

**FAMILY QUALITY OF LIFE FROM THE PERSPECTIVES
OF INDIVIDUAL FAMILY MEMBERS:
A KOREAN-AMERICAN FAMILY AND DEAFNESS**

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Beginning in the mid-to-late 1980s, the focus on individual quality of life expanded to family quality of life (FQOL) in the field of intellectual disabilities. However, few studies examined FQOL for families who have children with hearing loss. Furthermore, most studies focused on mothers' perceptions of FQOL. The purpose of this study is to understand how different members of a family experience FQOL when there is a member with hearing loss and how those experiences contribute to aggregated FQOL perception as a family unit. Three Korean-American family members, including the father, mother, and individual with hearing loss, participated and presented diverse perceptions of their FQOL. Results indicated each family member described diverse perceptions in seven (58%) of the 12 indicators categorized in four of the five FQOL domains. Implications for future research were described.

In the developmental disabilities field, conceptualizing and measuring individual quality of life have made significant progress internationally (Cummins, 2001; Schalock, 2000). Because of the purposeful research effort to examine individual quality of life, Schalock and colleagues (2002) reported eight domains of quality of life for individuals with disabilities: Emotional Well-being, Interpersonal Relationships, Material Well-being, Personal Development, Physical Well-being, Self-determination, Social Inclusion, and Disability-related Rights. Beginning in the mid-to-late 1980s, the focus on individual quality of life expanded to family quality of life (FQOL), given the growing importance of a "family-centered service delivery model" in the disability field (Poston et al., 2003, p.313).

Conceptually, the basis of FQOL consists of three themes: the extent to which families' needs are met, family members' enjoying their lives together, and whether family members have opportunities to engage in activities they consider important (Park et al., 2003). The Beach Center Family Quality of Life Scale (Hoffman, Marquis, Poston, Summers, & Turnbull 2006) was validated through several national surveys or interviews of more than 1,500 family members of individuals with disabilities and professionals, resulting in a five-domain structure with 25 indicators. The domains include Family Interaction, Parenting, Emotional Well-being, Physical/Material Well-being, and Disability-Related Support. In addition, Brown and colleagues (2006) from three different countries (i.e., Canada, Australia, and Israel) structured the Family Quality of Life Survey, which included nine domains of FQOL: Health, Financial, Family Relations, Support from Other People, Support from Disability-related Services, Spiritual and Cultural Beliefs, Careers, Leisure, and Community/Civic Involvement.

Turnbull and colleagues (2007) synthesized research on investigating the extent to which FQOL research focused on internal family characteristics (e.g., family relationships) and external family support (e.g., support from organizations). In general, internal factors that influenced FQOL outcomes were "child behavior and family resources (e.g., income)"; external factors included "families' ratings of service adequacy" (Turnbull et al., 2007, p.351) and satisfaction levels of family-professional partnerships. In many studies, families report least satisfaction with external Support from Other People and/or Support from Disability-related Services, as contrasted to internal family characteristics such as family relationships (Brown, 2008; Brown, Ananda, Fung, Isaacs, & Baum 2003; Brown et al., 2006; Turnbull, Summers, Lee, & Kyzar, 2007; Werner, Edwards, & Baum, 2009). For instance, Brown and colleagues collected FQOL data from 470 people in eight countries (i.e., Australia, Belgium, Canada, Israel, Japan, Nigeria, Slovenia, and United States) by using the Family Quality of Life Survey (Brown, 2008). Results indicated that family respondents had the lowest scores for attainment and satisfaction in the domain of Support from Other People and Disability-related Services scored while they

scored highest in Family Relationships.

One shortcoming of FQOL research is that it focuses largely on families who have members with intellectual disabilities. The majority of studies has focused on families of individuals with intellectual disabilities and has excluded other vulnerable populations (Turnbull et al., 2007; Zuna, Turnbull, & Summers, 2009). For example, there has been limited attention to FQOL for families of individuals with hearing impairment concerning their FQOL, although these families may experience various unique challenges due to the hearing loss. Such challenges may include being aware of the impact of hearing loss, choosing communication options for the child, learning how to communicate effectively with the child, and dealing with emotional and practical difficulties in raising a child with hearing loss (Luckner & Velaski, 2004). Families also need to find appropriate services and supports for the child, which may result in professionals (e.g., audiologists, speech therapists, early intervention coordinators, and educators of the deaf) entering the family's life. Jackson and Turnbull (2004) synthesized published studies on perspectives of families of children with hearing loss. The authors used a four-domain structure (i.e., Family Interaction, Parenting, Resources, and Support for the Members with a Disability) of an earlier version of the Beach Center Family of Life Scale (Park et al., 2003) as a framework for reviewing literature on the impact of deafness on FQOL. Results indicated that deafness had an impact on all four domains and that the degree/type of FQOL impact varied depending on "severity of hearing loss, a family's ethnicity, the hearing status of parents, the education of parents, the mode of communication used, the proficiency of partners in child's communication mode, and family's access to social supports and parenting models" (Jackson & Turnbull, 2004, p.27). There were also certain types of support that benefited families, including "social support, parenting models, and access to information and training" (Jackson & Turnbull, 2004, p.27).

