

Feasibility of the Children's Health Questionnaire for Measuring Outcomes of Recreational Therapy Interventions in Autism Populations

Research Paper

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Abstract

Autism stakeholder groups prioritize applied intervention research to improve conditions co-occurring with autism spectrum disorders (ASD), but health-related quality of life measures aren't established for children with ASD. The purpose of this study was to estimate rates and variability of responses of parents of children with ASD on the Children's Health Questionnaire (CHQ) to inform future recreational therapy intervention research with this population. This study used pre-post design to gather parent responses for 31 children with ASD before and after intervention. Confidence intervals indicated CHQ summary scores were more precise than scale scores. Several profile scales showed greater variability at post-testing. Parents of children with ASD reported lower scores than the general population across all CHQ measures, particularly in behavior, mental health and psychosocial health. The CHQ PF-28 is an appropriate measure of health-related quality of life of children with ASD. Future research should confirm these findings and investigate use of child report versions of the CHQ with children with ASD.

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This study was supported in part by the Recreational Therapy Foundation, a NIH Clinical and Translational Science Award grant (UL1 TR002366) awarded to KUMC, and an internal Clinical Pilot Research Grant Program of the KUMC Research Institute and the School of Health Professions.

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Keywords

Assessment, autism, intervention, health-related quality of life, recreation therapy

Introduction

Autism spectrum disorder (ASD) is characterized by restricted social behaviors, impairments in communication and language, and a narrow range of interests and activities that are often carried out repetitively (American Psychiatric Association, 2013). In the United States about 1 in 54 children has an ASD, with all racial, ethnic, and socioeconomic groups impacted (Maenner et al., 2020). Prevalence of ASD continuously increases making it one of the most common developmental disorders present in children (Srivastava & Schwartz, 2014). In addition to the core symptoms of ASD, over 95% of children experience at least one co-occurring condition or symptom (Soke et al., 2018). For example, up to 80% have disordered sleep (Lawson & Little, 2017; Singh & Zimmerman, 2015), 95% of children experience sensory issues (Tomchek & Dunn, 2007), up to 85% have associated motor impairments (Hilton, 2011), and over 40% are overweight or obese (Lawson & Foster, 2016; Phillips et al., 2014) increasing risk of diabetes, cardiovascular disease, and certain cancers (Kumar & Kelly, 2017). These and other co-occurring conditions often contribute to poor health, a higher level of impairment, increased need for services, and impact the quality of life of children with ASD and their families (Soke et al., 2018).

Autism Research Priorities

The Interagency Autism Coordinating Committee (IACC), a federal advisory committee that advises the Secretary of Health and Human Services, recognized the importance of co-occurring conditions in its *2016-2017 Strategic Plan for Autism Spectrum Disorder*. The IACC acknowledges gains in understanding the nature and prevalence of co-occurring conditions in persons with ASD, but indicates further understanding is needed to develop strategies to target these co-occurring conditions successfully (IACC, 2017). Co-occurring conditions are specifically prioritized six times in the plan's objectives, including an objective to "create and improve psychosocial, developmental, and naturalistic interventions for the core symptoms and co-occurring conditions in ASD" (p. XII). A survey of 6004 community stakeholders, including individuals with ASD, confirmed that research of co-occurring conditions and health and well-being should be prioritized (Frazier et al., 2018). Furthermore, stakeholders prioritized applied research over basic science, particularly research to develop, evaluate or improve interventions. The autism community wants timely interventions and solutions to improve quality of life, creating opportunity for the therapeutic recreation profession to contribute to the body of knowledge through research and documentation of effective interventions (Devine & Ripp, 2017).

