know, if you don't survive this if you die, while taking care of her mental health, at the same time and thriving this teenager who thought she had her life ahead of her facing her own mortality? Well, yeah, it's, it's a lot. I mean, it was a lot. And I even remember sitting there watching this and thinking, how do they do this? How are they doing this? Because it was just like a dance. What they would do?

María Sangrador Torres: Well, okay, wait, I have this like free version of zoom. So I will have like six minutes left, but okay, this cuts? Like, I'll send you another one on that. But yeah, just for you to know. But okay. So you were talking about some, like, kind of would you talk about money? Well, like social workers like financial thing. So um, because here in Spain, we have this public health and public like, but they're you don't have like this kind of thing. Right? So how was this whole word?

Maria Matts: So I can't speak to a lot of what is wrong with the medical system here in America. So Nina's dad has very good health insurance. And they actually, for health insurance company, were very receptive and assigned like a caseworker. I didn't talk to them a whole lot. Because it was him and we were divorced. So if the word Lucky is another word that those of us who have gone through this, it means something different to us. So we were lucky, we had such good health insurance. And the hospital, this particular Children's Hospital is nonprofit. And so if you can't pay doesn't matter, they're still going to treat you like, I don't know, how about side works. But you don't get turned away and you get the same quality of care, no matter what. But insurance doesn't cover everything. And so the thing that what happened with I mean, I basically had to stop working, I started working remote as much as I could. But when things got really, really bad in April of 2020, and March, I just couldn't do it anymore. I just couldn't do it anymore. And so I just stopped working, which I think is the thing for a lot of parents whose children go through this you can't work if you're driving your child to the hospital to the clinic all the time or And, you know, and so it was a matter of, you know, we know of this foundation that maybe can, you know, you apply for it, and they can help ease this cost. The one in St. Louis, you know, they found one that would pay for it, travel costs, basically, that kind of thing. So little things that they would help find, you know, not the palliative care social worker, but the oncology social worker, literally walked around with gift cards, to restaurants in her pocket. Wow, there's a there's a sound, there's foundation that their child died. And so this is one thing they do, and they give all these gift cards, and then whatever, and they would hear $15 gift card to restaurants so you can go eat or do you know, that kind of thing. So that kind of financial, as far as Yeah, the actual paying of the medical bills. There's not a whole lot, there were a few things that they found for us that we could apply for. You know, I think one foundation sent me money because I had to stop working. Because my child lived in the hospital. Yeah, that kind of financial stuff. I don't know. And stuff. I don't know, I didn't pay for anything after Nina died, all the phone calls that were made for me. And then I got a phone call. Okay, you can come pick up her ashes, and I never paid for any. I don't even know who did that. I have no clue. Honestly didn't ask that kind of stuff.

María Sangrador Torres: Yeah. Okay. That's great. Yeah. Yeah, of course. Okay, so, here's my last question. Like when you first like the first contact with the social worker, like, after that, you said, like you didn't know anything like about palliative care, right? Correct. Like, did you got like the idea of what social worker was that? Like, in this case, Rachel, right. What she was going to be doing with you on with your family? Like, did you cut the idea? Like, okay, here's, did you have any, any other contact with social workers before? Like, in any other aspect of your life or whatever? Like, did you like cut the the saying, Okay, this is what social workers are. And this is what a social worker is going to do. For me in my life?

Maria Matts: No, not a clue. I had no idea. My knowledge of social workers was limited. I didn't have any experience in real life with them, it sets, you know, what you would see in TV and the movies and the things that they did. And when I went to, when I went to college, I thought about going to school of social work, but I decided to go to psychology, because that was more like individual. And that was, that's basically all I knew, I'd never had any experience with them. And then when Nina was admitted to the hospital, and the oncology, social worker came and talked to us, and basically said, I'm here to help, you know, anything you need, sort of help you navigate and all that kind of stuff. And so I was like, okay, you know, so, you know, she's like, here's some free mental health things and kind of saying, here's some things that I can give you. But it wasn't until and then of course, I didn't know what palliative care and after meeting them and then crying in front of them for like 30 minutes. I mean, you got a bond there, right. And then they kept coming in. Yeah. And this Rachel as a social worker for palliative, she felt a little bit of a different role. I mean, she did help with some of that stuff. But a lot of it really truly was emotional talk to me. So I got kind of, I think, the best of both worlds of what social workers can do in that setting. And then I just realized I have a third social worker now that she is my personal counselor after my…

María Sangrador Torres: Sorry? You were saying you had this third social worker?

Maria Matts: Yes. So after my second round of brief parents for group for palliative care, very specific, but it's so specific because we all had not just that our children had died. But the very fact that they received palliative care meant that they were medically complex. And and probably been through a lot of horrible things. Right. So it's exactly the right kind of people to be able to actually talk about those horrible things that you would never ever tell anybody ever, except for someone who's been there. And then during one of those, it was right before the holidays, Christmas. And one of the participants, a dad, he, he basically broke down like started saying, his wife was like, he's never said any of this out loud. I mean, it's, it's not funny, but I look back on it. And it just started a big trauma circle, maybe. And poor Rachel sitting there, like, everybody's just like, and that kind of like, oh, like, I think I have a handle on my grief. But what I don't have a handle on is the trauma. Yeah. And there's a lot of trauma. And so I went to a kind of look, try to find someone and that's very hard. And then I have a friend who's she's a social worker for a early childhood education program, and all of that kind of stuff. And so I've flat out I asked her, I said, I need you to help me. I don't have the mental capacity, like I'm not I can do to show up to work every day, I need you to help me find somebody. And she's like, on it. She's like, I have a friend. She's in practice with a friend. And that's you need to go see. And I did and she's like, she's a licensed social worker. But she does this. She does grief counseling and trauma. And I love her. Because I like her approach with me. With stuff, she's not trying to fix me, she's just letting me talk and then sits there and makes me reflect on everything until I figured out like, I know what you're doing. So yeah, so now that's actually a third social worker. And she's a to those familiar about the purchase kind of palliative care at whole family and whole everything. So yeah.

María Sangrador Torres: Okay. So nice. Okay, and would you say like, there's something? Okay. I know, it's hard, but try to forget that the social worker was Rachel. Okay. Okay. Imagine like, do ya? Do you think like, this social worker could have done something else? Or, like, help you in something that she was not, like, aware of what you were, like, needing at that time? Like, you know what I mean? Like, what would you improve, like about the treatment you have received? By the shots?

Maria Matts: Yeah, that one that's difficult only because I had the price of social worker and the oncology social workers. I had two of them. So I couldn't speak to if I didn't have the oncology one, what the other one might step up and do. Honestly, it's hard to think about what to improve because there's a lot about that full time that I I don't, it's not that I don't remember. But it's hard to, to really pinpoint stuff. I don't know. And it's not that that experience was perfect. I'm just really not sure. Because I don't know what more there could have been. Because it was all new to me that everything that they did was new to me. And I was actually getting support from so many places. That I I felt it, you know?

María Sangrador Torres: Yeah.

Maria Matts: As far as as lacking. I mean, I could speak more for when I got up to St. Louis and that palliative care team, but that's an unfair statement, because we were only there for eight weeks. Yeah. And the fact that they were literally They're waiting for me, because they had been told, Hey, someone's coming in, they need you. They were there and they were prepared and they did everything they could possibly do in that eight week time. So I can't even say anything about that. I didn't feel the same thing. But it's because I didn't get to know them. Like I got to know the other team that I had been living with for six months.

María Sangrador Torres: Yeah, of course. Yeah. Like things weren't given us. They were like, maybe you like you would not think about any other Things at that time, you know, like, yeah, that's fair.

Maria Matts: I mean, yeah, I mean, it's really like if I already knew, and like I said, once I met them, or having not known exactly what palliative care was and explained to me and what they could do and what they could offer, and then I was like, oh, yeah, like everybody on the team, I want everybody on the team. And I, we have been told, when we first when Nina got diagnosed and checked in the hospital, we had been told advised against, like, don't google anything, because you start Googling that? I mean, you okay, you're nodding like, you know, well, I absolutely was like, What is palliative care? Because then it was like, what is it? And I started reading about it. I was like, why doesn't everybody know about this? Why isn't every child in this unit using it? Or that hospital? We were just oncology that there were the heart unit? Why isn't everybody using this? The four member team? So that tells me not everybody's using it? Why isn't everybody using this people need to know. But even then, you know, if I'm googling and reading descriptions, it all comes down to to me is they'll be whatever you need them to be. Does that make sense? Yeah, of course. So what they gave to me was probably not what they gave to another family, right? What what I needed from that social worker was to sit next to me on the couch for an hour and talk. And I knew the kind of things that she was talking or whatever I knew, you know, she's, she's checking in. But that's what I needed from her, because of the other social worker was the one that was helping me, you know, what, not helping me making phone calls for me or contacting or, you know, that kind of stuff that that's what I needed. And maybe that was the magic of it is they were able to provide what was necessary, because I know for sure, the way that they talked to me and my daughter is not the way that they would have talked to another family because Nina was 17. And she has, she was an interesting person. And she had a lot of interesting likes, and she would talk to them about it, you know, and they enjoyed talking to her, and she was very invested in her own healthcare. Yeah. And so they figured that out, because she would have long conversations with her oncologist and all this kind of stuff. And they would write things down for her. And she did the same thing with these guys. What exactly are you doing? What are you here for, you know, and so they got to know her. And so I think, part of that quality of life. And this is, you know, this is from me, and I have no knowledge outside of my experience. Part of that was being what we needed them to be, and they stepped up. You know, and they absolutely did what was necessary, you know, and we certainly saw the doctor have words with a doctor and another department that didn't know us, and they're like, No, we're doing it this way. Because of this, and because of this and questioning things. But I think it takes a special person to be on a team like that. Because really, even though not every child that they're going to take care of and family is going to end you know, and if you end up in life, not every but things have got to be pretty bad for them to be brought in to begin with, though. And I look back now. And I was like, I don't know how they any of them did that and got to know my daughter the way they got to know her. And just to say goodbye to her. Yeah, you know, because we were trying to get back to Texas. Like the night she died the next day they were giving us medical transport because Nina wanted to, you know, to she said I want to die in Texas. I want to die. She wanted to go back to the hospital. She didn't want to die at home. She wanted to go there and they were all waiting for they had a room ready for her actually, I found out later because they were all ready. And you know, palliative care was ready, oncology was ready. They were ready for her to come home. And they were going to be there and she wanted them there. And they were going to be there to say goodbye. But they didn't get say that kind of goodbye.

María Sangrador Torres: And you know, yeah. Well, wow. This is more than enough. Like really? Nice. Thank you so much. Yeah, really.

Maria Matts: You're welcome. Like I said, I will read the Word and if I can spread the word in other countries and I will do that to no scores.

María Sangrador Torres: Yeah. But I mean, I have no words like now it's 1am in the morning, and I know I know I won´t be able to fall asleep.

Maria Matts: Sorry about that!

Maria Sangrador Torres: No, no, no Please! Thank you so much. Like, really?

Maria Matts: If you have any follow up questions just email me or anything like that because like I said, I will tell the story to as many people as they need to, to normalize to normalize it. Yeah.

María Sangrador Torres: Okay. Thank you so much for open, open up your heart and your life to me, like someone you don't even know. But thank you so much. Really.

Maria Matts: You're very welcome. I hope this helps.

María Sangrador Torres: Yeah, it does what it is. Okay. Yes, thank you. And have a nice rest of the day. Thank you. Bye T buyer. Thank you so much.

7.4. Entrevista a familia en EE. UU. (Sabrina Romero → E4)

SUMMARY KEYWORDS: social worker, dean, palliative care, rachel, ended, months, people, doctors, jaw, hospital, nicu, dell, program, felt, child, conversation, therapist, knew, palliative care team, ventilator

Sabrina R: I started recording it and I can send it to you when it's done.

María Sangrador Torres: Okay, nice, nice. Okay. All right. So let me start like, well, first of all, thank you so much. I'm sorry for my English. If you don't understand anything, please just let me know. And I'll try to say it again, or in another words or whatever. But yeah, so this is like my study. So I'm finding like to find out what is the paper that the social workers take in this process of pediatric palliative care. So last semester, I was in, in the US do like an exchange program with my school and whatever. So I decided like to do this project, comparing the patriotic patriotic palliative care between Spain and the US. So that's why I'm like doing some interviews to some people here. And then and there. So, yeah, thank you so much for helping me. Yeah, like, it's, it's really a really good thing, and it helps a lot. I think it's going to help a lot. So, yeah, okay, so you can, and please, if there's something you mean, you don't want to answer or like or whatever, just, it's important for me. Okay. Yeah. Is there anything? Okay, just in case, and like, this information is only going to be used to this project. Okay. So like this privately, policy and everything? Like, don't worry about it. Um, yeah. So that's it. I just want to know, like, first of all, like a little bit of like your story in general, like, the illness of D and right has been, like, how did you find out about this palliative care? Not program like, option? What, what were the other options you have on? Why did you decide to, to get enrolled in this process, etc.