Another shortcoming within research on FQOL to date has been the tendency to use only mothers and, in very few cases, fathers as sole respondents (Poston et al., 2003) with a major void being the exclusion of the perspective of the individual with a disability. Turnbull et al. (2007) noted that more than half the family research studies in the intellectual disability field for the past 10 years focus on mothers only. About research focusing on families of members who are deaf and hard of hearing, Turnbull and Jackson (2004) indicated that the respondents in all of their reviewed studies were mothers only. When considering the goal of family research, "...it is important to move beyond the study of the perceptions of individual members, especially mothers, to address the family as a unit of focus and to study the aggregation of family members' responses, in addition to the extent to which family members are similar or different in their perceptions of family variables" (Turnbull et al., 2007, p.352).

Given the dearth of studies focusing on the impact of deafness on FQOL and reporting family members' diverse perceptions of their FQOL, the purpose of this study was to understand how different members of a family experience FQOL when there is a member with hearing loss and how those experiences contribute to the aggregated FQOL perception as a family unit. Specifically, the two research questions related to family members' perceptions were: (a) When an individual with hearing loss is a member of the family, how do different family members perceive their FQOL?; and (b) How do family member's diverse viewpoints and experiences contribute to an aggregated family perception of their FQOL?

Method

We used qualitative methods to investigate family members' perceptions individually and collectively in relation to the impact of a family member with hearing loss on their FQOL. Qualitative methodology focuses on participants' perspectives concerning current phenomenon and describes them in descriptive and inductive ways (Mertens & McLaughlin, 2004; Rubin & Rubin, 2005).

Participants

A Korean master's student who conducted an earlier survey with several Korean-American families introduced us to a family who was interested in the interview. Of the four family members, the father (Kim), the mother (Park), and the second son with hearing loss (Kun) agreed to participate in the study. However, the first son, who is also a hard of hearing individual, expressed unwillingness to participate. Therefore, only three family members participated in the interview. Table 1 summarized the demographic information of each participant.

All of the family members are over 18-years old; the parents are first-generation hearing Korean-American parents. A first-generation Korean-American refers to "being born in Korea, speaking Korean as a first language, and self-identification as Korean" (Cho & Cannotti, 2005, p. 3). Kim and Park are in their early 60s or middle 50s and their English proficiency is intermediate. They reside in the state of California. Park manages a family-owned restaurant and Kim works as a real estate agent. They state that their economic status is moderately high and that they are well acculturated in the United States, largely because of interactions with

their American customers. Kun, age 26, has profound hearing loss and uses hearing aids. He uses total communication (American Sign Language [ASL] and oral English), with ASL his dominant communication mode. Kun resides in a college dormitory in the state of New York. Kun has received special education and related services in U.S. public education settings since moving to America at the age of 11. Shortly after he entered public school in U.S., he commuted to a school for the deaf based on the recommendation of his IEP team members.

Table 1. Demographic Information of Participants

Interviewee	Age	Marital status	Highest degree earned	Occupation
Kim (Father)	61	Married	Master's degree	Self-owned business
Park (Mother)	55	Married	Bachelor's degree	Self-owned business
Kun (Son)	26	Single	Associate degree	Freelance technician

Interview Protocol

We used three sources for developing an interview protocol. The first was the five-domain structure (i.e., Family Interaction, Parenting, Emotional Well-being, Physical/Material Well-being, and Disability-related Support) of the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) as the primary framework for developing an interview protocol and at a later point for data analysis. We also used a review of literature of the FQOL of families who raise children with hearing loss (Jackson & Turnbull, 2004). The third source was discussions with professionals in the area of disabilities and qualitative research methodology to develop a 10-question interview protocol (see Table 2). In some cases, we modified questions depending on the participant's role. For instance, we asked Kim and Park, "How familiar are you with Kun's life, such as schoolwork, activities, friends, and teachers?" and we asked Kun, "How familiar are your parents with your life, such as schoolwork, activities, friends, and teachers?" In addition to the 10 questions, we included additional probes to obtain more specific and in-depth perspectives.

Data Collection

The first author, a native Korean who speaks English as well, served as the interviewer for this study. She interviewed the parents by telephone because of the geographical distance from the Midwest to the West coast of the United States. Internet messenger was the tool the first author used for interviewing Kun because of his inability to communicate over the phone. She scheduled the interviews at the participants' convenience; each interview took approximately 1-1½ hours. She conducted the interviews in the Korean language with each of the parents and in English with Kun, according to each participant's preference of language use and audio-taped and transcribed for later analysis. When interviewing Kun, the first author used written communication through internet messenger, then copied and saved the transcript as a Microsoft Word document.

Data Analysis

Given the conceptual soundness of the five domains of the Beach Center Family Quality of Life Scale (Hoffman et al., 2006), we used this established framework for data analysis. Within the framework of the five domains, we conducted coding and analysis inductively by using an interpretive approach (Maxwell, 2005) and by constructing the meaning of participants' stories (Merriam, 2002). As a result, several indicators emerged within each of the five domains.

