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PROTOCOL EGUBE – Exploring parental barriers and experiences in accessing child therapy services in Germany: A mixed-methods protocol

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PROTOCOL EGUBE

Exploring Parental Barriers and Experiences in
Accessing Child Therapy Services in Germany: A
Mixed-Methods Protocol

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PROTOCOL EGUBE

EXPLORING PARENTAL BARRIERS AND EXPERIENCES IN ACCESSING CHILD THERAPY SERVICES IN GERMANY: A MIXED-METHODS PROTOCOL

Stephanie Rupp

Hanna Schwendemann

ABSTRACT:

Early and adequate speech and occupational therapy are essential for supporting children's development and reducing linguistic, academic, and social challenges. However, navigating the German healthcare system to secure these services often poses significant barriers for parents, especially in outpatient settings. This study's primary aim is to identify key barriers and facilitators influencing parental engagement with the healthcare system.

Using a mixed-methods approach, the study integrates data from a published pilot project, an online survey, and semi-structured interviews with parents of children receiving or having received therapy within the last two years. Quantitative data are analyzed via descriptive statistics and qualitative data by means of content analysis to capture both overall trends and in-depth perspectives. The role of health literacy and interprofessional collaboration in shaping access to care is also examined.

Preliminary insights from the pilot study indicate notable disparities in healthcare access. Findings are expected to highlight specific challenges parents face, including systemic inefficiencies and limited awareness of available resources. Anticipated recommendations include policy changes, practitioner guidelines, improvements in care settings, regulations to foster interdisciplinary collaboration, and the development of targeted informational materials for various parent groups.

By emphasizing family-centered care and health literacy-sensitive interventions, the study aims to inform healthcare policies and practices that address these disparities, thereby contributing to global strategies for reducing healthcare inequalities and enhancing therapeutic outcomes for children with developmental needs.

KEYWORDS:

Parental Experiences, Speech and Occupational Therapy, Healthcare Barriers, Developmental Disorders, Health Literacy

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Stephanie Rupp She first completed state-recognized professional training in speech and language therapy in Germany (Staatsexamen), before pursuing an interdisciplinary eight-semester degree in Teaching and Research in Speech and Language Therapy at RWTH Aachen University (Diplom Lehr- und Forschungslogopädie). This program combines coursework in speech, language, voice, hearing, and communication disorders with linguistics and psychology, with a particular focus on teaching and learning research. During her studies, she gained clinical experience as a speech and language therapist. After graduation, she held a position as a certified teaching speech and language therapist at a vocational school for speech-language therapy and also taught as a freelance lecturer in vocational training programs and academic degree courses. She earned her PhD in “Language and Communication” at the University of Mannheim in cooperation with Heidelberg University of Education (Pädagogische Hochschule Heidelberg).

Since 2020, she has been the head of the Speech and Language Therapy program and a professor at IU International University of Applied Sciences. Her research focuses on child language development as well as the application of theoretical models in clinical practice. In addition, she is dedicated to professionalization processes and the development of innovative and interdisciplinary teaching formats. Further areas of interest include parental counseling, the development of counseling competencies, empathy in therapeutic settings, and health literacy in the context of speech and language therapy.



Hanna E. Schwendemann has been a professor and head of the Master’s program of Health and Nursing Education at IU since 2021, combining her professional experiences with academic teaching and research. She studied health and nursing education (B.A.; M.A.) at the University of Education in Freiburg after completing her training as an occupational therapist. She earned her doctorate on the topic “Protective factors in adolescents with developmental risks, with a special focus on familial factors,” focusing on evidence-based prevention approaches. She worked as an occupational therapist in an outpatient neurological therapy center and is a lecturer in the practical training and further education of health professions, focusing on nursing and occupational therapy.

Her research focuses on the field of healthcare and education research, in the context of health literacy, digitalization in healthcare, public health, prevention and health promotion.

