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Abstract

In this study the authors explored maternal perceptions of life with Down Syndrome (DS) in Korea. Written responses to open-ended questions were collected as a part of a larger study and examined using content analysis. Most mothers commonly reported responses toward children with DS at both the societal and community level were negative. Many mothers acknowledged that even though there are ongoing challenges associated with being the mother of a child with DS, they have experienced unexpected joys as well. Increased awareness of cultural differences in beliefs and attitudes about children with DS and their care will help health care professionals develop culturally appropriate interventions.

Keywords

Culture, Down Syndrome, Koreans, Mothers, Social Values

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Maternal Perceptions to Open-Ended Questions about Life with Down Syndrome in Korea

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In this study the authors explored maternal perceptions of life with Down Syndrome (DS) in Korea. Written responses to open-ended questions were collected as a part of a larger study and examined using content analysis. Most mothers commonly reported responses toward children with DS at both the societal and community level were negative. Many mothers acknowledged that even though there are ongoing challenges associated with being the mother of a child with DS, they have experienced unexpected joys as well. Increased awareness of cultural differences in beliefs and attitudes about children with DS and their care will help health care professionals develop culturally appropriate interventions. Keywords: Culture, Down Syndrome, Koreans, Mothers, Social Values

Families caring for children with DS, the most common chromosomal abnormality associated with intellectual and physical disabilities, are more likely to experience increased stress than families of typically developing children (Hedov, Wikblad, & Anneren, 2006). However, some families successfully adapt to raising a child with DS in their families and even thrive (Van Riper, 2007). There is growing recognition that societal beliefs and attitudes about people with disabilities, as well as the availability of support and resources for people with disabilities, influence the family experience of living with DS (Blacher & McIntyre, 2006; Choi & Yoo, 2014; Gau, Chiu, Soong, & Lee, 2008; Hsiao & Van Riper, 2011; Ishizaki et al., 2005; Norizan & Shamsuddin, 2010; Sari, Baser, & Turan, 2006). For example, Blacher and McIntyre (2006) conducted a comparative study of 150 Anglo and 132 Latino mothers of young adults with intellectual disabilities (including DS). According to their report, Latino mothers showed higher depression symptoms and lower morale; however, they also reported higher positive impact (e.g., feeling more confident as a parent) from raising their child with a disability compared to Anglo mothers. The authors of the study suggested the differences found between these two cultural groups were probably due to *marianismo*, a unique Latino cultural aspect regarding female gender role where there is an emphasis on motherhood as well as submissiveness to the husband.

Societal beliefs and attitudes play a key role in shaping the meanings families construct from their efforts to deal with the ongoing challenges and struggles associated with raising a child with DS and, in turn, meanings play a fundamental role in shaping and maintaining the family's responses toward harmony and balance (McCubbin, Thompson, & McCubbin, 1996). For example, Gattford (2001) interviewed mothers from three different cultural backgrounds (i.e., White British, Black British, and Black African) and found that these mothers differed in how they responded to the diagnosis of DS, as well as how they viewed the support available for their child and their family. In a study with mothers of children with DS in Hong Kong, the coping mechanisms and resources available to mothers in Hong Kong were influenced by Chinese culture, particularly Confucianism (Lam & Mackenzie, 2002). These mothers were reluctant to have active discussions with their husbands to avoid arguments and maintain family

harmony and balance. Moreover, in a study conducted in Turkey, mothers of children with DS reported that people's negative responses were a great source of stress (Sari et al., 2006). In Korea, some people believe that disabilities are caused by supernatural powers (i.e., a punishment from God or ancestral curse), while others endorse the biomedical view of causation. A third explanation is that incorrect or poor prenatal care results in a child being born with a disability (Kim-Rupnow, 2005).

Mothers tend to be the primary caregivers for children with DS in Korea. Because of this, they are likely to be the ones who have the best understanding of how children with DS are treated in Korea at both the societal and community level. They are also the ones who are likely to have direct experience observing others interact with their child with DS. Therefore, to more fully understand life with DS in Korea, it is critical to explore how Korean mothers perceive the cultural and social contexts surrounding individuals with DS and also assess their experiences of raising a child with DS. Thus, the purpose of this study was to explore maternal perceptions of life with DS in Korea.

