Mothers’ Experience in Taking Care of Children with Special Needs: A Literature Review

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Abstract

Children with special needs experience long-term physical, mental, social, and emotional limitation which impact on family well-being, both physically and mentally. The impact of parenting on children with special needs is strong, especially on mothers, as main caregivers and the ones that support the children. Anticipation of the acceptance and support system for mothers is needed so that the potential and quality of life of the children with special needs can be achieved optimally. The purpose of this literature review is to investigate mothers’ experience in carrying out their caregiving role in caring for children with special needs. This literature study was conducted by collecting articles from online database that published between 2015 - 2019. The analysis showed that mothers’ experience can be grouped into experiences before the diagnosis, during the diagnosis, and after the diagnosis. The strongest experience was found in the after diagnosis, where experience loneliness, physical and mental health problems, burden, social isolation, maternal care, maternal needs in carrying out the caregiving role, obstacles in carrying out the caregiving role, and positive aspects from caring for children with special needs.

Nurses as health professionals who provide comprehensive interventions are expected to provide attention and assistance to mothers from pre-diagnosis up to the post diagnosis to help achieving optimal mothers and children well-being.

Keywords: mother, caring experience, children with special needs, disable children.

1. Research Background

Children with special needs are children experiencing long-term limitations or challenge on physical, mental, social, and emotional aspects which also have an impact on their growth and development (Winarsih, Jamal, Asiah, Idris, & Adnan, 2013). The term special needs can also be used to describe disabilities within a broader scope, as explained by The American with Disabilities Act (ADA), that it covers anything disrupting a person’s life functions, such as learning, talking, walking, and interacting with their environment (ADA, 2019).

The World Report on Disability estimates that 15% of the world's population has a disability, and an estimated 93 million children aged 0-14 years live with moderate or severe disabilities (Zuurmond et al., 2016).

National Survey of Children with Special Health Care Needs (2016) reported that over the last few decades there has been a steady increase in the number of children identified as having special needs. In addition, Riskesdas (Indonesia’s Basic Health Research) in 2018 showed that in Indonesia, the percentage of disabilities in children aged 5-17 years reached 3.3% of the total number of 265,469 children, where the highest rate occurred in Central Sulawesi Province by 7%, followed by Gorontalo and North Kalimantan respectively - 5.4% (Kementrian Kesehatan Republik Indonesia, 2018).

Children with special needs develop differently from children in general and need special attention in optimizing their development. A comprehensive intervention involving physical and intellectual stimulations can help children to develop more advance abilities. Children with special needs need to focus on their strengths of children themselves and their families should use these strengths to overcome limitations, and involve family assistance to develop their potentials. They also
expect to achieve quality of life (Bowden & Greenberg, 2010).

The results showed that gender plays an important role in coping mechanism and mental health of parents. Mothers experience significantly higher stress than fathers (Ang & Loh, 2019). In addition to the different acceptance of family conditions whose members suffer from illnesses or disabilities, parenting and parenting experiences are also reported varied as seen from their interactions with children, parenting styles, and coping mechanisms (Ang & Loh, 2019). Thus, it can be concluded that the burden of care on children with disabilities is more specifically given to mothers (Brekke, Früh, Kvarme, & Holmstrøm, 2017).

Mothers as primary caregivers for children with special needs are more likely to experience mental health problems in terms of child care and education compared to mothers who have normal children (Crettenden, Lam, & Denson, 2018). Mothers of children with special needs also experience various types of emotions and challenges while providing care for their children (Gadre & Mardhekar, 2015). If those health problems, emotional problems, and various challenges are not recognized and controlled properly, they will impact the development and quality of life of children with special needs. Based on the previous explanation, this literature study was conducted to investigate mothers’ experiences in dealing with various challenges in raising children with special needs.

