Article   **WALDEN UNIVERSITY**

Predictors of Quality of Life Among an International Sample of Mothers of Children 12 and Under With Corpus Callosum Disorders

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Abstract

Previous research supports application of the double ABCX model of family adaptation of parents of children with autism spectrum disorder and other pervasive developmental disorders. This is the first study to consider processes of adaptation among parents of children with agenesis of the corpus callosum. Using a quantitative cross-sectional design, an international sample of 266 mothers of children, aged 12 or under, with agenesis of the corpus callosum completed an online survey. Parental reports of stress, resources, coping, and sense of coherence were evaluated as predictors of four subdimensions of parental quality of life for 178 mothers. In general, findings support the double ABCX model as a viable approach to understanding processes that are related to quality of life among this group of mothers.

Keywords: *corpus callosum disorder; parent adaptation; mothers; double ABCX model; quantitative*

Introduction

When children are born with agenesis of the corpus callosum (ACC), the millions of nerve fibers in the brain's commissural pathway are partially or completely unformed (National Institutes of Health, National Institute of Neurological Disorders and Stroke [NIHNINDS], 2019). ACC is a rare, incurable disorder. Estimates of incidence rates of ACC have ranged from 1.47 per 10,000 live births (Ballardini et al., 2018) to as high as seven per 1,000 individuals (National Organization for Rare Disorders, 2019).

The corpus callosum is a structure that permits functional interaction between the hemispheres. These interactions support cognitive processes, such as executive functions, abstract reasoning, speed of processing, and problem solving. The interactions also are critical for development of social competence, emotional maturity, and communication of emotions (Paul et al., 2014). ACC may exist alone or in combination with other cerebral malformations or syndromes, cognitive impairments, developmental delays, communication disorders, and/or epileptic seizures (NIHNINDS, 2019). Children with ACC are not easily categorized, as the range of physical, social, behavioral, and cognitive outcomes vary, and there can be differing combinations of disabilities (NIHNINDS, 2019).

Similar to parents of children with other neurological developmental disorders, such as autism spectrum disorder (ASD; Pozo et al., 2014), parents of children with ACC are faced with challenges to effective coping and adaptation. As with ASD (Lau et al., 2013), children with ACC present parents with a broad variety of needs and symptoms (Margari et al., 2016), such as epilepsies and other neurological disorders (Unterberger et al., 2016), intellectual limitations (Paul et al., 2016), attention deficit disorder (El Ameen et al., 2019), limitations related to self-reference and social cognition (Anderson et al., 2017; Lombardo et al., 2012), and social and behavioral problems (Badaruddin et al., 2007).

Unlike research with parents of children with ASD (e.g., Pozo et al., 2014), to date, no research has sought to examine processes and predictors of adaptation among parents of children with ACC. Following the double ABCX model of coping (McCubbin & Patterson, 1983), the current study fills this gap in our understanding of experiences of adaptation among parents of children with ACC.

The Double ABCX Model of Family Coping and Related Research

The double ABCX model of family coping (McCubbin & Patterson, 1983) assumes that when parents are presented with the external stressor of a child with a disability, they may differ in their experiences of stress, perceptions of support, cognitive understanding and meaning of the situation, and coping strategies. Depending on the nature of these reactions, parents and families have better or worse adaptation and resilience to the demands with which they are faced.

Experiences of Stress

Parental stress has been defined as distress related to the role of parenting (Hayes & Watson, 2013). External stressors that are related to a child's disability put demands on parents' physical, psychological, social, and emotional reserves. Boyd (2002) and Dardas and Ahmad (2014) found that stress among parents, especially mothers, of children with ASD was higher when their children exhibited more difficult behavior and when the parent felt less able and less competent to parent. McStay et al. (2014) noted that symptoms of externalizing behaviors, such as aggressiveness, impulsivity, and control problems, among children with ASD were the most predictive of higher parental stress and lower family quality of life (QoL).

