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Perception on family support and predictors' of satisfaction with the healthcare service among families of children and adolescents with serious mental illnesses who are in active psychiatric treatment

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Abstract

Problem: Little is known about the factors related to satisfaction with healthcare services among families of children with serious mental illness who were in active psychiatry treatment.

Methods: A cross-sectional study was conducted to explore perceived family support, illness beliefs, and families' satisfaction with healthcare services. Sixty-eight families of children with anxiety, depression, attention-deficit/hyperactivity disorder, eating disorders, and autism/Asperger's syndrome participated. Data were collected from March 2015 to December 2016.

Findings: Illness beliefs and perceived family support explained 23% of the variance in family satisfaction with the healthcare service.

Conclusion: Family interventions need to specifically focus on the families' satisfaction with healthcare services and on utilizing the family support network, offering emotional support, and exploring illness beliefs.

KEYWORDS

active psychiatry treatment, children, families

1 | INTRODUCTION

Parents of children and adolescents with psychiatric illnesses/disorders are faced with complex caregiving tasks on a daily basis which impacts their quality of life (QOL; Derisley, Libby, Clark, & Reynolds, 2005; Ingoldsby, 2010; Sofronoff & Farbotko, 2002), and their satisfaction with the support from the healthcare system (Barber, Tischler, & Healy, 2006; Garland, Haine, & Boxmeyer, 2007). Ineffective or inappropriate coping may hamper parents ability to provide sufficient support and comfort to their afflicted child (Diamond, Diamond, & Levy, 2014). The child may have more than one psychiatric disorder/diagnosis, which creates an additional challenge for the parent(s) (Costello, Mustillo, Erkanli, Keeler, & Angold, 2003). When a psychiatric illness is diagnosed in children or adolescents, family members (especially parents) often become fearful and feel a loss of control, resulting in a need for support (Wright & Leahey, 2013).

At the same time, parents are an important resource and can be successful supporters to their child/adolescent. However for parents to be supportive they must be provided with sufficient support from healthcare professionals (Kendall & Tabacco, 2011; Krahé, Bondü, Höse, & Esser, 2015; Loren et al., 2015; Treasure et al., 2007) This support does not need to be a lengthy intervention. Parents have been found to be thankful for the support from healthcare professionals and have reported improved QOL and more helpful illness beliefs after five to eight sessions of a manualized psychosocial support intervention (therapeutic conversation intervention; Gisladottir & Svavarsdottir, 2017; Gisladottir, Treasure, & Svavarsdottir, 2016). Nevertheless, there is still a gap in identifying predictors of family satisfaction with the healthcare service; information that would help providers understand how to provide beneficial support, use illness beliefs effectively, and contribute or to maintain QOL for families of children and adolescents with serious mental illnesses who are in active psychiatric treatment.

2 | LITERATURE REVIEW

The National Institute of Health and Care Excellence (2004, 2013) has recommended that healthcare services provide parents with personal, emotional, and role support. The guidelines emphasize that early intervention is necessary to improve mental health and well-being to prevent escalation of problems, and to reduce the risk of a breakdown. Hence, the International Council of Nurses (2002) recommends that services for families should be developed and implemented and that families are encouraged to be involved. Healthcare professionals have shifted from a deficit- or dysfunctional-based approach to strength- and resiliency-based family interventions that address family functioning and "fit" (i.e., effectiveness; Wright & Leahey, 2013). Interventions should, therefore, be tailored to a family's personal situation and applied to help them discover new solutions to alleviate emotional, physical, and spiritual suffering (Wright & Leahey, 2013).

Family system models such as the Calgary family models were developed to identify the need for a family level intervention (Wright & Leahey, 2013), They have been found to also be helpful to evaluate family functioning, well-being, the need for family support, and to identify helpful and hindering illness beliefs among families who are dealing with chronic illnesses. Little is, however, known about how the components of these clinical models have worked when used to predict family outcomes in specific clinical situations such as within child psychiatry. Such knowledge can be further used to develop and test the effectiveness of such family level interventions.

2.1 | Impact on parents

Disorders or long-term psychiatric illnesses affect not only parents but the whole family and the effect exists mutually between family members (Wright & Bell, 2009). Jakobsen, Horwood, and Fergusson (2012) found that positive parent–child attachment in adolescence can act as a compensatory factor to the effects of childhood anxiety particularly the risk of developing anxiety and depression later in life. Strongly expressed emotions such as criticism, hostility, or over-involvement can also reduce symptom improvement, at least for those who are suffering from eating disorders (Rienecke, Accurso, Lock, & Le Grange, 2016).