Methods

This descriptive study involved a conventional qualitative content analysis of data collected as a part of a larger study conducted with mothers of children with DS in Korea that explored sibling adaptation and influencing family factors. Findings from the close-ended questions have already been reported (Choi & Van Riper, 2014). So for this study, the focus will be on maternal responses to the three open-ended questions that were included in a larger study.

Ethical approval was obtained from the University of North Carolina at Chapel Hill Institutional Review Board. In the original study, Korean mothers of children with DS were recruited through the Korea Down Welfare Center, local and online DS parents' support groups, and special schools in two metropolitan areas in Korea, from June to August 2011. Mothers older than 19 years of age who were the primary caregiver for both a child with DS and at least one typically developing child aged 4 to 19 years were invited for the study. However, mothers whose typically developing children were not living together in the same family were excluded from the study. A total of 105 Korean mothers of children with DS participated in the study and completed a set of questionnaires that included three open-ended questions. Because participating mothers were told that they could skip any questions they did not want to answer including open-ended questions, the number of mothers who completed the open-ended question varied from 77 to 81. The first open-ended question ("How does Korean society treat children with Down syndrome?") was asked to understand how Korean mothers perceive the general societal treatments (e.g., governmental policy, support) toward their children with DS and their families. The second open-ended question ("How do people in your region treat children with Down syndrome?") explored everyday interactions between the child with DS and people in the community where the child lives. The third open-ended question ("What is it like to be a mother of a child with DS in Korea?") was used to understand the overall experience of being a mother of a child with DS in Korea.

Maternal responses to the three open-ended questions were analyzed using a conventional qualitative content analysis because qualitative content analysis can provide a "subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns" (Hsieh & Shannon, 2005, p. 1278). The aim was to generate categories of maternal perceptions of life with a child with DS in Korea at the societal and community level. As recommended by Hsieh and Shannon (2005), all answers that were written in Korean were translated into English. The accuracy of a translated English version of responses was reviewed by another person who was fluent in both Korean and

English. Translated statements allowed both authors to read independently and classify codes. Responses from each open-ended question were written on a separate piece of paper, and the authors thoroughly read and re-read each transcript repeatedly and identified codes. A reference number was written on each statement of the respondents where particular codes were found. This not only helped the authors to track the respondents' statements but also avoid the repeated usage of codes. In order to find fully saturated categories, codes found from each author were analyzed and discussed repeatedly, and then organized into categories that best described the phenomenon. The codes that were generated from two authors were almost identical. Some categories were combined or divided into sub-categories during the process. These processes were continued until final agreement of both authors was reached. Authors also tried to name each category using the mothers' own expressions in their statements if possible. Although there were a wide range of responses, many of the mothers gave similar responses. Therefore, a total of four categories regarding responses to children with DS at the societal level and two categories at the community level, and three categories of maternal experiences were developed.

Results

The mean age of mothers was 42.93 years. The majority were married (95%) and had at least two children (73%). About one-third (31%) of mothers were not religious; among those who confessed their religion, about 61 percent were either Protestants or Catholics and 39 percent were Buddhists. About one-third (32%) of mothers had employment outside of their home. Most mothers described their current income as middle (55%) or middle-low (25%). Thirty-eight percent of mothers completed undergraduate education. Most mothers (97%) were informed of their child's diagnosis of DS after their child was born. The mean age for children with DS was 12.88 years and half of them were male (55%). As far as the severity of intellectual disability for the child with DS, about 40 percent of the children with DS had mild intellectual disability followed by moderate intellectual disability (38%).

Seventy-seven mothers answered the open-ended question, "How does Korean society treat children with Down syndrome?" and 81 mothers answered the open-ended question, "How do people in your region treat children with Down syndrome?" In general, answers to both of these questions suggest that the treatment of children with DS in Korea is less than ideal. That is, responses to children with DS tend to be negative in Korea. However, four mothers did report experiencing positive responses at both levels. Four themes were derived from answers to the question about societal responses to children with DS:

- 1) lack of awareness,
- 2) indifference,
- 3) insufficient support and resources, and
- 4) unfair distribution of resources.

Two themes were identified from answers to the question about community and regional level responses:

- 1) stigmatizing attitudes, and
- 2) unwanted attention.