2. Methods

Papers were searched based on keywords in several electronic databases, including EBSCO, Host, Scopus, Proquest, and Science Direct. The keywords entered were (mother * OR parent * OR caregiver *) AND (caring OR caring experience *) AND (children with special needs * OR special needs * children OR children with disability OR disabled children OR developmental disability). Inclusion criteria also applied as follows: 1) articles that have titles and contents relevant to the purpose of the study; 2) written in English and full text available; 3) research articles published between 2015 - 2019, with some exclusions on these criteria: 1) do not have a complete article structure; 2) articles with a review article design.

3. Result

This research reviewed 16 articles that discuss the experiences of parents or caregivers in caring for children with developmental challenges from various aspects, including physical, cognitive, and social aspects. Selected article were research reports conducted on various continents, including Asia, Australia, America, Africa, and Europe. The result of the article review can be seen in the Table 1.

Based on the review of the research article, it can be concluded that several sub-themes regarding mother's experience in caring for children with special needs are explained as follows:

3.1 Experience Before Diagnosis

Before diagnosis stating that children have special needs, Kyeremateng et al. (2019) explains that mothers experience complications during childbirth. This can explain that one of the factors causing children experiencing developmental disorders is problems during labor.

3.2 Experience During Diagnosis

Diagnosis was made by competent health professionals who conduct checkups to diagnose children with special needs. Kyeremateng et al (2019) explained that the experience of parents during diagnosis was meeting with a health professional. Participants in the study conducted by Kyeremateng in Ghana expressed their belief in superstition which caused their children to experience signs and symptoms of Cerebral Palsy (CP).

A study conducted in Hong Kong by Yi, Siu, Ngan, & Chan (2019) exploring the experience of parents during screening, assessment, diagnosis, and intervention in children with ASD stated that there are delays during the screening process to establish the diagnosis which also affects the intervention. This problem occurs due to limited resources available. This phase caused parents to experience frustration and confusion about the medical services for their children.
3.3 Experience After Diagnosis

Children with special needs will have to live with such condition for a long time, and it cannot be cured. This will affect the condition of the family, especially the mother, and also other family members. Significant experience will be experienced by mothers and families with children with special needs after diagnosis.

Self-feelings

Several feelings arising to a mother can be neutral, positive, or negative (Mokhtari & Abootorabi, 2019). Those negative feelings that can arise can be caused by stigma (Masulani-Mwale et al., 2016; Nazzal & Al-Rawajfah, 2018; Choi & Van Riper, 2016) or stereotypical views (Taderera & Hall, 2017) about the condition of children with special needs. Such stigma or stereotypes from the community will have an impact on mothers’ acceptance their children’s condition and delays in fulfilling their children’s needs.

Deep sadness is often experienced by mothers with children with special needs. Collins et al., (2016), in their exploratory studies about parents and children who have limited conditions, formulated one theme of "living with shadows" which means widespread sadness. This sadness results from the limitations that their children have to bear for a lifetime. Mothers are also more sensitive when they hear terms related to their children’s conditions (Sukmak & Sangsuk, 2018).

Feelings of loss and uncertainty (Heer, Rose, Larkin, & Singhal, 2015) are also felt by parents of children with special needs. Parents’ feeling of hopelessness about their children's condition and fear of the children’s future (Zechella & Raval, 2016) and fear to face the outside world (Courtney et al., 2018; Nazzal et al., 2018). Parents will experience depression, if this condition continues.

Physical and Mental Health

Parents who provide care for children with special needs can have their health disrupted (Collins et al., 2016), both physically and mentally (Masulani-Mwale, Mathanga, Silungwe, Kauye, & Gladstone, 2016). Courtney et al. (2018) also found similar results, stating that mothers who have children with life-limiting disabilities / neuro-developmental disabilities experienced physical, psychological and social consequences. Continuous sadness and anxiety without followed up by proper coping mechanism will affect mothers’ mental health.

The Burden from Caregiving

Caregiving role for children who have different needs from other normal children results greater caregiving burden for mothers (Courtney et al., 2018; Nazzal et al., 2018), especially over a long period of time. This causes mothers of children with special needs to have greater responsibility (Heer, Larkin, & Rose, 2015) compared to those of normal children. Such condition also requires mothers to adapt to the situation and choose appropriate coping strategies in carrying out their caregiving role. Sukmak and Sangsuk (2018) described this condition as a trapped-in-a-tunnel-of-distress condition.