Being a caregiver of a youth with a serious emotional disturbance is a demanding responsibility that presents unique challenges (Oruche et al., 2015). Parent of children with attention-deficit/hyperactivity disorder (ADHD) may experience conflict, chaos, and fatigue (Kendall, 1998; Moen, Hall-Lord, & Hedelin, 2011). They often experience stress and frustration in their caregiving role (Krahé et al., 2015; Moen et al., 2011). In addition, parents' own mental health can perpetuate particular behaviors, such as with eating disorders (Treasure, 2010), and their level of stress may affect aggressive behavior in children with ADHD (Krahé et al., 2015).

2.2 | Child experiences of illness that parents' confront

Parents of children or adolescents with psychiatry illnesses or disorders that are in active psychiatry treatment are often dealing with complexed health situations. In addition, they might not only be dealing with the primary psychiatry illness diagnosis of their child, but also with other behavioral symptoms that might follow the primary illness diagnosis. For example, parents of children with ADHD or eating disorders might at the same time be dealing with anxiety and depressive symptoms or suicidal ideations in their child/adolescent. Therefore, understanding family needs for educational and psychosocial support and what contributes to their satisfaction with the healthcare services, across a variety of psychiatric illnesses, might particularly be beneficial in clinical settings.

Anxiety disorders in children and adolescents are common and may become a lifelong psychiatric disturbance (Creswell, Waite, & Cooper, 2014). Parents of children with anxiety disorders usually perceive their offspring with excessive worries and feelings of fear, being restless and irritable, lacking concentration, sleeplessness, shortness of breath, and rapid heartbeat (World Health Organization, 1993). Anxious children have lower estimates of their ability to cope with danger than children who are not anxious; children with anxiety have dysfunctional cognition about ambiguous situations (Bögels & Zigterman, 2000). Therefore, parents of anxious children often face ongoing concerns as anxiety is a predictor of a range of psychiatric disorders in adolescence and adulthood (Bittner et al., 2007).

In contrast, adolescents with depression perceive that life is dark, the world unsafe and that they are unworthy (Diamond et al., 2014). Often, depressed adolescents lose their interests, passion for life, and their inner voice. They lack the expectation that their parents will understand their pain and instead use overregulation to protect themselves. As a result, depression may reinforce dependency when they are expected to develop autonomy (Diamond et al., 2014). Some parents experience their child's withdrawal from themselves, their activities, and friends. They may be faced with adolescents who self-harm or even attempt suicide.

Parents of children and adolescents with ADHD face developmentally inappropriate symptoms that may result in a persistent pattern of impairment in daily functioning and diminished school and social activities (Montoya, Colom, & Ferrin, 2011). These difficulties can lead to emotional problems, aggression, and learning difficulties (Barkley, 2005). Further, symptoms of ADHD may become more complex in adolescence as these children may suffer from anxiety or depression.

Finally are the dilemmas parents face when their child is dealing with an eating disorder. Parents of children with eating disorders may see worsening, physical, mental, and social health in their child (Muscari, 2002) which might have an impact on the family QOL. Additionally, these parents often develop hindering illness beliefs that hold them in a destructive cycle, dominated by their child's illness (Geller, 2006). Further, a consequence of the eating disorders may be that the children/adolescents can develop anxiety or depression, although some may have had it previously (Swinbourne et al., 2012).

For this current study, it was hypothesized that perceived family support and illness beliefs would predict satisfaction with the healthcare service among families of children with psychiatric disorders/illnesses such as depression, anxiety, ADHD, eating disorders, and autism/Asperger's syndrome. Additionally, the following research questions were asked: (a) What is the correlation between family support, illness beliefs, healthcare services satisfaction, and QOL among families of children with depression and anxiety, ADHD, eating disorders, and autism/Asperger's syndrome? (b) Is there a significant sex difference between parents (mothers/fathers) of children/adolescents with psychiatric illnesses, regarding their illness beliefs, family support, perception of QOL and satisfaction with the healthcare services? (c) Is there a significant difference in family support, illness beliefs, QOL, and satisfaction with the healthcare service among families of children/adolescents who are in active psychiatric treatment, based on the mental health diagnosis?

3 | METHODS

3.1 | Sample

In this study, participants were 68 families of children with depression, anxiety, ADHD, eating disorders, autism, and Asperger at the Children's Psychiatry Unit at Landspitali, the National and University Hospital (LUH). At the time of data collection, all parents (*n* = 97) of children in active treatment were invited to participate in the study; the resulting 68 represented a 70% response rate. See Table 1 for further information about the demographics of the sample, illnesses, and family variables. The child and adolescent psychiatry unit at LUH in Reykjavik Iceland is both an inpatient and an outpatient unit. It is the only nationwide service in Iceland but approximately 340,000 inhabitants live in the country (Statistics Iceland, 2016). The unit provides care to youths with a wide range of psychiatric disorders mainly anxiety, depression, eating disorders, behavioral problems, such as ADHD and suicidal ideation.