After interviewing each of the three participants, the first author transcribed the audio-taped interviews with each of the parents in Korean because, as noted earlier, the interviews with the parents were conducted in Korean. Then, she translated the interviews in Korean into English for data analysis. The record of written communication with Kun served as transcribed interview in English. Consequently, three transcribed interview data in English were obtained from each of the three participants. In order to confirm the accuracy of translation from Korean to English of the transcribed interview data, a Korean doctoral student in the field of special education read both the Korean and English transcription. The first author and the Korean doctoral student agreed that every translation was accurate.

Table 2. Interview Protocol

Domain	Questions
Family Interaction	What does it mean to have a child with hearing loss? (What does it mean to be an individual with hearing loss?) How does having a child with hearing loss affect your family communication? How have your family time and relationship changed because of Kun's (your) hearing loss?
Parenting	How is raising Kun different from or similar to raising a child without hearing loss? (How have your parents raised you similarly or differently due to your hearing loss?) How familiar are you with Kun's life, such as schoolwork, activities, friends, teachers, etc.? (How familiar are your parents with your life, such as schoolwork, activities, friends, teachers, etc?)
Emotional Well-being	Tell me about your family's experience of stress or frustration because of Kun's (your) hearing loss. What kinds of help can you count on for relieving your stress?
Physical/Material Well-being	How have the financial needs of your family affected the ability to provide special equipment?
Disability-Related Support	What supports and services have you received and to what extent have you been satisfied with the supports and services as well as the service providers? What supports and services have you needed?

The first and second author independently summarized all the English transcriptions, including the written communication with Kun, using matrices for the purpose of comparison across the interviews. According to Maxwell (2005), a matrix is a useful tool for data analysis as well as for ongoing monitoring of selecting and collecting data. As authors, we repeatedly checked and modified our summaries to ensure that the summaries aligned with the actual English description of the interviews. After we reached the consensus of summaries, we worked on sorting the summarized data into several indicators under the five-domain framework. Although the interview protocol was a product of systematic development from the five domains, which led to the clear classification of participant stories into the same domains, several indicators emerged within each domain. To validate indicators related to each of the five domains, each of the authors independently sorted the summarized data into several indicators within each domain and then discussed each others' indicators until we achieved an agreement of 12 indicators across the five domains.

The triangulation occurred between the first author and the Korean doctoral student in terms of translating the Korean transcription into English. Likewise, the triangulation occurred between the first author and the second author related to the alignment of the summaries with the interview descriptions and the identification of the indicators. In addition, the triangulation occurred with the member check because the first author did a member check with each of the participants sharing the results of this study to increase the validity and credibility of the collected data.

Results

The findings focus on the five domains of the Beach Center Family Quality of Life Scale (Hoffman et al., 2006) and the indicators that emerged from content analysis of participant responses to the interview. Together, the five domains included 12 indicators (see Figure 1)

Family Interaction

Family interaction refers to a family's ability to have open conversations with each other, to solve problems cooperatively, to enjoy their time together, and to have meaningful relationships with extended family members (Summers et al., 2005). Extended family refers to "members of the nuclear family, relatives, and others who are regarded as relatives" (Turnbull, Turnbull, Erwin, & Soodak, 2006, p. 40). Supports and accommodations for all family members, including a member with a disability, are necessary to enhance quality of family members' relationships with one another and to strengthen their affection and commitment (Turnbull, Turnbull, Summers, & Poston, 2008). The three indicators that emerged from the interviews in the Family Interaction domain were (a) communication, (b) family time together, and (c) relationships with extended family.

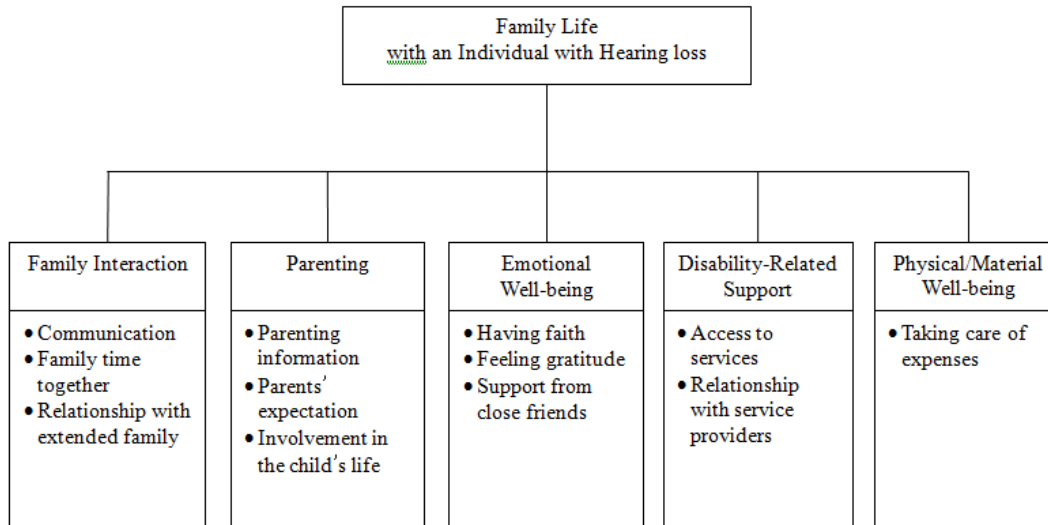


Figure 1. Five Domains and 12 Indicators.

