

**Lived Experiences of Parents Raising a Child with Cerebral Palsy: A
Phenomenological Study**

Akerke Tuzelova

Submitted in partial fulfillment of the requirements for the degree of

Master of Sciences

in

Educational Leadership

Nazarbayev University Graduate School of Education

April 2025

Word count: 16, 555

Author Agreement

By signing and submitting this license, I Akerke Tuzelova grant to Nazarbayev University (NU) the non-exclusive right to reproduce, convert (as defined below), and/or distribute my submission (including the abstract) worldwide in print and electronic format and in any medium, including but not limited to audio or video.

I agree that NU may, without changing the content, convert the submission to any medium or format for the purpose of preservation. I also agree that NU may keep more than one copy of this submission for purposes of security, back-up and preservation.

I confirm that the submission is my original work, and that I have the right to grant the rights contained in this license. I also confirm that my submission does not, to the best of my knowledge, infringe upon anyone's copyright.

If the submission contains material for which I do not hold copyright, I confirm that I have obtained the unrestricted permission of the copyright owner to grant NU the rights required by this license, and that such third-party owned material is clearly identified and acknowledged within the text or content of the submission.

IF THE SUBMISSION IS BASED UPON WORK THAT HAS BEEN SPONSORED OR SUPPORTED BY AN AGENCY OR ORGANIZATION OTHER THAN NU, I CONFIRM THAT I HAVE FULFILLED ANY RIGHT OF REVIEW OR OTHER OBLIGATIONS REQUIRED BY SUCH CONTRACT OR AGREEMENT.

NU will clearly identify my name(s) as the author(s) or owner(s) of the submission, and will not make any alteration, other than as allowed by this license, to your submission.

I hereby accept the terms of the above Author Agreement.

Author's signature:



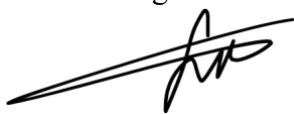
Date:

28.04.2025

Declaration

I hereby declare that this submission is my own work and to the best of my knowledge it contains no materials previously published or written by another person, or substantial proportions of material which have been submitted for the award of any other course or degree at NU or any other educational institution, except where due acknowledgment is made in the thesis. This thesis is the result of my own independent work, except where otherwise stated, and the views expressed here are my own.

Author's signature:

A handwritten signature in black ink, consisting of a long horizontal stroke followed by a stylized, cursive flourish.

Date:

28.04.2025



Ethical Approval

53 Kabanbay Batyr Ave.
Astana 010000
Republic of Kazakhstan
Date: 8 of November 2024

Dear Akerke Tuzelova,

This letter now confirms that your research project titled...

Lived Experiences of Parents Raising a Child with Cerebral Palsy: A
Phenomenological Study

has been approved by the Graduate School of Education Ethics Committee of Nazarbayev University.

You may proceed with contacting your preferred research site and commencing your participant recruitment strategy.

Yours sincerely ,

Dr Janet Helmer

On behalf of:

Dr Syed Abdul Manan, *PhD*

Chair , GSE Ethics Committee

Graduate School of Education

Nazarbayev University

Block C3, Room 5011



Office:

+7(7172)6016 Mobile: +

77079240053

email: syed.manan@nu.edu.kz, gse.irec@nu.edu.kz

CITI Training Certificate

Completion Date 05-Jun-2024
Expiration Date 05-Jun-2028
Record ID 62953885

This is to certify that:

Akerke Tuzelova

Has completed the following CITI Program course:

Responsible Research Training
(Curriculum Group)
Social, Behav, Edu, Etc
(Course Learner Group)
1 - Basic Course
(Stage)



Under requirements set by:

Nazarbayev University

Not valid for renewal of certification through CME.

CITI
Collaborative Institutional Training Initiative
101 NE 3rd Avenue, Suite 320
Fort Lauderdale, FL 33301 US
www.citiprogram.org

Generated on 27-Apr-2025. Verify at www.citiprogram.org/verify/?w2b6c4014-4fbf-43dd-817c-2907184e927d-62953885

Completion Date 02-Jun-2024
Expiration Date 02-Jun-2027
Record ID 62953884

This is to certify that:

Akerke Tuzelova

Has completed the following CITI Program course:

Social & Behavioral Research - Basic/Refresher
(Curriculum Group)
Social & Behavioral Research - Basic/Refresher
(Course Learner Group)
1 - Basic Course
(Stage)

Under requirements set by:

Nazarbayev University

Not valid for renewal of certification through CME.

CITI
Collaborative Institutional Training Initiative
101 NE 3rd Avenue, Suite 320
Fort Lauderdale, FL 33301 US
www.citiprogram.org

Generated on 27-Apr-2025. Verify at www.citiprogram.org/verify/?w14ee3a95-1305-445b-b982-5726d7d75895-62953884

Acknowledgments

I would like to thank professors, faculty members, academic English advisors, specifically Anita Jayachandran and Jeremy Richard Spring, and others who supported, directed, and motivated me in my two- year educational journey at Nazarbayev University. Firstly, I express my thankfulness to my supervisor Dr. Janet Helmer who has been very supportive and helpful in every part of writing my thesis project. I can say that she is a professional of her work as she always provided me with constructive feedback, that helped me be on a right track.

Additionally, I am thankful to my close family members, including my parents and siblings for their support and trust in me. More importantly, I have grown and still am growing academically, intellectually, and emotionally together with my daughter, with her love, trust, and understanding assisting the overall well-being of our small family.

Concluding, I would like to express my gratitude to Nazarbayev University, School of Preparatory Studies (Zero Year Program) for the remarkable experience I have gained there. I thank to all people who collaborated with me, including my peers, relatives, friends, and parents of a child with CP who helped to realize this project.

Abstract

Lived Experiences of Parents Raising a Child with Cerebral Palsy: A Phenomenological Study

This phenomenological research study explored the lived experiences of parents raising a child with cerebral palsy (CP) in the context of Kazakhstan. The aim of this study was to investigate challenges that parents face in accessing education for their child and to gather their recommendations for future improvement. It attempted to illustrate the complex nature of the educational and developmental experiences of parents of a child with CP. The study used Family Systems Theory and Social Support Theory to explore how family support and social networks influence and shape parental experiences. Six parents participated in interviews from various regions of Kazakhstan. The study findings revealed significant challenges, including poor family support, inadequate support services, negative societal attitudes, financial, emotional, and relational strain. The recommendations of parents pointed out the necessity to strengthen the state support, enhance service accessibility, provide free psychological support, and raise awareness of society to decrease parent's stress level and challenges they face. Despite parents facing these challenges, they showed remarkable resilience frequently acting as a strong advocate for their child's educational and developmental needs. Overall, the research study emphasizes the need for systemic changes to improve the family's support, which directly affects parents' quality of life as well as child's educational outcomes within the Kazakhstani context.

Keywords: children with cerebral palsy, experiences of parents, Kazakhstan

Аңдатпа

Бұл феноменологиялық зерттеу Қазақстандағы церебральды сал ауруымен бала тәрбиелеп отырған ата-аналардың өмірлік тәжірибесін зерттеді. Бұл зерттеудің мақсаты ата-аналардың балаларының білім алуына қол жеткізудегі қиындықтарын зерттеу және олардың болашақта жақсарту бойынша ұсыныстарын жинау болды. Зерттеу церебральды сал ауруы бар баланың ата-анасының білім беру және дамыту тәжірибесінің күрделі сипатын көрсетуге тырысты. Зерттеу отбасылық қолдау мен әлеуметтік ортаның ата-аналық тәжірибеге қалай әсер ететінін және қалыптастыруын зерттеу үшін отбасы жүйелері теориясы мен әлеуметтік қолдау теориясын пайдаланды. Сұхбатқа Қазақстанның әр өңірінен алты ата-ана қатысты. Зерттеу нәтижелері айтарлықтай қиындықтарды көрсетті, соның ішінде нашар отбасылық қолдау, жеткіліксіз қолдау қызметтері, қоғамдағы жағымсыз көзқарастар, қаржылық, эмоционалдық және тұлғааралық қиындықтар. Ата-аналардың ұсынымдарында ата-аналардың күйзелісі мен олар кездесетін проблемаларды азайту үшін мемлекеттік қолдауды арттыру, қызметтердің қолжетімділігін арттыру, тегін психологиялық қолдау көрсету және халықты ақпараттандыруды арттыру қажет екендігі көрсетілді. Осы қиындықтарға тап болғанымен, ата-аналар балаларының білім алу және даму қажеттіліктерін қорғаушы ретінде жиі қызмет ететін керемет төзімділік танытады. Жалпы, зерттеу Қазақстандағы ата-аналардың өмір сүру сапасына, сондай-ақ балалардың білім алу нәтижелеріне тікелей әсер ететін отбасылық қолдауды жақсарту үшін жүйелі өзгерістер қажеттігін көрсетеді.

Түйінді сөздер: церебральды сал ауруымен ауыратын балалар, ата-ана тәжірибесі, Қазақстан

Аннотация

Данное феноменологическое исследование изучало жизненный опыт родителей, воспитывающих ребенка с церебральным параличом (ДЦП) в контексте Казахстана. Целью этого исследования было изучение проблем, с которыми сталкиваются родители при доступе к образованию для своего ребенка, и сбор их рекомендаций по будущему улучшению. Исследование попыталось проиллюстрировать сложную природу образовательного и развивающего опыта родителей ребенка с ДЦП. В исследовании использовались теория семейных систем и теория социальной поддержки, чтобы изучить, как поддержка семьи и социальное окружение влияют и формируют родительский опыт. Шесть родителей приняли участие в интервью из разных регионов Казахстана. Результаты исследования выявили значительные проблемы, включая слабую поддержку семьи, неадекватные службы поддержки, негативное отношение общества, финансовое, эмоциональное и межличностное трудности. Рекомендации родителей указывали на необходимость усиления государственной поддержки, повышения доступности услуг, предоставления бесплатной психологической поддержки и повышения осведомленности общества для снижения уровня стресса у родителей и проблем, с которыми они сталкиваются. Несмотря на то, что родители сталкиваются с этими проблемами, они проявляют замечательную стойкость, часто выступая в качестве решительного защитника образовательных и развивающих потребностей своего ребенка. В целом, исследование подчеркивает необходимость системных изменений для улучшения поддержки семьи, что напрямую влияет на качество жизни родителей, а также на результаты обучения детей в Казахстане.

Ключевые слова: дети с церебральным параличом, опыт родителей, Казахстан

Table of Contents

Author Agreement	ii
Declaration	iii
Ethical Approval	iv
CITI Training Certificate	v
Acknowledgments.....	vi
Abstract.....	vii
Аңдатпа	viii
АННОТАЦИЯ.....	ix
Chapter 1: Introduction	1
Background	1
<i>Cerebral Palsy (CP)</i>	1
Statement of the Problem.....	2
Purpose of the Study and Research Questions.....	4
Significance of the Study	4
Summary	5
Outline of the Thesis	5
Chapter 2: Literature Review	7
The Theoretical Framework.....	7
<i>Family Systems Theory (FST)</i>	7
<i>Social Support Theory (SST)</i>	9
What is Cerebral Palsy?	9
A Family with a Child with Cerebral Palsy	11
<i>Parents' Challenges</i>	11
Cerebral Palsy and Challenges Related to Education	12
<i>Learning Profile</i>	12
<i>Early Intervention Service</i>	13
Education of Children with CP in Kazakhstan	14
<i>Homeschooling</i>	15
Teachers Perceptions of Inclusive Education	16
Summary	17
Chapter 3: Methodology	18
Introduction.....	18
Research Philosophy	18
Research Design.....	19

Research questions	19
Sample Selection.....	20
Instruments.....	20
Data Collection Procedure	21
Data Analysis	21
Ethical Considerations	22
Summary	23
Chapter 4: Findings.....	24
Introduction.....	24
Study Sample	24
Data Analysis	25
Finding out the Diagnosis of a Child	26
<i>Circumstances and Impact of Medical Personnel</i>	26
<i>Initial Reaction of Family</i>	27
<i>Type and Severity of CP and Comorbidities</i>	28
<i>Changing mindset</i>	30
Support and Challenges in Education of a Child with CP	31
<i>Child's Need and Education- Impact of Type and Severity of CP to Child's Education</i>	31
<i>Child's Need and Education- The Role of PMPC</i>	32
<i>Child's Need and Education- The Role of Mothers and Siblings in Education</i>	33
<i>Parental Expectations</i>	34
Challenges and Support Needs of Parents	35
<i>Challenges Parents Face Raising a Child with CP- Navigating Between Parental Roles</i>	35
<i>Challenges Parents Face Raising a Child with CP- Lack of Medical Guidance and Shortage of Specialists</i>	36
<i>Challenges Parents Face Raising a Child with CP- Societal Attitude</i>	37
<i>Current Challenges Parents Face Raising a Child with CP- Financial Hardship</i>	37
Areas of Support- Psychological	38
<i>Areas of Support- Providing Clear Route After Birth of a Child</i>	39
<i>Areas of Support- Family and Relative's Support</i>	39
The Role of the Government.....	40
<i>Current State of Support</i>	40
<i>Recommendations for Improvement- Social Worker</i>	41
<i>Recommendations for Improvement- Financial</i>	42

<i>Recommendations for Improvement- Forums on How to Develop Children with Different Types of CP</i>	42
Summary	43
Chapter 5: Discussion	44
Introduction	44
Lived Experiences	44
Parental Roles	45
Challenges	47
Areas of Improvement	48
<i>Diagnosis and Birth</i>	48
<i>Family support</i>	49
<i>Societal Attitude</i>	50
<i>The Quality and Accessibility of Services</i>	51
<i>Development and learning</i>	53
<i>Schooling</i>	55
<i>Parental expectations</i>	56
Summary	57
Chapter 6: Conclusion	58
The Study Summary	58
Implications for Future Research and Recommendations	59
Practical Implications	59
Strengths and Limitations	61
Final Reflections	62
References	63
Appendix A: AI Declaration Form	78
Appendix B: Recruitment Statement Addressed to Parents (English version)	79
Appendix C: Informed Consent Form for Parents (English version)	80
Appendix D: Interview protocol (English version)	82
Appendix E: Data Analysis – Transcripts, Coding Samples	83

List of Tables

Table 1 <i>Demographic Information of the Mothers</i>	24
Table 2 <i>The Study Themes and Subthemes.</i>	25
Table 3 <i>Type and Severity of CP and Comorbidities</i>	29

List of Figures

Figure 1 *Topographical Description in Cerebral Palsy: Unilateral and Bilateral Cerebral Palsy*..... 10

Chapter 1: Introduction

This first chapter introduces the study by providing essential background information. In the subsequent sections, the issue central to the study is presented: the challenges and needs faced by parents raising a child with cerebral palsy in Kazakhstan. This section aims to provide a rationale for why these parents' experiences need to be explored in detail. The chapter then introduces the research questions that will guide the investigation, followed by a section explaining the study's overall purpose and significance. The final section outlines the remaining chapters.

Background

Cerebral palsy (CP) is one of the main neurological conditions that can affect mobility, posture, and muscle tone development; it results from an injury to the growing brain, which usually happens either prior to or soon after birth. Although the original brain damage does not get worse, children with CP may eventually develop secondary conditions that influence their functional abilities (Patel et al., 2020).

Cerebral Palsy (CP)

An internationally accepted definition for CP is that it is a set of permanent movement and posture disorders that limit a child's activity. These limitations stem from non-progressive disturbances in the developing brain of a fetus. The movement disorders themselves can manifest as muscle contraction, involuntary movements, lack of coordination and poor muscle control, or a combination of these. (Patel et al., 2020; Vitrikas et al., 2020). According to the Zhakupova et al. (2023) study, CP mostly starts from early childhood and at birth, with risk factors including the pregnancy, prematurity, and certain infections during pregnancy. As highlighted by Alaei et al. (2014), it is the primary cause of childhood motor disabilities, resulting in lifelong developmental challenges that can affect movement, posture, and, in some instances, sensory,

communication, and cognitive functions. The study by Vitrikas et al. (2020) indicated that CP affects approximately 2 to 3 out of every 1,000 newborns worldwide. According to Zhakupova et al. (2023), recent research in Kazakhstan shows an increasing trend in CP diagnoses. Over a ten-year period, from 2006 to 2016, they accounted for the rate of newly identified CP cases among children fluctuating between 44.9 and 82.9 per 100,000, peaking at 88.1 cases in 2009.

In Kazakhstan, the hardships faced by a child with CP go beyond the medical condition. Despite the United Nations Convention on the Rights of the Child, Articles 5 & 23 (1989), which recognizes the rights of children with disabilities, parents and families in Kazakhstan encounter harsh realities. Those families face limited access to quality education and rehabilitation programs (Zhakupova et al., 2023). Furthermore, parents encounter financial strain doubled with negative social attitude and lack of assistance, which heavily limits parental ability to meet the child's basic needs. In addition to existing problems, according to Alae et al. (2014), it is complicated by a long-term dependency of a child with CP on their primary caregivers, commonly mothers. The long-term dependency, in turn, creates substantial nurturing responsibilities and constant hands-on care, which hinder mothers' ability to manage and maintain first their overall well-being and then the other family member's needs. These challenging circumstances are exacerbated by a shortage of systemic support, which directly promotes social isolation and stigmatization (Alae et al., 2014; Zhakupova et al., 2023).

Statement of the Problem

Studies by Murphy et al. (2011) and Kim et al. (2023) indicate that parents of a child with special needs, specifically those with intellectual and developmental disabilities, experience increased rates of stress, depression, and physical health problems compared to parents of typically developing children. These are due to their role as essential supporters.