Recreational Therapy Interventions for Co-occurring Conditions

Because restricted, repetitive patterns of behavior, interests, or activities is a core diagnostic feature of autism (APA, 2013), recreational therapists are in a powerful position to improve health and quality of life of individuals with ASD. Therapeutic recreation professionals understand recreation is an important component of the human experience (Devine & Ripp, 2017) and can provide recreation as treatment to improve

function or health, support acquisition of leisure knowledge and skills, and facilitate healthy leisure participation (Austin, 1998; Stumbo & Peterson, 1998). Evidence shows several recreational therapy interventions are encouraging for improving function and health of individuals with ASD. For example, animal-assisted therapies following specific recreational therapy protocols can increase social behaviors and decrease negative behaviors, stress and anxiety of individuals (Hallyburton & Hinton, 2017). They may also increase safety, motor skills, and autonomy, particularly for children (Hallyburton & Hinton, 2017, Hawkins et al., 2014). Camp experiences facilitated by recreational therapists are also favorable. For example, both quantitative and qualitative research showed participation in a family camp specifically designed for families with a child with ASD improved family well-being (Townsend & Van Puymbroeck, 2017; Wenzel et al., 2020). Additionally, a multi-sport camp specifically for girls with ASD resulted in improved motor skills, physical self-perceptions, and social skills (Guest et al., 2017).

Physical activity interventions, particularly physically active recreation interventions, are an especially promising solution to treat co-occurring conditions. Research shows children with ASD are more motivated and successful in physical activity when enjoyment is emphasized in a preferred activity with supports individualized to their specific needs (Lawson et al., 2017; Obrusnikova & Cavalier, 2011). Recreational therapy is individualized to each person's interests, making it the ideal therapy for developing and implementing physically active recreation interventions with individuals with ASD. Numerous studies suggest that physical active recreation interventions are beneficial to children with ASD, producing improvements in social skills (Stuhl & Porter, 2015), motor skills and motor function (Lawson et al., 2017), body measures (Lawson et al., 2020) and sleep (Lawson & Little, 2017; Oriel et al., 2016). Interestingly, water-based physical activity interventions such as surfing (Stuhl & Porter 2015), and swimming (Lawson et al., 2017; Lawson & Little, 2017; Lawson et al. 2020) show potential to be especially helpful, possibly because they are preferred recreation activities of children with ASD (Stanish et al., 2017).

But gaps in evidence for the ASD population exist (Lang et al., 2010; Sowa & Meulenbroek, 2012). Though there are several encouraging recreational therapy interventions for individuals with ASD, the research is limited by small samples, lack of comparison groups and inconsistency of outcome measures. Recreational physical activity research, in particular, is further hindered by lack of standardized measures for determining activity levels and evaluating outcomes (Lawson et al., 2019; Lawson & Lisk, 2019).

Diagnostic and Intervention Measures

Successful interventions for children with ASDs have the potential to greatly affect health outcomes for the child and can contribute to child and family quality of life. Understanding of the various approaches for measuring health outcomes and selecting appropriate instruments suitable to the population of children with ASD is critical for determining if interventions are effective (Payakachat et al., 2012). Best practice for autism research includes verification of the ASD diagnosis when participants are not recruited through physicians or diagnostic clinics (Daniels et al., 2012). Established measures for verifying ASD for research include the Autism Diagnostic Interview—Revised, Autism Diagnostic Observation Schedule and its Severity Score, Childhood Autism Rating Scale and the Social Responsiveness Scale (Constantino et al., 2003; Payakachat et al., 2012). Recommendations of physical activity measurement of chil-