Responses to Children with DS at the Societal Level

The majority of the mothers who answered the question about responses to children with DS at the societal level described negative responses. Only seven mothers described

positive responses at the societal level. Thirteen mothers noted areas where great improvements have been made, as well as areas in need of greater attention. The mothers who reported improvements typically included a description of how current awareness, attitudes, policies and services in Korea compare to those from past decades.

(1) Lack of awareness. Only two mothers indicated that people in Korea have become more aware of DS and children with DS through mass media (e.g., TV shows, newspapers), while 16 mothers reported a lack of understanding about DS and children with DS as well as a societal prejudice toward children with DS. For example, while one mother noted, “I think people are generous because there is a lot of information about DS and they often see people with disabilities (subject 19),” another mother said, “people seem to have strong judgment. It is very difficult to live with a child with disability in Korean society (subject 95).”

(2) Indifference. Sixteen mothers in this study reported that the Korean government or society “does not care about children with DS.” Seven mothers felt that caring for a child with DS was considered to be an individual or family matter (meaning that the family of a child with DS was responsible for all extra care-related responsibilities) rather than a societal or national issue. One mother wrote, “Although it gets better, there is still a sense that the family has to solely take care of a child with disability in Korea (subject 78),” and another mother noted, “There is nothing the society can do for us. It is all about an individual’s unhappiness and their parents are burdened (subject 100).”

(3) Insufficient support and resources. Thirty-nine mothers described a lack of adequate support and resources in the following areas: education, health care, finances, and employment. For most, the area of greatest concern was education. Eleven of the mothers indicated there was a particular need for improved services in the area of education (e.g., schools for their child with DS). One mother shared her negative experience with current educational support:

There are many middle and high schools that don’t have special classes. The office of education encourages us to attend places where there are special classes. I think that is because they couldn’t afford to open new classes in those places. And the governmental support isn’t enough... (subject 47)

Mothers also described the need for a more consistent and ongoing approach to the education of children with DS. For example, one mother said, “If children with DS can get appropriately educated, then that can help them afford school-life and social-life. I hope there are more governmental assistances for education (subject 60).” Mothers also shared their thoughts on other areas in need of additional support and resources, particularly health care and finances. A few mothers noted that discrepancies exist between support and resources available for children with DS and those available for children with other disabilities such as autism, physical disabilities, or acquired disabilities. One mother noted, “...the group of people with DS is small compared to those with other disabilities. I think particularly we are more isolated than people with autism or other intellectual disabilities (subject 28).” A second mother said, “The governmental support for people with intellectual disabilities isn’t good compared to the support for people with physical disabilities (subject 36).”

(4) Unfair distribution of resources. In addition to discussing the fact that there were limited resources for children with DS and their families, eight mothers also believed there was an unfair or ineffective distribution of the resources that did exist. These mothers insisted that resources should be given equally to all families caring for a child with DS, rather than just to those who qualify based on the family’s household income or the disabled child’s level of intellectual disability. One mother wrote,

The current policy considers the level of family income rather than considering each child with a disability and supporting them financially. The opportunities to have education and therapy cannot be evenly distributed (subject 35).

Responses to Children with DS at the Community Level

Almost half of the mothers who responded reported experiencing negative responses such as negative attention or indifference. Only about one-sixth of the mothers reported being pleased with the way people in their community treated their child with DS

(1) *Stigmatizing attitudes.* Fifty-eight of the 81 mothers who responded to the question about how their child with DS was treated in their community described stigmatizing attitudes toward their child with DS. Mothers indicated that people in their community typically thought of their child with DS as “different” from children with typical development. Children with DS were often viewed as “slow,” “poor,” “weird,” or in need of “help.” There were however a few mothers who reported that people in their neighborhood accepted their child with DS and treated him or her like any other child in the community. One mother suggested that attitudes and responses toward children with DS may change as people become more aware of what DS is and the challenges associated with living with DS.

People seem to think that our child is special, but at the same time they also seem scared. When they first think about our child with DS, I think they tend to create a boundary because of my child’s unfamiliar behaviors and inarticulate speaking. However, once they come to know my child, they think my child is special and have compassion for him. I think half of them consider him as a member of this community while half seem to think he is special (subject 13).

