

# Cross-cultural perspectives on the meaning of family quality of life: Comparing Korean immigrant families and Canadian families of children with autism spectrum disorder

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## Abstract

This study sought to examine and compare conceptualizations and descriptions of family quality of life, from the perspectives of Korean immigrant and Canadian families of children with autism spectrum disorder. Thematic analysis of semi-structured interviews from 13 Korean immigrant parents and 12 Canadian parents of children with autism living in BC, Canada was conducted. For Korean immigrant families, three themes were identified: family cohesiveness, value orientation, and acceptance from society. For Canadian families, themes comprising family interactions, support, emotional well-being, individual characteristics, and comparisons to other families were essential elements in defining their family quality of life. Findings highlight how cultural values and differences may translate into different conceptualizations of family quality of life and underscore the need for cross-cultural and diverse perspectives in the study and development of future assessment tools.

## Lay abstract

The purpose of this study was to compare Korean immigrant families and Canadian families of children with autism in their perceptions and definitions of family quality of life. Interviews were done with 13 Korean immigrant parents and 12 Canadian parents of children with autism living in BC, Canada. For Korean immigrant families, three themes were identified: family cohesiveness, value orientation, and acceptance from society. For Canadian families, themes comprising family interactions, support, emotional well-being, individual characteristics, and comparisons to other families were essential elements in defining their family quality of life. The findings emphasize how differences in culture may impact how we understand and assess family functioning and quality of life. If research informing the development of these tools lacks cross-cultural perspectives, service providers and professionals may fail to address these families' unique needs.

## Keywords

autism spectrum disorder, cross-cultural, family quality of life, qualitative research

In recent years, there has been a shift within disability research from considering the quality of life of the individual to that of the family system. This progression was marked by advancements in family-centered care and the acknowledgment that families play a crucial role in the well-being of the child with disability (Gardiner & Iarocci, 2012). As a result, the construct of family quality of life (FQOL) has evolved and expanded to reflect the presence of both risk and resilience factors influencing outcomes for families of children with a disability. While there are various definitions for FQOL, one of the most widely accepted describes it as “conditions where the family’s needs are

met, and family members enjoy their life together as a family and have the chance to do things which are important to them” (Park et al., 2003, p. 368). Measuring FQOL as an outcome within research and intervention allows both

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researchers and clinicians to evaluate family functioning across a range of domains and to comprehensively assess specific areas that may be targeted within interventions.

A number of measures are currently available to support the assessment of FQOL and include various dimensions. One example is the Beach Center FQOL Scale, which is a 25-item survey developed by Hoffman and colleagues (2006). This tool examines perceived satisfaction across five areas: family interaction, parenting, emotional well-being, physical and material well-being, and disability-related support. The evidence suggests that the Beach Center FQOL Scale is a valid and reliable tool and has been translated and used to assess quality of life among families of children with various disabilities internationally, including in Spain, China, and Australia (Andrade et al., 2008; Davis & Gavidia-Payne, 2009; Hu et al., 2012; Verdugo et al., 2005).

Another widely used tool was developed by the International Family Quality of Life Project led by researchers from Canada, Australia, and Israel. The Family Quality of Life Survey (FQOLS-2006; Brown et al., 2006) assesses FQOL across nine domains: health of the family, financial well-being, family relationships, support from others, support from disability-related services, influence of values, careers and preparing for careers, leisure and community recreation, and community interaction. This survey has been translated into more than 20 languages and is used by researchers in over 25 countries (Brown et al., 2010). Studies assessing the validity of this scale have shown moderate to strong internal validity (Samuel et al., 2018).

Moreover, there have been a growing number of studies translating and using these measures cross-culturally, although questions remain over the applicability and validity of these tools in non-Western contexts (see Ajuwon & Brown, 2012; Clark et al., 2011; Hu et al., 2012; Schmidt & Kober, 2010; Verdugo et al., 2005). These concerns are highly relevant when considering that the bulk of autism research has disproportionately focused on White, educated, high socioeconomic status individuals (Cascio, 2015; Norbury & Sparks, 2013). This has contributed to significant challenges when assessment tools are used in culturally diverse populations where some have argued that there are few standardized assessments that are valid and reliable outside of Western contexts (Norbury & Sparks, 2013).

Researchers have attempted to address such challenges through the development of new tools or by conducting qualitative studies (see Giné et al., 2010, 2013; Todd et al., 2004). Aznar and Castañón (2005), for example, conducted a participatory research study involving families of children with intellectual disability from 13 Latin American countries in order to develop an instrument that was meaningful to this population. Their tool examines FQOL across the following six domains: emotional and physical/material well-being, personal strength and development,

cohabitation rules, family life, and interpersonal and community relations.

Given that the majority of research informing our conceptualization and understanding of FQOL has been conducted in Western societies, it is possible that there are culturally bound assumptions inherent within these tools. For example, one study conducted by Samuel et al. (2018) used the FQOLS-2006 with low socioeconomic status (SES) and primarily African American families of children with developmental disabilities. Findings revealed only a moderate degree of construct and criterion validity. The researchers concluded that more studies are needed to refine and validate current FQOL tools to ensure cultural sensitivity and validity. Qualitative methods may be best suited to addressing this gap in understanding culturally bound versus universal features of FQOL. Furthermore, exploring how families from diverse cultures conceptualize and describe the meaning of FQOL in their own terms may help inform the development of tools that are more inclusive, culturally sensitive, and valid.

One culturally diverse group that may conceptualize FQOL differently is Korean immigrant families of children with autism spectrum disorder (ASD). As part of the International Family Quality of Life Project, Isaacs and colleagues (2007) compared families from Canada, Australia, Israel, South Korea, and Taiwan using the FQOLS-2006. Families from South Korea rated their satisfaction with the majority of the assessed FQOL domains (health, finances, family relationships, support from other people, support from disability-related services, influence of values, careers and planning for careers, leisure and recreation, and community interaction) substantially lower as compared to families from Canada and Australia. The domain of family relationships was the only domain where the majority of Korean family members were satisfied.