Introduction

Early and adequate speech and occupational therapy interventions are crucial for promoting the individual development of children and reducing the risk of potential linguistic, academic, and social challenges (AWMF, 2022; Hasselhorn & Sallat, 2014; Rommel et al., 2018). Research suggests that such interventions can significantly enhance a child's language development, communication abilities, and socio-emotional behavior, potentially leading to improved social integration and academic success (Fischer et al., 2023; Law et al., 2003). Health services research in Germany has identified systemic inefficiencies, including challenges in interdisciplinary coordination and integration, which may contribute to a lack of transparency in care delivery (Stollreiter & Stich, 2020). These inefficiencies, such as fragmented care pathways and limited professional communication, can create unclear care structures, increase parental insecurities, and potentially lead to the underutilization of essential health services, as also indicated by preliminary findings from the EGUBE pilot study (Rupp & Schwendemann, 2023). Moreover, low health literacy exacerbates challenges in navigating healthcare systems, often leaving parents unable to effectively access available resources (Morrison et al., 2019).

Parental commitment and knowledge of care structures play a pivotal role in determining whether children receive appropriate health care. Parents must navigate a complex system, requiring a high level of engagement, health literacy, and understanding of the available services (Buhr & Tannen, 2020). For children, access to health services is heavily dependent on the efforts and capacities of their parents, particularly in addressing developmental delays and securing timely therapeutic interventions. Research from the United States demonstrates that children with special healthcare needs experience significant unmet needs across various specialized health services, with care coordination playing a key role in improving access and reducing service gaps (Graaf & Gigli, 2022). Similarly, studies in Germany reveal disparities in healthcare access, particularly among disadvantaged populations, where increased support needs remain unmet, exacerbated by socioeconomic inequalities (Loss et al., 2023).

Addressing these systemic challenges is a societal responsibility, as emphasized by the United Nations Convention on the Rights of the Child (UNCRC) and the Sustainable Development Goals (SDGs) of Agenda 2030, particularly SDG Goal 3: "Ensure healthy lives and promote well-being for all at all ages" and SDG Goal 10: "Reduce inequality within and among countries" (United Nations Human Rights, 2020). These frameworks advocate for reducing inequalities in healthcare access and ensuring that all children, regardless of their socioeconomic background, have the opportunity to access essential services. In light of these challenges, the project **EGUBE – (Eltern gut begleitet? Translated as "Are Parents Well Accompanied?")** aims to identify obstacles, needs, and supportive factors for families of children with increased therapeutic needs. Through a qualitative research approach, EGUBE will capture parental perspectives on the process of accessing speech and occupational therapy services, focusing on their experiences navigating the health system and the resources they require to successfully engage in therapeutic care (Rupp & Schwendemann, 2023).

This study protocol provides a structured overview of the project's background, methodological framework, and ethical considerations. It draws on the guidelines outlined by Kaba and colleagues (Kaba et al., 2021), which recommends the inclusion of ten essential steps for a robust and detailed research design.

In the following section, we present the theoretical frameworks that provide a foundation for understanding systemic and individual barriers to accessing therapeutic care. These frameworks guide the study design and inform actionable insights for improving care pathways.

Theoretical Framework

The EGUBE project draws on several theoretical perspectives to examine the parental journey in securing therapeutic care for their children. This framework incorporates concepts from health services research, health literacy, interprofessional collaboration, and social determinants of health. These perspectives collectively provide a comprehensive foundation for understanding the systemic and individual factors that influence parental experiences within the healthcare system.

HEALTH SERVICES RESEARCH AND ACCESS TO CARE

Health services research aims to understand how individuals access healthcare, the barriers they encounter, and ways to improve the efficiency, quality, and equity of service delivery (Stollreiter & Stich, 2020). Children, as a vulnerable population, rely heavily on their caregivers to access specialized therapeutic interventions, such as speech and occupational therapy (Rommel et al., 2018; Weber et al., 2016). However, systemic inefficiencies, including fragmented care pathways and poorly coordinated interprofessional collaboration, complicate access to care for families in Germany (Rupp & Schwendemann, 2023; Zepp, 2020).

