

The Lived Experiences of Paternal Parents as Primary Caregivers in Raising Children with Developmental Disabilities



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ABSTRACT: This study delves into the lived experiences of paternal parents raising children with developmental disabilities within the City of Cabuyao Laguna. It aims to comprehend their unique challenges, explore how the distress of raising a child with developmental disabilities is manifested in them, and identify their coping strategies. Eight (8) paternal parents, acting as primary caregivers for children with Autism, Down syndrome, and Intellectual disability who were also reported to experience significant stress, were interviewed. The study used a Parental Stress Scale and interviews to collect data. By using a phenomenological research approach, three main themes emerged through thematic analysis: (1) Navigating Parenting Challenges and Sacrifices; under this theme are the subthemes: (1.1) lifestyles, (1.2) financial issues, and (1.3) social stigma. (2) Holistic Well-being Under Stress, its subthemes are (2.1) physical manifestation, (2.2) emotional impact, and (2.3) impact on the body. (3) Balancing Approach to Personal Development and Well-being, under this main theme are these subthemes: (3.1) coping and fostering resilience, (3.2) positive mindset in maintaining children's growth and well-being, (3.3) engaging diverse activities. The study recommends a Stress Management Program for Paternal Parents of Children with Developmental Disabilities, which aims to support paternal parents in raising children with developmental disabilities by providing them with essential stress management tools and fostering a supportive community. Throughout the 5-week program, participants will engage in interactive sessions focused on understanding stress, exploring coping strategies, strengthening physical health, enhancing parent-child interactions, building support networks, and accessing resources for ongoing support.

KEYWORDS: Paternal Parents, Developmental Disabilities, Parental Stress Scale, Parenting Challenges, Holistic Well-Being under Stress

I. INTRODUCTION

In the world of "caregiving," the role of fathers or paternal parents as primary caregivers to children with developmental disabilities is considered a significant but underrepresented topic. According to the study by Urine-Morales (2021), paternal parents were usually seen as the economic support of the household and not someone who could take care of their children.

Raising a child, without a doubt, is the most challenging task that a parent can face. If the child had a disability, the problems could become even more difficult. Both primary caregivers, whether mothers or fathers who were raising children with developmental disabilities, struggled in multiple aspects of their lives. According to Bogosian et al. (2021), mothers and fathers experienced increased psychological discomfort, physical health issues, financial challenges, and social isolation. Hence, paternal caregivers have to find their way through facing these challenges and personal aspirations, all while meeting their children's unique needs.

Moreover, according to the May Institute, an organization that raises awareness about Autism Spectrum Disorder and other developmental disabilities, the three most common developmental disabilities are Autism Spectrum Disorder, Intellectual Disability, and Down Syndrome.

Therefore, this study aimed to shed light and explore the lived experiences of paternal parents as primary caregivers of their children with developmental disabilities, specifically, their challenges, distress, and coping mechanisms in raising children with ASD, ID, and Down syndrome.

By strengthening the knowledge about this domain and amplifying the voices and experiences of paternal parents, this study strives to contribute to a deeper understanding of caregiving within the context of developmental disabilities. Through qualitative

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inquiry and thematic analysis, the researchers aimed to uncover the journey of paternal caregiving, acknowledge the resiliency and dedication of paternal parents, and advocate for greater recognition and support for their vital role in enhancing the well-being of children with developmental disabilities. Methodology

II. METHODOLOGY

A. Research Design

This study utilized a qualitative data methodology to understand people's experiences, attitudes, and activities, taking into account non-numerical data.

The researchers used a phenomenological approach, which aims to explore the subjective experiences or opinions of the participants regarding a particular phenomenon. Consequently, this approach helped the researchers to have an in-depth understanding that helped in gathering and exploring the experiences of paternal parents who had children with developmental disabilities, precisely the challenges, distress, and coping mechanisms.

This study also employed a semi-structured interview method. In-depth interviews are the most popular type of qualitative data source; this approach usually entails a conversation between the researcher and the participant, supported by an unstructured interview methodology and enhanced by follow-up inquiries to gather further information and comments.

B. Research Locale

This research was carried out within Cabuyao, Laguna, specifically the elementary schools of Barangay Poblacion Dos and Barangay Mamatid. The researchers chose the city because of the growing number of students enrolled in SPED learning institutions, which also correlated with the number of paternal parents who are primary caregivers of children with developmental disabilities.