Parents of a child with CP encounter exceptional psychosocial challenges related to their child's care, education, and medical needs (Alaee et al., 2014). In Central Asian nations, this burden is compounded by societal shame, particularly in rural areas, where parents raising children with disabilities often endure stigma. Consequently, some parents isolate their disabled children at home (Mukashev & Somerton, 2023), confining them to their homes, avoiding public places, and restricting their interactions with others, in an attempt to shield their children's disabilities from public view.

Caring for a child with special needs requires parents' patience, additional support, and energy. Despite performing a variety of tasks, parents of a child with CP often have less time and opportunity to devote to themselves and may not have access to the necessary practices and services compared to parents of typically developing children. Some challenges of caring for a child with special needs can strain parental relationships within the family (Wei & Yu, 2010). Studies have found that parents of children experiencing emotional, or health issues are more likely to divorce (Wei & Yu, 2010; Kim et al., 2023). A longitudinal study conducted by Wei & Yu (2010) confirmed that 81% of children with emotional disturbances are more likely to have divorced or single parents. A study by Kim et al. (2023) over a decade later found divorced or separated single mothers of children with intellectual and developmental disabilities reported a lack of involvement from the other parent.

Furthermore, families raising a child with disabilities often face heightened financial vulnerability due to the increased costs associated with specialized care and support (Alaee et al., 2014). The reduced time available for employment intensifies financial stressors on these families (Heiman, 2021). Therefore, according to (Majnemer et al., 2010), financial constraints can negatively affect how children perceive their abilities and self-worth.

Purpose of the Study and Research Questions

The present study aims to explore the experiences of parents raising a child with cerebral palsy. The primary objective is to understand the parental challenges, their engagement in their child's education, and the support mechanisms they need. The overarching research question of the study: What are the lived experiences of parents of a child with CP?

Sub -questions:

- How do parents support the education of their child with CP?
- What are the main challenges parents face in facilitating the education of their child with CP?
- What improvements do parents suggest for supporting their child with CP?

Significance of the Study

Parents of a child with severe disabilities, such as cerebral palsy (CP), who require extensive care, are more likely to experience mental health challenges, family difficulties, and a lower quality of life (Cook et al., 2022). Raising a child with lifelong needs is demanding and requires a deep understanding of the factors that impact both parents' and child's daily lives. While much of this research originates from Western and East Asian countries, studies by Yelissinova et al. (2013) and Mukashev & Somerton (2023) have begun to address this gap in Kazakhstan. However, Yelissinova et al.'s (2013) study focused on the general challenges faced by families with children who have CP, and Mukashev & Somerton (2023) explored experiences of parents of homeschooled children with special needs, without a specific focus on CP. Therefore, to better understand the impact of CP on families in Kazakhstan, it is important to study the experiences, available resources, and educational needs of these parents and their child with CP. This knowledge can inform the development of targeted support programs to enhance parents' and child's

well-being and improve social and educational outcomes. This study is valuable for parents, educators, policymakers, and the broader community. This research on parental perspectives can guide the development of more effective support and interventions. Additionally, the educators will be equipped with a deeper understanding of the strengths and needs of a child with CP, promoting more inclusive classrooms. This research aims to help reduce the stigma and misconceptions surrounding CP in Kazakhstan, promoting a more inclusive society, and improving the lives of children with CP and their families.

Summary

This chapter has presented an overview on parental challenges raising a child with disabilities. Relying upon this foundation, it has also emphasized the significance of exploring the lived realities of parents caring for a child with CP. Recognizing that extensive research on cerebral palsy exists within Western contexts, the experiences of families in Kazakhstan remain comparatively understudied. Consequently, to address this particular gap in knowledge, the research problem has been clarified, the research questions have been formulated, and the purpose of the study and the significance have been determined and justified within the context of Kazakhstan. The subsequent chapter will delve into the current body of literature concerning CP and the specific challenges encountered by Kazakhstani families. Furthermore, it will present a theoretical framework and critically analyze the work of various scholars.

Outline of the Thesis

This research narrative unfolds across six chapters. The first chapter provided an introduction to the study, outlining its aims and scope. Chapter 2 then builds upon this foundation by synthesizing existing scholarship through a detailed literature review. The methodological approach, outlining the design and data collection processes, is presented in Chapter 3. Following this, Chapter 4 delivers the empirical findings and research

outcomes. Chapter 5 offers an interpretive analysis and discussion of these findings, exploring their broader implications. Finally, Chapter 6 concludes the narrative by summarizing the study's key contributions and suggesting avenues for future research.

Chapter 2: Literature Review

The former chapter provided the necessary context, including the background, problem, objectives, questions, and significance of this research; this chapter, in turn, offers a review of the relevant literature. It introduces the chosen conceptual framework and then summarizes relevant studies on several key themes, including inclusive education in Kazakhstan, cerebral palsy, experiences of parents, challenges faced by families, and educational challenges of a child with CP. While some of the research may be dated due to the limited work on this topic, it remains valuable for understanding this underexplored area.

The Theoretical Framework

The current study employs two theoretical frameworks including Family Systems Theory (FST) by psychiatrist Murray Bowen (Metcalf, 2011) and Social Support Theory (SST) to explore the parental experiences of a child with CP.

Family Systems Theory (FST)

Gaff and Bylund (2010) viewed a family as a dynamic, complex, and ongoing developmental social system, where two or more individuals forming a relationship, start a communication and interaction processes, sharing positive, negative, or neutral information and support. Bowen's FST in this study provides a framework to understand the complexity of this interactive social system, where each family member has an effect on the other members, shaping new patterns of connection affecting the balance of the whole family (Gaff & Bylund, 2010, p 103; Rothbaum et al., 2002). According to Prest and Protinsky (1993), FST consists of three fundamental ideas that are particularly relevant to this study, including learned traditions, patterns shape behavior, and seeking balance.

The idea of learned traditions represents the learned generational and cultural views on issues within the family (Prest & Protinsky, 1993). This idea in the context of the

current research can show the traditional views on parental roles raising a child with disability. For instance, in Kazakhstan, traditionally, according to An et al. (2018), mothers are viewed and assigned in a role of primary caregivers in terms of health, education, and development of a child with special needs.

Reflecting on the learned traditions, the family system begins to develop certain patterns that shape family member's behavior (Gaff & Bylund, 2010). The idea 'patterns shape behavior' in the context of this study can investigate how generational patterns and views impact the lived experiences of parents raising a child with CP. For instance, continuing to refer to the study of An et al. (2018), it is stated that the mother, a primary caregiver, after discovering the diagnosis of a child develops new patterns, including daily care, visiting healthcare and developmental centers. All these patterns can shape mothers' behavior affecting her mental and physical well-being, which overall influences the family balance.

Bowen's family systems theory states that after the shaped behaviors, family members are seeking for balance only after becoming consciously aware of the family's patterns (Metcalf, 2011). For instance, Metcalf (2011) explains the idea of seeking balance in the example of a mother who is seeking several comfortable ways to correctly interpret the illness of a father to her children, helping both mother and children to understand and solve the issue. In the context of the current research, through the prism of the idea seeking balance of Bowen's family systems theory this study will explore how parents restore the balance and suggest areas for improvement.

Overall, Bowen's family system theory can help to explore parental roles within the family system, set family patterns and boundaries, identify both parents and a child with CP challenges and needs, how these factors can affect parental advocacy in child's education and development, and identify suggested areas for improvement.

Social Support Theory (SST)

Social support is viewed as a dynamic, not stable, complex concept that requires both provider's and recipient's interactions, focusing on increasing the recipient's well-being (Hupcey, 1998). Building on this, Hajli et al. (2014) define this concept as the measurement of an individual's feelings of being supported, cared for, and responded to by people within their social networks. This concept is broadly recognized in psychology, health care, and sociology as it is assumed as a factor that eases burden and offers protection from health issues and life stress (Hajli et al., 2014). Hajli et al. (2014) indicated that social support includes the following types of support: informational, emotional, instrumental and appraisal ones. To be specific, the nature of informational support can include advice and guidance of social networks; emotional support includes empathy, care, love and trust; instrumental refers to material and tangible assistance; and elaborating on appraisal support, it refers to feedback and validation. From the perspective of inclusive education, Desombre et al. (2021) state that a variety of sources that can provide social support, including peers, teachers, administrators. Moreover, the study by Saeed et al. (2023) which focused on examining the influence of social support on a child with special needs' academic achievement and overall educational outcomes, identified that children with increased social support outperformed children with lower social support in academic achievement. In the context of this study, this social support theory can assist the researcher in investigating how social support from relatives, friends, the state, organizations affect family development in educational settings.

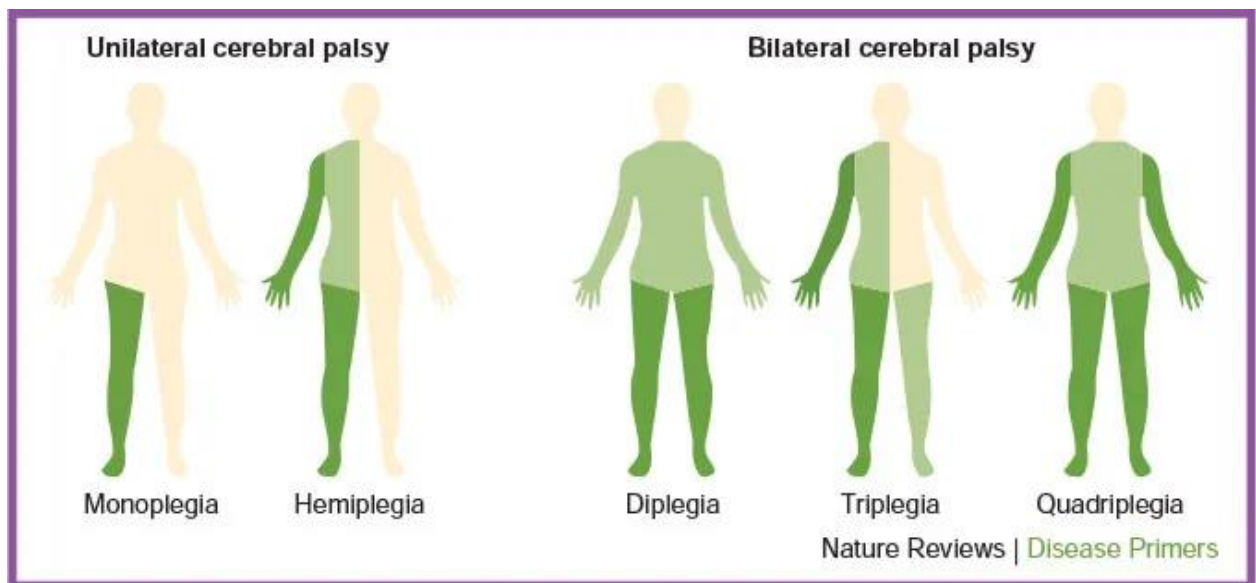
What is Cerebral Palsy?

Cerebral palsy, according to Novak et al. (2017) is a clinical diagnosis, which is grounded on a combination of neurological and clinical indications. Graham et al. (2016) state that this term refers to a collection of diseases with varying degrees of severity that

share key developmental characteristics rather than a single disease entity. Additionally, CP has different types and severity levels of motor and developmental disability (see figure 1). These include unilateral, that affects one side of the body, and bilateral cerebral palsy, where the legs are more affected than arms, or the whole body is affected (Graham et al., 2016; Novak et al., 2017).

Figure 1

Topographical Description in Cerebral Palsy: Unilateral and Bilateral Cerebral Palsy



Note. <https://musculoskeletalkey.com/cerebral-palsy-10/>

CP is commonly accompanied by several developmental issues in cognitive, communication, behavior, attention, and perception. Additionally, children with CP often experience epilepsy and a range of comorbidities and functional limitations, such as chronic pain, hearing and visual impairment, behavioral disorders, intellectual disability, musculoskeletal problems, sleep disorders (Graham et al., 2016; Novak et al., 2017; Tsibidaki, 2020). These motor, cognitive, and environmental factors can all influence social participation and daily life in children with CP (Bottcher, 2010). Moreover, Michelsen et al. (2005) in their study which was focused on education levels of people with cerebral palsy, identified that most people with CP had some education, but many did

not finish high school. Additionally, factors like IQ, type of CP, walking ability, and parents' education levels influenced whether a child with CP received education or not. However, they noted that even though children with CP often face challenges in education, many can still achieve educational goals with the right support.

A Family with a Child with Cerebral Palsy

According to Tsibidaki (2020), CP is a chronic disorder that has a major impact on a child's growth, well-being, and movements. It also makes it difficult for families to adapt and adjust. Parents who may still be having difficulty accepting the diagnosis may find this condition's continual, hands-on care stressful and emotionally taxing, which can result in a decline in their well-being. Research from Canada, Australia, Iran, and other Asian nations has repeatedly shown that parents of children with special needs, especially those with cerebral palsy, first face emotional and physical health problems, then social and psychosocial difficulties. These challenges can negatively affect parental overall quality of life (Alaee et al., 2014; Smith & Blamires, 2022).

Parents' Challenges

The complex, long-term nature of CP affects every facet of family life. Because each child is different, carers have to deal with changing expectations. Parents of children with cerebral palsy report worse life satisfaction than parents of children with usual development (Davis et al., 2009; Tsibidaki, 2020). Significant effects on independence, physical and social well-being, familial relationships, and access to support resources were noted in Davis et al. (2009) interviews with mothers and dads of children with different CP severities. For example, carers often said, 'You lose a lot of freedom', 'You can't do things like you used to be able to do', and 'I want time to myself', as a result of their child's continual care needs. Furthermore, maternal caregiving responsibilities often intensify as children with CP maintain prolonged dependence for basic needs like feeding, dressing,

and bathing. Regarding these increased pressures, Iranian moms who participated in a cross-sectional survey reported having less time for personal, professional, and recreational activities (Rassafiani et al., 2012). The study's shortcoming, though, is that it didn't investigate the availability of support networks.

Additionally, research on marital stability among caregivers presents conflicting findings. Kim et al. (2023) suggests an elevated divorce risk for parents of children with special needs. Conversely, Müller et al. (2022), examining Swedish families, found no increased divorce risk, except among those with lower education levels. However, this finding may indicate the strong social safety system of Sweden and cannot be generalized to populations with less developed social support system.

Cerebral Palsy and Challenges Related to Education

Parents face various challenges raising a child with CP, including emotional, social, and financial challenges. However, the educational challenges specifically require close investigation. For children with CP to be included and thrive in learning environments, it is important to understand several key areas.

Learning Profile

Since CP is a chronic neurodevelopmental condition with accompanying comorbidities such as visual and cognitive impairment, epilepsy, attentional and behavioral difficulties, that significantly affect every facet of everyday life, almost half of all children with CP have difficulties in learning (Micheletti et al., 2023; Wotherspoon et al., 2023). Depending on the degree, kind, and timing of the brain damage, the coexistence of these comorbidities can vary greatly (Micheletti et al., 2023).

Fluss and Lidzba (2020) identified that intellectual disability is frequent, especially in children with severe motor impairment and early epilepsy. Speech and language problems are common across all CP types. As a result, children who have severe physical

disabilities are occasionally placed in groups with children who have an IQ of less than 50, or their evaluation is based entirely or partially on clinical assessments by qualified doctors (Sigurdardottir et al., 2008).

Also, visuospatial functions, attention, and executive functions are often mildly to moderately impaired. Studies have found that there is a correlation between motor impairment and cognitive function; for instance, poor motor skills often indicate weaker cognitive abilities (Fluss & Lidzba, 2020; Pirila et al., 2007; Sigurdardottir et al., 2008).

In a systematic review of studies on cerebral palsy, cognition, and academic achievement published after 2000, a majority of them highlight the importance of considering cognitive and academic challenges alongside motor impairments in CP management (Fluss & Lidzba, 2020). A retrospective study, done by Pirila et al. (2007) that included 36 children identified that the severity of CP (motor limitations) was related to the child's language and motor speech problems. Sigurdardottir et al.'s (2008) study of 127 Icelandic children between the ages of 4-6 with CP found that a child with strong speaking skills but weak motor skills may have hidden learning difficulties. Additionally, the study found that children with milder movement limitations (hemiplegia and diplegia) generally performed better than those with more severe limitations (quadriplegia and dyskinetic CP). Interestingly, even children with very limited movement showed good skills in comprehension. However, the findings may have been different among children in other nations with different healthcare systems or socioeconomic backgrounds.

Early Intervention Service

There is a consensus among clinicians that a child with a damaged central nervous system must acquire rehabilitation interventions or early intervention (EI), as early as possible, during the critical period of brain development. EI includes various rehabilitation services focusing on five key areas: thinking, physical skills, communication, daily living

skills, and social and emotional skills (Buftac et al., 2020). However, not every approach will be beneficial for a child with cerebral palsy; the ideal course of treatment depends on several factors, including age, type, severity, parental variables, environmental factors, and neuroplasticity principles (Morgan et al., 2021). There are several studies (Hadders-Algra, 2014; Buftac et al., 2020) that focused on investigating whether these EI sessions might slightly improve how children with CP talk, move and develop. The study by Buftac et al. (2020) over a year analyzed the records of 351 children with CP in Moldova to assess the impact of EI programs on the development of these children. The study findings identified almost no differences between those who attended and those who did not attend EI programs in visual, communicative, and cognitive outcomes of children with CP, contradicting the claim about the EI programs can slightly enhance the cognitive development of children with CP. However, Buftac et al. (2020) emphasized in their study the importance of motor training programs, as they found their effectiveness in motor development, which may also assist the parents in preventing contractures.