Social Isolation

Other experience happened to parents is having a social isolation (Collins & Coughlan, 2016). Parents are stuffed with feeling of being ostracized from the community, including isolation by family (Mokhtari & Abootorabi, 2019) to negletion from the family and community (Kyeremateng et al., 2019). Exclusion from the community is also a major obstacle for mothers that prevents them from accessing the available support (Su, Cuskelly, Gilmore, & Sullivan, 2018).

The Role of Mother Care

After being able to accept their children’s conditions, mothers finally understand that they should make efforts to care for the children well (Mokhtari & Abootorabi, 2019). Sukmak and Sangsuk (2018) explained that mothers are children’s world which demands them play balance role as parent, mediator, and navigator (Vukkadala, Giridhar, Okumura, & Chan, 2019). Mothers must also learn to deal with stigma and try to protect their children under any circumstances (Heer, Larkin, et al., 2015). They are also expected to make the right decision to seek help and try to view disability in a new perspective (Heer, Rose, et al., 2015).

Mothers’ Needs in Performing Caregiving Role
Mothers need the support from their husbands, relatives, families (Mokhtari & Abootorabi, 2019) in carrying out their caregiving role. They also need financial support to provide care for their children. Support from the surrounding environment and the government to provide programs, services, and policies for children with special needs is also needed by mothers (Su et al., 2018; Taderera & Hall, 2017). Mothers need to develop strategies together with their family to manage and find sources of strength.

**Obstacles in Performing Caregiving Role**

Obstacles experienced by parents in providing care for their children can also come from the community. These obstacles are caused by lack of community awareness, ignorance, lack of support and strength, and unequal distribution of the sources of strength in the community (Choi & Van Riper, 2016). Another inhibitor is the inability to access hospitals and appropriate education facilities that facilitate their children's limitations (Kyeremateng et al., 2019). In addition, conflicts occurring in the family, being alienated from the community, and experiencing limited access to information sources become the main factors for mothers to be able to utilize the available support resources (Su et al., 2018; Taderera et al., 2017).

**Positive Aspects of Experience of Caring for Children with Special Needs**

Aside from the negative experiences experienced by mothers in carrying out their caregiving role, the condition of children with special needs also has a positive impact on them. One positive aspect relates to stronger spirituality. This is exemplified by the results of research by Masulani et al. (2016) which stated that the majority of parents in Malawi overcome the problems arising from carrying out their caregiving role for children with special needs by using spiritual coping mechanism.

**4. Discussion**

Based on the review of 16 articles, various experiences experienced by mothers in caring for children with special needs have been identified. This experience started from before, during and after the diagnosis. The most frequent and strongest stress experienced by mother is the after-diagnosis experience where mothers will go through the days with their children’s condition. This statement is supported by study conducted by Kyeremateng et al. (2019) which stated that after the doctor established a diagnosis for their children, mothers experience challenges in raising children, neglect in the family and community-related obstacles, financial impact due to treatment needs, and inability to access health care facilities and educational institutions.

Limitations to access health services and educational facilities were found in the results of a study conducted in the African continent (Ghana, Malawi and Namibia). Several countries in Asia such as Hong Kong in Yi, Siu, Ngan, Chan's study (2019), also show that mothers’ frustration also occurred due to delays related to health care and confusion about the services provided at local health facilities. The majority of research show that mothers’ problems are mostly related to feelings within herself/personal feelings, unfulfilled caregiving role and obstacles in carrying out her caregiving role.

**5. Conclusion**

Identification of mothers' experience in taking care of their children with special needs provides information about the challenges and positive aspects experienced by mothers. Nurses as health professionals who provide comprehensive interventions are expected to give attention to the conditions experienced by mothers, and can provide assistance to help them improve their welfare.

**Bibliography**


Sukmak, V., & Sangsuk, N. (2018). Living a tormented life: Caregivers’ experiences of...