Sabrina R: Okay, so we'll start from the beginning, Dean was born with multiple genetic mutations that lead to a lot of problems. We didn't know any of that was true before he was born. But he had what's called a precipitous birth, he was born very quickly. And as a result of that, he ended up with some fluid in his lungs. So he was breathing too fast. So they sent him to the NICU just until that could resolve. But when he was in the NICU, the doctors there noticed some slight cranial facial abnormalities. They said that they could just be his anatomy, like they weren't severe enough to be conclusively indicative of anything, but that they could be indicative of a chromosomal disorder. So they did a brain ultrasound and a heart ultrasound. His heart was fully normal. But they discovered that he was missing a structure in his brain called the corpus callosum. And it's basically like the communication highway between the two halves of the brain. It's what allows them to talk to each other, and he didn't have one. So we knew and that was on the day after he was born, that we got that news. So we knew that he was going to have challenges but we didn't know to what extent and we didn't know yet why he was born that way. We didn't know about the genetic mutations that came came later. In the beginning, he ended up staying in the NICU for five and a half weeks because it turned out he couldn't eat. He would get too exhausted just trying to swallow. He would drink like less than half an ounce of milk and then he would pass out for six hours and and then try again. And so we ended up having to get a feeding tube placed a G Tube. And so he got released from the NICU after we got the G to which he got it five weeks. So we went home with that. Then when he was three months old, he caught his first cold and went into respiratory distress. We had to go to the ER we went to Dell Children's and they discovered that he had severe obstructive sleep apnea. They did a sleep study and they found that he stopped breathing 59 times in one hour. From the obstruction. It turned out his jaw one of his like cranial facial abnormalities, his jaw if I talk too fast, by the way, telling me to slow down okay, I'm perfectly okay. His jaw was recessed. And it meant that when he would fall asleep, his tongue caused his epiglottis to block his airway. So they did a jaw distraction surgery, they cut the jaw on both sides, attached these distractors, and then slowly brought the jaw forward. One and a half centimeters total, when all was said and done in order to relieve that obstruction so he could read. So it went through that. And it was in the hospital for a month. With all of that, recovering, he ended up had to be intubated and sedated for eight days before it became safe to activate him while they brought the jaw forward. And because of the narcotics that he was on during that period, he ended up with really bad withdrawal symptoms. And it was several weeks before we were able to get that under control enough that he was safe to go home. So we were there for over just over a month. But then, a couple of weeks after that he started obstructing again, in his sleep, and it wasn't as bad as it had been before. But it was getting progressively worse. We ended up back in Dell Children's a month later in respiratory distress again, and they figured out that he had a floppy airway. So at that point, he got a trach tracheostomy. Okay, yeah. And that was one day shy of six months. He got the tracheostomy tube in between all of that he was not tolerating his feeds very well. He was throwing it up all the time. And there was concern about aspiration because he couldn't swallow well, so his G Tube ended up having to be changed to achieve j two. So we bypassed his stomach altogether with the formula just went straight into the small intestine. Also, in between those two hospitalizations, he ended up with a spiral fracture of his femur. Yeah, somebody was holding him, and she fell while holding him. And she protected him held them against her body. She just landed on her butt. But like somehow, the way she held him against her, his leg got like twisted, and he ended up with this full spiral fracture of the femur. But it was too small for a cast. So he got put in a hip dysplasia harness to stabilize the femur. So we were in that for six weeks. So he was still in that when he got his trach. That was another one month hospitalization with the trach. Then he came home. Then when he was nine months, he started having seizures developed epilepsy. Just prior to that two weeks prior to his first seizure when he was like eight and a half months, we finally did whole exome sequencing and learned about his genetic mutations or why he was having all of these struggles. And the good news was, we learned that one of those mutations, most of the kids who had it had epilepsy as well. So when he first started having seizures, it was two weeks to the day after we got that result back. And so I was able to be like, Oh, that's what that is. Okay, well, my kid now has epilepsy. Through all of that, I don't know at what point it was that we were approached for palliative care, but it was one of our many hospitalizations at Dell Children's. They came and sought us out and explained what the program was and asked if we were interested in that for Dean. And we were just so overwhelmed with everything that was happening with him. And it was, you know, one thing after another after another, and his whole life ended up being one thing after another like that. But we were like all the help. Yes, we'll take all the help. If this thing by all means yes. You know, and they had to explain like, and I've run across this in the adult world, as a nurse now, you know, people have this conception of palliative care as being synonymous with hospice. And I think part of the problem is that in the adult world that almost is synonymous with hospice. And so they had to explain that that's not what it means in pediatrics. But, you know, they explained all of that there was just basically additional support, help with quality of life help with pain management. And so we were like, by all means, yeah, of course.

María Sangrador Torres: Yeah. Well, well, that's a lot of things that yeah, really short period of time. Yes. But Rachel is like, how you felt when, like they asked you to maybe join the program is like, kind of relieved somehow or like, something like I lied on, like you were so, like, overwhelmed.

Sabrina R: Let's see. Okay, that's no, it wasn't really a relief. It was more like, just the next logical step, I guess. Uh huh. Um, you know, I was a computer engineer at the time, my husband is also an engineer. We're both like, just very logical people. And, you know, we kind of take this approach of gathering all the information and just making the best decision from the information that we have, you know, we, we're not those people who are like, you know, I run across this all the time, as a nurse, we're not those people who don't want to know, whatever it is, don't want the worst and best case scenarios, because it's just too much, and we can't handle it. And we'll be an emotional wreck, where the people were like, no, no, give me all the information, telling me the best case, tell me the worst case, give me like, approximate odds. I know, you don't really know. But you know, tell me, in your experience, what do you think, and then we'll go from there. And so not only didn't care, it was just like the next logical step in the journey, it was like the next thing that just made sense for everything that was going on. And we knew that we were overwhelmed, because it was a lot that was happening. And we were not going to turn down any support that was offered. And this was just more of that. So I wouldn't say like the program itself provided relief just because of the nature of the program. That said, though, the doctor that was with palliative care when we were there was Dr. Hurwitz.

And I don't know if you had a chance to meet him or not, because he's not with that team anymore. He was awesome. And one thing that I probably appreciated about him more than all all else, was that he was one of the very few doctors willing to have a completely frank conversation with us about Dean's prognosis. And it was surprisingly hard to find people willing to engage in that conversation. And I think, you know, they just a lot of times are like, worried that if they say something too dire, the parents will freak out? Or I don't I don't know, you know, I'm sure there are a lot of people who would freak out, like, I get that. But we needed to be able to have a frank conversation and know what the actual chances were, and have an understanding of how long might we have with our child. You know, we knew it wasn't going to be long term. So are we are we talking? You know, six months? Are we talking eight years? Are we talking 30 years, like we know, he's not going to live to be 90? Okay, but like, in that there's a long range in there, you know, and not that many people were willing to engage in that conversation. And Dr. Hurwitz was one who was and that was a big relief for me, because I needed to be able to have that in order to cope with the situation on the whole.

María Sangrador Torres: Yeah, of course, of course. Okay. And then, like, I'm in the US, like, since there's no public health for everyone, they're like, if you're in Spain, we have this public health for everyone. And then you if you want, like, in addition to the public attention, you can have your like your private one, right. But like, how was like the the legal process to get you had to like to?

Sabrina R: I'm glad you asked that question. It was a nightmare. It was horrible. Long story short, it was horrible. So we actually got very, very lucky, and I'll explain what happened when he was in the NICU. So social worker there approached us with a program that they called Social Security, which is, I guess, different from like, Adult Social Security. I don't know if something different but they but it was called Social Security. But it was basically like, funding. It was like, while he's, you know, hospitalized for this long term, stay in the NICU. This program will pay those bills. And we're like, Great, yes, Sign us up. And they helped us through that paperwork. And we got that going. What was supposed to happen was when he was discharged from the NICU that was supposed to go away that funding, and then it would just be our regular private insurance that we had through work but There, there was a mistake made somewhere and that funding did not go away. And I was actually freaking out about it. Because, you know, I, as I mentioned, like, by three months, we were already doing one month long hospital stays.

So the cost of that is astronomical. And I was terrified that because we weren't supposed to be getting this funding, but they were still paying for everything that they were gonna, like, expect me to pay it all back. And we didn't have that kind of money. That was that was we make good money as engineers? We didn't have that kind of money. I mean, it's like ridiculous how much hospital stuff costs? So um, I was trying to figure out okay, well, what are we going to do? And there's I found out from Rachel, actually, she's the person who saved my whole life when it comes to this. Because before Rachel, I pretty much thought social workers were useless. No offense. And and I have to say, most of the social workers that I had come across prior to Rachel kind of were useless for us.

María Sangrador Torres: Yeah.

Sabrina R: But Rachel, put me on to this notion of these federal programs, one of them being MDCP. I don't know how much you know about these different programs. MDCP stands for Medically Dependent Child program. It's a funding program for children who are, you know, very sick? And they will, it's basically it's a Medicaid program. It's a Medicaid waiver program. Yeah. So you know, Justin, I made good money. So we could never qualify for Medicaid from our income standpoint. But the you know, we learned about these Medicaid waiver programs that based on your child's medical diagnosis, you could still get Medicaid for that child. But MDCP had like a eight to 10 year waiting list. That said, there's this like List of 10 conditions, that if your child has two of the 10 conditions on this list, you get to jump ahead of the waiting list, jump to the front of the line to get into this program. And that matter, too, because the way the program was designed, and I only know all of this because of Rachel. But the way the program was designed, it's meant to be a program to allow children who would otherwise have to be institutionalized live in a hospital style setting to be able to live at home. That's the whole point of the program. So in order to qualify, your child has to have lived in an institution for 30 days. Well, okay, we're not doing that. First of all, we're not sending our child to some random institution for 30 days. But if your child has to have these 10 conditions, and jumps, the waiting list, because now they're considered medically fragile, then your stay is only 24 hours, not 30 days. Well, Dean qualified, he had two of the 10 conditions. He had a tracheostomy, he had a feeding tube. Eventually, he was put on a ventilator. He had epilepsy, between all of the things. I don't remember what the list was, but he had two of them. Yeah, so we got to jump ahead of the waiting list to the front of the line. Then we had to find an institution that is like on the government approved institution list, get him in for a 24 hour stay, during which time we at this point, he already had his trach. So we had Home Health Nursing, we got that starting when he got his trach way. So we took the home health nurse with us, we went the three of us, the home health nurse, myself and Dean when stayed at this institution overnight to qualify for the stupid program and get Medicaid. Well, this time leading up to that we were still getting that Social Security thing that we weren't supposed to be getting. But I finally got a hold of somebody to ask about. It's like I was terrified, I was gonna pay back that money. And I got sent on the runaround, like nobody's business trying to contact these agencies just to figure out what are we doing here? And I finally got a hold of somebody from MDCP. Who said, if the government messed up and didn't take you off that list that's on them, and no, you will never have to pay that money back ever. And so we went straight from Social Security over to MDCP got Medicaid, everything was paid for. So we are very lucky because there's could have been a period of months in there where we were having to cover all of that and we didn't have to Okay, once he was on Medicaid, then then we reset Medicaid paid for everything.

María Sangrador Torres: Yeah, okay. Okay, got it. Got it. Okay. So I mean, that makes sense. But I wouldn't question like, at that point, I guess Is Dean did not have like siblings, right? Does he have any older sister?

Sabrina R: Yeah, he's a second child.

María Sangrador Torres: Okay, okay. Okay look like later or I got that but she's just like, Okay, so, um, um, sorry. Okay, so, um, I had this question, but you already answered but it's like, I just wanted to know a little bit more like, what was the the, the contact you had with social workers before? Like you said, like they didn't help like you. Like, in concretely, but I don't know, like, tell me a little bit more about like this contract for work before.

Sabrina R: So my first interactions with social work were in the NICU, I hadn't done it before, then we had the one social worker who was helpful got us on the social security thing. But, um, other than that, what it felt like, and I have no idea if that was intentional or not, but what it felt like was they all just wanted to be a counselor for us, basically, they, they, you know, every social worker who approached us wanting to know, like, did we want to talk about the hardships? Or did we need a therapist, basically, it seemed like they all wanted to be a therapist. And neither Justin nor I were really interested in talking to a therapist at that time. Now, that changed later, I have a therapist now that I see regularly and have for years and will never quit. But at that time, we were not so interested in like, you know, baring our soul to some random stranger at the hospital. Like that was not something we felt like doing. And as far as I could tell, that was their only use. Like, I couldn't, I didn't know, I don't understand what a social worker does. And they never seem to offer anything other than that. So like, I had no use. Yeah. So then later, when people like you want to talk to a social worker? Oh, no, I'm good. Thanks. At Dell Children's. I think the reason we were talking with Rachel was because of her affiliation with palliative care. And so it was like, when we decided to go this route with palliative care. Well, Rachel just sort of came with that. And she is just a special human, and, you know, makes everything better just being around her. Like, she just, I don't know, she, I still participate in a grief group that she is a facilitator for, because like, and I probably would not do the grief group if she wasn't part of it. Like, she's just special. But she always, you know, remembered us. She remember Dean, she took a legitimate interest. She was happy to have factual conversations about anything and everything provided concrete help when we needed it. You know, she didn't just want to be a therapist. She was more like an overall resource. Which I think is why I valued her so much more than any other social worker. I had come across up to that point.