Resources

Several types of resources have been studied to define this element of the double ABCX model among parents of children with ASD. Examples include self-reports of family cohesion, social support, and family support. McStay et al. (2014) conceptualized resources as perceived support within a family system. They found that hardiness, perceived dependability, activity and flexibility, and control over life, provided the strongest predictor of level of stress and/or family QoL for mothers and fathers.

The resources factor within the double ABCX model also is compatible with the construct of family empowerment. Family empowerment involves beliefs regarding rights, competence, motivation, and ability to reach out to obtain and use formal (e.g., agencies and professionals) and informal (e.g., friends and family) resources on behalf of their child with a disability (Koren et al., 1992; Vuorenmaa et al., 2013). Weiss et al. (2012) reported that acceptance and empowerment were statistically significant mediators between behavior problems of children with ASD and parent's mental health. Weiss et al. (2015) also found that empowerment served as a significant mediator between the level of the child's problem behaviors and the experiences of distress among a sample of mothers of children with ASD.

Cognitive Appraisal

The double ABCX model includes a factor designated as the parent's sense of coherence. This element considers types of cognitive responses that parents may employ to make sense of the situation, such as, self-blame and catastrophizing, feelings of threat, and framing the implications (positive and negative) of raising a child with a disability (McStay et al., 2014). Antonovsky (1987) developed the Sense of Coherence (SOC) Scale, which has been used in numerous studies of the double ABCX model of family adaptation. The SOC involves three dimensions: (a) comprehensibility, seeing the world as structured; (b) manageability, expecting things to be manageable; and (c) meaningfulness, seeing life as meaningful (Sivberg, 2002). For example, Pozo et al. (2013) found that higher SOC scores were associated with higher family QoL among parents of children with ASD. Using a short form of the SOC, McStay et al. (2014) also found that SOC scores were a statistically significant predictor of both stress and of family QoL among mothers and fathers of children with ASD.

Coping Strategies

The double ABCX model assumes that coping strategies add another dimension to processes defining family resilience and adaptation. The model conceptualizes coping as the family's attempts to restore balance. In general, when coping is effective, outcomes such as improved adaptation and higher QoL ensue. When coping strategies are less effective, outcomes are less positive (Fairfax et al, 2019). In fact, McCubbin and Patterson (1996) found that positive and negative coping strategies play a particularly significant role in understanding family functionality. McStay et al. (2014) evaluated coping among parents of children with ASD. They examined five dimensions of coping: acquiring social support, mobilizing to acquire and accept help, reframing, passive appraisal, and seeking spiritual support. Coping responses significantly predicted family QoL among mothers and stress among fathers of children with ASD.

Other researchers have used the Coping Health Inventory for Parents (CHIP; McCubbin et al., 1983). There are three subscales as dimensions of coping within the CHIP: (a) family integration, cooperation, and having an optimistic view of the situation, (b) maintaining social support, self-esteem, and psychological stability, and (c) understanding the health care situation through communication with other parents and health care professionals. CHIP scores generally are related to QoL among parents of children with disabilities (Fairfax et al., 2019). With respect to parents of children with ASD, effective coping is negatively related to stress (Dwirexsi et al., 2018; Kiami & Goodgold, 2017).

Adaptation

In the double ABCX model, adaptation may be defined through outcome variables such as QoL. In a review of the literature of studies of QoL among parents of children with ASD, Vasilopoulou and Nisbet (2016) noted inconsistent findings regarding the relationship between severity of the child's ASD (external stressor) and QoL. However, factors such as difficulties with the child's behavioral difficulties, parental unemployment, and lack of social support were predictors of lower QoL, especially among mothers.

McStay et al. (2014) specifically applied the double ABCX model to predict family QoL among parents of children with ASD. They found that externalizing behaviors by the child predicted higher maternal stress and both parents' evaluations of family QoL. Dardas and Ahmed (2015) found that two coping strategies, seeking social support and escape avoidance, among parents of children with ASD moderated the relationship between stress and QoL, while accepting responsibility served as a mediator factor.