Access to healthcare is further shaped by social determinants, including socioeconomic status, education level, and parental health literacy (Kuntz et al., 2018; Poethko-Müller et al., 2018). Research consistently shows that children from socioeconomically disadvantaged families experience significant challenges in accessing timely and adequate care, exacerbating health inequalities (Loss et al., 2023). The importance of cross-sectoral collaboration has been emphasized in international studies, such as Graaf and Gigli (2022), who highlight how poorly coordinated healthcare systems exacerbate gaps in care for vulnerable children. The EGUBE project builds on these insights to advocate for coordinated and equitable access to therapeutic services in Germany.

HEALTH LITERACY AS A CRITICAL FACTOR

Health literacy is a key determinant of how parents engage with the healthcare system. Defined as the ability to access, understand, and apply health-related information, health literacy enables parents to make informed decisions about care (Sørensen et al., 2012). For parents of children with developmental needs, health literacy is essential for navigating complex care arrangements, advocating for their child's needs, and coordinating between multiple professionals (DeWalt & Hink, 2009; Sørensen et al., 2012).

Parents with higher levels of health literacy are better equipped to manage these challenges, while those with lower health literacy—particularly those from disadvantaged socioeconomic backgrounds—face greater obstacles (Buhr & Tannen, 2020; Morrison et al., 2019). The EGUBE project explores how parental health literacy impacts their ability to secure care and assesses whether parents feel adequately supported by healthcare professionals (Schwendemann & Rupp, 2024). This analysis aims

to identify opportunities for interventions, such as improved communication strategies and parent education initiatives, to enhance health literacy and support parents in navigating complex healthcare systems more effectively.

INTERPROFESSIONAL COLLABORATION IN CHILD HEALTHCARE

Effective interprofessional collaboration is critical for managing the complex developmental needs of children, who often require input from pediatricians, speech therapists, occupational therapists, and educators (Autor:innengruppe Bildungsberichterstattung, 2022; AWMF, 2022; Hasselhorn & Sallat, 2014). Despite its importance, interprofessional communication in the German healthcare system is often insufficiently regulated, leaving parents to coordinate between professionals with minimal guidance (Rupp & Schwendemann, 2023; Schwendemann & Thieme, 2024).

The EGUBE project examines the role of interprofessional collaboration in shaping parental experiences, identifying both barriers and facilitators to coordinated care. Strengthening collaboration can reduce parental burden, enhance care coherence, and improve developmental outcomes for children. Conversely, poorly coordinated communication increases parental stress and complexity in care management (Graaf et al., 2024). By addressing these challenges, the project seeks to inform strategies that enhance interprofessional communication and care coordination, ultimately improving accessibility and efficiency for children with developmental needs.

SOCIAL DETERMINANTS OF HEALTH AND INEQUALITY IN ACCESS TO CARE

Social determinants of health provide a broader framework for understanding how external factors—such as socioeconomic status, education, and access to resources—influence health outcomes. Children from socioeconomically disadvantaged backgrounds, families with low education levels, or those facing language barriers often encounter significant challenges in accessing healthcare (Poethko-Müller et al., 2018; Loss et al., 2023).

By focusing on parents' navigation of the healthcare system, the EGUBE project seeks to uncover how social determinants intersect with health literacy and interprofessional collaboration to shape access to care. Health services research has long emphasized the importance of addressing inequalities to ensure equitable healthcare for all children (Pfaff & Pfortner, 2016). The project adopts this perspective to generate actionable insights into reducing disparities and promoting equitable access to therapeutic services. Study results (Loss et al., 2023) underscores the importance of addressing unmet pediatric healthcare needs through improved care coordination, particularly for socioeconomically disadvantaged populations. These findings align closely with the goals of the EGUBE project, which seeks to identify and mitigate barriers faced by families navigating fragmented care systems.

In summary, the EGUBE project integrates various theoretical perspectives to provide a comprehensive analysis of the factors influencing parents' access to therapeutic care for their children and their strategies for overcoming related challenges. By linking parents' individual capabilities (e.g., health literacy) with systemic barriers (such as insufficient interprofessional collaboration and social inequities), the study aims to generate practical insights that promote the development of equitable and parent-friendly healthcare services. These foundational theoretical considerations serve as a

guiding framework for the study's methodology, supporting an analysis that takes into account both contextual factors and the resources available to parents.

