LA COMUNICACIÓN EMOCIONAL EN NIÑOS Y NIÑAS CON NECESIDADES COMPLEJAS DE COMUNICACIÓN Y SUS MADRES Y PADRES

EMOTIONAL COMMUNICATION IN CHILDREN WITH COMPLEX COMMUNICATION NEEDS AND THEIR PARENTS

TESIS DOCTORAL PRESENTADA POR

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"Educar la mente
sin educar el corazón
no es educar en absoluto"
Aristóteles

Resumen

La comunicación emocional es esencial para un desarrollo emocional óptimo. Las personas con necesidades complejas de comunicación (NCC) suelen tener dificultades para expresar y hablar de emociones mediante el uso de métodos convencionales y vivencian menos oportunidades para aprender y conversar sobre emociones. Este colectivo se puede beneficiar de sistemas de comunicación aumentativa y alternativa (CAA) para satisfacer sus necesidades comunicativas, incluidas las de contenido emocional. Sin embargo, se desconocen los alcances de las intervenciones en CAA en el área emocional, ya que la literatura sobre este tema en personas que tienen NCC es aún escasa. La presente tesis, en formato de compendio de publicaciones, explora la comunicación emocional en niños/as con NCC y su entorno. Propone y analiza herramientas y estrategias que faciliten oportunidades para hablar de emociones, y estudia el cambio en la interacción comunicativa que se da tras la implementación de dichas propuestas.

Específicamente, se presentan tres estudios. El estudio 1 explora y analiza, a través de un análisis temático, las percepciones de madres y padres sobre los elementos que entran en juego en la expresión y comunicación emocional de niños/as con NCC. Se visibilizan las emociones y formas de expresión emocional de los niños/as, así como posibles desencadenantes emocionales y retos existentes para hablar de emociones. También se comparten los posibles detonantes y emociones experimentadas por los cuidadores ante la crianza, y los retos y estrategias utilizadas para promover un aprendizaje y comunicación sobre emociones.

El estudio 2 propone el diseño y desarrollo de un perfil del estado emocional que puede ser compartido con personas clave en la vida del niño/a. Está pensado para ser un recurso que brinde información, visibilice retos y proponga estrategias para sensibilizar y

promover una comunicación y aprendizaje emocional. Presenta dos casos ilustrativos sobre su uso y validez social, además propone una guía para dar soporte al proceso de toma de decisiones que orienten la intervención clínica y educativa en relación con la adquisición de competencias emocionales.

El estudio 3 presenta un estudio de caso madre-hijo donde se analiza el proceso comunicativo que se da tras la madre recibir una formación enfocada en promover espacios para hablar de emociones en una actividad de lectura de cuento. Se utilizó un diseño observacional (nomotético / de seguimiento / multidimensional) para detectar y analizar los cambios en la interacción comunicativa en torno a las emociones. Se utilizan sistemas de CAA para que el niño acceda a vocabulario que le permita participar en las conversaciones con su madre. Este estudio muestra la prometedora eficacia de formar a compañeros de comunicación a incentivar oportunidades para hablar de emociones en entornos cotidianos.

La tesis ofrece una narrativa que permite dar coherencia y enlazar los tres estudios, facilitando un puente de discusión entre estos. Los hallazgos contribuyen a la literatura científica sobre el estudio, comprensión y promoción de la comunicación emocional en la infancia de personas con NCC. Se presentan herramientas y recursos que pueden favorecer el acompañamiento clínico y educativo en beneficio de fomentar conversaciones emocionales en entornos cotidianos mediante el uso de CAA.

Palabras Clave: emociones, infancia, necesidades complejas de comunicación, comunicación aumentativa y alternativa, comunicación emocional, familia, lenguaje

Resum

La comunicació emocional és essencial per a un desenvolupament emocional òptim. Les persones amb necessitats complexes de comunicació (NCC) solen tenir dificultats per a expressar i parlar d'emocions mitjançant l'ús de mètodes convencionals i tenen menys oportunitats per a aprendre i conversar sobre les emocions. Aquest col·lectiu es pot beneficiar de sistemes de comunicació augmentativa i alternativa (CAA) per a satisfer les seves necessitats comunicatives, incloses les de contingut emocional. No obstant això, es desconeix els abastos de les intervencions en CAA en l'àrea emocional, ja que la literatura sobre aquest tema en persones que tenen NCC és encara escassa. La present tesi, en format de compendi de publicacions, explora la comunicació emocional en nens/es amb NCC i el seu entorn. Proposa i analitza eines i estratègies que facilitin oportunitats per a parlar d'emocions, i estudia el canvi en la interacció comunicativa que es dóna després de la implementació d'aquestes propostes.

Específicament, es presenten tres estudis. L'estudi 1 explora i analitza, a través d'una anàlisi temàtica, les percepcions de mares i pares sobre els elements que entren en joc en l'expressió i comunicació emocional de nens/es amb NCC. Es visibilitzen les emocions i formes d'expressió emocional dels nens/es, així com possibles desencadenants emocionals i reptes existents per a parlar d'emocions. També es comparteixen els possibles detonants i emocions experimentades pels cuidadors/es davant la criança, els reptes i les estratègies utilitzades per a promoure un aprenentatge i comunicació sobre emocions.

L'estudi 2 proposa el disseny i desenvolupament d'un perfil de l'estat emocional que pot ser compartit amb persones clau en la vida de l' infant. Està pensat per a ser un recurs que ofereixi informació, visibilitzi reptes i proposi estratègies per a sensibilitzar i promoure una comunicació i un aprenentatge emocional. Presenta dos casos il·lustratius sobre el seu ús i validesa social, a més proposa una guia per a donar suport al procés de presa de decisions

que orientin la intervenció clínica i educativa en relació amb l'adquisició de competències emocionals.

L'estudi 3 presenta un estudi de cas mare-fill on s'analitza el procés comunicatiu que es dóna després que la mare rebés una formació enfocada a promoure espais per a parlar d'emocions en una activitat de lectura de conte. Es va utilitzar un disseny observacional (nomotètic / de seguiment / multidimensional) per a detectar i analitzar els canvis en la interacció comunicativa entorn de les emocions. S'utilitzen sistemes de CAA per tal que el nen accedeixi al vocabulari que li permeti participar en les converses amb la seva mare. Aquest estudi mostra la prometedora eficàcia de formar a companys de comunicació a incentivar oportunitats per a parlar d'emocions en entorns quotidians.

La tesi ofereix una narrativa que permet donar coherència i enllaçar els tres estudis, facilitant un pont de discussió entre aquests. Els resultats obtinguts contribueixen a la literatura científica sobre l'estudi, comprensió i promoció de la comunicació emocional en la infància de persones amb NCC. Es presenten eines i recursos que poden afavorir l'acompanyament clínic i educatiu en benefici de fomentar converses emocionals en entorns quotidians mitjançant l'ús de CAA.

Paraules Clau: emocions, infància, necessitats complexes de comunicació, comunicació augmentativa i alternativa, comunicació emocional, família, llenguatge

Abstract

Emotional communication is essential for optimal emotional development. Individuals with complex communication needs (CCN) often have difficulties expressing and talking about emotions using speech and non-verbal conventional methods, and experience fewer opportunities to learn and discuss emotions. This group can benefit from augmentative and alternative communication (AAC) to satisfy their communication needs, including those with emotional content. However, the scope of AAC interventions in the emotional domain is unknown since the literature on this subject in individuals with CCN remains scarce. This three-article dissertation explores the emotional communication in children with CCN and their environment. It proposes and analyzes tools and strategies that facilitate opportunities to talk about emotions and studies communicative changes after implementing those proposals.

Specifically, three studies are presented. Study 1 explores and analyzes parent views on the elements that come into play in emotional expression and communication in children with CCN, through thematic analysis. Children's emotions and their modes of emotional expression are displayed, as well as the possible emotional triggers and challenges to talk about emotions. Moreover, caregivers' emotions, potential emotional triggers around parenting, challenges, and strategies to promote learning and communication about emotions with children are also exposed.

Study 2 proposes the design and development of an emotional profile that can be shared with key people in the child's life. This resource is intended to provide information, share challenges, and propose strategies to raise awareness and promote emotional communication and learning. The study presents two illustrative cases to show its use and social validity. In addition, it proposes guidelines to support the decision-making process

that could direct clinical or educational interventions related to the acquisition of emotional competencies.

Study 3 shows a case study that analyzes the communication process between a mother and her child with CCN after the mother receives training focused on promoting opportunities to talk about emotions in a storybook reading activity. An observational design (nomothetic / follow-up / multidimensional) was used to detect and analyze the changes in the communicative interaction around emotions. AAC systems were used to give access to vocabulary that supports the child's participation in conversations with his mother. This study presents the promising efficacy of training communication partners in encouraging opportunities to discuss emotions in everyday settings.

The thesis offers a cohesive narrative that links the three studies and facilitates a discussion between them. The findings contribute to the scientific literature on the study, understanding, and promotion of emotional communication in children with CCN. Promising tools and resources for clinical and educational intervention are presented in favor of promoting emotional conversations in everyday settings using AAC.

Keywords: emotions, childhood, complex communication needs, augmentative and alternative communication, emotional communication, family, language

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Gabriela A. Rangel Rodríguez fue responsable de desarrollar las preguntas, objetivos, diseño y procedimiento de la investigación, así como llevar a cabo el proceso de selección de la muestra, creación de materiales e instrumentos, análisis de datos y escritura de los manuscritos. Las coautoras ofrecieron guía, retroalimentación y comentarios en el desarrollo de la investigación y la estructura de los artículos.

En 2019, se recibió el premio Idea Puzzle por el mejor diseño de investigación doctoral.

Lista de Publicaciones Adicionales

Las siguientes publicaciones son relevantes para la tesis, pero no están incluidas en ella.

Póster y Presentación en Conferencias

Na, J. Y., **Rangel-Rodríguez, G. A.,** y Brandt, B. (2018, July 21-26). *Early Development of Emotional Competence (EDEC) Tool for Children using AAC: Its Application in Different Communities* [Conference session]. 18th Biennial Conference of the International Society of Augmentative and Alternative Communication (ISAAC), Gold Coast, Australia.

Rangel-Rodríguez, G.A. (2021, August 9-12). El Uso de la CAA en Contextos Naturales para Promover Comnunicación Emocional. En G. Soto (Chair). *De la Investigación en CAA a la Práctica: Investigaciones Actuales y Necesidades en la Comunidad Hispanohablante* [Simposium]. International Society of Augmentative and Alternative Communication (ISAAC-Connect), online.

Rangel-Rodríguez, G.A., Badia, M., y Blanch, S. (2019, October 15-17). *Let's Talk About Emotions! An Intervention in Natural Settings to Promote Effective and Affective Communication with Children who have Complex Communication Needs* [Poster presentation]. Assistive Technology and Communication Conference, Zagreb, Croatia.

Rangel-Rodríguez, G.A., Badia, M., y Blanch, S. (2021, July 18-23). *Encouraging Emotional Conversations in Children with Complex Communication Needs* [Poster presentation]. The 32nd International Congress of Psychology, Prague, Czech Republic.

Wilkinson, K. M., Na, J. Y., Liang, J., **Rangel-Rodríguez, G. A.**, Crawford, E., y Armendariz, K. (2018, November 15-17). *The EDEC tool for American, Mandarin Chinese, Native American, Spanish, Korean, and Mexican American children* [Conference session]. The Annual Convention of the American Speech-Language-Hearing Association, Boston, MA, United States.

Artículo de Divulgación

Rangel-Rodríguez, G. A., y Bhana, N. (2020). ¿Y cómo te ha ido hoy? La comunicación en niños/as con capacidad verbal limitada. *Aula de Innovación Educativa*, *299*, 69–70.

Capítulo de Libro

Wilkinson, K. M., Na, J. Y., **Rangel-Rodríguez, G. A.,** y Sowers, D. J. (2021). Fostering Communication about Emotions: Aided Augmentative and Alternative Communication Challenges and Solutions. En B. T. Ogletree (Ed.), *Augmentative and Alternative Communication: Challenges and Solutions* (pp. 313–338). Plural Publishing Inc.

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Abreviaciones

AAC   Augmentative and Alternative Communication

CAA   Comunicación Aumentativa y Alternativa

CCN   Complex Communication Needs

NCC   Necesidades Complejas de Comunicación

EDEC   Early Development of Emotional Competence

EDEC-P   Early Development of Emotional Competence Profile

Definiciones

Compañero de comunicación: toda persona que tiene un intercambio comunicativo con otra. Un compañero/a de comunicación eficaz de personas con NCC es aquel que brinda los apoyos necesarios para facilitar una comunicación exitosa (Kent-Walsh y McNaughton, 2005).

Comunicación: Proceso activo de intercambio de información e ideas. Implica comprensión y expresión. Algunas formas de expresión pueden ser: movimientos, gestos, vocalizaciones, verbalizaciones, señas, imágenes, símbolos, escritura y uso de dispositivos de CAA (American Speech-Language-Hearing Association, 2021b).

Comunicación Aumentativa y Alternativa (CAA): Ámbito de conocimiento y práctica clínica que busca complementar [aumentar] la comunicación, o compensar [dar alternativas a] las dificultades en la comprensión y/o producción del habla y lenguaje, ya sea de forma temporal o permanente (American Speech-Language-Hearing Association, 2021a; Elsahar et al., 2019).

Necesidades complejas de comunicación: término usado para describir a personas que presentan barreras en el habla convencional, comunicación y lenguaje, por lo que necesitan de recursos, apoyos y oportunidades que les permitan tener una comunicación y participación eficaz en su entorno (Beukelman y Light, 2020).

Sistemas Aumentativos y Alternativos de Comunicación: herramientas que apoyan a las personas con NCC a satisfacer funciones comunicativas. Incluyen múltiples modalidades de comunicación que pueden ser "sin ayuda" (p.ej. gestos, señas vocalizaciones) y "con ayuda" externa (p.ej. tableros de comunicación, dispositivos generadores de voz) (American Speech-Language-Hearing Association, 2021a).

Capítulo 1

Introducción

Las competencias emocionales juegan un papel importante en el bienestar general, salud mental, logro académico, motivación hacia el aprendizaje, competencia social, autodeterminación, entre otros (Jones et al., 2015; Miller-Slough y Dunsmore, 2016; Saarni, 1999; Taylor et al., 2017; Test et al., 2005; Trentacosta y Izard, 2007). Es por ello que, en los últimos años, se ha promovido apoyar de forma activa a la niñez y juventud en la adquisición de competencias emocionales a través de ofrecer espacios que promuevan una comunicación emocional que permita visibilizar, modelar, hablar de emociones y aprender a dar respuestas apropiadas y genuinas ante la vivencia emocional (Catalano y Kellogg, 2020; Denham, 2019).

En un entorno ideal, la promoción de salud y bienestar emocional tendría que estar al alcance de cualquier persona (World Health Organization, 2018), asegurando oportunidades de aprendizaje de calidad que aprecien la diversidad y tengan una mirada inclusiva y equitativa (UNESCO, 2016). Sin embargo, la realidad actual difiere mucho de lo "ideal". Aún hay un largo camino por recorrer para ofrecer espacios que favorezcan la comunicación emocional y desarrollo de competencias emocionales para todos y todas. Tal es el caso de la población que tiene necesidades complejas de comunicación (NCC) quienes, por diferentes etiologías, presentan barreras en el habla, comunicación y lenguaje, por lo que necesitan de recursos, apoyos y oportunidades que les permitan tener una comunicación y participación eficaz en su entorno (Beukelman y Light, 2020). La comunicación es la base para el aprendizaje y adquisición de competencias, y cuando hay retos comunicativos, diversas áreas pueden verse impactadas, incluida el área emotiva. La población con NCC puede mostrar limitaciones en el lenguaje receptivo y expresivo emocional (Brinton et al.,

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2007; Brinton y Fujiki, 2011; Metsala et al., 2017) y un rezago en comparación con sus pares de desarrollo neurotípico en competencias comunicativas y emocionales (Brinton y Fujiki, 2009; Saarni, 1999). Estudios e intervenciones que den soporte al desarrollo de competencias emocionales (y salud emocional) en esta población en la etapa infantil aún son escasos y muy necesarios (Blackstone et al., 2007; Wilkinson et al., 2021).

El presente estudio se origina a partir de las experiencias y necesidades de las personas con NCC y su entorno, tras el acompañamiento observado en la práctica clínica y educativa. En mi labor como psicóloga clínica y psicoterapeuta, acompañar a personas con NCC y su entorno ha sido un reto y aprendizaje compartido. Las personas con NCC no son las únicas que tiene dificultades comunicativas, sus compañeros de comunicación[1] tenemos dudas y muchas veces carecemos de los recursos, apoyos, conocimientos y habilidades para modelar y promover una comunicación e interacción eficiente que permita brindar el espacio oportuno para un desarrollo óptimo (incluido el emocional). No es que los compañeros de comunicación no queramos comunicarnos ni ofrecer recursos, es que no siempre contamos con las herramientas, la enseñanza y el acompañamiento para poder hacerlo. En mi caso, tanto aprender estrategias (gracias al acompañamiento de terapeutas especializadas en comunicación aumentativa y alternativa), como conocer a cada persona con NCC, sus particularidades comunicativas y sus posibles alternativas de comunicación futura, fue un paso fundamental, para entonces buscar recursos y brindar espacios que promuevan bienestar y salud emocional. Los muchos desafíos y logros encontrados en el camino fueron, siguen y seguirán siendo, el motor del interés en (y pasión por) explorar, proponer y valorar el impacto de intervenciones en entornos que favorezcan un desarrollo emocional sano a lo

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[1] En la presente tesis se utiliza el término compañero/a(s) de comunicación para hablar de toda persona que tiene un intercambio comunicativo con la persona con NCC. Un compañero/a de comunicación eficaz es aquel que brinda los apoyos necesarios para facilitar una comunicación funcional.

largo de la vida de este colectivo. Esta tesis recoge una parte de estos esfuerzos: pretende crear conciencia de la importancia de realizar investigación en esta área, y busca contribuir al estudio, conocimiento y desarrollo de espacios que permitan fomentar, en entornos cotidianos, conversaciones emocionales con los niños y niñas con NCC.

1.1 Descripción y Estructura General de la Tesis

La tesis está estructurada con formato de compendio de publicaciones. El capítulo 2 introduce los referentes teóricos y conceptuales que articulan y fundamentan el presente trabajo. Pone de manifiesto el rol del lenguaje y comunicación en la socialización emocional, y las prácticas utilizadas para promover espacios para hablar y aprender sobre las experiencias emocionales. Muestra los aspectos involucrados en la socialización y comunicación emocional en el colectivo con necesidades complejas de comunicación (NCC). Y finalmente, expone la justificación y los objetivos que guiaron la investigación doctoral, así como un esquema para situar al lector en el proceso llevado a cabo para dar respuesta a las preguntas de investigación.

Los capítulos 3, 4 y 5 presentan los estudios que conforman la tesis, siendo los estudios 4 y 5 los que integran el compendio de publicaciones. El primer estudio (capítulo 3) presenta las perspectivas de padres y madres de niños/as con NCC en torno a la comunicación emocional. Los hallazgos contribuyen al conocimiento de los factores intrínsecos y extrínsecos que pueden estar involucrados cuando los niños/as con NCC experimentan, expresan y hablan de emociones con los demás. En el segundo estudio (capítulo 4) se propone y da pautas para la creación de un perfil del estado emocional actual del niño/a con NCC con la finalidad de ser compartido con compañeros de comunicación clave en la vida del menor y ofrecer estrategias de apoyo para favorecer espacios de comunicación emocional. El tercer estudio (capítulo 5) muestra, en un estudio de caso

madre-hijo, la comunicación y el cambio tras la enseñanza de estrategias enfocadas a brindar acceso al lenguaje necesario para hablar de emociones (utilizando sistemas de comunicación aumentativa y alternativa [CAA]) y a facilitar conversaciones que permitan hablar de eventos relacionados con las emociones en una lectura de cuento. Los resultados exponen la posible relevancia del rol de los compañeros de comunicación y la importancia de dar acceso a sistemas de CAA para fomentar la participación de la persona con NCC en conversaciones emocionales.

El capítulo 6 ofrece una discusión de los hallazgos de la tesis vistos en su conjunto. Este apartado se orienta a destacar las contribuciones e implicaciones de la tesis al campo de la comunicación emocional en el colectivo con necesidades complejas de comunicación. Se ofrecen materiales de consulta, obtenidos de los estudios, que pueden ser de utilidad para la intervención con este grupo y su entorno. A su vez, se comparten las limitaciones y fortalezas del trabajo desarrollado. Para terminar, se ofrecen conclusiones generales de la tesis.

Capítulo 2

Revisión Literaria

Este capítulo introducirá los referentes teóricos y conceptuales que articulan y fundamentan el presente trabajo científico. Se analizará la importancia del lenguaje como herramienta para la socialización y comunicación emocional, así como la relevancia de ofrecer espacios que favorezcan conversaciones emocionales. Posteriormente, se expondrán los desafíos que se presentan cuando se tiene una necesidad compleja de comunicación, así como los estudios realizados hasta ahora que buscan explorar y promover la adquisición de competencias emocionales en este colectivo. Se finalizará con los objetivos y estructura del trabajo realizado para la presente tesis.

2.1 Referentes Teóricos

Este trabajo se fundamenta especialmente en dos perspectivas teóricas: el modelo de competencia emocional de Saarni (Saarni, 1999, 2007) y los modelos centrados en la familia (Dunst, 1997, 2002; Dunst et al., 2002). Ambos modelos toman en cuenta el impacto de las interacciones sociales y contexto cultural en el desarrollo emocional y comunicativo. En este sentido, se entiende que las configuraciones comunicativas que se desencadenan desde las relaciones interpersonales serán el espacio para proporcionar prácticas y oportunidades que permitan un aprendizaje y desarrollo de competencias emocionales en la niñez y la juventud (Cekaite y Ekström, 2019; Goodwin et al., 2012; Saarni, 2000). Es desde la comunicación e interacción con otra persona que se puede observar, comprender, aprender, expresar y responder a las vivencias emocionales (de uno mismo y los demás).

2.1.1 Modelo de Competencia Emocional de Saarni

> "In many respects, affective social competence is emotional communication, a topic of great interest to researchers, clinicians, educators and policy developers alike" (Saarni, 2001, p. 127)

Para Saarni (1999a; Saarni et al., 2008), la competencia emocional es un conjunto de habilidades cognitivas, conductuales y reguladoras orientadas a la emoción que una persona necesita para hacer frente a las demandas de un ambiente cambiante. Propone una teoría con enfoque constructivista social y funcionalista sobre el desarrollo de la competencia emocional (Buckley et al., 2003; Saarni, 1999).

La postura socioconstructivista sostiene que los individuos aprendemos a dar significado (y respuesta) a nuestra vivencia emocional gracias al contexto, a través de las interacciones sociales (lenguaje verbal y no verbal), experiencias, el discurso y narrativas en torno a las emociones. Por tanto, argumenta que la vivencia emocional es inseparable del significado que le da una persona, y ese significado refleja valores e ideas del contexto sociocultural (Saarni, 2001). Este modelo asume que los niños y niñas van construyendo sus significados al implicarse y participar activamente en su proceso de aprendizaje y desarrollo.

El enfoque funcionalista recalca la función adaptativa-social de la emoción, siendo una perspectiva intrínsecamente relacional (Campos et al., 1994). Considera que para entender una emoción hay que examinar de forma conjunta al individuo y los eventos que vive, asumiendo que la emoción aparece cuando el individuo percibe eventos de su entorno como significativos. Afirma que, para poder determinar el nivel de significancia que tiene para una persona específica un evento específico, hay que tomar en cuenta, al menos, los objetivos/metas de la persona en una situación dada, los intercambios o señales sociales con su entorno, la estimulación que la experiencia genera en la persona (p.ej. placer vs dolor), y los recuerdos de experiencias pasadas.

Tomando en cuenta estos fundamentos, Saarni presenta su modelo de competencia emocional exponiendo que, para ser emocionalmente competente, se requiere de ocho habilidades (expuestas en la tabla 2-1) que van desde conocer las emociones en uno mismo hasta llegar a mostrar autoeficacia en el área emocional.

Cabe resaltar que, aun cuando las habilidades que constituyen la competencia emocional las describe como una secuencia (ver tabla 2-1), ésta no es un orden de desarrollo de habilidades. Por el contrario, se pueden observar diferentes manifestaciones de cada habilidad en diferentes edades (sin orden pre-establecido). La competencia emocional es un proceso fluido, evolutivo y dinámico que se va estructurando con el tiempo a medida que nos desarrollamos y desenvolvemos en un contexto social (Saarni, 1999, 2010).

En la evolución del niño/a, el contexto, principalmente el más cercano (familias y cuidadores), puede fortalecer u obstaculizar la comprensión y desarrollo de competencias emocionales (Saarni, 1999, 2007; Saarni et al., 2007). Idealmente, en las primeras etapas de desarrollo, el conocimiento emocional es más concreto, necesitando de mayores apoyos externos para lograr un entendimiento del contexto social y regulación emotiva. Conforme se va creciendo y se adquieren mayores habilidades comunicativas y conciencia del entorno, los niños y niñas muestran mayor habilidad para comunicar sus emociones y las situaciones que las pudieron desencadenar. Posteriormente, muestran mejores estrategias para inferir lo que otros sienten, no sólo por lo que observan, sino también por su experiencia, aprendizajes e historia de vida. Más adelante hay mayor capacidad para entender y expresar emociones complejas como orgullo o vergüenza, así como adquirir mejores estrategias para lidiar con estas emociones con menos apoyo que antes. En la adolescencia/adultez, se contaría más con un análisis crítico que permite revalorar la situación tanto externa como interna, buscar opciones de afrontamiento y escoger la mejor solución.

Tabla 2-1

Habilidades necesarias para ser emocionalmente competente. Modelo de Competencia Emocional de Saarni (1999, 2000)

Habilidades	Descripción	Ejemplo
1. Conciencia emocional en uno/a mismo/a	Reconocer la propia emoción (incluyendo la posibilidad de vivenciar múltiples emociones). En niveles más avanzados, saber que se pueden dar procesos emocionales no conscientes debido a inatención selectiva o dinámicas inconscientes.	Ser capaz de conocer y diferenciar si me siento triste o preocupado.
2. Diferenciación y comprensión de emociones de otros	Reconocer emociones de otros. Con base en señales situacionales y expresivas (relacionado con aprendizajes / roles socioculturales).	Entender cuando otra persona está triste y no enfadada.
3. Uso de vocabulario emocional y expresión apropiada (social y culturalmente).	Expresar palabras adecuadas al entorno sociocultural para hablar de emociones. Con el tiempo, también implica usar "guiones" deseables de afrontamiento social (acorde a lo esperado en el entorno).	Poder describir que alguien está angustiado de una forma culturalmente adecuada.
4. Empatía y sensibilidad a experiencias emocionales de otros.	Comprender las emociones de otros y ponerse en el lugar del otro.	Ser sensible a la tristeza de otros.
5. Reconocimiento de que el estado emocional interno no siempre corresponde con expresión externa.	Este reconocimiento es tanto en uno/a mismo/a como en otros. En niveles más avanzados, comprender que la expresión de emociones puede impactar en otras personas, por lo que es algo a considerar en las propias estrategias.	Reconocer que se puede sentir ira, pero mostrar tranquilidad en un contexto específico.
6. Afrontamiento adaptativo de emociones desagradables y circunstancias incómodas.	Implica usar estrategias auto-reguladoras que ayuden a disminuir intensidad y/o duración de estados emocionales.	Alejarse de una situación que genera gran estrés para minimizar su intensidad, planear y hacer una actividad que ayude a relajarse.
7. Conciencia del impacto de la comunicación emocional en las relaciones con otros.	Conciencia de que las relaciones interpersonales se definen en parte por la calidad de la comunicación emocional existente (reciprocidad, sinceridad/autenticidad emocional).	Saber que, si me enfado constantemente con un amigo, puede afectar mi relación con éste.
8. Autoeficacia emocional.	Capacidad de sentirse cómo realmente uno quiere sentirse. La autoeficacia es definida como el tener la confianza y la habilidad para poder lograr un resultado adaptativo deseado en un contexto dado. En este sentido, implica aceptar la experiencia emocional propia en coherencia con los propios pensamientos o creencias. Hay balance emocional que se integra a los propios principios morales.	Saber y sentir que soy capaz de lidiar con el estrés que se presente en mi vida.

Diversos estudios han evidenciado el impacto de las competencias emocionales en la vida de las personas, mostrando su eficacia en diversas áreas. Por mencionar algunas, la adquisición de competencias emocionales se relaciona con: (a) asertividad (necesario para negociar con otros y auto-representarse[2]), (b) bienestar subjetivo, (c) resiliencia, (d) competencia y ajuste social, (e) creación de relaciones sanas, y (f) participación en actividades escolares con mejores resultados académicos (Buckley et al., 2003; Denham, 2018; Saarni, 1999, 2007; Test et al., 2005). Ser un niño/a, adolescente o adulto competente emocionalmente no significa vivir una vida sin problemas, pero sí implica tener una serie de estrategias internas y apoyos ambientales para hacer frente a los desafíos que su entorno pudiera presentar.

2.1.2 Modelos de intervención centrados en la familia

> "In attempting to involve families in our plans or activities, we have often failed to recognize that we are the ones who should be asking how we might involve ourselves in their lives" (Crais, 1991, p. 5)

Los modelos centrados en la familia consideran a la familia como un sistema social dinámico en el que cada uno de sus miembros está interrelacionado. Esto es, cualquier experiencia que impacte a alguno de sus integrantes tendrá un impacto en los demás (Donahue-Kilburg, 1992; Tomasello et al., 2010). A su vez, se reconoce que la familia es la constante y el elemento más importante en la vida del niño/a, jugando un papel esencial en su cuidado, soporte, desarrollo y bienestar (Dunst, 1997; Dunst et al., 2002; Shelton y Stepanek, 1994). Por tanto, estima que para incidir en el desarrollo del niño/a, es fundamental apreciar e involucrar a la familia y acompañar a padres y madres a adquirir estrategias y fortalecer habilidades que beneficien la crianza. Estos modelos abogan por reconocer a las madres y padres como socios *"parents as partners"* y por consiguiente tener

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[2] Defenderse y abogar por sus derechos (de forma autónoma).

intervenciones colaborativas con ellos (Epley et al., 2010; Trute y Hiebert-Murphy, 2018; Xu, 2020).

Dunst y colaboradores (Dunst et al., 2002, 2007), tras investigar los servicios centrados en las familias, concluyeron que hay dos características centrales en la aplicación de estos modelos: las prácticas relacionales y las prácticas participativas. Las prácticas relacionales enfatizan tanto el uso de competencias interpersonales (p.ej. empatía, escucha activa y reflexiva, calidez), como la incorporación de creencias y actitudes positivas hacia la familia (p.ej. confianza en las capacidades de los participantes). Las prácticas participativas se asocian con reconocer la responsabilidad de la familia en el crecimiento y fortalecimiento de esta, animando a que sus miembros estén al tanto y se involucren activamente en la intervención (que debe ser sensible a las características, necesidades, retos, intereses y prioridades familiares).

Las intervenciones centradas en la familia se fundamentan en prácticas que incluyen (Dunst, 1997, 2002; Dunst y Espe-Sherwindt, 2016):

a) un trato digno, honesto y respetuoso (honrando la diversidad),

b) un apoyo colaborativo, individualizado, sensible y flexible a sus necesidades, haciendo énfasis en los recursos y fortalezas de la familia y sus integrantes,

c) una constante comunicación profesional-familia para impulsar la toma de decisiones informada y esfuerzos hacia el logro de objetivos compartidos, y

d) un espacio donde se facilita la participación familiar y se comparten soportes y recursos enfocados en movilizar a la familia hacia el logro de metas y bienestar.

Las prácticas centradas en la familia tienen como objetivo mejorar competencias y empoderar a los integrantes del sistema con la finalidad de lograr bienestar, sensación de competencia y desarrollo óptimo tanto en la individualidad de sus integrantes como en la colectividad familiar. Estas prácticas dan una mirada a la promoción de conductas enfocadas

al crecimiento, fortaleza y la salud de los integrantes de la familia. En lugar de poner el foco en las problemáticas o prevención de respuestas negativas, se enfoca en las necesidades, intereses, soluciones y fortalecimiento familiar.

El uso de este modelo en la práctica ha demostrado mejoras continuas en diversas áreas del desarrollo infantil (p.ej. en el desarrollo de competencias emocionales y comunicativas), así como en el funcionamiento familiar, bienestar y calidad/satisfacción de vida, reducción de estrés, aumento en la percepción de autoeficacia y confianza de los padres/madres, entre otros (Dempsey y Keen, 2008, 2017; Dunst et al., 2007; Mas et al., 2019).

2.2 El lenguaje como herramienta para la socialización y comunicación emocional

> "Las emociones nos acompañan diariamente, forman parte de nosotros y deben educarse para poder crecer, desarrollarse y convivir mejor con uno mismo y con los demás." (López Cassà, 2011, p. 71)

La literatura en torno al desarrollo de competencias emocionales pone al margen la importancia de estudiar las interacciones sociales en contextos cotidianos. La cultura impacta en el moldeamiento y socialización de las emociones y, en este sentido, la comunicación y lenguaje tienen una relación innegable en el proceso de expresión y aprendizaje emocional (Saarni, 1984; Saarni y Harris, 1991; Shablack y Lindquist, 2019). Los modelos centrados en la familia hacen hincapié en la importancia que tienen los miembros de la familia y cómo éstos, a través de la interacción y comunicación, juegan un rol central en el desarrollo de habilidades en la infancia. A continuación, abordaremos la socialización y comunicación emocional en contextos cotidianos desde su relación con el lenguaje.

2.2.1 El desarrollo de competencias emocionales y su relación con el lenguaje

La comunicación y el lenguaje es esencial para el proceso de desarrollo de diversas habilidades, incluida las competencias emocionales. A su vez, las emociones juegan un papel importante en la comunicación, ya que estas pueden fungir como señales que permiten organizar y motivar la conducta (de uno mismo y del otro) e impactar en la comunicación. Algunas investigaciones han explorado y sugerido la existencia de un vínculo entre las competencias emocionales y lingüísticas, mismas que serán expuestas a continuación.

Por una parte, el lenguaje receptivo y expresivo permite ampliar la identificación, comprensión, expresión y gestión de los estados afectivos propios y de otros, promoviendo a su vez, los significados utilizados socialmente (Ortíz, 2001). Estudios evidencian cómo el lenguaje ayuda no sólo a comunicar lo que sentimos, sino a moldear e influir en procesos cognitivos y perceptuales sobre la emoción (Doyle y Lindquist, 2018; Lindquist et al., 2016; Lindquist, MacCormack, et al., 2015; Lindquist, Satpute, et al., 2015; Shablack y Lindquist, 2019). Como ilustración, se ha demostrado como la falta de acceso a vocabulario emocional está relacionado con dificultades para distinguir emociones específicas. En otras palabras, la falta de conceptos lingüísticos hace que las personas perciban las emociones en, por ejemplo, categorías de tipo placentero, displacentero y neutro. Esto permite explicar las diferencias culturales sobre las emociones al tener un léxico distinto (Pavlenko, 2006; Wierzbicka, 1999). Widen (2013) encuentra que, a mayor número de palabras emocionales adquiridas en el tiempo y a lo largo de la vida, hay mayor habilidad para categorizar, diferenciar y percibir las expresiones emocionales (faciales, comportamentales, lingüísticas, etc.).

Otros estudios hacen hincapié en el impacto del lenguaje en la regulación emocional. Ochsner et al. (2004) explican cómo el diálogo interno es un recurso que puede permitir la re-evaluación de un evento y, por tanto, modificar una emoción. Por su parte, investigaciones de Lieberman y colaboradores (Lieberman et al., 2007, 2011; Torre y Lieberman, 2018)

afirman cómo la simple etiquetación de la emoción ayuda a regularla. El tipo de palabra utilizada para referir una emoción, impacta en toda la experiencia emocional (misma que se puede modificar). Por ejemplo, en español, no es lo mismo decir "estoy fúrico" a "estoy enojado/enfadado", el lenguaje brinda matices a la emoción y estos matices lingüísticos ayudan en la toma de decisiones para brindar respuesta a la vivencia emocional (transmitir lo que me genera molestia vs alejarme de lo que me molesta para calmarme). A su vez, expresarse en formas adecuadas a las normas del entorno se relaciona con respuestas emocionales y conductuales adaptativas (Saarni, 2001; Saarni et al., 2007). Personas que son capaces de expresar emociones mediante la palabra manifiestan una reducción en la intensidad y duración de la emoción, presentan mayores estrategias de gestión emocional y encuentran formas eficaces para defenderse y abogar por sus derechos si lo requieren (Aro et al., 2014; Buckley et al., 2003; Cole et al., 2010; Roben et al., 2013; Test et al., 2005; Torre y Lieberman, 2018).

En suma, el acceso a lenguaje relacionado con las emociones aumenta la percepción emocional (habilidad para categorizar, percibir y atender emociones de uno mismo y otros) y, por consiguiente, permite una preparación y puesta en marcha para la toma de decisiones hacia la gestión emocional.

2.2.2 La comunicación y lenguaje en la socialización emocional en la familia

El término *socialización* hace referencia al proceso mediante el cual las personas adquieren habilidades sociales, creencias, valores y comportamientos necesarios para tener un desempeño efectivo en la sociedad o en un grupo en particular (American Psychological Association, 2020). La *socialización emocional* es un concepto utilizado por diversos autores para hablar del proceso de adquisición de habilidades para expresar, comprender y gestionar las emociones (Buss et al., 2019; Eisenberg et al., 1998; Lugo-Candelas et al.,

2015), promoviendo entonces, competencias emocionales. Por norma, la socialización, incluyendo la emocional, sucede dentro de un contexto y por tanto las vivencias, significados y formas de comunicar/gestionar las emociones están fuertemente influenciadas por la comunicación que se da con las personas dentro del entorno socio-cultural en el que se vive. Los procesos de socialización emocional se pueden presentar entre adultos, sin embargo, es mejor explicado cuando se hace referencia a la interacción entre adulto-niño/a donde se tiene el objetivo específico de brindar información sobre la socialización de las emociones.

La relación entre padres-madres y sus hijos/as es el primer acercamiento donde los niños/as aprenden acerca de las emociones. Además, estas relaciones son un vínculo que permanece en el tiempo y, aunque al crecer hay otros vínculos que influyen en el desarrollo de competencias emocionales, esta interacción sigue siendo significativa, idónea y fundamental en el proceso de aprendizaje y comunicación emocional en la niñez. Por otra parte, cabe resaltar que la socialización emocional es un proceso bidireccional, las características temperamentales, neurobiológicas, conductuales, emocionales y de desarrollo de los hijos/as influyen en lo que sus padres/madres sienten, piensan y hacen acerca de las emociones y viceversa (Saarni, 1999, 2008; Saarni et al., 2008). Por ejemplo, estudios identifican que aquellos padres que perciben a sus hijos temerosos, cautelosos e inhibidos tienden a mostrar menos sorpresa y decepción ante la timidez de sus hijos, sin embargo, se volvieron más restrictivos, directivos y protectores de las actividades autónomas de sus hijos/as (Hastings y Rubin, 1999; Rubin et al., 1999)

La familia, principalmente los padres/madres, promueve un aprendizaje emocional de forma tanto directa o indirecta como deliberada o involuntaria (Dunsmore et al., 2009; John M. Gottman et al., 1996; Hastings, 2018; Lewis y Saarni, 1985; Meyer et al., 2014; Thompson, 2014). Los procesos de socialización emocional de corte indirecto—sutil y posiblemente involuntario—se dan a través de los actos comunicativos (verbales y no

verbales) de los padres, que está influenciado por el propio sistema de creencias y valores acerca de las emociones. Los padres modelan y transmiten mensajes implícitos sobre qué tanto una vivencia y expresión emocional es aceptable y apropiada en un contexto dado, y esto, incluso lo manifiestan mediante sus propias expresiones emocionales. La expresión emocional de los padres puede provocar emociones y respuestas en los hijos/as. Por ejemplo, hay evidencia que demuestra cómo las emociones desagradables de los padres/madres pueden contribuir a una activación de estrés persistente en los niños/as y a una dificultad para autorregularse (Moore, 2009, 2010). Por el contrario, niños/as de padres que demuestran altos niveles de afecto positivo, utilizan más lenguaje emocional relacionado con emociones agradables (Halberstadt y Eaton, 2002) . Otro contenido indirecto de enseñanza/aprendizaje emocional es la calidad de la relación padre/madre-hijo/a (Hastings, 2018), pues ésta genera un clima emocional específico que influye en las emociones.

La aproximación directa de la socialización emocional, frecuentemente mediada por el lenguaje (Lutz y White, 1986), es cuando se instruye y anima a la niña/o a conversar y utilizar palabras que compartan su sentir (p.ej. "estás triste porque tu torre se cayó"), así como usar estrategias u opciones de respuesta para las vivencias emocionales (p.ej. "respira y ya más tranquilo/a, vamos a buscar una solución"). Las conversaciones entre padre/madre-hijo/a acerca de las emociones dan forma a las representaciones que el niño/a tiene respecto a dicho tema. Esto es, a través de la comunicación directa con los demás, los niños/as pueden ampliar su conocimiento/vocabulario emocional, identificar y comprender las causas de las emociones, las consecuencias de las respuestas emocionales, así como comprender las expectativas socioculturales sobre cómo expresar, responder y afrontar una emoción en determinado contexto.

En condiciones óptimas, la familia facilita el espacio para empezar a desarrollar habilidades emocionales que sean socioculturalmente apropiadas (Cole y Tan, 2015;

Denham et al., 2015; Eisenberg et al., 1998; Zahn-Waxler, 2010). Pero la realidad es que, a menudo, las familias no están preparadas para educar en competencias emocionales y requieren espacios de formación para lograrlo (Bisquerra, 2011). El acompañamiento desde el modelo centrado en la familia ha mostrado eficacia, ya que se enfoca en conocer el entorno y las características, creencias, valores e intereses de los integrantes de la familia, su lenguaje y conductas hacia la socialización emocional. Esto permite generar un plan *ad hoc* a sus necesidades/objetivos que sea sensible a las especificidades del entorno del infante o joven (Dunst, 2002; Mandak et al., 2017).

2.3 Prácticas para la promoción de conversaciones relacionadas con las emociones

> "Caregivers who engage their children in emotion talk may strengthen the ability of their children both to understand and to regulate emotion."
> (Brinton y Fujiki, 2009, p. 262)

Las prácticas para la promoción de una socialización emocional deliberada y apropiada a las necesidades de la familia y el niño/a han mostrado resultados favorables en el desarrollo y bienestar (Brand y Klimes-Dougan, 2010; Johnson et al., 2017; Zinsser et al., 2021). Para ello, es necesario tener una adecuada comprensión del estado actual emocional del niño/a y de las prácticas parentales utilizadas para la socialización de las emociones (p.ej. aceptación/evitación de emociones). La entrevista y observación son recursos utilizados tanto para la exploración, como para el asesoramiento y seguimiento de cambios en la comunicación emocional entre padres/madres-hijos/as (Hastings, 2018; Stettler y Katz, 2014).

Proveer espacios para tener conversaciones relacionadas con las emociones se relaciona con un desarrollo emocional sano (Beck et al., 2012; Cohen y Mendez, 2009; Denham et al., 2015). Particularmente, estudios demuestran como las conversaciones entre

padres-hijos, que incluyen referencias y explicaciones socioemocionales[3], están positivamente relacionadas con el desarrollo de la comprensión y regulación emocional del niño/a (Denham et al., 2015; Fivush, 2007; Laible, 2004; Sales y Fivush, 2005) y se asocian con una reducción de problemas conductuales (Brophy-Herb et al., 2015) y emocionales (Suveg et al., 2008). Hablar de eventos relacionados con las emociones es una oportunidad para concientizar, aprender y tomar perspectiva acerca de los sentimientos, pensamientos y afrontamientos posibles (propios y de otros) ante vivencias emocionales (Denham y Burton, 2003).

De igual forma, se ha observado que cierto tipo de actos comunicativos lingüísticos en el adulto promueven respuestas comunicativas en el niño/a y viceversa. Por ejemplo, estudios realizados con madres y niños/as con desarrollo neurotípico, refieren que las madres que realizan preguntas y comentarios asociados a las emociones en sus conversaciones, tienen hijos/as que expresan más comentarios con referencias emotivas (Fivush et al., 2003; Leyva et al., 2021; Van Bergen et al., 2009). A su vez, se ha encontrado que las madres que brindan retroalimentación hacia los comentarios de sus hijos/as (p.ej. "tienes razón, se siente triste"), tienen hijos/as que realizan más comentarios con tinte emocional (Leyva et al., 2021). Al respecto, la retroalimentación a las respuestas del niño/a sugiere una señal al niño/a con el mensaje de que sus contribuciones son bienvenidas y valiosas (Fivush et al., 2006).

El contenido emocional parece ser otro dato relevante al tener conversaciones emocionales. Murray et al. (2014) evidenció en un estudio con niños/as de preescolar que entablar conversaciones con un énfasis en emociones desagradables (miedo, ansiedad, amenaza, dificultades para afrontar dichas emociones) pudiera estar asociado con síntomas

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[3] Nombrar emociones (*"está triste"*), dar información del contexto (*"porque perdió a su gato"*), hablar de indicadores comportamentales de la emoción (*"mira, está llorando"*), posibles afrontamientos (*"puede pedir ayuda"*), y enlazar la experiencia con vivencia personal (*"tú estuviste triste cuando se te perdió tu peluche"*).

de ansiedad social después del primer año de escuela. El tipo de contenido emocional al que hacen referencia las familias (por ejemplo si se habla sobre eventos percibidos como agradables y/o desagradables) parece depender de factores socioculturales (Leyva et al., 2021; Nelson et al., 2012). Hablar con los niños/as con diferente tipo de contenido emocional (agradable y desagradable), de una forma positiva (segura, cálida, no amenazante) y alentando a que ellos también participen en la conversación, está relacionado con comportamientos emocionales adaptativos (Leerkes y Bailes, 2019).