The Current Study

The objective of the current study was to provide the first examination of experiences of parents of children with ACC. Using the double ABCX model as the theoretical framework, our specific goal was to explore the relationships of perceived stress, resources/empowerment, sense of coherence, and coping strategies to parental adaptation, here defined as QoL, among parents of children with ACC.

We predicted a negative relationship between levels of parents' stress and QoL, but positive relationships of experiences of empowerment, sense of coherence about the meaningfulness of the process of parenting, and coping with parental QoL. Although some researchers (McStay et al., 2014) have reported some differences in prediction patterns for mothers versus fathers of children with ASD, no specific hypotheses were advanced for parental differences in this study.

Method

Recruitment and Sample Demographics

Following approval by the university's institutional review board and permission of participating groups, notices about the study were posted between May and June 2018, on over 12 international Facebook group sites established as informational and support sites for professionals and families with interest in ACC. The notice was directed to parents, 18 years or older, of children who had been diagnosed with ACC and were ages 12 and under. Information contained a link to the survey site for any who were interested in participating in research to advance understanding of their experiences. When individuals went to the online survey site, they were presented with the informed consent form. Those who indicated agreement to participate then advanced to the survey materials.

The first questionnaire was demographic. Due to the overall length of the survey, only information on gender and country of origin was requested. In total, 266 eligible respondents participated in the survey. Although not by design, the full sample was composed only of mothers. The majority (66.7%) were from the United States, and 12.4% from Great Britain, 6.4% from Australia, 4.5% from Canada, 2.2% from New Zealand, 2.7% from other European countries, 1.8% unknown, and 5 others (less than 1%) from Africa, India, and Asia.

Survey Measures

Brief World Health Organization Quality of Life (WHOQoL-BREF)

The World Health Organization (WHO, 1996) developed the WHOQoL-BREF assessment to be used cross-culturally to determine parental perception of their lives in four domains: physical, psychological, social relationships, and their interactions with the environment. Parents are asked to answer 26 questions while focusing on their experiences during the last two weeks. Items are presented with a 5-point response scale (1 = *very poor* through 5 = *very good*). Dardas and Ahmad (2014) reported the overall Cronbach's alpha as .93. There are four subscales for domains of QoL. Low QoL scores generally are related to higher disability severity and greater behavior problems (Markowitz et al., 2016). Following directions for scoring the QHOQoL-BREF, transformed scale scores were computed for each of the four domains. The internal reliabilities for this study's sample were physical health, α = .785; psychological health, α =.780; social relationships, α = .789; and environmental health, α = .788.

Questionnaire on Resources and Stress–Short Form (QRS-SF)

The QRS (Holroyd, 1974) was developed as a screening instrument to identify stress in families with a member who is disabled. The QRS is commonly used in published research and has good psychometric properties (Hayes & Watson, 2013). The short form (QRS-SF) presents 66 items with true–false response options. The items assess self-reported personal problems (health, time demands, negative attitudes toward index case, overprotection/dependency, lack of social support, overcommitment/martyrdom, and pessimism), family problems (lack of family integration, family opportunity, finances), problems of index case (physical incapacitation, lack of activities, occupational limitations, social obtrusiveness, difficult personality, personality characteristics). Internal reliability has been estimated at α = .93 (Saloviita et al., 2003). The Kuder–Richardson-20 coefficient (equivalent to Cronbach's alpha) was used to evaluate internal consistency among the scale's dichotomous items. The resulting value was α = .85 for the mothers in this sample. Responses of true were coded as 1 and responses of false were coded as 0. The sum of the items was used for the overall scale score.