Background and Rationale

Health services research aims to identify and address gaps in healthcare delivery, ensuring equitable access to services for all children. In Germany, children remain an underrepresented group in health services research, as evidenced by the fact that only 10% of projects funded by the Innovation Fund of the national joint committee target children and adolescents (Zepp, 2020). Researchers have called for more attention to the specific care and support needs of this population (Loss et al., 2023).

Children with persistent physical, developmental, behavioral, or emotional conditions require specialized health services, such as speech or occupational therapy, to support their development (Graaf & Gigli, 2022, AWMF, 2022, Rommel et al. 2018). Unmet needs in these areas are particularly concerning, as they can lead to significant social-emotional, psychological, or educational challenges for affected children (Graaf et al., 2024). If these children's needs are unmet, they may face significant social-emotional, psychological, or educational challenges. Early, specific, and adequate therapeutic interventions are crucial in preventing long-term negative outcomes and promoting equal opportunities for children, also in the education sector (Autor:innengruppe Bildungsberichterstattung, 2020, 2022; Hasselhorn & Sallat, 2014; Rosenbrock & Kümpers, 2006).

Through speech and occupational therapy, early treatment of health disorders can help ensure the best possible development of children (Rommel et al., 2018). Evidence-based interventions improve children's language development, communication skills, socio-emotional behavior, and attention, all of which can enhance their social integration, boost self-confidence, and improve academic performance (AWMF, 2022; Breuer & Piso, 2014; Law et al., 2003; Söchting, 2014). Despite these clear benefits, the German healthcare system presents structural complexities that hinder access to care, particularly in outpatient settings, where families often assume the role of primary coordinators for their children's therapeutic needs (Rupp & Schwendemann, 2023).

Unmet needs in occupational therapy and speech-language therapy are presumed to exist, particularly in outpatient care, where children are highly dependent on their parents' knowledge, engagement, and ability to navigate the healthcare system. Factors such as socioeconomic status, language barriers, and migrant backgrounds are frequently discussed as potential influences on the utilization of therapeutic services (Grimm & Schulz, 2014; Rommel et al., 2018; Scharff Rethfeldt, 2017). Access to therapeutic services in Germany typically begins with pediatricians, who must prescribe the necessary interventions. Once parents receive this prescription, they are responsible for organizing appointments with therapists, often with minimal guidance on how to coordinate these services effectively. Fragmented care structures—spanning pediatricians, educators, social workers, and therapists—compound this challenge. Parents frequently report difficulties in managing these processes, citing unclear roles and responsibilities across the involved professionals and limited system-level support (Hamacher, 2020). Interprofessional communication is poorly regulated, and care pathways are frequently unclear for families (Hasselhorn & Sallat, 2014; Rommel et al., 2018; Rupp & Schwendemann, 2023).

Parental health literacy is widely regarded as a pivotal factor in accessing and managing a child's healthcare. Studies suggest that parents with higher health literacy are more likely to navigate the healthcare system successfully, make informed decisions, and secure appropriate care for their children (Buhr & Tannen, 2020; DeWalt & Hink, 2009; Morrison et al., 2019). Conversely, limited parental health literacy has been linked to increased barriers, particularly among socioeconomically disadvantaged families, who may face additional challenges such as time and financial constraints (Kunst et al., 2005; Pfaff & Pförtner, 2016). These issues are often compounded by systemic barriers, including insufficient institutional support for health literacy, which exacerbates inequities in access to care (Ernstmann et al., 2020; Sørensen et al., 2012).

To address these gaps, the EGUBE project examines the intersection of parental health literacy with systemic challenges, such as fragmented care pathways and interprofessional communication. The findings aim to illuminate how these factors collectively shape access to speech and occupational therapy. While these families may be underrepresented in the study sample, the identification of barriers and resources is expected to provide insights that are transferable to socioeconomically disadvantaged families, who are likely to face similar challenges, often compounded by additional barriers (Pfaff & Pförtner, 2016). These insights aim to deepen our understanding of both structural and individual-level challenges in accessing therapeutic services, providing actionable recommendations for the development of equitable, parent-centered healthcare pathways. By embedding its investigation within a broader framework that considers interprofessional collaboration and social determinants of health, the EGUBE project seeks to address not only immediate barriers but also the systemic inequities underlying them.