2.3.1 Conversaciones Emocionales en la Lectura de Cuentos

La lectura de cuentos compartida es una actividad que se realiza en contextos naturales relajados y cariñosos con una rutina que puede ser predecible y divertida. Esta actividad puede ser utilizada como herramienta para estimular conversaciones emocionales y enriquecer las interacciones entre los participantes de la lectura (Liboiron y Soto, 2006; Rose et al., 2018).

La exposición a medios narrativos en las primeras etapas de desarrollo ha sido de gran interés y sus beneficios han sido ampliamente reconocidos. Estos medios han mostrado un impacto positivo en las competencias lingüísticas (Scarborough y Dobrich, 1994; Sénéchal y LeFevre, 2002), cognitivo-sociales (Mar et al., 2010) y emocionales (Garner et al., 1997; Symons et al., 2005).

Los niños/as al leer logran: (a) simular el cuento mentalmente (Mar y Oatley, 2008), (b) mostrar una comprensión de la fantasía (Skolnick y Bloom, 2006), (c) adoptar diferentes y nuevas perspectivas (Rall y Harris, 2000), (d) relacionar la historia con la imaginación y el juego simulado (Carlson y Taylor, 2005), y (e) sentir la experiencia a través de experimentar reacciones fisiológicas y emocionales que indican que están inmersos en la historia (Bar-Haim et al., 2004). Los cuentos infantiles, brindan información sobre el

funcionamiento del mundo, las normas sociales y las respuestas socialmente aceptables (Mar et al., 2010; Rose et al., 2018). En la exposición a materiales literarios con menores, el adulto suele propiciar, de forma natural, una conversación con el niño/a sobre los estados internos cognitivos y emocionales que ocurren en los personajes (Ruffman et al., 2002) y, de hecho, estas conversaciones son más frecuentes en la lectura del cuento que en situaciones del día a día (Dyer et al., 2000).

Investigaciones han sugerido que la lectura de cuentos compartida entre padres/madres-hijos/as provee una gran oportunidad para la socialización emocional (Garner et al., 2008; Rose et al., 2018). No solo brinda el espacio para hablar de las experiencias emocionales de los personajes, también permite abrir conversaciones sobre vivencias propias. Esto intensifica en los niños/as la conciencia emocional, aumenta vocabulario y comunicación, y enseña estrategias para poder responder a las emociones propias y de otros en contextos específicos. Las actividades literarias en casa son una potente herramienta tanto para promover conversaciones emocionales como para el desarrollo de competencias lingüísticas, sociales y emocionales.

2.4 La socialización y comunicación emocional en el contexto de las personas con necesidades complejas de comunicación

> "Just as a dance couldn't possibly be a dance unless people moved to it, so language doesn't become communication until people grow to understand and express it back. It has to be a two-way exchange. This is why 'communicating' is an action word." (Staehely, 2000, p.1)

Las personas que tienen necesidades complejas de comunicación[4] (NCC) se caracterizan por presentar barreras para realizar intercambios comunicativos eficientes mediante herramientas "convencionales", como el habla, por lo que requieren otro tipo de

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[4] Término adoptado del inglés "complex communication needs" (CCN).

estrategias comunicativas para poder participar eficazmente en una comunicación. Las NCC pueden deberse a diferentes etiologías, en las que se pueden encontrar (Beukelman y Light, 2020): discapacidades del desarrollo (p.ej. parálisis cerebral), discapacidad intelectual, trastornos degenerativos (p.ej. distrofia muscular), desórdenes adquiridos (p.ej. lesión cerebral), trastorno del espectro autista, entre otros.

A menos que tengan enseñanza y acceso a una comunicación *ad hoc* a sus necesidades, capacidades y recursos, las personas que tienen barreras para comunicarse eficazmente mediante el habla enfrentan severas restricciones en su comunicación, participación e inclusión en diferentes áreas de la vida (familiar, educativa, social, emocional, cognitiva, médica, laboral, etc.) (Beukelman y Light, 2020). De hecho, hay una fuerte evidencia de que este colectivo puede presentar mayor riesgo a desarrollar dificultades emocionales y psicológicas en comparación con el colectivo de desarrollo típico (Boyce et al., 2009; Di Marco y Iacono, 2007; Lowry, 1998; Smith, 2005; Watson et al., 2021) y a tener un acceso limitado -en oportunidades y vocabulario- para tratar cuestiones de salud mental y emocional (Bell y Cameron, 2003; Bennett, 2014; Collier et al., 2006; Di Marco y Iacono, 2007; Foley y Trollor, 2015; Watson et al., 2021).

Para la comunidad con NCC, resulta beneficioso la enseñanza, aplicación y el uso de comunicación aumentativa y alternativa (CAA). La CAA involucra investigación y práctica en el área clínica que busca complementar [aumentar] la comunicación, o compensar [dar alternativas a] las dificultades en la comprensión y/o producción del habla y lenguaje, ya sea de forma temporal o permanente (American Speech-Language-Hearing Association, 2021a; Elsahar et al., 2019). La CAA utiliza técnicas y herramientas diversas que apoyan a las personas con NCC a satisfacer funciones comunicativas, que van desde expresar deseos y necesidades, hasta compartir información, pensamientos, ideas y emociones (Beukelman y Light, 2020; Wilkinson et al., 2021). Los sistemas de CAA incluyen múltiples modalidades

que pueden ser "sin ayuda" externa (p.ej. vocalizaciones, gestos, señas) y "con ayuda" externa para comunicarse (p.ej. tableros de comunicación, dispositivos generadores de voz). La CAA apoya, da acceso y aumenta la comunicación, aprendizaje y participación de las personas con NCC en su comunidad, favoreciendo su autonomía, regulación emocional, poder de decisión y auto-determinación, mejorando así la calidad de vida y promoviendo bienestar (Iacono et al., 2013; Light y McNaughton, 2012; Speech Pathology Australia, 2020; von Tetzchner y Grove, 2003).

La habilidad para comunicarse es reconocida como un derecho humano esencial (si no es que de los más fundamentales; International Communication Project, 2014). Aquellas personas que muestran barreras comunicativas tienen el derecho a acceder a los recursos, intervenciones y apoyos necesarios para potenciar una comunicación que les permita participar de forma activa en las diferentes áreas de su vida (Brady et al., 2016); así como reducir posibles riesgos a los que, desgraciadamente, su contexto les puede someter (p.ej., exclusión, negligencia, abuso; Browne y Millar, 2016; Bryen et al., 2007; Taheri et al., 2016). Es primordial que el entorno de este colectivo brinde espacios y recursos para estimular y fomentar las herramientas comunicativas que les permita ser independientes, tener una vida digna y abogar por la defensa de su propio bienestar (físico, emocional, mental, etc.).

Para que la interacción comunicativa sea exitosa, es fundamental no solo brindar acceso a sistemas aumentativos y alternativos de comunicación, también hay que brindar acompañamiento y formación a las personas (interlocutores o compañeros de comunicación) que conviven con el usuario de CAA. Una gran cantidad de investigaciones han evidenciado que formar a los compañeros de comunicación es imprescindible para tener un resultado favorable en las intervenciones con personas que utilizan CAA (Kent-Walsh et al., 2010, 2015; Kent-Walsh y McNaughton, 2005; Muttiah et al., 2018; Na y Wilkinson, 2018; Billy

Townsend Ogletree et al., 2016; Timpe et al., 2021). Esto es debido a que, al relacionarse con personas con NCC, los interlocutores tienden a (Blackstone, 1999; Light et al., 1985):

- Dominar la interacción (toman la mayoría de los turnos comunicativos y dirigen la interacción).

- Realizar mayoritariamente preguntas cerradas.

- Brindar menos oportunidades para iniciar o participar en conversaciones.

- Interrumpir respuestas/expresiones de personas que usan CAA.

- Atender más el sistema de asistencia comunicativa (tecnología) en lugar de focalizarse en el emisor y su mensaje.

El entrenamiento a los interlocutores permite brindar estrategias que faciliten la interacción y comunicación con personas que tienen NCC. A pesar de que hay una amplia gama de estudios en CAA y su uso para brindar oportunidades que fomenten el desarrollo lingüístico y comunicativo, aún son escasas las investigaciones referentes a la promoción de desarrollo de competencias emocionales y facilitación de espacios para hablar, expresar, etiquetar, comprender, responder apropiadamente y aprender acerca de las emociones (Wilkinson et al., 2021).

2.4.1 Los Retos para una Comunicación y Socialización Emocional

> "*No person is an island*. When a child or adult experiences a developmental, acquired, degenerative, or temporary condition that results in complex communication needs, it impacts not only the individual, but also family members and other people in the individual's life." (Beukelman y Light, 2020, p. 125)

Pocos estudios han explorado la relación existente entre el lenguaje y la socialización referente a lo emocional en personas con NCC que se benefician de CAA. No obstante, existen diferentes razones para considerar que este vínculo es igualmente fundamental para

la comunidad que utiliza CAA (Wilkinson et al., 2021). Sin embargo, este colectivo se puede encontrar con diversos retos para tener un desarrollo emocional óptimo.

Retos en la comunicación y lenguaje y su relación con las competencias emocionales. Dada la relación que se encuentra entre lenguaje y habilidades emocionales en estudios de personas con desarrollo típico[5], es muy posible que las personas con barreras en el lenguaje y comunicación presenten retos en el desarrollo de competencias emocionales. Algunos estudios con personas que presentan retrasos o trastornos en el lenguaje refieren la existencia de una clara limitación en la expresión, comprensión y gestión emocional (Brinton et al., 2007; Brinton y Fujiki, 2009, 2011; Metsala et al., 2017). Blackstone y Wilkins (2009) sugieren que las personas con NCC tienen barreras para manifestar claramente sus emociones debido a los retos físicos, motores o intelectuales que pudieran presentar.

Retos en la expresión emocional y su relación con respuestas desadaptativas. Estudios sustentan que los comportamientos desadaptativos y desafiantes (p.ej. golpear, gritar, destruir), relacionados con una reacción emocional, tienen una función comunicativa (p.ej. llamar la atención, obtener algo, evadir/escapar de algo). En este sentido, se ha demostrado cómo el aprendizaje y adopción de estrategias de comunicación adaptativas (p.ej. acceso a la comunicación lingüística vía CAA) sustituye los "problemas" comportamentales (Mirenda y Brown, 2007; Wilkinson y Reichle, 2009), y por tanto sugeriría mayor gestión emocional. Por su parte, Wilkinson et al. (2021) ilustran cómo las personas con NCC pueden mostrar comportamientos poco convencionales debido a sus dificultades para expresar su sentir y/o entender situaciones emocionales que ocurren en su entorno. En un estudio reciente, Belmonte-Darraz et al. (2021) presentan evidencia acerca de cómo niños y niñas con parálisis cerebral, en comparación con sus pares de desarrollo

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[5] Para más información, ver el apartado de este mismo capítulo titulado: "El desarrollo de competencias emocionales y su relación con el lenguaje".

típico, presentan mayores problemas de conducta y peor regulación emocional, y que esto a su vez, correlacionaba negativamente con el conocimiento emocional.

Retos de los compañeros de comunicación y su relación con la socialización emocional. El rol de los interlocutores (p. ej. padres/madres, educadores, terapeutas) es esencial para la socialización emocional. La forma de modelar y dar estrategias de andamiaje[6] para la comunicación sobre emociones (detectar, nombrar, hablar y razonar sobre estas) es crítico para el aprendizaje (Warren y Yoder, 1998). Sin embargo, se podría pensar que, así como hay estudios que refieren que los compañeros de comunicación suelen brindar menos oportunidades para involucrar activamente a la comunidad con NCC en conversaciones, los espacios para una socialización emocional directa (participar y hablar de emociones para promover adquisición de competencias emocionales) podrían estar igualmente reducidos. A esto se le puede añadir que los compañeros de comunicación pueden tener dificultades para detectar/interpretar algunas señales emocionales de las personas con NCC (Blackstone y Wilkins, 2009; Di Marco y Iacono, 2007) lo que puede resultar en un obstáculo para satisfacer y dar acompañamiento a las necesidades emocionales que pudieran requerir. A pesar de esta posible dificultad, estudios refieren que los padres/madres son los más equipados para brindar información sobre los intentos comunicativos de sus hijos/as (incluido los de expresión emocional). Por tanto, el compartir dicha información con otros compañeros de comunicación del niño/a puede ser útil para impulsar su desarrollo e independencia (Kruithof et al., 2020; Noyek et al., 2020; Stringer et al., 2018).

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[6] Andamiaje o *scaffolding* es el proceso mediante el cual se brindan apoyos para favorecer un aprendizaje (Vygotsky, 1962). Es un término que se adaptó de la construcción: los constructores utilizan andamios de forma temporal para sostener una estructura (p.ej. edificio) durante la construcción, y posteriormente -una vez que la estructura puede permanecer por sí misma- se retira el andamio.

2.4.2 Los Recursos y Estrategias para una Comunicación y Socialización Emocional

Tomando en cuenta los retos expuestos anteriormente, un grupo de investigadoras se dio a la tarea de explorar, proponer recursos y valorar estrategias que fomenten la comunicación sobre emociones en niños/as que tienen NCC (Na, Wilkinson, Karny, et al., 2016; Na, Wilkinson, et al., 2018; Na y Wilkinson, 2018; Wilkinson et al., 2021). La investigación hasta ahora ha sentado las bases para que eventualmente se lleve a la aplicación y validez clínica. Los estudios ponen de manifiesto que la CAA podría ser un recurso para dar soporte a la socialización y comunicación sobre las emociones. Para ello, primero se diseñó una entrevista que tiene como objetivo explorar el desarrollo temprano de competencias emocionales en personas con NCC. A la par, se proponen unas pautas para brindar acceso a la comunicación con contenido emocional. Y posteriormente, se propone una estrategia para fomentar conversaciones emocionales. En todo momento, se hace hincapié en que el acompañamiento, recursos y estrategias propuestos deben respetar las características individuales y los antecedentes culturales y sociales de cada individuo y compañeros de comunicación. A continuación, se desglosan los recursos y estrategias propuestos hasta el momento:

Entrevista: El Desarrollo Temprano de Competencias Emocionales. La herramienta EDEC[7] es un instrumento de evaluación descriptivo (*no* diagnóstico ni prescriptivo) conformado por una entrevista semiestructurada dirigida a padres, cuidadores, especialistas y/o profesores de niños/as con retos comunicativos que requieren del uso de CAA (Na, Wilkinson, et al., 2018). Está compuesta por dos secciones principales. La primera contiene preguntas sobre el temperamento y las características comportamentales del niño o niña. La segunda incluye preguntas sobre los medios actuales de expresión y

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[7] Por sus siglas en inglés: Early Development of Emotional Competence

conocimiento emocional del niño/a, así como la dinámica y expectativa sociocultural del entorno (p.ej. familia) asociada a la socialización y comunicación sobre las emociones.

La entrevista tiene como objetivo crear conciencia sobre la relación existente entre lenguaje y competencia emocional. Y con ello, tomar decisiones que promuevan intervenciones comunicativas que incluyan acceso al lenguaje de las emociones, permita hablar de estas y contribuya en el desarrollo de competencias emocionales en coherencia con los valores, cultura, intereses, necesidades, fortalezas del niño/a con NCC y su entorno. En este sentido, fue deliberadamente diseñada[8] para facilitar la comprensión de las diferencias culturales acerca de las creencias y actitudes de las familias en torno a la manera de expresar emociones. Está destinada a permitir que el entrevistador colabore con el entrevistado para recopilar información útil para apoyar y, con estos datos, crear un plan de intervención *ad hoc* para dar soporte y acceso a la comunicación sobre las emociones. Actualmente, la entrevista ha sido probada en diferentes culturas, comunidades e idiomas (inglés, español, chino mandarín, coreano, danés; Na, Rangel-Rodríguez, et al., 2018; Na, Wilkinson, Liang, et al., 2016; Wilkinson et al., 2018).

Recurso: Diseño de Sistemas Aumentativos y Alternativos de Comunicación sobre Emociones. Na, Wilkinson, Karny, et al. (2016) sugieren que los sistemas de CAA tendrían que incluir vocabulario relevante que permita tener conversaciones con contenido emocional. Esto no sólo implicaría tener acceso a un amplio vocabulario emocional (p.ej. alegría, tristeza, decepción, frustración, miedo, preocupación, esperanza, etc.), sino también acceder a vocabulario que permita dialogar acerca de la experiencia emocional. Por tanto, proponen incluir en el diseño de CAA vocabulario acerca de las causas de la vivencia emocional (p.ej. "terminó una actividad", "iré a pasear", "me ignoran", "no puedo"), así

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[8] Desarrollada en 2012, actualizada en 2014, publicada en 2018.

como de las posibles respuestas que un individuo pueda dar ante una emoción (p.ej. "pedir un abrazo", "pedir ayuda", "escuchar música", "llorar", "hablar con alguien", "volver a intentarlo"). En las publicaciones de Wilkinson et al. (2021) y Na, Wilkinson, Karny, et al., (2016) se presentan ejemplos de cómo se podría diseñar un tablero de comunicación tomando en cuenta estas pautas sugeridas. La figura 2-1 presenta un ejemplo de un diseño de tablero simple (adaptado de estas pautas) para fomentar conversaciones emocionales.

Figura 2-1

Ejemplo de Tablero de Comunicación adaptando las pautas propuestas por Na, Wilkinson, Karny, et al. (2016) y Wilkinson et al. (2021).
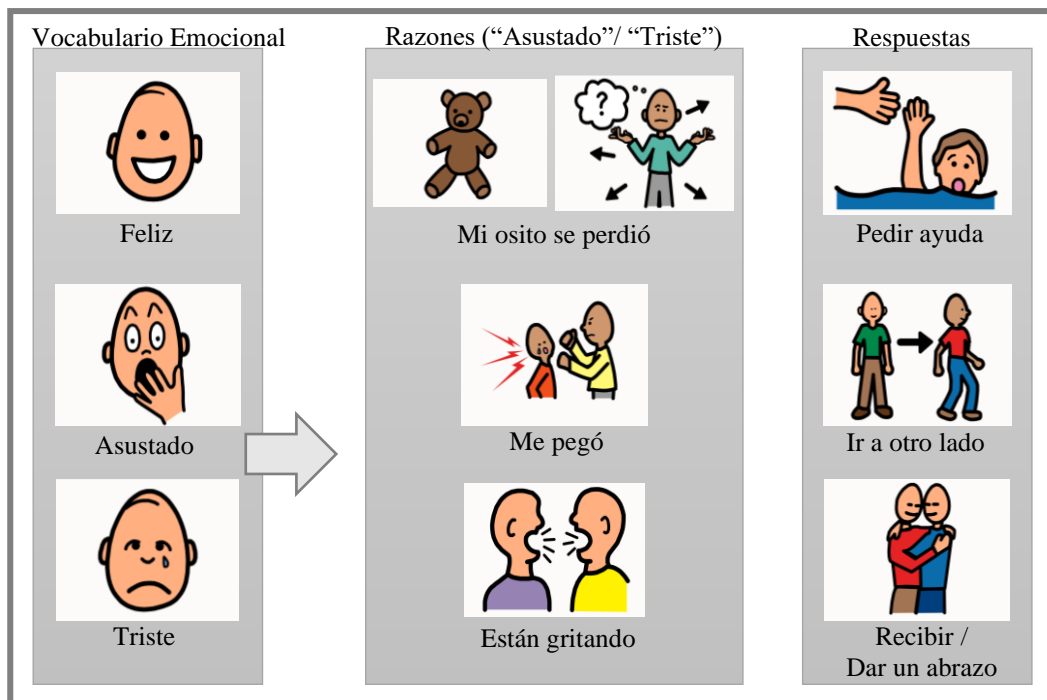
Nota: Imágenes de PCS y Boardmaker por Tobii Dynavox.Todos los derechos reservados. Usados con permiso.

Las investigadoras hacen hincapié en que el tablero debe servir a las necesidades de la persona y entorno al que va dirigido. Por tanto, debe contener el vocabulario que se requiere para: a) que el niño/a con NCC pueda participar en conversaciones, y b) pueda recibir de su entorno un modelo de comunicación adaptado a sus necesidades comunicativas (estrategias de andamiaje).

Estrategias para Hablar de Emociones como Compañeros de Comunicación (STEPS[9]). Las estrategias para hablar de emociones es una propuesta de entrenamiento dirigida a los compañeros de comunicación (p.ej. padres, madres, profesores, terapeutas, etc.) propuesta por Na y Wilkinson (2018). Tiene como objetivo enseñar herramientas comunicativas que favorezcan espacios para dialogar sobre las emociones utilizando CAA. La instrucción consta de la explicación de tres pasos para fomentar la comunicación emocional:

- Paso 1. Provee y modela vocabulario emocional (nombra la emoción).

- Paso 2. Valida y dialoga sobre la causa de la emoción.

- Paso 3. Dialoga sobre respuestas apropiadas ante la vivencia emocional.

En la enseñanza se pide que, en cada paso, se utilicen las siguientes estrategias comunicativas:

- Pregunta: haz una pregunta abierta (p.ej. ¿cómo se siente?, ¿por qué?, ¿qué puede hacer?)

- Espera: realiza una pausa de mínimo 5 segundos para que el niño/a dé una respuesta.

- Responde: brinda una respuesta ante la presencia o ausencia de la respuesta comunicativa de tu hijo/a, modelando el uso del tablero comunicativo (p.ej. señala o selecciona el vocabulario).

En la formación se presentan ejemplos de diseños de sistemas de CAA que dan acceso a hablar de los tres pasos de la formación (siguiendo las pautas de diseño de sistemas de CAA descritas en el apartado anterior). Y se explica la importancia de dar acceso a la

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[9] Por sus siglas en inglés: Strategies for Talking about Emotions as PartnerS

comunicación emocional, diseñando tableros que coincidan con las características socioculturales, familiares y del niño/a. Por tanto, en la instrucción, se anima a los compañeros de comunicación a involucrarse en el diseño de los sistemas de CAA. Además, se sugiere que, inicialmente, para la aplicación de las estrategias propuestas, se fomenten diálogos sobre emociones en actividades placenteras y significativas para el niño/a (p.ej. videos, cuentos, películas, series, juegos de rol, etc.).

Na y Wilkinson (2018) llevaron a cabo un estudio experimental de caso único con línea base múltiple entre participantes para evaluar el efecto del programa de instrucción STEPS en tres díadas padre/madre-hijo/a con síndrome de Down. Se utilizó una actividad de lectura de cuentos como contexto para fomentar las conversaciones sobre las emociones. Antes de que los participantes utilizaran las estrategias propuestas, se pidió a los adultos de la muestra que proporcionaran el vocabulario del que les gustaría hablar, tomando en cuenta el entrenamiento STEPS, para poder diseñar los tableros de comunicación emocional que utilizarían en la actividad de lectura de cuentos posteriores. Los resultados evidenciaron que, tras la sesión de formación STEPS, los adultos participantes brindaron más oportunidades para dialogar sobre las emociones usando el sistema de CAA y sus hijos/as mostraron un aumento en las expresiones referentes a lo emocional utilizando comunicación multimodal (incluyendo CAA).

2.5 Justificación y Objetivos del Presente Estudio

Como se ha mostrado a lo largo de este capítulo, el brindar espacios para hablar de emociones es un medio para fomentar el aprendizaje y desarrollo emocional óptimo. La investigación sugiere que aquellos niños/as con desarrollo típico que participan en conversaciones emocionales tienden a mostrar una mayor adquisición de habilidades emocionales como: reconocer y etiquetar emociones, comprender sus causas y

consecuencias, a la vez que a tener y elegir recursos para una gestión y expresión adecuada de las emociones (Aznar y Tenenbaum, 2013; Beck et al., 2012; Cole et al., 2010; Saarni, 2007; Tenenbaum et al., 2008). Si ofrecer espacios para la comunicación sobre las emociones es benéfico para niños/as con desarrollo típico, puede resultar incluso más importante y necesario en niños/as con necesidades complejas de comunicación.

Los padres/madres suelen ser los primeros modelos y facilitadores emocionales y comunicativos que proveen oportunidades para comprender el mundo emocional interno y externo. Es posible que los cuidadores de niños/as con NCC requieran de acompañamiento para fomentar conversaciones emocionales que apoyen el desarrollo emocional infantil. Los niños y niñas con retos comunicativos tienen derecho a vivir en un entorno que reconozca y dé respuesta a sus necesidades, y a que se les brinde el acceso a la adquisición de habilidades comunicativas y emocionales, favoreciendo su participación y bienestar. Es menester de la sociedad brindar los recursos y oportunidades para un desarrollo sano, para esto a menudo hay que apoyar a las familias para que se sientan capaces de hacerlo.

A pesar de que la comunicación, el lenguaje y las emociones son un área fundamental para un desarrollo óptimo, los estudios sobre este ámbito en niños/as que tienen NCC y sus padres/madres aún son insuficientes. De hecho, estudios recientes siguen abogando por la exploración, estudio, análisis, divulgación y fomento de intervenciones que impulsen el desarrollo de habilidades emocionales y comunicativas en esta comunidad, tanto en entornos terapéuticos como en entornos naturales (Blackstone y Wilkins, 2009; Na, Wilkinson, Karny, et al., 2016; Na y Wilkinson, 2018; Noyek et al., 2020; Stephenson, 2016; Wilkinson et al., 2021). Esta investigación no estudia directamente las competencias emocionales, pero sí un componente fundamental para el fomento de éstas: la comunicación de y acerca de emociones (Saarni, 1999, 2001). La necesidad de acompañar al entorno a facilitar espacios y oportunidades para abordar el tema emocional junto con la relevancia de generar mayores

aportes a la literatura científica en el área, fueron el motor principal en la estructura de la presente tesis.

Los estudios presentados en esta tesis se ciñen al objetivo general de explorar la comunicación emocional en niños y niñas con NCC y su entorno, así como ofrecer y analizar herramientas y estrategias para facilitar la conciencia, atención y fomento de espacios para hablar de emociones. Todo esto respetando las características individuales, culturales y sociales de las y los participantes. A fin de alcanzar el objetivo planteado, en la tabla 2-2 se presentan las preguntas de investigación y objetivos específicos que sustentan cada uno de los estudios que conforman esta tesis.

Tabla 2-2

Preguntas de Investigación y Objetivos Específicos

Estudios	Preguntas	Objetivos Específicos
1	¿Cómo los padres/madres participantes perciben la expresión, comunicación y respuesta emocional de sus hijos/as?, ¿Cómo las madres/padres participantes expresan y dialogan sobre emociones con sus hijos/as? y ¿Cuáles son los desafíos experimentados al hablar de emociones entre los niños/as con NCC y sus compañeros de comunicación?	Explorar, describir y analizar las percepciones y experiencias de padres y madres sobre la expresión y comunicación emocional con sus hijos/as con NCC.
2	¿Cómo transmitir a los compañeros de comunicación información clave sobre el estado emocional y comunicativo del niño/a, y brindar sugerencias para fomentar oportunidades para la comunicación y aprendizaje emocional?	Proponer y presentar con casos ilustrativos un perfil emocional que permita compartir información y sugerencias a los compañeros de comunicación clave del niño/a para comprender y favorecer la comunicación y aprendizaje emocional.
3	¿Se detectan cambios en la interacción comunicativa madre-hijo en una lectura de cuento tras la implementación de un programa de formación a una madre de un niño con NCC?	Describir y analizar el cambio comunicativo dado en el transcurso de la implementación de un programa diseñado para fomentar conversaciones emocionales durante una actividad de lectura de cuento.

La tesis se presenta en un formato por compendio de publicaciones, donde todos los estudios contribuyen al objetivo general de esta tesis. Cada estudio, expuestos en los próximos capítulos, está conformado por una introducción referente al tema abordado, el método llevado a cabo, la presentación de resultados y una discusión. La figura 2-2 tiene como objetivo situar al lector en el proceso llevado a cabo para dar respuesta a las preguntas de investigación y así introducir los estudios que articulan el trabajo presentado en los siguientes apartados.

Figura 2-2.

Estructura general de los estudios derivados de la tesis

La Comunicación Emocional en Niños/as con Necesidades Complejas de Comunicación y sus Madres/Padres

PROBLEMA

- Personas con NCC corren más riesgo de presentar dificultades emocionales/conductuales.
- El área emocional ha sido un ámbito ignorado en el colectivo con NCC.
- Estudios e intervenciones enfocadas a entender y promover la comunicación emocional en niños/as con NCC y sus compañeros de comunicación son insuficientes.
- Faltan recursos que habiliten el acceso a una comunicación emocional.

OBJETIVOS

General: Explorar la comunicación emocional de los niños/as con NCC y su entorno, y ofrecer/analizar herramientas y estrategias que fomenten su promoción.

Específicos

1 Explorar, describir y analizar las percepciones y experiencias de padres y madres sobre la expresión y comunicación emocional con sus hijos/as con NCC.

2 Proponer y presentar con casos ilustrativos un perfil emocional que permita compartir información y sugerencias a los compañeros de comunicación clave para comprender y favorecer la comunicación y aprendizaje emocional.

3 Describir y analizar el cambio comunicativo dado en el transcurso de la implementación de un programa diseñado para fomentar conversaciones emocionales durante una actividad de lectura de cuento.

MÉTODO

- Aprobación de comité ético para llevar a cabo la investigación
- Muestreo: por conveniencia
- Criterios de inclusión: padre/madre de niño/a con NCC
- Cuestionario de características de participantes
- Consentimiento informado

1 **Administración de Entrevista EDEC**

Metodología Cualitativa
- 22 participantes
- Análisis Temático

Estudio 1: en revisión

2* **Creación y Propuesta de Perfil Emocional (EDEC-P)**

- 2 Casos Ilustrativos
- Validez Social

Estudio 2: publicado en American Journal of Speech-Language Pathology

3 **Programa de Formación para Promover Espacios para Hablar de Emociones**

Fases del programa

Exploratoria — Implementación — Iteración — Mantenimiento

Sesión Formativa
- Estrategias para hablar de emociones.
- Participación activa en diseño de CAA relacionado con emociones.

Metodología Observacional
- 1 diada madre-hijo
- Análisis Secuencial de Retardos
- Análisis de Coordenadas Polares
- Validez Social

Estudio 3: publicado en Frontiers in Psychology

*No estaba programado inicialmente, pero tras ver las necesidades de las familias, se realizó la propuesta de un perfil emocional.

Capítulo 3

Estudio 1: Parent Views on Emotional Communication in Children with Complex Communication Needs

Referencia: Rangel-Rodríguez, G.A., Blanch, S., y Badia, M. (en revisión). Parent Views on Emotional Communication in Children with Complex Communication Needs.

Notas:

- El presente estudio muestra la versión en revisión.

- Las tablas y figuras a las que se hace referencia dentro del texto se pueden encontrar a partir de la página 71.

Abstract

Emotional communication is essential for development; nevertheless, there is a paucity of information about emotional communication and children with complex communication needs, despite how challenging it can be for them and their parents. This study presents findings from 22 interviews regarding emotional communication with parents of children who use unaided and aided augmentative and alternative communication (AAC). The interviews were examined via thematic analysis. Two themes were identified and described: children's emotional communication, and caregivers' emotional communication. Participants shared their views about their children's emotions and modes of expressing them, emotional trigger events, and responses to other's emotions. They also discussed their own and other caregivers' use of emotional expression, feelings and triggers, responses to children's emotional expression, strategies they used to foster and teach emotional communication, and challenges they faced in discussing emotions. Findings provide insight into both intrinsic and extrinsic factors that may impact children with complex communication needs when experiencing, expressing and discussing emotions. Implications for practice and future research that increase AAC interventions that target the development of emotional communication are considered.

Keywords: Augmentative and alternative communication; Complex communication needs; children; Emotions; Emotional communication; Rights

Parent Views on Emotional Communication in Children with

Complex Communication Needs

Emotional development is essential for any individual. It fosters learning, participation, self-expression and self-determination (Miller-Slough & Dunsmore, 2016; United Nations, 2015). Although there is substantial literature related to the importance of emotional development and communication in individuals without disabilities, less is known about individuals who have complex communication needs and rely on different modes of augmentative and alternative communication (AAC). Emotional development occurs across life experiences and in different contexts (family, school, community, etc.; Blackstone & Wilkins, 2009; Shablack & Lindquist, 2019) where individuals learn ways to acknowledge, label, understand, express and cope with emotions in culturally and linguistically specific ways (Saarni, 2000). These learned skills, known as emotional competencies, are a set of emotion-oriented skills individuals use to face the demands, objectives and challenges that are presented in life.

The processes of learning emotional competencies are embedded in life experiences that occur through communication and language. In fact, research indicates that the development of emotional competencies correlates with language development. For example, expressive and receptive language skills are linked to emotional vocabulary, emotional awareness, understanding, and emotion regulation (Beck et al., 2012; Roben et al., 2013; Torre & Lieberman, 2018). Emotional competencies may be negatively impacted by challenges in language abilities. For instance, limited emotional vocabulary, and insufficient comprehension of language subtleties or ambiguities reflect semantic characteristics. Pragmatics (e.g., not knowing conversational rules), narratives (e.g., problems in expressing and understanding own and others' experiences), and prosody (e.g., difficulties processing/interpreting emotional tone of voice) may also play a significant role in the

development of emotional competencies (White, 2011). If communication and language play a significant role in the development of emotional competencies, children with complex communication needs "are most certainly at risk for failing to develop competencies in these areas" (Blackstone & Wilkins, 2009, p.78).

Children with communicative challenges often have difficulty expressing and managing emotions using conventional and culturally appropriate communicative methods, and have restricted opportunities to express, talk, and learn about them (Giusti et al., 2018; Wilkinson et al., 2021). As specified in the *Communication Bill of Rights*, despite any extent or severity of a disability, individuals have the right to express feelings, make comments, interact, maintain social closeness, and build relationships (Brady et al., 2016). Individuals who lack ways to understand or express emotions in a socio-cultural adaptive manner are at high risk for mental health disorders (e.g., depression, anxiety) and emotional and behavioral disturbances (e.g., loneliness, frustration, challenging behaviors) (Lieberman, 2018; Prizant et al., 1990). As described by McNaughton et al. (2012), adults who are effective communicators through AAC have described how difficult and overwhelming it was for them to express and understand how they felt as children and to engage in discussions about their emotional experiences. For example, a person who uses AAC described the following: "I was about to be left with total strangers (…) These were the concerns that a little boy had to deal with (…) I felt isolated since I couldn't tell anybody what I was thinking or feeling" (Estrella, 2000, p. 33).

Emotional competencies emerge with familiar communication partners, particularly during parent-child interactions (Mayer et al., 2011). Whether parents are aware or not, they communicate and teach their children how to respond and interact when an emotion appears by their responses to their children's emotional expressions, their conversations about emotions, and through their own emotional displays (Brackett et al., 2016; Eisenberg et al.,

1998). Gottman and colleagues (1996) highlighted how parents' emotion-related beliefs often guide behaviors that impact their children's emotional development. In particular, research suggests that parents who consider emotions as problematic or dangerous tend to disdain, minimize or ignore their children's emotions, as well as to mask their own emotions. On the other hand, parents who view emotions as valuable are inclined to consider emotional experiences as opportunities to instruct, respond and engage children in discussing emotions (Castro et al., 2015).

Partner-child interactions are affected when children have communicative challenges. Children may respond less to emotionally-laden stimuli, and may also express subtle or unclear emotional, social, and vocal signals (Okimoto et al., 2000; Rangel-Rodríguez, Martín, et al., 2021). Primary communication partners may feel emotionally burdened (Woodman, 2014) and/or have beliefs about children that impact how they respond (Larkin et al., 2020). Partners may also have challenges in: reading children's emotional signals, being sensitive to their emotional needs and states, responding contingently, and providing adequate stimulation (Blackstone & Wilkins, 2009). Finally, although AAC systems can provide access to language and might be used to support emotional interactions, AAC systems can become a barrier when children have limited access to vocabulary to discuss emotions (Wilkinson et al., 2021). All these challenges can too often, turn into unbalanced communicative and emotional transactions (Giusti et al., 2018).

Studies of children with developmental disabilities reveal that conversations about emotional experiences are crucially important (Bougher-Muckian et al., 2016; White, 2011). Na et al. (2016) suggested that AAC systems should be set up to support children with complex communication needs to develop autonomy in recognizing, labeling, understanding, and managing emotions. Current research indicates the important role parents play in the process of developing emotional and communicative skills in these children (Na

& Wilkinson, 2018). However, the need to identify and provide ways for children to demonstrate and express their emotions requires that better practices and AAC systems need to be made available to support the development of these competencies in natural settings (Rangel-Rodríguez, Badia & Blanch, 2021). To better comprehend the emotional communication in individuals with complex communication needs and their partners, parents' views are important because children's emotional communication is influenced by familiar partners (Eisenberg et al., 1998). Parents' perspectives can help lay the foundation for practices that promote effective emotional facilitator partners and emotionally competent individuals who use AAC approaches.

This research is situated in a larger project that addresses how parents and children with complex communication needs can engage in emotional conversations using AAC. This study presents the first part of the project. The aims were to explore, describe, and analyze parents' views and experiences specific to how they communicate about emotions with their child who has complex communication needs. In this paper, the following research questions are addressed: (a) How do parents perceive how their child expresses, communicates, and responds to emotions? (b) How do parents express and discuss emotions with their child? (c) What are the challenges experienced in discussing emotions between children with complex communication needs and their partners?

Method

Participants

The participants were recruited via word of mouth and snowball sampling. Recruitment messages were sent to clinical contacts and special-education centers requesting nominations of families that could be interested in participating in the study. All participants were regularly in contact with service providers. The convenience sample of individuals was selected based on the following criteria: (a) currently parent of a child with complex

communication needs, (b) having at least a high school diploma, and (c) having speech, language and hearing within functional limits.

In light of the scarcity of studies on a research topic, the representation of diversity in qualitative research is critical (Allmark, 2004; Cohen et al., 2001; Lyons et al., 2013). Thus, the researchers decided to include any parent with a child who has complex communication needs: a child with impairments in speech-language production and/or comprehension that faces restrictions in meeting their communication requirements (Beukelman & Light, 2020). This sampling approach allowed for the inclusion and representation of parents of children with diverse backgrounds. A total of 22 families volunteered to participate, provided informed consent and agreed to be recorded during the interview process. Table 3-1 displays participants' characteristics. Of the 22 participants, 15 lived in Mexico, one in the US, four in Spain, and two in Sweden. Participants described their child's communication as multimodal, using vocalizations, gestures, body posture, signs, some natural speech, and/or aided communication.

Setting

This research was conducted in the preferable participant setting to incorporate all parents that wanted to be involved in the study. Settings chose by participants included phone calls, videocalls and face-to-face meetings. Online settings are adequate to overcome problems of distance, sample access, and to increase participation (Williams, 2015).

Research Design

A qualitative descriptive approach was selected for this research as it has been demonstrated to be adequate for exploring new or under researched topics relevant to the AAC field (Balandin & Goldbart, 2011). Individual semi-structured in-depth interviews were conducted. Interview transcripts were analyzed using thematic analysis. Ethics

approval was obtained from the university's review board, and the protection and confidentiality of the participants' data was guaranteed.

Researchers

In qualitative research it is common to acknowledge the possible influence from the researchers due to their prior experiences and backgrounds (Holloway & Biley, 2011). The first author is a trained clinical psychologist, PhD candidate, co-author of the EDEC interview, with more than 14 years of experience treating with individuals who benefit from AAC and their communication partners. This background was likely to influence data collection, analysis, and interpretation. Nevertheless, by critically reflecting on it, the researcher aimed to focus on the participants' views, encourage conversations, follow the direction of the interviews, ask for clarification when needed, and use her experience in analysis and interpretation as a resource without making assumptions. The second and third authors, PhDs in educational psychology, have extensive experience in qualitative studies and supervised research to ensure trustworthiness. All researchers are native Spanish speakers.

Materials

The Early Development of Emotional Competence (EDEC) questionnaire is a non-prescriptive assessment interview, with a protocol of open-ended and closed-ended questions, designed to elicit information about how the interviewees (professionals, parents or caregivers) perceive and discuss emotions with children with complex communication needs (Na et al., 2018). The tool consists of 24 questions divided in two sections. Section I includes questions regarding the child's temperament, interaction and behavior characteristics. Section II collects data about the child's emotions, modes of expression and partners' dynamics around emotions. The EDEC was developed with a target population of young children (birth-10 years old), although it might be possible to use with older

individuals. The tool has been implemented across different communities, cultures and languages, applied in case studies with children with complex communication needs and translated into different languages (Na et al., 2018; Rangel-Rodríguez, Martín, et al., 2021; Wilkinson et al., 2021). For this study, the Spanish[1] and English[2] versions, available online, were used.

Procedures

Data collection and analysis

Parents were asked for their preferred language and interview method. In all, 15 interviews were conducted online, one via telephone and six face-to-face by a clinical psychologist with prior experience in AAC and in supporting individuals with complex communication needs and their families. The interviewer used the EDEC tool script proposed and asked for more information to promote a two-way dialogue with which to clarify or gain depth on a specific theme (Rangel-Rodríguez, Martín, Blanch, et al., 2021). Participants' interviews were audio-recorded with their consent, and lasted around 60 to 120 min, over one to three appointments, depending on the participants' availability. When needed, follow-up questions were conducted to encourage in-depth explanations and clarification. At the beginning of the session, the interviewer explained the themes to be addressed, as well as their right to skip any question if participants felt uncomfortable responding. All participants chose to answer all questions in the interview. The interviews were transcribed verbatim by the first author and identifying information was removed to ensure confidentiality.

All transcripts were coded and analyzed with ATLAS.ti Version 9. The research team decided to revise and employ part of the coding scheme proposed by Na et al. (2018). The

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[1] https://doi.org/10.23641/asha.14219777.v2
[2] https://doi.org/10.23641/asha.5643076.v1

initial coding scheme was meant to characterize possible responses and enhance sensitivity to subtle features of the data according to the relevant literature background of the topic (Tuckett, 2005). The codebook used by Na and colleagues was applied to a sample of families who have a child without disabilities. Consequently, revisions were necessary to reflect the full perspective of parents who have a child with complex communication needs. For that reason, an inductive approach, which is suitable for studies who have relatively limited research (Braun & Clarke, 2006), was utilized to identify crucial and emerging aspects of the research topic. The first author conducted the analysis in consultation with the second and third authors.

The thematic analysis guidelines by Braun and Clarke (2006) were employed. Transcriptions of all data collected, and repeated reading were undertaken, theoretically driven and possible emerging themes of interest were initially obtained and coded independently by the first two authors. Themes and subthemes were developed to identify broader units of analysis (i.e., sorting several codes into the proposed themes). Several verifications of the coded data extracts within the candidate themes/subthemes were carried out by the research team to support a coherent pattern and create a suitable thematic map. When the coding was considered unclear or incoherent between the theme or subtheme, they were reconstructed or discarded from the analyses. Once coders produced a suitable thematic map, the categories were further refined, and themes/subthemes were finally established. The final theme map was divided into two categories: Children's Emotional Communication and Caregivers' Emotional Communication.

Reliability

On completion of the thematic coding, 20% of the data were selected randomly and recoded by a trained coder, a speech-language pathologist Ph.D. candidate. Cohen's Kappa was calculated including all codes that pertain to each subtheme resulting in an agreement

of 0.94. Kappa values above 0.81 are considered as almost perfect (Landis & Koch, 1977). Finally, the authors extracted and, when necessary, translated quotes that best summarize the themes and subthemes for this manuscript. The researchers consulted with two native English speakers to ensure translation fidelity and clarity of the extracts.

<div align="center">

Results

</div>

Two major themes emerged from the data: Children's Emotional Communication, and Caregivers' Emotional Communication. Each was divided into subthemes (see Figure 3-1), which are described below with representative comments from participants[3].

Children's Emotional Communication

This theme captures participants' descriptions of their children's emotional communication. Four subthemes were identified: (a) Emotional expression and linguistic content, (b) Emotions and triggers, (c) Responses to others' emotions, and (d) Challenges in discussing emotions.

Emotional Expression and Linguistic Content

Modes of Emotional Expression. Participants identified a range of modalities used by their children to express emotions. Emotional expressions were frequently recognized through facial expressions (e.g., smiles, grimaces, frowns), body postures and movements (e.g., body shaking, moving specific body parts [legs, fingers], flapping), conventional gestures (e.g., crossing arms for angry), conventional and unconventional actions (e.g., kick, pinch, bite, hug, kiss, clap, hide), and vocalizations. In relation to vocalizations, participants perceived that children's tone of voice cued communication partners and helped them identify and differentiate emotions: "I notice my child is surprised because he makes this special sound (…) it's a very high-pitched sound" (P13).

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[3] Authors operationalized quantifiers as follows: few as a code occurring in less than 40% of participants, some between 40-60%, most as more than 60%, and the majority as more than 90%.

General expressions through body posture and movement could be complex for certain children, however, some participants considered it a way to display emotions: "When excited, his body will be twisting" (P2), "When she shows a very strong feeling, her body gets stiff" (P18).

Linguistic emotional expressions were also described. Some participants reported learning about their child's emotions through direct messages using aided AAC to express emotions (e.g., I am happy, sad, angry, scared). A few participants reported their child expressed emotions using natural speech or manual signs (e.g., I LOVE YOU sign). A couple of participants commented that they recognized their child's emotions through somatization[4]: "Every time there is a change [in his life], my child gets a fever (…) I associate these fevers with his emotions" (P15). Other examples included a child who used word repetition ("When she experiences fear, she repeats words or sounds" (P4)); stuttered ("When he is nervous, he stutters" (P20)); and became silent ("When sad, he remains quiet" (P14)).