There may be a number of reasons that account for this discrepancy. Studies have shown that cultural values and practices impact how parents identify and interpret the same behaviors in their child. For example, whereas a lack of eye contact is considered a diagnostic indicator of ASD in Western contexts, in Korean culture, direct eye contact is discouraged depending on status or familiarity of the individual and therefore, Korean parents may not endorse the lack of eye contact as an atypical behavior in their child (Kang-Yi et al., 2013; Norbury & Sparks, 2013). However, in Korean culture, certain communicative conventions such as the use of grammatical forms (honorifics) to convey respect or one's place in the social hierarchy may be especially diagnostically sensitive, and it has been suggested that diagnostic or screening instruments for Korean children include a question about the appropriate or inappropriate use of honorifics (Kang-Yi et al., 2013).

There are also demonstrated differences in how Korean parents make sense of their child's atypical behaviors within a society that values sameness, particularly, when the popular view of autism is that it is a severe and intellectually

disabling condition. For example, in an ethnographic study of how Korean mothers understand and manage autism, researchers found that parents were less likely to accept an ASD diagnosis for their child when their child was cognitively and academically able (Grinker & Cho, 2013). A lack of acceptance of a formal label or diagnosis meant that the children and family could not benefit from public clinical and special education services and would likely impact the family's financial well-being.

These culturally embedded interpretations of normative behavior may extend to a family's perceptions of quality of life. For example, parental responsibility or investment may be viewed differently in Western societies that value individual independence and self-actualization versus in Korean culture wherein one's sense of identity is shaped by interdependence and social connections. The underlying assumption that aspects critical to FQOL in one culture are equally important to another culture is inherently flawed. For example, evidence from the family resilience literature, a related construct to FQOL, also suggests that different concepts are valued cross-culturally (Genero, 1995; Greeff & Nolting, 2013; McCubbin, 1998). Cultural variation in areas such as spirituality and belief systems appeared to be impactful on resilience in families (Greeff & Nolting, 2013; McCubbin, 1998). Indeed, studies have shown that families from collectivist cultures, such as Korea, differ in how they perceive their well-being and what factors are most influential to their quality of life (Kang-Yi et al., 2018). For example, Kang-Yi and colleagues (2018) found that traditional forms of support from religious leaders and organizations played a significant role in helping families of children with disabilities cope and gain acceptance in their communities. In collectivist cultures, well-being is very much tied to social interdependence and to an individual's social status (Krys et al., 2019). Independence and autonomy are less valued in collectivist versus individualist cultures. In addition, other cultural factors, such as stigma, which exists in Western cultures (Green, 2003; Kinnear et al., 2016; Yu et al., 2020) but has been reported to be particularly salient in a number of Asian cultures due to the association with shame and dishonor (Hwang & Charnley, 2010; Mak & Cheung, 2008; Mak & Kwok, 2010; Zhou et al., 2018), may be a powerful predictor of FQOL. In confronting adversity, the concept of resilience may be valid in both Western and Korean cultures and may be potentially valuable when attempting to assess how the family navigates between personal experience with ASD and cultural beliefs about ASD (Hwang & Charnley, 2010).

The existing research examining the definition and conceptualization of FQOL in diverse groups is extremely limited. If FQOL measures and tools, which are primarily developed in Western societies, are to be used cross-culturally, but do not include domains valued by the family's culture, practitioners and service providers will fail to understand their experience and to address their specific

needs. Thus, this study sought to answer the following two research questions:

*RQ1.* How do Korean immigrant families and Canadian families of children with ASD define FQOL?

*RQ2.* What are the similarities and differences across how Korean immigrant families and Canadian families of children with ASD define and describe FQOL?

## Methods

### Participants

*Korean immigrant families.* In order to attain the perspectives of families from Korea, the researchers selected a total of 13 participants using purposive sampling from a list given by an organization providing services, information, and advocacy for Korean immigrant families of children with developmental disabilities in the community, and from a lab database comprised of families of children with ASD who had expressed interest in participating in future studies. Purposive sampling was used to ensure that parents from various socioeconomic backgrounds were included, and that all were born in Korea. All families were immigrants to Canada within the last 20 years (mean ( $M$ ) = 13.5; standard deviation ( $SD$ ) = 4.5). The final sample of Korean immigrant families of children with ASD ( $N = 13$ ) was determined based on saturation of the themes arising from the qualitative data.

The majority of parents were mothers (76.9%) and the age range was between 39 and 59 years ( $M = 52.5$ ;  $SD = 6.3$ ). Complete demographic information for the parents and families is provided in Table 1. The age range of participants' children with ASD was between 6 and 33 years ( $M = 21.4$ ;  $SD = 8.0$ ).

*Canadian families.* Fifteen participants from 12 Canadian families (participants self-identified as Canadian or Canadian citizens) of children with ASD participated in the interview. In total, nine individual and three couple interviews were conducted. Most ( $n = 11$ ) interviewees were mothers, including the one who was a foster parent. The age range of participants' children with ASD was between 6 and 17.5 years ( $M = 12.8$ ;  $SD = 3.69$ ; see Table 1).

*Diagnostic confirmation.* All children included in the study had received a standardized clinical diagnosis of ASD from a qualified psychologist, pediatrician, or psychiatrist associated with the provincial government-funded autism assessment network, or through a qualified private clinician. Each child's diagnosis was based on the Diagnostic and Statistical Manual of Mental Disorders and confirmed using the Autism Diagnostic Interview-Revised (ADI-R; Rutter et al., 2008) and the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1999), both of which are gold standard tools of ASD diagnostic assessment.