Aims and Objectives

The primary aim of the EGUBE project is to explore parents' perspectives and experiences as they navigate the healthcare system, starting from the initial recognition of developmental concerns in their child to securing appropriate therapeutic care. By identifying barriers and resources encountered along this journey, the study aims to generate actionable insights that support the development of medium-term solutions to improve healthcare pathways for children requiring speech and occupational therapy.

Specific Objectives

- To capture and analyze parental experiences, challenges, and solutions in securing care for children with speech and/or occupational therapy needs. This includes examining parents' perceptions of the healthcare system, the obstacles they faced, and the support mechanisms they utilized. (Primary Outcome)
- To investigate the role of interprofessional communication and health literacy in shaping parents' experiences. This includes analyzing the impact of different dimensions of health literacy—organizational, navigational, professional, and individual—on service access, care coordination, and parental decision-making processes. (Secondary Outcomes)

By addressing these objectives, the study seeks to uncover actionable insights that can inform the design of more accessible, effective, and parent-centered healthcare services for children with developmental needs.

Research questions

TARGET GROUP

This study focuses on parents of children who are currently receiving or have received occupational therapy and/or speech therapy within the last two years. The children must have been diagnosed with at least one developmental disorder. The study exclusively examines parents' perspectives and experiences in navigating the healthcare system and accessing therapeutic care.

PURPOSE

The research questions aim to explore parents' experiences and challenges along the healthcare pathway, from recognizing developmental concerns to obtaining therapeutic care. These open-ended questions facilitate an in-depth understanding of their journey, supported by a structured interview guide provided during the study.

RESEARCH QUESTIONS

Parental Journey to Therapeutic Care

- How do parents perceive the process from the recognition of developmental concerns to securing appropriate therapeutic care?
- What key events, barriers, and supporting factors have influenced parents' experiences in this process?

Navigating the Healthcare System

- How do parents navigate the complexities of accessing care for their children?
- What strategies and resources do parents use to overcome systemic obstacles?
- How do different professionals and institutions contribute to supporting parents in navigating therapeutic care?

Emotional Experiences and Support Needs

- What emotional experiences, challenges and positive aspects do parents encounter throughout the process of securing therapeutic care?
- How do these emotional experiences impact their engagement with the healthcare system?
- What forms of emotional and structural support do parents find helpful, and what additional support would they need?

Role of Health Literacy and Information Sharing

- How do parents assess the quality and accessibility of information provided by healthcare professionals?

- What roles do different individuals or professionals play in providing guidance to parents?
- What additional resources would have improved parents' ability to coordinate care?

ALIGNMENT WITH OBJECTIVES

These research questions are directly aligned with the study's aims and objectives. They are structured to encourage parents to reflect on their journey from the first signs of developmental concerns to their current engagement with therapeutic care. The findings aim to generate actionable recommendations for improving care pathways, interprofessional collaboration, and support systems for families.

Methods

STUDY DESIGN

The EGUBE project adopts a convergent mixed-methods design, integrating quantitative and qualitative data collection strategies to explore parents' experiences in navigating healthcare pathways for children requiring speech and occupational therapy. This design enables comprehensive insights into both statistical patterns and nuanced individual perspectives, supporting the development of actionable recommendations.

PILOT STUDY

A preliminary pilot study was conducted to assess feasibility and refine the methodology for the main study. Results from the pilot informed adjustments to the data collection instruments, including the survey and interview guides, ensuring relevance and clarity (Rupp & Schwendemann, 2023).

DATA COLLECTION AND TIMELINE

Data collection strictly adhered to ethical research standards and began only after obtaining ethical approval from the IU University Ethics Committee on April 22, 2024.