Communication.

Choosing and developing strategies to communicate with the individuals with hearing loss was the biggest challenge for this family. Kim and Park expressed their shock, disbelief, and devastation when they were informed of their sons' hearing loss because they understood little about what it was like to have a child with hearing loss. Park stated that hearing loss and communication presented ongoing learning challenges for the family:

I believe that hearing loss rarely means incapability, but inconvenience. In reality, however, I am still learning what hearing loss is like and how to better communicate with my sons.

Kim expressed his concern about his sons' future life in the dominantly hearing society even though he continuously encouraged his sons to keep learning and be confident. In particular, Kim focused on being patient in communicating with his children. He reflected on a day in the past:

One day, I wanted to talk with Kun and found he did not have his hearing aids on him. He seemed not to understand me fully, and I felt a sense of frustration in him. I repeated what I said patiently and we both were happy with our communication.

For Kun, hearing loss meant exclusion from hearing society because of the communication barrier. He decided to accept it and to find helpful accommodations:

At first, it bothered me because I'd be "left out" from the hearing society. But... eventually I learned to accept it and found a way to accommodate my hearing loss such as using interpreters... using paper and pen... I'll be always left out when watching TV shows without captions, and having to wait till there's an open captioned movie available, but hey, life isn't always fair. So, I've decided to deal with it.

Kun believed that it is more important for parents to understand and love their family members with a hearing loss, as contrasted to parents always being able to communicate.

I strongly advice to interact with them as much as possible. Yes, the communication barrier is there, but the biological bond is still there. Make memories with the family and let the children know they have loving parents and they are loved very much. I was fortunate to have my parents do that for me, and I hope the same for other children as well.

Each family member considered both the hearing and hard of hearing needs of other family members when deciding on a communication mode. As a result, Kim and Park learned sign language to the best of their ability, and Kun and his brother worked hard on the spoken language. However, it turned out Kim and Park mostly used the spoken Korean language with Kun and written Korean language with their older son rather than using sign language. While both parents believed that they usually communicated openly with their sons, Kun expressed his difficulty in openly communicating with his parents because of different communication tools:

I understand my parents' use of spoken Korean language because my family is a strong hearing-based family. However, I had to work hard on communicating with my parents and often did not understand them. My brother often gave up talking with my parents because his understanding and speaking of the Korean language is even less clear than it is for me. I think all these restricted our open communication.

On the other hand, Park believed that the family members' characteristics affected open communication:

I am concerned about my first son who is very shy, unlike Kun. When he wants to speak with me, most often times, he used Kun as his interpreter. When Kun did not want to do it, he changed his mind and did not say it. It's harder to openly communicate with him.

Kim, who was hardly able to spend time with the rest of the family members due to his business, stated that lack of time affected their family communication.

I am very busy with my business. I work hard to make a living for my family. I am sorry that I cannot have more time with my family members. If we had more time to be together, our communication would be more open.

Regardless of diverse perceptions of hearing loss and communication, all the participants agreed that they desired to engage in more communication with each other and to do so as often as possible.

Family time together.

The nature of spending family time together within the participant family was similar to that of hearing families. They tried to have family time together as much as possible. They went on trips, took part in church activities, went shopping, ate at restaurants, worked at the family-owned restaurant, and talked about their dreams and school lives. Kim and Kun reported that the challenge in having time together was not because of their Kun's hearing loss, but because of the Kim's insufficient time to be with his family. Kim stated the following:

Since we moved to America, I have had to work hard all day long for a living. In addition, I like to be involved in various activities, including the Korean immigrants' organization, Korean church, and other social groups, even though my family is also important. I try to have more time with my family.

Kun agreed that his father was too busy to be with his family:

While I do not mind dad being so busy, it would be nice to be home more often and have more family time. Sooner or later, I'll be living my own life, so time for all family to stay together is running out... not that I am complaining though.

Park also pointed out the lack family time. She has been more involved in the family-owned restaurant since Kun has become an adult, which has resulted in less family time together. Although all of the family members had a desire to have enough family time together, the parents' long work hours kept their lives busy.

Relationship with extended family.

The family moved to America in 1994 and their extended family resides in Korea. Despite the geographical distance, the family shared their life with their extended family. Park addressed that she often talked with her parents and sister in Korea to share their lives together:

My parents and sister are very important to me. They encourage me and support me all the time. I doubt if I could endure all the difficult times without their help.

Kim emphasized the importance of their extended family and stated that he used a video phone when the family talked with his parents and other extended family members:

I want my sons to think of their extended family in Korea. A video phone is very helpful because my sons can see the faces. We use all the possible tools to communicate with the extended family. They include emails, text messages, TTY (teletypewriter), and letters. I think my sons enjoy talking with the extended family in Korea.