María Sangrador Torres: Yeah. Wow. Yeah, that's so nice. Like, I got the chance to talk to her like during her interview, and like when I hang up, let know when I hang up. I don't know. Well, when you close the call. I said, like, I want to be a social worker. Thanks. Can fire that? Yeah, right. Yeah. I mean, yeah. I usually like it to to get to know her, I think because it's like, I don't know, I got to meet Emily, too. Well, I don't know. Do you know her? But she's so nice to, but it's like, well, they are different, right. But yeah,

I don't know, social workers in this, like, maybe it's palliative care. I don't know. But they are like so. So nice. And they like professional, right? It's not only like a friend, but maybe two but it's like, professionally speaking is so cool.

Sabrina R: Well, I might do this now who I see weekly, is a social worker. She's a licensed therapist, but she's the Social Work version, right? Like she's, I forget, it's like LCSW, licensed counselor, social worker, something like that. But um, you know, I didn't realize that that's like, part of their job is to just be a therapist. I didn't know that before, either. And so like, I hadn't realized that there was such a variety of what you can be as a social worker. I love my therapist. She's amazing. So like, you know, I've changed my tune about the value of social workers. But initially, I was not seeing it.

María Sangrador Torres: Yeah, yeah. It's I mean, I understand totally, um, okay, so but once you arrive to the hospital like, well, like when you got enrolled in this program, not to the hospital, because it's like, like, how would the different aspects of your life like affected like maybe, like, on your you talked about like some of the economy like feel but like in the family How was the, like more like the things that surrounds the situation that like the medical one, but like just said about this other sister right? Agenda? Like how you?

Sabrina R: Yes. So hello, I had to piece all the different pieces together because the other piece that was really helpful like for Ellen, who was my other child, was the child life specialists in the hospital. And I'm trying to think, I don't remember if we just got approached by child life specialists because we were there and that's what they do. Or if Rachel put us in contact with them, I don't remember how that worked. But um, that was a big help, because the child life specialist and sometimes Rachel herself would do this would take Ellen out of the hospital room down to like the sibling playroom, and just go play with her separately. While we were dealing with it, we were dealing with Dean in the hospital room itself. And that was really, really beneficial for us not having to worry about both children, Ellen was handled, she was taken care of. And we could focus on the medical complexity of our son, but also for her, because you know, she spent so much of her life, all of her life, the Dean was around, almost having to like, take second place, right? Like she very much had to defer to whatever was happening with Dean because everything with Dean was life or death. And okay, my meeting is gonna be like this, so this is just free zoom. So it's gonna run out in 10 minutes. If it runs out, I'll just restart it, and it will go again. Okay.

María Sangrador Torres: Nice. Nice. Thank you. Yeah.

Sabrina R: But, um, so Rachel was a big help with that. Because she also just would entertain Ellen, she would bring stuff for Ellen to do. And then the child life therapists would do that, as well. But the other thing that was nice was, every time we ended up at Dell Children's because we were in there constantly, Dean had, in addition to all the things, he had primary immunodeficiency, and he got constant respiratory infections, and where he needed to be ventilated. And we didn't have a ventilator at home for a long time, because he didn't need to be ventilated unless he was sick. And so every month we were back in the hospital dealing with another respiratory infection on a ventilator. And one thing that was nice about being with palliative care is it was a group of people who checked in with us every time we were there. And so it was like somebody who already knew your kid already knew your situation, who could help aid that continuity of care piece with each hospitalization. And eventually, we were there so often that we didn't even necessarily need that because all the doctors knew us. But you know, depending on what we were there for, we'd end up in different units. And so we were either in the ICU in the IMC and the respiratory unit, or in the neurological unit. And so some of those units, we read a lot more than others. And so we were less well known, depending on where we were, and it was people who could step in, oh, hey, how are you doing? You know, what's going on with Dean this time, they knew the history, they knew all about us, they knew our names, and it made the situation more comfortable. And what I mean by that is, Dell almost felt like a second home after a while, like we were just there all the time. So I mean, it's kind of hard to get around that but they made it so that I didn't hate being there. I hated the circumstances that led us to be but I always felt loved at Dell. And I think we're a big piece of that. I don't think it would have been that way without the palliative care team to at least yeah the same extent.

María Sangrador Torres: And when you when you see these people that you know knew you on like God to okay, how is Dean doing this time, like, whatever. Like, what people do you mean like it's just like the doctors or like nurses or like it's a mix of people or social workers or you know.

Sabrina R: It was Rachel and Dr. Hurwitz mainly. Yeah, mainly, it was mostly those two individuals. I mean, eventually it was also all the doctors and whatever unit we were in if we were in that unit a lot, but you had to it was the doctors and then it was Rachel and Dr. Hurwitz. And those two people were the ones who would just check in with us. Every time we were there. Ask if there's anything we needed. You'll be willing to entertain any conversations we need. Oh, and you know, one other thing palliative did for us, I just thought of this, but this was huge. They organized our care conferences. So Dean had to be followed by so many specialists. I mean, we had gi respiratory neurology. Musculoskeletal when he had the fractures, we had immunology. I mean, there was like, there was just a ton of them. And so anytime something was going on in one system, and inevitably affected every system, and we would need something from all of these freakin people, and the palliative care team, often were the ones who sort of organized these care conferences for it with all of these doctors together so that we can all sit in a room and have a conversation with everybody. So we're all on the same page and make a plan and figure out what to do. I think they spearheaded that. I think that was them. And that was huge. We needed that.

María Sangrador Torres: Yeah. Yeah. Maybe you didn't know you need it. But yeah, it's really helpful. Yeah.

Sabrina R: And then they also were the ones who took over a lot of the pain management. So Dean had visceral hyperalgesia, which basically just means he had extreme, not normal levels of visceral pain, internal, like organ pain, and just all the time. And that turned out that was a big piece of why he didn't tolerate all of the formulas, all of the food was because he had all of this gut pain. And the doctors would prescribe pain medicine, but it wouldn't be enough. And Dr. Hurwitz, as the palliative doctor took over the pain piece of it, and was able to, to really more aggressively, I guess, prescribe pain management medications, that, you know, we could find the right balance between managing the pain but not knocking him out. Right. We didn't want him to just be sleeping all day long. But he was the one who really did that piece for us, too. So that was a big help just for quality of life.

María Sangrador Torres: Well, yeah. Yeah. Well, yeah, that's a big job. Yeah. Okay, and like, I'm so you after after this, like all the process, I've never think like, when kind of sorry to say this this way. Like, like, we need ended up like when? And then that everything? Like I? Yeah, like you said, you were in this grieving. Right. But like, is that the only contact us to you still have with the social worker with Rachel in this case? Or is like, like after that? Did you feel Did you feel like maybe warm? I don't know. Is that the word like maybe covert or supportive?

Sabrina R: Yeah, that's the word by social world like the palliative care team. So that's harder to answer because after Dean died, I very much didn't talk to any of the medical professionals. At all, like our other favorite doctor, asides from Dr. Hurwitz was his neurologist, Dr. Kane. And I mean, like, hands down. My favorite. And part of that was the fact that he also was the he was the other doctor besides Dr. Hurwitz, he was the other one who was willing to have the frank conversations with us. But we knew him from the beginning. He came and saw Dean in the NICU in the very, very beginning. And so, you know, he knew Dean's whole life story. And I had a really good relationship with him. And I have not spoken to him a single time since Dean died not once. And I just couldn't bring myself to do it, frankly, like it was just like, I didn't even know what to say. It just felt awkward and weird and only conversations we'd ever had were about my son who now is not here. And so I just never did that. And so that was true across the board. So I didn't really have any interaction with palliative care either. The only exception to that is Rachel, specifically, I had not joined a grief group, I didn't think I wanted to join a grief group. And Rachel sent out an email. I know Dean had been dead for like six or nine months or something like that. And it was probably about six months. And she sent out an email offering a four week long grief group for specifically parents of children who died who had been part of that palliative care program. So this was part of her palliative care thing. They did just a little miniature four week long grief group, for those families where the kids died. And I decided to participate in that and found it to be very, very helpful. And so after that, that was when I decided to seek out a permanent grief group and it turned out she facilitates one of those two and that was the one I joined. But, um, I would say from that standpoint, yeah, palliative care, and Rachel specifically was directly responsible for me finding that support after Dean died because I would have never done it otherwise.

María Sangrador Torres: Okay. Okay. So it's not something you were looking for, right?

Sabrina R: Nope.

María Sangrador Torres : Okay. Okay.

Sabrina R: I didn't think I would like it. I didn't think it was something I wanted. And I only was willing to try it because it was bounded as for weeks, you know, and it was free.

I didn't have to pay anything for it. And so I was willing to give it a try with with that in mind. And it turned out like I said that I found it very helpful. And now I still participate in a grief group now. So it's my daughter who both too early. Yeah, she's in one for children. Same organization, but it's hers is targeted for children.

María Sangrador Torres: Wow. And how will Ellen know?

Sabrina R: She's nine now. Wow, it was five when Dean died.

María Sangrador Torres: Wow. Yeah. Well, yeah. Well, so these are all my questions, but thank you so much again!

7.5. Entrevista a trabajadora social en España (Elena Catá → E5)

María: ¿Hola? Elena. Elena, soy María. ¿Qué tal?

Elena: Hola. Muy buenas.

María: ¿Te pillo bien?

Elena: Si. Cuéntame a ver qué es lo que necesitas.

María: Vale, mira, no, simplemente son unas preguntas muy facilitas, perdón que estoy de viaje yendo en tren, por si hay algo raro, simplemente. Estoy haciendo eso. Un estudio sobre los cuidados paliativos pediátricos. Y estoy haciendo una comparación entre España y Estados Unidos. Entonces, nada. Básicamente es un poco ver cuáles son las funciones que como trabajadores sociales tenéis para con las familias y luego qué necesidades son las que suelen expresar las familias cuando llegan a ahí al centro de cuidados paliativos, en este caso el Niño Jesús, ¿no? Entonces es un poco eso. Y luego ya por último, bueno, sino luego te lo digo, pero para que tú te organices un poco el discurso. Básicamente los retos a los que crees que tú te estás enfrentando como trabajador social, como lo que no está cubierto o esto no está tan atendido, etc.

Elena: Y de donde estás sacando los datos de Estados Unidos.

María: Pues he entrevistado a dos trabajadoras sociales de allí, de un hospital de cuidados paliativos pediátricos, también.

Elena: ¿De un hospi o de un hospital?

María: De un hospital.

Elena: Que bueno y de qué zona son.

María: Yo es que estuve en mi primer cuatri en Texas de intercambio entonces pues en un hospital de allí de Austin.

Elena: Qué bueno.

María: Sí, la verdad es que es muy interesante. Está siendo muy interesante el estudio.

Elena: Qué bueno, que bueno. Pues yo quiero el estudio, con lo que te salga.

María: Vale, perfecto. Pues yo sin problema te lo paso vamo. O sea, yo encantada. De verdad.

Elena: Claro, cuando ya lo tengas presentado y todo por ver un poco qué es lo que ha salido.

María: Vale, perfecto. Yo encantada. De verdad

Elena: Me parece súper interesante. Sí, sí.

María: Mil gracias. De verdad.

Elena: Bueno, y entonces un poco lo que necesitas son las funciones. ¿No? De lo que hace el trabajador social en cuidados paliativos pediátricos. Y vale, ¿has revisado algún documento o algo?

María: ¿Del hospital el Niño Jesús?

Elena: No, en general de funciones de trabajo social.

María: Sí, pero básicamente la idea que tengo... Vale perdón, porque también hice una entrevista en Laguna. Que allí no hay trabajadores sociales pediátricos como tal. Pero estuve hablando con Araceli y con Lourdes. No sé si te suenan que son las encargadas como de... Osea no son trabajadores sociales, ni siquiera son psicólogas ni nada, pero yo eso no lo sabía. Me lo dijeron allí y entonces me estuvieron contando y tal. Y básicamente lo que me contaron era un poco como la labor de gestión que se tiene de recursos, de poner en contacto, de derivación, a lo mejor de la familia. Pero si eso.

Elena: Vale, vale.

María: ¿Sabes? Que lo tengo como muy por encima y como con pinceladas, ¿sabes?

Elena: Claro. Bueno, normal. Ya, según vaya avanzando irás construyendo un poco todo. ¿Las funciones, empezamos entonces?

María: Sí, genial. Perdón, lo voy a estar grabando, ¿vale? Porque luego lo tengo que transcribir. Tengo aquí ordenador y aparte lo estoy grabando. Vale.

Elena: Vale, vale. Mil gracias. Nosotros en la Unidad de Atención Integral Paliativa, que es como nos llamamos o AIPP Pediátrica del hospital Niño Jesús es una unidad donde desde el primer momento el jefe de la unidad, junto con el Trabajador Social integrado dentro del equipo. Las funciones de trabajo social van dirigidas a la familia, al paciente y al equipo. Me voy a poner los cascos, que así puedo ir haciendo más cosas.

María: Vale, perfecto, perfecto. No te preocupes. Sí, sí.

María: Si, ni te preocupes. Vale, genial.

Elena: Vale, entonces, lo que te decía, que las funciones van a ir un poco en función de a quién va dirigido, si es con el equipo o si es con el paciente y familia.