**Table 1.** Participant demographic characteristics.

Demographic information	Korean immigrant families (N = 13)	Canadian families (N = 12) <sup>a</sup>
Respondent relationship to child with ASD		
Mother	10 (76.9%)	11 (73.3%)
Father	3 (23.1%)	4 (26.7%)
Primary caregiver age (years)		
30–39	1 (7.7%)	1 (6.7%)
40–49	3 (23.1%)	7 (46.7%)
50–59	9 (69.2%)	4 (26.7%)
Marital status		
Married or common law	12 (92.3%)	9 (75%)
Divorced or separated	1 (7.7%)	1 (8.3%)
Never married	0 (0.0%)	2 (16.7%)
Maternal education		
Elementary school	–	1 (8.3%)
High school	–	2 (16.7%)
Professional diploma	1 (7.7%)	1 (8.3%)
Undergraduate degree	7 (53.8%)	2 (16.7%)
Graduate degree	4 (30.8%)	4 (33.3%)
Other	1 (7.7%)	2 (16.7%)
Paternal education		
High school	–	3 (25%)
Professional diploma	–	2 (16.7%)
Undergraduate degree	4 (30.8%)	2 (16.7%)
Graduate degree	8 (61.5%)	2 (16.7%)
Other	1 (7.7%)	3 (25%)
Family income		
<\$20,000	1 (7.7%)	1 (8.3%)
\$21,000–\$49,999	2 (2.0%)	2 (16.7%)
\$50,000–\$79,999	4 (30.8%)	2 (16.7%)
\$80,000–\$109,999	4 (30.8%)	1 (8.3%)
\$110,000–\$139,999	–	1 (8.3%)
\$140,000–\$169,999	1 (7.7%)	1 (8.3%)
>\$170,000	1 (7.7%)	4 (33.3%)
Family member most responsible for child with ASD		
Mother	9 (69.2%)	6 (50%)
Father	–	1 (8.3%)
Mother and father	3 (23.1%)	1 (8.3%)
Parents and siblings	–	2 (16.7%)
Parents, siblings, and other members	1 (7.7%)	2 (16.7%)

ASD: autism spectrum disorder.

<sup>a</sup>For the Canadian sample, 12 interviews were conducted; however, three of these involved couples (both mother and father), and nine were completed with a single parent. As such, 15 participants were interviewed on behalf of 12 families.

Caregivers also provided information about the main study child's intellectual functioning, adaptive functioning, behavioral problems, and disability severity (see Table 2). To assess adaptive and behavioral functioning, Canadian parents completed the Vineland Adaptive Behavior Scales, Second Edition Survey Interview (Vineland-II; Sparrow et al., 2005) and the Nisonger Child Behavior Rating Form (NCBRF; Aman et al., 1996). The Vineland-II provides an

**Table 2.** Child characteristics.

	Korean immigrant families (N = 13)	Canadian families (N = 12)
Intellectual functioning ( <i>parent-report</i> )		
Low	–	1 (8.3%)
Low average	9 (69.2%)	3 (25%)
Average	3 (23.1%)	6 (50%)
High average	1 (7.7%)	1 (8.3%)
Superior	–	1 (8.3%)
Adaptive functioning <sup>a</sup>		
Low	–	4 (33.3%)
Moderately low	7 (53.8%)	4 (33.3%)
Adequate	4 (30.8%)	4 (33.3%)
Moderately high	1 (7.7%)	–
High	1 (7.7%)	–
Presence of behavioral problems ( <i>parent-report</i> )		
Behavioral problems		
Mild	5 (38.5%)	–
Moderate	6 (46.2%)	–
Severe	2 (15.4%)	–
NCBRF total problem behavior mean (SD) <sup>b</sup>	–	50.5 (27.16)
Child disability severity ( <i>parent-report</i> )		
Mild	5 (38.5%)	7 (58.3%)
Moderate	5 (38.5%)	3 (25%)
Severe	3 (23.1%)	1 (8.3%)
Very severe	–	1 (8.3%)

NCBRF: Nisonger Child Behavior Rating Form (Aman et al., 1996); SD: standard deviation.

<sup>a</sup>Ratings of children's adaptive functioning were based on parental report for Korean immigrant families and on the Vineland Adaptive Behavior Scales, Second Edition Survey Interview (Vineland-II; Sparrow et al., 2005) standard score for Canadian families (low = 55–70; moderately low = 71–85; adequate = 86–104).

<sup>b</sup>This is based on the raw score of the Problem Behavior scale of the NCBRF and has a theoretical range of 0–198.

Adaptive Behavior Composite standard score (M = 100; SD = 15) ranging from 20 to 160, in which higher scores indicate better functioning. For the NCBRF, total problem behavior score can range from 0 to 198, and higher scores indicate more frequent and problematic challenging behavior. In order to accommodate participants for whom English was not their first language, and to reduce the number of surveys required, Korean immigrant parents rated these domains of child functioning from “Mild” to “Very Severe.”

### Interview

An Interview Guide was developed consisting of open-ended questions around how parents defined FQOL and the aspects perceived as important to their FQOL (e.g. “Tell me what Family Quality of Life means to you”). Questions were developed by the researchers in consultation with

**Table 3.** Trustworthiness criteria and procedures.

Criterion	Technique	Description
Credibility	Member checking	Interviewers clarified responses with participants to check for accuracy. Interpretations of the data were also verified with participants.
	Prolonged engagement	This criterion was met through ongoing interaction with the community studied by participating at community events, workshops, and continued research activities.
Dependability	Peer debriefing	This strategy involved meeting with other researchers and colleagues outside of the study to provide feedback on coding, and theme development.
	Reflective journaling	This technique involved documenting all research decisions and justifications, coding instructions and their revisions, and theme development.
	Memos	Memos were written following each interview and involved recording participants' non-verbal language, willingness to participate, and any other relevant contextual details.
Transferability	Audit trail	This strategy involved collecting raw data, creating time- and date-stamped memos, and documenting all revisions to coding and theme development.
	Thick description	This criterion was met by providing rich descriptions and direct quotes from participants exemplifying themes. Sufficient detail was provided regarding the participants and settings of the research.

relevant stakeholders, including caregivers of children with ASD, community advocates, and service providers. The researchers used prompts and follow-up questions to clarify, modify, or obtain additional information and took detailed notes of the participant's tone, and pauses, providing rich contextual detail to their responses.