Linguistic Emotional Content. Participants who reported that their child used linguistic methods of expression (e.g., natural speech, signs, aided AAC) also described the content of the linguistic expression (classified in emotional vocabulary and emotion-related events). Participants informed that children who discuss their feelings generally label the emotion (e.g., sad, happy, scared), or use vague concepts (e.g., good, bad). In fact, the emotional labels that participants described were basic and limited (within a range from 1 to 5 words). This was true even when the children's aided-AAC system contained more emotion symbols (within a range of 2 to 23 emotional words). Some participants also commented that when their child cannot label an emotion, it can result in challenging

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[4] the expression of psychological disturbance through body symptoms.

behaviors: "When he cannot express what he feels [with words], he becomes frustrated, no longer uses his words (…) and aggression starts" (P22).

Very few participants indicated their child had the means or vocabulary available to discuss why an emotion appeared. For example, "I asked [my child] why are you sad? And he responds *Because* [my pet] *died*" (P22), as well as ways to communicate what the child might need in response to that emotional situation: "I asked him why are you crying? And he says, *'I want to rest'*" (P5). Most of the participants whose child used an aided AAC system commented their children did not have access to the vocabulary they needed to discuss emotional situations.

Emotions and Triggers

The interview contains a list of emotions to support interviewees in identifying their children's emotions. Moreover, participants were asked to share other emotions that do not appear on the list. All participants recognized pleasant and unpleasant emotions in their child (see Figure 3-2) and described some triggering events that impact their child's emotional world.

Pleasant Emotions and Triggers. Emotions like love, joy, excitement, and pride were related to particular trigger events. These trigger events included enjoying leisure and recreational activities, participating in social interactions ("In the pool he does enjoy interacting with peers, it is the only environment where he feels equal to others" (P8)), enjoying the company of others, receiving affection/love, having a sense of achievement ("he celebrates when he could communicate with others using [his AAC device]" (P14)), and understanding their external world (e.g., having routines, time to adapt to situations, anticipating what may happen).

Unpleasant Emotions and Triggers. Participants also spoke about some recurrent triggers linked to unpleasant emotions, such as fear, sadness, anger, frustration, and anxiety. Some triggers were related to biological, physical or sensory causes such as tiredness, hunger, sleep, specific visual/auditory stimulation (darkness, too many colors, echo, noise), bodily (hot/cold) or vestibular and proprioceptive sensations (sense of falling). Others were related to social, cognitive, motor, or communicative task challenges ("my child tries too hard when he can't do something (…) if he doesn't accomplish it, he gets angry" (P11)), or intrapersonal causes such as feeling different to others ("he wants to eat like the other kids, using his mouth, and gets sad and frustrated (…), but well he can't swallow." (P5)) or vulnerable:

> When he realized that I cut his nails, he started crying and scratching his nails in my arm and said: *See, I told you, I can't*. As if he was telling me: now I don't have a way to defend myself (…), to hurt when he feels frustrated. (P22)

Other unpleasant emotional triggers were related to interpersonal relations such as: not being understood by others ("he hits himself when others don't understand him, he gets so frustrated" (P14)), when someone leaves (e.g., when a parent goes to work, friends leave after a meeting, etc.), feeling judged ("If I scold him in public, he feels ashamed" (P22)), pressured ("[my child gets annoyed when] someone is pressuring her" (P17)), being ignored or rejected, or having someone take their belongings without permission [iPad, food, toys, etc.], and talking on behalf of the child ("We were at a friend's house and he wanted to say something on [his AAC device], but I ended up saying it, and then he got really upset." (P3)).

Participants also identified triggers for unpleasant emotions related to not obtaining what the child expects, like being told "no", or when an activity can't be done: "He would prefer to do more things, but he can't because it can trigger epilepsy (…), so he gets angry at me." (P2). Additionally, participants reported specific events that might trigger unpleasant

emotions, like specific situations (e.g., being in a specific emotional atmosphere [conflicts]), specific media (e.g., horror movies, specific type of music, sad storybooks, etc.), or unexpected or new events: "she shows distress when we take her without explaining where we are going." (P12).

A few participants identified moments where their children prefer to conceal unpleasant emotions: "In meetings, if my child drops the juice, (…) she gets frustrated, but she suppresses the emotion because she feels ashamed." (P10).

Responses to Others' Emotions

The majority of the participants reported that their child responds to the emotional expressiveness of other people. Most perceived that these responses appeared when the other person was expressing clear emotions (e.g., a kid crying or excited). Nevertheless, two families reported that their child responded to others' emotions with familiar partners only or in specific social settings ("he will laugh with us only if he is also interested in it" (P17)). One father commented that his child does not show responses to others' emotions.

Responses using non-linguistic methods. Participants reported that non-linguistic methods of expression are the most frequent type of responses that children tend to show when others express emotions. The vast majority indicated that their child observes or reacts by laughing when others laugh or crying when others express anger: "he perceived his grandma was different [sad] and started being more irritated (…) I think he identified the emotion but doesn't know how to express or talk about that" (P7). Some participants reported their child displays responses that offer empathy or comfort, such as, giving a hug or caress:

> [When she noticed I was angry] she approached me, grabbed my face and I felt like she was apologizing, like saying, "Mom, sorry, I didn't know how to control myself." That was a very nice thing for me because I felt she was aware of the anguish she caused me (P12).

Participants also mentioned they identify their child's facial expressions as confusion, particularly if the child is observing certain emotions in others:

> If she sees me angry, she notices it, but she doesn't know how to tell me "Don't be angry" as any other child would. She is like thinking, looks at me, and I think she gets a little nervous and confused (…) like, "what's wrong?" (P4).

Others reported their child respond by informing the adult that something is happening:

> He informs us when someone is angry or having an emotion, but he doesn't tell us what emotion is; he only comes to where we are, looks at us like saying, "come and see my brothers," but he doesn't explain anything. I understand it once I see it (P8).

Responses Using Linguistic Skills. A few families indicated that their child responds to others' emotions using language. All of these children had some ability to use their speech or manual signs. Four families reported their child sometimes labels the emotion, for example: "When his grandfather is sad, he says *sad* and kisses him" (P20); another family commented that their child sometimes tries to comfort verbally ("Calm down" (P6)); while another family expressed their child uses signs to ask what's going on: "He identifies that you are sad or angry, but instead of expressing that you are sad, he says WHAT'S-WRONG? [manual signs]" (P14).

Challenges in Discussing Emotions

Vocabulary Limitations. Even though most of the participants identified emotions in their child, many of them explained their child had no way to talk about emotions: "We've looked for many signs [so he can] tell us things, like mom, dad, I'm sleepy, hungry, but he doesn't have any [sign] to express how he feels" (P9). Other children have limited emotional vocabulary to discuss their feelings: "I asked him what's wrong? but he can't answer me" (P14). A mother of a child who uses an AAC device noted:

You ask him, how do you feel? and says *"sad"*, although I'm not sure if it was sad or maybe it was frustration or something else. But he labels everything negative as sad and everything positive as happy. In his vocabulary he just uses those two. (P8)

For children immersed in a context with more than one language, participants also perceived vocabulary limitations. In this regard, a participant shared: "We ordered the new bilingual [AAC software], so he can change the language. I believe that once he discovers he can express with the same words as his peers, he will express more" (P4).

Opportunity Limitations. Most participants stated that their child is not exposed to opportunities to hear, talk or learn about emotions. These participants commented they do not label emotions in front of their child: "It is true that I often identify his mood, but I don't tell him" (P6). Other participants indicated that their child does not have a way to discuss what causes the emotions or what coping strategies might be used to deal or respond to emotions:

In a storybook, there is a part where the character is angry and I just realized that we only tell him he is angry, but we do not explain why he is angry neither what can he do, we haven't worked to that level. (P7)

A father thinks his child understands emotions but "We haven't given him the opportunity or the means to express it [linguistically]" (P9). Another mother shared that even though she makes comments about her child's emotions, she never asked how her child feels: "Sometimes you don't think about those details" (P14).

Lack of Access to or Models of the AAC System. Individuals with complex communication needs could benefit from AAC systems, nevertheless, not all the children have access to one. However, some participants whose children already have an AAC system explained they do not promote its use to discuss emotions: "We use the iPad for many things, but not for emotions" (P8). Other participants commented they do not offer access to the

AAC system in their homes: "The problem is that we don't have a good way to place it [the AAC device]" (P5). Some participants expressed that even though they offer the child access to the AAC system, they do not model its use: "We don't use the board so much, when I bring it closer to him, he throws it at me. It's because we don't use it" (P9).

Caregivers' Emotional Communication

This theme resulted in the following subthemes related to caregiver responses: (a) Emotional expression, feelings, and triggers; (b) Responses to the child's emotional expression; (c) Strategies to foster and teach emotional communication with their child; and (d) Challenges in discussing emotions.

Emotional Expression, Feelings and Triggers

Emotional Expressions to the Child. Participants were questioned about the emotions they feel comfortable expressing in front of their child, as well as the emotions they prefer not to express in their child's presence. Four participants commented they feel comfortable expressing all types of emotions ("I feel comfortable expressing all because [the child] is not going to judge me" (P19)), whereas six participants explained feeling more comfortable expressing only pleasant emotions to their child (e.g., love, calmness, tender, happiness, joy, pride). The rest of participants felt comfortable conveying only specific emotions:

> When I am angry, it is difficult for me [expressing emotions]; however, once I assimilated it (…), I can explain it. And I tell [my child] I am very angry about this, there are even times that I have said to him, "I'm not in the mood for us to fight, please don't yell" (…) But I try not to talk to him [about being afraid], so he doesn't learn it. (P7)

Some participants reported that they prefer to avoid expressions of anger, worry, sadness, fear, and embarrassment, hoping their child does not feel these types of emotions:

> He doesn't walk alone and when we do let him walk or do something by himself,

it scares me, but I try to stifle the emotion and change my gesture to a positive one, so he doesn't get fear and do it. (P8)

Other participants reported that they try not to express some emotions because of personal beliefs related to the child ("She won't understand" (P10)), parenting ("Parents don't get sad (…), so I avoid and turn around" (P1)), or individual characteristics ("I don't like to express my feelings, neither good nor bad" (P9)).

Feelings and Triggers Related to Parenting. Even though the EDEC tool does not specifically inquire about caregivers' emotions related to the child, during the interview several participants shared their views on the joys and challenges of raising their child. On one hand, participants shared experiencing pleasant emotions like gratitude, love, pride, and surprise. Triggers for these emotions were related to observing their child in an inclusive environment for their child: "I was amazed, (…), what a beautiful boy [child's peer] that he didn't leave my son out [of the game]" (P22); and the child's achievements and abilities: "He is growing up and acquiring skills that we didn't think he would have it, and suddenly he surprises us." (P6).

Participants also reported experiencing unpleasant feelings such as nervousness, worry, anguish, fear, frustration, helplessness, sadness, confusion, anger, shame, and guilt. These triggers were linked to their child's challenging behaviors: "When he had those shrieks, throws himself to the ground, (…) everyone is looking at us, (…) it makes me angry, or I feel guilty (…) because sometimes you feel ashamed and sad" (P13); the child's communicative challenges: "I'm worried because this [speech difficulties] could be a cause of bullying" (P15); the child's relapses: "She started again with horrible tantrums, self-injuries (...). We already had a lot of control [of the tantrums] as a family, and we fall back again, we cried a lot." (P12); difficulties understanding the child: "I also get frustrated when I don't understand him" (P8); thoughts about parenting: "If I don't know the cause of her

emotion, I feel frustrated cause [as her mother] I should know" (P10); and thoughts about the child's feelings: "It comes down to is he ok with himself? (…) And if he is happy, then I'm happy, then it's ok. But, if he is not happy, I would like to know and do something about it." (P3).

Responses to the Child's Emotional Expression

Participants had diverse ways of responding to their child's emotions, which were classified into three categories.

Responses That Seek to Diminish Emotional Communication. Participants reported that when they noticed a child's emotion, they sometimes tried to diminish its expression. Some of the techniques included distracting the child (e.g. playing music, joking, changing activity), avoiding contact: "Sometimes we just let her cry" (P21); questioning the legitimacy of the child's emotional experience: "There is no reason to feel angry" (P12) or "You are exaggerating" (P19); punishing the child's unconventional emotional expression (e.g., no iPad, no games) and/or medicating when considering the emotional expression is intense: "If I notice she gets very angry and I can't control her, I give her droplets [medication] (…) and it works" (P10).

Responses that Acknowledge/Encourage Emotional Communication. Participants indicated that when a child's emotion is detected they attempt to comfort the child (e.g., give a hug/kiss, caress, comforting words), respond to their needs: "I try to know why the emotion came and try to give what he needs" (P2); offer time alone: "Take your time and I'll come back in 5 minutes" (P9); give physical containment: "Hold him tight" (P3); show comprehension: "I understand you don't like to wash your teeth but you have to" (P1); and discuss the child's emotion by labeling: "I know you are angry" (P5); explaining or corroborating the cause of the emotion: "I think this is why you are crying, Am I right?" (P3); and suggesting possible strategies, solutions and responses: "Breathe and count to 4,

(…) use your [AAC device] to explain" (P5) or "how can we solve it? I try to give him options (…) and he says yes or no" (P7).

Some participants expressed that they first try to encourage emotional communication with the child by discussing emotions; however, because the child often lacked a functional communication system to express and discuss emotions, participants end up implementing ways to diminish the emotional communication:

I deduce what she likes (…) but sometimes she tells me no, not this mom (…) that frustration she gets, it's complicated (…) I would like to have a little conversation (…) I say, "tell me what's wrong with you?", but it's difficult (…) [So,] when she's angry, (…) I say go to your room. (P10)

Responses Related to Child's Triggering Events of Unpleasant Emotions. Some participants identified events that trigger unpleasant feelings in their child and reported having developed strategies to prepare or avoid those moments. Most of the participants anticipate possible challenging situations. Some discuss what will happen in advance: "After everybody is done with their class, there's gonna be many people" (P3); and/or explain how the child might respond: "You are gonna have to calm down" (P3). Others provide support: "Me and your teacher will be there for you" (P6); and offer a possible reward: "We can go after to [favorite restaurant]" (P6). Depending on the situation, participants commented that they prepared with stimulus or objects in advance to help their child manage challenging events (e.g., bring [noise-reduction] headphones) or prepare a plan: "We anticipate who goes home with her, and we go in separate cars" (P12). Nevertheless, other participants mentioned they prefer to avoid situations that could stress the child: "We just skip these [social situations], is just not worth it" (P3). Some participants also reported they had to prepare emotionally for challenging moments: "[It's important that my child] sees me calm" (P1).

Strategies to Foster and Teach Emotional Communication with their Child

Situations used to Prompt Emotional Discussions. Some participants took

advantage of situations to prompt their child to discuss and learn about emotions during reading, movies or tv series: "Why is [the character] crying? Why is she sad?" (P16). Others point out the emotions in others: "Look, [your brother] is angry because they lost the football game" (P10). Some participants expressed that they only discuss emotions when they consider it necessary. Six families commented they do not prompt any conversations about emotions: "Particularly I don't focus or talk about the emotions" (P2). One mother expressed that she asks about her child's emotions as part of their morning routine: "Mostly starting the day off, I show her feelings symbols to see how she feels" (P21).

Methods used to Foster and Teach Emotional Communication. Most of the participants who discuss emotions with their child reported doing it via gestures and verbal expressions: "Oh he is sad [sobbing and with sad gestures]" (P16). None of the participants said that they modeled the child's AAC system. The most frequent methods used by participants to teach and discuss emotions were to make comments (e.g., Oh, look, they are scared!), followed by yes/no questions (e.g., Are you happy?). Methods used less frequently were open-ended questions (e.g., Why are you angry?); choice questions: ("I understand you are angry, what do you need to feel better? Do you want to take a walk, be alone or get on the swing?" (P4); and some others indicated they tried to foster their child's use of the AAC system to discuss emotions: "I guide her [via auditory and visual scanning], is in this line? Are you sad? Are you angry?" (P18).

Linguistic emotional content used by caregivers. Participants expressed talking more about the name of the emotion: "If she starts laughing, sometimes I say to her: Ah, you're happy, or if she complains, I say: you're angry" (P1); followed by the causes of the emotion: "I'm excited because they said you are the best friend in the class" (P4); and to a lesser extent, they commented on discussing ways to respond to a specific emotion: "Your grandma is sad because her friend died, she needs a hug" (P7).

Communication Partners' Challenges in Talking about Emotions

Difficulties in Recognizing or Understanding the Child's Emotions. Participants reported facing challenges when interpreting and recognizing their child's emotional expression: "He makes a gesture (…) but I don't know exactly what he means by that" (P8). Others mentioned that it is complex to identify specific emotions in their child:

I have never identified how he expresses fear. (…) There are two ways [the child expresses emotion]: either he smiles, or he doesn't answer anything at all. He has never shown discomfort in any situation. It's difficult to identify it. (P19)

Participants described obstacles to identifying the possible child's emotional triggers:

We are trying to figure out why he starts having these emotional changes, if it is because we move out or because he is growing up or if it's some neurological or behavioral issue (…) We don't know if he is crying or doing something out of frustration from not being able to express what he wants, or because we don't understand him or because he wanted something and couldn't get it. (P9)

Lack of Resources or Training. Although parents expressed providing responses when identifying a child's emotion, many participants felt that, in general, adults lack resources or training to properly understand and address their child's emotions: "[communication partners] are not trained to get to know [my child] emotionally. Unfortunately, at school only [the paraprofessional] knows, but not her teachers nor the school psychologist" (P4). Some participants remarked that lack of time was an important factor for not talking about emotions "What happens is that sometimes I don't have time [to explain emotions]" (P18).

Personal or Socio-cultural Beliefs. Participants indicated they had some ideas and questions about their child that could interfere in offering opportunities to discuss emotions. For example: "I think he can't demonstrate affection" (P19), "I don't discuss ways to deal with emotions, I think that because she doesn't talk, she won't be able to tell what she needs,

so I just do something to control her." (P12). In addition, some participants believed that labeling or explaining unpleasant emotions might trigger that emotion in their children. For instance, "I told my mother [child's grandma] to not express or talk about fear in front of him, so he doesn't learn it" (P7). Others expressed concern that discussing some emotions could intensify the unease: "I didn't tell him he was sad; I didn't even mention the word to him, so we don't continue with the topic that he was having a hard time." (P6).

Discussion

This study explored parents' experiences around emotional communication with their children with complex communication needs. Due to the scarcity of research on this matter, the present study, as a starting point, sought to include and represent the views of parents with diverse backgrounds and display the common patterns that intersect that diversity. The findings provide insight into specific characteristics and variables that come into play when having emotional communicative exchanges. The identified themes could contribute to an area little explored and may help lay a foundation for AAC assessment and interventions that seek to promote emotional competencies by providing access to language needed to understand and communicate effectively about emotions.

Emotional Communication in Children with Complex Communication Needs

Participants reported that they primarily depend upon their children's use of non-linguistic methods of expression like tone of voice or body movements to identify and differentiate children's emotions, even when their child has concomitant sensory or physical disabilities. Nevertheless, it is not sufficient nor efficient for an individual to just rely on that level of emotional expression. As Light and McNaughton (2015) noted, children with complex communication needs may require support in learning methods, such as the use of AAC, that enhance communication effectiveness in all areas; this will also include emotional communication and learning. Linguistic emotion concepts allow individuals to expand,

understand, and perceive the emotional world in a refined way (Shablack & Lindquist, 2019).

Participants also indicated their children often had very limited and/or even no access to emotional vocabulary using manual signs or on their aided AAC system. Most of them remarked their children did not have a way to discuss emotion-related events or to employ effective strategies in response to emotional situations. These data support previous research that stressed the need to assess, target and encourage the development of emotional skills in children with complex communication needs (Biggs & Hacker, 2021; Blackstone & Wilkins, 2009; Na et al., 2016). The current study presented a list of children's emotional triggers exposed by the participants that could be considered when assessing, creating AAC systems and implementing interventions focused on promoting emotional learning and conversations. Understanding the emotional experience is critical to designing meaningful, sociocultural, and linguistically appropriate resources so children can gain access to emotional communication (Wilkinson et al., 2021). Providing access to communication will support the development of emotional skills such as awareness, understanding, expression and regulation (Beck et al., 2012; Roben et al., 2013; Torre & Lieberman, 2018). It is necessary to generate and implement plans and strategies considering the child's age, traits, personal experiences, linguistic and socio-cultural context. For instance, including access to emotion-related vocabulary (to support emotional awareness, understanding and expression) and responses (to support emotional regulation) that are specific to the child's context. By acknowledging emotions and triggers, communication partners can offer vocabulary related to emotional coping that may allow children to choose appropriate responses based on their socioemotional needs and experiences.

Communication Partners' Emotional Communication

Studies have demonstrated the importance of communication partners' emotions,

emotional expressivity, beliefs, and responses to emotions in children's emotional development (Brackett et al., 2016; Eisenberg et al., 1998). This study explores these domains in parents of children with complex communication needs. Similar to research done with parents of children with typical development (Castro et al., 2015; Gottman et al., 1996), participants reported expressing or suppressing certain emotions in front of their children depending on their own beliefs, for instance, if emotions are considered important or problematic. However, the findings also revealed other beliefs in play, specific to this group, that may impact opportunities to support emotional communication. For instance, ideas about children's characteristics (e.g., my child won't understand emotions or won't be able to express emotional needs). The underestimation of people with diverse conditions (Corrigan, 2014) may influence attitudes to foster children's emotional development.

Participants reported using many strategies to manage their child's emotions like avoiding target-eliciting situations, diminishing emotional experiences, and/or acknowledging and encouraging emotional communication. Participants who acknowledge and try to give opportunities to discuss emotions, commented on their child's lack of ways to respond, so it was difficult to promote conversations. Most of the participants that tried to foster and teach emotional communication indicated that they mostly used verbal comments, closed-ended questions, and gestures. Several noted that these strategies did not fully engage their children in active emotional talk. AAC interventions might play a significant role in supporting emotional communication by guiding partners and providing access to the tools needed to communicate, and thus allowing such conversations to occur (Dark et al., 2011; Na & Wilkinson, 2018).

Clinical practitioners must consider assessing the emotional expressivity and personal/cultural beliefs of communication partners before starting interventions. For example, communication partners must be included in the decision-making process to design

an intervention plan that provides the right support and instruction to promote emotional conversations in natural settings (Rangel-Rodríguez, Martín, et al., 2021). An intervention that offers culturally appropriate linguistic resources to the child (e.g., emotional vocabulary, relevant causes, possible responses when someone is experiencing an emotion), and suggests activities that are emotionally comfortable for those involved in discussions with the child (e.g., starting with feelings that communication partners feel more comfortable in discussing) is essential.

Challenges to Discussing Emotions Between Children and Communication Partners

Participants perceived that children with complex communication needs faced challenges in expressing, learning and discussing emotions. In addition to lacking access to vocabulary to fully engage emotional conversations, they may have limited or no opportunities to hear, learn or discuss emotions (Giusti et al., 2018). Moreover, when communication partners make an emotional comment (verbally), they do not provide children with models they can use to discuss emotions (e.g., AAC, sign language). These challenges are consistent with Blackstone and Wilkins (2009) who argued that these children lack opportunities to explore feelings and have limited life experiences or access to media that could help understand and express emotions using language. AAC interventions must focus on providing opportunities to minimize all these barriers. For that purpose, emotional assessment in AAC services is necessary.

Communication partners also faced challenges when discussing emotions with children with complex communication needs. In line with other studies, many participants indicated that the non-linguistic methods of expression their children rely on are often unclear or easily misinterpreted (Okimoto et al., 2000; Rangel-Rodríguez, Martín, et al., 2021). They also noted that it is sometimes challenging to identify their children's emotional triggers, making it difficult to effectively support them. Some participants expressed doubts

about the possibility of their child becoming an emotionally competent communicator (Hagiliassis et al., 2005), and others considered discussing unpleasant emotions as counterproductive, preferring to dismiss opportunities to engage their child in conversations. In addition, they noticed partners lack resources and training to understand and meet their children's emotional needs (Dark et al., 2011). In consequence, discussing possible misconceptions around emotions with key partners might help to promote adequate emotional communication. To foster emotional learning, communication access and advocacy, interventions might target supporting partners to consider the value and functionality of emotions (Castro et al., 2015; Lench, 2018), their relationship with communication and language (Torre & Lieberman, 2018), and the importance of using AAC strategies with children to support communication around emotions (Wilkinson et al., 2021).

It is critical, therefore, to find strategies that support partners to introduce opportunities that encourage emotional communication with individuals with complex communication needs, including modeling conversations about emotions using the individual's own communicative systems. Adapting communication partners instruction (Kent-Walsh & McNaughton, 2005) to provide a stimulating environment that supports emotional conversations is an interesting model that needs further research (Na & Wilkinson, 2018; Rangel-Rodríguez, Badia & Blanch, 2021).

Emotional Communication as a Right

Research has shown that emotional learning is fundamental to the development of emotionally competent children (United Nations, 2015), and that at least some of this learning occurs through being able to access and use language (Beck et al., 2012; Torre & Lieberman, 2018; Wilkinson et al., 2021). As this study shows, participants identified many challenges children with complex communication needs experience in emotional development. Being an emotionally competent person does not mean living a life without

difficulties, but it does imply the benefits of having access to the internal strategies and environmental supports one needs to face life's challenges. Certainly, key communication partners (parents, therapists, teachers, etc.) and other advocates have an important role to play in promoting and advocating to help others to comprehend that communication, and specifically communication about emotions, is a need and a right. Children have the right to express, understand and choose how to respond to emotions in a healthy manner (Rangel-Rodríguez, Martín, et al., 2021), they also have the right to be respected emotionally. Expanding upon the right to express feelings proposed in the Communication Bill of Rights (Brady et al., 2016) and the UN sustainable development goal of ensuring healthy lives and wellbeing for all (United Nations, 2015), the authors of the present manuscript advocate for consideration of an Emotional Bill of Rights, presented below.

All individuals with or without disabilities have the right: (a) to recognize, understand, feel and express emotions; (b) to receive proper support to enhance emotional abilities and resources; (c) to communicate emotions using personal resources and supports as needed (e.g., signs, gestures, body language, speech, writing, AAC, etc.); (d) to have opportunities to listen, learn and manage emotions (of oneself and others); (e) to have access to clear, meaningful and socio-culturally appropriate vocabulary of emotions and emotion-related events; (f) to receive clear information about emotional health and develop emotional skills; (g) to be heard, validated and respected, even if one's emotions are different from others; (h) to ask and receive help and emotional support if needed; and (i) to receive a dignified, respectful and courteous emotional treatment. All individuals have the right to express emotions and receive the proper support to enhance their emotional development.

Limitations and Future Directions

Although this study provides some insight into parents' views on emotional communication between children and communication partners, findings need to be

interpreted in light of some limitations. First, the sample size is small and drawn from parents who reside in North America and Europe who speak different languages. Studies have shown cultural variations in expressing and responding to emotions (Hofstede & McCrae, 2004; Scherer & Wallbott, 1994); therefore, general conclusions across contexts, cultures and linguistic groups cannot be drawn about the emotional communication of children with complex communication needs and their partners. This research reflects a diverse demographic sample, but future research is needed to understand how findings presented here align, diverge or expand the subthemes and units when more communication partners (not only parents), from different backgrounds respond. Second, most of the participants were mothers. Further exploration is necessary to collect fathers' views and to study the existence of gender variations in emotional communication. Third, the study includes parents of children with complex communication needs. No differentiations were made with regard to the type of communication challenges and other demographic characteristics of the children (gender, age, language, co-existing disabilities, education level) or the parents (languages, cultural identity, education, socio-economic level). Future directions could focus on identifying actions (e.g., clinical practices, design characteristics, training modules) aimed at improving the understanding of parents and professionals so they can increase access to emotional vocabulary and enhance the development of emotional competencies for individuals with particular communicative challenges.

Future research is critical to improving the conditions that support the emotional development of children with complex communication needs. Research should focus not only on communication partners' perspectives, but also the views of individuals with communicative challenges. It is necessary to investigate how to create interactive learning environments for these individuals that promote emotional knowledge and understanding, as well as opportunities to discuss emotion-related events in different settings (e.g., school,

home, between peers).

Conclusion

This study presents parents' views about the emotional communication between children with complex communication needs and their partners. Different factors, intrinsic and extrinsic to the child, come into play when expressing and discussing emotions. The results begin to address the need for more attention and understanding of this important area of development. Emotional communication is essential and key to emotional development. Findings offer evidence on the need to provide and advocate for services and AAC assessment and interventions that ensure individuals' emotional rights.

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Table 3-1

Participants' Demographic Characteristics

Characteristic	*n*
Ethnicity of parents	
Hispanic	19
Non-Hispanic	3
Interviewed parents	
Mothers	18
Fathers	1
Both parents	3
Child's age	
3-6 years	9
7-9 years	5
10-12 years	8
Child's communication mode	
Facial expressions	22
Body posture	18
Gestures	14
Vocalizations	22
(Some kind of) natural speech	11
Manual signs	12
Aided AAC	
Non-electronic communication display	1
Speech generating device (SGD)	11
Non-electronic communication display + SGD	6
Services received by the child	
AAC services	17
Other services	5
Language(s) used with child	
Monolingual	17
Bilingual	2
Trilingual	3
Language used during interview	
Spanish	19
English	3

Note. n=22.
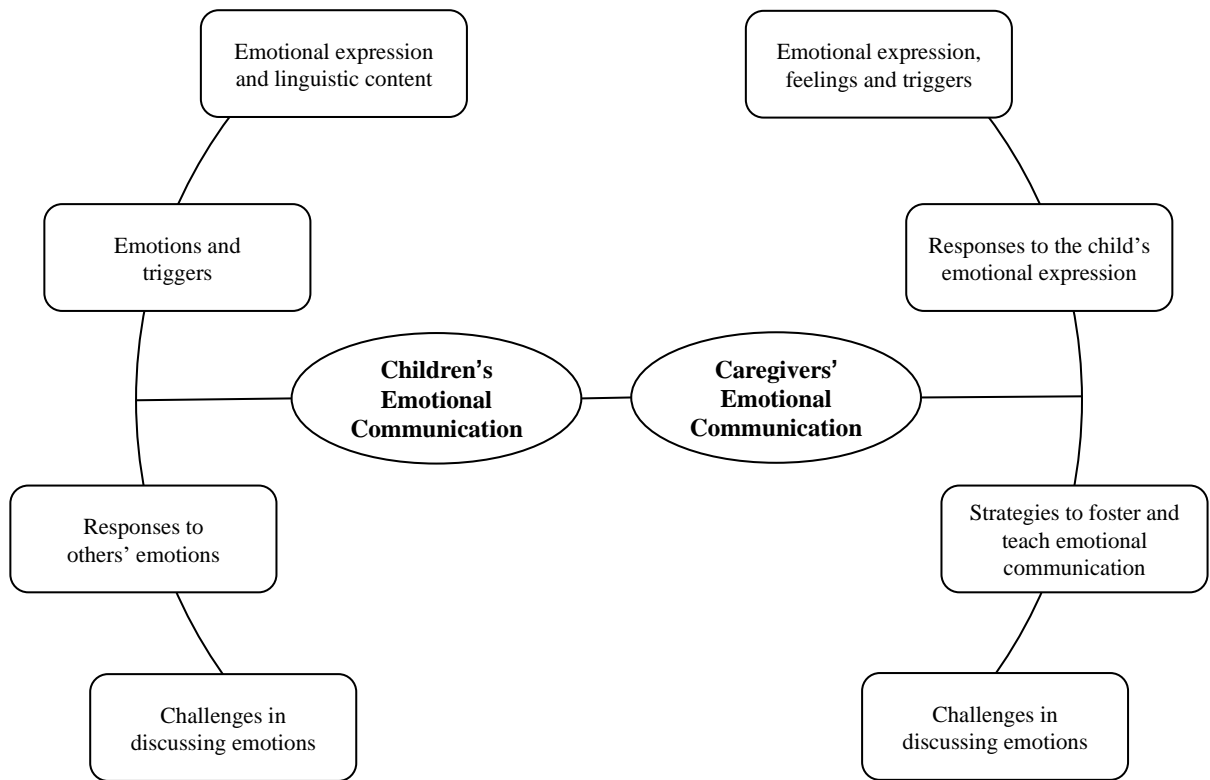
Figure 3-1. Thematic Map: Emotional Communication between Children and Caregivers
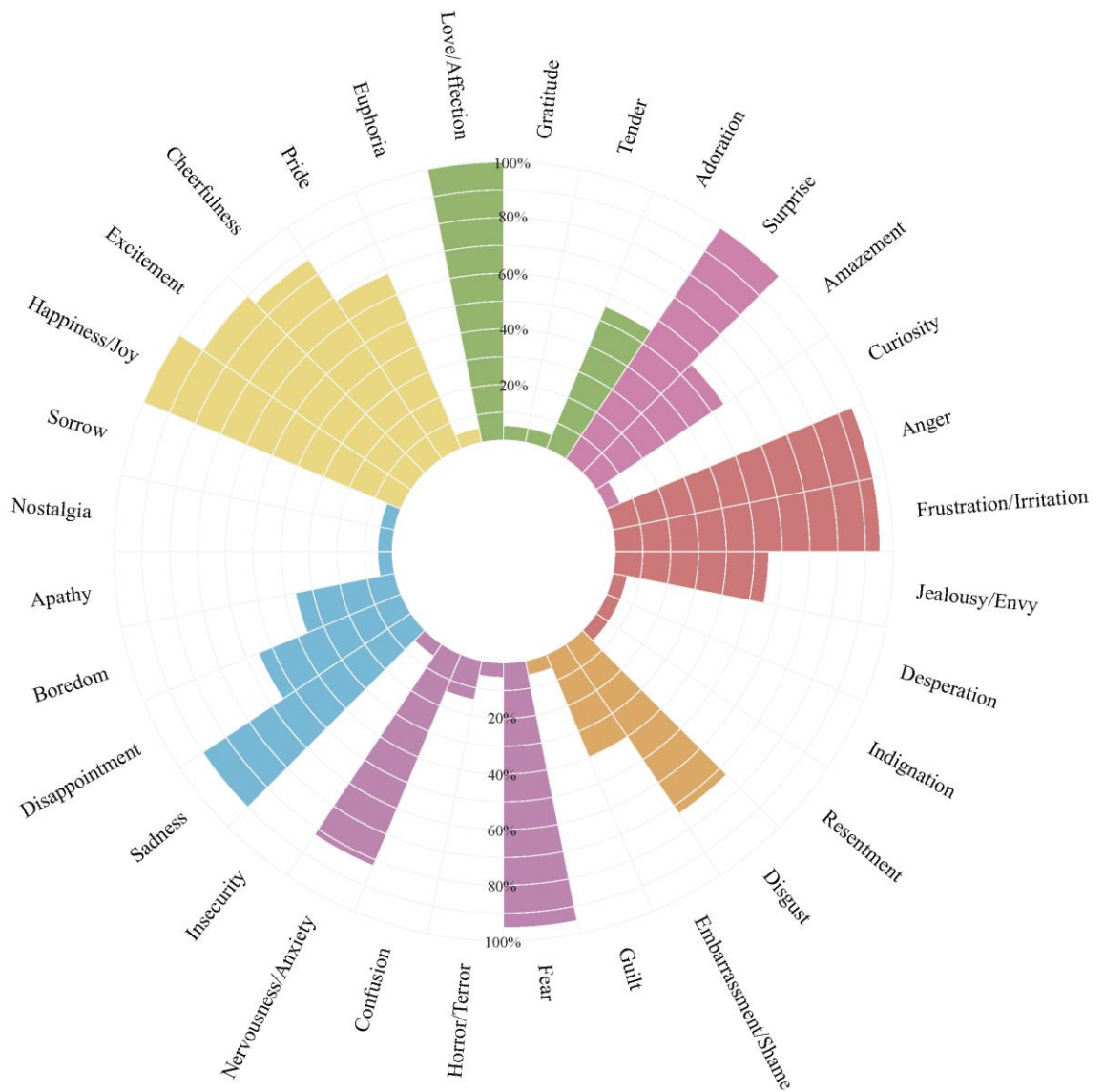
Figure 3-2. Children's Emotions Detected by the Participants

Note. The percentage refers to the proportion of participants that reported detecting the given emotion in their children. Color ranges include emotions with similar characteristics (i.e., red stripes are related to rage, yellow to happiness and joy, green to love, pink to surprise, blue to sadness, purple to fear and nervousness, and orange to disgust and embarrassment). Emotions with a percentage lower than 20%, along with boredom, were emotions not included in the interview protocol that parents expressed perceiving in their children.

Capítulo 4

Estudio 2: The Early Development of Emotional Competence Profile: A Means to Share Information About Emotional Status and Expression by Children with Complex Communication Needs.

Referencia:

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Notas:

- El presente estudio muestra la versión aceptada. Se recomienda al lector revisar la versión publicada en: https://doi.org/10.1044/2020_AJSLP-20-00209
- Las tablas y figuras a las que hace referencia este artículo se pueden encontrar a partir de la página 106.
- Errata de versión aceptada: en apartado de materiales, la cita textual hace referencia a la versión en inglés de la entrevista EDEC (Na et al., 2017, p. 2).
- Todos los materiales suplementarios se encuentran en acceso abierto en https://doi.org/10.23641/asha.14219777
- El material suplementario que sugiere el proceso para completar el perfil emocional (EDEC-P) se encuentra en el anexo 4-1 (versión en español) y 4-2 (versión en inglés).

ABSTRACT

Purpose: This article introduces a summary profile template, called the Early Development of Emotional Competence Profile (EDEC-P). This Profile distills information from a longer interview tool that solicits a detailed case history (the EDEC), but in a format that is readily accessible for communication partners of children with complex communication needs, including parents, educators, and other professionals.

Method: In this article we will (a) introduce the EDEC-P structure; (b) illustrate via case examples the types of information that can be shared; and (c) offer preliminary feedback from parents and other professionals on its usefulness. We will review literature that supports the importance of scaffolding communication about emotions by specialists who work with children with complex communication needs as well as by parents and other communication partners.

Results: An EDEC-P was generated for two participants as an illustration of the process. Feedback was solicited from these children's parents and other communication partners. The feedback demonstrated that the EDEC-P was viewed as a positive tool and identified some of the ways that it might be used.

Conclusions: The EDEC-P may be useful for professionals who are interested in approaching communication about emotions in children with complex communication needs. Guidelines are proposed to present and discuss the results from the interview to support the decision-making process in the clinical practice and next steps in research.

Supplemental materials: EDEC (Spanish version), EDEC-Profile templates, and EDEC-P description process.

Keywords: Emotional Competencies; Augmentative and Alternative Communication; AAC; Communication partners; Complex Communication Needs; Children; Profile

INTRODUCTION

The notion of "emotional competencies" refers to a variety of skills, including; (a) the ability to identify one's own emotions as well as the emotions of others; (b) recognition of the general emotional climate of a specific environment; (c) development of empathy and sensitivity to emotional experiences from others; (d) labeling the emotions; (e) detection of differences between emotions (e.g. sadness vs. anger); (f) the ability to understand and talk about the emotions, their causes and possible consequences and ways to manage them, and; (g) to express culturally approved emotional responses in an adaptive way that is appropriate to the situation (Na et al., 2016; Saarni, 1999; Wilkinson et al., in press). Emotional competencies play a significant role in a variety of important developmental outcomes, including social skills, the use of conventional communication vs. challenging behavior, motivation to learn, self-advocacy, conflicts and ethics (Aro et al., 2014; Malti et al., 2019; Trentacosta & Izard, 2007).

There is likely a critical relationship between the development of emotional competencies and the development of communication and language. Language acquisition is associated with increased emotional knowledge, emotional understanding and emotional perception (Doyle & Lindquist, 2018; Halberstadt & Lozada, 2011; Perlman et al., 2008; Widen, 2013). When individuals have the opportunity to engage in conversations about emotions, they can learn to identify emotions in themselves and others, and develop strategies to respond to these emotions (Beck et al., 2012; J. S. Cohen & Mendez, 2009). This link is supported by research. For instance, children with more advanced expressive linguistic skills display fewer quick, intense and sustained anger expressions and more regulatory strategies than children who have more limited expressive language skills (Cole et al., 2010; Roben et al., 2013). Additionally, labelling of emotions is reported to attenuate the emotional experience itself (Torre & Lieberman, 2018). In receptive language, a study

by Beck and colleagues (2012) reported that receptive vocabulary is linked to components of emotional competence like emotional knowledge, awareness of mixed emotions, and facial emotion recognition. Indeed, a growing body of studies present evidence that emotional language may also support the perception of others' emotional displays (Barrett, 2017; Lindquist et al., 2016), as well as shape the way individuals perceive, categorize, and experience their emotional world (Doyle & Lindquist, 2018; Lindquist et al., 2006, 2015).

Although research has provided some insight into emotional competence and its relationship with language in children with typical development as well as those with specific language impairment (Fujiki, Brinton, & Clarke, 2002; Fujiki Spackman, Bronton, & Hall, 2004; K. A. Lindquist et al., 2015; Saarni, 2000; Shablack & Lindquist, 2019; Torre & Lieberman, 2018), few studies have examined this in individuals who have complex communication needs (CCN) resulting from significant communication impairment and/or intellectual/developmental disabilities (see Wilkinson et al., in press). The speech of children with CCN does not meet all of their expressive or receptive language needs;, some children have virtually no expressive speech or understanding of spoken input (Ganz & Simpson, 2018). The barriers in speech can result from diverse etiologies including cerebral palsy, autism spectrum disorders, Down syndrome, developmental disabilities, or speech-language impairment. Children with CCN benefit from augmentative and alternative communication (AAC) supports that replace or supplement conventional speech. A complete AAC assessment must include the individual with CCN, their communication partners and their socio-cultural context in order to guide the intervention, promote the individual's current communication, and prepare them for future communication needs (Beukelman & Light, 2020).

Acknowledging the Importance of Emotional Development in Children with CCN

Emotional development occurs in a socio-cultural setting, and emotional expression is one of the fundamental methods by which caregivers and children convey their emotions (Buss et al., 2019). Emotional expression serves as a signal to others, that supports individuals to communicate (Saarni et al., 2007), interact, and connect to others (Lench, 2018). The ways that individuals respond to emotions, including the preferred language used to talk about emotions, are closely tied to cultural social norms (Cole et al., 2002, 2006). Emotional learning and competencies are influenced by individuals' interactions, relationships, culture and experiences (Saarni, 1984; Twenge et al., 2003).

Children with CCN typically show limitations in expressive language and emotional comprehension compared to children with typical development (Brinton & Fujiki, 2009; Saarni, 1999; Scherer, 2012). Blackstone and Wilkins (2009) highlighted the importance of exploring emotional competencies in children with CCN since "they are most certainly at risk for failing to develop (these) competencies" (p. 78). Additionally, individuals with disabilities are at risk for experiencing abuse, exclusion, neglect, and for developing behavioral, mental, social and emotional disorders (Browne & Millar, 2016; Cannella-Malone et al., 2011; Einfeld et al., 2011; Robinson & Chenoweth, 2012; Taheri et al., 2016). Intervention studies suggest that promoting appropriate expression of feelings is related to effective self-advocacy by individuals (Test et al., 2005)**.** It is therefore critical to raise awareness about the importance of emotional competence (Blackstone & Wilkins, 2004; Na et al., 2016) as well as the risks when children have restricted opportunities to learn adaptive means to communicate about emotions (Wilkinson et al., in press).

Various interventions exist that can promote healthy emotional development through the life span in individuals who use speech (Buss et al., 2019; Hemmeter et al., 2006; Saarni, 2000). Professionals must consider developing interventions that can promote emotional

competencies in individuals who have CCN, as interventions developed for children without disabilities may not be optimal for those who have disabilities. The interventions must include access to emotional vocabulary in AAC systems to promote conversations about emotions, to enable modelling of emotional communication, and to provide strategies to respond to specific emotions (Na & Wilkinson, 2018). If emotional competencies are related to communication and language, then collaboration between speech-language pathologists (SLP) and psychologists and other professionals is necessary in order to develop interventions that (a) contain appropriate vocabulary to foster communications about emotions, as well as (b) incorporate strategies to enhance emotional competencies. Clinicians and others involved could work together and plan interventions that are meaningful to the child's and family's emotional interests and needs.

Challenges in Promoting Emotional Development and Communication via AAC

There are a number of challenges in communicating about emotions, which can be either intrinsic to the child with CCN or extrinsic to the task of communicating via AAC. For instance, emotions can be conveyed via body posture and facial expression. Some children with CCN may have motor challenges that make it difficult for communication partners to recognize and interpret emotional messages that are conveyed through these means. In addition, children could also have cognitive, sensory or language obstacles that make it challenging for the communication partners to understand what the child with CCN is feeling, why they are feeling this way, and how to respond to and discuss their emotional needs/wants (Blackstone & Wilkins, 2009; Na et al., 2016). This uncertainty on the part of the communication partners can in turn result in unpleasant emotions like frustration, desperation, or anxiety (Rauscher & Hesse, 2014; Wilkinson et al., 2021).

Another barrier relates to communication partner attitudes. Misconceptions exist about children who use AAC; these include, but are not limited to, beliefs that AAC hinders

or stops speech development, AAC systems are just for people with intact cognition, or that there are prerequisite skills that must be in place before beginning AAC interventions (M. A. Romski & Sevcik, 2005). Those misconceptions could delay interventions related to language development and emotional communication. The use of AAC also presents specific challenges to communication partners in terms of interaction style. For instance, communication via AAC is often much slower than natural speech (Beukelman & Light, 2020); as a result, the balance of the conversation may be altered such that the communication partner dominates the conversation and in turn, the child's linguistical expression of emotions. Finally, in successful AAC interventions the partner must establish interactions and provide models and opportunities, such as, scaffolding and co-construction (O'Neill et al., 2018; M. Smith & Grove, 2003). Therefore, it is critical to engage children's partners in learning the AAC systems and the skills to become a successful communication partner (Biggs et al., 2018) who can scaffold and model conversations about emotions.