About this study, the researchers found twenty-two registered public SPED schools in Laguna, including the four public SPED schools in Cabuyao, that accommodated children with developmental disabilities, from elementary to high school, public and private schools, by the National Council Disability. Cabuyao catered to different kinds of developmental disabilities of children that correlated to the number of parents who were struggling in raising children with developmental disabilities. Furthermore, the researchers observed an existing phenomenon in Cabuyao.

C. Sampling Design

The target participants of the study consisted of fathers who are the primary caregivers of children with developmental disabilities and were interviewed in a semi-structured format, discussing the challenges they commonly face and the strategies they use to cope with their experiences as parents of children with developmental disabilities.

Furthermore, in this study, the researchers utilized a non-probability sampling method to select specific samples. Also, the researchers employed purposive sampling to identify and choose particularly informative examples linked to the study's focus. Through this technique, the researchers deliberately chose participants who closely aligned with the research topic and met specific criteria, resulting in more profound and authentic study outcomes.

The number of participants was determined by the requirement to comprehensively explore all crucial aspects of the phenomenon in the study. In this study, the researchers gathered eight (8) participants: four (4) fathers of children diagnosed with ASD, two (2) fathers of children diagnosed with ID, and two (2) fathers of children diagnosed with Down Syndrome.

The researchers visited various SPED schools in Cabuyao City to identify potential participants, subsequently arranging formal interviews and observations. The researchers then analyzed participant responses to derive the themes and codes essential for the study's outcomes.

D. Research Participants

The main subjects of this research comprised eight (8) paternal parents (fathers) living in Cabuyao, Laguna, with children aged between three (3) and seventeen (17) years old who have developmental disabilities. The primary data source for investigating their experiences in raising children with developmental disabilities was their responses during semi-structured interviews. Additionally, the researchers administered the Parental Stress Scale to delve deeper into their experiences and verify if they were undergoing significant distress. Purposive sampling was employed to select participants to ensure their relevance to the study.

The researchers established criteria for participant selection, including: (1) a paternal parent who carries the role of being the primary caregiver of their children with developmental disabilities, (2) has been their children's primary caregiver for at least one year, (3) must be working from home or have part-time job/s, (5) the paternal parent's spouse is the primary provider of the family or is separated from his spouse, (4) their children are clinically diagnosed with the developmental disabilities specifically, ASD, ID,

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and Down syndrome, (6) residents of Cabuyao, (7) willing to participate in the study. Participants who did not meet the listed qualifications are excluded from this study.

E. Research Instrumentation

The researchers used a standardized parental stress scale and a semi-structured interview as an instrument. Before conducting the interviews, they administered the parental stress scale to the chosen participants to assess their stress levels and to confirm that they were facing moderate to severe distress. Additionally, the researchers developed a series of open-ended questions concerning the life experiences of paternal parents as primary caregivers to children with developmental disabilities. These questions were supplemented by additional inquiries prompted by participants' responses so that they could express their experiences naturally.

During the interview, the participants willingly provided their answers. At the same time, the researchers attentively listened and made written notes, ensuring that the session was recorded with the participants' permission and comfort in mind. Subsequently, the interview was transcribed word for word. The researchers then analyzed the transcribed data thematically to uncover underlying codes or themes.

F. Data Gathering Procedure

To identify potential participants from public SPED schools in Cabuyao, the researchers prepared a signed formal request letter seeking permission from the City School Division.

The research questions were reviewed with the research adviser, Dr. Araceli Paster. Afterwards, before the interview, the participants were given an Informed Consent Form (ICF) to seek their approval for participation in the study and to apprise them of its potential risks and importance. Data collection involved conducting interviews with paternal parents as primary caregivers, specifically for Autism Spectrum Disorder, Intellectual Disability, and Down Syndrome.

The responses provided by the participants were then transcribed and validated. Subsequently, the data underwent textual and contextual analysis to extract essential themes from the lived experiences of paternal parents raising children with developmental disabilities.

G. Ethical Consideration

Thorough attention was devoted to addressing relevant concerns and issues throughout the research. These considerations included obtaining participants' consent, safeguarding their privacy and confidentiality, and proactively mitigating potential harm and distress.