María: Porque como trabajador social ¿también trabajáis en paliativos con el equipo te refieres al equipo de profesionales?

Elena: Claro, claro. O sea, trabajamos integrados dentro del equipo y entonces la forma de trabajo que tenemos de verdad es interdisciplinar y es distinto a como se trabaja en otros servicios del hospital, donde tienen que hacer una interconsulta con la historia clínica electrónica y si no tienen la interconsulta, pues no intervienen. Nosotros intervenimos con el equipo desde el primer momento, incluso cuando nos derivan a algún paciente, pues hay veces que lo que hacemos es para valorar la atención en el domicilio, hacemos incluso una valoración en domicilio previa antes de que vaya el equipo sanitario.

María: Perdón, el equipo, por así decirlo, el equipo de cuidados paliativos es distinto luego al equipo sanitario que tenga cada paciente en función de su necesidad, no?

Elena: No sea la Unidad de Atención Integral Paliativa Pediátrica del Hospital del Niño Jesús atiende a niños que tienen enfermedades que no se curan y que en función de la de la situación o de la situación de enfermedad avanzada del paciente o del pronóstico que puede hacer pensar en una muerte temprana se incorporan en la cartera de pacientes. Se les puede ver en forma de consulta externa si es una situación en la que todavía no está muy avanzada su situación y no se espera una muerte a corto plazo, es más una situación de cronicidad y se le conoce en consulta externa o se puede hacer alguna atención en un hospital de día si necesita alguna cura de alguna úlcera con el personal de enfermería o algo así. Y luego los pacientes que están peor son los pacientes que se valoran para la atención en domicilio, porque los que vienen a consulta no se le garantiza la atención 24 horas en el domicilio, a no ser que estén hospitalizados a domicilio. Entonces, los pacientes que están hospitalizados a domicilio llevan el pack completo de atención de todo el equipo.

María: Vale

Elena: Igual que el resto, pero hacemos más hincapié en los que están en domicilio, que son los que están peor. Y entonces todos los pacientes que se hospitalizar a domicilio tienen un médico de referencia que es un pediatra, una enfermera, un psicólogo y un trabajador social.

María: Vale

Elena: Nosotros tenemos dividida la Comunidad de Madrid en cuatro rutas, porque lo tenemos dividido pues en quesitos, porque los trabajadores sociales somos dos, nos repartimos Madrid por la mitad, una mitad la atiende Alejandra y la otra mitad la atiendo yo. Y vamos con el equipo a hacer las visitas de manera conjunta o vamos con la enfermera a hacer una visita de cuidados de manera conjunta con la enfermera o vamos con la psicóloga para hacer una valoración de claudicación en un momento dado, o vamos con el médico para hacer una propuesta de ingreso, para respirar en el hospital, o vamos con todo el equipo y una visita rutinaria o de manera independiente. Oye, me interesa valorar contigo cuál es tu situación y cómo te estás organizando y si tienes todos los recursos apañados, entonces la visita en domicilio es solo con el trabajador social.

María: Vale, perfecto. Vale. Y todos los pacientes que están hospitalizados en domicilio tienen el mismo equipo. O sea, entre ellos no dicen: mira, yo necesito solo enfermera y médico.

Elena: No no, se incorpora con todo.

María: Vale, perfecto. Vale. Vale.

Elena: Es el pack completo.

María: Vale. Vale.

Elena: De hecho, se les hace firmar un documento de consentimiento informado donde aceptan y se comprometen a abrir la puerta al equipo, a colaborar en la atención, se comprometen a utilizar el teléfono del médico y de enfermera responsable, en horario por la mañana de 8 a 3 y después el equipo de guardia que queda para garantizar atención continuada desde las 15:00 de la tarde hasta las 08:00 del día siguiente a llamarle en cualquier incidencia.

María: Vale, ya, es algo consensuado, que ellos saben perfectamente con lo que cuentan.

Elena: Claro.

María: Vale, perfecto.

Elena: Bueno. Y entonces, o sea, nosotros en lo que nos basamos es en los estándares europeos de cuidados paliativos, donde dice que todo niño que necesite cuidados paliativos tiene derecho a tener su asistencia y que esa asistencia se debe prestar en forma de equipo interdisciplinar, donde tiene que ir incluido al trabajador social para valorar las necesidades del niño y de su familia. Y así es como hacemos y así es como lo justificó el coordinador de la unidad desde 2008, donde empezamos a funcionar como comunidad. Y el trabajador social lo que hace es valorar primero las necesidades sociales de los niños, no? Pues que según el documento de la Unión Europea dicen son actividades de ocio, actividades educativas, pues por ejemplo, si se pueden ir de vacaciones si quiere ir al cine, si, pues que tenga una vida social activa, asegurar que todos los niños están escolarizados o que reciben una atención en las mismas condiciones que un niño que no tenga una enfermedad en cuidados paliativos y si puede ir al colegio, pretendemos que los niños mantengan la normalidad yendo al colegio. Las visitas del equipo sanitario se hacen en el colegio para evitar que pues que rompa la rutina y favorecer así que la familia pueda mantener pues con su trabajo o su actividad del día a día y cuando no es posible gestionamos el profesor en casa para asegurar la atención domiciliaria en el servicio de apoyo educativo domiciliario que funciona en Madrid. Y luego la tercera necesidad es la la interacción con sus hermanos, con su grupo de iguales, con sus amigos. Y si ellos no tienen esa interacción, pues les ponemos en contacto con alguna entidad que pueda hacer actividades de ocio y colaboramos con muchísimas asociaciones para para poder conseguirlo. Y luego valoramos las necesidades sociales de las familias y en función de la familia, pues así vamos interviniendo. Pero no todos los pacientes tienen familia como tal porque hay niños que viven bajo alguna medida de protección en la Comunidad de Madrid, la que también les atendemos en su residencia, que es donde que es donde vive y nos desplazamos allí. Entonces nos coordinamos con la Comisión de Tutela del Menor y con los directores de los Centros para organizar la asistencia y asegurar también que el niño tenga todas sus necesidades cubiertas y garantizando que al ser un niño en cuidados paliativos, que también pueda tener el contacto con la familia de origen, si así la familia quiere. Entonces vamos a centros donde hay niños que están con tutela o con alguna medida de guarda. Y cada familia es distinta, claro, y hay pocos recursos y cada uno pues cuenta con lo que tienen. ¿Lo primero es que las familias se hagan responsables de los cuidados de los niños y que acepten el tratamiento según les va marcando el equipo no? Entonces pues nos encontramos con familias pues que están muy desgastadas, claro, donde no siempre ambos padres están implicados de la misma manera. Hay familias que sólo tienen un hijo y otras familias que han perdido antes incluso algún otro hijo previo. O hay familias extranjeras o tiene dificultades económicas, o están aisladas. Entonces, bueno, pues todas las repercusiones de la familia las tenemos en cuenta y valoramos cada situación en particular, y les acompañamos haciendo un poco una detección de indicadores de riesgo social o de factores de protección. Y después de hacer la valoración le incorporamos en la historia clínica y nos reunimos con el equipo asistencial para decir pues la familia qué dificultades tiene o en qué situación está. Pero sobre todo para que todos vayamos en la misma línea y nos marquemos objetivos comunes desde cada profesión. El psicólogo hace su valoración, el trabajador social hace su valoración, el médico también, la enfermera también. Y luego ya nos marcamos objetivos comunes y realistas en función de las peculiaridades de cada familia.

María: Vale, vale, vale, vale.

Elena: Entonces el trabajador social es el que detecta situaciones de necesidad y asesora a la familia sobre los recursos en función de la situación. Incluso te diría que uno de nuestros puntos fuertes es la imaginación, porque no siempre hay recursos cuando detectamos la situación de necesidad.

María: Claro.

Elena: Pues intentamos dar respuesta a todas las necesidades que nos van planteando de una manera un poco tirando de los recursos y de asociaciones que hacen cosas que la administración pública no llegue a cubrir.

María: Claro, como sería a lo mejor el hospital Laguna, no?

Elena: Claro, entonces, cuando empezamos a funcionar vimos que, por ejemplo, necesitábamos ir a los domicilios y en el proyecto inicial, aunque estba incorporado que la Comunidad de Madrid se dotara de chofer y de coches, no nos daban nada de eso y a través de un paciente conseguimos que nos donaran un coche. Y yo le dije al jefe: oye, que tenemos un coche, vale fenomenal que lo donen al hospital. Pero cuando fuimos a hablar con gerencia nos dijeron no, no, no, no esto es un hospital público, no podemos tener una donación de un vehículo, esto se tiene que hacer a través de una ONG. Y entonces mi jefe dijo: pues voy a crear una y creo la fundación, la asociación, Por Qué Viven.

María: ¡Sí, sí qué fuerte!

Elena: Así es como empezamos con la fundación y ahora pues bueno, pues es una fundación que colabora estrechamente con nuestros pacientes y que, por ejemplo, gracias a ellos hemos conseguido que las familias tengan musicoterapia o fisioterapia en domicilios. Bueno, pues algunas de las cosas y cuando los niños veíamos que no podían estar escolarizados porque no podían, no tenían las condiciones que a nivel clínico pues se iban a beneficiar de estar en un colegio y pasaba mucho tiempo en casa en aislamiento pues al final conseguimos que en Laguna tuvieran sensibilidad por estos pacientes y se creó el centro de día y algunos de nuestros niños asisten. Y el criterio es valorar, porque no todos los niños pueden tener acceso, valorar qué recursos están utilizando y si el niño está en aislamiento en un colegio y no es un recurso muy oportuno tenerlo en un colegio o en un centro de día, pues se proponen la asistencia a Laguna y eso siempre se hace con una valoración previa de la situación social y de los recursos que tiene y que es el mejor interés del niño.

María: Sí, vale. Y en Laguna, por ejemplo, porque siguen siendo vuestros pacientes, aunque allí no haya la figura del trabajador social, no la hay, porque vosotros seguís asistiendo y brindando con una atención ahí, ¿verdad?

Elena: Claro. A todos los pacientes que van a Laguna ya les conocemos.

María: Vale, justo.

Elena: En la presentación pues ya hacemos el seguimiento. Luego, la fundación Por Qué Viven funciona también como equipo de apoyo psicosocial, con un programa que tiene La Caixa de cuidados paliativos y ellos tienen un EAP que es un equipo de apoyo psicosocial formado por un psicólogo y un trabajador social que hace de apoyo a los equipos y ellos asisten todas las semanas a reuniones con Laguna, donde recogen la información más importante que luego nos lo transmiten tanto a Alejandro como al resto del equipo para tener una continuidad. O sea que aunque Laguna directamente no le atienda el trabajador social de Laguna el trabajador social de la UAIPP sí que conoce las necesidades y la situación de la familia y además y les sigue acompañando en función de cada situación y además toda la semana si hay algo que detectan en Laguna pues una familia que se ha separado un niño que viene sucio, que hace falta una silla de ruedas o todos aquellos aspectos psicosociales nos lo trasladan al equipo para asegurar de que recibimos toda la información de la familia para luego hacer la atención directa con ellos.

María: Claro. Vale. Perfecto. Vale. Vale. Y luego una duda, ¿para entrar como en la unidad esa que dices de cuidados paliativos? Que bueno, has dicho otro nombre. ¿Esto quién le deriva? Porque yo ya he hecho también entrevista a familias que tuvieron el Niño Jesús y tal y como que les derivan de otros hospitales o cómo, ¿cómo llegan las familias a conocer ese “servicio” de cuidados paliativos pediátricos?

Elena: Pues mira, es un servicio público de salud. La manera de acceder a un servicio, a una consulta de un hospital siempre es a través de su médico de cabecera o el pediatra. Ese es el trámite del procedimiento habitual. ¿Qué pasa? Que estos niños muchas veces son tratados por especialistas, como el oncólogo, el Traumatólogo, el neurólogo...

Entonces la relación con el pediatra no es muy estrecha. Entonces nos puede llegar a traer el pediatra a través de otros especialistas o a través de otros sitios donde ya nos conocen y piensan que pueden beneficiarse. Y puede ser que no sea solo de algún sistema de salud del hospital La Paz pues pueden derivar directamente al Niño Jesús a esta unidad, porque es la única unidad que hay en Madrid. Pero también los colegios de Educación Especial que nos conocen, pues hay veces que pueden hacer la consulta a través de su personal sanitario o directamente la familia pueden hacer una solicitud o a través de su pediatra que pida una visita directa o directamente llamando al teléfono de la consulta de cuidados paliativos y pidiendo una cita para hacer una valoración. Pues hay distintas vías.

María: Sí, sí, sí, genial.

Elena: La realidad es que muchas veces nos llega de otros hospitales que ya nos conocen y que saben lo que hacemos.

María: Vale. Y ya la última pregunta: las familias. Vale. Me refiero sobre todo a los padres que tengan a su hijo hospitalizado en domicilio o que acuda a consultas externas, ¿tiene una relación más estrecha con el trabajador social? O sea, es que por ejemplo en Estados Unidos sí que es verdad que he visto que hacen mucha labor también de acompañamiento, no solo profesional, ¿sabes?