Factors related to AAC technologies could also either support or interfere with the development of emotional language and competencies. According to Scherer (1986, 2003), vocal expressions provide acoustic/prosodic cues that support the recognition of emotion. Currently, high-tech AAC speech-generating devices (SGDs) do not fully replicate the prosody of natural speech (tone of voice, intonation, volume, etc.) and are thus typically fairly monotone. Individuals who use SGDs must therefore rely on other expressive resources (i.e., body-based methods) to support the emotional expression in their AAC messages.

Conversations about emotions can also be challenging when there is only limited emotional vocabulary on the AAC display (Blackstone & Wilkins, 2009; Wilkinson et al., in press). For instance, often the available labels for emotions in AAC systems are limited to a small set of pleasant (happy) or unpleasant (sad, angry) emotions. Yet, emotions are in

fact far more varied than just feeling "happy" or "sad." For example, a feeling of sadness is different from boredom, or frustration, and any one of these emotions may be caused by a variety of reasons. Therefore, the type of emotion and the reason why it is occurring are both critical elements of conversations about emotions. Moreover, the type of response the child requires, along with the communication partner support and strategies provided, will depend on the kind of emotion, the trigger for the emotion and the socio-cultural preferences of the family (Wilkinson et al., 2021).

Early Development of Emotional Competence Questionnaire

Given the unique constraints of AAC in regards to understanding and expression of emotion, clinicians must pay special attention to creating AAC systems and interventions that deliberately engage the children and their communication partners in conversations about emotions (Na, Wilkinson, Karny, et al., 2016). Some AAC systems offer pre-established communication boards or pages, such as "emotions and sensations" pages. The limitations of those pages are that they may not be tailored to the child's emotional needs and/or may not include vocabulary that corresponds to their socio-cultural emotional context. Furthermore, Na et al (2016) argued that for communication about emotions to be successful, it is necessary to design pages that include vocabulary for possible reasons and responses to emotions.

In response to these constraints, Na and colleagues (2018) developed a semi-structured questionnaire, based on the notion of emotional competencies explained above, called the EDEC (Early Development of Emotional Competencies) that invites parents, caregivers and professionals to consider the interaction between language and emotional competence. The EDEC collects detailed descriptive case history information that helps inform the decision-making process for designing AAC systems that contain emotional

vocabulary as well as vocabulary for discussing emotions in ways that are consistent with the socio-cultural environments in which the child communicates.

This EDEC interview can be conducted by a professional (e.g. psychologist, occupational therapist, SLP) in conjunction with other communication partners (e.g. parents, caregivers, teachers). The EDEC consists of two sections that offer a script for conducting the interview. The first section includes 10 questions regarding child's temperament, interaction with others and behavior characteristics. The second section contains 14 questions about the child's common emotions, emotional expressions and communication partners dynamics around emotions. The tool has been providing systematic and interpretable information regarding the interviewee's perception of the child's emotional competencies and communication needs and preferences (Na, Wilkinson, et al., 2018).

The interview has been tested across different cultures, communities and languages in English, Korean, Mandarin Chinese, and Spanish (Na, Wilkinson, et al., 2018; Na, Rangel-Rodríguez, et al., 2018; Wilkinson et al., 2018). The Spanish version is included in the supplemental materials of this manuscript; the other versions were supplemental materials in Na et al. (2018). As described in Na et al in detail (2018), in the translation process of the EDEC, the authors emphasized the efforts in achieving cross-cultural and cross-linguistic adaptation, mainly focusing on syntax, idiomatic, semantic, experiential and conceptual equivalence (Guillemin et al., 1993).

Purpose

The EDEC had two stated goals: (a) to raise awareness of the importance of communication about emotions, and (b) to inform decision-making for clinical AAC interventions. Descriptive information about how the EDEC helped raise parents' awareness was provided in a book chapter describing parent responses (Wilkinson et al., in press). It is now critical to explore more directly the second goal, that is, the clinical applications and

uses that might be derived from the information solicited by the EDEC. Na and colleagues (Na, Wilkinson, et al., 2018; Na, Rangel-Rodríguez, et al., 2018; Wilkinson et al., 2018, 2021) suggested that the information collected can be analyzed for several purposes, including: a) obtaining a picture of the child, his or her emotional world (from the interviewees' perspective); b) understanding the caregivers' responses to their child's emotions as well as the emotions the caregivers do or do not feel comfortable expressing in front of the child; c) guiding decision-making about choosing meaningful AAC vocabulary to converse about emotions, and; d) guiding decisions about which family activities might best facilitate communication about emotions. In this paper, we offer some suggestions for these purposes, that is, discussing how a clinician might distill information obtained from the EDEC for clinical use. Specifically, we introduce the EDEC-Profile (EDEC-P), which distills important information from the EDEC that can be shared with parents or school/clinical professionals to raise awareness and better understand the emotional status of the child with CCN. It can be also used to suggest some guidelines to foster the child's emotional development and to guide AAC design and intervention. We present two illustrative case-studies and also offer parent and professional perspectives on the EDEC-P, as a means to demonstrate its initial social validity.

METHOD

Participants

Two mothers who each had a child with CCN were interviewed with the EDEC by a psychologist with experience working with children with CCN using AAC. Table 4-1 presents participants' information (names are pseudonyms). The full EDEC interviews were conducted as part of a larger ongoing PhD research project, carried out by the first author, surveying how families engage in emotional conversations with their children who have CCN. The development of the EDEC-P summary was not the primary research question in

the larger project but rather was developed as a means for the researcher (who is also a licensed clinician) to share useful but condensed information about the results of the EDEC interview with the families. Ethics approval was obtained from the Autonomous University of Barcelona review-board (the Ethics Committee on Animal and Human Experimentation) prior to starting the study. Participants were recruited via word of mouth and snowball sampling. Recruitment electronic messages were sent to clinical contacts, families of a child with CCN and SLPs requesting families who could be interested in participating in the study.

Materials

The Early Development of Emotional Competence (EDEC) Tool

Table 4-2 provides a detailed review of the components of the original EDEC tool. The tool collects descriptive data about the perceptions of the parent or other reporter about the child with CCN and their social networks and socio-cultural context:

> The EDEC tool is a descriptive instrument designed to elicit information about how families and professionals talk about emotions with children with complex communication needs…The EDEC tool seeks to raise awareness about the relation of language and emotional competence, and to ensure that a child's communication intervention includes language to discuss emotions in ways that are consistent with the values and goals of the family. It is not developed for prescriptive purposes, nor as a norm-referenced instrument. Rather, it is intended to allow professionals to collaborate with family members and other professionals to gather information that can be useful to support communication about emotion.

As a descriptive instrument, the EDEC was designed as a means to support acquisition of a thorough case history with regards to communication about emotions. The instrument was developed with a target of young children from birth to 10 years, although it might also be useful with older individuals (Na, Wilkinson, et al., 2018). As noted in the introduction, the EDEC has been translated in different languages. For the present study, we used the English version for case 1 and the Spanish version for case 2.

Procedure

The EDEC interviews were conducted by the first author in case 1 and a psychologist trained by the first author in case 2. Both interviewers were trained clinical psychologists with a master's degree in cognitive and behavioral psychotherapy, and with more than 10 years of experience treating individuals with CCN and their families. The first author is also a coauthor of the EDEC tool and the author of the EDEC-P process. Each psychologist contacted the family to ask if they were interested in participating, obtained informed consent and gave them a brief questionnaire that included the child's name, age, nationality, language(s) used in the family and the context, diagnosis, experience with AAC systems, therapies that the child attend, current forms of communication, medication and a brief description of the child.

The psychologist used the interview script proposed in the EDEC and sometimes asked for more information to clarify or gain depth on a specific subject. Interviews lasted 1 hour 45 minutes in both cases and were completed in a single session in case 1 and in two sessions in case 2. At the beginning of the interview, the interviewer explained the themes they would be talking about in the meeting. The psychologist commented that, if for some reason, the mother felt uncomfortable responding to any question, she could ask the interviewer to skip it and go to the next question. Both mothers chose to answer all questions. Once the interview finished, the psychologist thanked the mother for her time. The first author then transcribed each interview, generated the EDEC-P (in English in case 1 and Spanish in case 2) and shared it with each mother.

Procedure for Generating the EDEC-Profile (EDEC-P)

The information from the full EDEC was distilled into a profile, the EDEC-P. Table 4-3 presents the rationale behind the template of the EDEC-P, as well as how it is organized. The EDEC-P consists of two parts. Part 1 is an "About me" section that includes an image or picture of the child and information about the child, their strengths and skills, as well as

information about communication partners' input. Part 2 presents "Challenges and Strategies" and consists of challenges, functional emotional communication goals expected in the short term, and suggested strategies for intervention with the child and the child's communication partners. The first goal in the short term aims to prompt to the communication partners to focus on one first objective, the challenges and the strategies to achieve it. Nevertheless, the clinician must have in mind the longer-term objectives to foster emotional development and competencies, and so clinicians are encouraged to consider discussing and sharing these goals with other communication partners if needed.

As in any interview, on occasion communication partners may give an answer to an earlier question but then later say something that extends the earlier answer. Many times the information will be expressed organically over the course of the interview. For this reason, the clinician creating the EDEC-P will need to be aware that its content will be informed by the dialogue throughout the interview.

We designed templates to help clinicians to create the child's EDEC-P; these are presented in the supplemental materials S2-S5, with templates in English and Spanish. We opted to write the first part of the profile in the first person, as we believed this would have the greatest impact on the reader and may be easier to learn and more family-friendly. In addition, the EDEC interview includes some questions about the emotions that caregivers do or do not express in front of the child (questions 9 and 10). This particular information was not included in the EDEC-P, because those two questions were specifically about within-family interactions that the family might want to keep private. However, even though the information does not appear in the EDEC-P, we suggest that clinicians will need to be aware of and sensitive to the information from those questions as they design AAC interventions resulting from the EDEC and the EDEC-P.

The EDEC-P should be accompanied by a verbal explanation, especially when presenting the second section of "challenges and strategies." This serves to obtain feedback from communication partners, resolve questions and, if necessary, make some relevant changes to the EDEC-P. Figure 4-1 presents a scheme of the suggested process to facilitate the clinicians moving from the EDEC interview to elaborate the EDEC-P, and to present the profile to communication partners. A description of each step of the process can be found in English and Spanish in Supplemental Materials S6 and S7.

Social Validation

Social validity refers to the assessment of the social significance and appropriateness of goals, methods, and outcomes (Kazdin, 1977; Wolf, 1978). To evaluate the social validity of the EDEC-P, the clinician encouraged the mothers to "share your ideas, perceptions and/or feelings about the profile that you just read. There is no minimum length required, but please expressed everything you can think of." Caregivers were also encouraged to share it with other communication partners. In case 1, Amir's mom shared it with Amir's dad and also shared it in a meeting with the habilitation team. In case 2, feedback was solicited from three of Rosa's communication partners: her school psychologist, speech-language therapist and clinic director.

RESULTS

Case Study Illustration

Case 1: Amir A.

Figure 4-2 presents the EDEC-P that was generated from the EDEC information, following the steps suggested in Figure 4-1, for Amir, a 7-year-old boy. The first page of Amir's EDEC-P discusses his temperament, favorite activities, communication and emotional profile and communication partners' input reported by his mother. The second

page proposed an emotional-communication goal and presented the challenges and strategies to achieve it.

In this case, the EDEC interview revealed that Amir's mom could identify different emotional expressions from Amir (Figure 4-2: "Emotions I express" section). Nevertheless, she expressed that it is difficult for others to recognize Amir's emotions. Amir's ways of emotional expression (Figure 4-2: "Current ways I express my emotions" section) are non-linguistic (body postures, vocalizations, facial expressions). Although he has an AAC system with a pre-established "feelings and sensations" page, he doesn't make use of it, in part because the AAC system is quite new for him and the communication partners (less than one year). Moreover, it seems that Amir is sensitive to others' emotions and he sometimes adopts the emotions of others (Figure 4-2: "I recognize and respond to others' emotions by" section). When Amir's emotion is recognized by his parents, they try to guess what would be the cause and respond to what they think could be the best for him (Figure 4-2: "Current ways people respond when I express an emotion" section).

Amir's mom expressed that when someone uses Amir's belongings or takes pictures of him, he gets angry and expresses it with facial expressions and vocalizations. Therefore, it seems that one of Amir's needs is to be recognized and to be asked for his opinion and consent to use his belongings or for taking pictures of him. The clinician considered that it would be beneficial for Amir to have another, more conventional way to express these needs. The clinician suggested to Amir's parents that they begin talking about emotions with him as a first goal (Figure 4-2: "Goal" section in page 2). The challenges (Figure 4-2: "Child's challenges" section) would be for him to learn emotional language, to discuss causes of his or others' emotions, and to talk about possible responses when feeling a specific emotion. The clinician recommended starting with emotions that are significant for Amir, and designing specific boards to talk about the reasons and responses to emotions and give

opportunities to learn and practice communication (Figure 4-2: "Strategies to achieve child's goal" section). Some of the methods could be to give deliberate opportunities to talk about emotions, as well as to encourage and model emotional communication. In order to scaffold Amir's communication, partners would need to collaborate with the clinician to become a successful emotional communication partner (Figure 4-2: "Communication partners" sections).

Case 1 - Social Validity

Amir's EDEC-P was shared with his mother, followed by an explanation about the Challenges and Strategies page (proposal for next steps). Amir's mother responded that the EDEC-P was adequate and that she wouldn't make any changes. The EDEC-P was also well received by Amir's other communication partners (father and habilitation team). Amir's mother noted that the strategies are very useful and believed it would help her to understand her son better. Amir's dad said, "it is very helpful for us to get such a professional observation and very detailed in easy understand format." The habilitation team noted that his EDEC-P was very clear, and the psychologist on the team reported that the profile helped her to understand Amir better.

Case 2: Rosa

Figure 4-3 presents Rosa's EDEC-P, generated from the information collected by the EDEC interview and following the process suggested in Figure 4-1 and Table 4-3. Rosa is 12 years old and has several ways to communicate and express emotions (Figure 4-3: "Emotions I express" section). According to her mother, Rosa expresses quite a range of emotions, however, Rosa has difficulty identifying her own emotions and expressing them in socially acceptable ways (Figure 4-3: "Current ways I express my emotions" section), particularly when she feels unpleasant emotions like frustration, anger and anxiety. The clinician considered the possibility that some of the challenging behaviors that Rosa presents

(e.g. shout, throw, bite her nails, rub her eyelashes) may be in response to unpleasant emotions that she is having difficulty labelling and responding to. For this reason, offering Rosa opportunities and modelling ways to talk about emotions using her AAC device could help Rosa to understand others' emotions as well as her own (Figure 4-3: "Challenges and Strategies" section). Once she labels the emotion, she could identify different ways and more appropriate options to express the emotion, respond to it appropriately, and get what she needs.

Rosa's EDEC-P is structured using the same template used for Amir, however, some changes were made. In particular, Rosa's mother commented about games that Rosa enjoys. Consequently, the topic "My favorite shows" was changed to "My favorite games" in the "About Me" section. It is also important to include the vocabulary that the family and others in Rosa's social context use. For example, when the clinician asked if Rosa expressed anger, her mother could identify the emotion, but she commented: "I consider that it is not anger, it is more annoyance, she doesn't label it, but you can notice it in her face." While the interview was conducted, Rosa's mother became aware that her daughter was actually able to express more different emotions than she had realized. The EDEC interview offered a space in which to reflect on her daughter's emotions and the nuanced ways that Rosa has to express them.

The EDEC-P was shared with Rosa's mother. Rosa's mother responded positively to the information from the first page, however, she felt that the information on the second page could be more specific. In particular, Rosa's mother asked questions about what some challenges and strategies refer to. The clinician clarified the questions she had and took into consideration her perceptions and needs. This profile was also shared with Rosa's school and clinical team (psychologist, SLP and clinic Director). Two of them suggested that more examples could be added in the challenges and strategies sheet. Other comments of Rosa's

team appear below in the social validation section. Based on this feedback, the Challenges and Strategies section was adjusted, and examples were added (figure 4-4). Upon receiving these modifications, the team and Rosa's mother were satisfied with the outcome.

Case 2 - Social Validity

The EDEC-P was well received by Rosa's communication partners (mother, school psychologist, SLP and clinic director). All of them reported that they liked the profile and considered it useful, helpful, easy to read, well organized, clear and they appreciated the visual design of the profile. The SLP wrote: "Sounds like a great tool to me! I am sure it will be very useful for the adults who live with these children, it will help them to have more accurate information". The clinic director expressed:

> Seems to me a very nice, complete and clear report, (…) we can see the variety of ways the child uses to express emotions. It turns to be a tool that is super useful for people who interact with her and those who don't know her very well. It helps also to realize that probably all the emotions that she shows less, it is not because she doesn't feel them, but because she does not have a clear way of expressing them, and therefore the need to have all that vocabulary in her emotions' page. (…) I imagine that for children for whom this topic is ignored, and for children who have few resources to express them, it will be shocking for the family to realize how little they can express regarding emotions and the possible cause of their constant crying during the day.

The school psychologist shared:

> The challenges and strategies sheet seem to me that will raise awareness and help parents to be aware about the emotions and how to intervene. (…) It points out the importance of working with parents about the use of AAC at home.

The clinical and school team considered the EDEC-P to be a helpful assessment for both familiar and unfamiliar communication partners. In addition, they noted that the profile raises awareness about the emotions of the child and the importance of communication. As one SLP remarked:

> Knowing all this can help to have a better communication with the children and a better understanding of their emotions from the beginning. Therefore, it will help lower the level of frustration that children normally have when they realize that not everyone understands certain communicative intentions.

While the participants found the first section to be satisfactory, they also commented that the challenges and strategies section would be more helpful if it was explained in more detail. They noted, for instance, that: "more examples are needed to clarify the strategies," "it would be great if it was more explicit, so that if the parents want to share it with other adults, the others can understand the new goals and how they can help the child." With their feedback, the profile was re-adjusted; after this readjustment, the professionals responded positively: "This section is appropriately adjusted to the current needs of the child and her family", "The challenges are clear." One respondent noted:

> A strategy that I really liked is being able to talk about emotions in activities such as stories and games with Rosa, since I consider it to be a strategy that suits her due to her dynamic and imaginative personality during activities like these.

DISCUSSION

The EDEC-P distills the extensive information obtained from a full EDEC interview in order to guide practitioners and family members in establishing culturally and linguistically relevant and valid goals and strategies to foster the development of linguistic and emotional competencies. The EDEC-P supports the decision-making to design a dynamic, meaningful and valuable intervention plan according to a child's current situation and emotional development, competencies and needs. The EDEC-P shows promise to be applicable among diverse contexts, although clearly further direct research is needed to evaluate this promise.

The EDEC-P shares information with communication partners about how a child with CCN expresses themselves emotionally, supporting communication partners to raise

awareness about all the means by which the child conveys emotions (including idiosyncratic/body-based methods and aided AAC). Because speech-generating devices yet lack acoustic cues (such as intonation, volume) that contribute to how emotion is conveyed in natural speech, it is critical to ensure that partners can understand idiosyncratic or body-based methods of emotional expression (Scherer, 1986). The EDEC-P helps to acknowledge the current forms of emotional expression.

One of the prominent features of the EDEC and its profile is that it gathers and analyzes information and current data incorporating the child's team and it can be adjusted to support the child's emotional communication goals. Beukelman and Light (2020) argued that including the family and the individual with CCN in AAC decision making may promote trust, a feeling of "ownership" of the interventions, and motivation to learn as well as collaborate actively in the team. Mothers and individuals who participated in the social validation of the EDEC-P mentioned that it is a useful tool that not only raises awareness about the child's needs and emotions, but also provides information and guidelines about the child's challenges and strategies to current and new communication partners.

Tailoring the EDEC-P to Individual Clients

The two cases presented show the different ways that this template can be tailored to the specific needs and goals of the individual child and family. In case 1, the family was satisfied with both sections of the profile presented. The parents shared it with the habilitation team, who also felt that the profile was helpful to understand Amir's emotional communication. In case 2, Rosa's mother and clinical team were satisfied with the first section, but gave feedback about their preferences of giving more details in the challenges and strategies section. Once it was adjusted, the family and the team considered the profile complete and personalized to their needs. The differences between the perceptions of the EDEC-P could be due to the specific characteristics of the child's individual and socio-

cultural-context. Clinicians must consider these factors in the assessment and the creation of the EDEC-P. Beukelman and Light (2020) argued that interventions should be personalized, hence, the template proposed can be modified and represented differently according to the feedback and unique needs that the EDEC-P will serve. Moreover, as the child's emotional competencies change and evolve, through ongoing experience as well as through the result of interventions, regular assessment of how the AAC may need to change will continue to be important.

It is possible that while interventions with people who have CCN have focused on important dimensions of communication, these interventions may have overlooked the emotional domain. There is an urgent need to promote communication about emotions. Several findings in typical development have suggested that language could be a means for teaching and acquiring emotional vocabulary and knowledge (Beck et al., 2012), causes and consequences (Dunn et al., 1991; Russell, 1990), and regulation (J. S. Cohen & Mendez, 2009). Consistent with this argument, the cases presented in this article demonstrate that one of the first goals in promoting emotional development and communication must be to start talking about emotions in pleasant moments and activities. Communication and socialization between caregivers and children is a significant way to start learning about emotions (Shablack & Lindquist, 2019). Therefore, communication partners play an important role in consciously exposing children with CCN to culturally appropriate means of discussing emotional situations. Clinicians, including SLPs and psychologists, must work to scaffold communication partners to become successful emotional communication facilitators.

Collaboration among disciplines will be potentially fruitful. For example, psychologists may not have the tools to fully understand language and AAC systems, but SLPs may not have the knowledge to fully understand behavior, mind and emotion. If they work together with the family, other communication partners and the child, these

professionals will be creating a supportive network that seeks the complete development of the child, including emotional development.

Limitations, Implications and Future Directions

Clearly, systematic research is needed to confirm the utility of the EDEC-P, most particularly in larger controlled samples, as well as to help refine the process of generating the EDEC-P itself. In addition, research is needed about the utility of the EDEC-P across partners and contexts. For example, we collected information from the mothers' perceptions for the creation of the profiles presented. Children may use different AAC techniques, behave and express emotions differently depending on the person that they are with or across different settings. Consequently, for each child it would be of interest to collect information from more communication partners to get a fuller picture of the child's emotional expression. In addition, the assessment could be more consistent if clinicians are able to make observations in natural settings about the communication of emotions between communication partners and the child with CCN.

Another important direction for future studies would be to include the child's perceptions about the profile. Some children might not feel comfortable with sharing in the EDEC-P some of their feelings, and other children might like to add more information that was not mentioned by the first informant. For example, the clinician might say to the child: "We want to share some things about you with your teachers so they can know you better. This will help them to understand your feelings better and support you effectively if needed", "Do you like it?", "Would you like to share this?", "With whom?", "Would you like to add something else?", "Is there something you prefer to avoid?" According to the child's ability to understand and express such ideas, the clinician can ask specific questions to determine the child's validation.

In the two cases presented, the clinician made the decision to begin discussing emotions as a starting point to intervene. Yet, to validate the effects of the interventions, future research should focus on evaluating the efficacy and impact of the strategies suggested in the EDEC-P. In particular, it will be important to examine how providing opportunities to talk about emotions, as well as designing, modelling and using emotional communication boards, might impact the way communication partners and children with CCN interact and how they understand, express, discuss and cope with their own and others' emotions. Na & Wilkinson (2018) showed promising results of instructing communication partners to promote dialogue about emotions with children, yet the small sample size and homogenous diagnosis of the child participants limit the generalizability of the interventions featured in the study. Thus, there exists considerable scope for future inquiry into the emotional competencies and development of individuals with CCN promoted by strategies suggested in an EDEC-P. A possible way to carry out this could be to readminister the EDEC and remake the EDEC-P to report the current child's emotional and communicative state, the impact of the strategies executed, and support the new decision-making process towards the next steps in fostering the development of emotional and communicational competencies. Such a research effort would offer more insight into clinical contributions to children's emotional development and allow communication partners to recognize that each child with CCN, just like any other individual, has the right to understand, express, and decide how to respond to emotions in a healthy way.

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TABLES AND FIGURES

Table 4-1. Characteristics of the participants' children / sample

	Case 1: Amir	Case 2: Rosa
Child's nationality	Indian	Mexican
Child's place of residence	Sweden	Mexico
Child's diagnosis	Dystonic CP, GMFCS level 5, Reflux Epilepsy, Developmental Delay	Developmental Disorder Intellectual Disability
Child's age	6 years, 9 months	12 years, 1 month
Child's current means of communication	Facial Expressions Eye gaze Vocalizations	Facial Expressions Body Language Gestures Vocalizations Speech
Child's communication aids/equipment	Tobii eye gaze computer	iPad with Proloquo2go
Years with AAC systems	Less than 1 year	2 years
Language(s) use with the child	Telugu, English, Swedish	Spanish
Language of the interview	English	Spanish

Note. CP = cerebral palsy; GMFCS = Gross Motor Function Classification System; AAC = augmentative and alternative communication.
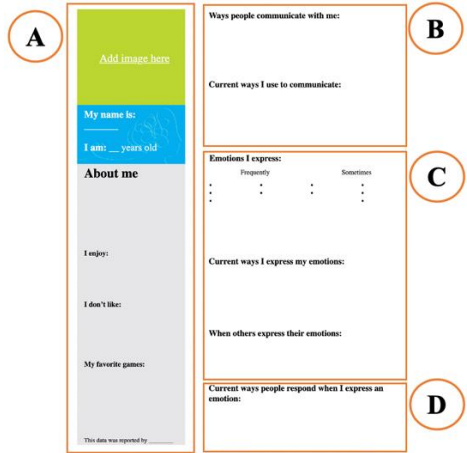
Table 4-2. Contents of the EDEC tool

Section	Type of questions	Description of the questions	Goal
Section I. About temperament/behavioral characteristics (10 questions)	Regarding temperament (question 1a, 1b)	Questions about behavioral characteristic patterns. They allow giving general information about how a child might react emotionally to a particular situation.	To understand temperament characteristics (who can provide insight into how these characteristics may impact in child's communication needs, behaviors and emotions).
	Regarding behavior (question 2-10)	Questions about social behaviors and interactions, as well as some challenging behaviors.	To identify possible child's emotional competencies regarding emotional regulation, communication and coping techniques.
Section II. Questions about the child with CCN and family dynamics	Regarding emotions that child expresses and some emotional triggers. (questions: 1a, 1b)	Questions about the emotions expressed by the child and its frequency and some trigger events.	To recognize most of the emotions that the child expresses and that their partners are able to perceive. To identify possible trigger events for those emotions.
	Regarding means of emotional expression, settings and emotional knowledge (vocabulary) (questions: 2-5, 8)	Questions about current and emerging modalities of the child emotional expression (linguistic and non-linguistic), if the child label and/or discuss their own emotions and from others. Identify the repertoire used (emotional vocabulary, causes of emotions and responses to emotions).	To comprehend the current emotional skills and ways of communicating it. To provide a framework for communication partners to propose ways to scaffolding the child to express emotions according to their emotional development.
	Regarding communication partner input behaviors (questions: 6, 7, 9-14)	Questions about how communication partners support, promote and model the expression and communication about emotions.	To identify the current communication partners' input that promotes emotional communication and competencies. To identify the models of emotional expression by caregivers.
Thorough all sections	*Regarding socio-cultural expectations of partners	Questions about the expectations that the communication partners and socio-cultural environment have on the way of expressing and responding to emotions.	To identify socio-cultural patterns that might shape expectations of the child's environment concerning the expression of emotion (e.g. when, with whom and how certain feelings can be shared).

Note. CCN=complex communication needs.
*Some of the content and organization has change since the original description by Na and colleagues (2018).

Table 4-3. The rationale behind the template of the EDEC-P and its organization

		Part 1. About me
	A. About me	Child's temperament and behaviors 1. Who is the child? Describe some behavioral and temperamental characteristics.
		Child's favorite activities, preferences, dislikes. 2. What does the child like/dislike/love?
	B. Communication	Partners' communication input 3. How do the child's communication partners scaffold communication (in general)?
		Child's communication modes 4. How does the child communicate (methods available in general)?
	C. Emotions	Child's emotional world 5. What emotions does the child feel/express?
		Child's emotional expression 6. How does the child express emotions (linguistic and non-linguistic modes)? What are the child's emotional expression preferences?
		Recognition and response to others' emotions 7. How does the child recognize and respond to others' emotions?
	D. Communication Partners' Emotional Input	Communication partners' responses to child's emotional expression 8. How do the child's communication partners respond to the child's emotions?
		Part 2. Challenges and Strategies
	E. Goals	Child's emotional goals 9. According to the information collected, what are the child's emotional needs? What goals could be beneficial for the child? Make a list, prioritize and select where to start (according to the child's development). What would be the first goal? Write just the first one in part 2.
	F. Child's Challenges and Strategies	Child's Challenges: 10. What are the child's emotional challenges? What would be the child's challenges to achieve the proposed goal? Are the existing means of the child's emotional expression sufficient to serve their needs? Are there some AAC challenges? Behavioral challenges? Motivational challenges? Communication barriers?...
		Strategies to achieve child's goal:

		11. Once you identify the first goal and child's challenges, propose strategies to achieve the goal.
		*Does the child need aided communication?
		*Could the child benefit from specific emotional vocabulary?
		*Which vocabulary?
		*Which activities motivate the child the most? What type of activities could be exciting to adapt or introduce to talk about emotions?
		*What strategies could support the comprehension of emotions, reasons of emotions, and ways of coping with them (or responding)?
		Communication partners challenges / goal:
		12. What does the child need from communication partners to pursue the proposed goal (consider the information collected about the child's communication partners)? How can the communication partners scaffold the child to express emotions? What are the communication partners' challenges? Do they give opportunities to promote emotional development? Are there some emotions they prefer to avoid? Do they have a specific concern about the child referring to emotions? Is it possible to assist them with it?
	G. Communication Partners' Challenges and Strategies	Communication partners strategies:
		13. Once you identify the communication partners' challenges, propose strategies to achieve the goal.
		*What prompts do the communication partners need to introduce?
		*What type of emotional language (label emotion-cause of the emotion-responses to emotion) could they add in their interactions with the child?
		*What type of partners' instruction could be beneficial to promote emotional competencies and communication about emotions with the child?
		*What behavioral responses could be helpful for them to learn?
		*What activities could be enjoyable and pleasant for the child and their communication partners to talk about emotions?
		*What communication partners' strategies could be beneficial to achieve the child's emotional goal?

The image on the left contains a template labeled:

CHALLENGES AND STRATEGIES
(About emotional development and communication)
GOAL:

E

CHILD'S CHALLENGES

COMMUNICATION PARTNERS'
CHALLENGES / GOALS

F

G

STRATEGIES TO ACHIEVE
CHILD'S GOAL

COMMUNICATION PARTNERS'
STRATEGIES

Made by
(Name)
(Credentials)
(Institution)
(Email)
(Date)

EDEC-P template developed by Rangel-Rodríguez, 2020

FIGURES

Figure 4-1. Suggested process for using the EDEC-P

Note. EDEC-P: Early Development of Emotional Competence Profile

My name is:
Amir A.

I am: 7 years old

About me

I'm happy, positive and in a good mood most of the time.

I prefer to be active and like to do different things, although I can't always because sometimes it can trigger spasms. At the beginning of a social interaction, I'm shy. I need time to get to know other people and gain confidence. I like to take my time meeting others. If you do something funny, I will probably start laughing.

I enjoy: watching cartoons, listening to stories, going out, playing, seeing and spending time with peers, getting attention from others and participating, laying in the sun near the lake, and funny things.

I don't like: when I stop an activity I enjoy (makes me SAD), seeing balloons and hearing them blast (makes me SCARED), when someone I know says bye (makes me SAD), when I hear someone talking about my discomforts, and when people don't ask my consent to: 1. use my belongings, 2. take pictures or videos of me (makes me ANGRY).

My favorite shows: Ellen scares videos and Curious George.

This data was reported by my mom

Ways people communicate with me:

- Yes / No questions
  - Do you want to play? / Do you want to go out? – I mean yes if I wink or smile.
- Two choices (using hands) so I can choose with my eyes -- but this (eye coordination) sometimes is still difficult for me when my body twists.

Current ways I use to communicate:

- *Eye blinking or gaze*
  - If I blink, I mean yes.
  - But sometimes eye coordination is difficult for me, mostly when my body twists.
- *Facial expressions:*
  - If I smile, I mean yes.
  - I express a lot with my face!
- *Vocalizations:*
  - Sometimes, I can shout if I want attention.
  - I sometimes cry if I don't like something.
  - I make sounds to interact with others.
  - I laugh a lot!

Emotions I express:

Frequently:
- Happiness/Joy
- Love
- Surprise
- Sadness
- Excitement

Sometimes:
- Anger
- Fear
- Disgust
- Disappointment
- Nervousness
- Irritation
- Boredom

Current ways I express my emotions:

- *Body postures* (even though it's not voluntary): If I love something or I'm surprised, I jump (e.g., if someone says my favorite cartoon, if my dad comes home).
- *Vocalizations:* I... shout, cry, laugh, make sounds (aaah).
- *Facial expressions:* I... smile, put my mouth down (when angry) and my face lights up.
- *AAC device:* I have access to vocabulary about emotions with my AAC device (tobii) but currently, I don't use it.

I recognize and respond to others' emotions by:

- Feeling the same: if someone is crying, I also express sadness. If someone is happy, I feel happy.

Current ways people respond when I express an emotion:

- They respond to emotion itself.
- They try to figure out what I could need and give it to me.
- They help me to feel better by playing songs I like, take me out from situations that makes me feel uncomfortable and making something fun so I can laugh

CHALLENGES AND STRATEGIES
(about emotional development and communication)
GOAL: Let's Talk About Emotions

CHILD'S CHALLENGES

- Emotional Learning:
  - name-reason-options to cope
- Increase vocabulary of emotions.
- Use of AAC Device.
- Increase ways to: name emotions, explain/ask what he needs or wants.

STRATEGIES TO ACHIEVE CHILD'S GOAL

- Ensure access to AAC device.
- Design optimal emotional boards.
- Reorganize emotional board (it is mixed with sensations, he doesn't use the one he has, we can reorganize it) and create new boards: causes and responses.
- Give opportunities to learn (storybook reading).

COMMUNICATION PARTNERS' CHALLENGES / GOALS

- Give opportunities to talk about emotions (name, reason and responses).
- Encourage participation: make questions, comments.
- Promote turn taking.
- Present meaningful opportunities for the child.
- Make the communication device accessible.
- Use the emotional communication boards.

COMMUNICATION PARTNERS' STRATEGIES

- Engage in communication partner instruction.
- Facilitate communication (give opportunities to talk (ask/comment - wait - give feedback) and make sure the AAC device has the options to respond.
- Offer the child time in order to promote turn taking.
- Create a fun environment.
- Model child's communication.
- Respect his needs and rights (ask consent to use his AAC device and explain why you respond to him in a specific way so he can understand).

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September 2019

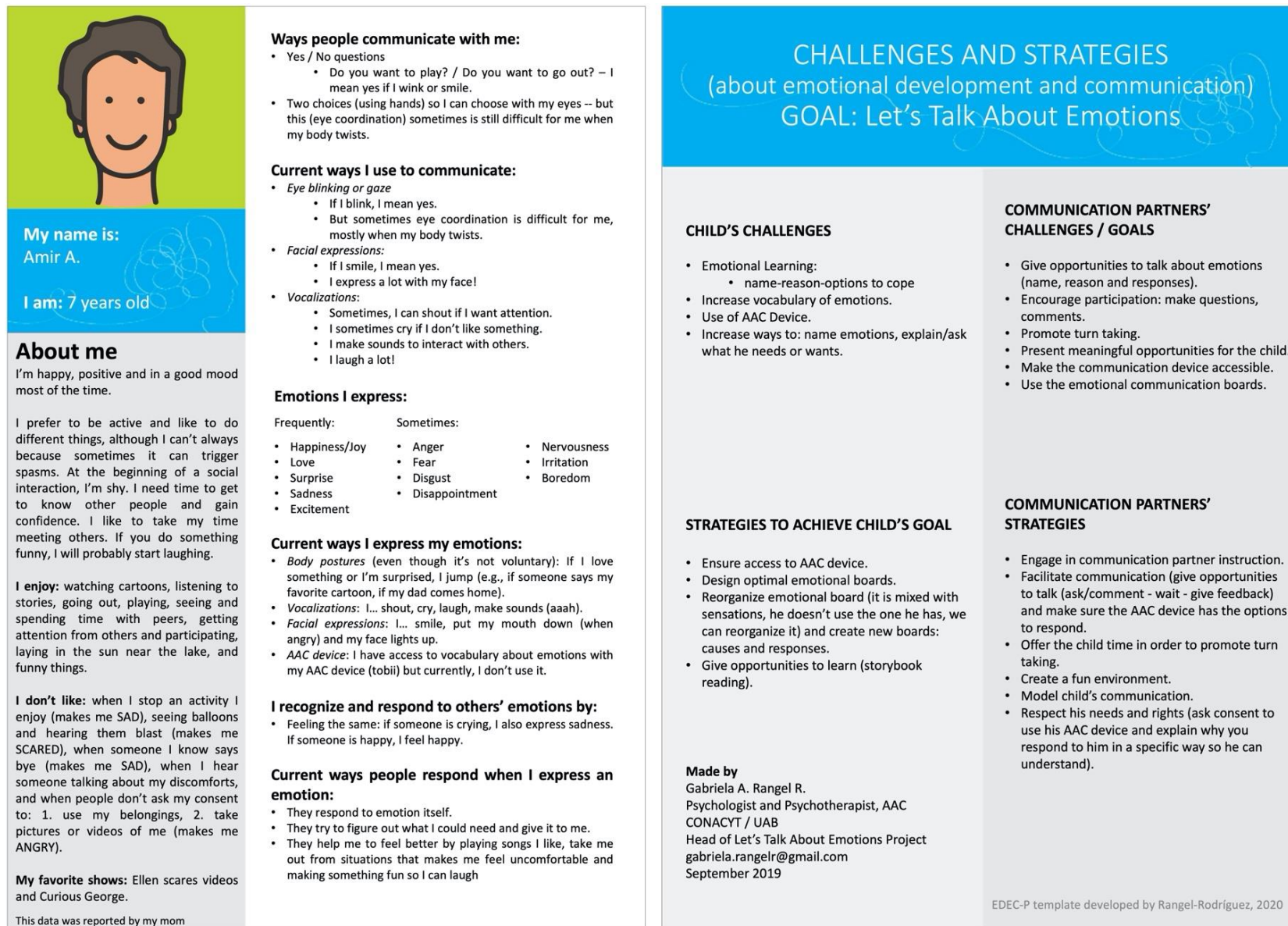EDEC-P template developed by Rangel-Rodríguez, 2020

Figure 4-2. Amir's Early Development of Emotional Competence Profile.
Note. AAC = augmentative and alternative communication. PCS and Boardmaker by Tobii Dynavox. All rights reserved. Used with permission.
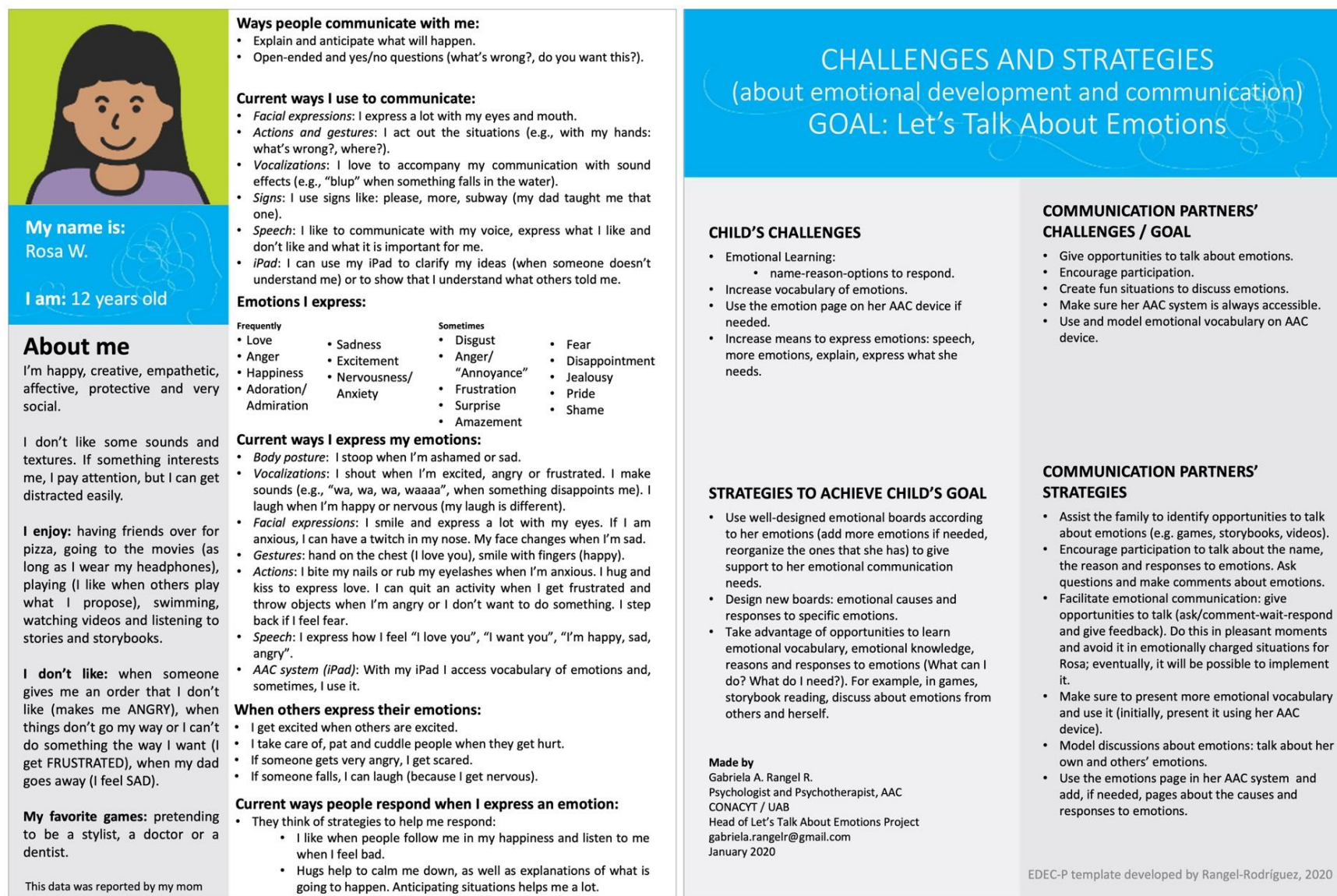
111

My name is: Rosa W.

I am: 12 years old

About me

I'm happy, creative, empathetic, affective, protective and very social.

I don't like some sounds and textures. If something interests me, I pay attention, but I can get distracted easily.

I enjoy: having friends over for pizza, going to the movies (as long as I wear my headphones), playing (I like when others play what I propose), swimming, watching videos and listening to stories and storybooks.

I don't like: when someone gives me an order that I don't like (makes me ANGRY), when things don't go my way or I can't do something the way I want (I get FRUSTRATED), when my dad goes away (I feel SAD).

My favorite games: pretending to be a stylist, a doctor or a dentist.

This data was reported by my mom

Ways people communicate with me:
- Explain and anticipate what will happen.
- Open-ended and yes/no questions (what's wrong?, do you want this?).

Current ways I use to communicate:
- *Facial expressions*: I express a lot with my eyes and mouth.
- *Actions and gestures*: I act out the situations (e.g., with my hands: what's wrong?, where?).
- *Vocalizations*: I love to accompany my communication with sound effects (e.g., "blup" when something falls in the water).
- *Signs*: I use signs like: please, more, subway (my dad taught me that one).
- *Speech*: I like to communicate with my voice, express what I like and don't like and what it is important for me.
- *iPad*: I can use my iPad to clarify my ideas (when someone doesn't understand me) or to show that I understand what others told me.

Emotions I express:

Frequently
- Love
- Anger
- Happiness
- Adoration/ Admiration
- Sadness
- Excitement
- Nervousness/ Anxiety

Sometimes
- Disgust
- Anger/ "Annoyance"
- Frustration
- Surprise
- Amazement
- Fear
- Disappointment
- Jealousy
- Pride
- Shame

Current ways I express my emotions:
- *Body posture*: I stoop when I'm ashamed or sad.
- *Vocalizations*: I shout when I'm excited, angry or frustrated. I make sounds (e.g., "wa, wa, wa, waaaa", when something disappoints me). I laugh when I'm happy or nervous (my laugh is different).
- *Facial expressions*: I smile and express a lot with my eyes. If I am anxious, I can have a twitch in my nose. My face changes when I'm sad.
- *Gestures*: hand on the chest (I love you), smile with fingers (happy).
- *Actions*: I bite my nails or rub my eyelashes when I'm anxious. I hug and kiss to express love. I can quit an activity when I get frustrated and throw objects when I'm angry or I don't want to do something. I step back if I feel fear.
- *Speech*: I express how I feel "I love you", "I want you", "I'm happy, sad, angry".
- *AAC system (iPad)*: With my iPad I access vocabulary of emotions and, sometimes, I use it.