3.2 | Procedures

Data were collected from March 2015 to December 2016. Approval for the study was received from the Scientific Ethical Board of LNUH (39/2014), and the National Bioethics Committee in Iceland (S7110). Participants who meth the inclusion criteria were introduced to the study by a research assistant at the children's psychiatric unit. The parents who agreed to participate received an introduction letter about the study. All participants needed to be able to read at the 4th grade level. Inclusion criteria were (a) being a parent of a child diagnosed with a psychiatry

TABLE 1 Demographic characteristics of the sample (*n* = 68)

Background variables	*n*	%
Age of child/adolescent		
6–11 years	6	8.8
12–16 years	38	55.9
17–22 years	24	35.3
Child's sex		
Boy	26	38.2
Girl	42	61.8
Child's disorder or illness diagnosis		
Anxiety and depression	24	35.3
ADHD	26	38.2
Eating disorder	8	11.8
Autism/Asperger	10	14.7
Has the child other diagnosis than mental illness diagnosis or developmental delayed disorder?		
Yes	17	25.8
No	49	74.2
Is the child in individual therapy now?		
Private practice	2	4.3
At LUH-children's psychiatry unit	45	95.7
How long time has the child been in therapy?		
1–6 months	14	30
7–12 months	11	24
1–2 years	11	24
2 years or more	10	22
Do you think you child is well rested when she/he wakes up in the morning?		
Yes	22	32.8
No	45	67.2
Do you think the disorder/illness diagnosis has had an impact on the child's skap (lundarfar) mental stage?		
Yes	60	90.9
No	6	9.1
How do you evaluate your child's physical health?		
Very good	13	19.4
Good	25	37.3
Poor	20	29.9
Very poor	9	13.4
How do you evaluate you child's mental health?		
Very good	3	4.5
Good	14	20.9
Poor	17	25.4
Very poor	33	49.3
Does you child take medications regularly?		
Yes	53	81.5
No	12	18.5
Has you child been hospitalized because of an illness?		
Yes	24	35.8
No	43	64.2
Have you received information regarding your child's disorder/illness?		
Yes	51	77.3
No	15	22.7
Do you now need support from healthcare professionals?		
Yes	48	71.6
No	19	28.4

(Continues)

TABLE 1 (Continued)

Background variables	*n*	%
Does the child have more than one home?		
Yes	13	19.4
No	54	80.6
How would you describe your physical health?		
Very good	13	19.4
Good	22	32.8
Poor	19	28.4
Very poor	13	19.4
How would you describe your mental health?		
Very good	11	16.4
Good	30	44.8
Poor	22	32.8
Very poor	4	6
Has someone in your family experienced a crisis within the last 12 months?		
Yes	32	47.8
No	35	52.2
If yes what was the reason for the crisis'		
Diagnosed with a serious illness	7	33.3
Serious accident	1	4.8
Lost work	2	9.5
Death	10	47.6
Miscarriage	1	4.8
Have you received a family interview?		
Yes	37	56.1
No	29	43.9
Do you and your child with the disorder/mental illness diagnosis have arguments?		
Yes	46	68.7
No	21	31.3
Parent's sex?		
Male	13	21.7
Female	47	78.3
Parent's age		
31–40 years	14	23.3
41–50 years	32	53.3
51–60 years	13	21.7
61 years or older	1	1.7
Education		
Primary and secondary school	9	18.4
High school	14	28.6
University	9	18.4
Graduate education in University(es)	17	34.7
Marital status		
Married	25	41.7
Cohabiting	14	23.3
Divorced	6	10
Divorced and remarried	7	11.7
Widow	1	1.7
Single parent	7	11.7

Note. n varies due to missing data.
ADHD: attention-deficit/hyperactivity disorder.

illness/disorder who was in active psychiatry treatment at the time of the data collection; and (b) being able to read and understand Icelandic or English. Participants were excluded if they were participating in another study at the time of data collection. Participants who were willing to participate in the study signed an informed consent, which was provided by the research assistant at the children's psychiatric unit. Once this was completed, the parents were given a code to login to a home page where they could complete the study questionnaires.

3.3 | Measures

The following self-administered measures/instruments, plus a demographic questionnaire, were used for data collection. Information regarding sex, age, education, and marital status were collected as well as background information regarding the child's health status such as (e.g., illness diagnoses, if in individual therapy now, how long the child has been in therapy, physical health, medication, etc.).