The Coping Health Inventory for Parents (CHIP)

The CHIP was developed by McCubbin et al. (1996). The 45-item parent questionnaire assesses parents' perceptions of how they manage family life with a child with a chronic illness. Items evaluate optimistic family definition of the situation, family stability, and understanding of situations with medical staff and other parents. Items are presented with a 4-point Likert scale: 0 = *not helpful*, 1 = *minimally helpful*, 2 = *moderately helpful*, 3 = *extremely helpful*. Test–retest reliability has been reported as ranging from .68 to .86 and Cronbach's alpha for all items ranged from .90 to .86 (Aguilar-Vafaie, 2008). Internal reliability for the current sample was .818. The score was the sum of the items' ratings.

The Family Empowerment Scale (FES)

Koren et al. (1992) developed the FES to measure three factors reflecting different areas of a family's life where they are empowered or need support on behalf of a child/family member with special needs: feeling empowered in their own home, able to get what they need from the service systems available, and the ability to maneuver and acquire their community needs. There are 34 statements and a 5-point response scale for each statement: 1 = *never*, 2 = *seldom*, 3 = *sometimes*, 4 = *often*, and 5 = *very often*. Cronbach's alphas have ranged from .867 to .895 for the five subscales (Kageyama et al., 2016) and .84 to .90 for all items (Vuorenmaa et al., 2013). Concurrent validity has been reported for families who participated in service activities in school settings (Vuorenmaa et al., 2013). Overall internal reliability for the current study was α = .818. The score was the total of the ratings.

Antonovsky's Sense of Coherence Scale–Short Form (SOC-13)
The SOC was developed to assess perceived comprehensibility, manageability, and meaningfulness of one's life. The short form includes 13 statements, each presented with a 7-point response scale, with response items related to the nature of the question (e.g., 1 = *no clear goal or purpose at all* to 7 = *very clear goals and purpose*). The SOC-13 has good test–retest reliability (e.g., *r* = .54 over a 2-year interval), internal reliability (Cronbach's alphas range from .74 to .91 for total score), and construct validity (Antonovsky, 1993). Overall internal reliability for the current sample was .822. Scores were the total of ratings.

Results

Data were analyzed using SPSS (Version 25). Descriptive statistics for total scale scores for the current study are summarized in Table 1.

Hypothesis Testing

Our goal was to examine adaptation (QoL) among parents of children diagnosed with ACC by applying the double ABCX model, which posits predictive factors of parental stress, coping, resources, and sense of coherence. We hypothesized a negative relationship between levels of a parent's stress and QoL, but positive relationships for experiences of empowerment, sense of coherence about the meaningfulness of the process of parenting, and coping with parental QoL, and that the overall model would predict a significant amount of the variance in QoL.

After assessing data for compliance with assumptions, we computed bivariate correlations between predictors and with scores on each of the dimensions of QoL. The correlations, which are summarized in Table 2, initially suggested that, except for reported levels of parental stress, individual factors in the double ABCX model were related to each of the various dimensions of QoL.

Table 1. *Sample Means and Comparison of Current Scores for Mothers of Children With Agenesis of the Corpus Callosum (ACC) With Scores Previously Reported for Mothers of Children With Autism Spectrum Disorder (ASD) and Other Disabilities*