Kun, however, stated that he had only a little interaction with their extended family in Korea:

It is hard to talk with them because they don't know sign language. I just smile at the video camera. It's awkward, you know. Furthermore, I don't remember much about my grandparents, uncles, aunts, or cousins because I left Korea when I was little.

The relationship with their extended family was very important for both parents, while Kun put little emphasis on it.

Parenting

The three indicators identified within the Parenting domain were (a) parenting information, (b) parents' expectation, and (c) involvement in the child's life.

Parenting information.

Kim and Park reported that they experienced an increased demand on their time in looking for parenting information for their sons with hearing loss. They had to find an appropriate communication option for each of their sons. In addition, they spent a lot of time on finding a good education program for their sons. Other families who have raised children with hearing loss and an organization for Asian deaf people in southern California served as the most valuable agents in providing parenting information on topics such as education, social activities, and careers. Kim and Park also experienced comfort in getting information from others who had firsthand experience related to hearing loss. Furthermore, they learned how to raise their sons through their own experiences. Park stated her difficulty in parenting:

It would be different if I had hearing children. However, I had to learn how to raise my children with hearing loss. I reached some Korean-American parents who also raised children with hearing loss. I first felt comfort from them. They listened to me and understood me. They suggested deaf schools and sign books. However, I hardly got precise information about communication options because they chose different communication methods according to each of their children's hearing status and their own perceptions about hearing loss. There were so many things that we had to find out for ourselves.

Kim added his difficulty in being knowledgeable about the ways his sons learned best:

It is important not to cover your mouth when talking with people with hearing loss. Also, what matters is clearness in addition to an appropriate volume. There are a lot of small things that hearing people take for granted, but actually are difficult for people with hearing loss.

Kun, in contrast, believed the way that Kim and Park parented was rarely different from parents of hearing children except for the communication matter. Furthermore, he stated that his hearing loss created a physical proximity between his parents and himself:

I don't think parenting has changed. Well, the way of communicating would have been different. I mean, my parents wouldn't need to blink the light, or come in my room just to talk. They would just shout my name, and I would be able to respond. I think the physical contact would have been reduced... maybe it was a good thing that my older brother and I were deaf because that required them to make physical contacts with us like coming into our room, having to look at us when they talk (that way we can lip read) and be able to see them while in communicating... it's like subtle way of say, 'we are still here for you,' I guess.

Parents' expectation.

In spite of their difficulty in raising their sons with hearing loss, Kim and Park always encouraged the sons and expressed their high expectation for Kun and his brother. Kun reflected on his parents' teaching throughout his life:

My parents taught me that my hearing loss is just a handicap... and that a handicap shouldn't stop me from anything. They were religious, of course. Most of their teachings were religion-related, and at the same time, taught me to rely more on God... because of my inability to hear... They repeatedly said to me, "Whose son are you? You're my son! I believe in you!" It's a typical Korean saying, which is like saying you can do it.

Kim emphasized having high expectations for the child:

I allow my children to be exposed to both hearing and deaf worlds and meet diverse people. I believe that they can find their strengths and become positive. I am proud of my sons. They are just precious to me. I trust them.

Park focused on teaching her sons polite versus impolite social behaviors. She also tried to be positive and to not to give up, saying, "The child already has the power to overcome his difficulties." Based on his learning from parents, Kun added his opinions on parenting with high expectations:

Having a deaf child is like... a child with a gifted mind... Show your child that you're there for him, love the child, get to know the child, have high expectations, show interest in his hobbies, and be a typical, loving parent to your child.

Involvement in the child's life.

The participants differed in their understanding about Kun's life including schoolwork, activities, friends, and teachers. They agreed that they all understood the particulars of Kun's schoolwork and the activities in which he participated. Interestingly enough, both parents indicated that Kun had difficulty making friends with ease, whereas Kun stated that he could make friends without difficulty. Kun had both hearing and hard-of-hearing friends, although he felt more comfortable with his deaf and hard-of-hearing friends since they could understand each other better given their similar situation. When interacting with his hearing friends, Kun used text messaging, chat rooms, and some spoken language. Concerning Kun's teachers, Park interacted with them only a few times because of difficulty in communication and difference of culture:

In Korean culture, we rely on teachers about our child's educational decision rather than asserting parents' thinking or ideas. In addition, English was another barrier to interact with the teachers. So, I let Kun interact with teachers most of the time.

Likewise, Kim had little information about or interaction with Kun's teachers because of his busy work schedule. Mostly, Kun interacted with teachers and informed his parents about their conversations, mainly his mother.

Emotional Well-being

Emotional well-being involves having support to relieve stress, to take care of special needs, to spend time with friends, and time to receive care-giving (Jackson, Wegner, & Turnbull, 2010). Park expressed extreme stress from increased efforts and time demands due to her sons' hearing loss. Likewise, Kim stated that he often experienced stress because of his sons' hearing loss. Kim and Park both described a sense of isolation as a source of stress. In contrast, Kun believed the biggest stressors for the family are cultural barriers and the generation gap. The participants shared their ways of achieving emotional well-being within the Emotional Well-being domains: (a) having faith, (b) feeling gratitude, and (c) support from close friends.