Education of Children with CP in Kazakhstan

Over the past two decades, the Ministry of Education and Science of Kazakhstan has confirmed several important educational reforms and prioritized joining the global movement to inclusive education (Passeka & Somerton, 2022). Reflecting these confirmed reforms, Article 30 of the Constitution of the Republic of Kazakhstan, every child has the right to get free based compulsory secondary education (Passeka & Somerton, 2022), and Article 24 also states that children with special needs have the right to receive education in a mainstream school with their peers (Helmer et al., 2020). However, despite the confirmed policies, the reality of how the schools accept and support this commitment depends on several factors, including country's historical background and social roots (Helmer et al., 2020), and the recommendation of the Psychological-Medical-Pedagogical

Consultations (PMPC) (Human Right Watch, 2019; Passeka & Somerton, 2022). The PMPC determines a child's unique learning ability and gives the recommendation for parents about the child's educational placement, ranging from mainstream, special school or home-school them (Allan & Omarova, 2020; Passeka & Somerton, 2022). A child is categorized by his or her main diagnosis and is suggested to be placed in relevant school type with relevant remedial curriculum (Passeka & Somerton, 2022). However, according to Human Right Watch (2019), the PMPC's recommendation is mostly treated for parents as a final educational placement decision of a child with disability. Also, reflecting on the former historical background and social roots factor by Helmer et al. (2020), this is often seen as the legacy of the Soviet system that promoted the 'correctional' or 'special' education approach, where children with disabilities and special needs were placed in correctional and special schools or educated at home by excluding them from the mainstream educational system (Makoelle, 2020; Rollan & Somerton, 2019). Kazakhstan's special education system has its roots in the Soviet medical model of disability. This model views disability as a personal failing within the individual. As a result, their approach to educating students with disabilities is called 'defectology.' Defectology historically was structured and focused to correct and put a child into the existing education system, rather than to meet child's specific educational needs and adapt the system (Makoelle, 2020; Mukashev & Somerton, 2023).

Homeschooling

Children with disabilities may get their education in Kazakhstan in a variety of settings, including homeschooling, special education, or 'correctional' education, as well as public/ mainstream or private schooling. The state of home education is however unclear. Homeschooling in Kazakhstan is generally not permitted by law, except for

specific cases such as temporary foreign residents and children with special needs (Mukashev & Somerton, 2023).

Children, who need special education first go to a local medical center's Medical Advisory Commission (VKK) for a health check. The VKK's findings are then considered by the PMPC, which includes medical and education professionals.

For children who cannot go to school, Kazakhstan offers publicly funded home schooling with a teacher visiting for just 8 hours a week. They focus on basic subjects and the child has no opportunities for socializing, which is a key goal of inclusion. It also creates a segregated environment, something Kazakhstan's inclusion policy aims to avoid (An et al., 2018; Mukashev & Somerton, 2023).

Additionally, An et al.'s (2018) qualitative study, that focused on documenting 17 parents' experiences and perceptions in two major cities of Kazakhstan, found that teachers lack the training and qualifications to work with these children. If this finding is representative of parents' experiences in urban areas, the experiences of families in smaller towns and rural areas may be far more challenging.

Teachers Perceptions of Inclusive Education

Although Kazakhstani teachers are largely shared a positive attitude towards inclusive policy and practice, the majority of them are against including in mainstream schools children with severe levels of disability (Makoelle, 2020; Passeka & Somerton, 2022). For instance, one of the teachers in Makoelle's (2020) study expressed: 'I have a child with mental retardation in my class, but he is [a] very difficult child.' This implies that although teachers are generally positive toward inclusive education, inclusion of learners with mental and intellectual disabilities brings with it a certain level of concern. Another case study done by Passeka and Somerton (2022) that explored the perceptions, feelings, and beliefs of special educators in a particular city, found that teachers sometimes

exclude a certain group of children with special educational needs from mainstream schools, which is contrary to the core principles of the inclusive education model.

Summary

As in every country, children with cerebral palsy in Kazakhstan struggle in many areas of development and receive learning that can be uneven, mainly arising from the challenges in the education system that is still holding on to elements from the past. This review explored the challenges and experiences of parents raising a child with CP and presented the challenges of inclusive education in Kazakhstan. This chapter highlighted the value of using frameworks like Family Systems Theory and Social Support Theory. The following chapter will present the methodology used in this study.

Chapter 3: Methodology

Introduction

The previous chapter included a general review of the topic of this research, explored the reality of raising a child with cerebral palsy, and analysed the knowledge gained from earlier research studies. The focus of the current chapter is the methods used in this investigation. The research design and methodology are presented in this chapter together with other significant elements such as research questions, sample size and selection, data collection methods, and the analysis that follows. Ethical considerations are also discussed.

Research Philosophy

The two main components of philosophy are ‘ontology’, which deals with the basic assumptions about the nature of our reality, and ‘epistemology’, which is concerned with how we comprehend or learn about it (Leavy, 2014). The current study adopts a philosophical stance known as interpretive epistemology, which is based on the idea that reality is random and depends on personal interpretation. Specifically, the current research study employs phenomenology, a human being’s philosophy (Qutoshi, 2018). This approach, according to the Qutoshi (2018), is directed to identify our position, focused to expand our vision about the reality, and to research the lived experience deeper. Researchers should therefore avoid making the assumption that they are aware of the meanings that people ascribe to specific phenomena. According to Leavy (2014), as cited in Muratkhan (2024), the researcher's job is to uncover the parts of people's perceptions that they take for granted.

The researcher has a close family relative, who is raising a child with cerebral palsy. Although the researcher's perspective of parental experiences and the support needs of children with cerebral palsy has been impacted by this experience, the current study was

purposefully designed to avoid confirming any prior assumptions the researcher may have. To avoid any unexpected impact on the results, potential researcher biases were carefully considered at every stage, from participant interviews to data processing.

Research Design

This study uses the qualitative research approach of phenomenology to explore lived experience of parents raising a child with cerebral palsy. Phenomenology focuses on understanding the shared experiences of participants and the underlying meaning or essence of those experiences (Padilla-Díaz, 2015). Additionally, the philosophy of phenomenology aims to understand how we experience the world around us. This includes interactions with others i.e.(teachers and students, nurses and patients, therapists, and clients) and our encounters with things (books, news, hobbies, anxieties) (Vagle, 2018). According to Anagnostaki and Zaharia (2020), this research approach, includes a deep examination of a small group of participants and requires a dynamic interaction between the researcher's prior knowledge, and the data collection. Particularly, in the current research study, the researchers' background as a researcher informed by an understanding of family systems theory (FST) and social support theory (SST), serves as how the parents' accounts of their experiences raising a child with CP in Kazakhstan can be interpreted. By using this approach, the researcher is able to delve into the parental unique perspectives and concentrate on the challenges and resources they face within their social and cultural environment. Therefore, to understand the parental experience of parents raising children with cerebral palsy, the research employs a phenomenological method.

Research questions

Research questions are the foundation of any study. They are helping researchers to understand the phenomenon they're investigating (Leavy, 2018; Creswell, 2015). The main

question guiding this study is: What are the lived experiences of parents of a child with CP?

Sub -questions:

- How do parents support the education of their child with CP?
- What are the main challenges parents face in facilitating the education of their child with CP?
- What improvements do parents suggest for supporting children with CP?

Sample Selection

Phenomenological studies typically involve a small group of people to interview who have experienced the studied phenomenon (Qutoshi, 2018). This research was focused on parents with at least one child diagnosed with cerebral palsy. The participants were recruited based on snowball sampling for this study. Goodman (2011) defines snowball sampling as a technique for conducting interviews with members of an individual's close social circle while employing guided questions to the interviewee. The researcher is familiar with one family who already agreed to participate in the study and other participants were referred by initial family's connections. Also, using snowball sampling, potential participants were reached through social media networking sites as well as personal acquaintances. Factors such as the child's age, socioeconomic background, gender, and the extent of the CP condition were not considered in the screening criteria. I also met with a group of parents who have a child with CP and explained about my research and its purpose in order to possibly secure additional participants.

Instruments

In this qualitative inquiry, the data was collected from the main participants raising a child with CP through semi-structured interview. According to Jamshed (2014), the

semi-structured interview is an in-depth interview where the respondents must answer pre-designed open-ended questions. This data collection technique is one of the most important for the present study, as it can shed light on main research questions. By merging the data collection technique and the employed theoretical frameworks in this research, the researcher structured an interview protocol (see Appendix D) with questions that gave parents a complete understanding of how they navigated the emotional, social, and educational challenges of having a child with cerebral palsy.

Data Collection Procedure

Once the study received ethics approval from Nazarbayev University Graduate School of Education (NUGSE), recruitment began. The consent form was sent via Telegram or WhatsApp chat, and/or individually delivered by the researcher. The study's objective and aims, the research methodology, potential risks and benefits, participant rights, and the researcher's contact information were all thoroughly outlined on the form. According to Creswell and Poth (2017), this documentation procedure protects participants' rights during the whole data gathering process. Participants' preferred day, time, and place were taken into consideration when scheduling interview appointments after obtaining their consent. All the sessions were done via whatsapp audio or Google Meet depending on the preference of the participant. These sessions lasted for between 30 to 45 minutes. Each interview was digitally recorded with participants' prior consent for recording of the conversation, verbatim transcription, and interpretation of data. Once the interview had been transcribed, I checked back with each participant to be sure it was presented correctly.

Data Analysis

Phenomenological data analysis in qualitative data involves reviewing interview transcripts to identify key statements that reveal how participants experienced the

phenomenon being studied (Creswell & Poth, 2017). The researcher analyzed the interview data in several steps. First, I transcribed the interviews converting audio recordings into written text. Subsequently, translated the initial text from Kazakh or Russian to English. And then I started the coding process. In this context, the researcher applied the following codes: Descriptive and In Vivo codes (Saldana, 2013, p.27). It can be suitable to employ multiple coding systems simultaneously in various situations (Saldana (2014). Following this, key themes and patterns were identified, similar data were grouped under specific categories or subcategories, respectively. And finally, it was possible to generate a number of themes that addressed the research issues of the present research study.

Ethical Considerations

Ethics (Göçen, 2021) is presented as a branch of philosophy which broadens into many fields. Bon and Bigbee (2011) state that ethics is the endeavour to behave by a set of values, beliefs, and principles. It suggests that the person is willing to act in accordance with their particular ethical principles and is conscious of them. However, according to Oliver and Eales (2008), researchers must be more aware of the possible consequences regarding the personal, and emotional issues, as the ethical concerns may stem from a variety of factors, including the nature of the research project itself, the context in which it is being conducted, the procedures that will be put in place, the methods of data collection, the participants, the type of data that will be collected, what will be done with the data, and how the data will be reported.

The first step was to de-identify all of the data collected during the interview in order to preserve the participant's confidentiality and privacy. In order to maintain the confidentiality of the data, all information that might be used to identify the participants was deleted after the research project was completed. The researcher kept the collected

data on a password-protected laptop. Furthermore, as recommended by Clark et al. (2017), transcription verification by study participants had been done to ensure data reliability and proper representation of parent voices.

During the interview process, the research topic and questions may also evoke unpleasant memories or experiences, as the questions, particularly related to "The First Reaction" may seem sensitive in the interview process. During the interview, the researcher was ready for any uncomfortable scenarios that might come up. Specifically, when confronted with the emotional pain of participants in qualitative research, researchers may become distressed (Oliver and Eales, 2008). Interviewers may consequently get overly attached to the participant or overly disengaged. As a result, the interview protocol also contained a script or language for providing assistance, pausing, or ending an interview.

Summary

This chapter has outlined the research methodology used in this study. It covered the chosen qualitative design, specifically a phenomenological approach. This approach delves into the lived experience of parents raising a child with cerebral palsy. The chapter also detailed the research questions, participant selection, data collection instruments, interview procedures, data analysis plan, and ethical considerations.

Chapter 4: Findings

Introduction

The present phenomenological research study's purpose is to explore the experiences of parents raising a child with cerebral palsy. Particularly, it focuses on understanding the difficulties they face, their role in their child's education, and the support they need. Data was collected through semi-structured interviews from six parents.

Interview data was coded and analyzed, identifying key themes that shaped this chapter.

These themes are used to address the main research question and its sub-questions. This chapter presents the findings with direct quotes of participants from the interview to better understand the phenomenon in this context.

Study Sample

Table 1 presents the demographic information of participants in the study. Each participant was assigned a pseudonym. The interview was collected from various regions of Kazakhstan, specifically Astana, Almaty, Kostanay, Atyrau, where two of them resided in rural areas.

Table 1

Demographic Information of the Mothers

#	Participant pseudonym	Child (age, gender)	Residence	City of residence
P1.	Guli	Son, 21y	Rural	Atyrau
P2	Alla	Daughter, 9y	Urban	Astana
P3	Fariza	Son, 12y	Urban	Astana
P4	Aidyn	Daughter, 13y	Rural	Almaty

P5	Aliya	Daughter, 11y	Urban	Almaty
P6	Dana	Son, 4y	Urban	Kostanay

Data Analysis

After two stages of coding and categorizing, there were four main themes and twelve subthemes developed. These themes represent parent's diverse lived experiences of directing the journey of their child with CP (see Table 2). The main themes include: (1) Finding out the diagnosis of a child (2) Support and challenges in education of a child with CP; (3) Challenges and support needs of parents; (4) The role of the government. Furthermore, these themes were divided into sub-themes giving a detailed understanding of participant's diverse experiences.

Table 2

The Study Themes and Subthemes.

	Themes	Subthemes
1	Finding out the diagnosis of a child	a) Circumstances and impact of medical personnel b) Initial reaction of family c) Type and severity of CP and comorbidities d) Changing mindset
2	Support and challenges in education of child with CP	a) Child's need and education <ul style="list-style-type: none"> · Impact of type and severity of CP to child's education · The role of PMPC · The role of mothers and siblings in education b) Parental expectations

3	Challenges and support needs of parents	<p>a) Current challenges parents face raising child with CP</p> <ul style="list-style-type: none"> · Navigating between parental roles · Lack of medical guidance and shortage of specialists · Societal attitude · Financial hardship <p>b) Areas of support</p> <ul style="list-style-type: none"> · Psychological · Providing clear route after birth of a child · Family and relative's support
4	The role of the government	<p>a) Current state of support</p> <p>b) Recommendations for improvement</p> <ul style="list-style-type: none"> · Social worker · Financial · Forums on how to develop and learn child with different types of CP

Note. CP = Cerebral palsy.

Finding out the Diagnosis of a Child

The first theme represents the circumstances where mothers discover the diagnosis of their child; the family members reaction; the type and severity of CP and comorbidities; and the factors that help mothers to change their mindset and be an advocate. These processes are individual for every family and shaped by several factors.

Circumstances and Impact of Medical Personnel

Most of the participants reported a range emotional feeling when they discovered the diagnosis of their child, including a sense of helplessness, panic, shock, and self-blaming. All the participants went through the range of emotions when they found out their child had CP. Two of the participants (Guli and Aliya) realized the news during the first year of development of their child, the other four participants highlight unprofessionalism

of the medical personnel and have blamed them for the fact their child is disabled. For instance, Fariza and Aidyn argue that because of doctors did not control the level of bilirubin in blood during the jaundice, harmful components, having reached the child's head, penetrated all brain cells and killed neural connections. This straightly led to a severe type of cerebral palsy. According to Fariza:

I have never expected to have a special child. After two pregnancies, 12 years ago I got pregnant with twins. The pregnancy was so easy that the doctor allowed me to give birth on my own. Both my twins weighed well at birth, I gave birth in a private clinic, and both were born healthy. However, one of the twins became disabled due to the illiteracy of the medical staff. Bilirubin exceeded the norm, although the doctors assured me that it would go away on its own. I still cannot forgive myself for listening to those irresponsible doctors.

Two other participants, Alla and Dana, shared that because the obstetricians performed the birth incorrectly, the baby's head was severely damaged due to lack of oxygen, which led to the diagnosis of cerebral palsy. On the other hand, the former two participants, Guli and Aliya, say nothing negative about the birth of the child, but still replied that they never expected to have a child with CP. For example, Guli states the following:

I didn't know in advance that my child would be special, it started to become clear and visible from six months.

Initial Reaction of Family

Interview findings revealed that almost every mother endured a double burden of emotional stress: the news of her child's diagnosis coupled with blame from her family. They (Guli, Alla, and Dana) report that initially close family members often react negatively, blaming the mother, give little support, insisting that such diseases are foreign

to their family history, and even suggesting the child be sent to a boarding school. Fariza attributes this to a low level of education and understanding of people in Kazakhstan about children with special needs, adding that this leads to the breakdown of the family in many cases; parents get divorced, the father leaves the mother without financial support.

According to Fariza:

Few people understand the situation of the mother, and more and more people blame her. I think this shows a low level of education and understanding of people here. Additionally, my close relatives suggested sending the child to a boarding school. Also, my husband couldn't stand it for long, family dramas began, he became a gambling addict, got into debt, it was a big burden for me, and soon we got divorced.

Aidyn shares almost the same experience, relating to the initial reaction of her family. She reported that even her own parents abandoned her. Also, 'My husband's family,' she explains, 'still blames me for our daughter's condition, subjecting me to cruel words and even eviction. But my daughter is my strength, and I will endure anything for her.'

On the other hand, Aliya and Dana shared that they experience strong support and positive reaction from their husband and mother. Aliya says: 'First, my mother helped me to accept my child. Then, my husband was always with me.' Similarly, Dana expressed:

My husband did not abandon me in a difficult situation with a special child, and I decided to continue to fight for the preservation and development of our family.

Type and Severity of CP and Comorbidities

Participants in this study shared the information about the specific type of CP and comorbidities (see table 3) that can be a barrier for successful educational, physical, and emotional development.