3.3.1 | The Iceland Family Perceived Support Questionnaire (ICE-PFSQ)

Parents' perceived support was measured with the ICE-PFSQ. The ICE-PFSQ is a valid 14-item questionnaire with the cognitive and emotional support subscales (Sveinbjarnardottir, Svavarsdottir, & Hrafnkelsson, 2012). The questionnaire is a valid and reliable Likert-type scale that ranges between 1 and 5 (Sveinbjarnardottir et al., 2012); where higher scores represents better formal support for families. Cronbach's α in the current study for the total scale = 0.961; $\alpha = 0.874$ for the Cognitive subscale and $\alpha = 0.937$ for the Emotional subscale.

3.3.2 | Icelandic-Family Illness Beliefs Questionnaire (ICE-FIBQ; Gisladottir & Svavarsdottir, 2016)

Parental illness beliefs were assessed with the ICE-FIBQ. The ICE-FIBQ is a seven-item questionnaire which measures illness beliefs. The ICE-FIBQ is a five-point Likert-type scale which evaluates the control of the illness, cause of the illness, the effect that the illness has, suffering because of the illness situation, and support. The ICE-FIBQ measures illness beliefs when family members are struggling with a complex and difficult situation. Higher scores indicate more reassurance about a caregiver's beliefs. In the current study, Cronbach's $\alpha = 0.789$. The instrument has been found to be both valid and reliable (Gisladottir & Svavarsdottir, 2016).

3.3.3 | PedsQL$^{\text{TM}}$—Family Impact Module

The family QOL was measured with the PedsQL instrument. The PedsQL is a 36-item measurement tool designed to assess the impact of pediatric chronic health conditions on families. It includes eight subscales that measure parents' self-reported functioning: physical functioning, emotional functioning, social functioning, cognitive functioning, communications, worry, daily activities, and family relationships. Cronbach's α has been reported to be 0.97 (Varni, Quiggens, & Ayala, 2000). Family members response range from 0 to 4 on a Likert-type scale, but then the scale items are transformed to 0–100; where higher scores point to better family QOL. In the current study, the Cronbach's α ranged from 0.739 to 0.974.

3.3.4 | PedsQL$^{\text{TM}}$—Healthcare Satisfaction Generic Module

Satisfaction with the healthcare service was evaluated with the PedsQL$^{\text{TM}}$—Healthcare Satisfaction Generic Module, which is a valid 24-item self-report instrument. The items are clustered into six domains associated with healthcare satisfaction: information, family inclusion, communication, technical skills, emotional needs, and overall satisfaction. Parents respond between 1 and 5 at a Likert-type scale. Higher scores representing being more satisfied with the healthcare service. Cronbach's α for this scale has been reported to be 0.79 (Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004). For this study, the Cronbach's α ranged from 0.856 to 0.974.

3.4 | Data analysis

Descriptive analyses were conducted on demographical variables; *t* tests (independent) were conducted to test sex differences between the mothers and the fathers' who participated in the study (there was only one of the parents' participating from each child). A stepwise regression analysis was conducted to identify predictors of the satisfaction with the healthcare service. Additionally, analysis of variances were conducted to test the differences in means in the main study variables, including illness beliefs, family support, family QOL, and satisfaction with the healthcare service among all families of children with anxiety/depression, ADHD, eating disorders and autism/Asperger. Post-hoc tests were conducted (Tukey, HSD) to find out where or between which illness groups, the significant difference actually was.

Field (2013), emphasize appropriate sample size in correlational and stepwise regression analysis is 10–15 participants per variable. We had, therefore, enough numbers ($n = 55$) for the two variables to be included in the regression model. IBM SPSS Statistics version 24.0 (IBM Corp. Released, 2013) was used for data analysis. Differences were considered statistically significant if $p < 0.05$.

4 | RESULTS

The families were dealing with severe psychiatric illnesses; but all families were receiving care at the Children's Psychiatry Unit at LUH. Diagnoses of the children included anxiety and depression ($n = 24$; 35%), ADHD ($n = 26$; 38%), eating disorder ($n = 8$; 12%), autism or Asperger's ($n = 10$; 15%). Further, one-quarter of the children ($n = 17$; 25.8%) were dealing with another illness diagnosis in addition to the primary psychiatric diagnosis. The majority of the children were in active individual therapy at the outpatient clinic at LUH at the time of the data collection ($n = 45$; 96%); for about half of the children ($n = 21$; 46%) the child had been in therapy for a least 1–2 years; for some it was more than two years. Respondents indicated that the child took medication(s) regularly ($n = 53$; 81.5%); the child had been hospitalized because of an illness in over a third of the families ($n = 24$; 35.8%). Most of the children were preteens or adolescents ($n = 62$; 92%). Although many parents perceived their child's physical health to be very good or good ($n = 38$; 57%), three-quarters rated their child's mental health to be poor or very poor ($n = 50$; 75%). Most of the parents believed that the mental illness had had an impact on the child's mood within the last month ($n = 60$; 91%); most parents indicated that they had gotten information regarding their child's illness or disorder ($n = 51$; 77%); but at the same time, that they now needed support from healthcare practitioners ($n = 48$; 72%).