When others express their emotions:
- I get excited when others are excited.
- I take care of, pat and cuddle people when they get hurt.
- If someone gets very angry, I get scared.
- If someone falls, I can laugh (because I get nervous).

Current ways people respond when I express an emotion:
- They think of strategies to help me respond:
  - I like when people follow me in my happiness and listen to me when I feel bad.
  - Hugs help to calm me down, as well as explanations of what is going to happen. Anticipating situations helps me a lot.

CHALLENGES AND STRATEGIES
(about emotional development and communication)
GOAL: Let's Talk About Emotions

CHILD'S CHALLENGES
- Emotional Learning:
  - name-reason-options to respond.
- Increase vocabulary of emotions.
- Use the emotion page on her AAC device if needed.
- Increase means to express emotions: speech, more emotions, explain, express what she needs.

STRATEGIES TO ACHIEVE CHILD'S GOAL
- Use well-designed emotional boards according to her emotions (add more emotions if needed, reorganize the ones that she has) to give support to her emotional communication needs.
- Design new boards: emotional causes and responses to specific emotions.
- Take advantage of opportunities to learn emotional vocabulary, emotional knowledge, reasons and responses to emotions (What can I do? What do I need?). For example, in games, storybook reading, discuss about emotions from others and herself.

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COMMUNICATION PARTNERS' CHALLENGES / GOAL
- Give opportunities to talk about emotions.
- Encourage participation.
- Create fun situations to discuss emotions.
- Make sure her AAC system is always accessible.
- Use and model emotional vocabulary on AAC device.

COMMUNICATION PARTNERS' STRATEGIES
- Assist the family to identify opportunities to talk about emotions (e.g. games, storybooks, videos).
- Encourage participation to talk about the name, the reason and responses to emotions. Ask questions and make comments about emotions.
- Facilitate emotional communication: give opportunities to talk (ask/comment-wait-respond and give feedback). Do this in pleasant moments and avoid it in emotionally charged situations for Rosa; eventually, it will be possible to implement it.
- Make sure to present more emotional vocabulary and use it (initially, present it using her AAC device).
- Model discussions about emotions: talk about her own and others' emotions.
- Use the emotions page in her AAC system and add, if needed, pages about the causes and responses to emotions.

EDEC-P template developed by Rangel-Rodríguez, 2020

Figure 4-3. Rosa's Early Development of Emotional Competence Profile.
Note. AAC = augmentative and alternative communication. PCS and Boardmaker by Tobii Dynavox. All rights reserved. Used with permission.

CHALLENGES AND STRATEGIES
(about emotional development and communication)
GOAL: Let's Talk About Emotions

CHILD'S CHALLENGES

- Learn about emotions and develop emotional and communicative competencies:
  - Discuss about name-reason-options to respond.
- Increase vocabulary of emotions and emotional knowledge.
- Increase the frequency of usage of the emotion page on her AAC device.
- Increase and learn other means to express emotions: speech, signs/gestures, AAC device.
- Explain, comment and talk about how she/others feel: What happened? Why? What does she need to feel better? How does she want to respond?

STRATEGIES TO ACHIEVE CHILD'S GOAL

- Facilitate proper emotional board use (adding more emotions if needed, reorganizing the ones that she has) to give support to her emotional communication needs.
- Design new boards: emotional causes and responses to specific emotions.
- Take advantage of opportunities to learn emotional vocabulary (How do you feel?), reasons (Why?) and responses to emotions (What can you do? What do you need?). For example, in games, storybook reading, discuss about emotions from others and herself.

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COMMUNICATION PARTNERS' CHALLENGES / GOAL

- Give opportunities to talk about emotions.
- Encourage participation.
- Create fun situations to discuss emotions.
- Make sure her AAC system is always accessible.
- Model communication about emotions using the emotions page in her AAC system.

COMMUNICATION PARTNERS' STRATEGIES

- Support the family to identify opportunities and include moments at home to talk about emotions (e.g. games, storybooks, videos).
- Encourage participation to talk about the name, the reason and responses to emotions.
- Facilitate communication about emotions: give opportunities to talk (ask/comment-wait-respond and give feedback). Start in pleasant moments. Eventually, implement it in emotionally charged situations (avoid at the beginning).
- Present and teach new vocabulary of emotions that are meaningful to the child.
- Model communication using her AAC device. For example, you can use her device to comment on how you feel or to give your opinion of how you think she or someone else feels.
- Use the emotions page in her AAC system and add, if needed, pages about the causes and responses to emotions.
- Help her to differentiate her own emotions from others.

EDEC-P template developed by Rangel-Rodríguez, 2020

Figure 4-4. Rosa's Early Development of Emotional Competence Profile (Challenges and Strategies section adjusted after discussing with the mother and Rosa's school and clinical team).
Note. AAC = augmentative and alternative communication.

SUPPLEMENTAL INFORMATION

Supplemental material[14]:

S1. Spanish version of the Early Development of Emotional Competence (EDEC)

S2. English version of the Early Development of Emotional Competence Profile (EDEC-P) template, letter size

S3. English version of the Early Development of Emotional Competence Profile (EDEC-P) template, A4 size

S4. Spanish version of the Early Development of Emotional Competence Profile (EDEC-P) template, letter size

S5. Spanish version of the Early Development of Emotional Competence Profile (EDEC-P) template, A4 size

S6. The EDEC-P Process (English version)[15]

S7. The EDEC-P Process (Spanish version)[16]

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[14] Todos los materiales suplementarios se encuentran en acceso abierto en https://doi.org/10.23641/asha.14219777

[15] Disponible en el anexo 4-2

[16] Disponible en el anexo 4-1

Capítulo 5

Estudio 3: Encouraging Emotional Conversations in Children with Complex Communication Needs: An Observational Case Study

Referencia:

Rangel-Rodríguez, G. A., Badia, M., y Blanch, S. (2021). Encouraging Emotional Conversations in Children With Complex Communication Needs: An Observational Case Study. *Frontiers in Psychology*, *12*, 674755. doi: 10.3389/FPSYG.2021.674755

Notas:

- El presente estudio muestra la versión aceptada. Se recomienda al lector revisar la versión publicada en: https://doi.org/10.3389/FPSYG.2021.674755
- Las tablas y figuras a las que hace referencia este artículo se pueden encontrar a partir de la página 157.
- Los materiales adicionales se encuentran en los anexos 5-1 a 5-3

Abstract

Children with complex communication needs (CCN) regularly have barriers to express and discuss emotions, and have fewer opportunities to participate in emotional conversations. The study explores and analyzes the changes after a training program focused on offering an interactive home learning environment that encouraged and modeled emotion-related conversations between a parent and a child with CCN within storybook-reading contexts. An observational design (nomothetic/follow-up/multidimensional) was used to explore and analyze the changes in the communicative interaction around emotions between mother-child. Augmentative and alternative communication (AAC) technologies were used to provide the child access to emotion-related vocabulary. The training program resulted in the mother providing more opportunities to engage her child in emotional conversations, suggesting that when opportunities and resources to talk about emotions were promoted, the child showed more engagement in emotion-related conversations using his AAC system. The mother-child communicative patterns and behavioral relationships observed during the phases are also presented. This case study illustrates the importance of a primary communication partners' role in facilitating emotional conversations, and the promising efficacy of a training program implemented in a storybook interactive learning environment to promote conversations about emotion-related events while encouraging children with CCN to learn, explore, express, and discuss emotions.

Keywords: emotion, complex communication needs, home reading, augmentative and alternative communication, interactive learning environments, emotional education, parent-child interaction, family.

1   Introduction

Communication and language are essential to understand, express, and adaptively regulate and respond to emotions. Children with complex communication needs (CNN) may have impairments in language production and/or comprehension (Beukelman & Light, 2020), resulting from different etiologies such as cerebral palsy, Down syndrome, developmental disabilities, or speech-language impairment. Recent studies have revealed some evidence that people with CCN often face barriers in expressing and/or understanding emotions, and may have fewer opportunities to talk and learn about emotions (Na & Wilkinson, 2018; Rangel-Rodríguez, Martín, et al., 2021; Wilkinson et al., 2021).

The literature has shown that learning to express and communicate emotions linguistically and appropriately (according to socio-cultural and family norms) is related to adaptive emotional-behavioral outcomes. As an illustration, individuals who are able to express their emotions linguistically (e.g., emotional vocabulary) are more likely to be aware of and recognize their own and others' emotions, exhibit less intense and sustained emotions, present more emotional management strategies, and display effective ways to self-advocate (Cole et al., 2010; Doyle & Lindquist, 2018; Roben et al., 2013; Test et al., 2005; Torre & Lieberman, 2018). Children with CCN often present some challenges in expressing emotions, not only via linguistic modes of communication (e.g., difficult to produce speech or to access vocabulary that enables them to understand and express emotions), but also in non-linguistic modalities (e.g., motor and/or sensory difficulties). Thus, their communication partners' may face difficulties in identifying, interpreting, and discussing emotions (Wilkinson et al., 2021) with a child and may over or underestimate the child's emotional experience (Reed et al., 2020). As a result, emotional learning for children with CCN can be challenging, restricted, or even ignored.

There is a significant body of evidence on the benefits of augmentative and alternative communication (AAC) in supporting the language and communicative development of children with CCN (Light & McNaughton, 2012). To have effective communication through AAC, it is critical to offer interactive and dialogic learning environments that support those who rely on AAC and their communication partners (Beukelman & Light, 2020; Dattilo & Camarata, 1991; Kent-Walsh & McNaughton, 2005; Ogletree et al., 2016). Dialogic and interactive learning environments must be created to maximize children's learning opportunities and outcomes (García-Carrión et al., 2018). In addition, encouraging conversations between children and communication partners provides opportunities to interact, express, and share thoughts, opinions, emotions, knowledge, as well as create new learning (Brinton & Fujiki, 2011; Rogoff, 1990; Vygotsky, 1962). Interactive learning environments that promote conversations are also beneficial for supporting social, emotional, and communicative learning outcomes for children with special needs (Fleury & Schwartz, 2017; John Mordechai Gottman et al., 1997; Jenkins et al., 2003; Schmidt & Stichter, 2012). However, research on the possible benefits of AAC strategies to support children's emotional development remains scarce (Wilkinson et al., 2021) and "desperately needs direct attention" (Na et al., 2016, p. 447).

Emotion talk refers to having conversations about emotion-related events. Emotional conversations are a medium to foster emotional learning, which means that children must understand words that describe emotions and also have access to emotion-related vocabulary. Through dialogue, communication partners can discuss and teach the language of emotions, and they can suggest strategies for managing and understanding emotional experiences (Aznar & Tenenbaum, 2013; Eisenberg et al., 1998; Eisenberg & Morris, 2003; Harris et al., 2018; Morris et al., 2007; Tenenbaum et al., 2008). Hence, children can learn skills such as recognizing and labeling emotions, comprehending their causes and

consequences, talking about them, and choosing appropriate ways to manage and respond to different emotions they and their partners experience (Beck et al., 2012; Saarni, 1999; Saarni et al., 2007). Suggestions have been proposed to design interventions that promote opportunities to have conversations about emotions with children who could benefit from AAC. Na et al. (2016) suggested that initially, communication about emotions should occur during an enjoyable and meaningful activity with the child (e.g., storybooks, videos, movies, games, role-playing, tv programs, morning conversations, etc.). Initiating emotional discussions amid a heightened emotional state (e.g., in the course of a temper-tantrum) is not ideal (Wilkinson et al., 2021). These assumptions are consistent with studies that indicate the importance of presenting a joyful and comfortable context in teaching practices and its positive relationship in facilitating students' learning (Bueno & Forés, 2018; Schutz & Lanehart, 2002; Willis, 2007).

Another key aspect for an effective interactive learning environment that supports the development of children with or without speech, language, or communication needs is the skills and performance of communication partners (Biggs et al., 2018; Brinton & Fujiki, 2011; Kent-Walsh et al., 2015; Mermelshtine, 2017; O'Neill et al., 2018; M. Romski et al., 2011). Partners must learn scaffolding strategies such as providing opportunities to talk and learn about emotions (making comments, asking questions, etc.), modeling the use of a child's communication system, and offering feedback (Na & Wilkinson, 2018; Wilkinson et al., 2021). Brinton and Fujiki (2011) illustrated the crucial role of communication partners' attitudes in children's development by pointing out that "emotion talk that is carefully constructed and timed to be most accessible to children can support the development of both emotional competence and social communication" (p. 271). The role of communication partners is essential to support children's socio-emotional and communicative learning.

Additionally, to promote conversations about emotions in children with CCN, it is essential to design AAC systems that provide significant emotional vocabulary and a diverse range of emotion-related communication tools that are culturally sensitive to the child and the family's linguistic and cultural context (Blackstone & Wilkins, 2009; Na, Wilkinson, Karny, et al., 2016; Wilkinson et al., 2021). For example, vocabulary that serves to explain why a person feels the way they feel (e.g., "I'm irritated because it's too noisy"), and some possible responses to those emotions (e.g., "I need a break and go somewhere else"). The AAC system must be functional for the child to communicate about emotions and useful for the child's partners to model emotional communication. Interviews can be critical to gather the information that guides intervention decisions that support communication about emotions. The Early Development of Emotional Competence (EDEC) is a semi-structured interview developed to meet this purpose (Na, Wilkinson, et al., 2018).

Evidence concerning the use of AAC systems in conversations about emotions provides some insight about the promising benefits of supporting children who have CCN. Na and Wilkinson (2018) developed the Strategies for Talking about Emotions as PartnerS (STEPS) program and examined it with three parents and their children with Down Syndrome, conducting a single-subject multiple-baseline across participants design. They selected storybook time as the context to foster conversations about emotions. Interactive storybook reading has the advantage of involving the child in an active role and provides a rich and natural setting for emotional and language development (Bedrosian, 1999; Drummond et al., 2014; LaForge et al., 2018). The STEPS program focused on supporting communication partners to implement communicative strategies for encouraging conversations about emotions with children with CCN. The STEPS training (see Na, 2015; Na & Wilkinson, 2018; Wilkinson et al., 2021) consists of three steps: Step 1: provide and model emotional vocabulary (label the emotion); Step 2: validate and discuss emotions (talk about the reason

for the emotion); Step 3: communicate about appropriate responses to emotions (talk about the possible responses/coping strategies to emotion). These steps, in combination with other communication partner strategies (e.g., ask, wait, provide feedback) and the design of emotional-communication boards resulted in parents providing more opportunities to discuss emotions using the AAC system, and the children increasing their utterances referring to emotions using different communication modes (including AAC). Even though further research is needed, the STEPS program appears to be a beneficial resource to initiate conversations about emotions with children who have CCN in natural settings.

Giving children with CCN access to key and meaningful emotion-related vocabulary, as well as encouraging its usage, is critical to support effective conversations between the children and their communication partners (Rangel-Rodríguez, Martín, et al., 2021; Wilkinson et al., 2021). Nuclear family members are life partners and the primary communication partners in the child's social networks (Blackstone & Hunt-Berg, 2012); its engagement in children's healthy development, learning, and emotional well-being are fundamental (Lehrl et al., 2020; Mandak et al., 2017). Therefore, families are certainly "children's first and most important teachers, advocates, and nurturers" (U.S. Department of Health and Human Services and U.S. Department of Education, 2016, p. 1). Supporting families in promoting learning environments is essential to aid children's learning (Lehrl et al., 2020) and thus reduce or prevent behavioral, social, or emotional conflicts in the future (Dishion et al., 2014; Sanders, 2008).

The current study describes and analyzes a program designed to increase and encourage conversations about emotions during a storybook reading activity with a child who has limited speech using a case study approach. The goal of the program is to facilitate interaction skills that encourage emotional talk. This study is part of a larger research project carried out by the first author.

2   Materials and Methods

2.1 Design

This study highlights the importance of the sociocultural context, communication, language, and experiences generated from the intervention, as well as examining the efficacy of the program through the behaviors of its participants in natural settings. Therefore, a paradigm that allows an integrative and complementary study was needed. A pragmatic epistemological framework and mixed-method approach were used to allow for the coexistence, integration, and/or combination of quantitative and qualitative elements in the study and enable the use of analytical techniques in either sequential or parallel phases (Anguera et al., 2020; Teddlie & Tashakkori, 2010). For the present study, an observational methodology was employed.

This case study was carried out by an observational design, which was configured based on three dichotomous criteria (Anguera & Izquierdo, 2006):

- Unit of study: one unit or individual (*idiographic*) or a group of units/participants (*nomothetic*) studied.

- Temporality: one session (*point*) or several sessions (*follow-up*) observed over time)

- Number of dimensions: one (*unidimensional*) or several (*multidimensional*) behaviors considered to study).

Hence, this study employed a nomothetic/follow-up/multidimensional observational design (N/F/M) for the following reasons:

- Nomothetic: a parallel and independent analysis of the behavior of the child and the mother was conducted.

- Follow-up: intra and inter-sessional recordings analyses between the 4 phases of the program (13 complete storybook reading sessions) from the collected data were performed.

- Multidimensional: several dimensions of interactive responses from the child and the adult in each session were recorded.

The observation was direct through video recordings of storybook reading sessions that the mother shared with the researcher, allowing the researcher full auditory and visual accessibility of the interaction.

2.2 Participants

A mother-child dyad participated in this study. They were recruited through convenience sampling. The inclusion criteria were 1) have a child who has functional hearing and vision per parent report and CCN, with previous or current exposure to aided AAC systems; 2) parents who have no speech, language, or hearing impairments; and 3) have an internet connection. The mother participated in the study and although the father could not participate, he was also interested in the study.

The mother was 44 years old, and the child was 7 years old. The child had a medical diagnosis of dyskinetic and dystonic cerebral palsy that affected the ability to control muscle movement, posture, and coordination; specifically, characterized by slow unintentional writhing movements (dyskinetic) and varying patterns of muscle tone (dystonia) (Center for Disease Control and Prevention (CDC), 2020). The child's speech intelligibility was severely impaired. The mother stated that her child "understands everything and can sound most of the words, but the sound level is very faint (lots of air in the sound)," so he also communicates via gestures (e.g., eyes up for yes, eyes down or stick his tongue out for no), facial expressions, and through an AAC electronic device. The child has used a speech-

generating device since he was 2 years old. Currently, he accesses his device through eye-gaze. The mother commented that he has functional hearing and vision level, uses glasses, and attends a 1st grade class in an mainstream school program.

Ethical approval was obtained from the Ethics Committee from the Autonomous University of Barcelona prior to starting the research.

2.3 Materials

Storybooks were selected for the program, specific materials were used to illustrate the training session conducted with the mother, and communication boards were designed in conjunction with the mother to provide the child access to emotion-related vocabulary.

2.3.1 Storybooks

The selected storybooks had to fulfill the following criteria: a) being an illustrated book, b) with text appropriate to the child's characteristics, interests, and cultural background, c) showing at least two different emotional categories (e.g., sad-happy), and (d) a length of at least 20 pages. The selection criteria taken was proposed by Na & Wilkinson (2018), who adapted the guidelines from Kent-Walsh et al. (2010).

2.3.2 Instruction session materials

2.3.2.1 STEPS Instruction Page

The STEPS instruction page contains a detailed description of each step proposed in the training to encourage communication about emotions during the storybook-reading activity (see supplementary material 5-1). The mother received a copy of the instruction page as support. This page was an adaptation of the handouts suggested by Na and Wilkinson (2018; Wilkinson et al., 2021), where suggestions to encourage mother-child communication were included.

2.3.2.2 Communication Board Design Page

To create communication boards that were culturally and family-appropriate, the researcher asked the mother to read the selected books and (a) choose the emotions with which she could feel comfortable talking with her son; (b) identify the causes for the emotion; and (c) propose possible responses or coping strategies to these emotions. The communication board design page contained a table to write the book page, the emotion selected to talk about, the trigger for that emotion, and the possible responses when that emotion appears.

2.3.2.3 Communication Board Example

According to the child's AAC communication, the clinician designed an example of pages to explain how the boards could be created in the child's current AAC system (see supplementary material 5-2).

2.3.2.4 Video-demonstrations of Storybook Reading Activity

Five short videos, around 1 minute each, were presented to the mother in the training session. Each video showed a role-playing situation between two individuals (one acting like a child and the other as a parent) in a storybook reading activity. Each video explained the different parts of the training.

2.3.3   Communication Boards

Once the mother filled in the material "communication board design page" for each book, suggestions were made by the researcher and agreed upon by the mother. The researcher then created the communication board pages using the child's communication system (Snap-Core First App, a system that permits dynamic display pages), and shared it with the mother. Vocabulary was added to the emotion page in his AAC system, as needed. Also, new communication pages were created throughout the program: (a) one page per book to talk about the possible causes of the emotion, and (b) one section with vocabulary to talk about possible responses to emotions. As the mother suggested new words that enabled her and

the child to discuss emotions, the child's access to emotion vocabulary grew. An example of the child's AAC emotion-related pages used is presented in figure 5-1.

2.4 Instruments

2.4.1 Observation Instrument

To analyze the data collected in an interactive natural context between communication partners and children with CCN, an observation tool was constructed *ad hoc* to fully adapt to the interests of the research (Anguera et al., 2021), based on the data obtained from preliminary interactions observed (fifteen mother-child with CCN dyads in a storybook-reading activity), and previous theoretical and empirical work (Girolametto et al., 2007; Girolametto & Weitzman, 2011; Kent-Walsh et al., 2010; Na & Wilkinson, 2018; Parish-Morris et al., 2013; Poyatos, 2015; Rowland, 2011). Therefore, the instrument combined a field format with category systems: "this combination is possible when some or all of the dimensions in the field format have a theoretical framework and the object of research is atemporal" (Anguera et al., 2018, p. 7).

The full-version observation instrument is presented as supplementary material 5-3. Figure 5-2 only presents the dimensions and units analyzed for the purposes of the present study, which includes 6 dimensions (out of the 15 dimensions included in the full-version) that allowed for the capturing of mother-child emotional interaction in the storybook reading activity.

2.4.2 Recording and Analysis Instruments

All the video-recording sessions were recorded and coded according to the full-version observation instrument using the software LINCE 1.4 (Gabin et al., 2012). The data obtained were time-based and concurrent, categorized as type IV; that is, "the observer notes the duration of events, but different events can overlap and occur together" (Bakeman, 1978, p. 65).

For data analysis, different software were employed: GSEQ 5.1 (Bakeman & Quera, 2011) to conduct the intra-observer reliability and lag-sequential analysis, HOISAN 1.6.3.3.6 (Hernández-Mendo et al., 2012) for the polar coordinate analysis, and the R program to obtain the graphic representation on polar coordinate analysis (Rodríguez-Medina et al., 2019).

2.5 Procedures

The study procedures consisted of an interview and exploratory observations of a video-recorded storybook reading activity at home, followed by a training session and post-observations of videorecords of the storybook interactive learning environment suggested during the program.

Once the mother and child were selected for participation, a semi-structured interview called EDEC, the Early Development of Emotional Competence tool (Na, Wilkinson, et al., 2018), was conducted between the researcher (the first author) and the mother. The purpose of the interview was to identify the current child's emotional state and communicative characteristics, as well as some caregivers' emotional and communicative socio-cultural aspects, in order to support the family better (Rangel-Rodríguez, Martín, et al., 2021). In this meeting, the researcher explained the study and the importance of recording the storybook reading sessions throughout their participation. The mother provided informed consent and agreed to participate in the study.

As part of the interview, the mother was asked to share her son's favorite storybooks. As the sessions progressed, other storybooks were suggested based on the research's criteria, family values, and the child's interests and preferences.

The training program was an adaptation of Na and Wilkinson's (2018) protocol and consisted of four phases (1. exploratory, 2. strategy implementation, 3. iteration, and 4. maintenance). One additional training session was carried out after the exploratory phase.

The book reading sessions in all phases took place in the participants' home and were video-recorded by the mother, who used her own videocamera device. The child was informed and agreed to be filmed too. Before the first recorded session, a filming tips handout was provided to ensure the whole interaction was captured. The filming tips were (a) use a room with good light and no noise; (b) leave the camera in a fixed place; (c) make sure to have enough memory on your card and enough battery; (d) in case of recording with a cellphone, turn off the mobile data to avoid calls or notifications while recording; and (e) verify the interaction scene is in focus. The mother shared the videos online with the researcher for later analysis and, depending on the program's phase, for providing feedback.

2.5.1 Exploratory phase

After the storybook selection, the mother was asked to record the storybook reading activity with her child in their home. The only instruction for this phase was: "read the storybook the way you always do with your child."

The mother sent a total of 7 videos in this phase. The first 4 videos were used to minimize reactivity bias, give a period for camera sensitization, and optimize recordings' quality (e.g., camera angles, background noise, etc.). These first four videos also served to identify behaviors that might contribute new categories in the observation instrument. The last three sessions were taken for analysis.

2.5.2 Online training session

One online training session was offered and lasted about 1 hour 20 minutes. Throughout the session, the clinician encouraged the mother to share her ideas, doubts, or questions. This session consisted into four stages presented below.

2.5.2.1 Conversation and commitment

The session started with a conversation about the interaction and emotional communication obtained through the EDEC interview and exploratory phase observations. In this stage, the

researcher promoted a discussion about the importance of emotional development and its relationship with language and communication, as well as the importance of fostering emotional learning by creating environments to talk about emotions, using the storybook reading activity as an opportunity to pursue this matter. The clinician also shared the purpose of the training session, which is to receive suggestions and strategies to implement in the storybook reading activity with her son to foster conversations about emotions that can continue supporting her child's emotional learning and development. The stage finished with asking the mother if she would like to commit to the training.

2.5.2.2 STEPS description

This stage aims to explain the Strategies for Talking about Emotions as Partners (STEPS) and their communicative components, including the design and use of AAC systems.

Graphic materials supported the training (see materials section) to explain the steps for fostering conversations about emotions (name-cause-response): 1. Discuss the name of the emotion, 2. Discuss the possible causes for that emotion, and 3. Discuss possible responses to the emotion. The communication strategies suggested that in each step (name-cause-response), the parent: a) Asks an open-ended question (e.g., How does Louis feel?), b) Waits for child's response (at least 5 seconds), and c) Responds and provides feedback using the child's communication system (e.g., "you're right, Louis needs to ask for help," selecting at the same time the words in his AAC device).

The researcher gave other types of suggestions to promote and model communication with the child. For instance, if the child does not respond after an open-ended question, provide a double-choice question by pointing to the word-choices in the child's communication system (e.g., "Do you think Louis is angry because his friends *went away* or because he *doesn't like Kelly*?"). If the child still does not answer, give the correct answer while modeling the communication using the child's device (e.g., "Louis is *angry* because he *doesn't like*

Kelly"). The researcher also encourages the mother to have the child's communication system available at all times during the session and make comments using the AAC device to model and encourage communication without requiring it.

Subsequently, an example of how to design an emotional communication board that includes the steps (label-cause-response) was presented (see materials section). It was explained that the vocabulary added in the communication boards must coincide with the vocabulary used in the family and child's context. Therefore, it is emphasized that it is of the utmost importance that the mother gets involved in the AAC board design, that is, to scan in the storybook selected, choose the situations to talk about, and write down the vocabulary she would like to discuss with her child (using a template to write it down according to the STEPS). The mother had the freedom to choose whatever emotion she would like, and in which she felt comfortable, to discuss with her son.

2.5.2.3 Strategy demonstration

After the STEPS description, short video demonstrations (see materials section) were presented with the purpose of modeling and illustrating the strategies presented. Discussions on the strategies were encouraged, and the researcher gave in-depth explanations about the interaction and strategies performance.

2.5.2.4 Verbal practice and feedback

The mother was asked to describe the three steps suggested for discussing emotions she just learned, including the communication strategies to encourage emotional conversations in children with CCN (ask, wait, respond, comment, model AAC). This stage aimed to affirm and ensure the mother's learning in the training session and give feedback.

2.5.2.5 Commitment to employing the strategy

At the end of the training session, the mother was asked if she would like to continue with the program and try the strategies. She responded, "yes, absolutely, it's really fascinating

and sounds so nice." Nevertheless, she expressed possible difficulties in having the time to make the activity and record it due to different family situations. The researcher commented that the program would adapt to their needs and family time (one of the benefits of using observational designs is its applicability in natural settings and everyday life). The mother agreed to fill in the communication board design page and sent it to the researcher. Moreover, once the pages were created, she could start implementing the strategies suggested.

2.5.3   Strategy implementation phase

Once the AAC pages were designed, and the mother was satisfied with them, the mother video-recorded four sessions of the storybook reading activity with her child while implementing the training session's strategies suggested. The researcher watched the recordings and gave feedback and suggestions. In this phase, the mother was also encouraged to ask questions and express her ideas about the mother-child interaction; the clinician offered a space for listening and addressing her needs, concerns, and thoughts. For example, in the beginning, she commented that it was awkward to discuss while reading "because that breaks the rhythm of the book."

2.5.4   Iteration phase

Three different storybooks were used in this phase. Therefore, new vocabulary, if needed, was added to the AAC pages. Three sessions of the storybook reading activity were recorded in this phase, and the mother was encouraged to continue fostering opportunities to talk and learn about emotions. The researcher gave less support; nevertheless, the mother was still encouraged to express her ideas, doubts, or questions about the interaction with her son. For example, she asked how she can encourage more discussions about her child's emotions during the storybook.

2.5.5 Maintenance Phase

The mother asked the child which storybook he would like to read, with the possibility of choosing all the storybooks used in the program. Three storybook-reading sessions were recorded. In the maintenance phase, the researcher did not give feedback about the participants' performance. The objective in this phase was to identify communicative changes generated by the program.

2.6 Data Quality Control

Before data analysis was carried out, a data quality control was performed through intra-observer agreement using GSEQ 5.1 software (Bakeman & Quera, 2011). The first author recoded fifteen percent of the sessions, with at least 3 weeks of difference between the first and second codification. Cohen's Kappa (J. Cohen, 1960) resulted in a satisfactory agreement average of 0.87. The sessions used for data quality control were selected randomly and using different extracts from different sessions from each of the phases in the program.

2.7 Data Analysis

A total of 13 storybook reading sessions held over a period of 11 months were analyzed. The average observation sessions lasted 18 minutes, 7 seconds. All videos were imported and coded through Lince software (Gabin et al., 2012). The first author observed and coded each of the behaviors included in the observation instrument. The coded data considered the frequency, order, and time of each behavior observed.

Two data analysis techniques were used: (1) lag-sequential analysis and (2) polar coordinate analysis. These techniques have proven efficacy in different research areas, including individuals with special needs, such as clinical psychology (Arias-Pujol & Anguera, 2020), education (Escolano-Pérez et al., 2019), communication (Rodríguez-Medina et al., 2018),

and AAC (File & Todman, 2002; Todman et al., 1994). Data were also analyzed descriptively (frequencies of communicative turns and emotional content in each phase).

2.7.1   Lag Sequential Analysis

This technique is used to identify how one or more behaviors work and presents, if any, a sequence of statistically significant actions (not due to chance) connected to specific given behaviors (i.e., the behavioral triggers that may initiate or promote a behavior pattern along time; Anguera et al., 2021; Bakeman & Quera, 2011). In other words, this analysis provides a measure of how likely is that one behavior (i.e., the "given" behavior) is followed by another (i.e., the "target" behavior(s)), either immediately (i.e., lag 1) or after two (i.e., lag 2) or more (i.e., lag 3, lag 4, etc.) successive behavioral events.

The analysis, adequate for the identification of patterns of social interactions, consists in proposing the given behavior(s), the conditioned or target behavior(s) (i.e., the actions that could be significantly associated with the given behavior), and the lag (i.e., the distances or place of order within the conditioned behavior in relationship with the presence of the given behavior). Once these criteria are defined and based on the given behavior, the matched frequencies are calculated, which is a parameter that is comprised of the number of times that a certain conditioned behavior appears before (if the lag is negative), after (if the lag is positive) or concurrently (if lag =0) with the specific given behavior. From the matched frequencies, the expected and conditional probabilities are calculated for each lag, and adjusted residuals are obtained (Allison & Liker, 1982), revealing the likelihood of occurrence/co-occurrence of each conditioned behavior in association with the given behavior. Z scores are statistically significant (p<0.05) for values > 1.96 (i.e., the association between behaviors is activated) or < -1.96 (i.e., the relationship is inhibited). To decide when the behavioral pattern ends conventionally, the following interpretative guidelines were considered (Anguera et al., 2021): (a) when there is an absence of statistically significant

behaviors in the lags; (b) when there are two successive empty lags; or (c) when in two consecutive lags, various statistically significant behaviors appeared, if so, the first of these lags is defined as the MAX LAG. Considering these guidelines are only recommendations (not compulsory criteria), when various statistically significant behaviors appear, but the significant lags after the MAX LAG were considered illustrative in understanding the mother-child communicative sequences, it was decided to incorporate the subsequent lags' significant behaviors.

The mother's communicative behaviors concerned with implementing the strategies suggested in the training session were selected as the given behaviors. Hence, the mother's behaviors related to asking open-ended questions, waiting, giving the answer, providing feedback, and making comments were considered to be of special interest. Both responses from the child and mother were chosen as the conditional behaviors to identify significant interactive patterns during the conversation about emotions. A particular interest in the analysis was the child's behaviors in discussing emotions: answering, making comments, and asking questions. The analysis only deemed the units from the observational instrument with a frequency > 4 at least in one of the phases. Values lower than 5 are considered not significant in observational methodology (Sackett, 1980).

The search for associations between the given and the conditional behaviors was made prospectively (lag 1 to lag 5) and retrospectively (lag -1 to lag -5). Concerning the retrospective analysis, only the given behaviors expected, in theory, to be the next part of a conversational sequence already begun (e.g., providing feedback, giving the answer) are presented in the results section. The child and mother's utterances and their simultaneity with the type of emotional content discussed and method of expression were also analyzed (in lag 0). The lag-sequential analysis was applied to each of the program phases to identify communicative patterns among them.

2.7.2   Polar Coordinate Analysis

Polar coordinate analysis (Sackett, 1980) is performed to identify a representative map that explains the type of relationship between a focal behavior (i.e., the behavior of interest) and the selected conditioned behaviors (i.e., actions that could be associated with the focal behavior). This technique employs the adjusted residual values obtained in the lag sequential analysis. It integrates both prospective (e.g., lag 0 to +5) and retrospective (e.g., lag 0 to -5) perspectives, which are used to calculate the Zsum scores (prospective and retrospective), as well as the vectors (length and angle) for each conditioned behavior. For this analysis, the genuine retrospectivity proposed by Anguera (1997) was used. Each conditioned behavior can be represented graphically; depending on the quadrant in which the vector is located, the relationship between the focal and conditioned behavior is interpreted (activation vs. inhibition):

- Quadrant I: Both behaviors (focal and conditioned) are mutually activated (prospective and retrospectively).

- Quadrant II: The focal behavior inhibits the conditioned behavior, whereas the conditioned behavior activates the focal one (prospective inhibition/retrospective activation).

- Quadrant III: The focal and conditioned behaviors are mutually inhibited (prospective and retrospective inhibition)

- Quadrant IV: The focal behavior activates the conditioned behavior, whereas the conditioned inhibits the focal one (prospective activation/retrospective inhibition)

The behaviors that were suggested to be implemented in the training session to the mother, and that showed a frequency >4 at least in one of the phases, were identified as the focal behavior: ask, make comments, respond, model AAC communication; while the child's

communicative behaviors: answers, makes comments, asks questions, expressing with conventional gestures or AAC were selected as the conditioned ones.

2.8 Social Validation

Mother and child satisfaction surveys were completed at the end of the maintenance phase to evaluate the program's social validity. The questionnaire included multiple-choice and open-ended questions about their ideas and opinions about the program's process and participation. The child answered with his AAC device.

3 Results

3.1 Development of emotion-related conversations

Figures 5-3 and 5-4 illustrate the interactive communication progress (frequencies) per phase, between the mother and her child, regarding their participation and emotional content discussed (emotional label, causes, and responses to emotions) in the storybook-reading activity. It can be noticed that in the exploratory phase, there is little stimulation in both participants about having an emotional talk. The sessions that followed the training session showed maintained progress by both the child and mother, concerning their active participation in conversations about emotions.

To examine the participants' utterances in conversations about emotions, the type of emotional content (i.e., emotion label, cause, response), ways of expression (i.e., method of expression in the child and communication model in the adult), and to whom the emotional discussion was addressed (i.e., the child, storybook characters, or other people), a lag sequential analysis was performed in lag 0. Lag 0 indicates a simultaneous appearance of the selected behaviors. The results revealed highly significant concurrences (>1.96, $p<0.01$) between these dimensions (figure 5-5), demonstrating that discussions richer in emotion-related content and about different referents appeared as conversations developed over time. Additionally, it is noticeable that, after the training session, the mother showed AAC models

while commenting about emotions, and the child participated in emotional discussions using his AAC and conventional gestures.

The exploratory phase was characterized by the child's gestural responses to the mother's questions about the emotional label from the storybook's characters and the child. After the training session, the mother and his child showed engagement in discussions related to more than just labeling emotions (they discuss the reason and responses to emotions) about the storybook and the child. In the iteration and maintenance phases, the child's interest in asking questions about emotions referring to himself (e.g., what can I do?) and his mother (e.g., how do you feel?) emerged.

3.2 Behavioral sequential patterns of mother-child interaction when fostering conversations about emotions

Figures 5-6 to 5-8 present the statistically significant sequential communicative patterns related to the dyad interaction during the storybook-reading activity in each phase. Only the patterns that showed activation (i.e., $Z > 1.96$, $p < .05$) between the given (the mother's behaviors that encourage emotional conversations) and conditioned behaviors (the child's behaviors in emotional conversations, as well as the mother's behaviors that encourage emotion-related conversations) are presented.

3.2.1   Encouraging child's participation openly

Even though the closed-ended questions were not part of the training sessions' suggestions, it was considered important to present them in the results section as closed-ended questions are part of the communication flow during any conversation. Yes-no questions about emotion-related events were followed by a stable behavior pattern of the child's response, succeeded by another mother's query in all of the phases (figure 5-6). One exception to this appeared in the implementation phase, which was followed by the mother's feedback and then another closed-ended question or comment about emotions. In the exploratory phase,

the mother showed a pattern of asking more than one closed-ended question at a time, followed by the child's response. A significant change in the pattern was shown in the maintenance phase where the child, after a second closed-ended question, tended to respond with also a spontaneous comment:

> [Talking about character's feelings]
> M: Mmm, I wonder why, do you know why?
> C: Stick tongue [gesture for no]
> M: Or do you think he is gonna be angry?
> C: Looks up [gesture for yes], confused [selected via AAC]
> M: Yes, and he is confused.

A considerable difference before and after the training session can be seen when the mother asked emotion-related open-ended questions (figure 5-6). In the exploratory phase, even though the mother asked open-ended questions, it was immediately followed by a closed-ended question (e.g., What do you do when you are scared? Can I see a face that you think is scared?). Nevertheless, in the phases following the training session, significant combinations of conversational turns about emotions were observed when the mother asked an open-ended question: 1. the child engaged actively in the conversation by responding (answers), and this behavior was followed by the mother's feedback; 2. The mother, after questioning, answers immediately, and 3. Repeats the question, which in turn could finish the sequence with the child's response. The following clinical vignette, taken from the implementation phase, demonstrates the first sequence explained above:

> M: So, when somebody is so sad, what they can do?
> C: Need a hug [AAC]
> M: Oh, need a hug, yes, he was so sad that he needs a hug, ok.

An example of the behavioral sequence of open-ended question – mother's comment – repeat question – child answers observed in the iteration phase would be:

> M: And when you feel stressed, what should you do?
> M: Cause when you feel stressed your body tenses up
> M: So, if you feel stressed, what should you do?
> C: [child smiles] Cheer up mate! play [AAC]
> M: Oh, I know, you want someone that says cheer up! And you wanna play.

3.2.2 Answering and giving feedback

Answering and giving feedback are behaviors expected to be contingent on previous actions; thus, significant behavioral patterns observations from the retrospective (e.g., lag -1 to -5) and prospective (lag + 1 to 5) analysis were included in this section (figure 5-7).

Feedback providing utterances significantly changed and were maintained after the training session. In the exploratory phase, this behavior related to emotional content was not observed, whereas in subsequent phases it was preceded by the child's emotional comments and responses, and feedback, in turn, activated another child's emotional comments:

> [Discussing character's emotions]
> C: Overwhelmed
> M: Overwhelmed, yes, it's too much [for the character]
> C: Surprise
> M: Yes, he is probably surprised, because he lost his M.

In other cases, offering feedback activated another mother's query or emotional comment (the mother's comment was only significant in the implementation phase).

The mother's expression of answering her questions was not directly associated with the child's response, neither retrospectively nor prospectively. In phases 3 and 4, after the mother answered, she made another open-ended question encouraging the child's conversation:

> [discussing storybook]
> M: They were what?
> M: Maybe there is not an emotion, but they were safe
> C: Looks up [gesture for yes]
> M: So, they are now rescued. How do you think they felt?
> C: Glad, happy [AAC]
> M: Absolutely, yes, that's great. So, they were so happy now because they were safe.

3.2.3 Commenting to encourage child's participation

The mother's emotional comments were observed in all phases (figure 5-8), with a simultaneous mother's use of AAC in the phases after the training session (remember lag 0, figure 5-3). During the phases 1 and 2, the mother's personal comments about emotions were not prospectively associated with a significant child's communicative behavior, whereas, by phases 3 and 4, the mother's emotional opinions were followed by the child's comments about emotion-related events:

> [Talking about what the child can do when he feels sad because his body tenses up]
> M: Maybe you can "wait" [AAC] a little bit and "breathe" [AAC]
> C: Try again [AAC]
> M: Yes, you can also try again.

In phases 3 and 4, the mother's emotional comments were significantly preceded by child's questions:

> [Talking about what can the child do if he were the book's character]
> M: What can you do?
> C: I need a break [AAC]
> M: Yes, sure, you will need a break from all these crayons
> C: What would you do? [AAC]
> M: If I were him, I would say, "good job" guys, "thank you" for your service, and then I will say I will "think of a strategy" [AAC].

3.3 Relationships between mother-child interactive communication about emotions

Figures 5-9 to 5-14 show the vectorial graphs from the polar coordinate analysis in each phase. Those graphs present the relationships between mother-child interactive emotion-related conversations. Behaviors taken as focal were mother's closed-ended question, open-ended question, multimodal feedback, give answer, emotional comment, and AAC model. The child's answers, comments, questions, and modes of expression were selected as the conditioned behaviors. In this section, only the vectors with significant results will be discussed (i.e., with a length > 1.96, $p < 0.05$, are represented in purple; vectors with a length > 2.58, $p < 0.01$ are represented in red). Vectors in blue are not significant.

3.3.1 Mother's questions and child's engagement in conversations

Similar to what was found in the lag-sequential analysis, figure 5-9 shows the significant stable mutual activation (Quadrant I) in all of the program phases between the mother's closed-ended questions and the child's answers through gestures. The child's AAC mode of expression in the maintenance phase was also significant and located in quadrant II, indicating that closed-ended questions inhibit the child's use of AAC, whereas this expression activates mother's closed-ended questions.

Concerning open-ended questions (figure 5-10), a stable mutual stimulation with the child's emotion-related answers was identified during all of the phases. Nevertheless, changes were found in terms of the child's modes of expression. In the exploratory phase, the mother's open-ended questions inhibit the child's gestures, but this behavior, in turn, activates the mother's questioning. A different pattern was observed after the training session, where the child's AAC use mutually activate the mother's open-ended questions in phase 2 and 4. In contrast, in phase 3, the child's AAC use is situated in quadrant IV, indicating that the mother's open-ended questions activate the child's AAC expressions, but the AAC use inhibits the mother's open-ended questioning.

3.3.2 Mother's emotional comments and child's engagement in conversations

No relationship was found in the exploratory phase between the mother's emotional comments and the child's behaviors (figure 5-11). Phase 2 presented a mutual excitatory association between the mother's comments and the child's emotional comments. However, in phase 3, the reciprocal activation was between the mother's comments and the child's questioning. By phase 4, this communicative link changed to quadrant II, implying that the child's inquiry about emotions stimulates the mother's comments but not vice versa. A similar relationship was observed with the child's gestures (quadrant II) in phases 3 and 4; that is, the mother's comments inhibit the child's gestures, but those gestures activate the

mother's comments. Finally, the AAC child's mode of expression was significantly associated with the mother's comments in the iteration phase (quadrant IV), where the focal behavior stimulates the child's AAC use but not conversely.

3.3.3 Mother's feedback/answer and child's engagement in conversations

A significant relationship was found between the mother's multimodal feedback and the child's behaviors after the training session (figure 5-12). Feedback was strongly mutually activated with the child's emotional comments in all phases, and with the child's responses to questions in phases 2 and 4. In phase 3, the mother's feedback inhibited the child's answers, but this response activated the mother's feedback.

Concerning the mother's answering of her questions (figure 5-13), in phase 2, the child's AAC use and the mother's giving the answer inhibited each other (Quadrant III). At the same time, the child's gestures activated the mother's giving the answer (a similar association was also observed in phase 3). In addition, significant excitatory association was noted in the iteration phase between the child's response and the mother's answering. Phase 4 did not present a significant relationship between the focal behavior and the child's behaviors or expression methods.

3.3.4 Mother's AAC modeling and child's engagement in conversations

In the exploratory phase, no AAC model was presented (figure 5-14). Nevertheless, in the implementation phase, the mother's use of AAC, while discussing emotions, involved mutual activation with the child's gestures and prospective activation with the child's emotional answers to the mother's questions.

By the iteration phase, modeling AAC showed a reciprocal activation with the child's answers, questions, and AAC use to communicate emotion-related events; and a unilateral activation with the child's comments. However, these relationships were not sustained in the maintenance phase. It was observed that the child's questions stimulated the mother's AAC

model, and the mother's AAC model activated her child's AAC use, but none of them conversely.