Table 3***Type and Severity of CP and Comorbidities***

Participant's child	Type and severity of CP and comorbidities
Guli's son	Severe form of spastic hyperkinesis, epilepsy, severe mental disability
Alla's daughter	Severe form of spastic hyperkinesis, visual impairment (one eye), curvature of the spine, severe mental disability
Fariza's son	Severe form of spastic hyperkinesis, epilepsy, severe mental disability
Aidyn's daughter	Severe form of spastic hyperkinesis, poor mental development
Aliya's daughter	Epilepsy, poor mental development
Dana's son	Severe form of spastic diplegia, epilepsy

Four parents (Guli, Alla, Fariza, and Aidyn) report that their child has a complex form of cerebral palsy, namely spastic hyperkinesis and comorbidities like visual impairment, epilepsy, severe mental disability. In general, they say that their children, in addition to their comorbidities, are unable to move their arms and legs independently, sit, or perform daily needs. However, Alla and Aidyn say that their daughters could express emotional feelings and try to make contact through it. Another participant's (Dana) son has severe type of spastic diplegia and epilepsy. She states: 'Our son has a severe type of CP,

specifically, spastic diplegia and epilepsy. He has severe muscle tension, which prevents him from performing new skills and speaking.’

In contrast, there is one participant’ child (Aliya’s), whose physical, emotional, mental performances improved vividly after several rehabilitations. Mother says:

At the beginning my daughter was not able to do any movements, walk, or speak.

But maybe it’s magic, after a long period of supervision, love, my attention, rehabilitation, she is able to speak and walk now.

Changing mindset

When the interview questions got to the point to what helped parents accept their child’s situation several talked about, trust in God (Guli, Alla, Fariza, Aidyn), then being an advocate (Guli, Alla, Fariza, Aidyn, Dana) and third, the educational background (Guli, Fariza, Aliya) unified the ideas almost of every mother. For instance, Fariza indicates this transformation, stating:

Caring for my child with special needs opened my eyes to the difficulties faced by families like ours. These challenges transformed my outlook and spurred me to make a difference. We established an NGO to advocate for these families, working closely with the Department of Health to bring their concerns to the government's attention. We achieved significant progress, securing essential resources like strollers, diapers, and free bus passes for parents. My dedication led me to become president of the NGO, where I fought tirelessly for our community. While this work was incredibly fulfilling, it came at a cost: I struggled to balance my advocacy with my own child's educational and developmental needs. Additionally, two things are important to mention: First, my faith provides me with answers and guidance. Second, I have a strong educational background.

Another participant (Aliya), a psychologist, connects her educational background to a source that helped her not only change her mindset but also, to accept her child's diagnosis and love her uniqueness. She describes:

Before, when I did not have children, I worked as a psychologist, met children with disabilities, and I tried to make them happy. It gave me incredible sense of joy.

Now, I think my profession changed my mindset and helped to accept my child as she is. In turn, this acceptance and love helped make positive changes in her development.

Support and Challenges in Education of a Child with CP

The next theme presents the overarching topic of the educational journey of children with cerebral palsy. This theme requires careful consideration of several key factors, such as: the child's education, more specifically, impact of type of CP to child's education; the role of the Psychological Medical Pedagogical Commission (PMPC); the role of mothers and siblings, and parental expectations.

Child's Need and Education- Impact of Type and Severity of CP to Child's Education

According to the explanation of all parents, the educational experience of children with CP is closely bounded with the medical diagnosis, where alongside the primary diagnosis they frequently struggle with comorbidities (see table 3). For instance, Guli and Fariza are not able to support their child's educational needs because of severity of type of CP and severe cognitive disabilities. Moreover, some doctors suggested Guli not to develop her son with CP. She shared:

In the village, one woman, a doctor, said that if I put him on his feet and develop, I would not be able to keep him at home. If he gets up, he will not be able to control himself, react to the environment, it will be very dangerous for me and others as well. She asked not to develop his abilities.

Alla explains that although her daughter has severe type of CP and severe cognitive disability, she is able to express her feeling, and because of this she attends public kindergarten. She states:

My daughter is able to express her feelings, that is why when she was 6, we found public kindergarten to attend for children with various special needs. Here she gets massage, exercise therapy. The teachers are specially trained, selected to work with special children. They teach children to draw, sing, express emotions, and we as parents, in close contact with the teachers, actively participate in such events.

Two mothers (Aidyn and Aliya) reported that their children receive education at home and show positive development. Aidyn says:

She is homeschooled. The teachers come and teach a regular lesson, 45 minutes, or an hour, depending on the child's mood. Every year a new subject is added. I am happy that she is getting an education.

Dana expressed that her son is too young to attend the school, saying: "At the moment we don't go anywhere. We're focusing on working with him while he's young and more malleable." However, she clarified that they are actively pursuing rehabilitation and seeking out qualified specialists, stating:

Our child has a complicated diagnosis, his muscles are very stretched, they do not allow him to perform new skills, spastic diplegia, plus epilepsy. Not long ago we visited a defectologist, an occupational therapist, but I think this is not enough.

Since he has spastic diplegia (severe form), I think we need a good speech therapist, speech therapy massage, a pool to relax tense areas of the body.

Child's Need and Education- The Role of PMPC

The interviews revealed that PMPC's decision and PMPC's psychological tests can determine the future educational journey of a child. For example, Aidyn and Aliya

indicated that after passing PMPC's psychological test, this commission gave permission to receive homeschooling. Aidyn says:

We passed the PMPC commission, and then we were accepted to the school. Not all special children can pass the commission, we received permission as my daughter does not have severe mental disability, and additional illnesses.

On the other hand, for the interview question whether a child goes to school or no, parents (Guli, Alla, and Fariza) reply that their children could not pass even PMPC's psychological test due to severe cognitive disability. Fariza states:

The PMPC decides whether we can receive an education at school, as our child can't even pass their psychological test. There can be no talk of school here. The severity level of him is so high.

Child's Need and Education- The Role of Mothers and Siblings in Education

The responses of the several participants (Aidyn, Aliya, Dana) indicated that education happens not only with teacher, at school, or during therapy, but it happens daily at home with parents, and surrounding people, like siblings. According to Dana:

During rehabilitation, I always observe specialists, remember their actions, and repeat them at home. For example, not all children like other people's hands until they trust them, but they trust their parents. In this way, I participate in their development. Such support in the development and education of a child with cerebral palsy is a very important aspect, since a child with such a diagnosis needs daily massage, exercise therapy, and we do not go to rehabilitation every day or every month.

Aidyn discussed that she tries to give comprehensive development and learning, saying that she has dedicated her whole life her daughter. She expressed:

I take my daughter to various concerts and teach her to use a tablet. Thanks to this, she expresses her feelings and needs. I try to develop my daughter as comprehensively as possible. Even though we live in rural area, we go for walks to keep my daughter's mind clear, I monitor her mood, and she signals her needs with her voice or eyes. We draw together, she is happy and loves music.

Aliya reports the same, but also highlighting the importance of sibling's role, stating:

I try to do daily exercises with her so that my daughter can get education, I train her fine motor skills, we talk a lot, I tell her how to behave on the street, tell her what is right and what is not. Not only me, but also her sisters, teach her what they know. I systematically teach them how to help each other with compassion. It is crucial for me to foster a sense of community and shared responsibility.

Parental Expectations

During the interview, parents discussed their long-term expectations for their child. Several parents' responses indicate on the one hand, they have no hopes and expectations for the future, other than to improve their child's current physical state (Guli, Alla). However, Fariza expressed, 'I hope my son will speak at least, if a comprehensive support would be presented, like a social worker, financial support, and others', pointing out there is no support in her environment.

On the other hand, there are positive responses from other parents (Aidyn, Aliya, and Dana), who not only research, put much effort today, to realize hopes in true. For example, Aidyn says:

In the future, I dream of my daughter developing and getting an education, and for this I always look for different programs. Now there is such a program EYE TRACKING, that determines what the child wants by reading where the eyes are looking, but it is very expensive.

Aliya and Dana had the same opinion, emphasizing they hope to reveal a specific talent or skill of the child. Aliya states:

Despite the challenges, I'm determined to support my daughter's interests and help her reach her full potential. She may struggle with logic, but her artistic skills are exceptional. I wish to see her working in a beauty salon one day. We're working hard to develop her talents and help her find a career she loves. Never stop to believe in and hope for the bright future of your child.

Challenges and Support Needs of Parents

This theme explores various aspects of parenting a child with CP, focusing on the challenges parents face and the support they need. The theme is organized into subthemes, each addressing key challenges and support areas. For instance, challenges include parental burnout, lack of medical guidance, and societal attitude. Support areas encompass financial assistance, psychological support, providing a clear route after a child's birth, such as medical guidance, family and relative support, and parental activism.

Challenges Parents Face Raising a Child with CP- Navigating Between Parental Roles

During the interviews, all participants discussed their family roles and parenting styles, considering not only their experiences as mothers of children with CP but also their relationships with their other children. All participants described navigating multiple family roles, including full-time mother, wife, homemaker, and career. Some work outside the home, and others fulfill the roles of both parents. While juggling these responsibilities, most of the parents reported experiencing parental burnout, and development of complexes in how they are parenting their other children. For example, Guli states the following:

As a single mother whose husband passed away, I am the sole provider and caregiver for my son with cerebral palsy and my other child. I'm responsible for all aspects of our family life, including financial stability, which requires me to work.

Caring for my son with CP, especially as he grows older and stronger, is physically and emotionally demanding, and the strain is exhausting. Adding to this burden, my other child is being bullied because of his brother's condition. Navigating all these challenges is becoming increasingly difficult.

Fariza's interview also discussed parental burnout, but mostly highlighting family dramas, lack of external support, stating:

External support systems can significantly assist a mother of a child with special needs help prevent burnout, navigating various roles. However, my situation lacks these supports. The absence of stable home, and consistent employment, divorce with husband, a lost of contact with my older daughter, combined with the absence of grandparents, who could assist me, only enhances the challenges, and negatively impacts my overall well-being, performance and navigating my life.

Parents in this study discussed the stressors in their lives that added to the challenges of parenting their child with CP.

Challenges Parents Face Raising a Child with CP- Lack of Medical Guidance and Shortage of Specialists

Participants discussed the lack of medical guidance in different stages of development and shortage of specialists (Alla, Fariza, Dana). Dana describes that she relies on other parents' experiences with a child with CP for information, explaining that doctors often fail to provide complete information or adequately address the child's specific needs. She expresses:

We have a WhatsApp group chat for parents of children with CP from across Kazakhstan. I get most of my information and support from this group, especially from more experienced parents. They offer advice on everything from required rehabilitation documents and where to go for services, to alternative therapies.

Unfortunately, we've found that doctors are often negligent, even after moving to a different city to find better care.

Alla and Fariza gave an insight shedding light on shortage of specialists, recounted their experience, saying 'There are specialists who have not prepared to work in the position they are employed' or 'It is not easy to find good specialists, and we've had unpleasant experiences with some of them.'

Challenges Parents Face Raising a Child with CP- Societal Attitude

Interview responses identified that many parents experience negative societal attitudes. Alla and Aidyn pointed out on lack of understanding, empathy and awareness about CP. While Alla expresses her experience, stating:

For example, in hospitals, parents of special children stand in the same line with normal people, while ordinary people, without any empathy or human respect, start to swear, saying that it's not their fault that I have a child with special needs.

Aidyn highlights the lack of awareness of people in the community about CP, discussing the following:

Many people in the street avoid us, point fingers, think that my daughter has a contagious disease. Maybe because people in the rural area know little about it, in contrast, when we went to another country for treatment, people were drawn to her, admiring her beautiful eyes, offering hugs, and genuinely wanting to get to know her.

Current Challenges Parents Face Raising a Child with CP- Financial Hardship

During the interview parents shared another major challenge that completely influences her parenting, the financial challenge. Guli shared her experience how financial needs influenced her decisions. She is stated:

I am very afraid to talk about it, but no matter how terrible it sounds, due to lack of money I was forced to go to work and leave my child alone at home. When I came home, there were days when he ate raw meat from the refrigerator, tore the wallpaper, broke the dishes. In such cases, I tied him with a rope to one place and went to work. Now I leave him with the TV on in one room. I have no other choice, who will financially support us except me.

Fariza discussed her experience with financial hardship from different perspective, stating the next:

I used to have everything, money, a good job, recognition. But once I had a disabled child, everything started to turn upside down. Twelve years passed, I left my job, since caring for the child did not allow me to work, we sold everything that could be sold for the treatment of my son with cerebral palsy, sometimes there was not even money left for bread. Now I do not work, and financial difficulties mean I cannot afford to take my child to rehabilitation.

Areas of Support- Psychological

Participants emphasize the need of psychological support for parents, specifically for mothers. Fariza says, “Mothers need psychological assistance for free twice in a month” indicating that it could prevent burnout and stress. Aliya also highlight this need for other parents, as being a psychologist, she is helping many parents for free who addressed her with various issues. Dana shares the same but significantly emphasizing the result of relief after a visit to the psychologist:

We really need psychological help, a stranger to whom we can tell all our past, all our difficulties, who will listen to everything, understand, will not judge, but on the contrary will accept and understand. It gives such relief, as if a lump got stuck in

the throat and a psychologist helps to get rid of it. Even now, telling you my experience, I feel like I am at a psychologist.

Areas of Support- Providing Clear Route After Birth of a Child

Alla, Aidyn, and Fariza suggested another crucial area of support for parents: establishing a clear route immediately after a child's birth. Fariza elaborated, stating, 'Statistics show an increase in the number of children born with CP in Kazakhstan. While parents and doctors are focused on managing the effects,' she emphasized, 'we need to address the root causes.' She suggested that medical personnel should provide comprehensive information, guidelines, and brochures to raise awareness among parents about what steps to take from the first moments after birth. This includes guidance on how to assess their baby's well-being, understand potential warning signs, and know when and where to seek emergency care.

Areas of Support- Family and Relative's Support

Family and relative's support was extensively discussed by Fariza: 'There should be family and relative's support for the mother until the child improves'. She highlights that mothers never ask for help, stating:

In Kazakhstan, people often donate to charity or perform ritual animal sacrifices.

However, it would be far more beneficial to direct these resources to struggling mothers who raise a child with special needs. Furthermore, given that roughly one in three Kazakhstani citizens owns a car, those who have friends or relatives raising children with cerebral palsy should proactively help, such as transportation to rehabilitation appointments, rather than waiting to be asked. Mothers in these situations are often reluctant to ask for help, even from close relatives.

The Role of the Government

During the interviews, parents shared their perspectives on the government's role in developing and improving services to promote greater inclusion. Overall, they assessed the current state of government support and offered recommendations for supporting inclusive education by providing financial support and ensuring equitable resource allocation for children with CP, particularly those in underserved remote areas and ensuring its sustainable development.

Current State of Support

In general, most of the parents expressed dissatisfaction with the current level of support. Guli shared her experience: 'I haven't been able to take my son to rehabilitation since 2017 due to my own health issues, and my request for a state-provided social worker was denied.' Dana voiced her disappointment with specific individuals working within the system, saying the following:

The most difficult thing in raising a child with cerebral palsy is to get the necessary service, material resources, correct instructions, and direction from the state.

People who provide social assistance do their job as if they are taking the money out of their own pockets, demonstrating a significant lack of care and professionalism.

Other parents (Alla, Aidyn) highlight the importance of the state's role, however discussed that there is little support from there and try to solve their issues by themselves not addressing their concerns to the government. Alla expresses:

State assistance and services have its place, but we do not ask for help, because we have to wait a very long time, and besides, the quality of the service leaves much to be desired.

In addition, they noted about the poor wheelchair accessibility and its quality, Aidyn states:

The wheelchair provided by the state does not meet our criteria, although we order indicating her diagnosis and additional diseases, these wheelchairs are completely unsuitable. We faced excessively long wait times.

On the other hand, Fariza and Aliya expressed that they are not eager to complain about the government's current state of support, but despite all the difficulties they ask parents to be active. Aliya states:

I always ask for what I really need from the state, ... and I think parents should actively communicate their needs to the relevant authorities and negotiate, because the state can't always know what exactly is needed.

Recommendations for Improvement- Social Worker

Guli and Fariza highlight the need of the assistance of a social worker who could come and help in daily care of their child with CP. Fariza says "I treat my child the same way I treat a baby every day. But it's getting harder and harder ... I'm getting weaker. I even can't take him to rehabilitation. I need a social worker, who can assist with child's physical needs, emotional, social, and developmental aspects." Additionally, Guli described needing a social worker when traveling for professional development opportunities:

I need a social worker. Sometimes I have to go to another city for work. When I do, I hire someone to care for my son at my own expense. It's quite expensive. Also, twice a week I hire assistants to bathe my son.

In addition, Fariza hopes that the social worker could support a child in development and learning, discussing the next:

Of course, ... I just need a help of the social worker who would visit my child twice a week to come, read books to him and work on his motor skills, even if only a little.

Recommendations for Improvement- Financial

From the interview responses the parents suggested the government to increase the financial aid for parents raising a child with CP. On the one hand, Guli discussed, 'I receive my son's disability benefits on time, they even increased the amount a little.'. However, Aidyn states: 'The money we got now does not even cover my daughter's medical expenses.' Additionally, as Aidyn does research on new apps that could help her daughter to develop and learn she mentions the following:

In Russia, a modern device called Eye Tracking has been released, but it is expensive, it costs two million tenge. If such a new device were available in our country and at an affordable price by the state, then we, parents, would have more hope for the future.

Recommendations for Improvement- Forums on How to Develop Children with Different Types of CP

Fariza made a strong request for the government to organize forums on how to support the development and learning of children with various types of CP. She contrasted this with the numerous forums currently organized by governmental and non-governmental organizations that focus on autism spectrum disorder (ASD), saying the following:

Cerebral palsy presents in various forms, each requiring different developmental approaches. Many parents are unaware of these distinctions and simply follow advice that worked for other parents. It would be incredibly beneficial if the state organized forums for parents, providing information on working with specific types

of cerebral palsy. These forums could offer guidance on which specialists to consult, how to find qualified professionals. Essentially, parents need access to comprehensive information on the development and education of children with cerebral palsy.