One crucial step is ensuring that the participants are fully informed about the study's objectives, methodologies, potential risks, benefits, and their significant role in the process, as well as their rights to withdraw their participation. The researchers also ensured the protection of participants' identities and confidential information. Access to such data was strictly limited to authorized individuals, including the researchers, participants, and research adviser. Additionally, participant-related data was retained for three months before being securely discarded, with the researchers refraining from delving into personal matters or disclosing confidential information without consent.

A careful approach was adopted to acknowledge participants' emotional needs and other limitations, which involved arranging interview schedules at their convenience and including intervals to avoid potential interview-related distress. These cautious measures aligned with the study's objective of minimizing negative consequences. The researchers were tasked with preventing any manipulation, distortion of data, or preconceived results that could compromise the integrity of the study. An unwavering commitment to transparency and accountability characterized the research process.

III. RESULTS AND DISCUSSIONS

This chapter presents the results and discussion from the qualitative research, offering an in-depth understanding of the paternal parent's experiences as their child's primary caregiver.

The results of this study unfold three discussions encompassing three derived themes and twelve sub-themes. This study sought to understand paternal parents' complex and challenging experiences in fulfilling their caregiving responsibilities.

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Table 1. Superordinate themes and Constituent Subthemes

THEMES	SUB-THEMES
1. Navigating Parenting Challenges and Sacrifices	Lifestyle Adjustment
	Child-Centric Responsibilities
	Prioritization of Parental Duties over - Personal Growth
	Financial Problems
	Social Stigma
2. Holistic Well-being Under Stress	Physical Manifestation
	Emotional Impact
	Impact on the Body
3. Balancing Approach to Personal Development and Well-being	Coping and Fostering Resilience
	Positive Mindset in Maintaining Children's Growth and Well-being
	Engaging Diverse Activities

Table 1 presents the three (3) themes and twelve (12) sub-themes that emerged in the lived experiences of paternal parents as the primary caregivers of children with developmental disabilities: (1) Navigating Parenting Challenges and Sacrifices with its sub-themes: (a) Lifestyle Adjustment, (b) Child-Centric Responsibilities, (c) Prioritization of Parental Duties over Personal Growth, (d) Financial Problems, and (e) Social Stigma; (2) Holistic Well-being Under Stress with its sub-themes: (a) Physical Manifestation, (b) Emotional Impact, and (c) Impact on the Body; (3) Balancing Approach to Personal Development and Well-being with its sub-themes: (a) Coping and Fostering Resilience, (b) Positive Mindset in Maintaining Children's Growth and Well-being, (c) Engaging Diverse Activities.

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Table 2. Superordinate Theme 1: Navigating Parenting Challenges and Sacrifices