3.4 Mother-Child Social Validation

A written satisfaction survey was sent to the mother and her child by the end of the maintenance phase to evaluate the training and program's social validity.

The mother expressed feeling extremely satisfied with the support provided during the program and considered it helpful and very easy to learn emotional communication strategies. She commented that participating taught her:

> how to have a deeper conversation with my son. To be mindful of the characters in the books and use them as a tool to talk to my son (…) this [the emotion communication strategy learned] enables otherwise a superficial, two-dimensional conversation to be more interesting. I got to learn more about how my son feels. (…) Got to understand more about the importance of discussing the emotions and how to deal with the emotions. (…) [the "how to respond" page] has helped my son to also think deeper. [this program] opens up many more opportunities to use AAC and talk about more abstract issues (not just factual questions).

The child indicated that he enjoys talking about emotions in the storybook reading activity "a lot" and that he learned something new about emotions: "(I learned) to ask questions like How are you? To answer like fantastic. To communicate". He also shared that he "absolutely" likes to talk with his mom using his AAC device, and what he likes the most about the emotion-related AAC pages is "to be able to express I like, I love," whereas what he like the least was "dizzy – too many choices." When asked to complete the sentence "I want to say that…", he commented, "Ready and sharing - Enjoyed".

4 Discussion

The present study highlights the importance and promising implications of providing interactive learning experiences in natural settings to encourage emotional conversations in children with CCN. Similar to the findings presented by Na & Wilkinson (2018),

participating in the program resulted in improvement in the communicative exchanges between mother-child about emotion-related events.

During the exploratory phase, the child rarely had opportunities to discuss emotions, and his participation was mainly summarized in answering yes/no questions. Although the mother occasionally promoted a richer emotional discussion (asking open-ended questions), this was followed by a closed-ended question. Research has shown that asymmetries between discourse patterns between partner-individual with CCN are frequently expected (Todman et al., 1994) and that there is a tendency to engage individuals with CCN through yes/no questions in communicative exchanges as it speeds up the interaction. Nevertheless, asking closed-ended questions limits their experience and opportunities to learn, discuss and interact actively (Beukelman & Light, 2020; Light et al., 1985).

After the training session, a considerable improvement in the child and mother's utterances and communicative patterns was observed. The mother's prompts to encourage the child's involvement in conversations about emotions, as well as the proper culturally sensitive AAC system design, facilitated the child's active participation during the storybook-reading activity. The availability of emotion-related vocabulary contributed to the child's ability to sustain and start conversations about emotions. The behavioral patterns obtained permitted analyzing the communicative change over time between mother-child emotional conversations. Maintaining the mother's prompting to foster emotional talk helped increase the child's conversational contributions substantially in terms of making spontaneous comments rather than just responding to questions, asking questions about emotion-related events to others, and talking about himself rather than only the storybook's characters.

The analysis carried out allowed for the identification of what types of the mother's behavior encourage or inhibit particular behaviors by the child. For example, it was noticeable how the conversational sequence and relationship with the child's behavior changed during the

program phases around the mother's emotional comments. Even though the mother made emotional comments during the exploratory phase, the child did not show any conversational response. In contrast, in the following phases, when she commented about emotions, concurrently with modeling the use of AAC, the child showed interactive behaviors that were significantly connected to that mother's prompt. These findings are consistent with the literature that highlights the importance of supporting communication partners in providing models and opportunities, deliberately, to foster interaction and development of emotional and communicative competencies in individuals with CCN (Biggs et al., 2018; O'Neill et al., 2018; Wilkinson et al., 2021).

The present case study sheds light on the promising efficacy of supporting communication partners online in creating interactive learning environments at home to encourage emotional and communication skills to discuss emotions, while respecting the family conditions and cultural background. At the beginning of the program, the mother expressed some concerns about engaging in the intervention due to specific family situations and difficulties in having the time to make the activity and record it. Despite the family time barriers to engaging in the program within a brief period (e.g., less than three months as in Na & Wilkinson (2018)'s multiple-baseline research design), the intervention still showed positive results. Sometimes, family effective engagement in interventions may be hindered by logistical barriers like parents' work schedules (Brotman et al., 2011). Being flexible to the context and understanding the child with CCN, family, and socio-cultural needs and interests are essential in creating appropriate and sensitive interventions that support children's learning (Rangel-Rodríguez, Martín, et al., 2021). Systematic observation approaches provide the flexibility needed to studying natural settings and everyday life without losing rigor in the investigation (Anguera et al., 2018).

An evident drawback of the study was the limited number of participants. However, the observational methodology employed in the present study allows intensive research, being inversely related to the extensiveness required by other methodologies. Moreover, single case studies are the best path to follow when the topic to be studied is emerging (Swanborn, 2010). The analysis used illustrates a novel approach for conducting single case studies in the field of communication (including AAC), psychology, and education. Polar coordinate analysis and lag sequential analysis provide an innovative way to model the conversational pathways that change over time after an intervention in everyday contexts. These analyses offer information on the relationship and sequences between behaviors that cannot be understood through other conventional analyses, such as those that measure the frequency of appearance of a target behavior.

Further research is needed to continue validating the intervention and involving more children with CCN, from different socio-cultural backgrounds and linguistic levels. Additional work is warranted to identify the generalization of the emotion conversational abilities obtained in other settings outside the storybook-reading activity. The mother commented they had conversations about emotion-related events outside the storybook-reading sessions, where the child accessed his AAC emotional communication pages to discuss specific events. Further studies are relevant to adapt the program in other contexts, such as including both parents, siblings, or group settings (e.g., at school, group therapy); and in other activities, such as role-playing, watching movies or series, playing games, etc. To sum up, significant communicative changes between the mother and child occurred in the interaction when the mother encouraged opportunities to discuss emotions in a storybook-reading activity. The present findings support the promising outlook of providing interactive home learning environments to foster emotional talk in children with CCN who may benefit from AAC.

5   Data Availability Statement

The datasets generated for this study are available on request to the corresponding author.

6   Ethics Statement

The study was reviewed and approved by the Ethics Committee of the Universitat Autònoma de Barcelona. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

7   Author Contributions

GAR-R documented, designed, developed the project, carried out the study, and wrote the manuscript. MB and SB made direct contributions to the work, revised the manuscript, and approved it for publication.

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11 Tables and Figures

Figure 5-1. Example of Emotion Communication Dynamic Display Page [emotions, causes, and responses to emotions].

Note. The Picture Communication Symbol® and Boardmaker by Tobii Dynavox® All Rights Reserved. Used with permission.

Macro-dimension	Dimension	Subdimension/Units (codes)/Examples
Adult's Interactive Communication	Behaviors that encourage emotional conversations	Encourages participation openly*
		closed-ended question (acEQ): Do you think he is sad?
		open-ended question (aoEQ): Why is she angry?
		two choices (aETC): Do you think the wizard is scared or surprised?
		sentence completion (aESC): The mouse feels excited because…
		multiple choices (aMC): does the horse need to take a break, ask for help, or explain how he/she feels?
		repeat question (aREQ)
		Turn-taking signal *
		indirect turn (IT): waits for response
		direct turn (DT): it's your turn
		Responds/gives feedback*
		multimodal feedback (aFB): you are right, the monster feels happy
		non-verbal feedback (anvFB): looks at the child, smiles, nods
		give answer (aEAns): they feel disappointed because…
		Encourages participation without requiring it*
		Emotional comment (aEPC): I think the child feels ashamed because he is naked. (includes comments that respond to child's questions)
	Behaviors that model emotional communication	AAC model (aAACE): model the AAC use (select words in the child's system)
		Gestures/Signs
		manual signs model (aEMS): "love" with manual signs.
		emotional gesture model (aEG): surprised face
	Conversational emotion-related content*	Emotional content
		label (AECn): how do you feel? / she is scared
		reason (AECca): why he feels sad? / she feels sad because…
		responses/coping strategies (AECrs): what can he do? / he needs a hug
		unspecific label (AECun): he feels good/bad, I'm ok.
		Related to
		storybook character (aECS): the dragon feels lonely…
		child (aECC): how would you [the child] feel? what would you do?
		another person/situation (aECO): I [the mother] would do… I think your father will prefer to take a break.
Child's interactive communication	Methods of expression*	Augmentative and Alternative Communication (cAACE)
		Auditory perceptible
		vocal (cVB)
		speech (cS)
		word approximation (cWA)
		Visually perceptible
		body movement (cBM): move head, change posture, etc.
		action (cACT): run, jump, take something.
		manual signs (cMS): sign language
		pointing (cP)
		conventional gestures (cCG): gestures defined by the child's context with the intention to communicate (e.g., look up for yes, look down for no)
		facial expressions (cFE): smiles.
		emotional gestures (cEG): lips down for sad, crossing arms to express anger.
	Behaviors in social interactions (conversations about emotions)	Answers/gives information (cEAnsw): if questioned, the child responds, she is angry
		Asks questions (cEQue): how do you feel? What would you do?
		Comments (cEComm): she needs to breathe
	Conversational emotion-related content*	Emotional content
		label (CECn): angry, sad, happy, excited
		reason (CECca): the witch doesn't have friends; the girl receives a present
		responses/coping strategies (CECrs): the little prince needs to express his feelings
		unspecific label (CECun): good, bad, ok, well
		Related to
		storybook character (cECS): the penguin felt angry
		child (cECC): I would feel happy; I don't like that book
		another person/situation (cECO): my friend would feel ashamed

*category systems

Figure 5-2. Observation Instrument.
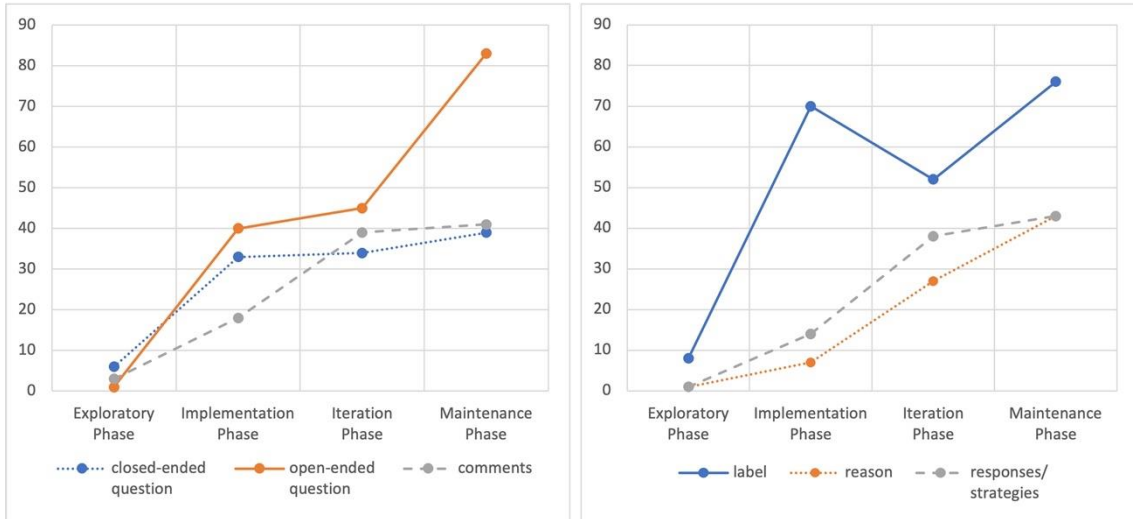
Figure 5-3. Development of the mother's conversational utterances about emotions [closed-ended questions, open-ended question, comments] and type of emotional content discussed [label, reason, and responses to emotion].
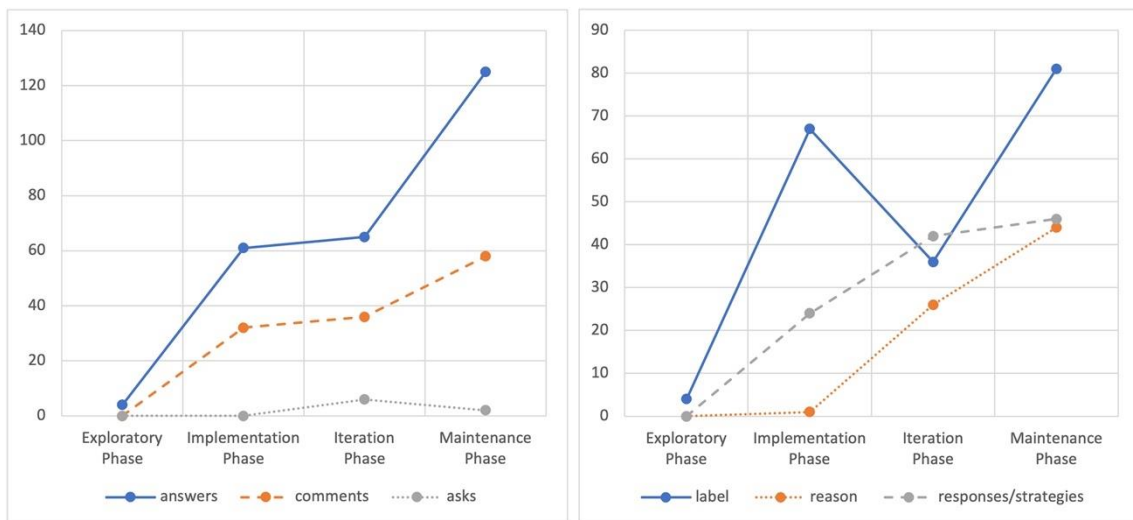
Figure 5-4. Development of the child's conversational utterances about emotions [answers, asks questions, comments] and type of emotional content discussed [label, reason, and responses to emotion].

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Child's Interactive Communication (concurrences)		Target							
		Method of Expression		Conversational Emotion-Related Content			Discussion related to		
	Given	AAC	conv. gestures	label	reason	response/ strategies	book character	the child	other person
Exploratory Phase	answers		11.19	41.56			25.41	32.83	
	asks								
	comments								
Implementation Phase	answers	37.73	13.11	41.08	5.39	16.22	36.53	19.87	
	asks								
	comments	44.18		26.15		35.43	29.18	30	
Iteration Phase	answers	32.77	15.74	28.85	23.96	17.96	32.55	24.84	
	asks	12.34		9.01	2.16	6.74		3.74	46.91
	comments	34.11	6.49	6.63	12.98	35.53	28.79	20.02	
Maintenance Phase	answers	53.80	13.08	35.95	32.07	30.12	42.65	37.01	2.07
	asks	5.01		3.57		4.38			35.36
	comments	27.30	13.81	18.58	17.13	14.79	29.67	19.83	8.07

Mother's Interactive Communication (concurrences)		Target							
		Communication Model		Conversational Emotion-Related Content			Discussion related to		
	Given	AAC	gestures	label	reason	response/ strategies	book character	the child	other person
Exploratory Phase	closed-ended q.			32.34			19.66	23.46	
	open-ended q.					41.56		20.74	
	comments			15.13	25.41		26.19		
Implementation Phase	closed-ended q.	6.68		25.65			22.17	6.75	
	open-ended q.			19.83		21.93	23.68	15.04	
	comments	24.95		10.44	16.87	15.78	21.13	6.79	
Iteration Phase	closed-ended q.	6.75		7.67	8.75	6.14	6.75	15.25	
	open-ended q.			22.60	7.34	11.29	19.51	19.43	
	comments	34.50		13.74	15.20	9.68	17.30	2.41	27.74
Maintenance Phase	closed-ended q.			11.15	2.57	9.99	9.62	13.59	
	open-ended q.			23.15	22.27	15.62	31.76	22.64	
	comments	34.30	2.35	17.98	10.23	11.97	16.05		40.01

Figure 5-5. Adjusted residuals showing significant concurrences (lag 0) between emotional conversations utterances from the mother and child, and their modes of expression, and type of emotional content discuss (content and related to).
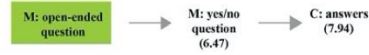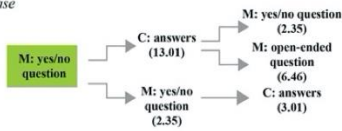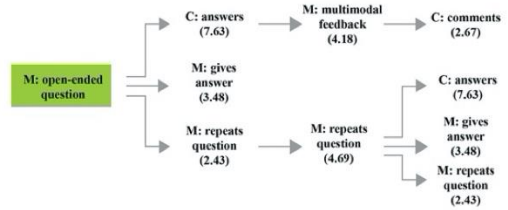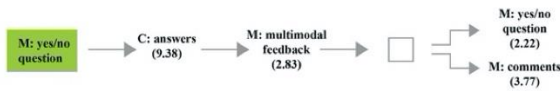
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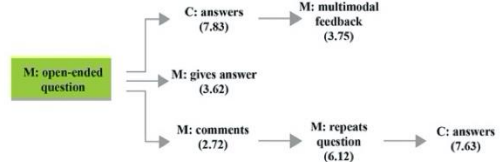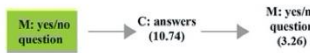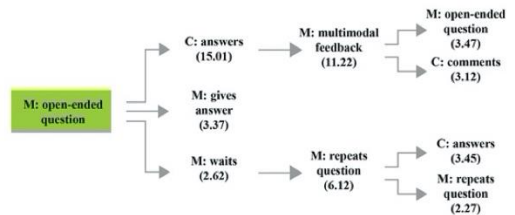
Figure 5-6. Sequential communicative patterns obtain in each phase during the storybook reading with the mother's closed-ended and open-ended emotion-related questions as given behavior [M: Mother, C: Child].
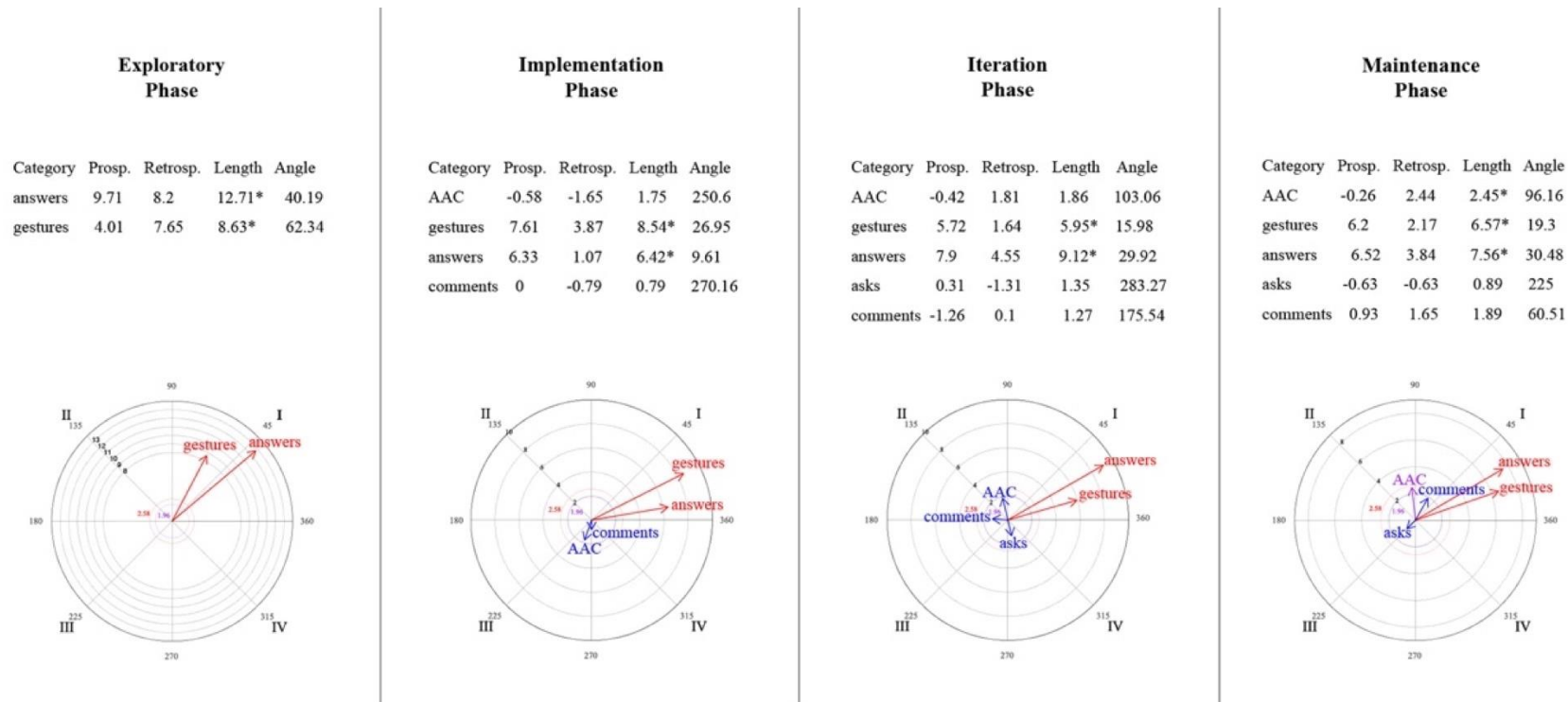
Figure 5-7. Sequential communicative patterns obtain in each phase during the storybook reading with the mother's providing feedback and answers as given behavior [M: Mother, C: Child].
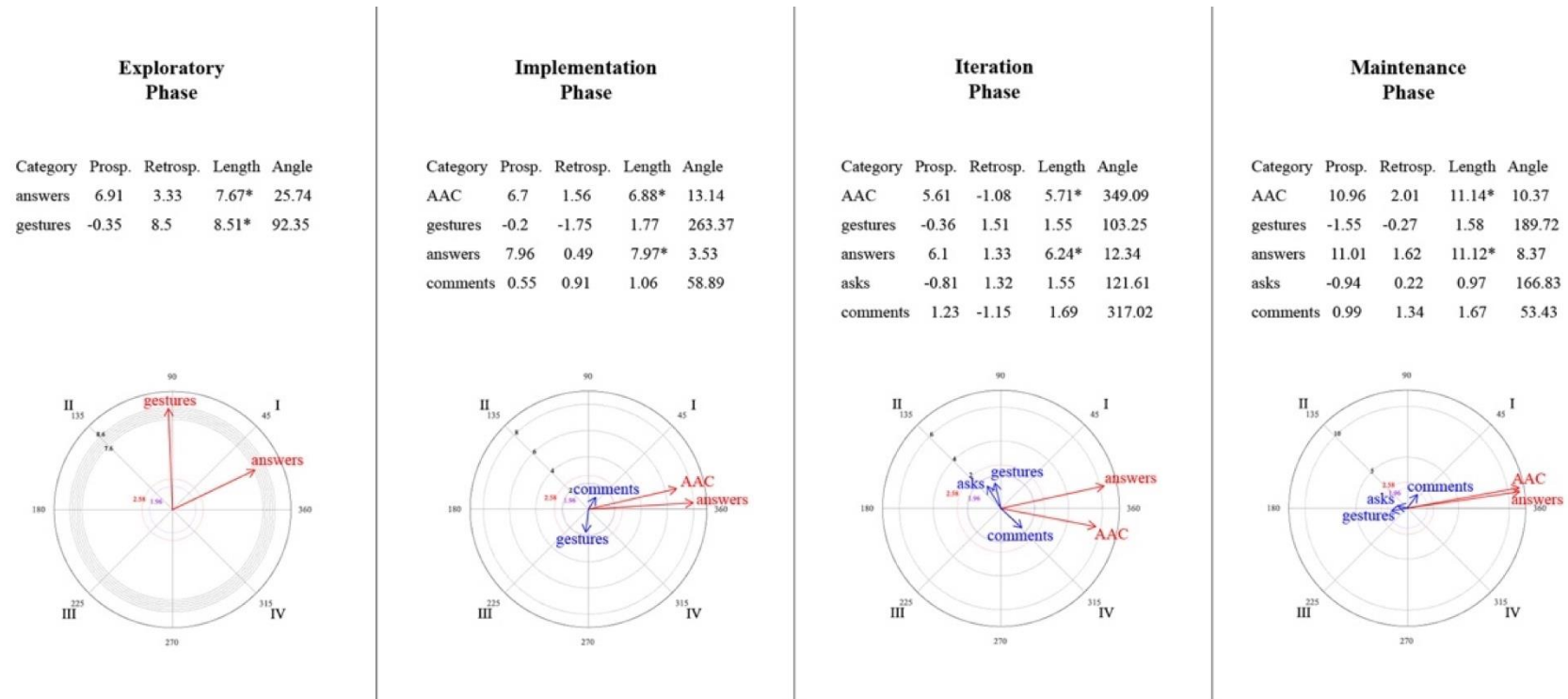
Conversational Sequences
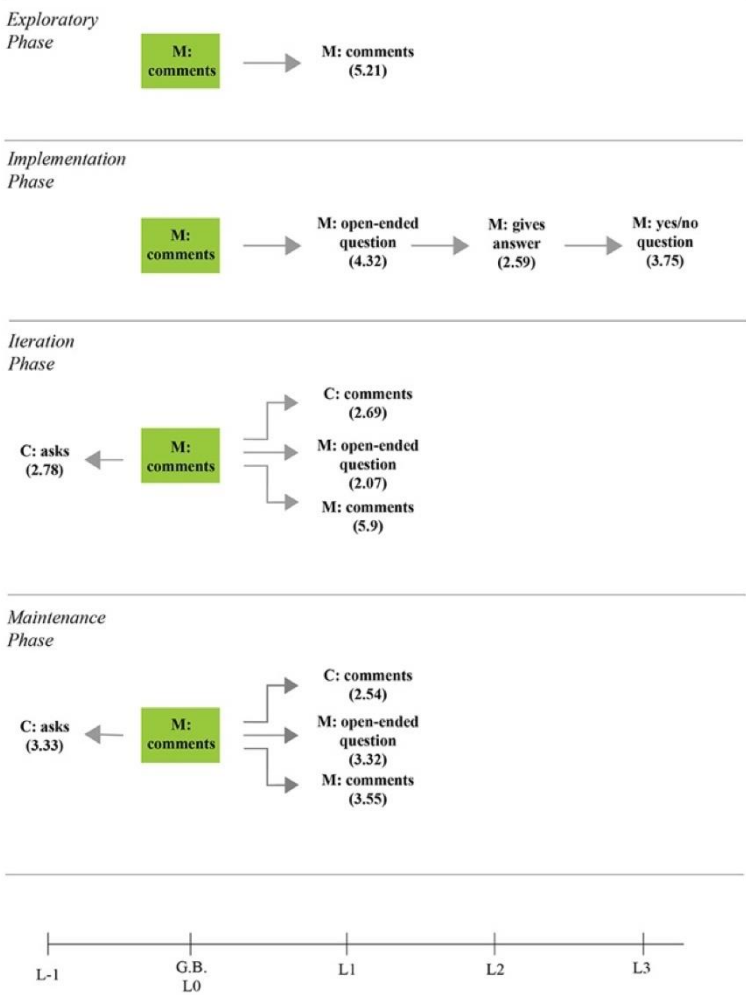
Figure 5-8. Sequential communicative patterns between mother-child during storybook reading with the mother's emotion-related comments as given behavior [M: Mother, C: Child].

Exploratory Phase

Category	Prosp.	Retrosp.	Length	Angle
answers	9.71	8.2	12.71*	40.19
gestures	4.01	7.65	8.63*	62.34

Implementation Phase

Category	Prosp.	Retrosp.	Length	Angle
AAC	-0.58	-1.65	1.75	250.6
gestures	7.61	3.87	8.54*	26.95
answers	6.33	1.07	6.42*	9.61
comments	0	-0.79	0.79	270.16

Iteration Phase

Category	Prosp.	Retrosp.	Length	Angle
AAC	-0.42	1.81	1.86	103.06
gestures	5.72	1.64	5.95*	15.98
answers	7.9	4.55	9.12*	29.92
asks	0.31	-1.31	1.35	283.27
comments	-1.26	0.1	1.27	175.54

Maintenance Phase

Category	Prosp.	Retrosp.	Length	Angle
AAC	-0.26	2.44	2.45*	96.16
gestures	6.2	2.17	6.57*	19.3
answers	6.52	3.84	7.56*	30.48
asks	-0.63	-0.63	0.89	225
comments	0.93	1.65	1.89	60.51

Figure 5-9. Vectors corresponding to the mother's emotion-related closed-ended question as focal behavior, and the child's emotion-related communicative turns [answers, comments, asks] and methods of expression [AAC, conventional gestures] as conditional behaviors.

Exploratory Phase

Category	Prosp.	Retrosp.	Length	Angle
answers	6.91	3.33	7.67*	25.74
gestures	-0.35	8.5	8.51*	92.35

Implementation Phase

Category	Prosp.	Retrosp.	Length	Angle
AAC	6.7	1.56	6.88*	13.14
gestures	-0.2	-1.75	1.77	263.37
answers	7.96	0.49	7.97*	3.53
comments	0.55	0.91	1.06	58.89

Iteration Phase

Category	Prosp.	Retrosp.	Length	Angle
AAC	5.61	-1.08	5.71*	349.09
gestures	-0.36	1.51	1.55	103.25
answers	6.1	1.33	6.24*	12.34
asks	-0.81	1.32	1.55	121.61
comments	1.23	-1.15	1.69	317.02

Maintenance Phase

Category	Prosp.	Retrosp.	Length	Angle
AAC	10.96	2.01	11.14*	10.37
gestures	-1.55	-0.27	1.58	189.72
answers	11.01	1.62	11.12*	8.37
asks	-0.94	0.22	0.97	166.83
comments	0.99	1.34	1.67	53.43

Figure 5-10. Vectors corresponding to the mother's emotion-related open-ended question as focal behavior, and the child's emotion-related communicative turns [answers, comments, asks] and methods of expression [AAC, conventional gestures] as conditional behaviors.
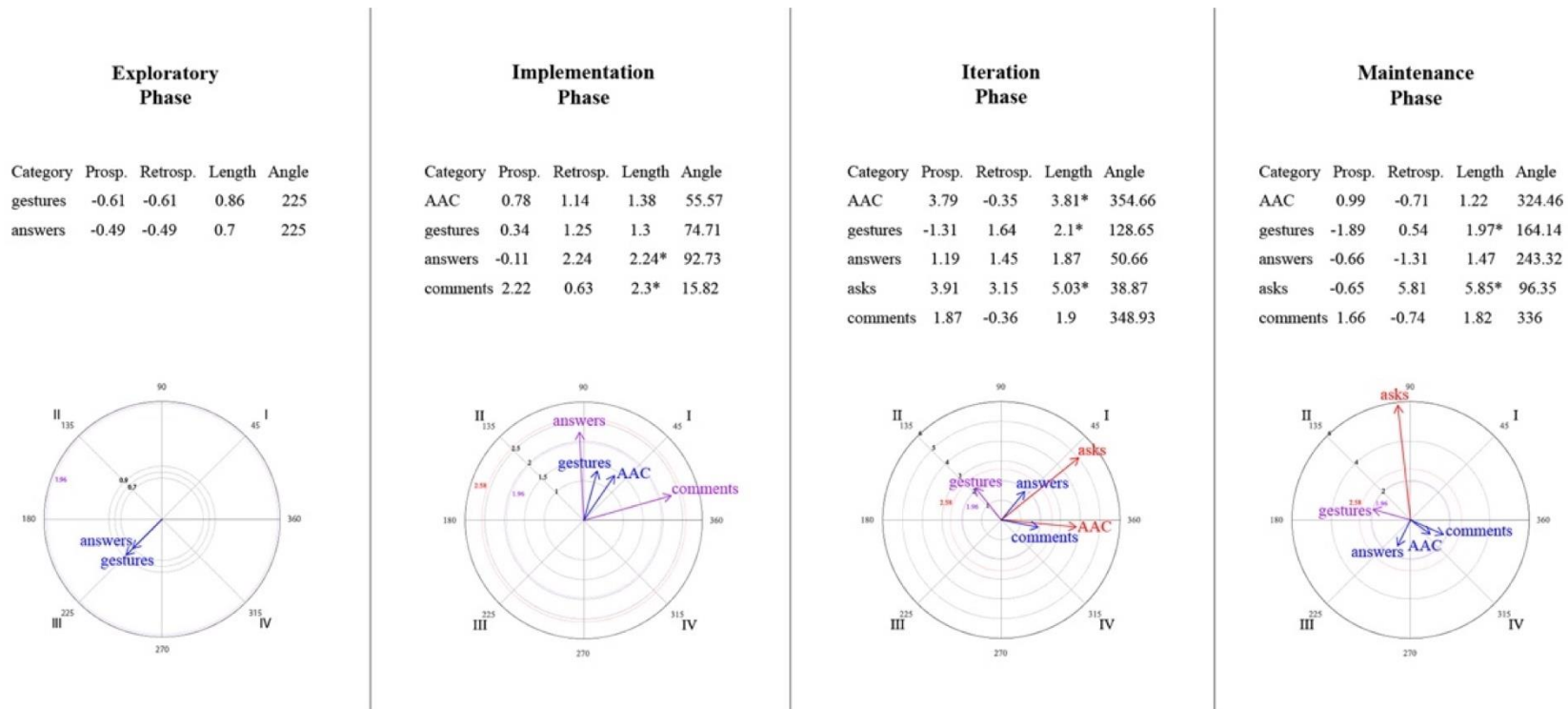
Figure 5-11. Vectors corresponding to the mother's emotion-related comments as focal behavior, and the child's emotion-related communicative turns [answers, comments, asks questions] and methods of expression [AAC, conventional gestures] as conditional behaviors.

	Exploratory Phase	Implementation Phase	Iteration Phase	Maintenance Phase

Implementation Phase

Category	Prosp.	Retrosp.	Length	Angle
AAC	5.16	9.07	10.43*	60.36
gestures	-1.28	-0.42	1.35	198.01
answers	0.56	6.68	6.7*	85.17
comments	6.3	4.55	7.77*	35.82

Iteration Phase

Category	Prosp.	Retrosp.	Length	Angle
AAC	2.94	9.24	9.69*	72.35
gestures	0.57	-1.3	1.42	293.56
answers	-1.06	5.22	5.33*	101.49
asks	0.61	0.61	0.86	44.98
comments	5.87	5.4	7.98*	42.58

Maintenance Phase

Category	Prosp.	Retrosp.	Length	Angle
AAC	2.72	9.1	9.5*	73.39
gestures	0.71	-2.98	3.07*	283.38
answers	0.41	7.16	7.17*	86.73
asks	0.59	-1.26	1.39	295.26
comments	4.01	1.78	4.39*	23.96

*Absence of behavior

Figure 5-12. Vectors corresponding to the mother's providing multimodal feedback as focal behavior, and the child's emotion-related communicative turns [answers, comments, asks] and methods of expression [AAC, conventional gestures] as conditional behaviors.

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Exploratory Phase

*Absence of behavior

Implementation Phase

Category	Prosp.	Retrosp.	Length	Angle
AAC	-1.65	-1.65	2.34*	225
gestures	-0.39	2.18	2.21*	100.17
answers	-0.75	-0.01	0.75	181.09
comments	-1.06	-1.06	1.49	225

Iteration Phase

Category	Prosp.	Retrosp.	Length	Angle
AAC	0.59	-0.81	1	306.06
gestures	-0.77	2.17	2.3*	109.42
answers	0.71	2.19	2.3*	71.92
asks	-0.22	-0.22	0.31	225
comments	-0.55	-0.55	0.78	225

Maintenance Phase

Category	Prosp.	Retrosp.	Length	Angle
AAC	0.51	-0.84	0.98	301.53
gestures	0.55	-0.82	0.99	303.75
answers	0.53	-0.83	0.99	302.5
asks	-0.1	-0.1	0.14	225
comments	-0.55	-0.54	0.77	224.72

Figure 5-13. Vectors corresponding to the mother's giving of the answer to her own questions as focal behavior, and the child's emotion-related communicative turns [answers, comments, asks] and methods of expression [AAC, conventional gestures] as conditional behaviors.
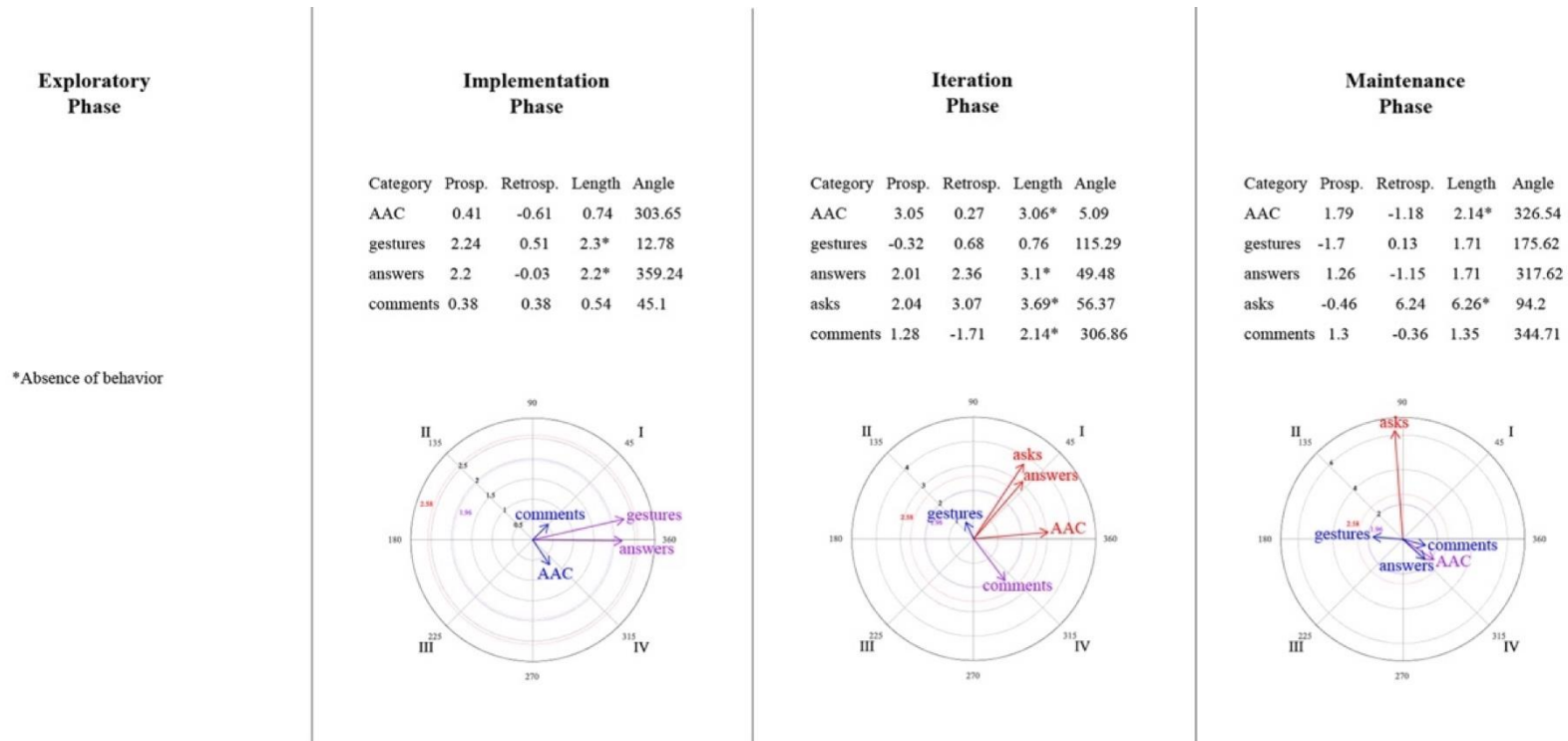
Figure 5-14. Vectors corresponding to the mother's AAC modeling as focal behavior, and the child's emotion-related communicative turns [answers, comments, asks] and methods of expression [AAC, conventional gestures] as conditional behaviors.

12 Supplementary Material[17]

5-1. STEPS Instruction Page (adapted).

5-2. Example of AAC emotion-related boards.

5-3. Observation Instrument for interactions between communication partners and children with CCN during a storybook-reading activity (full version).

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[17] Ver anexos

Capítulo 6

Discusión

A lo largo de la presente tesis se ha abordado la comunicación emocional de niños y niñas con necesidades complejas de comunicación (NCC) y su entorno, principalmente enfocado en sus vínculos primarios (papá y/o mamá). Cada capítulo ha presentado evidencias de cómo la comunicación es prioritaria para el aprendizaje y desarrollo. Por lo tanto, cuando una persona no cuenta con los medios de comunicación convencional es fundamental que el entorno se capacite. La formación tiene que estar dirigida hacia ofrecer oportunidades y estrategias adecuadas que habiliten, den acceso y fortalezcan formas de comunicación que sean sensibles a las necesidades de la persona, así como funcionales, convenientes y adecuadas para un desarrollo emocional óptimo.

La comunicación aumentativa y alternativa (CAA) aparece como recurso que abre esta ventana de oportunidades para el colectivo con NCC. Sin embargo, son aún insuficientes los estudios e intervenciones que aborden el desarrollo de competencias emocionales con un enfoque en habilitar la comunicación para ello (Na y Wilkinson, 2018; Wilkinson et al., 2021). Explorar las prácticas de comunicación emocional en niños y niñas con NCC es crucial. Este colectivo tiende a mostrar dificultades para expresar, comprender emociones (propias y de otros) y regularse emocionalmente (Belmonte-Darraz et al., 2021; Blackstone y Wilkins, 2009; Brinton et al., 2007; Brinton y Fujiki, 2009, 2011; Metsala et al., 2017; Wilkinson et al., 2021). Por tanto, es necesario diseñar espacios para fomentar una comunicación emocional que funja como entrada a la adquisición de competencias emocionales. Los estudios que integran esta tesis no se enfocan en valorar las competencias emocionales directamente (Saarni, 2000, 2007), pero sí buscan empezar a comprender cómo

el colectivo infantil que tiene NCC se comunica emocionalmente y de qué forma su entorno incide en ello. Los estudios que componen esta tesis contribuyen a:

a) Aportar a la literatura científica sobre el estudio y la comprensión del campo de la comunicación emocional en la infancia de personas con NCC que se benefician de la CAA.

b) Concientizar sobre la importancia de la comunicación emocional en la niñez de personas con NCC.

c) Ofrecer y valorar alternativas y recursos para concientizar la necesidad de mirar las emociones, así como facilitar, en entornos cotidianos, conversaciones con tinte emocional.

Debido a que cada estudio presentado ofrece una extensa discusión, este capítulo se enfoca a exponer los principales hallazgos obtenidos en línea con los objetivos que constituyen esta investigación. Posteriormente se plantea una discusión acerca de las implicaciones de los hallazgos desde la perspectiva de la comunicación emocional y sus agentes involucrados. Se valoran las implicaciones prácticas y futuras líneas de investigación. Finalmente, se abordan las fortalezas, limitaciones y conclusiones.

6.1 Hallazgos principales

Hasta donde se conoce, el **estudio 1** es único al ser el primero en explorar e integrar las percepciones de diversos padres/madres sobre la comunicación emocional de niños/as con NCC. Los principales hallazgos obtenidos (ver tabla 6-1), tras realizar un análisis temático (Braun y Clarke, 2006), permiten identificar los ámbitos que entran en juego en los intercambios comunicativos que tienen un contenido relacionado con las emociones.

Tabla 6-1

Principales hallazgos del estudio 1 – Percepciones de padres/madres sobre la comunicación emocional en niños/as con NCC

Objetivo: Explorar, describir y analizar las percepciones y experiencias de padres y madres sobre la expresión y comunicación emocional con sus hijos/as con NCC.			
Hallazgo 1	**Hallazgo 2**	**Hallazgo 3**	**Hallazgo 4**
Los padres/madres pueden llegar a identificar distintas emociones en sus hijos/as, pero sus hijos/as tienen un vocabulario y métodos de comunicación lingüística reducido (o nulo) de expresión emocional.	Existen emociones con las que los padres/madres no se sienten cómodos expresando frente a sus hijos/as con NCC. Hay detonantes comunes generadores de emociones agradables y desagradables ante la crianza de su hijo/a.	Las madres/padres tienen diversas formas de responder al detectar una expresión emocional del/la menor, siendo estas relacionadas con: disminuir expresión emocional, reconocer o incentivar una comunicación emocional, e incidir directamente con el detonante emocional.	Las/los menores tienen pocos soportes y modelos comunicativos, así como oportunidades limitadas para hablar, escuchar o aprender sobre emociones. Sus compañeros de comunicación pueden mostrar dificultades para reconocer, entender y acompañar adecuadamente las emociones que experimentan.

Pese a que la expresión emocional de personas con retos comunicativos podría ser limitada, ambigua y compleja (Blackstone y Wilkins, 2009; Brinton y Fujiki, 2009; Di Marco y Iacono, 2007), de los análisis se pueden extraer actos potencialmente comunicativos que podrían indicar expresión emocional (ver anexo 6-1) y con ello, ayudar en la detección adecuada de emociones. También, se puede obtener una lista de los posibles detonantes emocionales que los familiares llegan a percibir en sus hijos/as (ver anexo 6-2), el cual podría ser de interés para los profesionales que buscan crear intervenciones que den soporte a la comunicación emocional en entornos cotidianos. El hecho de tener una NCC no es indicador de no experimentar emociones. Por el contrario, cuando se brinda el espacio para pensar en las emociones que los niños/as experimentan, los padres y madres se encuentran con que, en realidad, su hijo/a experimenta un amplio bagaje emocional que puede ser identificado por el observador (como se mostró en la figura 3-2). Desgraciadamente, los niños/as con NCC no cuentan con el vocabulario adecuado ni las oportunidades para nombrar su sentir. Tomando en cuenta que una de las competencias fundamentales para comprender e identificar emociones es tener vocabulario emocional (Doyle y Lindquist, 2018; Lindquist,

MacCormack, et al., 2015; Saarni, 2000, 2008; Saarni y Harris, 1991; Shablack y Lindquist, 2019), los niños/as con NCC se convierten en población vulnerable a desarrollar dificultades en la adquisición de estas competencias.