Summary

This chapter presents the study findings, organized according to the themes that emerged during data analysis. Four main themes and their related subthemes are explored, offering detailed insights through direct quotes from participants. The results cover parenting experiences from the initial stages after birth and the subsequent shift in mindset, through the child's educational development journey. Additionally, the chapter addresses the challenges encountered along the way and incorporates parents' suggestions for improvement.

Chapter 5: Discussion

Introduction

The purpose of this phenomenological study was to explore the experiences of parents raising a child with cerebral palsy. Particularly, its goal was to understand the difficulties parents face, their role in their children's education, and the support they need. The previous chapter presented the study findings with direct quotes of participants from the interviews to support the themes. This chapter discusses the research findings emphasizing the implications. This goal will be met through directing how the research findings align with research question and how the theoretical frameworks guided the study findings.

The overarching research question of the study: What are the lived experiences of parents of a child with CP?

Sub -questions:

- ·How do parents support the education of their child with CP?
- ·What are the main challenges parents face in facilitating the education of their child with CP?
- ·What improvements do parents suggest for supporting children with CP?

Lived Experiences

The main purpose of this qualitative phenomenological research study was to explore personal experiences of parents raising a child with cerebral palsy, understanding their realities, including the difficulties they face, their role in their child's education, and the support they need. Thus, to fully understand the phenomenon, the broad scope of the main research question requires more specific inquiries.

To effectively discuss the research findings, the chapter is divided into sub-sections that delve into 1) Parental Roles, 2) Challenges, and 3) Areas of Improvement.

Parental Roles

Parents are the individuals who become visible and an authority from the first days of their child's lives (Tan & Yasin, 2020). Their parenting style of raising a child and their involvement in it can contribute to different children's outcomes relating to education, health, well-being, socialization, and future occupation (Irwin & Elley, 2012).

The experiences of mothers are significant in the context of this research study. According to the findings of the study, mothers try to navigate a variety of roles and responsibilities in the family, society, and workplace that has an impact on the development and education of their child. For instance, almost all participants, characterized their parenting experiences as full-time mother, wife, homemaker, researcher, part-time doctor and therapist, and part-time educator. These findings align with existing research of Heiman (2021). According to her, when a child is diagnosed with a disability, parenting seems to be a parents' life-long mission, and to cope with their new situation, they have to juggle different roles, approaches, and styles toward it. And this mission makes them advocates for their child with special needs due to their investment and commitment in advancing their child's development (Wright & Taylor, 2014).

According to several studies (Heiman, 2021; Pattison et al., 2022; Wright & Taylor, 2014;) parental advocacy is being demonstrated in different ways. At the beginning of their journey, and continuing throughout, parents in this study shared that they faced adverse circumstances, including unsympathetic reactions from family members that revealed a lack of understanding and contributed to feelings of guilt in mothers. Some family members of mothers with a child with severe CP even attempted to persuade them to place their children in boarding schools. In certain cases, medical professionals discouraged promoting further development, citing a potential threat to society. This persistent pressure and strained relationships with family members and

medical specialists remained with the mothers, surfacing during their navigation of rehabilitation services, childhood development, learning, and the overall nurturing of their child with CP. Participants emphasized the need for ongoing dialogue to secure necessary rehabilitation services, as well as additional social, technical, psychological, and educational assistance for their child. Parents specifically highlighted a critical shortage of formal, constructive, and instructional information about where and to whom to address concerns regarding various spheres of child development, tailored for families raising a child with CP. Consequently, parents in Kazakhstan are constantly searching for services. To address their needs, they are uniting together and organizing online chat communities and NGOs. These organizations are created not only by and for parents, but also to serve as a bridge between the government and parents. This finding is similar with Rassafiani et al.'s (2012) assertion that mothers, as primary caregivers, often sacrifice work, sleep, and personal time to meet their child's needs and empower them, the current study findings indicate that to realize these empowering efforts, some parents made major life changes, notably pausing, or ending their professional careers.

The findings in this study align with conclusions drawn from previous research. For example, Wright and Taylor (2014) found that parental ability to advocate is often limited by financial situations and logistical issues. Some parents in this study emphasized that families come from varying socio-economic circumstances. Specifically, they indicated that mothers with high incomes can afford additional support to meet their child's needs by paying for private services. In contrast, families with low and middle incomes often rely on government-provided services, which they perceive as being of lower quality and quantity. Additionally, logistical issues can present specific challenges for parents with low incomes (Wright & Taylor, 2014). This study included participants from diverse social groups, all of whom were families with middle or low incomes, including single mothers

and parents from rural areas. Throughout their journey, mothers encountered scheduling conflicts and issues related to transportation, communication, or coordination between different parties. Some parents living in rural areas, far from the city, missed rehabilitation and therapy services, which could stall or negatively affect their child's development. Irwin and Elley's (2012) research support the notion that a family's diverse social and socioeconomic background significantly influences the acts of advocacy, and future development of a child with special needs (Nurullah, 2013).

A fundamental parental role consists of advocating for their children; however, it often arises from the negative conditions, tensions, and ignorance of responsible individuals within the communities and systems that shape the realities of both parents and children with CP (Shrader et al., 2021). The following sections will expand on this relationship.

Challenges

Despite the families of children with special needs, particularly with CP, experiencing a unique difficult period following the initial diagnosis, stressors, demands over time, and their daily routines as documented in previous research (Glenn et al., 2008; Fritz & Sewell-Roberts, 2020; Heiman, 2021; Nurullah, 2013; Rentinck et al., 2006), the mothers in this study showed impressive resilience and adaptiveness raising a child with CP. Literature on parenting children with CP consistently identifies a series of challenges, such as difficulties accepting the diagnosis (Kandel & Merrick, 2007), social isolation, and stigmatization (Alaee et al., 2014; Zhakupova et al., 2023). These challenges, along with increased marital strain and divorce (Wei & Yu, 2010; Kim et al., 2023), financial burdens (Alaee et al., 2014; Nurullah, 2013), and career adjustments (Smith & Blamires, 2022), were also issues among the participants in this study. As noted by (Irwin & Elley, 2012), parents adapted by changing their lifestyles and perspectives. Aligning with the Family

Systems Theory by Murray Bowen (Metcalf, 2011); and Social support theory (Hupcey, 2002) which were adopted for this study, and existing literature, mothers in this study utilized various support systems—including family support (Metcalf, 2011; Prest & Protinsky, 1993; Rothbaum et al., 2002); social support, including friends, and peer networks (Hajli et al., 2015; Hupcey, 2002), faith (Treloar, 2002), and diverse resources like books and films—to view their experiences positively and find strength in their personal values (Heiman, 2021).

Notwithstanding parents' attempts to adjust their beliefs, perspectives, and coping mechanisms, raising a child with cerebral palsy, particularly regarding their education, remained difficult and dependent on the severity level of CP, aligning with existing literature (Bagazgoitia et al., 2023; Cook et al., 2021; Makoelle, 2020; Passeka & Somerton, 2022). Mothers in this study encountered varied challenges, including inadequate services, poor government support, medical, psychological, and family support, insufficient medical and developmental guidance, poorly skilled specialists, and negative societal attitudes. Additionally, some parents were very concerned about their child's future opportunities as they grew up.

Areas of Improvement

The challenges discussed above—related to birth and diagnosis, rehabilitation and schooling, parents' future expectations, and significant emotional and psychological difficulties in raising a child with CP—further complicated their experiences.

Diagnosis and Birth

The statement that diagnoses are typically developed during maternal pregnancy or in the first few months of a child's life (Zhakupova et al., 2023) resonates with most participants' responses, while contrasting with others. Participants whose responses resonated with this assumption indicated the diagnosis was discovered within the first year

after birth (Issayeva et al., 2020; Zhakupova et al., 2023). Additionally, several parents in this study complained about the unprofessionalism and lack of knowledge of medical personnel, blaming them for their child's disability. They specifically cited a failure to inform them about excessive serum bilirubin levels in their child's blood, which directly led to cerebral palsy (Wu et al., 2015). Consequently, parents in this study reported experiencing a situation where they were given outdated information, limited guidance by specialists, particularly when the diagnosis was delivered after childbirth. Conversely, these parents still blame themselves (Heiman, 2021) for missing the opportunity to intervene, believing that earlier awareness of the circumstances and appropriate actions could have changed the outcome. Therefore, according to Reid et al. (2010), it is crucial for healthcare professionals to use a comprehensive intervention, early identification strategy, and updated information materials, requiring them to actively engage and educate parents in their child's CP care. Parents in this study reported that this approach could improve the quality of life for all involved in the process.

Family support

Aligning with the adopted theoretical framework, Family Systems Theory by Murray Bowen (Metcalf, 2011), which emphasizes the influence of healthy boundaries, such as those within marital couples and parent-child units on the entire family's ability to maintain balance (Prest & Protinsky, 1993; Rothbaum et al., 2002), resonates with parents' beliefs in this study. In almost all families, the mother is the primary and constant caregiver of the child with CP, requiring strong family support (Alaee et al., 2014; Glenn et al., 2008; Rassafiani et al., 2012; Reid et al., 2010). However, not all mothers in this study received this support. The study participants included divorced mothers, widowed mothers, parents from rural areas, and mothers of multiple children. Some experienced emotional pressure from their spouses, family rejection, limited support, and even pressure

to place their child with CP in a boarding school. In turn, this implies that parents raising a child with CP, particularly mothers, experience a higher level of parenting stress (Glenn et al., 2008). Furthermore, study participants believe that familial and extended family support in daily struggles, as well as help with transportation and developmental issues, could reduce negative physiological and psychological consequences (Heiman, 2021).

However, not all mothers in this study reported this lack of support. Other participants highlighted positive spousal and close family support in the findings, emphasizing its positive impact on coping with the various daily challenges of raising a child with CP. These findings resonate with existing research by Müller et al. (2022), which suggests that low spousal support and divorce risk may be more prevalent among individuals with lower education and immigrant backgrounds. Specifically, one participant indicated a low level of understanding in individuals who lack understanding of the special circumstances faced by both the mother and a child. Furthermore, family support is important for mothers' levels of optimism, as it can contribute to the well-being, development, and learning of both the mother and child (Glenn et al., 2008; Heiman, 2021).

Societal Attitude

Children with cerebral palsy are individuals with physical and cognitive disabilities who face a higher risk of social isolation, psychosocial, and behavioral problems (Logar, 2012). They also experience exceptionally high levels of social stigmatization, a clear indicator of a lack of social support. In Kazakhstan, these challenges, in addition to the child's medical condition, affect families' further adjustment and shape their experiences, both positive and negative (Alaee et al., 2014; UN Convention on the Rights of the Child, Articles 5 & 23, 1989; Zhakupova et al., 2023). In the context of the current study, parents expressed concerns about negative societal attitudes, lack of awareness, misunderstanding,

and resistance, all of which contribute to a sense of isolation. For example, two participants from rural areas reported that people avoid communicating with them, believing the child's condition was contagious. This aligns with existing literature (Mukashev & Somerton, 2023) which indicates that in Central Asian nations, particularly in rural areas, parents raising a child with disabilities, especially CP, experience negative societal attitudes. From the perspective of urban area parents' responses, people demonstrate a lack of understanding toward parents of a child with CP. Mothers want people to be aware that it is not the fault of the mother that the child has CP. Thus, parents in the study suggest that it is important to foster social understanding and raise awareness about what cerebral palsy is, to be respectful toward parents of children with CP, as positive attitudes and social connections help families adjust and influence individuals' overall well-being (Hupcey, 2002). This directly aligns with Social Support Theory (SST), which emphasizes how social connections, the feeling of being cared for, valued, and supported by one's social network (Hajli et al., 2015), directly impacts a person's well-being.

The Quality and Accessibility of Services

The importance of rehabilitation interventions or early intervention (EI) services for children with damaged central nervous systems, as highlighted by Buftac et al. (2020), resonates with the current study's findings. In this study, the majority of parents of a child with CP actively participate in services aimed at addressing areas of deficit, which are individual for each child. This active participation is necessary because CP is divided into different types, levels of severity, and comorbidities, each being unique and diverse, requiring a tailored approach to strengthening both physical development and speech (Botcher, 2010). Physical needs require the involvement of massage therapists, developmental pediatricians, hydrotherapy, and adaptive sports, while cognitive aspects

are addressed by speech therapists and defectologists. According to participants' responses, the aforementioned therapies and services are provided by rehabilitation centers in different cities. However, the quality of these services is viewed as unsatisfactory. On the one hand, parents cited lengthy waiting lists, ineffectiveness of short therapy durations, a lack of essential therapies, and the remote location of rehabilitation centers for those residing in rural areas. They mentioned the absence of transportation, including appropriate child wheelchairs and shortage of daily transportation services to reach rehabilitation centers, as well as the lack of assistance with carrying and lifting their children as they grow heavier. These current findings resonate with the study conducted by Zhakupova et al. (2023), which also indicates a shortage of available rehabilitation programs in Kazakhstan. Thus, some parents of a child with severe CP doubt the effectiveness of rehabilitation and EI services, leading them to discontinue attendance and keep their children at home. Additionally, existing studies (Hadders-Algra, 2014; Buftac et al., 2020) have indicated that these rehabilitation and EI services may not significantly enhance children's developmental outcomes.

However, some parents had neutral responses about EI and rehabilitation services, highlighting that they are just one component of an ideal treatment program. These parents not only actively participate in attending centers and therapy sessions, but also try to repeat the therapies themselves at home through exercises and massages, aiming to increase their child's developmental outcomes. As Morgan et al. (2021) suggest, the ideal treatment course and its outcomes depend on several factors, including parental involvement. Furthermore, Buftac et al. (2020) identified in their study that children with CP can achieve successful developmental results with comprehensive parental support.

Alternatively, some parents who experienced undefective EI and rehabilitation services choose to attend commercial organizations, which demands additional financial

expenses from the family. However, regular attendance can cause additional financial challenges for parents (Alaee et al., 2014; Hiratani & Hohashi, 2021). Even if parents can afford private services, finding high-quality specialists remains difficult. Furthermore, some parents establish NGOs, forming large community groups, while others choose to enroll their child in such NGOs. According to Muratkhan (2024), parent-established foundations are a source of alternative services but cannot assume responsibility for the comprehensive spectrum of support services for both parents and children, which is solely provided by the government. Moreover, participants emphasize the necessity of government-driven inclusive education and social programs. For instance, Fariza, the head of an NGO, highlighted the importance of governmental support and indicated that the NGO can serve as a bridge between the state and parents, facilitating the communication of challenges and solutions.

Development and learning

Development and learning are necessary aspects of raising a child with CP, significantly impacting every aspect of life for both parents and the child (Micheletti et al., 2023; Patel et al., 2020; Wotherspoon et al., 2023). Their development and learning require considerable comprehensive caregiving, financial support, and parental monitoring (Nurullah, 2013). Also, as mentioned above, developmental and learning treatment plans and outcomes are entirely dependent on the type and severity of CP, as well as comorbidities. In turn, these factors can either encourage or discourage further development shaping the child's reality (Shrader et al., 2021). For instance, Guli's and Fariza's parental experiences represent examples where they were discouraged from continuing. Guli's child's developmental experience was halted due to doctors' advice against further development, citing severe cognitive delay and viewing the overall child's development as a potential threat to society. They argued that the child with severe

cognitive delay cannot control their own actions and therefore cannot be held responsible for them, posing the question of who would be responsible if the child were to harm someone. Fariza's experience was connected to a shortage of comprehensive support, including family, state, and financial assistance.

Conversely, the research findings also represent developmental and learning experiences from a positive perspective. They highlight parental resilience (Majnemer et al., 2010) in supporting the development of their child with CP. Parents shared stories of their child's remarkable progress, attributing these achievements to consistent effort, dedication, love, and acceptance. In the case of Dana, she persistently sought the necessary therapy, traveling to another city multiple times to access it, and ultimately secured it for free through state funding. In the case of Aidyn, due to financial constraints, she sought assistance from several social media influencers to raise money for her daughter's assistive device. This implies that, despite existing challenges, mothers demonstrate remarkable resilience in seeking specialized care, recognizing its value for their children's development and learning (Shattnawi & Balbaa, 2024).

Parents in this study highlighted the extremely essential role of sibling relationships in development and learning. According to Mophosho et al. (2010), siblings of children with CP can facilitate social, cognitive, and communicative development. For instance, Aliya described sibling relationships as powerful bonds, where they could learn together how to cope with the challenges of a child with a disability, taking on the roles of friends, teachers, and parents, regardless of their age. She shared that through this approach, development occurs on both sides. Children with CP gain new knowledge and skills, expressing feelings and emotions through communication. Siblings, in turn, learn feelings of respect, compassion, and warmth for people with disabilities (Mophosho et al., 2010).

Schooling

Schooling did not encompass all children with CP in the current study, as their age range varied from 4 to 21 years old. Parents of those who are homeschooled expressed full satisfaction with the type of school they were allowed to attend by the PMPC. According to existing research (Human Rights Watch, 2019; Makoelle, 2020; Mukashev & Somerton, 2023), the PMPC, after assessing a child's level of psychological and physical development, identifies and/or recommends the placement of the child in a specific school type based on their disability. However, this recommendation serves as a final decision for both parents and the child, as well as the school. In the case of Aidyn and Aliya, a teacher was assigned by school only after the PMPC's psychological test approval. Furthermore, the experiences of Guli, Alla, and Fariza revealed that their child's inability to pass the PMPC's psychological test, a consequence of their severe CP, resulted in denial of any school enrollment.