### Procedure

The researchers obtained ethical approval from the Institution's Research Ethics Board before carrying out the study. The Korean immigrant and Canadian participants completed two different demographics surveys, where the former group completed a shortened version to accommodate participants for whom English was a second language. A main difference between the two versions was that Korean parents did not complete the NCBRF, and instead indicated whether their child's behavior was "Mild/Moderate/Severe." The semi-structured interviews ranged between 35 and 60 min and were conducted in English. Semi-structured interviews were used to allow participants the freedom to express their viewpoints in their own terms and permitted extended probing on the researcher's end.

### Data analysis

Interviews conducted with Korean immigrant families and Canadian families were coded and analyzed by two separate teams using the NVivo software. The team examining data from Korean families was comprised of a researcher from the University and a parent partner/co-researcher from the Korean community. The other team examining data from Canadian families was comprised of different researchers from the University. All coders had backgrounds in qualitative data analysis and experience in the field of developmental disabilities.

This study adhered to a constructivist grounded methodology comprising three stages of coding: initial, focused,

and theoretical. Initial coding involved reading full transcripts several times and highlighting phrases or words that captured a participant's experience. This process involved fracturing and breaking down the data into smaller components to facilitate comparisons both within and across transcripts (Chun Tie et al., 2019). This produced a large quantity of codes where significant words or phrases were identified and labeled. All initial codes and later revisions of these codes were date- and time-stamped, and stored in a codebook that allowed researchers to track their assigned labels, developments, and hierarchical levels. The second stage, focused coding, involved identifying the most significant or frequent initial codes and synthesizing these codes into higher-order, meaningful units. Following these guidelines, the initial codes were re-organized into broader categories making careful comparisons across the various codes and grouping them together based on common properties and characteristics. Theoretical codes aim to "weave the fractured story back together again into an organized whole theory" (Glaser & Strauss, 1967, p. 72), and thus require in-depth analysis specifically focusing on relations and connections between these higher-order codes.

### Trustworthiness

Trustworthiness in qualitative research is measured by the degree of confidence in the data and the interpretation of findings (Denzin & Lincoln, 2005). The criteria for determining trustworthiness, outlined by Lincoln and Guba (1985), include credibility, dependability, and transferability. Table 3 presents the procedures implemented to address each criterion.

### Community involvement

Recognizing the expertise and knowledge of individuals and families impacted by ASD and the importance of

**Table 4.** Themes from interviews with Korean immigrant families.

Themes	Subthemes	Example codes	Definitions
Family cohesiveness	Encouragement	Being supportive Being responsive	Instances where the participant mentions behaviors or actions that bring the family together, or emotional bonds between members.
	Understanding	“Same mind” “Shared emotion”	
Value orientation	Personal sacrifice	Giving up personal ambitions and career goals	Instances where the participant mentions values, attitudes, and beliefs. May describe what is desirable and important in life.
	Religion	Having the same faith	
Acceptance from society	Inclusion	Sense of belonging	Participant mentions instances or feelings related to acceptance or belonging. They may mention these in relation to their interactions with professionals, families, communities, and society.
	Discrimination	Stigma Racism	
	Respect	Cultural sensitivity Family-centered care	

inclusion and shared decision-making in research, this study adopted elements of community engagement. For the Korean sample, a parent of a child with ASD collaborated with researchers in developing the research questions, providing feedback on surveys and the interview guide, recruiting participants from his community, translating study documents, conducting interviews with participants, and coding and analyzing data. For the Canadian sample, the researchers hosted a series of Knowledge Translation and Engagement events that brought together individuals with ASD and their families with researchers, service providers, clinicians, and government representatives. These events proved critical across the research process, as they informed the original study design, served as a venue for participant recruitment, and inspired the inclusion of key questions within the interview guide.

## Results

### *Korean immigrant families*

Thematic analysis of the interviews identified three themes: family cohesiveness, value orientation, and acceptance from society. The descriptive codes and subthemes comprising each overarching theme are summarized in Table 4.

**Family cohesiveness.** The theme of “family cohesiveness” appeared to emerge as an important factor impacting FQOL for 11 of the Korean immigrant families interviewed. According to parents, this was achieved when family members supported and encouraged one another. This involved managing expectations for each member of the family and focusing on strengths. For example, one parent provided advice for how to be supportive of their child with ASD:

Don’t push your child too much to learn practical skills. Don’t push them too hard. Put more priority in having them feel safe and comfortable . . . and be at their level. Don’t assume or

expect them to behave in a typical way because some of their behaviors are functional.

Similarly, another parent added that being responsive, encouraging and prioritizing the relationship with the child can facilitate cohesiveness and improve overall FQOL:

The most important thing is my relationship with my child. You need to believe in your child that he or she can do anything.

Parents also described the importance of family members being understanding of one another as a crucial factor impacting their FQOL. Specifically, parents identified “shared emotion” and having the “same mind” as contributing to understanding. “Shared emotion” was described as occurring when members are understanding of one another and are present throughout life’s challenges and triumphs. Experiencing the “same mind” and pursuing similar goals appeared to bring families closer and strengthen family bonds. One parent provided an example of the meaning of having the “same mind”:

My husband and I like to set a goal for my son’s life, his future, so we like to pursue the same goals . . . without any different ideas . . . we have the same ideas to set out his future that’s what “same mind” means.