En lo que respecta a la comunicación emocional de los padres/madres participantes en el estudio, el análisis permitió englobar las respuestas comunes de las madres y padres ante las emociones de sus hijos/as (ver anexo 6-3). Por otro lado, también posibilitó extraer las emociones y detonantes en común tras la paternidad/maternidad de un niño/a con retos comunicativos (ver anexo 6-4). Se destaca que, el mirar los avances y habilidades de los menores, así como el encontrarse en entornos inclusivos y respetuosos de las características de sus hijos/as son potenciadores de emociones agradables (gratitud, amor, orgullo, felicidad). Por su parte, las dificultades y conductas poco convencionales vistas como negativas en sus hijos/as (p.ej. gritos), así como no saber cómo responder y percibir un entorno de crítica y juicio son activadores de emociones desagradables (nervios, angustia, miedo, frustración, impotencia, tristeza, enfado, culpa). Una intervención integral tendría que tomar en cuenta el sentir de los cuidadores primarios y apoyarlos hacia el bienestar emocional, ya que la experiencia que tengan impactará en la crianza, soporte y cuidado brindado al niño/a (Dunst, 2002; Mas et al., 2019; Tomasello et al., 2010).

Ahora bien, como se presentó en la figura 2-2, el **estudio 2** no estaba inicialmente programado. Sin embargo, al trabajar con las familias participantes, se observó la necesidad de dar un soporte para transmitir información y sugerencias útiles que emergen tras la entrevista EDEC. Los hallazgos presentados en este artículo (ver tabla 6-2) contribuyen a crear conciencia y comprensión de cómo las personas con NCC expresan y comunican emociones. Y ofrece un punto de partida al lector para promover espacios de comunicación emocional *ad hoc* con las necesidades y retos individuales del/la menor a quien acompañamos en su desarrollo.

Tabla 6-2

Principales hallazgos del estudio 2 – Propuesta de Perfil Emocional (EDEC-P)

Objetivo: Proponer y presentar con casos ilustrativos un perfil emocional que permita compartir información y sugerencias a los compañeros de comunicación clave del niño/a para comprender y favorecer la comunicación y aprendizaje emocional.		
Hallazgo 1	**Hallazgo 2**	**Hallazgo 3**
El perfil EDEC puede ser útil para profesionales interesados en abordar la comunicación sobre emociones en la etapa infantil de personas con NCC.	El perfil EDEC permite compartir información que apoya en el reconocimiento y comprensión del estado emocional actual del niño/a con NCC, así como sugerir estrategias a implementar para lograr objetivos a nivel emocional y comunicativo.	Tiene valor incluir a personas clave en la vida del niño/a para ajustar objetivos y estrategias necesarias que promuevan habilidades comunicativas y emocionales *ad hoc* con la situación del/la menor.

Cada persona es diferente, necesita herramientas y estrategias de acceso a la comunicación específicas, así como intervenciones personalizadas (Beukelman y Light, 2020). Por tanto, es fundamental valorar las habilidades, formas de expresión, respuestas, gustos, intereses, necesidades y retos del/la menor con NCC y su contexto. La toma de decisiones sobre los siguientes pasos para dar soporte a un desarrollo emocional y comunicativo óptimo se beneficiaría de comprender qué hace a cada persona única. Por esta razón, colaborar con la familia, el/la menor y su entorno es imprescindible. Compartir información del niño/a con personas clave puede ser útil para comprender su estado actual, estimular e impulsar su desarrollo (Kruithof et al., 2020; Noyek et al., 2020; Stringer et al., 2018). El perfil emocional propuesto es una herramienta que busca servir para ese propósito.

El **estudio 3** presenta un análisis de caso madre-hijo en el que se explora y analiza, a través de un enfoque mixed-methods (Anguera et al., 2020), el cambio comunicativo tras la implementación de un programa de formación para promover conversaciones emocionales en un contexto cotidiano (lectura de cuento). Los hallazgos de este artículo (ver tabla 6-3) aportan una visión de lo que podría suceder cuando ofrecemos espacios para hablar de emociones (incluyendo el nombre de la emoción, la causa y las posibles formas de responder a estas). La comunicación es una "calle amplia y de doble sentido". El que los medios de

comunicación sean distintos a los convencionales, no trunca la vía/interacción comunicativa. Al contrario, si sabemos cómo transitar en esta "calle", podemos participar en ese ir y venir, y, de hecho, darnos cuenta de lo lejos a lo que se puede llegar, y los nuevos caminos que se despejan al andar.

Tabla 6-3

Principales hallazgos del estudio 3 – Estudio de Caso Observacional

Objetivo: Describir y analizar el cambio comunicativo ocurrido en el transcurso de la implementación de un programa diseñado para fomentar conversaciones emocionales durante la lectura de cuento.			
Hallazgo 1	**Hallazgo 2**	**Hallazgo 3**	**Hallazgo 4**
La participación en el programa resultó en cambios significativos en los intercambios comunicativos entre madre-hijo sobre temáticas relacionadas con las emociones.	Las estrategias sugeridas para incentivar comunicación sobre emociones, junto con dar acceso a vocabulario, mostró patrones comunicativos que, con el tiempo, son más dinámicos y ricos en contenido lingüístico emocional.	Al brindar espacios y herramientas comunicativas para hablar de emociones, ambos agentes comunicativos participan activamente en la conversación.	Participantes refieren satisfacción al participar e involucrarse en conversaciones sobre emociones.

Los análisis realizados en la interacción comunicativa madre-hijo nos abren posibilidades de estudio y comprensión sobre los cambios que se pueden tener cuando deliberadamente se da acceso a la comunicación y se incentivan conversaciones sobre emociones. En este sentido, los análisis permitieron identificar cómo ciertas conductas (estrategias[18] y uso de herramientas de CAA), en el tiempo, pueden impactar en la interacción comunicativa y generar patrones de comunicación con mayor dinamismo y riqueza en contenido temático (hablar del nombre, causa, respuesta ante emoción) y referencial (sobre el personaje del cuento, uno mismo u otras personas referentes). Los hallazgos son ligeramente diferentes a lo que ocurre en estudios con niños con desarrollo neurotípico (Fivush, 2007; Fivush et al., 2003; Leyva et al., 2021; Van Bergen et al., 2009). Parece ser que el sólo hecho de que las madres/padres realicen comentarios o preguntas relacionadas con las emociones no se relaciona con mayores expresiones o comentarios

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[18] preguntas abiertas, comentarios, dar retroalimentación, modelar comunicación.

emocionales del menor con NCC. Para ello, los niños/as además requieren acceder a la comunicación emocional (p.ej. mediante sistemas de CAA) y a estrategias que incentiven su propia forma de comunicación (p.ej. modelar uso de sistema de CAA).

Similar conclusión se puede obtener en cuanto a la actividad seleccionada para promover conversaciones emocionales. La lectura por sí misma no fomenta la directa interacción y promoción de conversaciones emocionales entre niños/as con NCC y sus padres/madres. Sin embargo, hacer adecuaciones en la lectura de cuento (p.ej., brindar estrategias comunicativas al cuidador y vocabulario disponible al niño) puede generar una comunicación sobre emociones fluida en la que sus integrantes participan en la interacción. Sugiriendo que siempre y cuando se den los apoyos necesarios, entonces la lectura es una excelente oportunidad para fomentar espacios para hablar y aprender de emociones y, por tanto, para la socialización emocional (Garner et al., 2008; Rose et al., 2018).

Ahora bien, la selección de realizar análisis secuencial de retardos (Bakeman, 1978; Bakeman y Quera, 2011), así como coordenadas polares (Anguera, 1997; Sackett, 1980), permitió obtener una mayor cantidad de información. Esto logró visualizar la complejidad de la dinámica interactiva, en comparación con otro tipo de metodologías utilizadas en estudios de caso (p.ej. aquellas en las que sólo se valora el número de aparición de la respuesta a estudiar, Na y Wilkinson, 2018). Sin duda, este estudio clarifica y brinda una guía para futuras investigaciones que nos lleven a comprender cómo promover e identificar el *baile comunicativo* (Staehely, 2000) con personas que se comunican de formas no convencionales. Y como buen baile, el baile no es el mismo cada día, tiene matices y cambios. El análisis observacional nos permite explorar su movimiento.

Cabe destacar que, a pesar de que esta tesis presenta únicamente un estudio de caso madre-hijo, para llevar a cabo la construcción del instrumento de observación (versión completa, anexo 5-3) se observó la comunicación de la interacción en la lectura de cuento

de más familias con hijos/as con NCC (n=15). El estudio de la interacción entre personas con retos comunicativos importantes y sus compañeros de comunicación puede resultar altamente complejo. La rigurosidad del instrumento de observación, cumpliendo con los requisitos de exhaustividad y mutua exclusividad (Anguera et al., 2007, 2018), aporta una herramienta más para el estudio de la interacción comunicativa en esta población.

6.2 Comunicación Emocional en niños/as con NCC y su entorno

Aun cuando la tesis se enfoca en la comunicación emocional entre padres/madres y sus hijos/as, hay que recordar que no es un vínculo aislado (Mandak et al., 2017; Turnbull et al., 2011) y se ajusta acorde al entorno que habita (Gallimore et al., 1996; Minuchin, 1985). Los hallazgos de los estudios presentados en la tesis permiten identificar cómo la comunicación emocional con personas con NCC, al menos durante la etapa infantil, es un asunto que requiere del involucramiento y compromiso de varios actores como: niño/a, compañeros de comunicación (familia, profesionales colaboradores, etc.), investigadores y profesionales en políticas. La participación de cada uno es fundamental y el trabajo colaborativo el puente medular para comprender, proteger y favorecer un desarrollo y bienestar emocional óptimo; y prevenir riesgos psicosociales (Bell y Cameron, 2003; Di Marco y Iacono, 2007; Foley y Trollor, 2015; Stancliffe et al., 2010; Watson et al., 2021). Reconocer, respetar y potenciar el rol de cada actor asegura que se instauren oportunidades y espacios favorables para la convivencia, aprendizaje y bienestar. A continuación, se profundizará en el rol de cada uno.

6.2.1 El rol del niño/a con necesidades complejas de comunicación

La comunicación es un proceso bidireccional. Las características y habilidades de los niños/as influyen en su entorno y viceversa (Saarni, 1999, 2008). Por tanto, cuando se busca promover comunicación emocional en personas con NCC, se necesita no subestimar el rol

que ellos mismos juegan en su desarrollo y aprendizaje. "Nada sobre nosotros sin nosotros" tendría que ser el eje del cual partir para la investigación, evaluación, creación e implementación de herramientas, estrategias y apoyos que guíen el aprendizaje de habilidades (Beukelman y Light, 2020), incluidas las emocionales y comunicativas.

El hecho de tener dificultades para comunicarse de forma convencional no significa que no puedan comunicar. Simplemente significa que su entorno (compañeros de comunicación) necesita adquirir recursos adecuados para comprender la experiencia del niño/a, dar acceso a la comunicación y ofrecer vivencias que sean significativas para su desarrollo. A lo largo de los estudios realizados, las familias participantes compartieron experiencias, conductas y emociones de sus hijos/as que son clave para el diseño respetuoso de intervenciones relacionadas con la promoción de comunicación emocional. El estudio de caso también es un ejemplo de cómo fomentar que el menor participe en su desarrollo y aprendizaje de forma activa. Brindar espacios para hablar de emociones, tomando en cuenta las habilidades, fortalezas, intereses, necesidades, retos y contexto del niño/a es una forma de visibilizar, reconocer, valorar y respetar el papel que juega el niño/a en su desarrollo.

6.2.2 El rol de los compañeros de comunicación

Los hallazgos encontrados a lo largo de esta tesis ponen en evidencia que los compañeros de comunicación brindan pocas oportunidades para involucrar activamente a los menores con NCC en conversaciones emocionales. Sin embargo, el rol del compañero de comunicación es crítico para el aprendizaje y promoción de comunicación emocional. El modelamiento y las estrategias de andamiaje que utilicen son clave para el aprendizaje (Warren y Yoder, 1998). Cada compañero de comunicación, desde su lugar, cumple una función importante en el desarrollo de la comunicación y competencia emocional.

El rol de cuidadores primarios. Pese a que en los hallazgos derivados de la tesis, los padres/madres refieren tener dificultades para detectar ciertas emociones y, por tanto, dar una contención y acompañamiento emocional adecuado, los cuidadores primarios son los más equipados para ofrecer información acerca de los actos comunicativos de corte emocional de los menores (Kruithof et al., 2020; Noyek et al., 2020). Impulsar su rol es imprescindible para el bienestar y desarrollo comunicativo y emocional.

La familia, y principalmente el vínculo padre/madre con su hijo/a, suele ser la constante en la vida del menor. Los cuidadores primarios son los primeros agentes de socialización emocional (Mas et al., 2019; Saarni, 2007). Ya sea de forma directa o indirecta, las actitudes, emociones, expectativas y comportamientos que tengan impactan en el desarrollo de sus hijos/as (Dunsmore et al., 2009; Hastings, 2018; S. Meyer et al., 2014). La integración de los hallazgos de esta tesis permite estipular cuán importante es tomar en cuenta las vivencias y habilidades de los cuidadores, así como favorecer su inclusión y participación en la intervención y comunicación con sus hijos/as (p.ej. en el diseño de CAA, inclusión de vocabulario esencial y significativo, creación de espacios para hablar de emociones y necesidades comunicativas). Cuidar a los cuidadores, incluirlos en la toma de decisiones y enfocar recursos en animar el aprendizaje e implementación de estrategias para hablar de emociones con las que se sientan cómodos, favorece el fomento de espacios de conversación emocional con sus hijos/as. Aunque aún se necesitan más casos de estudio y evidencia que de soporte a estas estrategias y su impacto, la presente investigación presenta hallazgos alentadores.

El rol de profesionales colaboradores. Todos los profesionales, sin importar su objetivo, pueden colaborar hacia el mantenimiento, uso y desarrollo de espacios y soportes comunicativos que promuevan la participación del menor en sus interacciones y acompañen hacia la comunicación y bienestar emocional de todos los involucrados. Cuando

colaboramos y damos un servicio a las personas, no podemos deslindarnos de la interacción comunicativa. Si además, a quienes se ofrecen servicios son personas con NCC y su entorno, es muy posible que con mayor razón habrá que dar lugar a la expresión y validación de las emociones, y de ser posible, acompañar en la gestión. Poner en juego la habilidad de facilitar espacios emocionalmente seguros, con frecuencia, es más fructífero para los involucrados en la interacción que el solo hecho de recibir información y atención específica sin tomar en cuenta la dimensión emocional (Luterman, 2006).

El papel de los profesionales colaboradores es reconocer, defender y hacer valer los derechos emocionales y de la comunicación de las personas desde su lugar de acción. Su responsabilidad radica en tener apertura para ir adquiriendo las estrategias necesarias, basadas en la investigación, que los lleven a brindar un servicio humano, culturalmente apropiado y de calidad a cada una de las personas con quienes colaboran. La formación y desarrollo en competencias comunicativas y emocionales del/la profesional son un aspecto clave para el éxito de su labor con personas con NCC y su entorno (Duncan et al., 2010; Luterman, 2006; Stone-Goldman, 2013). Para ello, como se aborda en los estudios presentados en este trabajo, se requiere al menos del compromiso y empuje de los profesionales en las materias de CAA, psicología y educación emocional. Mientras no haya una cultura global de respeto a la diversidad y se vivan con naturalidad los diferentes métodos de comunicación posibles, los profesionales -principalmente en CAA, psicología y educación emocional- tienen la responsabilidad de concientizar, defender, abogar, crear redes de apoyo, acompañar al entorno y a las personas con NCC a hacer valer sus derechos. Todo esto sin olvidar que para lograrlo, hay que involucrar a la familia y al menor implicado (Crais, 1993; Dunst y Espe-Sherwindt, 2016; Trute y Hiebert-Murphy, 2018; Williams et al., 2008).

El rol de otros compañeros de comunicación. Como se ha comentado a lo largo de esta tesis, los compañeros de comunicación son todas aquellas personas que interactúan de alguna forma con la persona con NCC. Por tanto, habrá personas que se mantengan constantes en el tiempo (como familiares), otros que se involucren por un periodo específico (educadores, terapeutas, amigos, asistentes), y algunos más que serán ocasionales (miembros de la comunidad, proveedores de servicios, p.ej. trabajador en algún establecimiento). Dependiendo de la periodicidad y la calidad de la relación, las interacciones con los compañeros de comunicación pueden impactar significativamente en la vida del niño/a que se benefica de CAA y su familia (Beukelman y Light, 2020; Binger et al., 2012; Blackstone et al., 2015; McNaughton et al., 2019) Con respecto a este ámbito, se quisiera hacer hincapié que uno de los papeles más importantes que este colectivo tiene es el uso de sus propias competencias emocionales para comprender la vivencia de las personas con NCC, reconocer y hacer valer sus derechos (como cualquier persona) y utilizar estrategias que permitan una adecuada y respetuosa interacción, sea cual sea esta. Para ello, resultaría provechoso facilitar la conciencia, preparación y aprendizajes (a nivel emocional y comunicativo) en las que todos y todas se beneficien. Como se observó en los hallazgos, las familias refieren bienestar cuando perciben un entorno propicio, respetuoso e inclusivo para sus hijos/as. Es fundamental destinar esfuerzos hacia crear entornos saludables que respeten la diversidad.

6.2.3 El rol de investigadores

El estudio riguroso de la comunicación emocional de personas con NCC es altamente complejo y extremadamente necesario. Esta tesis, presenta la unión de dos áreas (la CAA y la educación emocional) que, hasta ahora, no suelen encontrarse frecuentemente en la literatura científica. Además, como áreas aisladas, continúan abriendo camino, evidenciando

su importancia y haciendo un llamado a futuras investigaciones (Eisenberg, 2020; Kent-Walsh y Binger, 2018; Light et al., 2019).

El investigador/a interesado en los aspectos que potencian el desarrollo de competencias emocionales de personas con NCC tiene el rol de: a) explorar, b) identificar retos, c) proponer soluciones, d) desarrollar estrategias y herramientas, e) analizar su implementación, f) evidenciar el cambio tras la implementación y g) difundir los hallazgos para garantizar el soporte a la comunicación y bienestar emocional del colectivo con NCC y su contexto. Brownson y colaboradores (2006) hacen hincapié en la importancia de que las/los investigadores tengan el compromiso de comunicar sus hallazgos en una variedad de audiencias para asegurarse de que sus hallazgos se apliquen en beneficio a la salud y bienestar. En este sentido, el investigador/a en el área comunicativa-emocional podría incidir positivamente al explorar y difundir sus hallazgos en diferentes ámbitos (p.ej. científico, familiar, social, educativo, político, terapéutico, etc.), destinar sus esfuerzos en ello apoyaría en la defensa de derechos y bienestar del colectivo con NCC.

6.2.4 El rol de profesionales en políticas

Tener una necesidad compleja de comunicación, sin tener los apoyos necesarios, implica estar en desventaja en comparación con el resto de la población. La vulnerabilidad no se relaciona únicamente a una condición meramente individual, es también un reflejo de las barreras que las personas experimentan al negarles, impedirles o dificultarles el acceso a la participación, aprendizaje y recursos necesarios para un desarrollo óptimo (Miller et al., 2010; Organización Mundial de la Salud, 2011, 2013; UNESCO, 2016). Hay factores externos a la persona con NCC que pueden aumentar, mantener o reducir la brecha de oportunidades comunicativas y de espacios que den soporte a la comunicación y bienestar

emocional. Los profesionales en políticas públicas juegan un papel importante para influenciar positivamente en la vida de este colectivo (Blackstone et al., 2007).

Aún hay mucho que impulsar, atender y enfocar recursos hacia la creación de políticas y lineamientos que garanticen el acceso a la comunicación y que cuiden el bienestar emocional de todos y todas, y específicamente del colectivo con retos comunicativos. La presente investigación, aunque aparenta poca representatividad, suma a sentar las bases sobre la prioridad y relevancia que tiene este tema en la vida de las personas y en el bienestar social global. Los hallazgos refieren que hay un sector de la población que requiere apoyo y cuidado emocional, se propone una serie de derechos emocionales (ver anexo 6-5 y 6-6) a tomar en cuenta en las interacciones con este colectivo, y se presentan recursos prometedores para crear oportunidades que permitan incidir deliberadamente en este tema. Se requieren políticas que permitan crear conciencia, brindar acceso a la comunicación emocional y formación a los compañeros de comunicación para dar espacios y oportunidades, en la cotidianeidad, que promuevan el desarrollo de competencias emocionales y comunicativas. Se esperaría que estas políticas pudieran impactar en la sociedad en general y movilizarla, creando así servicios y espacios de convivencia e inclusión adaptada a las personas con NCC. Ejemplos de buenas prácticas en la creación de estándares y políticas de acceso a la comunicación (American Speech-Language-Hearing Association, 2021c; Communication Disabilities Access Canada, 2021) se pueden usar de referencia para su aplicación en aquellos países en los que aún no existen referentes.

6.3 Implicaciones prácticas y futuras líneas de investigación

Los esfuerzos recogidos en esta tesis tienen el objetivo de no solo aportar al conocimiento en esta área de estudio, sino de pasar de la investigación a la práctica, brindando estrategias eficaces, adaptadas al entorno y necesidades de cada individuo al que

damos servicio. Una de las grandes bondades de la presente tesis es que en cada uno de los estudios que la conforman se busca presentar implicaciones prácticas, así como futuras líneas de investigación. Aquí se toman en cuenta las más relevantes y se presentan nuevas aportaciones.

En línea con los hallazgos encontrados por Noyek (2021), conocer y compartir información de los padres/madres sobre las características comunicativas y emocionales de sus hijos/as con NCC permite comprender mejor al niño/a y podría habilitar la creación de espacios que mejoren las interacciones niño/a-compañeros de comunicación. La entrevista EDEC es una herramienta práctica para que el profesional recopile información necesaria para comprender el estado emocional actual del niño/a y su entorno (Na, Wilkinson, et al., 2018). Esto facilita la toma de decisiones hacia la creación de un plan de acción *ad hoc* a las necesidades del niño y su contexto sociocultural.

El perfil emocional propuesto (EDEC-P) permite de una forma sencilla compartir la información recopilada en la entrevista, así como los retos y las estrategias para incentivar encuentros comunicativos relacionados con las emociones. Sin embargo, podría ser de interés valorar el impacto que tendría crear un perfil audiovisual con el mismo fin, en lugar de sólo ser un perfil escrito. Esto abriría posibilidades para que otras personas (p.ej. amigos) pudieran comprender la expresión emocional del niño/a con NCC y se ofrezcan ejemplos audiovisuales de las sugerencias y recursos propuestos para lograr el objetivo emocional deseado. A su vez, sería de interés llevar a cabo estudios longitudinales que permitieran identificar el cambio en el estado emocional del niño/a en el tiempo una vez que se implementa el plan sugerido y los objetivos se alcanzan.

Por su parte, el estudio de caso ofrece un instrumento para identificar los intercambios comunicativos relacionados con las conversaciones emocionales y valorar el cambio en el tiempo al brindar espacios para hablar de emociones. Hablar de emociones no

significa únicamente poner nombre a la emoción (de uno mismo y de otros), implica también conversar sobre las causas y las posibles formas de afrontamiento o respuesta (Lutz y White, 1986; Na et al., 2016; Wilkinson et al., 2021). Esto supone implicaciones clínicas importantes, ya que como se observó en los hallazgos del estudio de las percepciones de los padres y madres: los niños/as carecen de contenido emocional en sus sistemas comunicativos que dé soporte a esta área.

Hasta la fecha, parece ser que los diseños de CAA no son lo suficientemente apropiados para satisfacer conversaciones y aprendizajes sobre las emociones. Por tanto, a nivel práctico, hay que poner atención a brindar acceso a la comunicación emocional. Futuras investigaciones podrían encaminarse a desarrollar un vocabulario núcleo sobre las conversaciones emocionales con la finalidad de ser una guía para saber por dónde empezar a intervenir. Sin embargo, en ningún momento se debe olvidar que por mucho que ayude tener vocabulario núcleo, es fundamental dar acceso a comunicación emocional que esté en consonancia con la individualidad y esencia de la persona y su contexto (familiar y cultural). Por ejemplo, hay muchas formas de "consolar" a alguien, desde dar un abrazo, poner una canción, estar presente sin decir nada, o decir "tú puedes", "confío en ti", "¿qué necesitas?", "vamos por un helado", "anímate". Cada persona utiliza estrategias y formas de expresión emocional que van en consonancia con uno/a mismo/a. Comprender las diferencias y necesidades individuales de las personas a las que servimos es una base importante para cuidar y brindar el mejor apoyo que necesitan emocionalmente. Es papel del clínico y/o educador brindar vocabulario relacionado con las características que reflejen la identidad del menor al que se acompaña para satisfacer sus diálogos y respuestas hacia las emociones (propias y de otros).

Ahora bien, actualmente, cuando se utiliza un método alternativo de comunicación de alta tecnología (con salida de voz), no se tiene la posibilidad de modificar el tono y

volumen de voz, tan importante en la comunicación con contenido emocional. Es necesario que los desarrolladores de tecnología puedan brindar apoyos para dar soporte a esta dimensión. Futuras investigaciones son esenciales para abordar este tema.

La propuesta de formación, adaptada de Na y Wilkinson (2018), presentada en el estudio de caso muestra estrategias y herramientas prácticas. Con recursos al alcance de todos (si incluimos los soportes de CAA de baja tecnología), es viable su puesta en práctica y parece que tras el entrenamiento se muestran cambios significativos en la interacción comunicativa sobre emociones. Los enfoques de observación sistemática brindan la flexibilidad necesaria para estudiar la vida cotidiana sin perder el rigor en la investigación (Anguera et al., 2018). En la vida diaria es común que haya imprevistos, falta de tiempo y situaciones que dificultan que las familias se involucren de forma constante en las intervenciones propuestas (Brotman et al., 2011). Sin embargo, el estudio de caso muestra cómo estos retos en la vida cotidiana parecieran no ser un problema para que se visualicen cambios en la interacción comunicativa sobre emociones. Por supuesto, aún se requieren investigaciones para evaluar si los resultados encontrados son similares en otras díadas madre-hijo/a. Explorar diversas díadas e identificar si comparten características comunes que nos permitan considerar la posibilidad de un caso múltiple (Anguera, 2018) podría ser el paso siguiente más adecuado a investigar.

No hay que olvidar que la socialización emocional no es resultado único de la díada madre-hijo (Cekaite y Ekström, 2019; Cole y Tan, 2015; Eisenberg et al., 1998; Miller-Slough y Dunsmore, 2020; Zahn-Waxler, 2010). Por tanto, resultaría de utilidad emplear como guía el programa presentado en el estudio de caso y adaptarlo a otros contextos (p.ej. terapia, escuela, etc.) y actividades (p.ej. juegos, hablar de anécdotas), así como con otros compañeros de comunicación (p.ej. hermanos, educador, terapeuta, amigos, etc.). Es fundamental seguir creando espacios para socializar y hablar de emociones, dar acceso al

vocabulario necesario y evaluar el impacto en el tiempo que esto tiene en el desarrollo de competencias emocionales en personas con NCC y su bienestar emocional.

Merece la pena empeñarse en investigar y seguir buscando alternativas que faciliten encuentros comunicativos en los que se fomenten las competencias emocionales, comunicativas y el bienestar de las personas con NCC. El estudio en este tema es muy escaso aún (Noyek et al., 2020; Wilkinson et al., 2021) y necesario para brindar buenas prácticas basadas en la evidencia. El proceso de aprendizaje de habilidades emocionales, idealmente, tendría que ir dirigido hacia la prevención de conflictos emocionales. La presente tesis, fue encaminada a este objetivo: dar apoyo a comprender y crear espacios para hablar de emociones (sin abordar conflictos específicos). Sin embargo, habrá momentos en que las personas con NCC ya se encuentran con alguna problemática de índole emocional (p.ej. violencia, depresión, ansiedad, soledad, abuso, trauma, bullying; Belmonte-Darraz et al., 2021; Browne y Millar, 2016; Hagiliassis et al., 2005; Taheri et al., 2016). Por ende, habrá que hacer una adecuada detección e intervención para acompañar a restablecer el bienestar. Futuras investigaciones tendrían que abordar estos dos ámbitos: la detección y la intervención. La creación de intervenciones con acceso a la comunicación y encaminadas a trabajar con, por ejemplo, la ira, ansiedad, duelo, soledad, etc. serían también una línea de estudio prioritaria.

Ahora bien, si se tuviera que dar una serie de recomendaciones prácticas (posteriores a la evaluación de habilidades y estado emocional) para iniciar con la promoción de comunicación emocional de niños/as con NCC, basados en la literatura y las experiencias ganadas del presente trabajo, se propondrían algunas sugerencias. En primer lugar, como mínimo, se tendría que considerar prioritario sensibilizar sobre la importancia de la comunicación emocional para un desarrollo óptimo en la niñez. Reconocer la relevancia de promover espacios y diseñar herramientas que permitan hablar de emociones y dar

oportunidades para conversar en la mayoría de los entornos de la vida del menor. Por ejemplo, en escuela, casa, ambiente terapéutico, visitas médicas, etc. y hablar de ello, cada que se considere necesario. Rangel-Rodríguez y Bhana (2020) ofrecen un ejemplo de cómo diseñar y crear espacios que promuevan la comunicación emocional en casa y escuela. Segundo, los compañeros de comunicación necesitan tener a su disposición los recursos comunicativos del niño/a, así como ser sensibles a sus necesidades emocionales (identificar el vocabulario que se necesita y asegurarse de dar acceso a este tras el diseño de sistema de CAA). Estos son esfuerzos encaminados al aumento y diversificación del uso y comprensión del lenguaje con contenido emocional. Por último, implementar las estrategias comunicativas propuestas en el estudio de caso[19], las cuales son muy concretas y, pueden ser perfectamente aplicables a gran escala (maestros, terapeutas, pares, etc.). Es indispensable comenzar en momentos divertidos, seguros y relajados para todos los involucrados en la interacción (Wilkinson et al., 2021). Por supuesto, investigaciones sobre el impacto de estas directrices nos permitirán dilucidar la eficacia de estas.

Para concluir, se plantea una reflexión sobre la implicación que los hallazgos presentados en esta tesis tienen a nivel global. Cuando se busca abrir camino para que un sector de la población tenga mayores oportunidades de participación (sea cual sea el ámbito), se incide en abrir camino hacia una sociedad, más equitativa (Browne y Millar, 2016; Soto et al., 2001; UNESCO, 2016), que promueve y valora la diversidad (Ainscow et al., 2006; Messiou et al., 2016) y en la que todos sus miembros son reconocidos, valorados y respetados (Echeita Sarrionandia, 2020). Las diferencias, junto con las adecuaciones que se realicen para respetar las necesidades de las personas, enriquecen a todos. Estudios con personas con condiciones distintas a lo convencional, ponen de manifiesto una necesidad

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[19] pregunta, espera, responde, haz comentarios, modela. Todo esto asegurándose que el niño/a tenga acceso a su sistema de comunicación.

que orilla a buscar soluciones creativas (Rose et al., 2005) y en las que se requiere la colaboración activa de varios agentes (Mas et al., 2018; Puigdellívol et al., 2017; Sanahuja-Gavaldà et al., 2016). En principio, las soluciones dan soporte a un colectivo concreto, pero posteriormente resulta ser funcional y benéfico para otras personas, e incluso para todos (Alba-Pastor, 2016; Meyer et al., 2014). Gracias al reto que nos ponen los niños y niñas con NCC y sus familias, podemos hacer propuestas innovadoras que pueden beneficiar la vida de muchos más. Los apoyos de CAA diseñados para hablar de emociones, así como las estrategias de comunicación presentadas en el estudio 3, podrían ser útiles para la población infantil general y su entorno. Futuras investigaciones y prácticas podrían valorar el impacto del uso de las herramientas de CAA en el aprendizaje emocional de personas con o sin NCC.

6.4 Fortalezas y Limitaciones

El presente trabajo se enfoca en la comunicación emocional de niños/as con NCC y sus madres/padres, un tema que no ha recibido suficiente atención en la literatura científica, pero que tiene importantes implicaciones para un desarrollo óptimo y bienestar. Una de las grandes fortalezas de esta tesis es su aporte hacia la comprensión de los elementos que pueden entrar en juego en la comunicación sobre emociones del colectivo infantil con NCC y su entorno; y su aporte práctico para aquellos profesionales que trabajan con estos menores y sus familias.

En los estudios se destaca la necesidad de mirar, comprender y ofrecer espacios para la comunicación emocional en situaciones cotidianas. Se visibiliza la importancia de fomentar el acceso al lenguaje necesario para tener conversaciones sobre emociones. Se ofrecen recursos para concientizar, atender y fomentar el desarrollo de habilidades emocionales y comunicativas del colectivo con NCC. Las investigaciones enfatizan las diferencias socioculturales y lingüísticas que hay dentro de las familias. Pone sobre la mesa

la importancia de honrar, y tomar en consideración, estas características e involucrar a personas clave en la vida del niño/a cuando se brindan intervenciones enfocadas en la dimensión emocional y comunicativa. Se reconoce la relevancia del trabajo interdisciplinario (p.ej. entre psicología y terapeutas de comunicación con especialidad en CAA) para la promoción de habilidades y oportunidades relacionadas con la comunicación y socialización emocional. Finalmente, se presenta la potencial utilidad de una formación para cuidadores primarios de hijos/as con NCC para brindar oportunidades de aprendizaje emocional en entornos cotidianos.

Otra fortaleza destacable en el presente trabajo es que, al tratarse de un estudio exploratorio, se tomó la cuidadosa decisión de incluir a cualquier padre/madre con un hijo/a con NCC. Esto bajo la premisa de dar representación a una población diversa de familias (Allmark, 2004; M. Z. Cohen et al., 2001; Lyons et al., 2013) con una variedad de antecedentes diagnósticos, culturales y lingüísticos. Dicha decisión permitió identificar y documentar en el estudio 1 los patrones que atraviesan esa diversidad (Patton, 2015) y en el estudio 2 ejemplificar el trabajo individual respetando las diferencias culturales y lingüísticas. Es necesario unir esfuerzos hacia el estudio detenido de las diferencias socioculturales y familiares en la socialización emocional del colectivo que presenta retos comunicativos importantes y respetar dichas características. Sin embargo, no hay que desestimar que, al vivir una situación similar, estos colectivos pueden compartir vivencias afines y, por tanto, encontrarse con retos parecidos en torno a la socialización emocional (p.ej. dificultad para tener recursos y oportunidades para hablar y discutir sobre las emociones, compartir eventos similares que generen emociones desagradables/agradables, etc.).

Por otra parte, en el presente trabajo sobresale el interés por poner en el centro de la investigación a los participantes: *"Nada sobre nosotros sin nosotros"*. Esto suma a la muy

necesaria creación de intervenciones con base científica sólida que den soporte a la comunicación y desarrollo emocional del colectivo con NCC. Además, la toma de decisiones de las metodologías de investigación empleadas permitió un análisis minucioso, intensivo y riguroso de las unidades de estudio. Mismas que permiten sentar las bases del estudio de las conversaciones emocionales con esta población, y propone un instrumento de observación del cual partir en futuros estudios. Las metodologías seleccionadas permitieron ser flexibles y adaptarse a la vida diaria familiar (p.ej. tiempo que podían destinar a la intervención o entrevista, opción presencial o formato online). Por último, en cada uno de los pasos para la consecución de los objetivos del trabajo doctoral se incorporó la validez social[20]. Siendo este un elemento de gran valor (aún visto como opcional en la investigación y en ocasiones ignorado) que permite considerar si los objetivos e impacto de las intervenciones son significativas para las personas que participan en el estudio (Schlosser, 1999).

Aunque este trabajo proporciona datos relevantes, estos deben interpretarse a la luz de algunas limitaciones. Claramente, los hallazgos requieren confirmación para identificar la utilidad de las herramientas y estrategias propuestas en un número más amplio de participantes. Si se quisieran sacar conclusiones generales sobre la comunicación emocional de un contexto cultural específico o una condición diagnóstica en el niño/a determinada, indudablemente se requeriría una muestra con características uniformes y *ad hoc* con las preguntas de investigación. Misma situación si se quisiera valorar las opiniones y respuestas de comunicación emocional que tienen los diferentes compañeros de comunicación (y así valorar si existen similitudes o divergencias en la socialización emocional).

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[20] En el estudio 2 y 3 aparece dentro del artículo. Aunque en el estudio 1 se llevó a cabo, no fue posible incorporarlo en el texto, pero se pueden revisar ejemplos de comentarios de padres/madres participantes posteriores a la entrevista EDEC en la publicación de Wilkinson, et al., 2021.

6.5 Conclusiones

El aprendizaje emocional es un proceso continuo y permanente que ocurre a través de la socialización que se da gracias a la comunicación y el lenguaje. La infancia es una etapa clave para facilitar conversaciones sobre emociones que apoyen la adquisición de competencias. Cuando se tiene un reto comunicativo importante, la expresión, comprensión y socialización emocional se ven alterados. La comunicación sobre emociones en niños/as con necesidades complejas de comunicación (NCC) es un tema que a menudo no ha surgido en la literatura científica y su investigación puede ser de gran relevancia para este colectivo, sus familias y su entorno. Los métodos de comunicación aumentativa y alternativa (CAA) y la formación al entorno son una solución para muchas personas que tienen dificultades para comunicarse por medios convencionales y puede ser de gran utilidad para incentivar conversaciones sobre emociones. Esto posibilitaría avanzar hacia una comunicación con mayor riqueza y profundidad emotiva, permitiendo conocer, entender, respetar y acompañar el mundo emocional de las personas con NCC, favoreciendo su bienestar emocional.

Esta tesis está conformada por tres estudios que contribuyen a la investigación, comprensión y promoción de la comunicación alrededor de las emociones en una muestra de niños/as con NCC y sus madres/padres. El tener una necesidad compleja de comunicación no significa que no se experimenten emociones, solo muestra que se requieren de ciertos recursos y estrategias para que las niñas y niños puedan identificar, comunicar, regular y hablar de las emociones eficientemente. Los hallazgos muestran la necesidad de brindar acceso a vocabulario y experiencias relacionadas con las emociones para que los niños/as participen en conversaciones emocionales y aprendan de ellas. Para ello, es fundamental incluir a la familia y a otras personas clave para ofrecer un acompañamiento que esté en consonancia con el entorno lingüístico y sociocultural del niño/a. Acompañar y dar formación a los compañeros de comunicación puede ser esencial para la creación de espacios

que promuevan la participación activa del niño/a y se ofrezcan oportunidades para el aprendizaje y desarrollo emocional. De igual forma, merece la pena identificar las expectativas y creencias de los compañeros de comunicación en torno a las personas con NCC, y las emociones en general, ya que estas pueden impactar en el proceso de socialización emocional. Los hallazgos ofrecen evidencias sobre la importancia de valorar, brindar y promover servicios e intervenciones de CAA centradas en la familia que garanticen los derechos emocionales y comunicativos de los menores con NCC.

Conclusions

L'aprenentatge emocional és un procés continu i permanent que ocorre a través de la socialització que es dóna gràcies a la comunicació i el llenguatge. La infància és una etapa clau per a promoure converses sobre emocions que facilitin l'adquisició de competències. Quan es té un repte comunicatiu important, l'expressió, comprensió i socialització emocional es veuen alterats. La comunicació sobre emocions en infants amb necessitats complexes de comunicació (NCC) és un tema que sovint manca en la literatura científica i la seva recerca pot ser de gran rellevància per a aquest col·lectiu, les seves famílies i el seu entorn. Els mètodes de comunicació augmentativa i alternativa (CAA) i la formació a l'entorn són una solució per a moltes persones que tenen dificultats per a comunicar-se per mitjans convencionals i pot ser de gran utilitat per a incentivar converses sobre emocions. Això possibilitaria avançar cap a una comunicació amb major riquesa i profunditat emotiva, permetent conèixer, entendre, respectar i acompanyar el món emocional de les persones amb NCC, afavorint el seu benestar emocional.

Aquesta tesi està conformada per tres estudis que contribueixen a la investigació, comprensió i promoció de la comunicació al voltant de les emocions en una mostra de nens/es amb NCC i les seves mares i pares. El tenir una necessitat complexa de comunicació no vol dir que no s'experimentin emocions, només mostra que es requereixen d'uns certs

recursos i estratègies per tal que les nenes i els nens puguin identificar, comunicar, regular i parlar de les emocions eficientment. Les troballes mostren la necessitat de brindar accés a vocabulari i experiències relacionades amb les emocions perquè els infants participin en converses emocionals i n'aprenguin d'elles. Per a això, és fonamental incloure a la família i a altres persones clau per a oferir un acompanyament que estigui d'acord amb l'entorn lingüístic i sociocultural de l'infant. Acompanyar i donar formació als/les companys/es de comunicació pot ser essencial per a la creació d'espais que promoguin la participació activa dels infants i s'ofereixin oportunitats per a l'aprenentatge i desenvolupament emocional. De la mateixa manera, val la pena identificar les expectatives i creences dels/ de les companys de comunicació en relació a les persones amb NCC, i les emocions en general, ja que aquestes poden impactar en el procés de socialització emocional. Les troballes ofereixen evidències sobre la importància de valorar, brindar i promoure serveis i intervencions de CAA centrades en la família que garanteixin els drets emocionals i comunicatius dels menors amb NCC.

Conclusions

Emotional learning is a continually unfolding process that occurs through socialization, which is not possible without communication and language. Childhood is a crucial stage for promoting emotional conversations and supporting the acquisition of emotional competencies. When having a complex communication challenge, the emotional expression, comprehension, and socialization are altered. Communication about emotions in children with complex communication needs (CCN) is a topic that has not often emerged in the scientific literature, and its research could be of great relevance for this group, their families and the community where they are involved. Augmentative and alternative communication methods and communication partners training are solutions for individuals

who have difficulties communicating with speech and non-verbal conventional modes, and could be beneficial in encouraging emotional conversations. This would enable communication with greater emotional richness and depth, allowing communication partners to know, understand, support, and respect the emotional worlds of people with CCN, favoring their emotional well-being.

This dissertation includes three studies that contribute to the research, comprehension, and promotion of communication around emotions in children with CCN and their parents. Having complex communication needs does not mean that emotions are not experienced; it only indicates that certain resources and strategies are required for children to be able to identify, communicate, regulate, and talk about emotions efficiently. The findings show the need to provide access to vocabulary and experiences related to emotions so that children can participate in emotional conversations and learn from them. For this, it is essential to include the family and key communication partners to offer support in line with the child's linguistic and socio-cultural context. Accompanying and training communication partners can be essential for creating spaces that promote the child's active participation and offer opportunities for emotional learning and development. Similarly, it is worth identifying the communication partners' expectations and beliefs around individuals with CCN, and emotions in general, because these might impact the process of emotional socialization. The findings demonstrate the importance of valuing, providing, and promoting family-centered AAC services and interventions that guarantee the children's emotional and communication rights.

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Anexos

Anexo 4-1

El Perfil de Desarrollo Temprano de Competencias Emocionales (EDEC-P): Proceso de Aplicación Sugerido (versión en español)

El Perfil de Desarrollo Temprano de Competencias Emocionales (EDEC-P): Proceso de Aplicación Sugerido

Rangel-Rodríguez, Badia, Blanch, and Wilkinson (2020)

Información de contacto: Gabriela A. Rangel-Rodríguez (gabriela.rangeln@gmail.com)

Acerca del Perfil EDEC (EDEC-P)

¿Qué es el EDEC-P?

El Perfil de Desarrollo Temprano de Competencias Emocionales [por sus siglas en inglés: Early Development of Emotional Competence Profile (EDEC-P)] es un perfil de apoyo para que el profesional resuma la información obtenida de la herramienta EDEC (ver: Na, Wilkinson y Liang, 2017) y presente un análisis de los retos percibidos, pasos siguientes en la intervención y posibles estrategias para alcanzar objetivos relacionados con promover una comunicación emocional en personas con necesidades complejas de comunicación (NCC) que pueden beneficiarse de comunicación aumentativa y alternativa (CAA).

¿Por qué desarrollamos el EDEC-P?

Al igual que con la herramienta EDEC (Na, Wilkinson y Liang, 2017), el EDEC-P busca conscientizar sobre la relación entre el lenguaje y las competencias emocionales, y asegurar que la intervención comunicativa y psicológica de un individuo con NCC deba incluir el lenguaje para hablar de las emociones en formas que sean consistentes con los valores y metas del contexto sociocultural del individuo. El EDEC-P también se desarrolló con el propósito de ser compartido con padres, madres y/o profesionales (escuela, otros clínicos) para crear conciencia y comprender el estado emocional de la persona con NCC, así como proponer pautas para fomen-tar el desarrollo emocional del niño/a y orientar el diseño e intervención en CAA.

¿Quién usa la plantilla EDEC-P?

Logopedas, terapeutas de lenguaje, psicólogos/as y otros profesionales (por ejemplo, terapeutas ocupacio-nales) que trabajan con personas con NCC y desean orientar la toma de decisiones clínicas sobre próximas inter-venciones a nivel emocional y comunicativo.

Idiomas

El EDEC-P está diseñado para usarse en diferentes idiomas. Actualmente, tenemos disponibles versiones en inglés y español. Comuníquese con el autor para la traducción a otros idiomas.

Contenidos y Organización

Sección 1 "Sobre mi": incluye una imagen o fotografía del niño/a e información sobre el/ella, sus fortalezas, emociones y habilidades comunicati-vas, así como información obtenida sobre los com-pañeros/as de comuni-cación.

Sección 2 "Retos y Estrate-gias": establece los objetivos de comunicación emocional esperados a corto plazo, así como una presentación de los retos y estrategias sugeridas para la intervención con el niño/a y sus compañeros/as de comunicación.