Emerging concept	Sub Theme	Main theme
<p>"Matututo kang ano eh mag-adjust sa oras mo"</p> <p>"Halimbawa ku— kumakain ka tapos may ano sa kanya— may nagpupo, iyong pagkain mo iwanan mo iyan, siya uunahin mo. Tapos ayun, gano'n. Tapos pag halimbawa, tulog ka nang tulog, tapos biglang umiyak na ano...nang walang dahilan, magiging ka. Oo full attention talaga."</p> <p>"Oo, kasi lahat yung utos mo sa kanya hindi magsusuot ng medyas hangga't hindi... hindi uutusan. Bihira man ang ano niyan neng 'yang maintindihan niya."</p> <p>"Mahirap kasi sa kanila yung ano eh behavior" "Ako nung una, medyo nagta-tantrum yun eh"</p>	Lifestyle adjustment	Navigating the Parenting Challenges and Sacrifices
<p>"Ayun nga mas naging focus ako doon sa bunso tapos pati kailangan namin mag-give up ng isa sa aming mag-asawa kailangan namin mag-iba ng trabaho isa sa amin para mag-focus sa kanya "</p> <p>"Syempre, unang-una 'yung patience talaga."</p> <p>"Hindi mo pwedeng iwanan iyan. Mamaya baka may mangyari sa kanya. Baka mamaya mahanap ng kutsilyo eh. Pagka gano'n mahirap"</p> <p>"Kailangan unahan mo siya kasi parang napapansin mo hindi na umiihi."</p> <p>"Kasi yung dalawa ko marunong yun e, eto naman kasi medyo alagain talaga need ng attention"</p>	Child-Centric Responsibilities	
<p>"Kailangan namin mag-give up ng isa sa aming mag-asawa. Kailangan namin mag-iba ng trabaho. Isa sa amin para mag-focus sa kanya."</p> <p>"Ngayon nalimitahan na yung mga projects namin na kinukuha namin kunyari dati sa isang buwan siguro nakakalimang nakakalimang cafe kami ganyan o restaurant bahay ngayon tutok na lang kami sa isang client namin gawa niya kasi"</p> <p>"Ginive-up ko si pagiging engineer ko para tutukan 'yung mga bata. So ayun, parang "Parang sa'kin kaya kong i-acce— i-sacrifice lahat para sa kanila"</p> <p>"Hinahati hati ko rin na syempre trabaho pero pagka yung araw gabi, araw... umaga magkasama tanghali minsan pagka nasa bukid talaga minsan hindi ko rin natututukan kasi nga nasa kanyang mga tita."</p> <p>"Nadagdagan nadagdagan yung responsibility mo syempre mismong sayo na mas tutok"</p> <p>"Kasi ang nangyari dyan, nung pinanganak nyan hindi na kami kumuha ng katulong, nangyari nag request ako don sa boss ko pangabi ako lagi"</p> <p>"Pang gabi basta pagdadating ko aalis naman ang asawa ko tapos alaga ko siya, walang tulog. Alaga, pag tulog sya nag lalaba naman ako"</p>	Prioritization of Parental duties over Personal Growth	
<p>"Ah financial. Yung pagte-therapy lang kasi medyo magastos yun eh. Weekly therapy kasi yun. Eh tinotherapy... siya'y OT, occupational therapy. Tsaka speech therapy tsaka yun nga medyo medyo magastos."</p> <p>"Sobrang mahirap ngayon kasi ito bali sa isang isang linggo three times a week siya nag-out ang ot niya ay 700 per hour sa isang linggo 3 beses"</p> <p>"Lahat ng sahod ko, full month lahat, padala yan. Kahit wala ako, wala nang natitira sa akin."</p> <p>3 times nga a week eh kaya lang napakiusapan ko na isang beses lang kasi tricycle driver lang ako</p>	Financial Strain	
<p>Sa jeep yung pagtitingnan ka ganun titingnan yung anak mo"</p> <p>"Ayaw namin ilabas yung mga bata"</p> <p>"Binubully na "ay hindi pa nakakalakad"</p>	Social Stigma	

The first (1) theme, "Navigating Parenting Challenges and Sacrifices," delves into the multifaceted journey of paternal parents caring for children with developmental disabilities, highlighting (1.1) lifestyle adjustments, (1.2) child-centric responsibilities, (1.3)

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prioritization of parental duties over personal growth, (1.4) financial problems, and (1.5) social stigma. Initially grappling with acceptance, they adapt schedules and parenting approaches to cater to their child's needs, often prioritizing the child's well-being over personal growth. Paternal parents undergo emotional adjustments and prioritize their child's needs, managing challenges like health unpredictability and communication difficulties with patience and adaptability. This commitment extends to proactive caregiving and integrating their child into everyday routines despite financial strain from therapy and medication costs. Additionally, they navigate social stigma, enduring judgmental stares and comments, adding emotional strain to their already demanding journey. Despite these challenges, paternal parents demonstrate unwavering dedication to creating environments fostering their children's growth and happiness, reflecting a profound commitment to their roles as caregivers.

Table 3. Superordinate theme 2: Holistic -Well-being under Stress

Emerging concept	Sub Theme	Main theme
<p>"Talagang nakakalbo na ako *laughs* natanda na rin e"</p> <p>"Tumaba ako. Syempre, and'yan ang stress ng bata, paano yung mga bata"</p> <p>"Naputi lang yung buhok kakaisip"</p> <p>"Aba nakakapayat din pala 'to *laughs* kasi diba na iistress ka diba *laughs* pag dating mo nanaman another day eto nanaman ang gagawin mo, another day nanaman."</p>	Physical Manifestation	Holistic-Wellbeing under Stress
<p>"Sumasakit lang ulo ko minsan"</p> <p>"Siguro yung sleeping pattern, oo yung sleeping pattern yun yung pagtulog-tulog kasi late na matulog yun eh"</p> <p>"Sumasakit ulo ko. Mas lalo sa katawan"</p> <p>"Masakit lang ang ulo pag ano minsan"</p> <p>"Siguro sa likod nananakit ganun"</p>	Impact on the Body	
<p>"Umiiyak kaming mag asawa iniisip namin paano na future nila"</p> <p>"Nalulungkot ako. Kaya lang ando'n na 'yun eh. Pero tanggapin na lang talaga"</p> <p>"Parang iniisip ko lang kasi nag-iisang lalaki nga tapos ganyan saying, hindi naman maiiwasan yung bakit... bakit sa amin na gano'n bakit lumabas na gano'n?"</p>	Emotional Impact	