**Value orientation.** The theme of “value orientation” appeared central for nine of the interviews with immigrant parents from Korea. Despite the majority of caregivers living in Canada for over 10 years, many parents still felt very close ties with their culture and pride in their traditions. However, some parents also reported the negative impact that cultural values around personal sacrifice had on their well-being, for example:

Because of him [son] I have to quit my job . . . to get a new life is pretty tough for me. I’m already old and it’s not easy to start new things. Attending college is pretty tough for me,

getting a job is really stressful because I am so disconnected with the community here.

Three parents described feeling a sense of responsibility to leave their family and friends in Korea to immigrate to Canada in order to pursue a better life for their child. Four parents reported not only their own personal sacrifices but also those of their spouse's when it came to giving up personal goals and career aspirations for their child's happiness. In regard to her husband, one participant noted,

He worked at a really nice company in Korea but he gave it up and changed his dreams, and instead of fulfilling his dreams he kind of sacrificed to get my son a better life.

For five families, the move to Canada was gradual and staggered with spouses, typically the husband, being left behind in Korea. This separation from their spouse not only caused strain on their marital relationship but also removed a crucial support system for their family unit and left parents feeling helpless and isolated. One parent expressed,

After my husband heard about my son's diagnosis, he felt so frustrated and so bad, and so sad because he cannot move to Canada right away. And he cannot help me or our son or family so the whole family was so sad.

A number of parents highlighted how their child's diagnosis had a positive impact on their life, providing them with a new perspective and, in some instances, new career opportunities. Two mothers changed career paths to work in an education setting, providing support for children with disabilities. One father reflected on how his child's diagnosis allowed him to prioritize his family and re-evaluate his values:

I thought I had to spend more time to work and to achieve some worldly goal for myself and make more money and get promotions. That was my goal. But when I realized my son has autism then I had to change my lifestyle, I had to think more about my family and what's the definition of happiness? What's the definition of life? What's the value for life? It's not only about making money and promotions. I started to think about what other values are important for families and then I changed the priority of my life and of my family values.

Five families also emphasized the importance of their religion and faith in helping them to not only achieve satisfaction with their quality of life but also to find comfort during difficult times. Religion appeared to facilitate coping and gave parents a more optimistic perspective, allowing them to make sense of the events in their lives. Some parents articulated that their faith inspired them to view their child as a "disguised blessing" and gave families new meaning and purpose in their lives. One parent shared,

I think it's my own devotion at times which gave me strength and hope and the capacity of thinking that everything will be better than now, that God will take care of us. That kind of faith is really important and was very important for me. I think it bound us together, having the same faith, similar value system and similar perspective of life. So me and my husband, my two kids, even though my character and my husband's personality clashes in many ways, our way of thinking, our perspective, was similar so it was really helpful to bind the whole family together.

*Acceptance from society.* The theme of "acceptance from society" appeared salient in the majority of interviews conducted ( $n = 11$ ). Parents reported inclusion in society as an important factor influencing their FQOL. For most parents, this meant that their child was accepted by their peers and teachers, and their families were welcomed and supported in the community. This support network in their community serves several functions, which include providing emotional support, childcare, information, and guidance to parents:

I think it is really important to build a connection with other families in the community. So that we can share information and so we can get emotional support from them because we are on the same page. As immigrants, because we don't know the system that means we have less capability to access that system.

It was common for parents to make comparisons between Canada and Korea when providing definitions of FQOL, many reported the former to be relatively more inclusive:

In Korea it's not easy for people with disabilities to freely go around without any prejudice or judgment. It seems like the Asian cultures see people with disabilities differently.

However, a number of parents ( $n = 4$ ) also recalled specific instances in Canada where they experienced racism and discrimination. Parents expressed feeling like outsiders and spoke about upsetting interactions with professionals where they perceived a lack of sensitivity, hostility, and that they were treated differently because of their cultural background. When trying to obtain services for her son, one mom described an incident with a service provider as follows:

She didn't listen to what I said and I felt racism. She just said what she wants, she didn't try to listen to what I said.

Respect emerged as an important theme in parents' definitions of FQOL in several interviews ( $n = 5$ ). Parents expressed that respect is central to their FQOL and involves recognition and acknowledgment from professionals of parents' expertise as primary caregivers who know their child best. Other parents articulated that respect involves

**Table 5.** Themes from interviews with Canadian families.

Themes	Subthemes	Example codes	Definitions
Family interactions	Discord	Communication challenges	This category reflects the environment within which family dynamics and interactions occur, as well as descriptions of the nature of those relationships and interactions, both harmonious and discordant.
	Harmony	Marital cohesion	
Support	Formal (service)	Supportive partnership with providers	Caregivers' descriptions of having access to support when needed, both disability-related (e.g. relationships with service providers) and more generally (e.g. social support).
	Informal (social support)	Feelings of social isolation	
Emotional well-being	Personal fulfillment	Perceptions of happiness Family members can attend to own needs	Poston et al. (2003) define this category as "the feeling aspects of life" (p. 322). Similarly, in this study, this domain refers to participants' reflections on personal well-being, as well as struggles to balance life's various demands.
	Personal sacrifice	Sacrificing health, achievements, and QOL	
Individual characteristics	Caregiver character strengths	Positivity and motivation	This category reflects perceptions of how individual family members' specific attributes contribute to FQOL.
	Child characteristics	ASD characteristics	
Comparisons to other families	Child capacity	Behavioral issues	This domain includes caregivers' observations that many families have greater obstacles to overcome, and expressions of gratitude for current circumstances.
	Caregiving capacity	Financial capacity	

QOL: quality of life; ASD: autism spectrum disorder; FQOL: family quality of life.

more than just recognition of cultural differences and requires specific actions to reduce barriers for immigrants by providing translators, building on strengths, practicing transparency and open communication, and involving the family in decision-making. For example, one parent stated,

We like to create programs in accordance to my son's condition. We like to have [programs] where we can share our culture together, we can share our food together, you know? Like we have same mind, same feelings, and we create our own programs.