1

Proceso Sugerido para Usar el EDEC-P

1 Administra la Entrevista EDEC

2 Extrae y Organiza la Información Recabada (Completa la Sección 1)

3 Identifica los Retos del Niño/a y sus Compañeros/as de Comunicación.

4 Crea un Plan para Fomentar las Competencias Emocionales y Comunicativas (Completa la Sección 2)

5 Comparte el EDEC-P y Obtén Retroalimentación.

Paso 1: Administra la Entrevista EDEC a las y los Compañeros de Comunicación.

Es fundamental que la persona que realiza la entrevista se familiarice con la herramienta EDEC y sus objetivos. Sentirse cómodo con el propósito de la entrevista, el lenguaje y las preguntas sugeridas ayudará a:
a) acompañar al entrevistado en caso de confusión con cualquier término o duda
b) permitir que el evaluador haga otras preguntas que le ayuden a tener una mejor perspectiva del estado actual emocional y comunicativo de la persona con NCC, y tener una visión clara de su contexto social (antecedentes socioculturales y respuestas comunes que el entorno hace a las expresiones emocionales del niño/a).

Paso 2: Extrae y Organiza la Información Recabada.

Es posible que, en el transcurso de la entrevista, los entrevistados hayan dado una respuesta a una pregunta, pero más adelante ampliar la respuesta anterior o viceversa (hablar sobre un tema que se discutirá posteriormente en la entrevista). Muchas veces la información se expresará de forma orgánica durante el transcurso de la entrevista. Por lo tanto, para completar la primera sección del EDEC-P, es importante releer la entrevista, extraer y organizar la información recopilada en áreas específicas:

1. Las Características del Niño/as: ¿Quién es el niño/a? – ¿Cuáles son sus intereses/pasatiempos? ¿Qué disfruta? ¿Qué le desagrada?

2

2. La Comunicación de las y los Compañeros de Comunicación: ¿Cómo el entorno se comunica con el niño/a? – ¿Qué necesita el niño/a de sus compañeros/as de comunicación para entender mejor su entorno? ¿Qué tipo de apoyos da el entorno para favorecer la comunicación con el/la niño/a?

3. Los Métodos de Comunicación del Niño/a: ¿Qué métodos (lingüísticos y no lingüísticos) utiliza el niño/a para comunicarse? ¿Qué métodos están a su alcance/disposición?

4. El Mundo Emocional del Niño/a: ¿Cuáles son las emociones que el entorno puede reconocer en el niño/a? ¿Qué emociones siente/expresa el niño/a?

5. Las Expresiones Emocionales del Niño/a: ¿Cómo nota el entorno que el niño/a está experimentando una emoción?, ¿Qué expresiones se interpretan como una emoción?, ¿Cómo expresa el niño/a sus emociones (modos lingüísticos y no lingüísticos)? ¿Cuál es la expresión emocional preferente del niño/a?

6. El Reconocimiento y las Respuestas del Niño/a ante Emociones de Otros: ¿El niño/a responde a expresiones emocionales de los demás? ¿Cómo? ¿El niño/a tiene formas de responder a los estados emocionales de los demás? ¿Cuáles?

7. El Apoyo Emocional del Entorno: ¿Cómo responden las y los compañeros de comunicación ante las emociones del niño/a? ¿Apoyan al niño/a a pasar de una emoción desagradable a una agradable? ¿Cómo? ¿Identifican qué necesita el niño/a? ¿De qué forma?

Escribe la información específica en el área correspondiente de la primera página (sección 1) de la plantilla EDEC-P. Te sugerimos que escribas la primera parte del perfil en primera persona; consideramos que, al hacerlo de esta manera, hay un impacto mayor en el lector y facilita la comprensión de una forma amigable.

Esta área muestra algunas características del niño/a (información general, temperamento, intereses/ pasatiempos, lo que le gusta/no le gusta).

Añade una imagen aquí

Mi nombre es:

Tengo: ___ años

Sobre mi

Me gusta:

No me gusta:

Mis juegos favoritos:

Estos datos fueron reportados por: __

Formas en que la gente se comunica conmigo:

Actualmente, para comunicarme utilizo:

Emociones que expreso:

Frecuentemente   Algunas veces

Actualmente, expreso mis emociones con:

Cuando otros expresan sus emociones, yo:

Maneras actuales en que las personas responden cuando siento una emoción:

Esta parte describe la comunicación general en dos niveles:
a) La comunicación de las/los compañeros de comunicación: ¿Cómo otras personas se comunican con el niño/a (en general)?
b) Los métodos de comunicación del niño/a: ¿Qué métodos utiliza el niño/a para comunicarse? y ¿Cuáles están disponibles?

Este apartado se enfoca en:
a) Las emociones del niño/a (reconocidas por las/los entrevistados)
b) Las maneras actuales que el niño/a usa para expresar emociones.
c) El reconocimiento y respuesta que da el niño/a ante emociones de otros.

Esta área da información acerca del apoyo que dan las y los compañeros de comunicación en el área emocional: Actualmente ¿Cómo responde el entorno ante expresiones emocionales del niño/a?

3

Paso 3: Identifica los Retos del Niño/a y del Entorno (Compañeros de Comunicación).

Identifica los retos del niño/a y de sus compañeros/as de comunicación relacionados con el área emocional y comunicativa. ¿hay algo que pueda mejorar la comunicación sobre las emociones con el niño/a? Presta atención especial a:

Persona con NCC	Compañeros/as de Comunicación
• Modos de comunicación emocional.	• Reconocimiento emocional del niño/a con NCC.
• Lenguaje emocional receptivo y expresivo: nombra/etiqueta emociones, explica/entiende emociones (sus posibles causas), y respuestas ante una emoción (¿qué necesita/puede hacer el niño/a ante una emoción específica?).	• Respuestas a emociones. • Creencias sobre hablar de emociones con otros (y especialmente al hablar con la persona con NCC).
• Uso y disponibilidad de expresiones emocionales lingüísticas (vocabulario emocional actual para expresar emociones y hablar de ellas).	• Emociones con las que se sienten cómodos/incómodos expresar frente a la persona con NCC. • Vocabulario y expresión emocional (palabras utilizadas, formas de expresión emocional que son aceptadas en el entorno). • Apoyos brindados al niño/a que fomentan la comunicación (en general y acerca de las emociones).
¿Cuáles son los desafíos/retos emocionales del niño/a? ¿Cuáles serían los retos del niño/a para lograr el objetivo propuesto? ¿Son suficientes los medios existentes de expresión emocional del niño/a para satisfacer sus necesidades? ¿Existen algunos retos relacionados con su CAA? ¿Hay algunos desafíos a nivel conductual? ¿Desafíos motivacionales? ¿Barreras en la comunicación?	*¿Cómo puede el entorno ayudar al niño/a a expresar sus emociones? ¿Cuáles son los desafíos/retos de las y los compañeros de comunicación? ¿Dan oportunidades para promover el desarrollo emocional? ¿Hay algunas emociones que prefieren evitar? ¿Tienen una preocupación específica sobre el niño/a referente a las emociones? ¿Es posible acompañarlos en ello?*

Contexto
• Posibles oportunidades para hablar de emociones. • Eventos o situaciones socioculturales específicos que puedan ser de interés para hablar de emociones. *¿Qué actividades pueden ser agradables y divertidas para el niño/a y sus compañeros/as de comunicación que puedan fomentar el hablar sobre las emociones?*

4

Paso 4: Elabora un Plan que Fomente las Habilidades/Competencias Emocionales y Comunicativas.

Una vez identificados los retos, establece metas y objetivos que se centren en la promoción del desarrollo de habilidades emocionales y comunicativas. *¿Cuáles son las necesidades emocionales del niño/a? ¿Qué objetivos podrían ser beneficiosos para el niño/a? ¿Qué necesita el niño/a de sus compañeros/as de comunicación para obtener el objetivo propuesto (considera la información recopilada sobre las y los compañeros de comunicación del niño/a)?*

Piensa en estrategias para alcanzar cada objetivo: *¿Qué necesitan las y los involucrados para lograr el objetivo? ¿Tener un espacio de acompañamiento e instrucción específica? ¿Aumentar el vocabulario? ¿Diseñar tableros CAA? ¿Identificar dónde y cómo hablar sobre las emociones? ¿Ofrecer oportunidades comunicativas en entornos naturales? ¿Introducir apoyos específicos?*

Prioriza los objetivos (acorde al desarrollo del niño/a) y determina los pasos y estrategias que se deben tomar a corto plazo para lograr el primer objetivo. Escríbelo en el área correspondiente de la segunda página (sección 2) de la plantilla del EDEC-P.

En este paso, presta especial atención a:

• Los intereses del niño/a y sus compañeros/as de comunicación (las primeras estrategias sugeridas deben ser aplicables en situaciones divertidas y cómodas para ambos).
• Situaciones/actividades que ya realizan (identifica si ellos pueden crear oportunidades para promover conversaciones emocionales en momentos que ya comparten en su día a día).

5
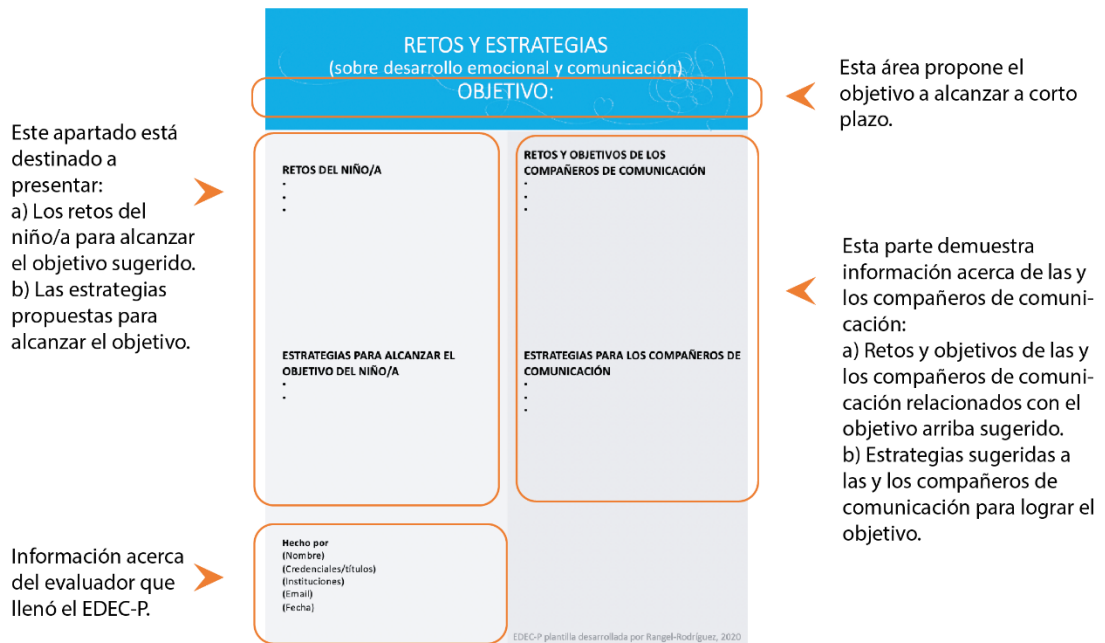
Paso 5: Comparte el EDEC-P y Obtén Retroalimentación.

Comparte el perfil con el adulto. Verifica si los datos presentados en la primera sección son correctos y si las y los compañeros de comunicación desean evitar, agregar o cambiar algún contenido. Explica la segunda página y asegúrate de que el objetivo, los retos y las estrategias sugeridas son claras y las/los compañeros de comunicación están de acuerdo con ellas. En caso de dudas, acompaña a los adultos y explica, comenta y ajusta el plan hasta que las personas involucradas comprendan y se sientan cómodas con el plan. Si es necesario, realiza cambios al perfil. Recuerda que la plantilla propuesta puede ser modificada y presentada de otra forma dependiendo de la retroalimentación y las necesidades específicas del niño/a y sus compañeros/as de comunicación.

En la medida de lo posible, consideramos importante compartir también el EDEC-P con la persona con NCC y preguntar si se siente cómodo/a con la información escrita en la primera sección. Si la respuesta es negativa, identifica qué área preferirían editar, agregar o cambiar, haz las modificaciones adecuadas hasta que la persona con NCC se sienta cómoda y con la sensación de que se respeta su privacidad emocional. Además, pregunta con quién le gustaría compartir el EDEC-P, para que otros le conozcan mejor y le acompañen a tener más conversaciones sobre emociones. Un ejemplo de cómo presentar esto a las personas con NCC podría ser:

> *Queremos compartir algunas cosas sobre ti con tus profesores para que puedan conocerte mejor. Esto les ayudará a comprender mejor tus emociones y a brindarte un apoyo eficaz si es necesario.*
>
> *¿Te gusta? ¿Te gustaría compartir esto? ¿Con quién? ¿Te gustaría agregar algo más? ¿Hay algo que prefieras evitar?*

Dependiendo de la capacidad del niño/a para comprender y expresar sus ideas, el evaluador/a puede hacer preguntas específicas para determinar el nivel de satisfacción del niño/a y su retroalimentación.

Seguimiento Sugerido

Te sugerimos dar seguimiento al plan propuesto en el EDEC-P. Puede ser necesario volver a administrar la entrevista EDEC y rehacer el EDEC-P para informar el estado emocional y comunicativo actual del niño/a, identificar el impacto de las estrategias ejecutadas y apoyar el nuevo proceso de toma de decisiones hacia los siguientes pasos para continuar con el fomento al desarrollo de habilidades emocionales y comunicativas.

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Anexo 4-2

El Perfil de Desarrollo Temprano de Competencias Emocionales (EDEC-P): Proceso de Aplicación Sugerido (versión en inglés).

The Early Development of Emotional Competence Profile (EDEC-P): Suggested Process

Rangel-Rodríguez, Badia, Blanch, and Wilkinson (2020)

Contact Information: Gabriela A. Rangel-Rodríguez (gabriela.rangelr@gmail.com)

About the EDEC Profile

What is the EDEC-P?

The Early Development of Emotional Competence Profile (EDEC-P) is a suggested profile where the clinician distills information obtained from the EDEC tool (see Na, Wilkinson and Liang, 2017), and presents an analysis of the challenges perceived, the next steps and possible strategies to achieve goals related to enhance emotional communication in people with complex communication needs (CCN) that could benefit from augmentative and alternative communication (AAC).

Why did we develop the EDEC-P?

Just like with the EDEC tool (Na, Wilkinson, and Liang, 2017), the EDEC-P seeks to raise awareness about the relation of language and emotional competencies, and to ensure that an individual's communicative and psychological intervention must include language to discuss emotions in ways that are consistent with the values and goals of the individual's social-cultural context. The EDEC-P was also developed to be shared with parents or school/clinical professionals to raise awareness and better understand the emotional status of the individual with CCN, as well as to proposed guidelines to foster the child's emotional development and to guide AAC design and intervention.

Who uses the EDEC-P template?

Speech-Language Pathologists, Psychologists, or other professionals (e.g., Occupational Therapists) who work with individuals with CCN, and want to guide clinical decision-making about upcoming emotional and communicative interven-tions.

Languages

The EDEC-P is intended to be used across different languages. Currently, we have English and Spanish versions available. Please contact the author for translation into other languages.

Contents and Organization

Section 1 "About me": includes an image or picture of the child and information about him/her, their strengths, emotions, and communicative skills, as well as information about communication partners' input.

Section 2 "Challenges and Strategies": consists of functional emotional communication goals expected in the short term, challenges and suggested strategies for intervention with the child and the child's communication partners.

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Suggested Process for Using the EDEC-P

1 Administer the EDEC

2 Extract and Organize the Information (Fill in 1st section)

3 Identify the Child and Communication Partners' Challenges

4 Create a Plan to Foster Emotional and Communicative Competencies (Fill in 2nd section)

5 Share the EDEC-P and Obtain Feedback

Step 1: Administer the EDEC Tool to the Child's Communication Partners that You Consider.

The person who conducts the interview must become familiar with the EDEC tool and its goals. Being comfortable with the interview purpose, the language, and the suggested questions will help to:
(a) assist the interviewee in case of confusion with any term or query, and
(b) allow the assessor to ask other questions that support him/her to have a better perspective of the current emotional and communicative status of the individual with complex communication needs, and to have a clear vision of their social-context (socio-cultural background and communication partners common responses to child's emotional expressions).

Step 2: Extract and Organize Specific Information from the Collected Data.

It's possible that in the interview, communication partners may give an answer to a question but then later say something that extends the earlier answer or vice-versa (talk about a topic that will be discussed later). Many times the information will be expressed organically over the course of the interview. Hence, to complete the 1st section of the EDEC-P, it is important to re-read the interview, extract, and organize the information collected into specific areas.

1. The Child's Characteristics: Who is the child? – What are their interests/hobbies? What things s/he enjoy? What things s/he doesn't like?

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2. The Partners' Communicative Input: How CPs communicate with the child? - What does the child need from their partners to have a better understanding of the world? How do the child's communication partners scaffold communication?

3. The Child's Modes of Communication: What are the methods (linguistic and non-linguistic) used by the child to communicate? What are the methods available?

4. The Child's Emotional World: What are the emotions that the CPs can recognize in the child? What emotions does the child feel/express?

5. The Child's Emotional Expressions: How do CPs notice the child is experiencing an emotion? What expressions are interpreted as a specific emotion? How does the child express emotions (linguistic and non-linguistic modes)? What are the child's emotional expression preferences?

6. The Child's Recognition and Responses to Others' Emotions: Does the child respond to others' emotional expressions? How? Does the child have ways to respond to others' emotional states?

7. The Partners' Emotional Input: How do the child's communication partners respond to the child's emotions? Do they assist the child transiting from an unpleasant emotion to a pleasant one? How? Do they identify what does the child need? How?

Write the specific information in the corresponding area in the 1st page/section of the EDEC-P template. We suggest you write the first part of the profile in the first person; we believe this would have the greatest impact on the reader and may be easier to learn and more family-friendly.

This area shows some child's characteristics (general information, temperament, interests/hobbies, likes/dislikes)

This section describes general communication in two levels:
a) The partners' communicative input: How others communicate with the child (in general)?
b) The child's modes of communication: What are the methods used (and available) by the child to communicate?

This section focuses on:
a) The child's emotions (recognized by communication partners),
b) The current ways the child expresses emotions, and
c) The child's recognition and responses to others' emotions.

This area gives information about the partners' emotional input: How do they currently respond to child's emotional expression?

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Step 3: Identify the Child and Communication Partners' Challenges.

Identify both the individual with CCN and communication partners' barriers and challenges related to the emotional and communicative area. Is there something that could enhance communication about emotions with the child? Pay special attention to:

Individual with CCN

• Modes of emotional communication.

• Receptive and expressive emotional language: labeling, explaining/understanding emotions (possible causes), and responding to emotions (what does the individual need/can do?).

• Use and availability of linguistic emotional expressions (current emotional vocabulary to express emotions and talk about them).

What are the child's emotional challenges? What would be the child's challenges to achieve the proposed goal? Are the existing means of the child's emotional expression sufficient to serve their needs? Are there some AAC challenges? Behavioral challenges? Motivational challenges? Communication barriers?

Communication Partners

• Emotional recognition of the individual with CCN.

• Responses to emotions.

• Beliefs about talking about emotions with others (and specifically with the individual with CCN).

• Emotions that they feel comfortable/uncomfortable expressing in front of the person.

• Emotional vocabulary and expression (words used, ways of emotional expression that could be acceptable).

• Prompts to promote communication (in general and about emotions) with the person with CCN.

How can the communication partners scaffold the child to express emotions? What are the communication partners' challenges? Do they give opportunities to promote emotional development? Are there some emotions they prefer to avoid? Do they have a specific concern about the child referring to emotions? Is it possible to assist them with it?

Context

• Possible opportunities to talk about emotions.

• Special socio-cultural events that could be of interest to communicate about emotions.

What activities could be enjoyable and pleasant for the child and their communication partners to talk about emotions?

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Step 4: Create a Plan that could Foster Emotional and Communicative Skills/Competencies.

Once you identify the challenges, establish goals and objectives that focus on the promotion of emotional and communicative development and skills. *What are the child's emotional needs? What goals could be beneficial for the child? What does the child need from communication partners to pursue the proposed goal (consider the information collected about the child's communication partners)?*

Think of strategies to achieve each goal: *What do those involved need to achieve the goal? Receive a specific instruction? Increase vocabulary? Design AAC boards? Identify where and how to talk about emotions? Offer naturalistic communicative opportunities? Introduce specific prompts?*

Prioritize the goals (according to the child's development) and determine the steps and strategies that need to be taken to achieve them in the short-term. Write them in the corresponding area on the 2nd page/section of the EDEC-P template.

In this step, pay special attention to:

• Interests from the child and CP (the first strategies suggested must be applicable in fun and comfortable situations for both).
• Situations/activities they already do (identify if they could create opportunities to promote emotional conversations in moments they already have in their daily life).

This area is intended to present:
a) the child's challenges to achieve the suggested goal.
b) The strategies proposed to achieve the child's goal.

Information about the assessor who filled out the EDEC-P

CHALLENGES AND STRATEGIES
(About emotional development and communication)
GOAL:

CHILD'S CHALLENGES
:
:
:

COMMUNICATION PARTNERS' CHALLENGES / GOALS
:
:
:

STRATEGIES TO ACHIEVE CHILD'S GOAL
:
:
:

COMMUNICATION PARTNERS' STRATEGIES
:
:
:

Made by
(Name)
(Credentials)
(Institution)
(Email)
(Date)

EDEC-P template developed by Rangel-Rodríguez, 2020

This area proposes the goal to achieve in the short term.

This section displays information about communication partners:
a) Challenges and goals from communication partners related to the suggested central goal.
b) Strategies for communication partners to achieve the goal.

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Step 5: Share the EDEC-P and Obtain Feedback.

Share the profile with the adult. Verify if the data presented in the 1st section is correct and if communication partners would like to avoid, add, or change any content. Explain the 2nd page and make sure that the goal, challenges, and strategies suggested are clear, and they agree with them. In case there are doubts, assist the adults and explain, discuss and adjust the plan until the people involved understand and feel comfortable with the plan. Make changes to the profile if needed. Remember that the template proposed can be modified and presented differently according to the feedback and unique needs of the communication partners and the child.

To the extent possible, we consider it important also to share the EDEC-P with the individuals with CCN and ask them if they feel comfortable with the information written in the 1st section. If the answer is not, identify what area they would prefer to avoid, add or change, and make proper modifications until the person with CCN feels comfortable and with a sense that his/her emotional privacy is respected. Additionally, ask who they would like to share the EDEC-P with so that people get to know them better and assist them in having more conversations about emotions. An example of presenting this to individuals with CCN could be:

> *We want to share some things about you with your teachers so they can know you better. These will help them to understand your feelings better and support you effectively if needed.*
>
> *Do you like it? Would you like to share this? With whom? Would you like to add something else? Is there something you prefer to avoid?*

According to the child's ability to understand and express such ideas, the clinician can ask specific questions to determine the child's validation.

Suggested Follow-up

We suggest you to follow-up on the plan proposed in the EDEC-P. It may be necessary to readminister the EDEC interview and remake the EDEC-P to report the current child's emotional and communicative status, identify the impact of the strategies executed, and support the new decision-making process towards the next steps in fostering the development of emotional and communicative skills.

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Anexo 5-1a

Supplementary Material 1. STEPS Instruction Page (adapted) (Rangel-Rodríguez, Badia, et al., 2021)

STEPS Training
Strategies to Talk about Emotions as Partners

Instruction Page

	Ask	Wait	Respond	
	Allow the board to be within reach of your child, but don't give him clues (e.g. pointing directly to the board). You can repeat/rephrase your question 1-2 times to help your child understand it. If necessary, you can provide double-choice questions (e.g. is the lion sad or angry?) by pointing to the images on the board.	Pause for at least 5 seconds or until your child begins to respond. Look directly at your child to convey an expectation that it is his turn in the conversation. Allow the emotional communication board to be within reach of your child, but do not provide clues (e.g. pointing directly to the board).	If your child answers properly, provide active listening (repeat what your child said) while pointing to the answer on the communication board.	If your child answers something different or does not respond after 10 seconds, give the correct answer while pointing to the corresponding symbol on the communication board.
1. Talk about the NAME of emotion	**How** does the lion feel?	… pause…	You're right, the lion is sad	The lion is sad
			pointing the word(s) on the board	
2. Talk about the CAUSE of emotion	**Why** is the lion sad?	… pause…	You're right, the lion is sad because he has no friends	The lion is sad because he has no friends
			pointing the word(s) on the board	
3. Talk about the RESPONSE to that emotion	**What** can the lion do?"	… pause…	You're right, the lion can use his words and ask them to play together	The lion can use his words and ask them to play together
			pointing the word(s) on the board	

*Remember that you can comment using the board to model and encourage communication without requiring it.

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Adaptation from Na & Wilkinson (2018)

Anexo 5-1b

STEPS Instruction Page (adapted) (versión en español)

Enseñanza STEPS

Estrategias para hablar de emociones entre iguales

Hoja de Instrucción

	Pregunta	Espera	Responde	
	Permite que el tablero esté al alcance de tu hij@, pero no le des pistas (p.ej. señalando el tablero). Puedes repetir/reformular 1-2 veces tu pregunta para ayudar a que tu hij@ la entienda. De estar muy necesario, puedes brindar preguntas de doble alternativa (p.ej. ¿el león está triste o enojado?) señalando en el tablero las imágenes.	Haz una pausa durante al menos 5 segundos o hasta que tu hij@ comience a responder. Mira directamente a tu hij@ para transmitir una expectativa de que es su turno en la conversación. Permite que el tablero de comunicación emocional esté al alcance de tu hij@, pero no proporciones pistas (p.ej. señalando en el tablero).	Si contesta adecuadamente, da escucha reflexiva (repite lo que tu hij@ dijo) mientras señalas la respuesta en su tablero de comunicación.	Si contesta algo diferente o no responde después de 10 segundos, dale la respuesta correcta mientras señalas el símbolo correspondiente en su tablero de comunicación.
1. Habla del NOMBRE de la emoción	**¿Cómo se siente** el león?	… pausa…	Tienes razón, el león está triste	El león está triste
			señalando la palabra(s) en el tablero	
2. Habla de la CAUSA de la emoción	**¿Por qué** está triste el león?	… pausa…	Tienes razón, el león está triste porque no tiene amigos	El león está triste porque no tienes amigos
			señalando la palabra(s) en el tablero	
3. Habla de la RESPUESTA/ AFRONTAMIENTO ante la emoción	**¿Qué puede hacer** el león?"	… pausa…	Tienes razón, el león puede usar sus palabras y pedir que jueguen juntos	El león puede usar sus palabras y pedir que juegan juntos
			señalando la palabra(s) en el tablero	

*Recuerda que puedes hacer comentarios usando el tablero para modelar y alentar la comunicación sin requerirla.

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Anexo 5-2

Supplementary Material 2. Example of AAC emotion-related boards (Rangel-Rodríguez, Badia, et al., 2021)
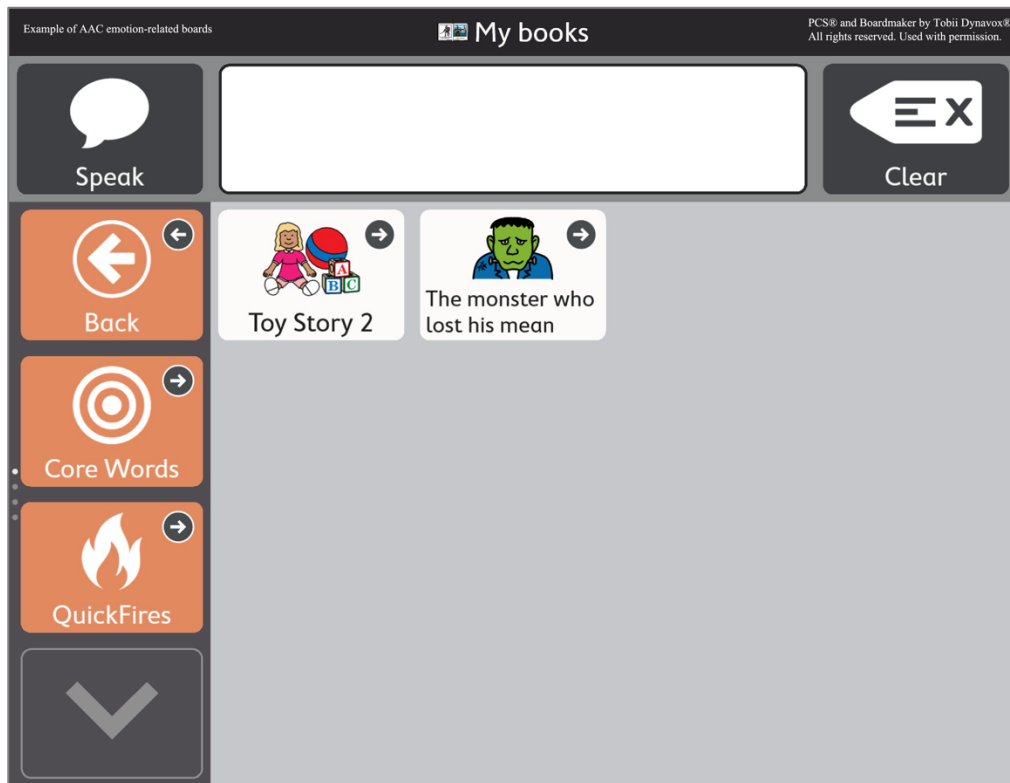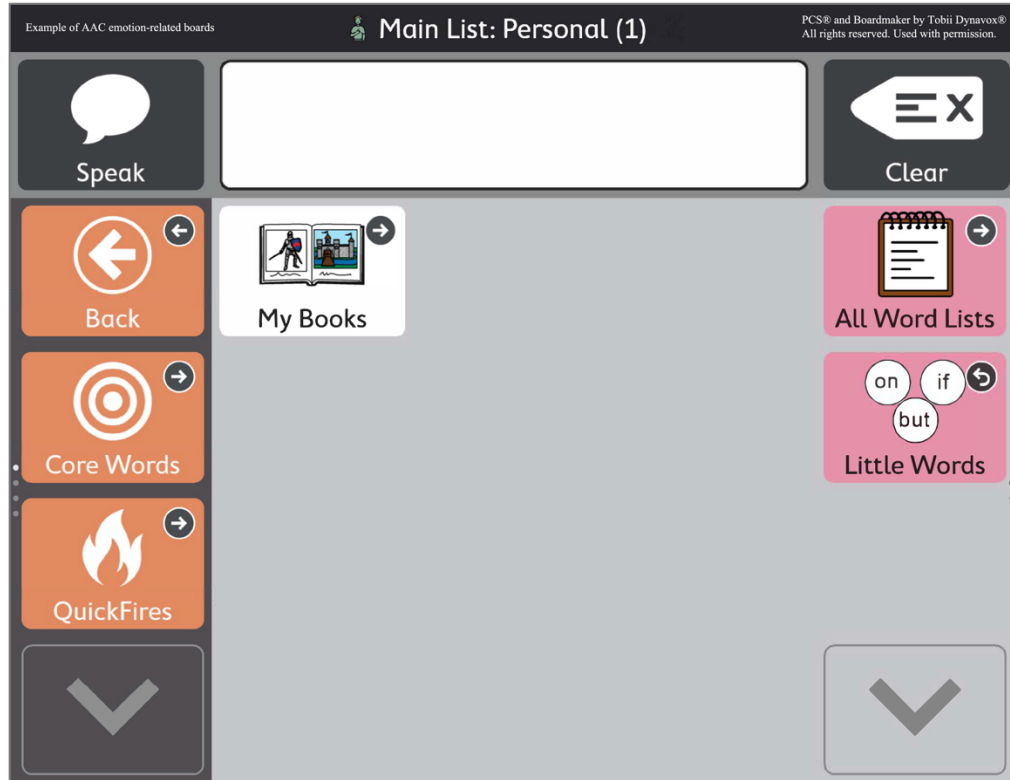
🧸 Toy Story

Speak

Clear

Back

Core Words

QuickFires

friend	new toys	unknown toys	can't
they are alive	friend in trouble	fly	can
	buzz	woody	
emotions	to inifinity and beyond		what can I do?

🫘 Main List: Feelings (1 / 2)

Speak

Clear

Back

Core Words

QuickFires

happy	sad	mad	All Word Lists
worried	frustrated	irritated	Little Words
bored	surprised	disappointed	embarrassed
excited	love	scared	

Anexo 5-3

Supplementary Material 3. Observation Instrument for interactions between communication partners and children with CCN during a storybook-reading activity (full version). (Rangel-Rodríguez, Badia, et al., 2021)

Macro-dimension	Dimension	Subdimension/Units (codes)/Examples

Adult's Interactive Communication	Behaviors that encourage conversations	Encourages participation openly*
		    closed-ended question (acQ): Do you think he is sad?
		    open-ended question (aoQ): Why is she angry?
		    two choices (aTC): Do you think the wizard is scared or surprised?
		    sentence completion (aSC): The mouse feels excited because…
		    multiple choices (aMC): does the horse need to take a break, ask for help, or explain how he/she feels?
		    repeat question (aRQ)
		 Turn-taking signal*
		    indirect turn (IT): waits for response
		    direct turn (DT): it's your turn
		 Responds/gives feedback*
		    multimodal feedback (aFB): you are right, the monster feels happy
		    non-verbal feedback (anvFB): looks at the child, smiles, nods
		    gives answer (aAns): they feel disappointed because…
		 Encourages participation without requiring it*
		    personal comment (aPC): I think the child feels ashamed because he is naked [includes comments that respond to child's questions].
		 Encouraging comments (aEnC): you can do it; try it; wanna say something more?
		 Encourage participation using AAC
		    encourages AAC use (aEnAAC): you can use your [AAC system]

	Behaviors that may difficult or interfere in the child's participation	Inform about erroneous answer (ERAns) Responds immediately [without waiting] (RI) Interrupts the child (AIC) Related to AAC Keep AAC out of the child's reach (aKOAAC) Ignores child's response (aIGN)
	Behaviors that promotes language comprehension and language clarification.	Explains vocabulary (aExV): thrilled means feeling extremely excited. Interprets/clarifies communication (aCIC): the child says "sad," adult comments "ooh you mean that the penguin is sad"

	Behaviors that model communication	AAC model (aAAC): model the AAC use (select words in the child's system)
		 Gestures/Signs
		    manual signs model (aMS): "love" with manual signs.
		    emotional gesture model (aEG): surprised face
		 Pointing (aBP): point to the book or other object (no AAC) to give explanations/ comments. e.g., look at his face (pointing to the book) he is sad.
		 Recast (aRec): responses that correct or add grammatical detail and/or information to the child's utterance, e.g., child says "me angry," adult responds "I am angry"
		 Direct Communication Support (aDSC): adult supports the child directly to communicate (e.g., take child's hand to select the word in AAC, prompt to say a specific word or help physically to make a sign/gesture.)

	Behaviors that focus the child on tasks to perform	Orders/requests about tasks/behaviors to be carried out by the child
		    Positive order (PO): pay attention, manual sign of silence, come here.
		    Negative order (NO): don't do that, don't guess
		 Informative comments about the activity/task about to perform (ICT): we are going to read a book.
		 Physical support [excludes support to communicate]
		    To do something (TDS): helps the child turn the page.
		    To stop something (TSS): removes objects from the child's hand to stop distraction.

	Conversational content	Non-emotional content (AO): where is the flower? Is it red or blue? do you want the toys? This is like the one your grandma has, which one would you like?
		 Emotional content*
		    label (AECn): how do you feel? / she is scared
		    reason (AECca): why he feels sad? / she feels sad because…
		    responses/coping strategies (AECrs): what can he do? / he needs a hug.
		    unspecific label (AECun): he feels good/bad, I'm ok.

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	Conversational theme* (related to)	Related to
		  storybook character (aCS): the dragon feels…, the grandma is so funny.
		  child (aCC): how would you [the child] feel? what would you do? What was your favorite part?
		  another person/situation (aCO): I [the mother] would do… I think your father will prefer to take a break.

	Behaviors related to the reading*	Reads (AR) Explains the storybook (aCexB) Paraphrase (P)

Child's interactive communication	Methods of expression*	Augmentative and Alternative Communication (cAAC)
		Auditory perceptible
		  vocal (cVB)
		  speech (cS)
		  word approximation (cWA)
		Visually perceptible
		  body movement (cBM): move head, change posture, etc.
		  action (cACT): run, jump, take something.
		  manual signs (cMS): sign language.
		  pointing (cP)
		  conventional gestures (cCG): gestures defined by the child's context with the intention to communicate (e.g., look up for yes, look down for no).
		  facial expressions (cFE): smiles.
		  emotional gestures (cEG): lips down for sad, crossing arms to express anger.

	Reasons to communicate	Refuses (cAv)
		Obtains/solicits (cOb)
		Behaviors in social interactions
		  Express interest/attracts attention (ISI)
		  Shows affection (ISA)
		  Shares (IS): share a toy.
		  Answers/gives information (cAnsw)
		  Asks questions (cQue)
		  Comments (cComm)
		  Asks for help/support (ISH)

	Conversational emotion-related content	Non-emotional content (COC)
		Emotional content*
		  label (CECn): angry, sad, happy, excited.
		  reason (CECca): the witch doesn't have friends; the girl receives a present.
		  responses/coping strategies (CECrs): the little prince needs to express his feelings.
		  unspecific label (CECun): good, bad, ok, well.

	Conversational theme* (related to)	Related to*
		  storybook character (cCS): the penguin felt angry.
		  child (cCC): I would feel happy; I don't like that book.
		  another person/situation (cCO): my friend would feel ashamed.

Distractions*		Child distraction (CDI) Adult distraction (ADI)

Impossibility of observation*		About the child
		  Lack of total visual access (cLTVA)
		  Lack of partial visual access (cLPVA)
		  Lack of auditory access (cLAA)
		About the communication partner
		  Lack of total visual access (aLTVA)
		  Lack of partial visual access (aLPVA)
		  Lack of auditory access (aLAA)

Interruptions*		Ambiental activity interruption (AmI): noisy sound, phone call. Video-camera interruption (VCI)

*category systems

Anexo 6-1

Actos Potencialmente Comunicativos de Expresión Emocional

Expresión Facial	Postura y Movimiento Corporal	Acciones (según contexto es convencional o no)
• Sonrisa • Mueca • Frunce ceño • Mirada (enfado, sorpresa...) • Cierra ojos • No mira (ignora) • Llanto/ lágrimas	• Reacción corporal (reflejo primitivo) • Cuerpo tiembla • Se encorva • Se retuerce • Cuerpo se tensa / rigidez • Hiperactivo/a / Agitado/a • Aletea • Mueve parte del cuerpo (brazos, cabeza, tronco, manos/dedos, piernas)	• Patear • Pellizcar • Morder • Abrazar • Besar (oclusión) • Aplaudir • Esconder • Correr • Dibujar • Otro_____

Vocalizaciones	Gestos (convencionales)	Lenguaje
• Risa • Lloriquea • Tono agudo • Tono grave • Tono de voz específico • Silencio	• Brazos cruzados o en cintura para enojo • Taparse cara para tristeza	• Señas manuales • Palabras (voz) • Palabras (CAA) • Escritura

Otros
• Repite una palabra • Ecolalia • Tartamudea • Sudor • Somatiza (convertir emociones en síntomas físicos, p.ej., vomito, fiebre, asma, pipí)

Anexo 6-2

Posibles Desencadenantes Emocionales en Menores con NCC

DETONANTES DE EMOCIONES DESAGRADABLES	
Causas biológicas, físicas o sensoriales	**Desafíos en tareas sociales, cognitivas, motoras o comunicativas**

• Sensaciones físicas (cansancio, hambre, sueño, frío/calor)
• Estimulación visual específica (oscuridad, demasiados colores)
• Estimulación auditiva específica (eco, ruido)
• Sensaciones corporales (frío / calor)
• Sensaciones vestibulares y propioceptivas (sensación de caerse)
	• Frustrarse porque:
	  o no puede / no logra lo que quiere.
	  o le lleva más tiempo hacer/lograr cosas
	• Dificultades para hacer amigos

Detonantes Intrapersonales	**Interacciones Interpersonales**
• Sentirse diferente (*"se siente triste porque no... come / camina / se comunica como los demás"*) • Sentirse vulnerable (la persona siente que no tiene formas de defenderse cuando es necesario)	• No ser entendido • Cuando alguien se va • Sentirse juzgado/a por otros • Sentirse forzado/a o presionado/a por otros • No ser tomado en consideración (sentirse ignorado/a, rechazado/a, tomar sus pertenencias sin permiso, hablar en nombre del niño/a)
No Obtener lo que se Espera	**Eventos Específicos**
• Recibir un no por respuesta • Detener una actividad / canción que deseaba continuar	• Situaciones (p.ej., clima emocional específico; ambiente tenso, conflictivo) • Medios de comunicación (películas de terror, música / canciones específicas, cuentos) • Eventos inesperados o nuevos

DETONANTES DE EMOCIONES DESAGRADABLES (OCULTAS)
Interacciones Sociales
• Reuniones sociales ("reprime la emoción porque le da vergüenza")

DETONANTES DE EMOCIONES AGRADABLES	
Disfrutar de actividades recreativas y de ocio	**Interacciones Interpersonales**
- Jugar - Leer - Escuchar música - Ver TV, series, películas… - Hacer bromas - Deporte (nadar, bicicleta, patinete…) - Paseo (naturaleza, parques temáticos, …)	- Participar en interacciones sociales (actividades con compañeros) - Disfrutar de la compañía de los demás - Recibir afecto / amor (abrazos, comentarios amorosos, caricias)
Detonantes Intrapersonales	**Comprensión del Mundo Externo**
Sentido de Logro	- Rutinas - Tiempo para adaptarse a un lugar nuevo - Anticipar lo que sucederá

Anexo 6-3

Respuestas usadas por los Padres/Madres ante Expresión Emocional de Menores con NCC

Disminuir Expresión Emocional	Reconocer/Fomentar Comunicación Emocional	Respuestas relacionadas con Eventos Detonantes de Emociones Desagradables

• Distraer (música, bromas, cambiar actividad).
• Evitar contacto (p.ej., dejar llorar).
• Cuestionar validez de experiencia emocional (p.ej. "no hay razón para enojarte", "estás exagerando").
• Castigar expresión emocional no convencional (p.ej. no iPad, no juegos).
• Medicar.
	• Confortar (beso, abrazo, cuidado, palabras de calma/confort).
	• Responder a necesidades (p.ej. entender razón de emoción y dar lo que necesita).
	• Ofrecer tiempo a solas (p.ej. "tómate un tiempo y regreso en 5 minutos").
	• Contención física.
	• Comprensión (p.ej. "entiendo que no quieres lavarte los dientes, pero tenemos que hacerlo).
	• Nombrar emoción (p.ej. "sé que estás enfadado/a").
	• Explicar o corroborar la causa de la emoción (p.ej. "creo que lloras porque... ¿es así?").
	• Ofrecer posibles estrategias, soluciones, respuestas (p.ej. "Respira, cuenta hasta 4", "usa tus palabras", "te voy a dar opciones para resolver esto… ¿A?, ¿B?").
	
	*Madres/Padres pueden intentar, pero al no obtener respuesta por parte del niño/a, refieren ignorar/disminuir comunicación emocional.
		• Anticipar situaciones difíciles/nuevas.
		   o A veces las discuten con el niño/a.
		   o A veces ofrecen opciones de respuesta.
		   o Avisan de apoyo (yo o tu maestra estaremos para ti).
		   o Avisan que darán reforzador/premio.
		• Prepararse con estímulos/objetos para apoyar a niño/a (p.ej. audífonos, juguetes).
		• Preparar plan (p.ej. "cómo responderán adultos").
		• Evitar situaciones.
		• Prepararse emocionalmente.

Anexo 6-4

Emociones y Desencadenantes Emocionales de Padres/Madres de Menores con NCC

DETONANTES DE EMOCIONES AGRADABLES DE PADRES (gratitud, amor, orgullo, sorpresa, asombro, felicidad)	
Habilidades y Logros del Hijo/a	**Interacciones Interpersonales**
• Nuevos aprendizajes • Lograr cosas que no esperaban	• Inclusión: Observar un entorno que incluye a hijo/a (actividades con compañeros)

DETONANTES DE EMOCIONES DESAGRADABLES DE PADRES (nervios, preocupación, angustia, miedo, frustración, impotencia, tristeza, confusión, enfado, vergüenza, culpa)	
Comportamientos Difíciles Hijo/a	**Interacciones Interpersonales**
• Gritos • Lastimar/se • Recaídas	• Percepción de juicios ("nos miran")
Retos del Hijo/a e Impacto	**Características Intrapersonales**
• Dificultades – "puede generar consecuencias sociales desagradables" (p.ej. bullying) • Dificultades comunicativas	• "No debería…" (sentir… vergüenza) • "Debería…" (entenderlo) • "¿Qué le pasa?" (para apoyar)

Anexo 6-5

Derechos Emocionales

Elaboración Propia (Rangel-Rodríguez, Blanch y Badia, en revisión)

Anexo 6-6

Emotional Rights

Emotional Rights

All individuals, no matter their condition or needs, have the right to:

feel, recognize, understand, and express emotions.

have opportunities to listen, learn and manage emotions (of oneself and others).

receive proper support to enhance emotional abilities and resources.

receive clear information about emotional health and develop emotional skills.

communicate emotions using personal resources and supports as needed

be heard, validated and respected, even if one's emotions are different from others.

have access to clear, meaningful and culturally appropriate vocabulary of emotions and emotion-related events.

ask and receive help and emotional support if needed.

receive a dignified, respectful and courteous emotional treatment.

All individuals have the right to express emotions and receive the proper support to enhance their emotional development.

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Elaboración Propia (Rangel-Rodríguez, Blanch y Badia, en revisión)