Elena: O sea, nos conocemos muchísimos y hacemos un acompañamiento, pero siempre es profesional. Por ejemplo, yo antes estaba en oncología con Choni, y cuando se moría algún niño, pues a mí había veces que me salía por la relación que yo tenía con la familia acompañarles, pues hacían una misa en el hospital o ir a un funeral que organizaban fuera, me salía a mí, Elena, ir de manera particular. Pero ahora no, ahora voy porque forma parte de mi trabajo. O sea, nosotros acompañamos durante todo el proceso, incluido el fallecimiento. Y de hecho una labor muy importante del trabajador social, es anticipar los trámites funerarios para dar herramientas a la familia de cómo organizarse, como estar preparados, como hacerlo, con qué recursos disponemos, si quieren que avisemos al cura o a alguien.

María: Claro, claro.

Elena: Esa relación, o sea, yo ahora vengo de ver a un paciente que está en el hospital que me ha dado un recordatorio de de su bautizo, por ejemplo. O sea que si la verdad es que les conocemos mucho.

María: Sí que hay mucha cercanía, sí.

Elena: Pero muchas veces cuando les conocemos es bastante frecuente que las familias sientan temor de la función del trabajador social, porque todavía nos ven como con esa función de "quita niños", claro, y cuando les conocemos muchas veces dicen y va a venir consejería, va a venir a casa y nos van a valorar y piensan que les estamos examinando. Incluso hay situaciones en los que previamente ya están amenazados con quitarles la custodia de su hijo y tenemos que ganarnos la confianza para que vean que nosotros lo que queremos es que el niño viva con ellos y ayudarles en esa tarea tan difícil que es cuidar a un niño con una situación clínica tan compleja. Claro, lo que es el objetivo de la intervención social, la de potenciar la capacidad cuidadora, acompañar desde la intervención profesional, apoyar en la resolución de aspectos prácticos y hacerlo de una manera en equipo y asesorando muchas veces al equipo para que esté pendiente de ese niño, y para que estén alertas de situaciones que pueden producirse.

María: Claro, claro.

Elena: Y fallecer en casa, siempre que la familia pueda y siempre que los síntomas clínicos, pues estén controlados. O sea que el que nosotros seamos capaces de decir al equipo de guardia oye, este niño si se pone peor es mejor que le trasladéis al hospital por la situación familiar, pues en caso de padres separados o de cualquier otra circunstancia y que el equipo médico tiene que tener esa información. Les compartimos mucha información para garantizar que el niño sea cuidado de la mejor manera posible y al final la familia no le cuentan lo mismo al psicólogo. Y si vuelve a lo mismo trabajador social que cada uno tenemos una relación diferente.

María: Exacto. Vale. Justo, sí, sí, justo me refería a la diferenciación de las funciones que hay, que si las familias también lo perciben, sabéis? Porque a lo mejor es que no sé ni lo que eres yo te cuento mi vida y punto, ¿sabes? Ya, no, pero sí que tienen eso. Vale, vale, genial, vale. Pues Elena, yo creo que poco más.

Elena: Bueno. Oye, pues nada, ya nos contarás como va. Que te salga fenomenal.

María: Ojalá.

Elena: Bueno, pues nada, que si necesitas cualquier otra cosita ya sabes dónde estoy, pero estamos súper liados. Perdona que no te he respondido.

María: Ni te preocupes, es que yo lo suponía. De verdad, lo suponía totalmente. Bueno, hasta luego., muchísimas gracias.

7.6. Entrevista a profesionales de lo social en España (Araceli y Lourdes → E6)

Araceli: El tema fundamental es que realmente las trabajas, que desde el Niño Jesús son las que identifican las familias que no tienen recursos y que, por otra parte, también es verdad que cuando hables con ella ya te va a dar mucha más información, pero realmente lo que nos llega a nosotros es que nos enviarán los niños que ellas consideran que su propio equipo del Niño Jesús no llega a atender por dificultades geográficas, por dificultades, por zona, ellos no llegan a atenderlas. Entonces dicen bueno, pues estas familias, por una situación precaria de localización geográfica y económica, son aptas para la mujer, pues ellos pasan esa familia a Laguna. Nosotros en Laguna no les hacemos el papel de trabajadora social pediátrica. Por qué? Quién tiene el contacto con esas familias? Son ellas. Entonces nosotros lo que hacemos es que la enfermera, ya sea la directora del departamento del hospital de Día Pediátrico o la propia enfermera, les llama a la familia para concertar y evaluar si están dispuestos a dejar su niño o no aquí en Laguna. Por qué? Porque ellos sean cabo las familias. Ten en cuenta que cuando cae un niño, o sea uno de los padres, tiene que dejar de trabajar, por lo tanto, es decir, un declive económico. Eso quiere decir que no se hacen cargo del resto de la familia. Eso quiere decir que tampoco se hace cargo de su matrimonio. Con lo cual los problemas que conlleva.

Lourdes: Que se va acumulando porque de atención no era de nada a dormir, de una atención exclusiva de tal. Y además, eso, sobre todo en las madres, crea una dependencia total del niño. Y el niño de la madre, de la madre increíble. Y eso crea también en la familia una serie de circunstancias muy que pueden llevar a dificultades en el matrimonio, las dificultades en los niños y los otros hermanos. O sea que que en un niño enfermo esa situación puede provocar si no está bien llevado y bien ayudado, que en esa situación es muy difícil, no.

Araceli: Se involucra a un niño, es una familia, es una.

Lourdes: Familia entera. No hablas de un niño que hay que cuidar, de una familia entera con un montón de circunstancias impresionantes. Y cuando fallece el niño también, porque la madre tiene esa dependencia. Osea que conocemos a muchas madres que siguen, que hasta que son capaces de superar tal situación, de que el niño ha fallecido y con una que ha tenido una dedicación total al 100% para que la vida de ese niño, pues superarlo también. Ahí sigue siendo un cuidado importante para la madre y para la familia.

Araceli: Pero ahí realmente no en realidad trabajadora social, entra exclusivamente el Niño Jesús y ellos se apoyan en nosotros.

Lourdes: Ellos aquí vienen una vez a la semana, vienen aquí, tienen una reunión, ven a los niños, están todo el equipo médico, equipo médico, la trabajadora social, la enfermera y están ahí, todos trabajan. O sea que aquí pueden ir a hablar con Pilar y con la enfermera. Osea realmente trabajo social, lo que llamamos trabajo social…

Araceli: Eso es un tema que depende exclusivamente del Niño Jesús.

Maria: ¿Y una duda entonces todos los pacientes son niños que traéis? O sea que hoy aquí sólo viene el niño Jesús, no pueden venir de otro, de otra vía.

Araceli: Mira, ten en cuenta que en un principio nosotros se comienza esta iniciativa porque hay un señor que se llama doctor Martino, que es el que coordina el Programa de Paliativos Pediátricos de la Comunidad de Madrid. Ese Programa de Cuidados Paliativos de la Comunidad de Madrid se coordina desde el Niño Jesús.

Lourdes: Entonces todos los niños que entran en fase paliativa pasan por él.

Araceli: Otra cosa es que luego, ya entre bambalinas, se pueda hablar de la diferencia que hay entre porque un niño crónico no quiere pasar a paliativos, porque cambia de equipo médico, etcétera A los padres no les convence, etcétera Entonces ahí hay una barrera que salvar y por eso aquí solamente vienen paliativos y por eso solamente vienen del Niño Jesús.

Maria: Claro, vale.

Araceli: Porque el resto de hospitales no tienen precios crónicos.

Maria: Vale justo. Vale, vale, vale.

Araceli: Es importante que conozcas ese pequeño detalle.

Lourdes: Porque esa es una línea muy, muy fina, la de la diferencia entre crónicos y paliativos. Porque son casi, casi. Vamos, de hecho nosotros a veces digo venga, cogemos crónicos, pero es que no es lo mismo. Y tiene que ser paliativos.

Araceli: Y paliativo es no reanimable.

Lourdes: Claro. Y el crónico sí es reanimable

Maria: Sí que es fino, pero que es determinante.

Lourdes: Determinante y que cuesta mucho distinguir.

Maria: Claro, y las familias, por así decirlo, saben que su hijo en qué punto está, si es positivo o crónico.

Araceli: De hecho, muchas veces lo que hacen es no quieren cambiar a paliativos, porque en paliativos cambias el equipo médico que te ha tratado toda la vida, cambias el centro, lo cambias todo. Prefieren continuar como...

Lourdes: Sí. Eso también es una línea de investigación.

Araceli: Bueno, eso también es muy delicado y es políticamente incorrecto lo que te estamos diciendo.

Maria: Ya, ya.

Lourdes: Muchas madres dicen dos qué bueno sería que ya un médico de paliativos estuviera en los crónicos. Para que haya paliativos hay una continuidad de equipo médico, pero claro eso es muy difícil. Sería una sugerencia muy buena.

Maria: Claro. Vale, vale.

Lourdes: Porque les cuesta mucho, si no ese recorte de un equipo médico a otro equipo médico.

Araceli: También tienes que tener en cuenta que nosotros aquí, por ejemplo, lo que tenemos es un hospital de día pediátrico paliativo que está absolutamente es 100% gratuito para las familias usuarias y luego además no tiene ningún tipo de subvención, no está sujeto a subvenciones, se nutre, se podría decir que el 90% de donativos y un 10% que suele cubrir una ayuda del IRPF de la Comunidad de Madrid. Estamos hablando de 10% frente a un 90. En total la suma son 400.000 €. Entonces que hay que levantar de privados que donan en donativos privados. ¿Que por qué te digo esto? Porque nosotros realmente ponemos un equipo de médicos, enfermeras, auxiliares, fisioterapeutas, músicoterapeutas y terapia ocupacional la verdad es que no, porque no hay nada que hacer. Entonces lo que decís que dentro de nuestro presupuesto no podemos incluir además una trabajadora social. Claro, porque esa labor, ese acceso a esos datos, los tiene que tener el hospital. Claro, por eso nosotros no tenemos una trabajadora social, porque además sería buenísimo traerla. Sí, porque estoy haciendo una labor muy buena para las familias estar más atento a las edades que tienen, porque al fin y al cabo ellos ya deciden. Las familias propias deciden ya cómo confiar sus necesidades a Laguna, porque dicen que había alguien en concreto que decía bueno, yo llevo ocho años con mi problema yo sola, porque de repente aparece alguien que me quiere ayudar. Buenísimo, todo gratis. Y esto es impensable que se trate tan bien a hijo porque no lo comprenden. Pero lo que dice es que nosotros tenemos solamente un presupuesto para ayudar a una labor a la que no llega el Niño Jesús. A la de trabajador social sí que llega el Niño Jesús. Es una pena que nosotros no podamos tener por presupuesto a trabajador social, porque ya la familia confía en nosotros y que hablar todo el rato con nosotros. Sería fantástico tenerla? Sí, pero por un tema de presupuesto.

Maria: Y luego la familia también. Un poco sería como por no pisar entre comillas las competencias que se tendría aquí, porque ya lo tienen ahí cubierto por trabajo social.

Araceli: Se supone, se supone que sí, pero insisto, al fin y al cabo, el que está día a día con ellos y que les ve todos los días es Laguna.

Maria: Claro, claro, vale.

Araceli: Ellos la necesidad del niño por el día a día. Quién? Quién se mete en la necesidad de la familia? Ten en cuenta que llega el día de Reyes, no se hace regalos a los niños enfermos. Les hacemos regalos a los hermanos de los niños que son más conscientes realmente a nosotros. Nosotros no nos metemos en la familia en general.

Lourdes: Que también tienen regalos. Pero el gordo es para los hermanos.

Maria: Claro, claro.

Lourdes: Que es todo cosas que decimos. O sea, un niño enfermo es toda la familia. Y eso es muy, muy llamativo, no?

Araceli: Entonces nosotros lo que hacemos es que también ten en cuenta que durante la pandemia que hicimos cerrar la unidad pediátrica e íbamos presencialmente a sus casas. Eso quiere decir que tú ya estás en un paso en el que la trabajadora social del Niño Jesús, no está pero no está por un tema de presencialidad día a día en sus vidas.

Maria: Ya. Tienen como una atención por parte del trabajador social como más intermitente. Tipo una vez a la semana.

Araceli: Como yo tengo la sensación, yo no controlo los valores de trabajador social. De Niño Jesús nos controla.

Lourdes: Yo creo que viene una vez a la semana aquí a ver a verlos.

Maria: vale, sí, pero que vienen aquí.

Lourdes: Sí, tienen que venir en el mediodía, que ya todo el equipo sabes.

Araceli: Yo no estoy segura si la trabajadora social viene llamamos a Pilar en un segundo y le preguntamos. Porque yo diría que solamente médico y enfermera, pero así te lo decimos seguro. Porque al final vas a contrastar tres unidades pediátricas, porque la otra unidad pediátrica paliativos está en el Niño Jesús, que es la de doctor Martino. Porque han abierto una unidad nueva y ya.

Lourdes: A que es muy bonito?

Maria: Si, si, si.

Louurdes: Es muy bonito.

Maria: Vale, vale. Fenomenal. Fenomenal. Vale. Y entonces, así como la atención. Así como más, entre comillas, psicosocial. Aquí, si no la tiene el médico, la enfermera será el terapeuta. Hay psicólogos?