### Canadian families

When participating Canadian families of children with ASD were asked to reflect broadly on what the term "Family Quality of Life" meant to them and on their satisfaction with FQOL, caregivers' responses represented five broad themes (see Table 5).

**Family interactions.** Fourteen participants described "family interactions," both harmonious and discordant, noting that a "high" FQOL should occur within a cohesive environment characterized by love, healthy communication and coping, and within which family members are able to spend meaningful time together. Participants also, however, described struggles to achieve this ideal FQOL. Harmonious interactions were most frequently described ( $n = 10$ ), and interviewees focused primarily on marital cohesion. These caregivers described their spouses as "supportive" and "understanding," and highlighted the importance of agreeing on their child's intervention. One mother

acknowledged that although she and her husband had differing ideas, they were receptive to each other's preferred approach: "We're drawn to different things . . . but we would oftentimes use each other's . . . between the two of us we centralized . . . I think we were both open."

In stark contrast, eight participants discussed discordant interactions, with individuals relating experiences of friction among spouses (and an ex-spouse) and within parent-child relationships. Within spouse relationships, interviewees described the stress that raising high needs children exerts on a marriage. One mother described her spouse's "inability to manage" due to his own difficulties with attention deficit hyperactivity disorder, and she communicated feeling alone in her parenting and management of family demands. This led to feelings of anger and resentment, and what she called a "communication shutdown." Three parents described disagreeing with their spouses over treatment and talked about how their partners did not accept the diagnosis, thus leaving them to develop an intervention plan with no spousal input. One mother said,

My husband, he always criticized what I tried to with . . . [child with ASD]'s program, because if [child] didn't act the way he wanted him to, it's obviously my fault because I didn't get the right programs in place for him . . . not on a different page, my husband's not on any page. He had no input on anything, he couldn't have cared less.

**Support.** "Support" was also frequently discussed as an important component of FQOL, and 13 participants made comments that fell within this theme. They distinguished between formal and informal support, and indicated their



level of satisfaction (and dissatisfaction) with both, and the important role this played in how they perceived their overall FQOL. Those ( $n = 4$ ) who talked about positive elements of formal service highlighted having supportive partnerships with their providers. These relationships provided clarity in terms of treatment goals and expectations, and instilled a sense of confidence, particularly when they observed their children making progress. One father described how establishing appropriate supports for his son had resulted in positive impacts for their FQOL, as it had allowed other relationships within the family to thrive:

I've seen various changes take place in [my son], and the family as a result . . . my younger daughter is blossoming because we can give her much more attention . . . even my wife—I wasn't the husband she needed because all of my effort was put into that boy, everything, literally everything.

Most ( $n = 10$ ) participants' discussions, however, focused on their service-related dissatisfaction. Individuals described being faced with "constant" issues in terms of accessing and navigating complex service systems, and they communicated an overarching perception that appropriate formal supports were unavailable when needed. They also described the challenges associated with becoming their child's therapy facilitator, which involved coordinating services, scheduling therapies, and completing associated paperwork. Others identified concerns about how they would continue to support their children after age 19 years when government-funded supports were no longer available. For example, one mother said,

For me, for our family, for our future quality of life, I'm very concerned. Because I am their mom . . . I am a foster parent, I guess they turn 19, I can walk away, but that's not what will happen here, so how do I support him . . . that's a big concern for me.

Four participants spoke about how informal (social) support was unavailable and explained how this contributed to their social isolation. One father suggested that a prevailing lack of understanding of ASD and its impairments led others not to "want to associate with them." A mother said, "When you have no one that you can talk to about these things . . . that isolates you more . . . your world shrinks dramatically which really does impact the family."

**Emotional well-being.** Twelve caregivers reflected on the importance of the family's "emotional well-being," describing both personal fulfillment and sacrifice. Within the former, caregivers equated "quality of life" with being happy and experiencing an absence of stress. For example, one parent said, "For me, it would mean happiness and well-being . . . most importantly that a family is solid and happy." Participants also communicated that perceptions

of happiness could hinge on each individual's ability to attend to their own day-to-day demands. For example, one father said,

[FQOL is] harmony in the home without that overbearing demand to try to continuously adjust behaviour. And trying to step away, to be honest, from the autism aspect for a period, and live at least part of your life in a normal fashion.

Interestingly, most ( $n = 7$ ) discussions centered around elements of personal sacrifice. Specifically, caregivers spoke about sacrificing their physical and emotional health as well as personal aspirations, in order to devote their energy to their children. For example, one mother reflected on how her needs were circumvented by her prioritization of her child's needs: "It takes a toll on your own health because you're doing so much for the other, . . . especially when you're a single mom, you forget yourself." One mother shared how she had put her personal relationships aside so she could focus on supporting her child:

It's been difficult. I've had no social life and I didn't want to bring anybody . . . I wanted to concentrate on my son, get him diagnosed, and get him the right support and on the right path and that has been my mission, which I feel I'm succeeding . . . I wanted my son to come first.

Two caregivers spoke about giving up careers, as well as the benefits that accompanied them, and adapting their personal goals. One mother reflected on how leaving graduate school to support her child had re-directed her career path:

In terms of being dissatisfied . . . I had to leave a doctoral program, I had to leave my job in order to make this work for my son . . . you have to make changes with your life goals. One of the parents often ends up being a full-time caregiver in a way that they didn't expect and there's no support for that, and of course I'm going to do that, he's my son and absolutely I see that as my job, but does it make our lives easy? It makes it incredibly complex.