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<tr>
<th>Article</th>
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<tr>
<td>Collins et al. (2016)</td>
<td>Phenomenology</td>
<td>14 parents who have 1 or more children (≤18 years) diagnosed with a life-limiting condition</td>
<td>In-depth exploration about the parents' experience in caring for children with life-limiting condition</td>
<td>Phase 1: Quantitative survey explaining unmet supportive children's care needs, distress and impact of caring. Phase 2: semi-structured face-to-face interview of 45 to 120 minutes' duration</td>
<td>Four key themes represented the prevalent experiences of parents: (1) trapped inside the house, (2) the protector, (3) living with the shadow and (4) traveling a different pathway. Those four themes describe parents' physical and social isolation, exclusion from the workforce, pervasive grief and associated impacts to their health and well-being.</td>
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<tr>
<td>Australia</td>
<td>Qualitative</td>
<td>12 mothers of children (aged &lt; 6 years) with LLNDD (life-limiting neurodevelopmental disabilities)</td>
<td>Exploring mothers' perspectives on experiences and impacts on themselves and their family when having children with life-limiting disabilities (developmental disabilities)</td>
<td>Semi-structured face-to-face interview home interview (10 people) and semi-structured telephone interview (2 people) of 40 to 210 minutes' duration.</td>
<td>4 themes were identified: 1) “Starting Out”, related to mothers’ experience during and after their child birth. 2) “Keeping the Show on The Road”, describing the family’s strategies to manage their everyday life and their source of strength. 3) “Shouldering the Burden”, describing some physical, psychological and social consequences of the current situation. 4) “The Bigger Picture”, related to how they face the world.</td>
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<td>Courtney et al. (2018)</td>
<td>Qualitative</td>
<td>n= 46 caregivers of children (&gt;12 years) diagnosed with Cerebral Palsy (CP) who live in densely populated areas</td>
<td>Establishing the welfare of caregivers in children diagnosed with Cerebral Palsy (CP) who live in densely populated areas</td>
<td>Using the The Caregiver Strain Index (CSI) questionnaire to measure the burden of caregiving, and The EuroQol 5 dimensions (EQ-5D) to measure the quality of caregivers' lives.</td>
<td>- The burden of caregiving experienced by caregivers is quite large, half of the respondents were reported to be within the range of 'clinical distress' of CSI scores. - Many caregivers experienced diverse pain, depression, and declared the overwhelming in providing care.</td>
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<td>Dambi, Jelsma, dan Mlanbo (2015)</td>
<td>Quantitative</td>
<td>n= 46 caregivers of children (&gt;12 years) diagnosed with Cerebral Palsy (CP) who live in densely populated areas</td>
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<td>Ireland</td>
<td>Qualitative</td>
<td>7 parents (5 mothers, 2 fathers) of different families who care for children 7-14 years with developmental / intellectual disabilities</td>
<td>Exploring the role of culture in shaping the experience of British South Asian families caring for children with developmental disabilities in the UK</td>
<td>In-depth face-to-face interview for 1.5 hours and interpretive phenomenological analysis</td>
<td>The main themes that emerge: 1) Living with loss, uncertainty, and extraordinary responsibility 2) Learning about disability and face stigma 3) Being obliged to protect.</td>
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<td>Heer, Rose, Larkin, Singhal (2015)</td>
<td>Qualitative</td>
<td>10 mothers of children with developmental /</td>
<td>Adopting a cross-cultural perspective to explore parental care for children</td>
<td>Using 3 focus group discussions (FGD) for 45 minutes to 1 hour</td>
<td>The main themes identified: 1) “Making the decision to get help” 2) “Viewing disabilities in a new perspective”</td>
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<td>Zimbabwe</td>
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<td>7 parents (5 mothers, 2 fathers) of different families who care for children 7-14 years with developmental / intellectual disabilities</td>
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<td>Singhal (2015)</td>
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<td>intellectual disabilities who can access services from Action for Autism (AFA)</td>
<td>with intellectual disabilities / developmental disabilities in India</td>
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<td>Masulani-Mwale, Mathanga, Silungwe, Kauye, Gladstone (2016)</td>