In addition, even though most of the parents described their own mental health to be good or very good ($n = 41$, 61%); only half of them described their physical health to be good or very good ($n = 35$; 52%). About half of the parents reported that someone in their family had experienced that the parents indicated that the reason for the crisis was that someone in their family was diagnosed with serious illness, death, or had a serious accident (see Table 1). The majority of the parents were women ($n = 47$; 78%), 41–50 years ($n = 32$; 53%), with a University education ($n = 26$; 53%). Most parents were married/cohabiting together ($n = 39$; 65%; Table 1).

4.1 | Correlations

Pearson's correlations (*r*) were conducted between all the major study variables. Satisfaction with the healthcare service was found to be significantly correlated with perceived family support ($r = 0.348$; $p < 0.01$); with illness beliefs ($r = 0.435$; $p < 0.01$) and with the family QOL ($r = 0.359$; $p < 0.01$). Perceived family support was found to be significantly correlated with the family QOL ($r = 0.275$; $p < 0.05$); this indicates that families who reported higher satisfaction with the healthcare service, also reported positive perceptions regarding their family support and positive perception regarding their child's illness beliefs. Families who reported positive perceptions of their family support also reported higher QOL (Table 2).

4.2 | Sex differences

A significant difference was found on the parents perception toward their illness beliefs: The mothers in the sample reported significantly higher illness beliefs than the fathers (mothers mean [MM] = 25.04, $SD = 4.10$; fathers mean [FM] = 19.83, $SD = 4.37$, $t = 3.864$; $p = 0.000$). This suggests that the mothers were more confident about the illness situation, they had greater involvement and a better understanding of the psychiatric illness compared to the fathers in the sample (see Table 3). However, the fathers reported significantly higher family support on both the total score (FM = 47.81, $SD = 16.00$; MM = 37.41, $SD = 13.96$, $t = -2.229$, $p = 0.030$) as well as on the subscale for cognitive support (FM = 18.38, $SD = 5.52$; MM = 14.06, $SD = 5\ \ 0.26$, $t = -2.560$, $p = 0.012$) than the mothers. Thus the fathers in this study perceived they received more family and cognitive support than the mothers (Table 3).

TABLE 2 Correlations between parents perception on satisfaction with the healthcare service, perceived family support, illness beliefs, and family quality of life, among families of children and adolescents with mental illnesses/disorders (*n* = 57)

	n	SHCS	PFS	IB	QOL
Satisfaction with the healthcare service (SHCS)	57	1.000	0.348**	0:435**	0.359**
Perceived family support (PFS)	56		1.000	0.116	0.275*
Illness beliefs (IB)	56			1.000	0.151
Quality of life (QOL) regarding the family	57				1.000

Note. n varies due to missing data.

On the family QOL scale, the fathers reported significantly higher physical functioning (FM = 7 0.51, *SD* = 2 0.51; MM = 51.42, *SD* = 25.84, *t* = −2.454, *p* = 0.017); as well as significantly higher QOL (total score; FM = 62.51, *SD* = 26.03; MM = 48.32, *SD* = 27.78, *t* = −2.326, *p* = 0.024; see Table 3). In contrast, mothers reported being significantly more worried than fathers (FM = 56.54, *SD* = 24.10; MM = 35.27, *SD* = 21.23, *t* = −3.106, *p* = 0.033; Table 3).

4.3 | Comparisons by diagnoses

Among families of children with eating disorders, a significant difference was found on perceived family support when compared to families of children with anxiety/depression, ADHD and Autism/Asperger's syndrome (mean eating disorder = 55.77, *SD* = 9.23; mean anxiety/depression = 39.84, *SD* = 13.02; mean ADHD = 33.58, *SD* = 11.76; mean autism/Asperger = 35.04, *SD* = 20.40; *t* = 5.501, *p* = 0.002); indicating families of children with eating disorder perceived significant higher family support, that is both emotional and cognitive support, compared to families of children with anxiety/depression, ADHD, and autism/Asperger (Table 4).