Having faith.

Kim and Park stated that they relieved their stress and frustration with raising their sons with hearing loss through faith in God and their prayers. Park stated that she experienced shock when she recognized her sons' hearing loss:

It was a shock when I recognized both my sons had hearing loss. I never saw any deaf people through my entire life, you know. I cried and prayed to God. He listened to me and gave me peace. Whenever life is tough and whenever I feel alone because of my sons' hearing loss, I pray and pray. God is always there to help me.

Kim stated that the family experienced social stigmatization and isolation from others. He shared his experiences of feeling isolated from society:

I think that society lacks understanding about deaf culture and people with hearing loss. As a family unit, we were not able to attend many social activities and events because of my sons' difficulty of communication with others. Also, we had few shared interests with hearing families or society. In heaven, however, we will be all alike. There will not be any isolation in God's world. That encourages me a lot. God has provided me with comfort and I believe that He takes care of my sons no matter when they need help. I encourage a family to have a faith and stick to it.

Both Kim and Park described their deep faith in God as a way of overcoming their stressors. Kun, however, rarely addressed his faith in God as a way of overcoming his stressors. Instead, he emphasized the importance of being grateful for his parents whenever he experienced stress as described in the following section.

Feeling gratitude.

While Kim and Park considered their sons' hearing loss as a major source of stress and frustration, Kun believed that the biggest stresses for their family were cultural barriers and the generation gap. For instance, Kun is more individualistic while Kim and Park maintained the collective perception of emphasizing "we" rather than "I". Kun also addressed that Kim and Park often sacrificed some enjoyable moments of life and kept working to earn and save more money for the future. For Kun, however, enjoying current life is as important as earning money. Kun stated that whenever he experienced stress, he kept reminding himself of the value of his family as his biggest supporter:

When I was little, I thought my father did not care for my family and only focused on his work. I now know how hard my parents have worked for my family, especially for my brother and me. They moved to America looking for a better environment for my brother and me. In addition, I am able to have all the things that I want to have including my own car thanks to my parents' sacrifice.

For Kun, thinking of and being thankful for his parents' sacrifice empowered his emotional well-being when he experienced stress because of the generation gap or cultural differences.

Support from close friends.

Another way that the family overcame their stressors and achieved emotional well-being was through having support from close friends. Kim and Park interacted as much as possible with other families who also had children with hearing loss for the purpose of sharing information as well as encouraging each other. In addition, Kim and Park each had his or her group of friends with whom they spent time and experienced stress reduction. Kim emphasized the importance of having close friends:

For me, having families who have similar situations as friends was a good way to overcome the stress from my children's hearing loss. I think that having other families as friends would contribute not only to the child's emotional well-being, but to that of the family as a unit. Also, I have a group of close friends who I can meet occasionally. We encourage each others' lives and keep our friendship.

Park also shared her positive experience with mothers who have children with hearing loss:

We understand each other even without a word. We cry together, and we laugh together. We encourage each other all the time. We are just like a family.

Kun shared his experience of achieving emotional well-being through a group of hard-of-hearing friends, including his brother.

We are all hard-of-hearing. We don't even think about our hearing loss. We chat and laugh just like hearing people do with their close friends. In particular, Korean-American hard-of-hearing friends understand how I feel differently from my parents in terms of cultural differences or generation gap. We similarly get through such challenges by encouraging each other to appreciate our parents' sacrifice and love.

Disability-Related Support

Disability-related support refers to support families receive from the formal service system and to their relationship with service providers (Jackson et al. 2010). Two indicators including (a) access to services and (b) relationship with service providers emerged from the Disability-Related Support domain.

Access to services.

As an adult with a disability, Kun has received vocational rehabilitation support from the federal government. U. S. federal government agencies implemented the Rehabilitation Act of 1973 to prohibit discrimination based on disability. The law's programs include financial assistance, federal employment, and employment practices of federal contractors. Kun received financial support to achieve his career goal:

I want to be an English teacher for the deaf. In order to become a teacher, I need a college education. That's where vocational rehabilitation comes in the picture... they support me financially by paying 50% of my college bills. RIT's (Kun's school, *Rochester Institute of Technology*) bill is about... almost \$6500 per quarter, but my dad pays only \$3200 in addition to dormitory and food expenses.

In addition, Kim stated that vocational rehabilitation support would assist Kun in finding jobs and paying for hearing aids if the request was reasonable. Kun and Park emphasized that people with disabilities must meet specific criteria to receive vocational rehabilitation. For example, Kun was required to maintain good grades in school and choose a more realistic and practical career goal such as becoming an English teacher for the deaf. He received Social Security Disability Income as a financial support. Social Security Disability Income provides a federal allowance of \$500 a month each for Kun and his brother.

Relationship with service providers.