The understanding of DS and attitudes toward children with DS also seemed to vary depending on whether people in their community were children or adults, whether they dealt with younger children with DS or older children with DS, and whether they lived in the city or in a rural area. For example, one mother said, “Children in the community make fun of my child with DS. They call him “dullard” and don’t play with him (subject 57).” Another mother noted, “People in my neighborhood seem to be nice to younger children with DS; however, I feel like they seem closed to older ones (subject 26).”

Some mothers seemed to suffer from people’s prejudice toward not only their child with DS, but also to their family as a whole. Mothers addressed their tough experiences. One mother wrote “...people in my neighborhood seem to have negative impressions and think that my family will be unhappy. Also they think that my child with DS is also unhappy. However, I don’t agree with that at all. We aren’t unhappy... (subject 72).” Another mother noted “...there are a few people that give negative attention and assume that “the family will not be happy because of the child with DS” or ask questions like, “does the child speak?” or “is he able to take care of his own hygiene? (subject 68).”

(2) *Unwanted Attention.* Twenty-two mothers reported on the kind of attention that their child with DS or their family as a whole attracted from others. The majority of these mothers reported negative experiences. They often used words such as “unfamiliar,” “unkind,” “unpleasant,” or “too much” to describe the unwanted attention (e.g., staring). One mother said “I can never get out of the *once again* attention from strangers (subject 41)” and another mother noted, “Still, people look at my child with DS as if they were an animal in the zoo (subject 15).” Moreover, mothers reporting on this particular issue seemed to suffer from people’s unwanted attention. This mother shared her difficulties:

Although I have lived in the same place for 20 years, I still have difficulties overcoming unkind attention to me and my child with DS. Because of this, it is hard to visit governmental offices in my town or province to get help (subject 21).

In contrast to the mothers who reported receiving negative unwanted attention, there were a few mothers who felt they received considerate attention and caring from people in their community. One mother reported “I have not received any unkind or special attention in my town because of the fact that I am the mother of a child with DS (subject 30).” Also, another mother noted that her neighbors seemed to be proud of her child with DS if they had seen a child with DS on TV shows. Some of them believed that their positive experiences were associated with the special environment of their community. For example, one mother noted,

Because there is a welfare center for people with disabilities in my community, the recognition for children with DS is fairly good. People do not pay too much attention and they aren’t indifferent as well. There is no need to think about how others will think about us and this makes our life pretty easy (subject 40).

Eleven mothers described people in their community as uncaring or indifferent toward their child with DS. According to these mothers, people in their community seemed to ignore or put a distance between themselves and the child with DS.

Maternal Experiences of Raising a Child with DS in Korea

Eighty-one mothers responded to the question, “What is it like to be a mother of a child with DS in Korea?” Of these, the majority (n=40) described the experience as a negative experience filled with ongoing challenges and difficulties, while 11 mothers described it as a positive experience filled with joys and rewards. However, 30 mothers described the experience as one with both negative and positive aspects. From these responses, three themes were identified:

- 1) challenges and difficulties,
- 2) adaptation, and
- 3) appreciation.

(1) Challenges and difficulties. Mothers who described their experience as a negative experience typically used words such as afraid, scared, marginalized, tough, worried, resentful, sorry, shocked, desperate, and desolated to describe their experience of being the mother of a child with DS. Their difficulties stemmed mainly from unwanted or unfriendly attention (n=15) and prejudice toward their child with DS and their family as a whole (n=9), financial burdens due to medical expenses and physical therapies (n=15), limited services and special education to be available for their child with DS (n=15), and the time and effort they have to devote to care for their child with DS (n=12). Many of these reasons were already described in the responses to the other two open-ended questions. In particular, three mothers among those who had difficulties dealing with people’s prejudice believed that their difficulties resulted from the Korean social contexts associated with great admiration for physical attractiveness. They believed their child’s unique facial appearance attracted people’s attention and led to their prejudicial attitudes toward their child with DS. One mother shared her thoughts and experiences:

Because it is important to have an attractive appearance in Korean society, it is much harder to raise a child with DS whose appearances are unique compare to children with other disabilities such as autism... (subject 68).