The study follows a structured timeline:

- October 2023 – March 2024: Preparation phase (ethics approval, finalization of instruments, piloting).
- 23. April 2024 – December 2024: Quantitative data collection via an online survey.
- 23. April 2024 – January 2025: Qualitative data collection through semi-structured interviews.
- December 2024 – March 2025: Quantitative data analysis (survey data processing and statistical evaluations).
- March 2025 – May 2025: Qualitative data analysis (transcription, coding, thematic analysis).
- October 2023 – October 2025: Dissemination phase (publications, conference presentations, workshops).

This timeline ensures systematic data integration and allows for a robust analysis of parental experiences in navigating therapeutic care pathways.

QUANTITATIVE COMPONENT: ONLINE SURVEY

An anonymous online survey serves as the primary quantitative data collection tool, targeting parents of preschool children aged 3 to 6 years who are currently receiving or have received occupational therapy and/or speech therapy within the last two years. The survey:

- Assesses demographic characteristics, parental health literacy, perceived barriers, and facilitators in accessing healthcare.
- Features a combination of closed-ended questions and numerical rating scales to capture participants' perceptions and experiences comprehensively.
- It was designed and administered using Tivian's Unipark platform (Tivian XI GmbH, 2024), ensuring secure, user-friendly participation.

Participants could voluntarily leave their contact information if they were willing to participate in follow-up qualitative interviews. The study aims to engage a diverse group of participants, ensuring a wide range of parental experiences are captured. While statistical representativeness is not the primary goal, the focus is on achieving heterogeneous sampling and data saturation, ensuring the validity of insights on parental challenges.

QUALITATIVE COMPONENT: SEMI-STRUCTURED INTERVIEWS

In-depth, semi-structured interviews were conducted with a subset of survey respondents who consented to further participation. These interviews:

- Focused on parents' lived experiences in navigating the healthcare system for their children.
- Used a structured interview guide informed by findings from the pilot study, addressing barriers, facilitators, interprofessional communication, and emotional aspects of the healthcare journey.
- The interviews were conducted via secure video conferencing, transcribed using F4x transcription software (Dresing & Prehl GmbH, 2024), and subsequently verified for accuracy.

A purposive sampling strategy was employed to ensure diversity in parental experiences. The final number of interviews was determined based on thematic saturation, aiming for approximately 10–15 interviews, unless new themes continued to emerge. Participants were selected based on key diversity criteria, including socioeconomic background, levels of health literacy, educational attainment, multilingualism, immigrant background and geographic location.

This approach ensured a heterogeneous sample, capturing a broad range of perspectives and increasing the generalizability of qualitative insights within the study's scope.

QUANTITATIVE ANALYSIS

Survey data were analyzed using descriptive and inferential statistics to identify trends and associations among key variables. Analysis was conducted using *PSPP* (GNU Operating System, 2013), an open-source software suitable for statistical computation.

QUALITATIVE ANALYSIS

Interview transcripts underwent qualitative content analysis, combining inductive and deductive coding methods. *MAXQDA* (VERBI – Software. Consult. Sozialforschung. GmbH, 2024) facilitated coding and thematic analysis, ensuring systematic organization of qualitative data.

- Systematic organization of qualitative data.
- Collaborative coding by multiple researchers to ensure inter-coder reliability.
- Thematic exploration of key issues, including health literacy, interprofessional collaboration, and systemic barriers.

To ensure trustworthiness and methodological rigor, the analysis adhered to the quality criteria for qualitative research as outlined by Mayring (2022). This included transparency in coding, systematic category development, intersubjective verifiability, and stepwise-deductive category application. Inter-coder reliability was maintained through collaborative coding by multiple researchers, ensuring consistency and replicability of findings.

INTEGRATION OF FINDINGS

Quantitative and qualitative data were integrated during the interpretation phase, following quality criteria for qualitative research as outlined by Mayring (2022). The integration process utilized methodological triangulation, ensuring that insights from the pilot study, online survey, and semi-structured interviews were systematically cross-referenced. This approach enhances the credibility, validity, and completeness of the findings by comparing different data sources to identify converging patterns and discrepancies.

This methodological approach ensured a robust and reliable analysis, allowing for a nuanced understanding of parental experiences in navigating therapeutic care pathways and the systemic factors influencing access and coordination.