Park reflected upon early experiences with Kun and his brother regarding experiences with service providers. She and their teachers identified needed support for her sons through the Individualized Educational Program (IEP) meetings:

I rarely met teachers because of my difficulty in understanding English. In the IEP meetings, however, teachers were supportive to provide appropriate services for my sons. Both of my sons had difficulty in acquiring ASL (American Sign Language) and they received additional training. In addition, Kun received intensive speech therapy, which resulted in his fairly good pronunciation. Teachers provided specific information about diverse communication methods for children with hearing loss. They emphasized the importance of communication methods because those methods would be critically related to later educational methods (schools for the deaf or public schools). They also informed me

about the most recent policies and laws in relation to supporting children with disabilities.

Park became knowledgeable about disability-related support because she received information from service providers, although Kun mostly delivered the service providers' messages. Kun agreed that he had good relationships with service providers, and was satisfied with their services. Kun explained his relationship with his teachers and other service providers:

For me, it is easier to have a better relationship with people who are able to sign. However, it does not mean that I have a bad relationship with people who cannot sign. For instance, my vocational rehabilitation supporter, who cannot sign, and my family, have a mix of a personal and professional relationship from working together for several years. I appreciate all of the service providers' support and am satisfied with them.

Kim, however, was uncertain about his relationship with service providers for Kun. In fact, he rarely interacted with teachers and service providers because of his busy work schedule.

I don't know much about Kun's teachers. Because I am very busy, it is hard to have a good relationship with school teachers and service providers. I wished I could have attended my sons' IEP meetings and built positive partnerships with the teachers and service providers.

Physical/Material Well-being

Physical/material well-being is met when a family is able to pay for basic necessities, health care, and other needs, as well as feel safe at home, work, school, and in their neighborhood (Summers et al., 2005; Poston et al., 2003). In particular, based on the fact that health care is critical for the family's welfare and satisfaction, the capability to access and benefit from appropriate medical services could be a significant factor in the family's physical/material well-being (Jackson & Turnbull, 2004). Based on the data collected, Kun's family rarely had difficulty in relation to physical/material well-being although they all agree that the disability-related expenses have been very high.

Taking care of expenses.

Similar to most disabilities, hearing loss is expensive. Costs include gaining access to medical services as well as the purchasing of technology equipment such as hearing aids. Kun did not recall his family being financially troubled:

My brother and I have received sufficient medical care and speech therapy. My parents paid for replacing four sets of my hearing aids and a similar number of hearing aids for my brother. I know it cost tremendously. However, my parents have not complained about the expensive hearing devices so far. Sometimes I wonder if my parents would have been rich if my brother and I were not deaf.

Kim and Park stated that they worked very hard to meet all of the expenses for their sons because the disability-related expenses have been so high. They increased their working hours to earn more money and often sacrificed their family time together. Because of their hard work, they did not experience strain due to family finances. Nonetheless, as described earlier, all participants agreed that the financial support from the vocational rehabilitation program, as well as Social Security income for Kun as an individual with a disability, was helpful when he became 18 years old.

Discussion

The purpose of this study was to understand how different members of a family experience family quality of life when there is a member with hearing loss and how those experiences contribute to the aggregated family quality of life perception as a family unit. These were the two research questions: How do different family members perceive their FQOL when an individual with hearing loss is a family member? How do family members' diverse viewpoints and experiences contribute to aggregated family perception of their FQOL?

Diverse Perceptions of FQOL Among Family Members

Kun's family described diverse perceptions of their FQOL indicating disagreement or agreement in all five domains and 12 indicators. In the domain of Family Interaction, the family members addressed their various perceptions about communication and their relationship with extended family. Kun's family agreed with the existence of communication barriers and challenges in their family supporting previous research studies (Jackson & Turnbull, 2004; Luckner & Velaski, 2004). In addition, Kim believed that lack of time affected their family communication, while Park identified her sons' shyness as a factor limiting family communication. Nonetheless, both parents believed they communicated openly with their sons. Kun, however, expressed his difficulty in communicating openly with his parents because of different communication modes. Concerning the extended family, both Kim and Park emphasized the importance of interaction with their extended family. In

contrast, Kun put little emphasis on his extended family. The family, however, described similar perceptions on their family time together. The parents' long work hours limited their family time.

The family also indicated diverse perceptions in the Parenting domain. Both Kim and Park spent much time searching for information on communication options and educational programs for their sons. As research has indicated (Luckner & Velaski, 2004), these parents were uncertain about how to interact with their sons with hearing loss. Other parents of children with hearing loss, an organization for the deaf, and the parents' own experiences, were sources of important parenting information. Kun, however, believed Kim's and Park's parenting was rarely different from what other parents of hearing children did, with the exception of their communication mode. While Kim and Park addressed their difficulty in finding and applying parenting information, Kun, from his personal experience growing up, thought a positive aspect of parenting children with hearing loss was having physical proximity for parents and children to better see each others' signs or gestures. In respect to involvement in their son's life, both Kim and Park lacked involvement and understanding for different reasons. Kim rarely interacted with Kun's school teachers because of insufficient time due to work demands, while Park reported she could not interact effectively with Kun's teachers because of language and cultural issues. For instance, Park rarely interacted with Kun's teachers in Korean culture settings because she followed teachers' decisions in terms of Kun's education rather than asserting her own opinions. Kim and Park agreed that Kun had difficulty making friends because of his hearing difficulty. Kun, however, stated that he easily made both hearing and hard-of-hearing friends. All three participants agreed that Kim and Park had high expectations.