Araceli: No, los psicólogos no pasan por pediatría.

Maria: Vale.

Araceli: Porque es el hospital de día pediátrico exclusivamente. Consta de. Enfermera, auxiliar, auxiliar, fisio, fisioterapia, musicoterapia y médica. También hay la terapia ocupacional también porque les hacen las férulas a las extremidades de los niños. Pero pero no tenemos una atención, o sea, la tenemos. O sea, para el resto de paliativos. Nosotros tenemos en adultos. Pero en el hospital pediátrico no la tenemos.

Lourdes: Porque sí, eso sí que depende del Niño Jesús.

Maria: Claro, claro, vale. Y entonces no sé si ha quedado claro, pero aquí hay niños hospitalizados?

Araceli: Es un hospital de día. Lo que hacemos, nuestra dinámica es, ten en cuenta que estos niños no tienen una atención continuada médica. Están.

Lourdes: Los niños de paliativos están en sus domicilios y cuando tienen una crisis van al hospital. Niño Jesús. Que en qué entramos nosotros? En que en vez de estar en el domicilio sin cuidados que tiene una atención precaria, bueno no precaria, la que hacen los padres, que es maravillosa, pero que. Fisio, la cuestión higiene también es impresionante lo que aquí se puede hacer en casa. Entonces, el hecho de que puedan venir aquí todo el día es que los niños están estupendamente cuidados. Los padres pueden volver a trabajar, pueden descansar, pueden atender a otros hermanos. Ese es un respiro para ellos, enorme. Y de esa manera mejora a toda la familia. Mejora el niño porque tienen mejores atenciones. De hecho, cuando empiezan a venir aquí, se reduce las veces que acuden al Niño Jesús en situación de crisis. O sea que eso es una cosa importante y muy positivo. Y los padres mejoran un montón. Los padres, la familia, la atención a los otros hermanos, todos mejoran.

Maria: Claro, claro, claro.

Araceli: Ellos vienen en ambulancia medicalizada, bien en torno a las 10:00 y se van en torno a 16:30 de la tarde.

Maria: Y fines de semana?

Araceli: No, de lunes a viernes.

Maria: Vale. Y de edades? Y cuántos niños tenéis

Araceli: De uno? Hasta 21. Ahora mismo. Si viniese uno de cero, tendríamos de cero. Pero ahora mismo tenemos una 21 y tenemos 13 niños.

Lourdes: Es una unidad espaciosa para los días de semana, sin orden ni espaciosa, porque sí. Que podríamos tener muchos más claro. Porque necesidades hay pero...

Maria: Sí, sí, claro. Vale, vale, perfecto.

Araceli: Sí, sí, efectivamente. Es una pena, porque al decir unidad pediátrica. Ya me da pena que hayas venido hasta aquí.

Maria: Para nada. A ver que me parece. Aun así súper interesante. Y también que no es bueno. Pues entonces nada. Porque también el niño tiene la atención y saber un poco como en general, y eso es una gran diferencia con Estados Unidos, por ejemplo. Ya solo eso.

Lourdes: Porque Estados Unidos que.

Maria: En el hospital que fui, que he ido, era, o sea, es un hospital que tienen como modalidad en casa, como sería así y que sería como si fuera el Niño Jesús, que si tienen algo vienen al hospital y también tienen niños hospitalizados ahí, pero en plan como más de pero claro, pero la diferencia que he visto un montón es que los cuidados paliativos ahí en los niños, en adultos no, pero en los niños sería como aquí lo crónico, yo creo, claro. O sea, no tiene por qué terminar inmediatamente en fallecimiento.

Lourdes: Sí aquí los niños tardan mucho más en fallecer. Sí, ya que aquí hemos tenido niños que han durado años. Claro, a diferencia de los adultos.

Araceli: O de una paciente de 21 años. Osea, los niños... Bueno, hemos tenido. Teníamos a una paciente que vino nada más nacer y dos años después se ha estabilizado de tal manera que ha dejado de estar en paliativos. Pero que en un principio nuestros los niños no tienen porque fallecer, igual que los mayores nos llevan, y la media estancia aquí son 16 días. Los niños pueden estar años perfectamente. O sea, recuerda que los niños. Creo que el punto principal sería decir que son crónicos, no reanimables.

Maria: Vale. Claro.

Araceli: Y supongo que eso será igual en Estados Unidos que. El niño dura.

Maria: Sí, sí, justo. Y luego a nivel, por ejemplo, de la familia y tal. Sabéis? No se si sabéis, pero tienen algo así como como grupo de apoyo cuando el niño fallece. O sabéis si siguen teniendo como contacto con laguna.

Lourdes: Ya con laguna contacto sigue, sigue habiendo, no hay algo así organizado y está mi padre si sigue en contacto, porque la unión es tan fuerte. Y que sigue en contacto y tal, pero pero no como un grupo de duelo. Eso sí que creo que el Niño Jesús lo tiene, no lo sé. Pero aquí no hay, no es organizado, aunque sigue muy en contacto porque se engancha.

Maria: Exacto. Sí, sí, sí.

Lourdes: Es verdad que al estar un poco repartido con el Niño Jesús de esa entidad y que hay cosas que no teniendo nosotros, la parte de psicología y trabajo social.

Araceli: Se tiene en cuenta, al fin y al cabo, que nosotros somos fundación. Claro, la la vocación realmente es de asistencia y de cuidado. La cultura del cuidado nuestra, nuestra, nuestra misión es una de las pautas de nuestra visión. Es expandir una cultura del cuidado. Por tanto, nosotros somos un apoyo para ellos. Pero realmente, quién lleva la labor principal siempre es la la sanidad pública. Nosotros somos un apoyo. Que parte de una iniciativa privada pero quees un apoyo.

Maria: Vale, justo.

Lourdes: Más preguntas. Más preguntas.

Maria: Creo que ya está. O sea. Si osea lo mejor más a nivel de familia. Bueno no, pero es que está todo. Al final, las necesidades que tienen que decir eso, es más, ellos tienen la posibilidad de seguir trabajando, económicamente pues supongo que será más positivo.

Pero en plan más a nivel emocional. Sabéis qué tipo de necesidades una vez tienen aquí a su niño qué necesitan.

Lourdes: Si aquí hay un proceso. Y es que cuando viene un niño va a venir un niño los primeros días y las madres no se puede separar de ellos y les cuesta confiar para poder dejarlo. Entonces lo que hacemos es que se queden, que se queden aquí tres días, que haga falta un.

Araceli: Máximo dos días.

Lourdes: Porque si no entorpece no queda nada y que al segundo día ya no es necesario. Confían plenamente y es muy bueno porque además ellos así cuentan todas sus necesidades. Lo que ven, porque conocen al niño perfectamente claro. Entonces este es una entrada fenomenal para que nuestro personal conozca también al niño de manera directa. Después, cada día si que tienen esa relación con los padres, porque van apuntando en un cuaderno todo lo que se le acerca y después los padres en ese mismo cuaderno apuntan lo que el tiempo que está en casa también. Entonces hay una comunicación perfecta entre enfermera y auxiliar y los padres y la familia. Entonces siempre está el niño súper controlado y superbién atento a las necesidades.

Maria: Claro, claro, claro. Vale, vale.

Araceli: También es. Yo creo que para que te hagas una idea un poco más real, te das cuenta que al final es una familia que tiene un bebé, nace un hijo que al principio tú lo llevas a comprar y vas a un carrito en tu en tu cochecito. Pero luego ten en cuenta que estos niños van pasando los años y estos niños ya no soportan el cochecito, tienen que estar en la cama constantemente. Entonces eso que dice que si la madre necesita ir al supermercado ya no puede salir con un cochecito y un bebé, claro. Y necesitan oxígeno y sabes de muchas cosas, claro. Tienen a una persona que necesita una atención de 24 horas, que sisgnifica que alguien no duerma para estar con ellos 24 horas. Y eso quiere decir que ya no tienes una movilidad, no puede ser supermercado, no puedes, no puedes ir a las tutorías de tus niños, no puedes llevar a tus hijos al colegio, no puedes atender la casa. No puedes hacer nada. Tienes que estar al lado de una cama.

Maria: Claro.

Araceli: Y eso. Los años que haga falta. A partir de ahí. Y ya después, quizás dibujar un cuadro un poco más exacto de la situación que viven las familias. De hecho, aquí no tenemos voluntariado. En la parte pediátrica tenemos un solo voluntario. Por qué? Porque. Porque los niños no soportan una sillita. Por eso necesitamos en las ambulancias máximo dos niños. Por qué? Porque tienen que ir acostados. Claro.

Maria: Claro. Y más o menos las enfermedades como que les traen así a rasgos generales que son.

Lourdes: Pues suele ser. Parálisis cerebral. Es. Casi todos son parálisis, enfermedades raras, ya sean raras, porque aquí no vienen los ecológicos sino colectivos. Tienen más ayudas otros sitios, más animales.

Araceli: Y eso es otra experiencia de enfermedad, porque el oncológico siempre tienen una esperanza por la que luchar. El niño con una enfermedad rara, no. El niño que entra en paliativo no tienen esa lucha popular. Esa Esperanza.

Maria: Claro. Claro. Claro.

Araceli: Yo me acuerdo que vino una niña que no podía tomar más de x calorías o más de x proteína, sin entrar en shock. Luego vino otra niña que tenía creo que cuatro años y es perfecta. Y a los cuatro años empezó a tener como los temblores, que además la madre no lo aceptaba. Esto fue hace como tres veranos. Entonces no aceptaba porquela niña, no, tenía ocho años, la niña que tocaba el violín, etcétera. De hecho, creo que la mamá fundó Héroes sin capa o algo por el estilo, porque no aceptaba que, como mi hija, de repente la niña no respondía en una enfermedad degenerativa. Luego vino otra niña. Bueno, vino un bebé de 18 años. Ese fue como a mí me impactó muchísimo.

Lourdes: Otro niño que desconecta y puede pasar varios días desconectado y de repente vuelve. Y bueno, no habla ni nada, pero sí que reacciona a todo. No son enfermedades muy raras.

Araceli: Otro niño que le crecía constantemente el paladar. El paladar que asfixia es al fin.

Lourdes: Son enfermedades o enfermedades raras. Sí. Después todos estos niños se van deformando.

Araceli: Luego vino otro niños que le faltaba medio cerebro. Entonces que conlleva eso? Porque tuvo un ictus en el seno materno. su madre está embarazada. El bebé. Claro. Entonces estos niños si no los mueves, sufren por su propia enfermedad. Y además el dolor añadido de la atrofia.

Maria: Por eso necesitan estar constantemente estimulado.

Lourdes: Necesitan fisio y tal, y moverlos. Si aparece una tontería, dices que está mal y si están así no se los mueve.

Maria: No al revés.

Lourdes: Moverlos es un beneficio enorme.

Araceli: Pues esa es nuestra vida.

Maria: Mil gracias de verdad. Mil gracias. En serio. Me parece súper interesante.

Lourdes: Muy bien.

7.7. Entrevista a familia en España (Paula Jiménez → E7)

Maria: Yo lo estoy grabando y eso. Vale. Bueno, es un poco lo primero que me gustaría saber. Es como. Qué historia súper breve. ¿Qué historia hizo llegar a Eugenia a cuidados paliativos en el Niño Jesús? Fue en el Niño Jesús, ¿verdad? Sí, vale. Osea en qué punto estaba, de qué situación estaba ella y porque decidisteis y cómo conocisteis los cuidados paliativos del Niño Jesús.

Paula: Vale, a ver, nosotros viviendo en Majadahonda empezamos a ir al hospital a Puerta de Hierro cada vez que tenía ella una urgencia o que se ponía malita y como cuando ella se ponía malita era pues era grave, no podíamos irnos corriendo. Sabíamos que el hospital más bueno y de referencia para toda la niña era el Niño Jesús. Y allí empezamos. Pero por comodidad y también por lógica familiar, empezamos a ir a Puerta de Hierro y Puerta de Hierro. Es verdad que muchas veces cuando ella llegaba tan mal nos decían no sabemos si la vamos a poder mantener aquí o la tenemos que llevar a la UCI. El Niño Jesús siempre Puerta de Hierro tomaba como referencia el hospital. Niño Jesús tuvo unos años que estuvo bastante estable y bastante bien, entonces nos apañamos fenomenal con el hospital.

Pero es verdad que durante el último año empezó a tener muchísima recaída respiratorias y muchísimos problemas respiratorias, porque perdona,

Maria: Perdona Paula, pero cuál es esa que es lo que la enfermedad que tenía Eugenia?