The mixed-methods design enhances the study by combining quantitative breadth with qualitative depth, enabling a comprehensive perspective on the challenges and resources parents encounter. This approach supports actionable recommendations directly informed by parents' lived experiences, ensuring the validity and practical relevance of the findings.

ETHICAL CONSIDERATIONS AND STUDY REGISTRATION

The study protocol received ethical approval from the IU University Ethics Committee on April 22, 2024. All participants provided written informed consent before data collection. Data is anonymized and stored securely in compliance with GDPR guidelines. Furthermore, this study is registered in the *Deutsches Register Klinischer Studien* (DRKS) with registration number DRKS00034313. The study is internally funded by the INCUBATOR Program of IU International University, covering personnel costs, software licenses, conference fees, and publication charges. The IU International University serves as the trial sponsor but had no influence on study design, data collection, analysis, or publication decisions.

Data Access & Privacy: All data are stored in compliance with ethical regulations. Only principal investigators and authorized team members (bound by confidentiality agreements) have access to the

anonymized final dataset. No personal identifiers are included in publications. The study adheres to established ethical guidelines by ensuring the anonymization of data and implementing robust measures to protect participant confidentiality. These steps enable a thorough investigation into a sensitive topic while respecting participants' rights and privacy.

Dissemination of Findings: The study findings will be published in peer-reviewed journals in pediatrics, public health, and health services research. Additionally, results will be presented at international conferences and workshops and shared with healthcare professionals and parent advocacy groups. Open-access publication is supported by IU International University to ensure broad accessibility.

Strengths and Limitations

The EGUBE study presents several notable strengths. Its mixed-methods design enables a comprehensive exploration of both quantitative trends and qualitative nuances in parental experiences. By targeting parents of children aged 3–6 years with diagnosed developmental disorders, the study captures a critical developmental window, offering insights into early intervention pathways that are particularly relevant for policymakers and practitioners.

Another strength lies in the integration of data from multiple sources: pilot studies, a broad online survey, and in-depth qualitative interviews. This triangulated approach enhances the reliability and depth of findings by cross-verifying insights across different data streams. Additionally, the use of validated tools and software for data collection and analysis—such as Tivian for surveys, MAXQDA for qualitative coding, and PSPP for statistical analysis—ensures methodological rigor.

However, the study also faces several limitations. First, the reliance on self-reported data introduces the possibility of recall bias, particularly when participants reflect on past experiences navigating the healthcare system. Second, the recruitment strategy, which leverages social media and professional networks, may result in a sample skewed towards parents with higher digital literacy and engagement levels, potentially underrepresenting more disadvantaged or less engaged populations. While this selective group of participants may not fully represent all parental experiences, it is likely that barriers identified by these engaged parents will be even more pronounced for less engaged parents or those facing additional challenges.

To address this, the study employs purposeful sampling to achieve diversity within the participant group, striving for heterogeneity in experiences, perspectives, and demographic backgrounds. This approach aligns with established quality standards for qualitative research and aims to ensure that the findings reflect a broad spectrum of parental challenges and needs.

The study's focus on a single national context (Germany) may limit the generalizability of findings to other healthcare systems with different structures and policies. Finally, while the mixed-methods design provides a rich dataset, the integration of diverse data sources also introduces complexity in analysis, requiring careful consideration of methodological consistency and alignment with established quality standards, such as those outlined by Mayring (2022) for qualitative research.

Significance of Mixed Methods: By combining quantitative and qualitative approaches, the study bridges the gap between large-scale trends and individual narratives. This methodological synergy

allows for the identification of actionable insights that are both statistically robust and deeply informed by parental perspectives, enhancing the practical relevance of recommendations.

EXPECTED OUTCOMES AND IMPACT

The EGUBE study aims to generate actionable insights into the barriers and facilitators parents face in securing therapeutic care for their children. The expected outcomes include:

- Identification of systemic gaps in the healthcare pathway that hinder timely access to speech and occupational therapy.
- Understanding of the role of parental health literacy and interprofessional collaboration in shaping care access and utilization.
- Development of evidence-based recommendations for improving the structure and accessibility of therapeutic services in Germany, with a focus on family-centered care.