The parental responses from the findings align with existing literature (Mukashev & Somerton, 2023) which indicates that homeschooling in Kazakhstan is a publicly funded type of schooling for children with disabilities, where assigned teachers visit the child and provide eight hours of instruction per week. Parents from the study perceive that one hour per day is entirely sufficient for their child, with some lessons lasting only thirty minutes depending on the child's mood. Additionally, one parent mentioned that teachers adhere to a rigid plan, illustrating this with the first year's focus on speech therapy and the current emphasis on brain development. Overall, these parents praised the teachers' attempts to involve their child and aid their education.

A parent, whose child with CP attends a kindergarten for children with disabilities, views it as a special school, citing the provision of necessary support and educational programs (Human Rights Watch, 2019). Parental satisfaction is further supported by the

observation that the child learns how to express feelings and emotions through drawing, teacher-parent-student interactions, and holiday celebrations, which contribute to the child's psychological well-being (Parkes et al., 2008).

Parents (Guli and Fariza) of a child who were not enrolled in any type of schooling cited various challenges that became barriers, including the severity of CP and comorbidities (Micheletti et al., 2023), financial strain (Alaee et al., 2014), lack of state and family support (Kim et al., 2023), low self-esteem and physical well-being (Yelissinova et al., 2013), the PMPC's recommendation (Mukashev & Somerton, 2023), and negative social attitudes (Zhakupova et al., 2023).

Parental expectations

According to Irwin and Elley (2012), parents' expectations and hope play an important role in shaping the future realization and occupations of children with disabilities. They postulated that fulfilling these expectations and hopes, and observing their outcomes impact various measures, including education, health, and overall well-being, requires parental involvement and specific parenting styles. This literature resonates with the current study findings regarding parents of a child with CP. Some parents positively reflected on their long-term hopes and expectations for their child. For instance, one parent hopes her daughter will work in a beauty salon one day, as she noticed her daughter's exceptional artistic skills. To realize this dream, the parent expressed that she puts much effort into developing her talents and helping her find a career she loves. Similarly, Dana, a mother of a 4-year-old child with severe CP, expressed that despite varied challenges, it is crucial to work on development now, while her child is still young.

On the other hand, several parents expressed no hope or expectations for their child's future, beyond maintaining their current physical state. For instance, Guli, a widowed parent, expressed her inaction and lack of hope for the future due to, first, the

severity type of her child's CP, and second, her role as the family's sole provider, which requires her to work and leaves her no time to think about the future (Irwin & Elley, 2012). Furthermore, another parent, with limited external and internal resources, expressed her hope that her child could learn to speak and is awaiting comprehensive support from the government, such as a developmental social worker who can visit and read books, financial support for the child's rehabilitation, and free psychological services for herself (Barlow et al., 2006).

Summary

The main research questions facilitated the exploration and understanding of the multitude of challenges faced by parents raising a child with cerebral palsy. This exploration of parental experiences helped to identify existing gaps within families, communities, and systems, including institutional and political ones, thereby enabling us to discuss areas requiring necessary changes. The Family Systems Theory by Murray Bowen (Metcalf, 2011) and Social Support Theory (Hupcey, 2002) were utilized to explore how family and social support systems (extended family, friends, disability-focused organizations) influence family dynamics within the context of education, and to explain the multifaceted systems influencing parental experiences.

Chapter 6: Conclusion

This research study shed light on a topic that has received limited attention previously in Kazakhstan: understanding and exploring the experiences of parents raising a child with cerebral palsy. While Yelissinova et al. (2013) explored the main challenges of parents of children with CP, comparing them to other families based on socio-demographic characteristics in Kazakhstan, this study provides a more comprehensive overview. It examines parental experiences throughout the various stages of a child's development, enriching the existing literature. Specifically, it reveals the unique challenges and perspectives of parents concerning various aspects, including birth, diagnosis, family rection and schooling experiences of a child with cerebral palsy.

The Study Summary

This qualitative phenomenological research study focused on exploring and understanding the lived experiences of parents, with a particular emphasis on the educational journey of their child with CP and the challenges they face. To collect data, semi-structured interviews were conducted with six parents of a child with CP.

Furthermore, The Family Systems Theory by Murray Bowen (Metcalf, 2011) and Social Support Theory (Hupcey, 2002) were used to explore how family and social support systems influence family dynamics within the context of education, and to reveal the multifaceted systems influencing parental experiences.

The study revealed outstanding parental adaptability and resilience in raising a child with CP and adjusting to various life changes. However, these skills were developed through navigating the challenging educational and developmental journey for their child encompassing stages of birth, diagnosis, family acceptance and support, development and learning, schooling, and future expectations. Ultimately, the parental challenges and their experiences directed them to advocate for their child, resulting in suggestions for specific

improvements for medical and service providers, family and social environments, educational institutions, and governmental initiatives.

Implications for Future Research and Recommendations

The current study broadly researched various stages of the lives of both parents and a child with CP to understand parental experiences in raising their child, as well as the child's educational journey. Building on this, the results of this study can serve as a basis for future research, which could adopt a more selective and scope. For instance, researchers could further explore the parental experiences engaging fathers in the discussions, increasing the number of participants, and adopting additional data collection instruments. Moreover, the current study interviewed parents from varied backgrounds, demographics, and primarily middle and low-income families. Therefore, it is recommended that future research narrow its scope to focus on the experiences of high-income parents raising a child with CP in Kazakhstan. Although the study's findings cannot be generalized, they can still be used in specific contexts and have valuable real-world applications.

Practical Implications

The implications of this research are relevant to a wide range of stakeholders, from parents to policymakers, given the study's focus on parents of a child aged 4 to 21 years.

Firstly, a key finding underscores the significant impact of medical personnel, specifically their professionalism, responsibility, and health literacy. Providing parents with timely, accurate, and up-to-date information is crucial for possible disease prevention, mitigating serious consequences, and navigating the diagnostic process. Consequently, this research emphasizes the need for standardized protocols in diagnosing and informing parents about cerebral palsy (CP). Implementing such protocols can minimize miscommunication and blame and facilitate referrals to relevant family support services

(Heiman, 2021). Medical professionals often underestimate the negative impact of their narratives on the social lives of parents of a child with CP, and, crucially, on the child's future development and education (Manuel, 2003; Nurullah, 2013). Therefore, disability cultural competency training and self-reflection are essential for mitigating professional biases toward children with cerebral palsy and its impact on their parents.

Secondly, this research reveals that mothers of a child with CP are forced to juggle daily difficulties while simultaneously advocating for their children's rights. The additional challenges these families face stem not from cerebral palsy and its comorbidities themselves, but rather from a lack of family support, societal prejudice, inadequate psychological support, and systemic failures. To address these issues, the following steps are crucial, drawing upon the Family Systems Theory by Murray Bowen (Metcalf, 2011) and Social Support Theory (Hupcey, 2002): developing comprehensive family support networks and resources, with emphasis on spousal and extended family involvement; building community awareness through community-based initiatives to educate the public about CP; and empowering parental advocacy by providing parents with resources, psychological support, and training to enhance their ability to navigate healthcare and education systems effectively.

Also, the study findings point to the lack of government and policy support. Parents responses revealed several key indicators that supported this challenge, including the shortage of appropriate wheelchairs that fit the child's specific type of CP, lack of sufficient social and financial support that hinder the education and development of a child with CP, which lead families to keep their child at home. These challenges require changes in policy support system, prioritizing improving the quality of providing services, including daily transportation support, providing wheelchairs tailored to the specific needs of a child with CP, remove barriers that hinder parental engagement in the child's

education and ease the process to pass the PMPC's psychological test to receive education. Also, it is important for the state to support parent-led NGO's and work collaboratively, as parents are the individuals who may become a bridge between a child and the government, the ones who face challenges regarding the education and development, policy and practice. Finally, it is crucial for government to increase the financial support first, for parents raising a child with CP, to solve the issue related to financial strain, which directly becomes a barrier to receive education and development. Second, for rehabilitation centers, to decrease long wait times and enhance the quality of services to fit the particular needs of a child with CP.

Strengths and Limitations

The strong theoretical frameworks, including Family Systems Theory by Murray Bowen (Metcalf, 2011) and Social Support Theory (Hupcey, 2002) helped the study to explore parental roles in raising a child with CP, challenges they face in child's engagement to the education, and support they need for future improvement. Additionally, the study represents experiences of parents from four cities of Kazakhstan, including both urban and rural area context, includes varied factors of child's age range, socioeconomic background, gender, and the extent type of the CP condition which assisted the researcher deeply explore the lived experiences of parents raising a child with CP.

On the one hand, the small sample size, and only one interview-based research may potentially limit the generalizability of the study. Although, on the other hand, these limitation points to the need for future research with a larger sample size to explore parental experiences. In line with parental voices, the current study represents only mothers' voices, as they hold the primary caregiver role in the context of Kazakhstan, and lack direct perceptions of fathers, serving as a recommendation for future study.

Final Reflections

Finally, I present my reflections stemming from the nine-month journey of composing this study. My decision to explore the experiences of parents raising a child with cerebral palsy was inspired by a relative of mine, a single parent in this situation. Prior to this research, my knowledge of cerebral palsy development and the challenges of parenting children with developmental and intellectual disabilities in Kazakhstan was limited. This research proved invaluable, both for its practical implications and for my personal and professional development.

Through exploring the parental experiences of raising a child with CP, I gained a profound appreciation for qualitative research, particularly phenomenology. This research project helped me develop key research skills across all its stages, from problem definition to data analysis. As a result, I developed into a more confident and objective researcher with greater empathy and understanding of the challenges of raising a child with cerebral palsy.

References

- Alaee, N., Shahboulaghi, F. M., Khankeh, H., & Kermanshahi, S. M. K. (2014a). Psychosocial Challenges for Parents of Children with Cerebral Palsy: A Qualitative Study. *Journal of Child and Family Studies*, 24(7), 2147–2154. <https://doi.org/10.1007/s10826-014-0016-3>
- Allan, J., & Omarova, T. (2021). Disability and inclusion in Kazakhstan. *Disability & Society*, 37(7), 1067–1084. <https://doi.org/10.1080/09687599.2020.1867073>
- An, S., Chan, C. K., & Kaukenova, B. (2018). Families in Transition: Parental Perspectives of Support and Services for Children with Autism in Kazakhstan. *International Journal of Disability, Development and Education*, 67(1), 28–44. <https://doi.org/10.1080/1034912x.2018.1499879>
- Anagnostaki, L., & Zaharia, A. (2020). A psychoanalytic and qualitative research on immigrants’ “left-behind” children: “I understand why they left, but why did they leave?” *International Journal of Applied Psychoanalytic Studies*, 17(4), 313–327. <https://doi.org/10.1002/aps.1646>
- Arfa, S., Solvang, P. K., Berg, B., & Jahnsen, R. (2020). Disabled and immigrant, a double minority challenge: a qualitative study about the experiences of immigrant parents of children with disabilities navigating health and rehabilitation services in Norway. *BMC Health Services Research*, 20(1). <https://doi.org/10.1186/s12913-020-5004-2>
- Bagazgoïtia, N. V. D., Perret, C., Himmelmann, K., Thyen, U., Ehlinger, V., Duffaut, C., Arnaud, C., & Sentenac, M. (2023). Employment and higher education in young adults with cerebral palsy: a cross-sectional analysis of the SPARCLE study. *BMJ Public Health*, 1(1), e000141. <https://doi.org/10.1136/bmjph-2023-000141>

- Bandura, A. (1985). Model of causality in social learning Theory. In Springer eBooks (pp. 81–99). https://doi.org/10.1007/978-1-4684-7562-3_3
- Barlow, J. H., Cullen-Powell, L. A., & Cheshire, A. (2006). Psychological well-being among mothers of children with cerebral palsy. *Early Child Development and Care*, 176(3–4), 421–428. <https://doi.org/10.1080/0300443042000313403>
- Bon, S. C., & Bigbee, A. J. (2011). Special Education leadership: integrating professional and personal codes of ethics to serve the best interests of the child. *Journal of School Leadership*, 21(3), 324–359. <https://doi.org/10.1177/105268461102100302>
- Bottcher, L. (2010). Children with Spastic Cerebral Palsy, Their Cognitive Functioning, and Social Participation: A Review. *Child Neuropsychology*, 16(3), 209–228. <https://doi.org/10.1080/09297040903559630>
- Brenner, M. E. (2012). Interviewing in educational research. In *Handbook of complementary methods in education research* (pp. 357-370). Routledge.
- Buftac, E. G., Andersen, G. L., Spinei, L., & Jahnsen, R. B. (2020). Early intervention and follow-up programs among children with cerebral palsy in Moldova: potential impact on impairments? *BMC Pediatrics*, 20(1). <https://doi.org/10.1186/s12887-020-1931-7>
- Bulekbayeva, S., Daribayev, Z., Ospanova, S., & Vento, S. (2017). Cerebral palsy: a multidisciplinary, integrated approach is essential. *the Lancet. Global Health*, 5(4), e401. [https://doi.org/10.1016/s2214-109x\(17\)30082-7](https://doi.org/10.1016/s2214-109x(17)30082-7)

- Burger, K., & Samuel, R. (2016). The Role of Perceived Stress and Self-Efficacy in Young People's Life Satisfaction: a Longitudinal study. *Journal of Youth and Adolescence*, 46(1), 78–90. <https://doi.org/10.1007/s10964-016-0608-x>
- Chuang, S. (2021). The applications of Constructivist Learning Theory and Social Learning Theory on adult continuous development. *Performance Improvement Journal*, 60(3), 6–14. <https://doi.org/10.1002/pfi.21963>
- Clark, L., Birkhead, A. S., Fernandez, C., & Egger, M. J. (2017). A transcription and translation protocol for sensitive Cross-Cultural team research. *Qualitative Health Research*, 27(12), 1751–1764. <https://doi.org/10.1177/1049732317726761>
- Cook, J. E., Tovin, M. M., & Kenyon, L. K. (2021). Understanding the lived experience of caring for a child with severe cerebral palsy: a critical step toward Psychologically Informed Family-Centered Care. *Physical Therapy*, 102(4). <https://doi.org/10.1093/ptj/pzab294>
- Creswell, J. W., & Poth, C. N. (2017). *Qualitative inquiry and research design: Choosing Among Five Approaches*. SAGE Publications.
- Creswell, J. W. (2014). *Educational research (4th ed.)*. Pearson new international ed. Harlow: Pearson Education Limited. Print.
- Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., & Davern, M. (2009). The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. *Child Care Health and Development/Child, Care, Health and Development*, 36(1), 63–73. <https://doi.org/10.1111/j.1365-2214.2009.00989.x>

- Desombre, C., Delaval, M., & Jury, M. (2021). Influence of social support on teachers' attitudes toward inclusive education. *Frontiers in Psychology*, 12.
<https://doi.org/10.3389/fpsyg.2021.736535>
- Dewantoro, D. A., Susilawati, S. Y., & Pradipta, R. F. (2018). Family Environment Support in Early Intervention of Children with Cerebral Palsy. Proceedings of the 1st International Conference on Early Childhood and Primary Education (ECPE 2018). <https://doi.org/10.2991/ecpe-18.2018.7>
- Fluss, J., & Lidzba, K. (2020). Cognitive and academic profiles in children with cerebral palsy: A narrative review. *Annals of Physical and Rehabilitation Medicine*, 63(5), 447–456. <https://doi.org/10.1016/j.rehab.2020.01.005>
- Fritz, H., & Sewell-Roberts, C. (2020). Family Stress Associated with Cerebral Palsy. In Springer eBooks (pp. 515–545). https://doi.org/10.1007/978-3-319-74558-9_213
- Gaff, C. L., & Bylund, C. L. (2010). Family communication about genetics: theory and practice. *Family Systems Theory*.
<https://findanexpert.unimelb.edu.au/scholarlywork/328229-family-communication-about-genetics--theory-and-practice>
- Gajjar, N. B. (2013). Ethical consideration in research. *International Journal for Research in Education*, 2(7), http://www.rajimr.com/ijre/wp-content/uploads/2017/11/IJRE_2013_vol02_issue_07_02.pdf
- Glenn, S., Cunningham, C., Poole, H., Reeves, D., & Weindling, M. (2008). Maternal parenting stress and its correlates in families with a young child with cerebral palsy. *Child Care Health and Development*, 35(1), 71–78.
<https://doi.org/10.1111/j.1365-2214.2008.00891.x>

- Göçen, A. (2021). Ethical Leadership: a Cross-Cultural Study. *Turkish Journal of Education*, 10(1), 37–57. <https://doi.org/10.19128/turje.811919>
- Goodman, L. A. (2011). Comment: On Respondent-Driven sampling and snowball sampling in Hard-to-Reach populations and snowball sampling not in Hard-to-Reach populations. *Sociological Methodology*, 41(1), 347–353. <https://doi.org/10.1111/j.1467-9531.2011.01242.x>
- Graham, H. K., Rosenbaum, P., Paneth, N., Dan, B., Lin, J., Damiano, D. L., Becher, J. G., Gaebler-Spira, D., Colver, A., Reddihough, D. S., Crompton, K. E., & Lieber, R. L. (2016). Cerebral palsy. *Nature Reviews. Disease Primers*, 2(1). <https://doi.org/10.1038/nrdp.2015.82>
- Gromova, C., Khairutdinova, R., Birman, D., & Kalimullin, A. (2021). Educational practices for immigrant children in elementary schools in Russia. *Education Sciences*, 11(7), 325. <https://doi.org/10.3390/educsci11070325>
- Hadders-Algra, M. (2014). Early diagnosis and early intervention in cerebral palsy. *Frontiers in Neurology*, 5. <https://doi.org/10.3389/fneur.2014.00185>
- Hajli, M. Nick et al. “Health Care Development: Integrating Transaction Cost Theory with Social Support Theory.” *Informatics for health & social care* 40.4 (2015): 334–344. Web.
- Heiman, T. (2021). Parents’ Voice: Parents’ Emotional and Practical Coping with a Child with Special Needs. *Psychology*, 12(05), 675–691. <https://doi.org/10.4236/psych.2021.125042>
- Helmer, J., Kasa, R., Somerton, M., Makoelle, T. M., & Hernández-Torrano, D. (2020). Planting the seeds for inclusive education: one resource centre at a time.