Paula: Pues Eugenia nació con parálisis cerebral o una agitación muy severa provocada por un virus que yo contraje durante el embarazo, al principio del embarazo que se llama el sistema galo. Virus es como un catarro para todo el mundo, pero si tú lo coges por primera vez, como fue mi caso y en el primer trimestre de gestación, es un virus muy peligroso para el bebé porque se alimenta del te de el cerebro del feto. Bueno, entonces pues eso fue lo que le provocó y ella nació con una parálisis cerebral muy severa, hipoacusia bilateral profunda, sorda de ambos oídos. Lo que veía y lo que no veía. Vale, perfecto. Entonces ya nosotros. Gracias a cuando. Bueno, cuando nació Eugenia, que yo tenía una amiga que había estado en activo de residencia, que de íntima amiga de Sevilla, que trabajó con el Niño Jesús en la unidad de paliativos, porque es que la creó ella aquí en Madrid, cuando nació Eugenia, y él se puso en contacto conmigo y me habló de esta unidad, pero me dijo vamos a ir día a día porque la hermana lo necesita, tu hija que si lo necesita en algún momento porque tú sabes que está ahí. Y entonces ah, yo sabía y tenía conocimiento de esta unidad de paliativos, pero es verdad que durante sus primeros años de vida, como iba la cosa, también se iba estable, pues no teníamos otros extraordinarios que no se pudieran solucionar con ingresos aquí normales en un hospital normal. Pues fenomenal. Y decía eso que los dos últimos años ya las recaídas eran como más intensa. Entonces empezamos, pedimos cita para que nos vieran en la unidad de paliativos, porque también nos lo recomendaron en En Puerta de Hierro. Vale, y entonces aquí cuando empezamos a ir, pues era como también un descanso para nosotros, porque estaba en un nivel dentro de la unidad de paliativos hay como varios niveles y nosotros estábamos en el nivel tres, que es en el nivel que estamos mejor llamado, en el mejor de los casos, sí, entonces para mí también es un descanso, porque yo cada vez que iba allí a la consulta de paliativos, siempre uy, que bien, va fenomenal y está bueno, sí, aunque tengas achaques, pues, aunque se vea que que esto, que esto no lo tiene bien controlado el tema pulmonar. Pero no pasa nada porque? Porque con esa medicación tiramos pa lante con su sí se sale y aguanta que vaya haciendo vida normal, que vaya a su educación especial. Entonces durante muchos meses estuvimos que se nos vino el novio, pero conocimos a todos los médicos, ya muchas enfermeras y tal hecho y más en ese nivel. Tres Y ya cuando en el último, en este último año ya nos pasaron al nivel uno, el nivel más grave, pero no tanto porque la veían que estaba muy mal, sino porque ha tenido tantos problemas respiratorios. Ellos veían la una posibilidad era que se estuviera como se dice, porque de todo lo que yo he hablado ya que se le estuviera yendo la comida al pulmón, vale, se ha dicho de una manera, en vez de que porque ya comía por boca. Sí, todo purés, pero me decían a eso que se está tirando y dice hay como una pequeña duda, tenemos que se pudiera estar aspirando el pulmón y eso hace que el pulmón pues al tener esa comida y le provoque una infección y eso ya le llega. Tener tanto mocos. Es optico de fiebre. Sin esa neumonía se habrían querido y tal. Porque claro, nosotros a lo mejor ya está fenomenal y de un día para otro una cantidad de mocos y una fiebre impresionante silencian pruebas de o de cobi o de cualquier cosa. Y no, no tiene neumonía, no tiene no nosequé qué? Pero el pulmón lo tiene muy manchado. Empezaron como hizo, a ver que podía venir la cosa por el tema de la comida, claro. Entonces, a raíz de eso, pues ya nos metieron en el nivel uno con idea de vamos a hacer con ella, vamos a dar un paso más que es que empieza a comer por sonda y ahora a través de la sonda que le llegue directamente la comida al estómago y no tenga que hacer ella. Todo eso se procesa y que se centre solamente ella en respirar claro y acá claro. Eso al principio dio un palo que te mueres porque yo no quería que ella dejara de comer, porque yo veía que disfrutaba comiendo y no sabía cuando era un chocolate o cuando era una cosa que no le gustaba porque era la medicina es bueno y estuvimos en ese proceso.

Maria: Sí, vale. Y una cosa, cuál es la diferencia entre el nivel que vosotros vierais? Nivel tres y nivel dos y nivel uno es sobre todo el la atención que reciba, no?

Paula: Sí, pues el nivel tres. Nosotros teníamos consultas externas, es decir, nosotros íbamos con nuestra niña en nuestro coche al hospital y nos atendieron allí en consulta. Y el nivel uno es lo mejor que te puede pasar en la vida cuando tienes un niño enfermo como un genio, porque tienes un servicio de 24 horas los 365 días al año de médico, enfermeras, psicólogos, trabajador social y todo ese acompañamiento y todo que te vienen a tu casa si que está mal Eugenia. Pero qué tiene? Tiene fiebre, tiene tal cual el oxígeno. Súbele más el oxígeno y de tal manera en una hora estamos allí. Vale, vale, ya es el nivel uno. Es que te vienen a casa y que están, o sea, tienes una asistencia 24 horas y es como es, como es. Y además no tienes que irte ya tú corriendo con tu hija a urgencias. Claro, eso era lo que más me agobiaba, irme con ella a urgencias, porque yo decía lo que la va a encontrar un médico, a lo mejor que está recién aterrizado en camino la niña sí, y la edad es fatal y a lo mejor está fatal porque yo siempre iba al médico y le decía de verdad que no es tan mal como lo que le he visto en muchas ocasiones. Y está bien, no está tan grave. Sí, claro, no la conocen. Entonces ven aquí, tienes a tu médico que la conoce, que tienen solamente niños como Eugenia, que todo son gravísimo. Y entonces encima, pues eso, tú te desde el teléfono te van como diciendo las cosas que harían en urgencias. Pues hala, ponle el oxígeno con la bolsa de Karim de Regurgitar de TAC y se lo ponen tanto. Y mientras tanto vamos nosotros. Vale? Y así iba haciendo yo lo que hacían en urgencias. Claro, llegaron, claro.

Maria: Y es en tu casa sin tener que coger el coche, atar a la niña, ponte. Claro, claro, claro, claro.

Paula: Ok, está convulsionando y la la tiene que iba convulsionando. Y luego por ejemplo, la última vez que vinieron aquí a casa, como ya la vieron tan mal, pues directamente ellos me llamaron a la ambulancia y ya vino aquí la ambulancia y nos fuimos a cruzar ella y yo de la ambulancia al hospital y ya.

Maria: ¿O sea que estuvo en algún momento ingresada a la Unidad de Cuidados Paliativos Pediátricos?

Paula: Sí, sí, estuvo tres o cuatro veces. Pues una vez cuando le pusieron la sonda provisional por la nariz para que la dejara de comer por boca, le pusieron la salita y se supone que a los dos o tres meses le iban a hacer ya la sonda la chica, pero no llegó ya. Y luego también tuvo otro, otra infección respiratoria que también estuvo en la unidad de Cuidados Paliativos.

Maria: Vale, vale. Va ingresada? Sí, vale, genial, vale. Y luego más a nivel familiar. O sea, desde que Eugenia estaba allí, ¿habéis tenido algún tipo de atención vosotros aparte de Eugenia? Porque supongo que Eugenia era como más, a lo mejor el médico o la enfermera o lo que fuera con vosotros por parte de ya no sé si trabajo o trabajo social por lo psicológico o más social.

Paula: Muchísimos. Por un lado, como tienen hoy por una la figura del trabajador social que a no ser a mí también me ayudaba mucho porque me para la ayuda que hay que LAURA Oye, Paula, porque yo como estaba con una reducción de jornada del 99,9 para no trabajar y cuidarla ella, pues me tenían que hacer unos informes, pues ese informe me lo hacían los trabajadores sociales, o sea eso fenomenal de papeleo, de gestión y todo eso que realmente simplifica mucho la vida. Y luego por otro lado, y es la psicóloga que en nuestro caso es verdad que no la utilizamos, o sea, como psicóloga no la utilizamos en ningún momento durante el proceso de Eugenia del ni de su enfermedad, pero sí cuando estábamos ingresando al hospital siempre venía lo que necesite, porque además allí en el hospital y la Unidad de Cuidados Paliativos estamos separados de todo el mundo. Tenemos cinco o seis habitaciones independientes en un. Queda todo un jardín independiente. Entonces estaba ahí como si estuviéramos en nuestra casa. Daba igual, cobi que no, cobi que quería venir toda la familia, que es lo que quería la psicóloga y lo que querían. Todo el mundo oye que venían aquí las hermanas, porque muchas veces son ingresos de larga estancia y que sigan viendo a su hermana y que puedan quitarse aquí la mascarilla y que podamos estar allí merendando, comiendo, celebrando un cumpleaños. Claro que en ese sentido súper bien, pero por ejemplo ahora la psicóloga Carola. Yo de ella pues si este tío ganara mucho de desfallecimiento, claro. O sea que es como un equipo, una unidad que te ayuda durante todo el proceso y el post.

Maria: Claro.

Paula: Y al final ellos, claro, todo. Todas las familias que cogen pasan y luego niños que acaban falleciendo.

Maria: Justo, justo antes de esta situación, ¿tú conocías la figura del trabajo social?

Paula: Eh. No, yo hasta que no lo hace, Eugenia no la conocía. Y para mí esa es igual que lo de los fisios. Han sido como la persona más importante de mi vida, con su energía y para mi mí y la alta, porque gracias a una trabajadora social del Niño Jesús me enteré que yo podía acogerme a la ley esta, que ahí he cuidado de la hija por enfermedad grave y que no tenía que trabajar y que yo seguía cobrando mi vida. Sabía que existía mi peso y que no era una cosa que dependiera de mi trabajo. Es una cosa que es de ley nacional, que todo el mundo sí que no le cuesta al Estado porque te paga como el seguro, no la mutua de trabajadores. Entonces, o sea, para mi trabajador social, que era totalmente desconocida, me ayudó. Para mí fue súper importante cuando claro, y luego a lo largo de su vida que me han estado enfermando de las prestaciones que hay en la cosa que.

Maria: Claro, claro, vale. Y luego, por ejemplo, porque Eugenia tiene hermanas, verdad?

Paula: Sí, vale, cinco hermanas, sí.

Maria: Y ellas para todo el tema de gestionar el momento de cuando ella estaba en cuidados paliativos, ella, o sea, gestionar ellas emocionalmente. Había algún tipo de profesional o alguna algo que estuviera como más pendiente de ellas o vosotros o no es eso de haber.

Paula: Podría haber sido la psicóloga. Sí, para eso es como la psicóloga, que nosotros también en determinados momentos, sobre todo, pues al final que nos decían oye, vosotros habéis hablado alguna vez con vuestras hijas de que Eugenia pues se puede morir mañana en plan. Así que. Que nunca le habíamos querido porque. O sea porque yo es como que herramienta. Yo creo que es momento de que vaya preparando ahora. Así que en ese sentido sí, pero es verdad que nosotras gracias a la vida que tenemos, a la empresa, a la familia, claro, pues como todo esto lo hemos hablado desde el primer momento que ella nació y que las hermanas han sido consciente, pues para ella también. Lo bueno que a lo mejor para otros niños tener un médico en casa con millones de aparatos y salir en una ambulancia es traumático. Que ellas era ya formaban parte de nuestra familia, claro. Entonces venía la enfermera china que era Choni y la enfermera a casa y entonces era unos besos y unos abrazos y claro, quedaros a merendar y tal. Es que no eran nada traumáticas. Es que yo siempre decía que descanso para mí porque yo no soy médico, pero es que tengo a este, esta persona que viene aquí a casa a cuidarla y se lo tengo que hacer. Claro, para mí es que era un lujazo. Siempre me acuerdo del día que cuando ya Eugenia falleció y vinieron todo el equipo, como era la visita del duelo se llama, como para ya cerrar el camino si todos mis hijos querían estar, no que nosotros nos queremos despedir de todo. Y le escribieron unas cartas a todos diciendo que bueno, que muchísimas gracias por haberles facilitado, decían para el facilitado tanto en la vida y por haber hecho que su hermana en vez de tener que estar tanto tiempo en el hospital, hubiera podido estar aquí tanto meses malita que aunque ya las hayan podido disfrutar porque si no el hospital no la hubiera, no hubiera sido igual y que hubiera sido todo más frío y todo. Entonces que por favor, que dejaran que siguieran su trabajo, así que no se preocuparan que se hubiera porque como que hubieran hecho las cosas mal, porque no creo que era el momento de que su hermana se fuera al Cielo y que yo estuviera súper tranquilos, que cogí materia, que había muchísima sin fe, la mayoría.

Maria: Claro, claro.

Paula. Entonces era en plan no os agobiéis, que vosotros la habéis hecho fenomenal y el Señor la quería con ella. Entonces por eso ya era su momento.

Maria: Vale, pues ya. En realidad básicamente se hicieron las preguntas. Ella Una última cosa, así como en Trabajo Social, vale por cerrar un poco en o sea, tú hubieras mejorado algo o has echado algo en falta del equipo en decir mira, yo creo que el trabajador social tendría que haber hecho más de esto y no tanto de gestión o más emocional, más o no sé si.

Paula: Yo creo que lo que se podría mejorar es yo veces. Como la sensación de que a lo mejor Eugenia hubiera tenido que pasar antes al nivel grave, pero que a lo mejor no pasaba porque también estaban como un poco saturados. Entonces que bueno que también pues pienso que las cosas han sido así sabes, que no pasa nada, pero que a lo mejor que a mi me hubiera dado muchísima más descanso que Eugenia en vez de hace seis meses, haber entrado en el nivel grave que hubiera entrado hace un año. Entonces pues eso a lo mejor el trabajador social, pues hubiera podido decir oye, que esta niña. Pues es que tiene pinta de que si no es dentro de un mes va a ser dentro de seis pues vamos a adelantar para que sea también un descanso para esta familia. Claro que pasa un momento de muchísima tensión aquí en casa, que no sabíamos que teníamos que hacer y que claramente no la tenemos que coger e ir corriendo al hospital, claro. Entonces pues eso, claro.