The second (2) theme that emerged is Holistic Well-being Under Stress, which delves into the profound distress experienced by paternal parents caring for children with developmental disabilities, encompassing physical and emotional manifestations of stress. (2.1) Physical Manifestation highlights physiological changes like fluctuating weight and hair loss attributed to stress hormone release, impacting body weight and hair growth. Paternal parents experience weight fluctuations due to stress-induced eating habits and the demanding nature of caregiving. (2.2) Emotional Impact reveals feelings of sadness, frustration, and self-questioning regarding their child's disability, leading to dissatisfaction and shame. Though eventual acceptance occurs, negative emotions can strain parent-child relationships and parental sensitivity. (2.3) Impact on the Body showcases body aches, headaches, and sleep deprivation from caregiving demands, resulting in fatigue and stress-related ailments like back pain. Paternal parents' stress contributes to poor physical health, signaling the necessity for support and interventions to alleviate its effects.

Table 4. Superordinate Theme 3: Balancing Approach to Personal Development and Well-being

Emerging concept	Sub Theme	Main theme
<p>"Challenges tinatawanan ko lang naman yun eh kasi pag inisip mo pa lalong yung problema lalong maaano iyon"</p> <p>"Ano lang pag may na ano kasi positive lang kami pag may nakakausap kaming magulang katulad namin sabi namin nagmamature din sila"</p> <p>"Meron anong minsan na parang napupuno ako diyan parang dinadaan ko parang dinudugtungan ko na lang ng biro..."</p>	Coping and Fostering Resilience	Balancing an approach to personal development and well-being
<p>"Yung anak ko, basta makatapos siya ng pag aaral niya at maging ayos pakikisama niya sa iba masaya na ko don. Lahat naman ng ginagawa ko ngayon e... para sa mga anak ko."</p> <p>"Yung mga bata, syempre. Fulfilling naman siya. Kaya okay lang. At least, basta masaya 'yung mga bata atsaka kita namin nag-i-improve kasi 'yun 'yung doon mo makikita 'yung... parang sakripisyong ginawa mo kapag nakita mo 'yung mga bata is nag-i-improve. Ayun."</p> <p>"Ang pangarap ko sa anak ko yung makapag-aral... matuto."</p> <p>"Hmm yung mga anak. Kasi lahat naman tayo gusto makatapos yung anak e"</p>	Maintaining Children's Growth and Well-Being	
<p>"Nagpi-ps4 lang ako pag ano ganun pag may free time yun lang para libangan ko pag wala pang ano."</p> <p>"Oo ayan minsan nakakapag-mobile games ako."</p> <p>"Mag travel. Noong nag-okay na, wala ng pandemic, once a month nag ta-travel kami."</p> <p>"Ano mahilig ako sa ano kasi sa sports sa TV. 'Yung mga basketball, volleyball. Mga babaeng ano, mga FIBA, mga UAAP."</p> <p>"Meron anong minsan na parang napupuno ako diyan parang dinadaan ko parang dinudugtungan ko na lang ng biro"</p> <p>"Wala naman akong naging libangan na eh. Hindi ko na ano yung mga libang libang eh. Basta't ang ano ko priority yung pamilya eh."</p> <p>"Pag-uwi namin sa bahay magkasama kami, manood kaming tv yung mga ganun lang."</p> <p>"Manood lang ng tv, dun lang kami, mag youtube lang-"</p>	Engaging diverse activities enriching personal recreation	

The third (3) theme, "Balancing Approach to Personal Development and Well-Being," encapsulates the participants' strategies for managing their well-being while caring for their children with developmental disabilities. This overarching theme emphasizes the importance of maintaining a healthy balance between parental and children's well-being. In subtheme (3.1), "Coping and Fostering Resilience," participants discuss support groups that provide a sense of belonging and mutual understanding among paternal parents facing similar situations as well as by simply laughing or finding humor in it rather than getting upset or taking their challenges and problems seriously. Subtheme (3.2), "Maintaining Children's Growth and Well-Being," highlights the participants' dedication to ensuring their children's future, particularly regarding education. They prioritize their children's well-being and are willing to make significant sacrifices to provide necessary resources for their development. Subtheme (3.3), "Engaging Diverse Activities," illustrates how participants alleviate stress through various leisure activities, such as gaming or spending time with family. Some paternal parents involve their children in these activities to foster relationships and enhance communication skills. This engagement promotes parental well-being, contributes to the child's development, and strengthens the parent-child bond.