<td>Phenomenology</td>
<td>Parents (mothers and fathers) of children with intellectual disabilities aged ≥ 18 years old</td>
<td>Exploring psychological experiences and understanding coping mechanisms and the psychosocial needs of parents caring for children with intellectual disabilities in Malawi</td>
<td>Using 10 focus group discussions (FGD) and 4 in-depth interviews at 2 places, conducted in community-based disability children's clinics</td>
<td>The challenges of parents in caring for children with intellectual disabilities include limited access to service providers, especially for parents' psychological problems; experiencing stigma and discrimination; experiencing mental health problems due to carrying out the caregiving role, having the idea of suicide, even forced by neighbors to kill children with disabilities. Most parents deal with problems with spiritual coping.</td>
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<tr>
<td>Mokhtari dan Abootorabi (2019)</td>
<td>Qualitative phenomenology</td>
<td>8 mothers (21-38 years old) who have children with CP aged between 2-12 years old</td>
<td>Conducting a phenomenological investigation of the mothers’ experience in Iran who have children with cerebral palsy (CP)</td>
<td>Semi-structured interview of 30 to 60 minutes</td>
<td>Identified themes include: feelings (neutral, positive, and negative) and self-expectation (efforts to give better care for their children); level of relations / relationships (self isolation and relations with relatives); level of support (being left by husband's family and others, lack of support from children's fathers, interference from others in caring for children, being underestimated, lack of emotional and financial support from husband's family)</td>
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<tr>
<td>Nazzal &amp; AL-Rawajfah (2018)</td>
<td>Phenomenology</td>
<td>7 mothers of children with disabilities who have experience of caregiving for children with disabilities in Jordan</td>
<td>Exploring the perspectives, challenges and adaptations of Jordanian mothers living with children with disabilities.</td>
<td>In-depth interviews using a semi-structured guide for 1-1.5 hours</td>
<td>Mothers' experiences are described in 4 main themes: 1) Increased stigma 2) Fears for the future 3) Increased caregiving burden 4) Adaptation to their children's disability</td>
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<td>Sukmak dan Sangsuk (2018)</td>
<td>Phenomenology</td>
<td>5 caregivers of children with autism spectrum disorder (ASD) living in rural areas of Thailand</td>
<td>Learning the meaning of caregiving for children with ASD for caregivers</td>
<td>In-depth, semi-structured, and face-to-face interviews for 45 minutes-1 hour</td>
<td>The themes that emerge: 1) Being sensitive to the word autism 2) Trapped in a tunnel of distress 3) Becoming the world for children</td>
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<tr>
<td>Vukkadala, Giridhar, Okumura, Chan (2019)</td>
<td>Qualitative (grounded theory)</td>
<td>33 people for focus groups and 7 parents who have permanent (unilateral or bilateral) hearing impaired children from the age of 36 months old for interviews</td>
<td>Identifying the main determinants of the quality of infants’ and toddlers’ life (&lt;3 years old) with hearing impairment</td>
<td>Using 4 focus groups for 2 hours and 6 semi-structured interviews (one interview was conducted for both parents) for 1 hour</td>
<td>The main code found is &quot;Searching for Equilibrium&quot;, with 3 main categories of caregiver experience, namely: 1) Parenting - modifying parenting styles because children experience hearing loss / impairment 2) Becoming a mediator - regulating and filtering interactions between children and their environment 3) Becoming a navigator - managing availability of medical treatment and education systems</td>
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<td>Choi, Van Riper (2016)</td>
<td>Qualitative</td>
<td>77-81 mothers &gt; 19 years old who have children with Down Syndrome aged between 4-19 years old</td>
<td>Exploring the mothers’ perception in living their life with Down Syndrome children</td>
<td>Using content analysis to collect data, conducting interviews with mothers who have children with DS</td>
<td>77 mothers answered the question &quot;How do Korean people handle children with DS?&quot;, 81 mothers answered the question &quot;How do people in your area treat children with DS?&quot;, with an average answer less than ideal. Themes stemming from answers to questions about community responses to children with DS are presented as follows: 1) Lack of awareness 2) Ignorance 3) Lack of support and source of strength 4) Unequal distribution of power sources Themes identified from answers to questions about community responses to children with DS are presented as follows: 1) The attitude towards the stigma 2) Unexpected attention</td>