International Journal of Inclusive Education, 27(5), 586–602.

<https://doi.org/10.1080/13603116.2020.1864791>

Hiratani, Y., & Hohashi, N. (2021). Family functioning of single-parent families with children attending a special needs school in Japan. *Pediatrics International*, 63(5), 581–588. <https://doi.org/10.1111/ped.14486>

Human Rights Watch (2019). “On the Margins”: Education for disabled education for children with disabilities in Kazakhstan.

<https://www.hrw.org/report/2019/03/14/margins/education-children-disabilities-kazakhstan>

Hupcey, J. E. (2002). Clarifying the social support theory-research linkage. *Journal of Advanced Nursing*, 27(6), 1231–1241. <https://doi.org/10.1046/j.1365-2648.1998.01231.x>

Insebayeva, S., & Insebayeva, N. (2021). The Power of Ambiguity: National Symbols, Nation-Building and Political Legitimacy in Kazakhstan. *Europe-Asia Studies*, 74(4), 660–682. <https://doi.org/10.1080/09668136.2021.1912296>

Irwin, S., & Elley, S. (2012). Parents’ hopes and expectations for their children’s future occupations. *The Sociological Review*, 61(1), 111–130.

<https://doi.org/10.1111/j.1467-954x.2012.02139.x>

Issayeva, R. B., Abzaliyeva, S., Myrzabekova, G., Seysebaeva, R., Ospanova, D., & Tashenova, G. (2020). The ROLE OF VARIOUS RISK FACTORS IN THE DEVELOPMENT OF INFANTILE CEREBRAL PALSY. *Interdisciplinary Approaches to Medicine*, 1(2). <https://doi.org/10.26577/iam.2020.v1.i2.04>

- Jamshed, S. (2014). Qualitative research method-interviewing and observation. *Journal of Basic and Clinical Pharmacy*, 5(4), 87. <https://doi.org/10.4103/0976-0105.141942>
- Kabakova, M., & Maulsharif, M. (2013). Transformation of social roles and marital relations in modern Kazakhstan: Social-psychological analysis. *Procedia - Social and Behavioral Sciences*, 82, 638–641. <https://doi.org/10.1016/j.sbspro.2013.06.322>
- Kandel, I., & Merrick, J. (2007). The child with a disability: parental acceptance, management and coping. *The Scientific World JOURNAL*, 7, 1799–1809. <https://doi.org/10.1100/tsw.2007.265>
- Karassayev, G., Naimanbayev, B., Abenova, G., Karibayev, M., & Mukataeva, Z. (2024). Origin, life and traditions of the Kazakhs in Central Asia, and their influence on modern Kazakhstan. *Critical Survey*, 36(4), 46–58. <https://doi.org/10.3167/cs.2024.360405>
- Kibria, N., & Becerra, W. S. (2020). Deserving Immigrants and Good Advocate Mothers: Immigrant Mothers' Negotiations of Special Education Systems for Children with Disabilities. *Social Problems*, 68(3), 591–607. <https://doi.org/10.1093/socpro/spaa005>
- Kim, H. S., Lee, C. E., & Kim, K. M. (2023). Challenges of single parents raising children with intellectual and developmental disabilities. *JARID. Journal of Applied Research in Intellectual Disabilities/Journal of Applied Research in Intellectual Disabilities*, 36(4), 777–786. <https://doi.org/10.1111/jar.13093>
- King, G., & Chiarello, L. (2014). Family-Centered Care for children with Cerebral Palsy. *Journal of Child Neurology*, 29(8), 1046–1054. <https://doi.org/10.1177/0883073814533009>

- Lee, Y., & Park, H. J. (2016). Becoming a Parent of a Child with Special Needs: Perspectives from Korean Mothers Living in the United States. *International Journal of Disability, Development and Education*, 63(6), 593–607. <https://doi.org/10.1080/1034912x.2016.1154139>
- Majnemer, A., Shevell, M., Law, M., Poulin, C., & Rosenbaum, P. (2010). Level of motivation in mastering challenging tasks in children with cerebral palsy. *Developmental Medicine & Child Neurology*, 52(12), 1120–1126. <https://doi.org/10.1111/j.1469-8749.2010.03732.x>
- Makoelle, T. M. (2020). Schools' transition toward inclusive education in Post-Soviet countries: Selected cases in Kazakhstan. *SAGE Open*, 10(2), 215824402092658. <https://doi.org/10.1177/2158244020926586>
- Manuel, J. (2003). Stress and adaptation in mothers of children with cerebral palsy. *Journal of Pediatric Psychology*, 28(3), 197–201. <https://doi.org/10.1093/jpepsy/jsg007>
- Micheletti, S., Galli, J., Vezzoli, M., Scaglioni, V., Agostini, S., Calza, S., Merabet, L. B., & Fazzi, E. (2023). Academic skills in children with cerebral palsy and specific learning disorders. *Developmental Medicine and Child Neurology/Developmental Medicine & Child Neurology*, 66(6), 778–792. <https://doi.org/10.1111/dmcn.15808>
- Michelsen, S. I., Uldall, P., Kejs, A. M. T., & Madsen, M. (2005). Education and employment prospects in cerebral palsy. *Developmental Medicine & Child Neurology*, 47(8), 511–517. <https://doi.org/10.1017/s0012162205001015>
- Milićević, M., & Nedović, G. (2018). Comparative study of home and community participation among children with and without cerebral palsy. *Research in Developmental Disabilities*, 80, 74–83. <https://doi.org/10.1016/j.ridd.2018.06.010>

- Mophosho, M., Widdows, J., & Gomez, M. T. (2010). Relationships between adolescent children and their siblings with cerebral palsy: A pilot study. *Journal on Developmental Disabilities*, 15(3), 81–87.
<https://espace.library.uq.edu.au/view/UQ:222378>
- Morgan, C., Fetters, L., Adde, L., Badawi, N., Bancale, A., Boyd, R. N., Chorna, O., Cioni, G., Damiano, D. L., Darrah, J., De Vries, L. S., Dusing, S., Einspieler, C., Eliasson, A., Ferriero, D., Fehlings, D., Forssberg, H., Gordon, A. M., Greaves, S., . . . Novak, I. (2021). Early intervention for children aged 0 to 2 years with or at high risk of cerebral palsy. *JAMA Pediatrics*, 175(8), 846.
<https://doi.org/10.1001/jamapediatrics.2021.0878>
- Mukashev, K., & Somerton, M. (2023). Disability and homeschooling: Parents experiences in Kazakhstan. *Children & Society*, 38(2), 436–455.
<https://doi.org/10.1111/chso.12713>
- Müller, V., Gerdtham, U., Alriksson-Schmidt, A., & Jarl, J. (2022). Parental decisions to divorce and have additional children among families with children with cerebral palsy: Evidence from Swedish longitudinal and administrative data. *Health Economics*, 31(10), 2170–2186. <https://doi.org/10.1002/hec.4567>
- Muratkhani, M. (2024). Lived experiences of parents raising children with Down syndrome: A phenomenological study. Nazarbayev University Graduate School of Education. <http://nur.nu.edu.kz/handle/123456789/7812>
- Murphy, N., Caplin, D. A., Christian, B. J., Luther, B. L., Holobkov, R., & Young, P. C. (2011). The function of parents and their children with cerebral palsy. *PM & R*, 3(2), 98–104. <https://doi.org/10.1016/j.pmrj.2010.11.006>

- Novak, I., Morgan, C., Adde, L., Blackman, J., Boyd, R. N., Brunstrom-Hernandez, J., Cioni, G., Damiano, D., Darrah, J., Eliasson, A., De Vries, L. S., Einspieler, C., Fahey, M., Fehlings, D., Ferriero, D. M., Fethers, L., Fiori, S., Forssberg, H., Gordon, A. M., . . . Badawi, N. (2017). Early, accurate diagnosis and early intervention in cerebral palsy. *JAMA Pediatrics*, *171*(9), 897.
<https://doi.org/10.1001/jamapediatrics.2017.1689>
- Nurullah, A. S. (2013). “It’s Really a Roller Coaster”: Experience of Parenting Children with Developmental Disabilities. *Marriage & Family Review*, *49*(5), 412–445.
<https://doi.org/10.1080/01494929.2013.768320>
- Odeh, K. B., & Lach, L. M. (2024). Barriers to, and facilitators of, education for children with disabilities worldwide: a descriptive review. *Frontiers in Public Health*, *11*.
<https://doi.org/10.3389/fpubh.2023.1294849>
- Oliver, J., & Eales, K. (2008). Research ethics. *Qualitative Market Research an International Journal*, *11*(3), 344–357. <https://doi.org/10.1108/13522750810879057>
- Padilla-Díaz, M. (2015). Phenomenology in Educational Qualitative research: Philosophy as science or Philosophical Science? *International Journal of Educational Excellence*, *1*(2), 101–110. <https://doi.org/10.18562/ijee.2015.0009>
- Parkes, J., White-Koning, M., Dickinson, H. O., Thyen, U., Arnaud, C., Beckung, E., Fauconnier, J., Marcelli, M., McManus, V., Michelsen, S. I., Parkinson, K., & Colver, A. (2008). Psychological problems in children with cerebral palsy: a cross-sectional European study. *Journal of Child Psychology and Psychiatry*, *49*(4), 405–413. <https://doi.org/10.1111/j.1469-7610.2007.01845.x>

- Passeka, Y., & Somerton, M. (2022). Bridging the gap: special educators' perceptions of their professional roles in supporting inclusive education in Kazakhstan. *Disability & Society, 39*(6), 1380–1401. <https://doi.org/10.1080/09687599.2022.2160925>
- Patel, D. R., Neelakantan, M., Pandher, K., & Merrick, J. (2020). Cerebral palsy in children: a clinical overview. *Translational Pediatrics, 9*(S1), S125–S135. <https://doi.org/10.21037/tp.2020.01.01>
- Pattison, S., Montañez, S. R., & Svarovsky, G. (2022). Family values, parent roles, and life challenges: Parent reflections on the factors shaping long-term interest development for young children and their families participating in an early childhood engineering program. *Science Education, 106*(6), 1568–1604. <https://doi.org/10.1002/sce.21763>
- Pirila, S., Van Der Meere, J., Pentikainen, T., Ruusu-Niemi, P., Korpela, R., Kilpinen, J., & Nieminen, P. (2007). Language and motor speech skills in children with cerebral palsy. *Journal of Communication Disorders, 40*(2), 116–128. <https://doi.org/10.1016/j.jcomdis.2006.06.002>
- Polkinghorne, D. E. (1989). Incarnate phenomenological reflection [Review of the book *Bodily reflective modes: A phenomenological method for psychology*, by K. J. Shapiro]. *Theoretical & Philosophical Psychology, 9*(1), 46–51. <https://doi.org/10.1037/h0091464>
- Powell, K. C., & Kalina, C. J. (2009). Cognitive and social constructivism: Developing tools for an effective classroom. *Education, 130*(2), 241–250. <http://go.galegroup.com/ps/anonymous?id=GALE%7CA216181184&p=AONE>

- Prest, L. A., & Protinsky, H. (1993). Family systems theory: A unifying framework for codependence. *the American Journal of Family Therapy*, 21(4), 352–360.
<https://doi.org/10.1080/01926189308251005>
- Qutoshi, S. B. (2018). Phenomenology: a philosophy and Method of Inquiry. *Journal of Education and Educational Development*, 5(1), 215.
<https://doi.org/10.22555/joeeed.v5i1.2154>
- Rassafiani, M., Kahjoogh, M. A., Hosseini, A., & Sahaf, R. (2012). Time Use in Mothers of Children with Cerebral Palsy: A Comparison Study. *Hong Kong Journal of Occupational Therapy*, 22(2), 70–74. <https://doi.org/10.1016/j.hkjot.2012.11.001>
- Reid, A., Imrie, H., Brouwer, E., Clutton, S., Evans, J., Russell, D., & Bartlett, D. (2010). “If I Knew Then What I Know Now”: Parents’ Reflections on Raising a Child with Cerebral Palsy. *Physical & Occupational Therapy in Pediatrics*, 31(2), 169–183.
<https://doi.org/10.3109/01942638.2010.540311>
- Rentinck, I. C. M., Ketelaar, M., Jongmans, M. J., & Gorter, J. W. (2006). Parents of children with cerebral palsy: a review of factors related to the process of adaptation. *Child Care Health and Development/Child, Care, Health and Development*, 33(2), 161–169. <https://doi.org/10.1111/j.1365-2214.2006.00643.x>
- Rollan, K., & Somerton, M. (2019). Inclusive education reform in Kazakhstan: civil society activism from the bottom-up. *International Journal of Inclusive Education*, <https://doi.org/10.1080/13603116.2019.1599451>
- Rothbaum, F., Rosen, K., Ujiie, T., & Uchida, N. (2002). Family Systems Theory, attachment Theory, and culture*. *Family Process*, 41(3), 328–350.
<https://doi.org/10.1111/j.1545-5300.2002.41305.x>

- Saeed, K. M., Ahmed, A. S., Rahman, Z. M., & Sleman, N. A. (2023). How social support predicts academic achievement among secondary students with special needs: the mediating role of self-esteem. *Middle East Current Psychiatry*, 30(1).
<https://doi.org/10.1186/s43045-023-00316-2>
- Saldana, J. (2014). *Thinking qualitatively: Methods of Mind*. SAGE Publications.
- Sedgwick, P. (2013). Snowball sampling. *BMJ*, 347(dec20 2), f7511.
<https://doi.org/10.1136/bmj.f7511>
- Shattnawi, K. K., & Balbaa, E. A. (2024). Resilience and challenges: A qualitative exploration of Jordanian Mothers' experiences with children who have cerebral palsy. *Journal of Pediatric Nursing*, 78, e314–e322.
<https://doi.org/10.1016/j.pedn.2024.07.020>
- Shrader, M. W., Church, C., Lennon, N., Shields, T., Salazar-Torres, J. J., Howard, J. J., & Miller, F. (2021). Well-Being of ambulatory adults with cerebral palsy: education, employment, and physical function of a cohort who received specialized pediatric care. *Frontiers in Neurology*, 12. <https://doi.org/10.3389/fneur.2021.732906>
- Sigurdardottir, S., Eiriksdottir, A., Gunnarsdottir, E., Meintema, M., Arnadottir, U., & Vik, T. (2008). Cognitive profile in young Icelandic children with cerebral palsy. *Developmental Medicine and Child Neurology/Developmental Medicine & Child Neurology*, 50(5), 357–362. <https://doi.org/10.1111/j.1469-8749.2008.02046.x>
- Sjøberg, S. (2010). Constructivism and learning. In Elsevier eBooks (pp. 485–490).
<https://doi.org/10.1016/b978-0-08-044894-7.00467-x>

- Smith, M., & Blamires, J. (2022). Mothers' experience of having a child with cerebral palsy. A systematic review. *Journal of Pediatric Nursing*, 64, 64–73.
<https://doi.org/10.1016/j.pedn.2022.01.014>
- Tan, W. N., & Yasin, M. (2020). Parents' roles and parenting styles on shaping children's morality. *Universal Journal of Educational Research*, 8(3C), 70–76.
<https://doi.org/10.13189/ujer.2020.081608>
- Treloar, L. L. (2002). Disability, spiritual beliefs and the church: the experiences of adults with disabilities and family members. *Journal of Advanced Nursing*, 40(5), 594–603. <https://doi.org/10.1046/j.1365-2648.2002.02417.x>
- Tsibidaki, A. (2020). Family functioning and strengths in families raising a child with cerebral palsy. *Research in Developmental Disabilities*, 106, 103767.
<https://doi.org/10.1016/j.ridd.2020.103767>
- Vagle, M. D. (2018). Crafting phenomenological research. In *Routledge eBooks*.
<https://doi.org/10.4324/9781315173474>
- Wei, X., & Yu, J. W. (2010). The concurrent and longitudinal effects of child disability types and health on family experiences. *Maternal and Child Health Journal*, 16(1), 100–108. <https://doi.org/10.1007/s10995-010-0711-7>
- Wotherspoon, J., Whittingham, K., Sheffield, J., & Boyd, R. (2023). Cognition and learning difficulties in a representative sample of school-aged children with cerebral palsy. *Research in Developmental Disabilities*, 138, 104504.
<https://doi.org/10.1016/j.ridd.2023.104504>

- Wright, A. C., & Taylor, S. (2014b). Advocacy by parents of young children with special needs: activities, processes, and perceived effectiveness. *Journal of Social Service Research*, 40(5), 591–605. <https://doi.org/10.1080/01488376.2014.896850>
- Wu, Y. W., Kuzniewicz, M. W., Wickremasinghe, A. C., Walsh, E. M., Wi, S., McCulloch, C. E., & Newman, T. B. (2015). Risk for cerebral palsy in infants with total serum bilirubin levels at or above the exchange transfusion threshold. *JAMA Pediatrics*, 169(3), 239. <https://doi.org/10.1001/jamapediatrics.2014.3036>
- Yelissinova, A., Rakhypbekov, T., Semenova, Y., Yelissinova, N., Kulzhanova, S., Markabayeva, A., & Grjibovski, A. (2013). Do children with disabilities in Kazakhstan live in different families than healthy children? *European Journal of Public Health*, 23(suppl_1). <https://doi.org/10.1093/eurpub/ckt124.028>
- Zagzebski, L. (2001). The uniqueness of persons. *Journal of Religious Ethics*, 29(3), 401–423. <https://doi.org/10.1111/0384-9694.00090>
- Zhakupova, M., Nurbakyt, A., Ospanova, D., Chuyenbekova, A., Kozhekenova, Z., Dauletova, G., Aitmanbetova, A., Abdikadir, M., Padaiga, Z., Izmailovich, M., Glushkova, N., & Semenova, Y. (2023). Epidemiology of cerebral palsy in the Republic of Kazakhstan: Incidence and risk factors. *Heliyon*, 9(4), e14849. <https://doi.org/10.1016/j.heliyon.2023.e14849>
- Zhasulan, K., Akbota, A., Aziya, Z., Kazhimukhanovich, K. N., Salikbayevna, Z. M., & Aigul, S. (2022). Psychological support for children with special educational needs in an inclusive education. *Cypriot Journal of Educational Sciences*, 17(4), 1024–1031. <https://doi.org/10.18844/cjes.v17i4.7103>

Appendix A: AI Declaration Form



Thesis Title: Lived Experiences of Parents Raising a Child with Cerebral Palsy: A Phenomenological Study

Declaration of the Use of Generative AI

I hereby declare that I have read and understood NUGSE's policy concerning appropriate use of AI and composed this work independently (please check one):

- with the use of artificial intelligence tools, or
 without the use of artificial intelligence tools.