Maria: Vale. Y ya la última perdona. Y después de. O sea, en el momento, ya después del fallecimiento de Eugenia, a partir de esa consulta de como lo has dicho, de duelo, de duelo si habéis tenido por lo menos como una opción a yo que sea seguir por parte del, por ejemplo, en Estados Unidos, las entrevistas que he estado haciendo, porque esto hace una comparación con Estados Unidos, el trabajador social como que tiene el el pie, como que da el primer paso, hay grupos de duelo para tal o umm no sé.

Paula: Si si a mi por ejemplo la psicóloga se puso a mi disposición para poder verla yo las veces que quiera. Me dice que hay encuentros de madres, de no sé qué pero es que claro, como que no me apetece, que con la psicóloga claro, hable, ya me conoce y sabe y le digo mira, yo tengo un acompañamiento espiritual, me ayuda un montón y me dice pues perfecto, sabes, hay gente que le hace su acompañante espiritual con la fe y tal, hay otro tipo de refieren, un grupo de madres, han perdido a un hijo, tienen reuniones tal hay otros que quieren ver al psicólogo, a ella en este caso suelto una vez al mes y yo con la actividad viendo cada tres meses para que ella también me haga el informe, porque yo lo que no quiero es incorporarme otra vez a trabajar, que todavía no estoy preparada..

Maria: Claro, claro.

Paula: Entonces pues bueno, ellas si te dan herramientas, pero de cara para no dejarte ahí osea fallece hija y siguen detrás tuya. Vale? Que necesitas tal y yo cada vez que puedo. El otro día que hubo un congreso de no sé que me planté allí a saludarles y todo porque es que como en forma parte de tu vida.

Maria: Claro, claro y habéis compartido cosas muy muy fuertes.

Paula: Pues pues es que vale, que muy bien.

Maria: Vale, genial.

8. Bibliografía

Real Academia Española - RAE. (s. f.). Cuidados paliativos. Diccionario panhispánico del español jurídico - Real Academia Española. Recuperado 12 de octubre de 2021, de https://dpej.rae.es/lema/cuidados-paliativos

Vivar, Cristina G., McQueen, Anne, Whyte, Dorothy A., & Canga Armayor, Navidad. (2013). Primeros pasos en la investigación cualitativa: desarrollo de una propuesta de investigación. Index de Enfermería, 22(4), 222-227. Recuperado el 24 de octubre de 2021 en https://dx.doi.org/10.4321/S1132-12962013000300007

Pérez Costa, E., Rodríguez Álvarez, D., García Boyano, M., & Noriega Echevarría, I. (2018, marzo). 10 cosas que deberías saber sobre. . .cuidados paliativos pediátricos. Pediatría Integral. Recuperado el 30 de octubre de 2021, de https://www.pediatriaintegral.es/publicacion-2018-03/10-cosas-que-deberias-saber-sobre-cuidados-paliativos-pediatricos/

National Institute of Nursing Research & U.S. Department of Health & Human Services. (2019, agosto). Cuidados paliativos para niños Apoyo para toda la familia cuando su hijo vive con una enfermedad grave. National Institutes of Health. https://www.ninr.nih.gov/sites/files/docs/NINR_508cBrochure_Spanish_2015.pdf

Organización Mundial de la Salud. (2020, 5 agosto). Cuidados paliativos. www.who.int. Recuperado 30 de octubre de 2021, de https://www.who.int/es/news-room/fact-sheets/detail/palliative-care

Cuidados paliativos para adultos vs. pediátricos. (2018, 30 diciembre). Obtenga cuidados paliativos («Get Palliative Care»). Recuperado 23 de mayo de 2022, de https://getpalliativecare.org/es/whatis/pediatric/adult-vs-pediatric-palliative-care/

Ley 4/2017, de 9 de marzo de 2017. Derechos y Garantías de las Personas en el Proceso de Morir. Boletín Oficial del Estado, *149*, de 26 de junio de 2017. https://www.boe.es/eli/es-md/l/2017/03/09/4

Ley 16/2003, de 28 de mayo, de cohesión y calidad del Sistema Nacional de Salud. Boletín Oficial del Estado, *128*, de 29 de mayo de 2003. https://www.boe.es/eli/es/l/2003/05/28/16/con

Martino Alba, R. et al., (2014). Cuidados Paliativos Pediátricos en el Sistema Nacional de Salud: Criterios de Atención. Ministerio de Sanidad, Servicios Sociales e Igualdad. Recuperado 20 de mayo de 2022, de https://www.sanidad.gob.es/organizacion/sns/planCalidadSNS/pdf/01-Cuidados_Paliativos_Pediatricos_SNS.pdf

New York State Department of Health. (2014). Questions and Answers About Palliative Care, Hospice, and the Palliative Care Information Act. Https://Www.Ny.Gov/. Recuperado 23 de mayo de 2022, de https://www.health.ny.gov/professionals/patients/patient_rights/palliative_care/practitioners/questions_and_answers.htm#q_4

GovTrack.us. (2022). S. 2748. 114th Congress: Palliative Care and Hospice Education and Training Act. Recuperado 23 de mayo de 2022, de https://www.govtrack.us/congress/bills/114/s2748

U.S. Department of Health and Human Services. (2021, 22 septiembre). About HHS. HHS.Gov. Recuperado 23 de mayo de 2022, de https://www.hhs.gov/about/index.html

Ministerio de Sanidad, Servicios Sociales e Igualdad. (2014). Cuidados paliativos en el Sistema Nacional de Salud: criterios de atención. Ministerio de Sanidad, Servicios Sociales e Igualdad Centro de Publicaciones Paseo del Prado , 18-20. Recuperado 28 de marzo de 2022, de https://www.sanidad.gob.es/ca/organizacion/sns/planCalidadSNS/pdf/01-Cuidados_Paliativos_Pediatricos_SNS.pdf

VITAS Healthcare. (s. f.). Cuidado de hospicio versus cuidado paliativo: ¿cuál es la diferencia? Recuperado 24 de mayo de 2022, de https://espanol.vitas.com/hospice-and-palliative-care-basics/about-palliative-care/hospice-vs-palliative-care-whats-the-difference#:%7E:text=El%20hospicio%20brinda%20cuidados%20de,con%20o%20sin%20intenci%C3%B3n%20curativa.

Fundación Paliar. (2020, 29 junio). Historia de los Cuidados Paliativos. Recuperado 24 de mayo de 2022, de https://www.fundacionpaliar.org.ar/historia-de-los-cuidados-paliativos/

Ignacia Del Rio, M., & Palma, A. (2007). Cuidados Paliativos: Historia y Desarrollo. VOL. 32 Nº 1. Universidad Católica de Chile. Recuperado 24 de mayo de 2022, de http://publicacionesmedicina.uc.cl/Boletin/20071/CuidadosPaliativos.html

SECPAL. (s. f.). SECPAL (Sociedad Española de Cuidados Paliativos). Recuperado 25 de mayo de 2022, de https://www.secpal.com/secpal-1#:%7E:text=El%208%20de%20enero%20de,%2C%20psic%C3%B3logos%2C%20religiosos%20y%20bioeticistas.

Navarro Vilarrubí S. El desafío de la cronicidad compleja y la atención paliativa en pediatría. An Pediatr (Barc). 2018; 88:1–2. Recuperado 25 de mayo de 2022, de https://www.analesdepediatria.org/en-the-challenge-complex-chronicity-palliative-articulo-S2341287917302144

PedPal. (s. f.). Unidades y Recursos – PedPal.es. PedPal.es. Recuperado 25 de mayo de 2022, de https://www.pedpal.es/site/quienes-somos/unidades-y-recursos/

Ferrer, G. (2018, 1 agosto). Medicina paliativa, su historia y barreras en su aplicación. Medscape. Recuperado 25 de mayo de 2022, de https://espanol.medscape.com/verarticulo/5902985?reg=1#vp_2

Carter, B. (2018). Pediatric Palliative Care in Infants and Neonates. Children, 5(2), 21. Recuperado el 25 de mayo de 2022, de https://doi.org/10.3390/children5020021

Marston RN, J. (2019, 29 julio). A Global History of Children's Palliative Care. ICPCN. Recuperado 25 de mayo de 2022, de https://www.icpcn.org/a-global-history-of-childrens-palliative-care/

Hospices & Palliative Care Centers in the US - Number of Businesses 2005–2026. (2020, 14 octubre). IBISWorld - Industry Market Research, Reports, and Statistics. Recuperado 25 de mayo de 2022, de https://www.ibisworld.com/industry/statistics/businesses.aspx?entid=4952#:%7E:text=How%20many%20businesses%20are%20there,of%20-2.2%25%20from%202021.

Berga Liarte, L. (2021, 7 julio). Cuidados paliativos pediátricos y su situación en España. RSI - Revista Sanitaria de Investigación. Recuperado 25 de mayo de 2022, de https://revistasanitariadeinvestigacion.com/cuidados-paliativos-pediatricos-y-su-situacion-en-espana/

National Center for Medical Home Implementation at the American Academy of Pediatrics & Catalyst Center at the Boston University School of Public Health. (2014). Your Child's Health Care and the Affordable Care Act (ACA): Concurrent Care for Children. https://medicalhomeinfo.aap.org/tools-resources/Documents/ACA-ConcurrentCare%20FINAL.pdf

Lindley, L. C., Keim-Malpass, J., Svynarenko, R., Cozad, M. J., Mack, J. W., & Hinds, P. S. (2020). Pediatric Concurrent Hospice Care: A Scoping Review and Directions for Future Nursing Research. Journal of hospice and palliative nursing: JHPN: the official journal of the Hospice and Palliative Nurses Association, 22(3), 238–245. https://doi.org/10.1097/NJH.0000000000000648

Courageous Parents Network. (2020). Understanding the Palliative Care and the Hospice Care. https://courageousparentsnetwork.org/. Recuperado 27 de mayo de 2022, de https://api.courageousparentsnetwork.org/app/uploads/2021/12/CPN-Understanding-Palliative-and-Hospice-Care_R1-Spanish.pdf

New York State Department of Health. (2013). Questions and Answers About Palliative Care, Hospice, and the Palliative Care Information Act. Https://Www.Health.Ny.Gov/. Recuperado 27 de mayo de 2022, de https://www.health.ny.gov/professionals/patients/patient_rights/palliative_care/practitioners/questions_and_answers.htm#q_4

Vossel, H. (2021, 29 junio). Illinois Approves Pediatric Palliative Care Benefit. Hospice News. Recuperado 27 de mayo de 2022, de https://hospicenews.com/2021/06/28/illinois-to-become-first-state-to-approve-a-pediatric-palliative-care-benefit/

Vossel, H. (2022, 23 mayo). New Legislation Provides Reimbursement Boost to Community-Based Pediatric Palliative Care. Hospice News. Recuperado 27 de mayo de 2022, de https://hospicenews.com/2022/05/23/new-legislation-provides-reimbursement-boost-to-community-based-pediatric-palliative-care/

Association of Palliative Care Social Workers. (s. f.). Social Worker Role. Association of Palliative Care Social Workers. Recuperado 30 de mayo de 2022, de https://www.apcsw.org.uk/social-worker-role/

Oriol, I. et al (2014). Informe de la situación actual en cuidados paliativos. Área de Programas y Servicios, Área de Relaciones Institucionales, Observatorio de Las Islas Baleares. Recuperado el 30 de mayo de 2022, en http://www.caib.es/sacmicrofront/archivopub.do?ctrl=MCRST3145ZI178957&id=178957

G.P.C. (2018, 30 diciembre). Pediatric Palliative Care Team. Get Palliative Care. Recuperado 30 de mayo de 2022, de https://getpalliativecare.org/whatis/pediatric/the-pediatric-palliative-care-team/

Corrales-Nevado, D., Alonso-Babarro, A., & Rodríguez-Lozano, M. A. (2012). Continuidad de cuidados, innovación y redefinición de papeles profesionales en la atención a pacientes crónicos y terminales. Informe SESPAS 2012. Gaceta Sanitaria, 26 (S1), 63–68. https://doi.org/10.1016/j.gaceta.2011.09.032

Riquelme Olivares, Mercè. (2017, Abril) El acompañamiento a personas enfermas y sus familiares en procesos de final de vida. Revista de Treball Social. Collegi Oficial de Treball Social de Catalunya, n. 210, páginas 54-68. ISSN 0212-7210.

Ministerio de Sanidad, Servicios Sociales e Igualdad. (2014). Cuidados Paliativos Pediátricos en el Sistema Nacional de Salud: Criterios de Atención. Ministerio de sanidad, servicios sociales e igualdad, centro de publicaciones. https://www.sanidad.gob.es/ca/organizacion/sns/planCalidadSNS/pdf/01-Cuidados_Paliativos_Pediatricos_SNS.pdf