dren with ASD are consistent with those for typically developing children with activity monitors considered the gold standard (Troiano et al., 2014). However, measurement issues exist because some children with ASD cannot tolerate wearing them and they do not measure water-based physical activity (e.g., swimming), which is most preferred by children with ASD (Stanish et al., 2017). Quality of life measures are also problematic for children with ASD, particularly health-related quality of life measures that encompass aspects of overall quality of life that can be clearly shown to affect physical or mental health (Health Related Quality of Life, 2018). Though measurement of health-related quality of life in the general population of children has improved dramatically over time with the development of several instruments specific to pediatric populations (e.g., NIH-initiated Patient Reported Outcome Measurement Information System, Pediatric Quality of Life Inventory™), they are not validated for use with children with ASD (Payakachat et al., 2012). Recognizing parents of children with ASD experience caregiving challenges and stress that may impact both child and family quality of life (Hayes & Watson, 2013), it is important to utilize measures that capture these concerns. The Children's Health Questionnaire is a promising measure for ASD recreational therapy research as it focuses on aspects of a child's health that might impact family functioning as well as behavior problems and self-esteem of a child (HealthActCHQ, 2013; Hullmann et al., 2011). It shows good reliability and validity with the general population of children and some disability groups (e.g., asthma, ADHD, epilepsy, and psychiatric disorder) (HealthActCHQ, 2013), but is not an established measure for ASD research.

Summary of Study Rationale

Both the IACC and stakeholder groups prioritize applied intervention research. Recreational therapy interventions, particularly physically active recreation interventions show promise for improving co-occurring conditions among individuals in the autism population. Current research is hindered by lack of established measures for ASD populations, particularly for health-related quality of life which is an important outcome in recreational therapy research. The Children's Health Questionnaire is a good measure in the general pediatric population and for several disability groups. Therefore, the purpose of this study was to estimate rates and variability of responses of parents of children with ASD on the Children's Health Questionnaire (CHQ) to inform future intervention research with this population.

Methodology

Design

This study used a pre-post design to estimate rates and variability of responses of parents of children with ASD on the Children's Health Questionnaire (CHQ).

Participants

Children were included if they had an SRS score indicating probable autism (>62), a diagnosis of ASD and parents could complete measures in English. The inclusion criteria were intentionally broad to capture a diverse sample of children with ASD. Children were excluded if they had co-occurring severe sensory impairments (e.g., blindness) as some evidenced-based teaching methods utilized in the intervention (e.g., visual aids) are not helpful for children with sensory impairments. At least 12

participants are recommended for studies with primary focus of estimating average values and variability for planning larger subsequent studies (Moore et al., 2011). This allows for reasonable width of confidence interval while considering study pragmatics. We aimed to recruit 35 participants to maximize variation of the sample.

Measures

Demographic Form

We created a demographic form questionnaire to collect information about families' characteristics, such as race/ethnicity, socioeconomic status, and number of children in the household. We also collected information about medications, associated medical conditions, and participation in formal and informal recreation activities.

Social Responsiveness Scale- 2nd Edition (SRS-2)

The SRS-2 school-aged form is a 65-item caregiver report that measures autism severity in children and adolescents ages 4 to 18 years (Constantino & Gruber, 2012). It has five subscales including Social Awareness, Social Cognition, Social Communication, Social Motivation and Restricted Interests and Repetitive Behavior Awareness. It takes about 15-20 minutes to complete the SRS-2 and higher scores indicate greater social impairment. It has been found to have a single factor structure (Constantino et al., 2003; Constantino et al., 2004) and convergent validity with the Autism Diagnostic Interview-Revised (Lord et al., 1999). A cutoff score of 62 identifies 96.8% of children with ASD yielding sensitivity and specificity values of .92. The SRS-2 was administered at baseline only.

The Child Sensory Profile 2 (CSP2)

The CSP2 is an 86-item caregiver report questionnaire designed to measure sensory processing in children aged three to 14 years (Dunn, 2014). This measure provides scores for four sensory processing quadrants (registration, seeking, sensitivity, and avoiding), six sensory sections (auditory, visual, touch, movement, body position, and oral), and three behavioral sections (conduct, social-emotional, and attentional). Higher 'quadrants' or 'sections' scores indicate more sensory traits related to these quadrants or sections. Internal consistency of sensory processing quadrants, sensory and behavioral sections range between $r = .60-.90$. The CSP2 has a strong internal consistency (Cronbach's $\alpha=0.88-0.92$ across scales) and test-retest reliability ($r=0.96-0.97$ across scales) (Dunn, 2014).