(If you have used AI tools as defined in the GSE policy document, please complete the rest of this form.)

During the preparation of this thesis/examination, I used Gemini AI to check the text and comment the text for the grammar errors, clarity, and flow, also I asked it to suggest me some linking words to improve the coherence of the text.

I also declare that I

- am aware of the capabilities and limitations of AI tool(s),
 have verified that the content generated by AI systems and adopted by me is factually correct,
 am aware that as the author of this thesis I bear full responsibility for the statements and assertions made in it,
 have submitted complete and accurate information about my use of AI tools in this work, and
 acknowledge that there may be disciplinary consequences if I have not followed NUGSE's guidelines regarding appropriate AI use.

Name: Akerke Tuzelova

Date: 28.04.2025

Signature:

Appendix B: Recruitment Statement Addressed to Parents (English version)

Dear Participant,

My name is Akerke Tuzelova, and I am currently a student in the MSc in Educational Leadership in Inclusive Education at Nazarbayev University. I am currently conducting a research study on the lived experiences of parents raising a child(ren) with cerebral palsy. The goal of this study is to gain a deeper understanding of the experiences of parents raising child(ren) with cerebral palsy (CP), with a focus on the obstacles and support that parents face as well as their participation in their child's educational journey. I plan to collect data for my research between November and December 2024

I am inviting you to participate in this study. Your insights and experiences will be invaluable in contributing to a better understanding of the challenges faced by parents of a child with cerebral palsy. Your participation in this study will involve an online or in-person interview lasting approximately 30 to 45 minutes.

Your participation in this study is entirely voluntary. You may withdraw from the study at any time without any negative consequences. All information collected during the interview will be kept strictly confidential.

If you are interested in participating in this study, please contact me via WhatsApp or Telegram at 8(775)993 63 38.

Thank you for your time and consideration. Sincerely,

Student,

M.Sc. Educational Leadership in Inclusive Education

Graduate School of Education

Nazarbayev University

Appendix C: Informed Consent Form for Parents (English version)

Lived Experiences of Parents Raising a Child with Cerebral Palsy: A

Phenomenological Study

DESCRIPTION:

You are invited to participate in a research study that will examine the lived experiences of parents of a child with cerebral palsy, emphasizing the difficulties they face, their roles in their child's educational journey, and their requirements for support. As part of your engagement, you will be asked to participate in an online or in-person interview where you will be asked to share your experiences and ideas about raising a child(ren) with CP.

The researcher will record your interview to help it to be transcribed it accurately. The recording will be kept safe on researchers' computer, that is password protected. All the data will be kept for three years following the submission of the thesis, and then it will be deleted. I'll protect your privacy by removing any personal information before analyzing the data and writing my Master's research thesis.

TIME INVOLVEMENT:

It is expected that your participation will take 30 to 45 minutes.

RISKS AND BENEFITS:

There is minimal risk involved in taking part in this study. You are free to refuse to answer any questions at all or to leave the research completely at any time without incurring any penalties, if any of the subjects covered in the interview make you uncomfortable. Your well-being will be ensured by the researcher throughout the process of the interview, and you can address any worries you may have during the interview. If you decide to opt out of the study after the interview, all your personal information will be removed immediately.

While your participation in this study has no immediate benefits, it could have a big impact on society. Through sharing your experiences, you may help educators, legislators, and the general public in Kazakhstan develop more inclusive education practices by fostering a greater awareness of the difficulties and benefits associated with raising and educating a child with cerebral palsy. Furthermore, your involvement can help eliminate the negative stereotypes associated with cerebral palsy and increase public understanding of the condition, which will ultimately help build a society that is more accepting and helpful to those who have the condition and their families.

PARTICIPANT'S RIGHTS:

Your involvement in this research is completely voluntary. You will not be penalized if you decide not to participate in the study or if you choose not to respond to a particular question.

CONTACT INFORMATION:

If you have further questions: Please feel free to email Janet Helmer, the master's thesis supervisor, with any questions, issues, or concerns you may have about this research study, its methods, risks, or advantages at janet.helmer@nu.edu.kz

Independent Contact: If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints, or general questions about the research or your rights as a participant, please contact the GSE Research IREC subcommittee at gse.irec@nu.edu.kz.

Please sign this consent form if you agree to participate in this study.

- I have carefully read the information provided;
- I have been given full information regarding the purpose and procedures of the study;
- I understand how the data collected will be used, and that any confidential information will be seen only by the researchers and will not be revealed to anyone else;
- I understand that I am free to withdraw from the study at any time without giving a reason;
- With full knowledge of all foregoing, I agree, of my own free will, to participate in this study;
- I agree that this interview can be audio recorded;

Signature: _____ Date: _____ Researcher's
signature _____ Date: _____

Appendix D: Interview protocol (English version)

Dear Participant [Name],

Thank you for agreeing to participate in my research! My name is Akerke Tuzelova. I am a master's student at Nazarbayev University, and this research is being conducted as part of my thesis. The purpose of the study is to understand the lived experiences of parents raising a child(ren) with cerebral palsy (CP), with a focus on the obstacles and support that parents face as well as their participation in their child's educational journey.

Your involvement in this research is completely voluntary. You will not be penalised if you decide not to participate in the study or if you choose not to respond to a particular question.

Let me start the process with the following questions:

Part 1 - The initial reaction

1. Could you tell me the age and gender of your child?
2. How did you feel when you heard you were expecting a special child? How did other people in your family react?
3. Did this result in any stress? How do you handle stress? What was helpful in dealing with this? Where did you seek out assistance?
4. What aspect of raising a child with cerebral palsy do you see as the most challenging?
5. Has there ever been a story or experience that transformed your viewpoint?

Part 2 - The Child

1. What specific support does your child need?
2. How do you support your child to develop and learn?
3. Can you describe your typical day? Do(es) your child attend any additional classes or therapies? If so, when did they (he/she) start, and how easy was it to find qualified professionals?

Part 3 - Education

1. Can you tell me about your child's educational experiences? What challenges have you faced?
2. What type of educational setting do you believe is best for your child?
3. How did you choose your child's current school?
4. How has the school supported your child's education?
5. What role do you think the government should play in supporting families in the education of a child with CP?

Part 4 - The Future

1. What do you hope to achieve both now and in the future for your child?
2. What kind of assistance do parents of child with CP require, in your opinion?
3. Is there anything else you'd like to share before we conclude?

If a participant becomes uncomfortable when discussing delicate subjects, provide comfort and give them the option to: 1) pause the interview; 2) reorganize; or 3) carry on.

Appendix E: Data Analysis – Transcripts, Coding Samples

Interview	First cycle coding	Second Cycle coding
<p>Part 1 - The initial reaction</p> <p>Interview 3</p> <p>1. <i>Could you tell me the age and gender of your child(ren)?</i></p> <p>12 years old, boy</p> <p>2. <i>How did you feel when you heard you were expecting a special child? How did other people in your family react?</i></p> <p>I have never expected to have a special child. After two pregnancies, 12 years ago I got pregnant with twins. The pregnancy was so easy that the doctor allowed me to give birth on my own. Both my twins weighed well at birth, I gave birth in a private clinic, and both were born healthy. However, one of the twins became disabled due to the illiteracy of the medical staff. Bilirubin exceeded the norm. We did a lot of work, hoping that the situation would change. We went through a long course of rehabilitation, and when we were in the hospital, my twin and I slept together, and at first my father helped me somehow. But few people understand the situation of the mother, and more and more people blame her. I think this shows a low level of consciousness. Sometimes parents even get divorced because of the child. We have many such situations. My close relatives suggested sending the child to a boarding school.</p> <p>3. <i>Did this result in any stress? How do you handle stress? What was helpful in dealing with this? Where did you seek out assistance?</i></p> <p>This situation is stressing me out. I could not forgive myself. It has had a big impact on my other children and our family life as</p>	<p>Age</p> <p>Mistake of medical personnel</p> <p>Not expecting=blaming, not accepting, few support, falling apart of the family, boarding school.</p> <p>Low level of consciousness of people</p> <p>Cannot forgive herself, still handles stress, struggles continue.</p>	<p>Finding out the diagnose of a child(ren): reaction and circumstances.</p> <p>Finding out the diagnose of a child(ren): family support and advice</p>

<p>a whole has changed dramatically. However, the struggle has not stopped, it continues. While we were struggling with this child's health, many things happened. I divorced my husband, my daughter went her own way, and I recently moved to another city. All this is very stressful for me, but my eldest son has helped me a lot. I have not worked; and still it is not known whether I have coped with the stress or accept my child. I even went to court, but the trial has been going on for 12 years already.</p> <p>4. <i>What aspect of raising a child(ren) with cerebral palsy do you see as the most challenging?</i></p> <p>It depends on the specific diagnosis of the child. There are different types, severity of cerebral palsy. We have spastic hyperkinesia. Also, children with CP have additional disease, we had epilepsy.</p> <p>5. <i>Has there ever been a story or experience that transformed your viewpoint?</i></p> <p>The special situation of this child taught me to be a fighter. This situation taught me what problems disabled children have. Additionally, these problems changed my point of view, and it became difficult for me. We started an NGO, made many changes, worked with the Department of Health, brought the needs of mothers to the government, it became easier to solve the issue of strollers, diapers, free bus passes for parents, etc. In a short time, I became the president of this NGO, fighting against all the problems. This environment gave me the strength to fight. However, I could not pay attention to my child's education and development. And one more thing I should mention first of all, is that the messages from above, Allah Almighty, answers all my questions, secondly, my education level is high.</p> <p>Part 2 - The Child</p> <p>1. <i>What specific support does your child(ren) need?</i></p> <p>My child has spastic hyperkinesia. He can show emotions, but he can't talk, he can't walk, he can only lie down. We need a</p>	<p>Divorce</p> <p>Assistance of the eldest son</p> <p>Unemployment</p> <p>Acceptance and love</p> <p>Depends on severity and type of CP,</p> <p>Comorbidities</p> <p>Becomes a fighter</p> <p>Identifying and solving parents' issues raising a child(ren) with CP</p> <p>Being a part of NGO, helping other people empowers, although, own child with CP leaves without attention.</p> <p>God helps</p> <p>Education level</p> <p>Need a social worker, but most of them are not trained</p> <p>Cannot support a child, because of mothers' overloads.</p>	<p>Source of support: change mindset</p> <p>Source of support: child(ren)'s need and not qualified specialists</p>
---	---	--

<p>social worker. But it's still not enough, and untrained specialists have fled from here.</p> <p>2. <i>How do you support your child(ren) to develop and learn?</i></p> <p>I can't afford it, mothers work is too much. She also needs to join society. Mothers need more support than children with special needs. Comprehensive support is necessary to achieve progress.</p> <p>3. <i>Can you describe your typical day? Do(es) your child(ren) attend any additional classes or therapies? If so, when did they (he/she) start, and how easy was it to find qualified professionals?</i></p> <p>I treat my child the same way I treat a baby every day. But it's getting harder and harder for me, because he's getting heavier and stronger. And I'm not young anymore, my strength is fading, I'm getting weaker. I can't take him to rehabilitation.</p> <p>Part 3 - Education</p> <p>1. <i>Can you tell me about your child(ren)'s educational experiences? What challenges have you faced?</i></p> <p>My child does not receive any education. All I can do is meet his daily needs.</p> <p>2. <i>What type of educational setting do you believe is best for your child(ren)?</i></p> <p>Of course, I cannot choose the best setting now but I just need a help of the social worker who would visit my child twice a week to come, read books to him and work on his motor skills, even if only a little.</p> <p>3. <i>How did you choose your child(ren)'s current school?</i></p> <p>I cannot fully answer this question because we do not go to school.</p>	<p>Treat child with CP as a baby. He becomes heavier and stronger, mother is weak to take him to attend any therapies.</p> <p>No educational experience due to the severity of CP.</p> <p>Assistance of social worker who can help to develop and learn.</p> <p>Cannot choose and attend the school</p> <p>Depends on PMPC decision, child is not able to pass even psychological test</p>	<p>Source of support: role of mothers</p> <p>Source of support: challenges in education</p>
--	--	---

<p>4. <i>How has the school supported your child(ren)'s education?</i></p> <p>There are additional options from the state. For example, home schooling for a child is a paid option. In order to receive free education, a child must first pass a test and receive a referral or a decision from the PMPC, but my child cannot pass this test, his condition is bad.</p> <p>5. <i>What role do you think the government should play in supporting families in the education of children with CP?</i></p> <p>The government plays an important role in the development of the child. I cannot say that there is no help from the state, but even if there is, it is very little. In order to improve the situation, parents need to work together and send their proposals to the relevant authorities. Issues that need to be resolved: financial, medical guidance for parents about the norm of baby growth, clear route for them after giving a birth, organizing forums on how to work with different types of CP, taxi for the disabled, queue for rehabilitation, how to get there with a child, social worker who will take care of the child. Additionally, society is not aware about CP, its type. People outside think that this disease is contagious and avoid us.</p> <p>Part 4 - The Future</p> <p>1. <i>What do you hope to achieve both now and in the future for your child(ren)?</i></p> <p>I hope for the future - to find a job, I still have potential. I want to help people, get paid for it and use it to hire a nanny and provide comprehensive support to my child. Even though my child has severe type of CP, I believe that my child will change. I believe that if I am given comprehensive help, I will be able to find hope for my</p>	<p>Important role but its help is very little.</p> <p>Areas for improvement</p> <p>Parents need to be active and ask for help from the government and work comprehensively.</p> <p>Hope depends on the severity With comprehensive support, child will be able to speak in the future.</p> <p>Family's, relatives support (financially, physically, emotionally) is needed</p> <p>Free psychological support</p>	<p>Source of support: government's role and parental activism</p> <p>Future expectations</p> <p>Areas of support for parents</p>
---	--	--

<p>child's future. I hope that in the future my child will be able to at least speak.</p> <p>2. <i>What kind of assistance do parents of child(ren) with CP require, in your opinion?</i></p> <p>Parents need comprehensive support. I would like there to be no drama in the family. Help from loved ones, relatives financially, physically, emotionally is very necessary until the child gets better. Where there is no support, stress arises. Free psychological help is very necessary for mothers.</p> <p>3. Is there anything else you'd like to share before we conclude?</p> <p>I'm very proud to be a part of your thesis project, because too many people struggle with many different issues raising a child with CP, but there are few who is doing any research on identifying, understanding parent's challenges, child's needs with CP, and support they need. I hope that your research will help and impact parents, society and the government as well, to improve and solve the current issues.</p>	<p>Few research on understanding lived experiences of parents raising a child(ren) with CP.</p>	
---	---	--

A list of codes

Case attributes

Age and gender: 12 y, boy

Parent: mother

Category: Finding out the diagnose of a child:

Reaction and circumstances

Not expecting

Illiteracy of the medical personnel

Family support and advice:

Family members blame mother, give a little support, advice to give a child to boarding school

Acceptance and love

Type and severity of CP and comorbidities

Category: Source of support in education

Change mindset

Teach to be a fighter

Identifying and solving issues

Faith in Allah

Profession of the mother

Child's need and not qualified specialists

Physical support (Social worker)

Most of the specialists are not qualified

Role of Mothers

Overloaded mother

Siblings

Challenges in education

Educational path depends on severity of CP

PMPC test decide what school to attend

Government's role and parental activism

Government's help is little > Areas for improvement >

> Financial

> Medical guidance for parents

> Organizing forums dedicated to children with CP (how to develop, educate, where to go to get rehabilitation, etc.)

> People who raise awareness of society about CP

Parental activism can impact on the state support

Category: Future expectations

Parental hope depends on:

Severity and support

Category: Areas of support for parents

Family's and relatives' support is needed:

- Financially
- Physically
- Emotionally

Free psychological support

Make more research

More research on the topic of CP from different perspectives

The themes

1) Theme: Finding out the diagnosis of a child

Sub-themes:

- a) Circumstances
- b) Illiteracy and negligence of medical personnel
- c) Initial reaction of family
- d) Type and severity of CP and comorbidities
- e) Changing mindset
- f) Acceptance and love

2) Theme: Support and challenges in education of child(ren) with CP

- a) Child's need and education
 - Impact of type and severity of CP to child's education
 - The role of PMPC
 - The role of mothers and siblings
- b) Parental expectations

3) Theme: Challenges and support needs of parents

- a) Current challenges parents face raising a child with CP
 - Parental burnout
 - Lack of medical guidance
 - Societal attitude
- b) Areas of support
 - Financial
 - Psychological
 - Providing clear route after birth of a child
 - Medical guidance
 - Family and relative's support
 - Parental activism

4) Theme: The role of the government

- a) Current state of support

b) Recommendations for improvement

- Financial
- Forums on how to develop and learn child with different types of CP