With regard to Emotional Well-being, the participants indicated different stressors that affected their emotional well-being. While the hearing loss of their sons and isolation from the hearing society were major reasons for the parents' stress, Kun's biggest stressors were cultural differences and the generation gap. For instance, Kun had individualistic perceptions while Kim and Park had collective perceptions focusing more on "we" than on "I". Kun also identified the value of enjoying current life while Kim and Park sacrificed enjoyable moments of their current life to earn more money for a better future. Both Kim and Park relied on their faith in God to relieve their frustration. By contrast, Kun rarely mentioned religious faith as a way of overcoming his stressors. Rather, he had appreciation of his parents for their love and sacrifice when he experienced stress. All three participants agreed that each of their close friends helped them to release their stress. In particular, Kun included his brother as one of his close friends who provided emotional support.

In the domain of Disability-Related Support, the family shared similar perceptions on access to services while indicating diverse perceptions on relationships with service providers. They agreed that they could easily access services including vocational rehabilitation support and Social Security Disability Income. Kim's perceptions of the relationship with service providers were different from those of Park and Kun. While both Park and Kun experienced a positive relationship with service providers, Kim had no relationship with them because he had few chances to interact with them.

All three participants indicated agreement in the domain of Physical/Material Well-being. Although disability-related expenses were high, Kun's family did not experience financial difficulty; rather, they increased their work hours in order to earn more money. They also agreed that Kun's governmental financial support was very helpful.

In summary, each family member described diverse perceptions in seven (58%) of 12 indicators categorized in four of the five domains (i.e., Family Interaction, Parenting, Emotional Well-being, Disability-Related Support). Specifically, each participant described disagreement on communication, relationships with extended family, parenting information, involvement in the child's life, ways of overcoming different stressors (e.g., having faith, feeling gratitude), and relationships with service providers. By contrast, family members expressed agreement on family time together, parents' expectation, support from close friends, access to services, and taking care of expenses. In general, discrepancy between parents and child was more likely than between mother and father. In other words, Kim and Park indicated diverse perceptions on their FQOL mainly in the three (25%) indicators (i.e., communication, involvement in the child's life, and relationship with service providers), while Kun described perceptions different from those of his parents on the above seven (58%) indicators.

Aggregated Family Perceptions on FQOL

This study indicates that different family members perceive their FQOL differently in many areas of their lives. Therefore, examining an aggregated understanding of family perceptions on FQOL becomes important. For instance, disability-related communication barriers did not constitute this family's sole challenge. Instead, communication barriers, lack of time to communicate, and family members' characteristics combined to affect

their FQOL in relation to the communication issue. In the Parenting domain, difficulty gaining parenting information on disability-related communication and education programs for the sons, which was a challenge, interacted with a positive aspect of parenting children with hearing loss (e.g., physical proximity) to influence this family's FQOL. Thus, aggregation of family perspectives must take into account disagreements and agreements that exist within individual family members, and within the family in a collective sense, as identified in Table 3.

Table 3. Indicators of Disagreements and Agreements Among Participants

Domain	Disagreements	Agreements
Family Interaction	<ul style="list-style-type: none"> • Communication • Relationship with extended family 	<ul style="list-style-type: none"> • Family time together
Parenting	<ul style="list-style-type: none"> • Parenting information • Involvement in the child's life 	<ul style="list-style-type: none"> • Parents' expectation
Emotional Well-being	<ul style="list-style-type: none"> • Having faith • Feeling gratitude 	<ul style="list-style-type: none"> • Support from close friends
Disability-Related Support	<ul style="list-style-type: none"> • Relationship with service providers 	<ul style="list-style-type: none"> • Access to services
Physical/Material Well-being		<ul style="list-style-type: none"> • Taking care of expenses

Limitations

One limitation of this study is the absence of Kun's brother as a participant. Including Kun's brother could provide a comprehensive view of this family. Another limitation is conducting interviews with telephone and internet messenger means. Both methods limited observation of interviewees' nonverbal behaviors such as facial expressions and gestures, which could have provided richer information.

Implications for Research

Several implications for future research emerged from this study. First, more research that investigates each family member's perceptions on FQOL when they have a member with hearing loss is needed to better understand a full family perspective. As previous research indicated, mothers have tended to be the sole responders of their FQOL. This exclusively maternal perspective has limited full understanding of FQOL from the perspective of all members, including siblings and extended family members (Poston et al., 2003). Second, research needs to compare and contrast different methods of aggregating FQOL ratings from multiple family members. This is an important next step to effectively measure, interpret, and support FQOL of each family as a unit.

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