However, parents of children with anxiety and depression reported significantly higher QOL (total scale score) than families of children with ADHD (mean anxiety/depression = 68.18, *SD* = 15.92; mean ADHD = 45.00, *SD* = 20.88, *p* = 0.001). That is, families of children with anxiety and depression reported higher QOL compared to families of children with ADHD. Additionally, families of children with ADHD were significantly more worried than families of children with anxiety/depression (mean ADHD = 30.67, 17.47; mean anxiety/depression = 48.70, *SD* = 23.51, *p* = 0.033); and the families of children with anxiety/depression reported significantly better functioning regarding daily activities compared to families of children with ADHD (mean anxiety/depression = 66.29, *SD* = 27.63; mean ADHD = 39.74, *SD* = 26.38, *p* = 0.004). Indicating, families of children with ADHD reported to be more worried and to be functioning worse regarding daily activities than families of children with anxiety and depression. Further, families of children with anxiety/depression reported significantly higher communications functioning in the family than families of children with ADHD, eating disorder or autism/Asperger (mean anxiety/depression = 68.18, *SD* = 15.92; mean ADHD = 45.00, *SD* = 20.88; mean eating disorder = 45.00, *SD* = 21.55; mean autism/Asperger = 42.50, *SD* = 18.60; *t* = 7.613, *p* = 0.000; see Table 4). Thus, parents of children/adolescents with anxiety and depression reported better communication in the families than parents of children with ADHD, eating disorder or autism and Asperger. In addition, families of children with Autism/Asperger reported significantly higher on the technical skills subscale of the satisfaction with the healthcare service scale, than families of children

TABLE 3 Independent *t* tests of mothers and fathers illness beliefs, perceived family support, perception on the quality of life for the family, and satisfaction with the healthcare service among families of children with mental illnesses or disorders (*n* = 60)

	Mothers			Fathers					
Caregivers outcomes	*n*	Mean	*SD*	*n*	Mean	*SD*	*df*	*t*-Value	*p*-Value
Illness beliefs	45	25.04	4.10	12	19.83	4.37	55	3.864	0.000
Perceived family support (total)	46	37.41	13.96	12	47.81	16.00	56	−2.229	0.030
Cognitive support	47	14.06	5.26	13	18.38	5.52		−2.560	0.012
Emotional support	46	23.48	9.22	12	29.31	10.70		−1.887	0.064
Family Quality of Life (total)	47	48.32	27.78	13	62.51	26.03	58	−2.326	0.024
Physical	47	51.42	25.84	13	70.51	20.51		−2.454	0.017
Emotional	47	47.32	22.74	13	60.48	21.82		−1.863	0.067
Social	47	50.00	29.18	13	24.73	6.86		−1.734	0.088
Cognitive	47	53.94	24.11	13	67.31	24.38		−1.766	0.083
Communication	46	44.57	27.06	13	58.97	29.4		−1.657	0.103
Worry	47	35.27	21.23	13	56.54	24.10		−3.106	0.033
Daily activities	47	48.40	27.78	13	61.54	26.03		−1.528	0.132
Family communication	47	52.23	21.86	13	54.62	19.94		−0.354	0.725
Satisfaction with healthcare service (total)	45	67.35	23.21	12	68.66	16.10	55	−0.183	0.855
Information	42	57.47	25.21	12	63.23	18.95		−0.732	0.467
Family	44	72.25	25.06	12	72.40	17.97		−0.018	0.985
Communication	33	68.79	22.78	9	68.33	23.95		0.053	0.958
Skills	29	67.10	26.90	10	73.33	18.34		−0.678	0.502
Emotional needs	28	58.78	23.20	9	67.36	18.16		−1.012	0.319
General satisfaction	43	75.87	25.85	12	68.66	16.10		0.064	0.950

TABLE 4 Analysis of variance results on parents illness beliefs, perceived family support, family quality of life and satisfaction with the healthcare service based on the children and the adolescent's disorder or mental illness diagnoses (n = 57)