Variable measure	Study	Children's condition	N	M	SD	t	p
Questionnaire on Resources and Stress–Short Form	Current	ACC	266	37.00	5.26		
	Bouma and	ASD	24	29.08	7.30	6.82	<.0001
	Schweitzer (1990)	Control[a]	24	13.17	5.10	21.31	<.0001
	Riley (2016)	ASD	22	34.00	11.60	2.27	.024
Sense of Coherence Scale–Short Form	Current	ACC	266	55.07	26.03		
	Olsson and	ASD	62	59.50	14.40	-1.29	*n.s.*
	Hwang (2000)	Intellectual disability	144	64.40	14.50	-3.98	<.0001
		Control[a]	202	69.10	11.90	-7.12	<.0001
Coping Health Inventory for Parents	Current	ACC	266	94.18	20.71		
	Hall and Graff (2011)	ASD	50	94.12	16.05	.02	*n.s.*
Family Empowerment Scale	Current	ACC	178	188.74	31.03		
	Taylor et al. (2017)	ASD	41	122.30	19.81	5.07	*n.s.*
Brief World Health Organization Quality of Life							
Physical	Current	ACC	265	70.03	20.29		
	Dardas and Ahmad (2014)	ASD	144	64.81	13.85	2.75	.0061
	Malhotra et al. (2012)	ASD	40	46.40	15.85	7.05	<.0001
		MR	40	46.67	12.44	7.08	<.0001
		Control[a]	40	59.35	14.40	3.21	.0015
Psychological	Current	ACC	265	63.80	20.95		
	Dardas and Ahmad (2014)	ASD	144	59.68	16.01	2.06	.0404
	Malhotra et al. (2012)	Autism	40	40.53	12.96	6.85	<.0001
		MR	40	35.05	9.41	8.54	<.0001
		Control[a]	40	55.35	14.48	2.46	.0144
Social	Current	ACC	265	63.26	27.20		
	Dardas and Ahmad (2014)	ASD	144	64.27	17.34	-.40	*n.s.*
	Malhotra et al. (2012)	Autism	40	46.25	13.61	3.88	.0001
		MR	40	38.12	20.06	5.62	<.0001
		Control[a]	40	62.80	16.91	.10	*n.s.*
Environmental	Current	ACC	265	74.66	17.80		
	Dardas and Ahmad (2014)	ASD	144	55.79	14.21	10.96	<.0001
	Malhotra et al. (2012)	ASD	40	49.10	17.14	8.51	<.0001
		MR	40	42.42	18.97	10.59	<.0001
		Control[a]	40	59.40	10.64	5.28	<.0001

Note. MR = mental retardation.
[a] Typically developing children.

Table 2. *Bivariate Correlations Between Total Scores on Each Double ABCX Model Predictor Variable and the Quality of Life Subscale Scores for Adaptation*

	Predictors			
Measure	**QRS-SF**	**CHIP**	**FES**	**SOC-13**
WHOQOL–BREF				
Physical health	−.16**	.38***	.29***	.46***
Psychological health	−.04	.44***	.58***	.38***
Social relationships	−.06	.43***	.44***	.42***
Environment	−.07	.33***	.38***	.41***
QRS-SF	—	−.32***	−.09	−.04
CHIP		—	.67***	.17
FES			—	.04
SOC-13				—

Note. QRS-SF = Questionnaire on Resources and Stress–Short Form (N = 265); CHIP = Coping Health Inventory for Parents (N = 265); FES = Family Empowerment Scale (N = 177); SOC-13 = Sense of Coherence Scale–Short Form (N = 264); WHOQOL–BREF = brief World Health Organization Quality of Life.
** $p < .01$. *** $p < .001$ (two-tailed significance).

Multiple linear regressions were used to evaluate the double ABCX model as a predictor of each of the four subdimensions of QoL. The sample size for the regressions was reduced to 178 due to missing survey responses for a number of participants for items on the FES scale. Assumptions were met and VIF values for the predictors were <10 for each of the regressions. Table 3 presents a summary of results for the multiple regression analyses. There was support of the double ABCX model as an overall predictor of each of the subdimensions of QOL. The highest proportion of variance was predicted for QoL related to the mother's psychological health, while lowest proportion was predicted for QoL related to physical health.

When controlling for the other predictors, coping was a significant predictor of three of the four dimensions of QoL and showed a trend (p = .07) for predicting environmental health. Empowerment significantly predicted all but physical health QoL scores. Stress predicted psychological and social dimensions of QoL, and sense of coherence significantly predicted psychological and environmental health QoL.