The study has the potential to inform healthcare policies by highlighting the importance of accessible, transparent, and parent-friendly service pathways. Findings may guide the development of targeted interventions, such as health literacy-sensitive educational materials and improved communication strategies among healthcare professionals. Furthermore, the results can contribute to reducing healthcare disparities, particularly for socioeconomically disadvantaged families, and enhancing overall therapeutic outcomes for children with developmental needs. In addition to informing national healthcare policies, the EGUBE project aims to contribute to international research on care coordination for children with developmental needs. By addressing gaps highlighted in studies like Graaf und Gigli (2022), the findings will help advance global strategies for reducing healthcare disparities and improving therapeutic outcomes.

TIMELINE

The study is planned over a two-year period, encompassing the following key phases:

(until 10/2023: piloting)

- 10/2023 – 3/2024: Preparation (Ethics approval, finalization of tools)
- 3/2024 – 12/2024: Acquis and Data Collection (Ethics approval, finalization of tools)
- 1/2025 – 6/2025: Data Analysis (Statistical and thematic analysis)
- 10/2023 – 10/2025: Dissemination (Publications, conference presentations, workshops)

DISSEMINATION OF FINDINGS

The study results will be disseminated through peer-reviewed publications, targeting pediatrics-focused journals, as well as journals in Public Health and Health Services Research. Dissemination efforts will also include conference presentations and practical materials for healthcare professionals and families. Additionally, findings will be shared via professional networks and public platforms to reach pediatric healthcare professionals, health policy researchers, and parent advocacy groups, ensuring broad accessibility and impact.

FUNDING AND CONFLICTS OF INTEREST

The EGUBE project is funded through the INCUBATOR program of the IU International University, which supports innovative research initiatives. The funding covers: Personnel costs for research staff and transcribers, Expenses for software tools (e.g., *MAXQDA*) and transcription services and Dissemination activities, such as conference fees and publication charges.

The authors declare no conflicts of interest in the design, implementation, or reporting of this study.

Discussion

The EGUBE study addresses critical gaps in understanding how parents navigate the healthcare system to secure therapeutic care for their children with developmental needs. By integrating qualitative and quantitative approaches, it aims to generate actionable insights into barriers and facilitators, informing improvements in family-centered care, health literacy interventions, and interprofessional collaboration.

This study provides valuable insights into how health literacy and interprofessional collaboration influence access to care. It identifies systemic barriers, such as fragmented care pathways and limited parental support, while offering recommendations to enhance service delivery. The mixed-methods approach bridges statistical trends with parental narratives, creating a comprehensive understanding of healthcare challenges. Findings aim to: Improve health literacy among parents and professionals, enhance care coordination through better interprofessional communication and address healthcare disparities affecting socioeconomically disadvantaged families.

These contributions support health equity goals and inform policy reforms to ensure equitable access to therapeutic services. Additionally, the study can guide the development of targeted interventions, such as tailored educational materials and community-based support programs.

The reliance on self-reported data introduces the possibility of recall bias, although triangulating diverse data sources enhances reliability. The recruitment strategy may overrepresent engaged or digitally literate parents, potentially underrepresenting less connected groups. To address this, purposive sampling seeks to capture diverse perspectives and ensure heterogeneity. While this study focuses on Germany, insights from research on care coordination and unmet healthcare needs, such as those by Graaf & Gigli (2022), highlight challenges that may also be relevant to other healthcare systems.

The findings have practical implications for healthcare providers, policymakers, and researchers. The study emphasizes the importance of developing health literacy-sensitive materials and implementing systemic reforms to create more accessible care pathways. Training programs for professionals, focusing on interprofessional collaboration and culturally sensitive communication, can further empower families. Future research should explore longitudinal outcomes, interventions to enhance coordination, and comparisons across healthcare systems.

The EGUBE study provides critical insights into the systemic and individual factors influencing access to therapeutic care. By addressing barriers and proposing actionable solutions, it contributes to

creating a more inclusive and supportive healthcare system for children with developmental needs and their families.

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