	Anxiety/depression			ADHD			Eating disorder			Autism/Asperger					Tukey HSD
Outcomes	*n*	Mean	*SD*	*n*	Mean	*SD*	*n*	Mean	*SD*	n	Mean	*SD*	*F*	*p*-Value	*p*-Value
Illness beliefs	22	24.68	4.64	18	23.50	3.94	8	23.50	3.70	9	23.44	6.82	0.288	0.834	
Perceived family support (total)	22	39.84	13.02	21	33.58	11.76	8	55.77	9.23	9	35.04	20.40	5.501	0.002	3 > 1*, 3 > 2***, 3 > 4*
Cognitive support	22	14.73	5.19	24	13.13	4.40	8	20.63	3.85	10	14.70	7.92	4.035	0.011	3 > 1*, 3 > 2**
Emotional support	22	25.12	8.43	21	20.96	8.06	8	35.14	6.36	9	21.27	12.76	5.423	0.002	3 > 1*, 3 > 2**, 3 > 4*
Family quality of life	22	60.27	21.38	26	44.52	18.64	8	53.21	17.40	10	47.48	13.14	2.957	0.039	1 > 2*
Physical	23	62.71	26.29	26	46.63	26.14	8	62.50	18.50	10	55.83	18.13	2.027	0.119	
Emotional	23	53.37	22.61	26	45.00	22.09	8	53.75	28.50	10	52.75	14.16	0.746	0.529	
Social	23	60.14	29.40	26	50.00	32.32	8	60.42	13.91	10	49.17	30.03	0.701	0.555	
Cognitive	23	60.00	28.20	26	53.51	25.76	8	57.50	16.48	10	50.00	20.14	0.477	0.699	
Communication	22	54.54	30.40	25	40.00	26.14	8	55.21	22.24	10	51.67	26.00	1.377	0.258	
Worries	23	48.70	23.51	26	30.67	17.47	8	41.88	27.77	10	32.00	26.79	2.984	0.038	2 > 1*
Daily activities	22	66.29	27.63	26	39.74	26.38	8	46.88	20.86	10	41.67	22.22	4.716	0.005	1 > 2**
Communications in family	22	68.18	15.92	26	45.00	20.88	8	45.00	21.55	10	42.50	18.60	7.613	0.000	1 > 2**, 1 > 3*, 1 > 4**
Satisfaction with healthcare service (total)	22	69.08	18.73	18	62.67	20.70	8	70.67	29.34	9	71.29	25.52	0.466	0.707	
Information	18	60.49	22.70	20	55.68	22.45	8	62.50	26.80	8	58.75	30.68	0.197	0.898	
Family	22	74.15	21.50	19	67.32	22.78	7	73.21	33.99	8	78.13	23.15	0.480	0.698	
Communication	15	72.33	22.17	15	63.67	16.09	6	67.50	33.58	6	73.33	29.44	0.443	0.724	
Skills	15	69.67	16.20	11	56.06	23.96	7	67.86	34.50	6	91.67	20.41	3.086	0.040	4 > 2*
Emotional needs	14	67.56	19.33	14	54.02	19.86	6	62.50	34.46	3	58.33	14.43	0.888	0.457	
General satisfaction	22	77.08	21.89	17	64.95	24.21	8	82.29	34.05	8	88.54	19.38	2.069	0.116	

Note. *n* varies due to missing data.
*$p < 0.05$
**$p < 0.01$
***$p < 0.001$

with ADHD (mean autism/Asperger = 91.67, *SD* = 20.41; mean ADHD = 56.06, *SD* = 23.96; *t* = 3.086, *p* = 0.040; Table 4).

4.4 | Stepwise regression analysis

Relationships among the variables in the IBM (Wright & Bell, 2009) and the CFAM/CFIM (Wright & Leahey, 2013), including the direct and indirect effects of family support, illness beliefs, and family QOL on satisfaction with the healthcare service were tested. The results from the stepwise regression analyze indicated that perceived family support and illness beliefs explained 23% of the variance in the outcome of satisfaction with the healthcare service (adjusted $R^{2 =}$ 0.22.8; $p < 0.001$; Table 5). The hypothesis was therefore supported.

5 | DISCUSSION

Knowing what components contribute to satisfaction with the healthcare service among families of children/adolescents with serious psychiatric illnesses, is important so that effective family interventions can be developed. The main finding indicated that illness beliefs and family support predicted healthcare satisfaction among families of children and adolescents with severe psychiatric illnesses. The parents had a major burden of caregiving and described the mental illness of their child to be poor. It is interesting, however, that most of the parents described their own mental health as being good or better, although only half had good or better physical health.

TABLE 5 Stepwise regression analysis for predicting satisfaction with the healthcare service among families of children with mental illnesses/disorders (n = 55)

	Model I		
Steps and variables	*B*	β^a	*t*
Constant	42.31		
Perceived family support	0.581	0.401	3.329**
Beliefs	1.293	0.268	2.231*
R^2	0.257		
Adjusted R^2	0.228		
F	8.976***		

[a] Standard coefficients.
*$p < 0.05$.
**$p < 0.01$.
***$p < 0.001$.

Most reported they were in need of support from healthcare providers, but only half had received a family interview at the psychiatric unit. Parents who reported the higher perception of support for their family, more understanding and knowledge about their child illness and better QOL were more satisfied with the healthcare service. In a similar study on satisfaction both on youth and parents in a mental health community-based care (Garland et al., 2007), higher parental satisfaction was revealed in association with lower caregiver strain, but an increased number of sessions and improvements in youth functional status were found to be correlated with higher satisfaction. In contrast, Barber et al. (2006) reported no relationship between caregiver strain and satisfaction with healthcare services.