**Individual characteristics.** "Individual characteristics" was one of the next most frequently discussed, as 11 participants described how individual family member's attributes contributed to FQOL satisfaction. These discussions focused on the role of caregiver strengths as well as the impact of child characteristics. In relation to the former, participants credited their own resourcefulness and motivation to persevere through difficulties, as well as positive outlook. For example, one mother underscored the importance of being a role model for her children, and recounted her efforts to always model optimism when presented with challenges:

We're always trying to teach the kids, you look at everything with a positive outlook . . . instead of focusing on what's not

right . . . We don't really have any other choice . . . we have to act how we would like them to grow up acting and I think that's the strength.

Her husband praised her consistent demonstration of these qualities, and described the resultant positive impact on family functioning:

A lot of these kids with autism, they cause a lot of stress around the household, and then the parents aren't getting along and they can't focus on getting the help that their kid needs, and it's like this vicious circle that we've managed to stay on top of because [wife] is so motivated.

In interviewees' discussions of child characteristics, challenges received the most attention, as participants ( $n = 7$ ) described examples of child inflexibility, such as having to complete schoolwork in a particular way or needing to sit in a specific seat at the dinner table. This rigidity resulted in the child experiencing significant anxiety about social situations, schoolwork, and objects (i.e. specific phobias), and participants described adapting to these demands "for the peace of everybody," as well as the resulting isolation: "We're prisoners in our own home, our child finds it very hard to go to restaurants or malls, grocery shopping, just the normal everyday things . . . so we're prisoners in our own home."

Participants also discussed the impact of children's lack of emotional expression and reciprocity. One mother described how her daughter had difficulty regulating, expressing, and detecting emotion, and her candid honesty could offend others within the family. Another father reflected on how the overall emotional environment of the family was affected by these aspects of ASD:

[Child with ASD] could never really express anything within the family . . . he cannot return [his mother's expressions of love] . . . and he's trapped inside, so that raises tension. You don't get that emotional development in the family.

*Comparisons to other families.* Eleven individuals made comparisons to other families, considering how poorer levels of child or caregiving capacity could negatively affect FQOL. Although caregivers identified their own challenges, it is interesting that almost all also acknowledged ways in which particular circumstances would present additional struggles, and described feeling lucky, blessed, and appreciative of what they had. One father said,

I think we're far luckier than many people that we hear about . . . and we've always been very thankful that it's never been that bad for us . . . it's sad to say, but when you see somebody else worse off than you, you begin to appreciate what you got and what you do and how you do it.

With regard to child capacity, participants acknowledged the heterogeneity that exists within the ASD spectrum, and

seven individuals suggested that FQOL would be more detrimentally impacted if their children were lower functioning or exhibited behavior problems.

One father alluded to the greater level of need demonstrated by lower functioning children, and elaborated on how this likely resulted in greater stress within the family:

Every child on the spectrum is radically different . . . and for children that are non-verbal or non-communicative, there's a different level of frustration and effort and anxiety that goes into some families that are raising an ASD child . . . potentially they would self-report a different quality of life just due to the overall anxiety in the household.

In terms of caregiving capacity, five interviewees spoke about their appreciation of having financial support that enabled them to stay at home with their children, job flexibility to attend relevant support-related meetings, and agreement with their spouse about parenting approach. With regard to the latter, one mother described how parenting disagreement takes away from their desired primary focus on the child:

On the parenting path . . . when the husband and wife, mom and dad, don't agree on disciplinary measures or just the way that they're raising their kids, I think it's such a huge struggle daily because not only then do you have a kid with possible behavioural problems, but you're also having a constant confrontation with your spouse or partner . . . in that way we are so fortunate that we really agree for the most part . . . that alleviates so much stress.

## Discussion

The first research question sought to understand how Korean immigrant families and Canadian families of children with ASD define FQOL. For Korean immigrant families, three themes were identified: family cohesiveness, value orientation, and acceptance from society. These elements emerged as central to their understanding and conceptualization of FQOL. In comparison to existing conceptualizations of FQOL, which emphasize opportunities to fulfill personal goals and achievements within the context of the family life, findings from the Korean immigrant sample highlight the importance of personal sacrifice and religion in their definitions of FQOL. Another key difference when comparing existing conceptualizations with current findings relates to the latter's emphasis on acceptance from society which is facilitated by a sense of inclusion and feeling respected. While current measures, such as the Beach FQOL Scale, assess supports and acceptance at the micro-scale (e.g. communities and schools), they do not currently assess these aspects at the macro-level. Acceptance from society appeared to play a significant role in how Korean immigrant parents perceived their FQOL and the absence of these factors in current assessment tools may serve to underestimate

the barriers and challenges families face in achieving an optimal FQOL.

For Canadian families, themes comprising family interactions, support, emotional well-being, individual characteristics, and comparisons to other families were essential elements in defining their FQOL. Interestingly, for Canadian families, the identified themes are very consistent with those identified by Poston et al. (2003), whose qualitative study with family members of children with and without disabilities, individuals with disabilities, and professionals established the FQOL domains assessed within the Beach Center Scale (family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support). This indicates that this commonly utilized FQOL measure is well suited to assess the domains most relevant to Canadian families' lives, and the item content of each scale nicely mirrored the identified interview themes. There was one theme that emerged; however, that is not assessed within the FQOL Scale. Specifically, "comparisons to other families" were very relevant, as most (73.3%) participants made related statements, and these kinds of comparative appraisals seemed to be an important way in which families contextualized their strengths and struggles. Almost all Canadian interview participants noted that "it could be worse" in some way, and acknowledged their appreciation of their family's perceived capabilities. The Beach Center FQOL Scale does not include any items explicitly relating to whether families consider themselves as demonstrating relative areas of strength. As interventions for children with disabilities operate from a strength-based orientation, these kinds of items may inform professionals about areas upon which they can build in order to help families view themselves in more positive ways.