Mothers reported that the increased time and effort they spent caring for their child with DS restricted their outside activities, as well as employment opportunities. Some of these mothers (n=3) noted that the increased time and effort they devoted to their child with DS also resulted in disadvantages to their typically developing children. They could not spend as much time with their typically developing children as they desired. Some mothers (n=5) were concerned about the child's future life regarding marriage and employment. In addition, there were mothers who noted that certain characteristics of their child with DS (e.g., stubbornness) made things more difficult. In particular, two mothers believed that their difficulties were associated with Korean culture (e.g., some people believe inappropriate prenatal care leads to the birth of a child with a disability, and thus those who endorse such idea tend to blame the mother of a disabled child) as well as negative attitudes toward individuals with disabilities. One mother wrote:

I guess it's a cultural issue. In my case, I had to deal with disadvantages from the family of my husband. My mother in law insisted that my child with DS needs to be inside whenever there is a guest. She thought all bad things were due to my fault. Even my husband didn't try to make her understand or advocate; instead, he blamed on me... (subject 61).

(2) Adaptation. In spite of ongoing challenges and difficulties, most mothers seemed to be well adapted to the life with their child with DS physically and psychologically. Five mothers disclosed that they accepted the fact that their child had DS and learned ways to deal with trivial conflicts in daily life. One mother said, "At first, it was hard to believe that my child has DS. As time goes by, I came to accept the fact and tried to find places to get my child educated (subject 33)." Another mother shared her adaptation process "I was scared and afraid in the beginning. However, as he grows, I have learned how to endure and realized there are other pleasures that my child can bring us (subject 19)."

(3) Appreciation. As noted previously, some mothers described the experience of parenting a child with DS as a positive experience. Responses of these mothers typically included words such as love, affection, pleasure, joy, and achievement. Words used to describe their child with DS include: charming, proud, pretty, cute, lovely, amazed, lucky, wondrous, and impressive. Six mothers noted that they now appreciate the fact that they have a child with DS instead of a child with other disabilities associated with more severe medical conditions. Many of the mothers (n=31) indicated they now appreciate trivial things such as small achievements and little progressions made by their child with DS. They also noted that these achievements and progressions result in unexpected joys. One mother noted:

We also have joys from our child's small progresses. This is more than what other children can give us. For example, I am so happy when my child speaks some words that other can easily do. This happiness is much greater than what I feel when my other children bring the best academic record (subject 105).

Many of these mothers (n=21) expressed love and happiness toward their child with DS describing the child as an angel. Others (n=3) shared the good aspects of raising their child with DS that they did not expect. These were often associated with the characteristics that children with DS usually possess (e.g., sense of humor, warm personality). In addition, four

mothers acknowledged personal growth (e.g., being mature, understanding unconditional love) and family harmony resulted from raising a child with DS. In that, they came to learn humility and ways to share things they have as well as unconditional love for their child with DS. One mother shared her thoughts about the contribution of their child with DS to the family as a whole:

My child with DS is the cutest child in my family. He does attractive behaviors and puts my family in a better mood. Whenever we come back home from work or school, we always look for him first. He is such a lovely child. If he weren't in my family, we couldn't have been together. He is the one who connects our family (subject 71).

Discussion

Maternal perceptions of how others in Korea respond to their child with DS suggest that negative responses are more common than positive responses. Societal responses were generally considered to be stigmatizing and inadequate. In particular, mothers noted there is a critical need for more educational resources for children with DS, as well as a need for these and other resources to be provided in a consistent, ongoing manner. In addition to the comments about the lack of educational resources, some mothers complained about the unfair distribution of the limited resources that did exist because eligibility for resources was typically based on family income and the level of their child's intellectual disability. Almost half of the mothers described not only a lack of understanding about DS and what life is like for children with DS, but also an attitude of indifference among people in Korean society. About one-fifth of these mothers noted that caring for a child with DS in Korea is considered a family matter, meaning that the family is responsible for all extra care-related needs. Because of these cultural and social contexts, Korean mothers were likely to experience difficulties with issues associated with caring for their child with DS. In addition, according to the responses at a community level, although some mothers experienced considerate attention and caring from their communities, the majority of mothers reported that they suffered from either unfriendly attention or indifference from people in their community.