Table 3. *Results of Multiple Linear Regressions to Assess the Double ABCX Model of Predictors of Quality of Life (QoL) Among Parents of Children With Agenesis of the Corpus*

QoL dimension	Predictor	Adjusted R^2	Overall F^a	β	t	p
Physical health	Full model	.149	8.73			<.001
	Stress			.057	.74	n.s.
	Coping			.441	4.19	<.001
	Empowerment			.085	.84	n.s.
	Sense of coherence			.147	1.56	n.s.
Psychological	Full model	.384	23.39			<.001
	Stress			.185	2.79	.006
	Coping			.252	2.81	.006
	Empowerment			.532	6.17	<.001
	Sense of coherence			.177	2.19	.030
Social relations	Full model	.241	14.98			<.001
	Stress			.151	2.05	.042
	Coping			.355	3.57	<.001
	Empowerment			.297	3.10	.002
	Sense of coherence			.134	1.50	n.s.
Environmental	Full model	.173	10.23			<.001
	Stress			.052	.68	n.s.
	Coping			.191	1.84	(.07)
	Empowerment			.412	4.12	<.001
	Sense of coherence			.265	2.83	.005

[a] $df = 4, 172$.

Discussion

Although considerable attention has been given to experiences and adjustment among parents of children with autism and other types of developmental disabilities, this is the first study to consider challenges and processes of adaptation among parents of children with ACC. We surveyed an international sample of mothers of children with ACC who were active on various online support and information networks. The theoretical framework and methods we selected drew directly from previous work to explore adaptation among parents of children with ASD and similar disorders. In general, findings support the hypotheses for this study that were based on application of the double ABCX model of parental adaptation to understand processes that are related to QoL among this group of mothers. Experiences of parental stress, resources, sense of coherence, and coping strategies were significant predictors of overall QoL as an indicator of parent adaptation. Further, there were observations of differences in the strength of prediction for different dimensions of QoL: overall, the double ABCX model was strongest for predicting psychological QoL, followed by social QoL, environmental QoL, and lowest for physical health QoL.

Comparing Mothers of Children With ACC With Other Groups

Although direct comparisons within a single study await future research, there are some early, and limited, indications of how mothers of children with ACC may compare with mothers of children with other developmental disabilities. Table 1 contains a sample of mean scores on the same scales that have been reported elsewhere for mothers of children with ASD or other developmental disorders, as well as for

comparison groups of mothers of typically developing children. As may be noted, our mothers' stress scores (QRS-SF) were significantly higher than those reported for mothers of children with ASD or typically developing children (Bouma & Schweitzer, 1990; $p < .0001$; Riley, 2016, $p = .24$). SOC-13 scores for sense of coherence among our mothers of children with ACC were significantly lower than those reported by Olsson and Hwang (2000) for samples of mothers of children with autism, intellectual disabilities, or typical development ($p < .0001$). However, our mothers of children with ACC were similar to mothers of children with ASD on both CHIP scores for coping (Hall & Graff, 2011) and FES scores for resources/empowerment. By contrast, with respect to the QoL measure, scores on subscales of the WHOQoL-BREF for our mothers of children with ACC tended to be higher, that is more positive, than those reported for mothers in other samples with children with autism disorder, MRR, or typical development (Dardas & Ahmad, 2014; Malhotra et al., 2012). Of course, future research is needed to provide direct comparisons of parents of children with ACC with other parent groups.

Limitations

There are several limitations to this first exploration of adaptation among parents of children with ACC. First, it was an online survey, with typical advantages and disadvantages (Nayak & Narayan, 2019). As a plus, this design allowed for collecting data from an international sample and assured anonymity and confidentiality. However, it is difficult to know the actual response rate without knowing how many of the groups' members visited the sites and saw the posting for the study. Further, the sample was nonprobabilistic: self-selection of participants, as well as sample size, limit generalization of these results. In addition, it was a cross-sectional design, exploring self-reports at one point in time. It may be that there are critical aspects of changes both in the child's symptoms and their severity, as well as the parents' status, that are not appreciated using cross-sectional designs. Also, we did not collect sufficient demographic information to appreciate other factors, such as age of child, formal diagnosis status, severity of child's symptoms, socioeconomic status, education level, marital status, that may have been specific to these mothers.