The second aim of the study was to examine the similarities and differences across Korean immigrant families and Canadian families in their descriptions of FQOL. The importance of family cohesiveness was central to both samples, with themes around understanding and family harmony emerging as central for both. Some differences between the groups were apparent, however, in their perceptions of how family cohesiveness is achieved. For example, Korean immigrant participants emphasized interdependence and having the "same mind." In contrast, Canadian families were more likely to reflect that each parent could have differing ideas about treatment, for example, but could come together. Canadian families also described how personal fulfillment (i.e. time to pursue individual goals) was important to FQOL. This finding appears congruent with research on collectivist cultures where members had, especially from Confucian Asian cultures, highly value interdependent happiness and a more relationship-oriented view of well-being (Krys et al., 2019).

Both Korean immigrant families and Canadian families mentioned the importance of personal sacrifice in achieving FQOL, yet differences were noted in the types of sacrifices that parents reported. For Korean immigrant families, a number of parents reported having to leave behind a network of supports from friends and family in Korea in order to pursue a better life in Canada. Whereas this theme did not arise for our Canadian families who were long-time residents of Canada, themes around sacrificing career goals, health, and finances in order to better support their child with ASD were common across samples.

Korean immigrant parents perceived their religion and faith as playing a defining role in impacting FQOL whereas the Canadian families did not mention this as impacting their FQOL. Having "shared emotions" facilitated coping during challenging times such as when the child was first diagnosed with ASD. Korean immigrant families described the role of their faith in providing perspective, strength, and hope for the future. This finding is supported by other research documenting the positive impact of religion for families of children with disabilities (Poston & Turnbull, 2004; Taub & Werner, 2016). Currently, commonly used tools measuring FQOL do not account for these factors or may underestimate the role of faith and religion, yet the present findings highlight the importance of these aspects for Korean immigrant families. The findings also stress the centrality of culturally congruent and family-centered care in how immigrant families from Korea define FQOL and the impact it has on empowering parents to reach their optimal FQOL.

Another difference between participating Canadian and Korean immigrant families was the emphasis among the latter group on acceptance from society. This particular theme was predominant in the majority of interviews conducted with Korean immigrant parents. Current assessments measuring FQOL may not effectively capture the diversity of the population or factors relating to immigration or acculturation experiences that are highly relevant in increasingly diverse contexts. For the Korean immigrant parents interviewed, all of whom are first generation immigrants, feeling respected and included in society was paramount. This finding is corroborated by research on collectivist cultures that has demonstrated the significance of interpersonal relations and an individual's roles and positions in society as central to quality of life and well-being (Markus & Kitayama, 1991).

Many immigrant parents from Korea described the deeply embedded and pervasive stigma and shame-socialized attitudes toward individuals with disabilities in their home country. This is consistent with the extensive research documenting the shame-socialized culture deeply engrained in many parts of Asia (Chang & Hsu, 2007; Holroyd, 2003). One of the main reasons participants in this study left Korea was to escape stigma and

discrimination. However, despite moving to Canada in hope of social inclusivity, a number of families recalled encounters with service providers where they faced discrimination and racism. Furthermore, some parents expressed that by not having material available in their language and not having translators available in their communities, they felt unaccepted or unwelcomed by mainstream society. This is especially concerning given the well-established link between social inclusion and quality of life (Esdaille, 2009; Parmenter, 2014). A perceived lack of belonging and inclusion may prevent families from seeking supports, thereby further negatively impacting their FQOL. In addition, feelings of stigma coupled with negative emotions such as guilt and shame may act as a barrier to seeking supports and services to which they are entitled.

### Limitations

There are a number of limitations that should be considered when interpreting the findings of this study. The first relates to the majority of respondents being mothers in both samples. This may limit the generalizability of findings as truly representative of all caregivers of autistic children including fathers. To facilitate recruitment of Korean immigrant parents, all were contacted from a local, non-profit support and advocacy organization for Korean families of children with ASD. Participants recruited from this support group may share a unique perspective and set of experiences that shape how they define FQOL compared to those without access to these supports. An additional limitation relates to the fact that demographic data related to nationality or country of origin were not collected for families who self-identified as “Canadian,” and as such it is possible that there are cultural differences among this sample. This limitation points to the complexities of research in multi-ethnic communities and the need for further study of these complexities.

Another limitation relates to the substantial age difference between the children in the Korean immigrant and Canadian samples, where the former were much older. It is possible that this age difference may have impacted parents’ perceptions and conceptualizations of FQOL. A final limitation is that although parents were able to choose the language they were most comfortable with when doing the interview, all participants included in this study chose English. More representative samples including non-English speaking parents and caregivers are needed in future studies to capture the broad and diverse range of perspectives that comprise each group.

### Conclusion

This study aimed to examine and compare conceptualizations and descriptions of FQOL, from the perspectives of

Korean immigrant and Canadian families of children with ASD. Importantly, the findings highlight how cultural values and differences may translate into different conceptualizations of FQOL. The vast majority of measures used to assess FQOL and well-being are developed in Western, individualistic societies. Therefore, the assumption that this conceptualization of FQOL is universally valued may be inaccurate. The findings indicate that other aspects such as having the “same mind” and “shared emotions,” following the same religion and faith, and feeling acceptance and belonging in society may be more representative of the defining features of FQOL for Korean immigrant families. The results also have broader implications in terms of understanding cultural issues in neurodevelopmental disabilities. Despite the biological bases of neurodevelopmental disabilities, current findings align with the existing literature (Cascio, 2015; Norbury & Sparks, 2013) which challenges our assumptions about what is universally valued in society and how families navigate their lives to achieve these goals.

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### Author contributions

V.F., E.G., and G.I. conceived of the study and participated in its design. E.G. and V.F. conducted the data collection and analysis. All authors participated in interpretation of the data and helped to draft the manuscript. All authors read and approved the final manuscript.

### Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Ethical approval

All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments.

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## Informed consent

Informed consent was obtained from all participants included in the study.

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