The importance of providing good support and adequate services for parents of children with DS was stressed in the two studies Choi and her colleagues conducted with Korean parents of children with DS. In her initial study (Choi, Lee, & Yoo, 2011), parents who received more resources such as up-to-date information about DS and information regarding parents support groups at the time of diagnosis of DS tended to report more positive emotional responses. In her later study (Choi & Yoo, 2014), parents were more likely to well adapt to the life with a child with DS when they received high quality of community services. Some of the difficulties that Korean mothers experienced in this study were also found in the previous studies conducted with families in other countries. For example, maternal psychological well-being and family well-being was negatively associated with behavioral problems of the child with DS (Blacher & McIntyre, 2006; Povee, Roberts, Bourke, & Leonard, 2012), lack of social support for the child with DS and the family (Hsiao, 2014), increased time and effort devoted to the child with DS (Hedov et al., 2006), and social stigma on individuals with disabilities (Ngo, Shin, Nhan, & Yang, 2012). In addition, a qualitative study of Sari and her colleagues (2006) conducted with a small number of mothers in Turkey disclosed frequent encounters of negative social reactions from acquaintances such as friends and neighbors in the community as a stressor. Moreover, according to a study conducted in Hong Kong (Tait, Mundia, & Fung, 2014), parents of children with autism spectrum disorders reported restricted social life (e.g., fewer family outings) due to social stigma and public discrimination. In contrast, some

Korean mothers noted good experiences of raising the child with DS as well. They appreciated small achievements and little progressions of their child with DS. The warm characteristics of the child also brought unexpected joys to them. Some mothers also described positive contributions to themselves (e.g., patience, unconditional love) and their families (e.g., family harmony) made by their child with DS, and these were reported in the previous studies conducted with families of children with DS (Skotko, Levine, & Goldstein, 2011).

Cultural and social values can influence important family factors such as family appraisal and family resources (McCubbin et al., 1996). Collectively, studies conducted with families from various cultural backgrounds have highlighted the importance of considering cultural and social contexts in understanding the experience of families that include a child with DS (Choi & Yoo, 2014; Gau et al., 2008; Hsiao & Van Riper, 2011; Norizan & Shamsuddin, 2010; Sari et al., 2006). Likewise, the fact that mothers in the current study reported more negative encounters with others related to their child with DS suggests that although people in Korea have become more aware of DS and what life is like for children with DS, and that governmental policies and support for people with disabilities have been improved, more attention needs to be paid to the societal understanding of living with DS and also to the provision of resources and social supports. These efforts are critical because the adaptation of individual family members and the family as a unit can be greatly influenced by the resources and support (e.g., support groups, respite care, community resources) those living with a child with DS have available to help them cope with difficulties stemming from having a family member with DS (McCubbin et al., 1996; Choi & Yoo, 2014). In particular, some mothers in this study described that their difficulties resulted in part from the traditional cultural beliefs (i.e., blames from in-laws). Therefore, it is important for health care professionals particularly nurses to understand family members' experiences in the cultural and social contexts and to provide culturally appropriate interventions to those who might have difficulties living with a child with DS in Korean families.

This is one of the first studies to explore and describe maternal perceptions of cultural and social contexts of having a child with DS in Korean families as well as maternal experiences of raising a child with DS. Although findings from this study are limited to provide only preliminary understanding, these will be used as an important foundation for health care professionals to acknowledge and identify the needs and challenges that Korean families may have due to caring for a child with DS. Although findings from this study were based on qualitative data obtained from maternal responses to open-ended questions, it may provide more reliable understanding because of the anonymous nature of the surveys than other types of research methods such as in-person interviews. However, study limitations should be considered when interpreting the results. The major limitation of this study is that it only explored maternal perspectives and their experiences. To increase our knowledge and thorough understanding of having a child with DS in Korean families, a future study needs to include multiple perspectives (e.g., fathers, siblings) and their experiences using other qualitative approaches (e.g., in-depth face-to-face interviews). In addition, the sample drew primarily from two major metropolitan areas in Korea, so, it is possible that the characteristics of participants living in metropolitan areas where more resources and up-to-date information are available may be different from those of children with DS living in rural areas or small cities in Korea.

Conclusion

Korean mothers experienced both positive and negative aspects of raising a child with DS and they indicated several areas to which more careful attention needs to be paid (e.g., being aware of what life is like for children with DS and their families, providing support and resources for families of children with DS). Health care professionals, particularly nurses who

have more opportunities to work with families of children with DS can utilize the findings from this study to supplement their contextual understanding of having a child with DS in Korea and develop appropriate, effective interventions in various settings (e.g., hospitals, community health centers).

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