IV. DISCUSSION

After analyzing the results of this study, the following emerging concepts have been designed to delve into the challenges faced by paternal parents raising children with developmental disabilities.

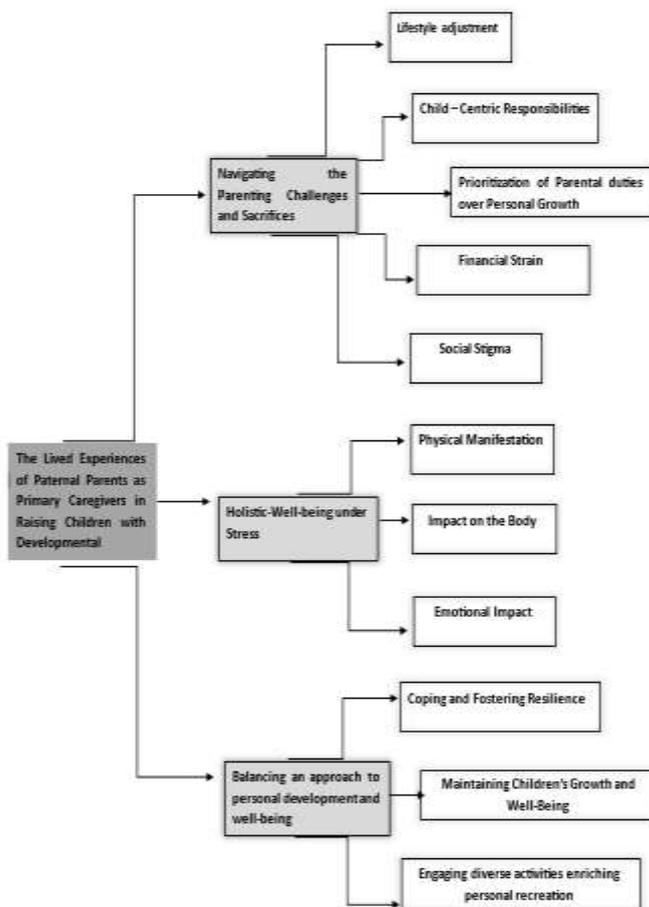


Figure 1. Thematic Map of Superordinate and Sub-themes

This study uncovered the multifaceted challenges faced by paternal parents in raising children with developmental disabilities and its effect on their day-to-day lives, careers, and finances. Paternal parents prioritize their children over their personal needs, adjusting their working hours and making sacrifices accordingly. Therapy expenses emerged as a common concern, with some paternal parents reducing sessions to manage costs. This study underscores the complexity of parental responsibilities, particularly concerning the financial aspects of therapy. Participants also face social stigma, emphasizing the need for awareness and support.

This study found that parental distress manifests in various physical and emotional ways, including hair-related changes, weight fluctuations, and emotional health effects. These findings align with previous research showing caregivers of children with developmental disabilities are more likely to experience poor physical health and psychological discomfort. Despite challenges, paternal parents exhibit positive coping strategies and resilience, focusing on their children's future and finding fulfillment in their growth. Leisure activities serve as stress-relief mechanisms and strengthen parent-child bonds.

Despite challenges, paternal parents exhibit positive coping mechanisms, relying on resilience and bonding time with their children to maintain optimism. Their coping strategies focus on their children's future and personal fulfillment, while leisure activities like gaming and media consumption serve as stress relief.

The study recommends a Stress Management Program for Paternal Parents of Children with Developmental Disabilities, which aims to support paternal parents in raising children with developmental disabilities by providing them with essential stress management tools and fostering a supportive community. Throughout the 5-week program, participants will engage in interactive sessions focused on understanding stress, exploring coping strategies, strengthening physical health, enhancing parent-child interactions, building support networks, and accessing resources for ongoing support.

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