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<tr>
<td>Kyeremateng et al (2019)</td>
<td>Qualitative</td>
<td>40 primary caregivers of children with Cerebral Palsy (CP) aged 1-15 years who have been reviewed by a multidisciplinary team and receive treatment from The tertiary hospital setting</td>
<td>Exploring the experience of primary caregivers during the diagnosis of CP (before, during and after) in the tertiary hospital setting</td>
<td>Face-to-face interviews for 30 minutes-1 hour</td>
<td>Experience before diagnosis: 1) Complications during childbirth Experience during diagnosis: 1) Meeting with professional health care 2) Believing in superstition Experience after diagnosis: 1) The experience of raising children with CP 2) Ignoring family and community</td>
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<td><strong>Su, Cuskel, Gilmore, Sullivan (2018)</strong>&lt;br&gt;China</td>
<td>Qualitative</td>
<td>12 mothers of children with intellectual disabilities at school age (grades 3-5)</td>
<td>Exploring the mothers’ perceptions in China who have children with intellectual disabilities regarding the support they received</td>
<td>Semi-structured face-to-face interviews for 30 minutes-2 hour</td>
<td>Mothers in China receive support from their family members, neighborhood, school teachers, and the government. The main obstacles for mothers to be able to access and utilize available support include family conflicts, alienation from friends and the community, unequal relations with school teachers, and limited access to information resources.</td>
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<td><strong>Taderera dan Hall (2017)</strong>&lt;br&gt;Namibia</td>
<td>Phenomenology</td>
<td>8 parents of children who have learning difficulties are around age 7-12 years old</td>
<td>Exploring and explaining the challenges faced by parents who have children with disabilities / learning difficulties in Opuwo, Namibia</td>
<td>In-depth interviews with thematic analysis</td>
<td>Some participants have a superficial understanding of learning difficulties because they do not have access to information sources. Participants are also lack awareness and availability of programs, services, and policies that bring benefits to children who have learning difficulties. Participants said that children and society have stereotypes about learning difficulties.</td>
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<tr>
<td><strong>Yi, Siu, Ngan, Chan (2019)</strong>&lt;br&gt;Hong Kong</td>
<td>Mixed-methods</td>
<td>249 parents of children with autism spectrum disorder (ASD)</td>
<td>Exploring the experience of screening, assessment, diagnosis and intervention in children with ASD</td>
<td>Qualitative analysis of the results of the questionnaire focusing on a) reviewing parental experiences regarding key milestones, including access time, expert support and availability of consultations, as well as referral and follow-up, b) assessing the relationship between milestone experiences. Qualitative themes through interviews, focus on the context of the difficulties felt by parents and the views of parents on services for children with ASD</td>
<td>There is a significant delay in the screening and diagnosis process for planning interventions for ASD children due to limited resources. Parents explain the frustration and confusion about service to ASD children.</td>
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<tr>
<td><strong>Zechella dan Raval (2016)</strong></td>
<td>Qualitative</td>
<td>15 parents (8 mothers and 7 fathers) of children</td>
<td>Describing experience</td>
<td>Semi-structured interviews carried out with mothers and fathers were done</td>
<td>5 domains: &lt;br&gt;1) Culture explanation, community response, and migration</td>
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USA

diagnosed with Down Syndrome, Autistic Disorder, or unspecified pervasive developmental disorder since they were 4 years old.

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<td>separately for 60-90 minutes, then analyzed using thematic analysis</td>
<td>2) Impact on themselves and their family</td>
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<td>3) A source of stress and a source of support</td>
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<td>4) Unique childcare approach</td>
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<td>5) Hopes and fears for the future</td>
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