Interestingly, when comparisons were made between perceived family support across psychiatric illnesses, thought-provoking results were revealed. The parents of children and adolescents with eating disorders perceived significant better family cognitive and emotional support than parents of children with other psychiatric diagnoses. One explanation for this finding is that families of children with eating disorders receive more family support from psychiatry nursing in Iceland than families of children with other psychiatry illnesses. These results are new and are in line with earlier results from Gisladottir et al. (2016), where most of the caregivers of youths with eating disorders reported a psychoeducational and support intervention provided both cognitive and emotional support.

Parents of children with psychiatric diagnoses are often dealing with multiple or changing diagnoses. For example, anxiety may evolve to depression and vice versa; ADHD may escalate to oppositional defiant disorder (Costello et al., 2003). It is known that anxiety in children is very common and is a predictor of a range of psychiatric disorders in adolescence and often, lifelong psychiatric illness (Bittner et al., 2007; Creswell et al., 2014). It is important to keep in mind that, positive parent–child relationships can reduce the aforementioned disorders (Jakobsen et al., 2012), which emphasizes, even more, the need to develop effective family level interventions.

In this study, parents of children/adolescents with ADHD had significantly more worries and poorer functioning regarding daily activities compared to than parents of children and adolescents with anxiety and depression. Parents of adolescents with anxiety and depression reported better communication than parents of children with ADHD, eating disorders, and autism/Asperger's syndrome and significantly better QOL than families of children and adolescents with ADHD. This finding emphasizes the need for more in-depth psychoeducational support intervention or for a bigger proportion of a psychoeducational and support intervention, for families of children with ADHD. ADHD is a complex disorder especially around the adolescents' years, which might require an intense support from psychiatric healthcare professionals. Further, this finding is in line with a study from Derisley et al. (2005) were parent perceptions of children with anxiety disorders of family functioning seemed to have poorer mental health and to use more avoidant coping. Gisladottir and Svavarsdottir (2017) studied a psychoeducational and support intervention for parents of adolescents with ADHD and reported the need for more intense intervention. Additionally, Gisladottir and Svavarsdottir (2017) and Gisladottir et al. (2016) found caregivers of adolescents with an eating disorder or ADHD had significantly better QOL, after a psychoeducational support intervention. Consequently, it is important to involve and retain families in mental health prevention and intervention programs to assure thorough public health impact (Ingoldsby, 2010).

In this study, mothers were found to have higher perceived illness beliefs than the fathers although the fathers reported higher family support. This finding is new and indicates that the mothers were more confident about the illness situation, which might be because the mothers might have been in general, more involved with the healthcare system than the fathers. Further, this finding is in harmony with results from Sofronoff and Farbotko (2002) on the benefit of a parental intervention. They found fewer problematic behaviors in children with the Asperger's syndrome and increased self-efficacy postintervention by the mothers but not the fathers (Sofronoff & Farbotko, 2002).

5.1 | Limitations

The major limitation of the study is few participants of families of children with eating disorder and of children with autism/Asperger. The findings should, therefore, be generalized with caution. However, the sample represents a nation with few inhibits, so increasing the number of participants in these illness groups, would require international sampling procedures. There are a number of missing data in some of the analyzes which might be due to the fact of the high level of caregiving demands among the parents. Future research should, therefore, focus on including a sample of families from multiple countries that would participate over time.

6 | CONCLUSION

Parents need help and professional guidance to meet the needs of their ill children and maintain their own health, QOL, and their satisfaction with the healthcare service. In general, they are resourceful individuals and highly motivated to accept support from healthcare professionals. When parents become involved in their child's care, the risk of a relapse for the child is reduced. The findings from this study emphasize the importance of family involvement in child psychiatric care, but knowing that formal family support from healthcare professionals is positively correlated with QOL is important. Psychiatric nurses need to remember this in order for them to be able to maintain or to reboost their support with the family network. Also, knowing that family support and illness beliefs are significant predictors of satisfaction with the healthcare service, is important for the development of effective family level interventions. These families need specific interventions where the focus is on the illness and formal family support.

The sex difference that might occur between the parents regarding their illness beliefs and their emotional and educational family support should be considered. Family support can decrease worries and might improve the behavior of children or adolescents with ADHD. Therefore, effective family level interventions need to be developed for families of children and adolescents with a variety of different psychiatric illnesses. Nurses working in psychiatric settings need to emphasize supporting families of children who have serious mental illnesses. It is crucial to develop and test effective family level therapeutic conversations for children with anxiety, depression, ADHD, eating disorders, autism, or Asperger's syndrome, where the focus could be on family QOL, illness beliefs, family support, on sex differences between the parents and on satisfaction with the healthcare service.

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CONFLICTS OF INTEREST

The authors declare that there are no conflicts of interest.

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