In hindsight, the FES may not be an ideal instrument to use with this population. There were missing responses by a number of respondents, which led to a listwise N of 178. Perhaps some of these items were not relevant for some of the respondents. Fatigue does not seem to explain these missing responses as the FES was completed as the next to the last survey in the package and the same respondents completed all the other survey instruments.

Finally, although each full model explained a statistically significant proportion of the variance in each the QoL subscale scores ($p < .001$), adjusted R^2 values only ranged from .149 to .384, indicating small to, at best, moderate effect sizes.

Recommendations for Future Research

Expanding consideration of demographics and other factors

As the first study with mothers of children with ACC, there is much room for ongoing research in this area. Future research should employ a broader sampling of parents from more populations and situations, including parents at various stages of experience with parenting children with ACC. In addition, information regarding respondent demographics, as well as parenting demands, child's symptoms, and other environmental factors (e.g., Miranda et al., 2019, with mothers of children with autism), certainly could expand the understanding of stress and adaptation among parents of children with ACC.

Reexamining relationships between stress, other predictors, and QoL

There are some questions about the relationship of stress to other predictors, which may be an artifact of our sampling or measure. We found that our mothers' self-reported stress was not related significantly to most of the other elements of the double ABCX model of functioning or adaptation. Stress was inversely associated

with coping responses and with only one dimension, physical health, of QoL. Notably, parental stress was not related to sense of coherence. This result is inconsistent with assumptions, such as those from the Lazarus and Folkman (1984) theory of stress, that experiences of stress are associated with cognitive appraisal of the event and coping responses. Further, stress usually has been related to lower sense of coherence among parents of children with ASD (Batool & Khurshid, 2015; Golfenshtein et al., 2016). Was this finding a function of the higher stress levels reported by our mothers of children with ACC, as compared with those reported for mothers of children with ASD? Was this outcome an artifact of the measure we used, the QRS-SF, to assess parental stress? We could not locate another published study that used both the QRS-SF and SOC to evaluate this relationship among parents of children with disabilities. The answer will await further research with parents of children with ACC.

Practical Significance

This is the first study to explore adaptation among parents of children with ACC. Continuing focus on the needs and functioning of this group of parents may enlighten both the parents and those who may be able to offer effective support. For example, results highlight the importance of considering mothers' experiences of empowerment in relation to the psychological, social, and environmental elements of their QoL. Empowerment, as defined in this study, is related to three factors: feeling empowered in their own home, ability to get what they need from the service systems available, and the ability to maneuver and acquire their community needs (Koren et al., 1992). There is background knowledge and experiences for supporting empowerment for parents of children with ASD (Webster et al., 2017). For example, providing family-centered care and parent-professional partnerships (Casagrande & Ingersoll, 2017), family-focused psychoeducational therapy (Zhou et al., 2019), and family peer advocates (Jamison et al., 2017) may be applicable to improve empowerment among parents of children with ACC.

Further, exploring parents of children with ACC through the lens of the double ABCX model of family adaptation may be useful for conceptualizing and responding to family needs and in planning interventions. Pickard and Ingersoll (2017) have argued that the double ABCX model should be used as a family-focused service delivery model for families of children with ASD. Xu (2007) reported an actual application of the double ABCX model for two culturally diverse families with young children with disabilities. Xu described a process that may be used by professionals: Step 1: observe and identify the primary stressor and others that accumulate along with it; Step 2: identify existing resources the family has used to cope, and those that are still needed, and work with the family's own situation (e.g., attitudes, accessibility), to develop plans and strategies for obtaining more resources; Step 3: examine and re-examine family perceptions across the process, recognizing that "perceptions are dynamic, especially where multiple variables are involved" (p. 436); Step 4: empower families with effective coping strategies. Thus, continued research, and its application for enhancing adaptation among parents of children with ACC, is warranted.

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