The Child Health Questionnaire (CHQ-PF28)

This is a parent-reported measure of health-related quality of life normed for children 5-18 years old. It measures 13 unique physical and psychosocial concepts with single or multi-item scales, including: general health perceptions, physical health, emotional/behavior role functioning, physical role functioning, bodily pain, global behavior item, general behavior, mental health, self-esteem, parental impact (emotional), parental impact (time), family activities, family cohesion and change in health (HealthActCHQ, 2013). CHQ scoring produces 13 profile scores and summary scores for physical and psychosocial health. The CHQ-PF28 can be completed in 5-10 minutes. Internal consistency reliability of the CHQ summary scales (Cronbach's $\alpha=.93$) is well established with a nationally representative sample, and the median coefficient

(0.75) for the multi-item CHQ-PF28 profile scales also indicated good internal consistency (HealthActCHQ, 2013). Comparisons to established measures of individual constructs indicate validity is moderate to substantial for CHQ scales. The CHQ adequately discriminates between populations with no chronic conditions and subgroups with conditions (e.g., asthma) (Raat et al., 2005).

Procedures

One week before the intervention, the research team met with all families to obtain consent and administer baseline measures. Baseline measures included the demographic form, Children's Health Questionnaire Parent Form (CHQ-PF28), Social Responsiveness Scale-2nd Edition (SRS-2) and Child Sensory Profile 2 (CSP2). Parents completed the CHQ-PF28 again after the intervention. This research was approved by the University's Institutional Review Board (HSC #00141824).

Intervention

Sensory Enhanced Aquatics (SEA) is a specialized swimming and water safety program for children with ASD. Details of the intervention have been previously published (Lawson & Lisk, 2019). The program incorporates evidence-based approaches for children with ASD, including: 1) visual supports, 2) sensory supports, 3) communication strategies, 4) physical supports, and 5) modeling to maximize skill acquisition (Breslin & Rudisill, 2011; Dunn et al., 2012; Lawson et al., 2017; Oh et al., 2011; Yanardag et al., 2013). The children participated in 30-minute lessons once or twice weekly for 8 weeks. Lessons were 1:1 with social opportunities (e.g., songs and games) at the beginning and end of each lesson. Like general swim lessons, skills were taught in progression from water orientation (e.g., blowing bubbles, submerging different body parts) to advanced swimming (e.g., swimming 15 or more yards of different swim strokes). All lessons included instruction of water safety skills. Instructors attended a one-day workshop and 8 weeks of shadowing an experienced instructor prior to working 1:1 with swimmers. Review of over 80 swimmers program records indicated consistency of SEA teaching methods (Lawson et al., 2014). A manager was always on deck to support instructors and ensure fidelity of lessons.

Analysis

Researchers used SPSS version 25 for all statistical analysis. Descriptive statistics summarized demographic information and precision was expressed with 95% confidence intervals of the variance pre- and post-intervention. To further explore use of the Children's Health Questionnaire with children with ASD, means, standard deviation, and range of pretest responses of parents of children with ASD were compared to published data for the general pediatric population (Raat et al., 2005). Researchers also calculated ANOVA to ensure group equivalency of the three groups prior to running analysis related to the feasibility of the CHQ questionnaire.

Results

Participants

We recruited 35 children from a university program list. Thirty-one children met inclusion criteria for the study and completed baseline and post-test measures. Four children were excluded from analysis because their SRS-2 score was <62. Most participants were male (74.2%), Caucasian (54.8%), and had challenges consistent with

“severe” autism (45.2%). Participants ranged in age from 4-17 years old, and the average age was approximately 8 ($SD=2.72$). Slightly more than half (54.8%) of the participants were reported to be on one or more medications. Most children participated in informal (e.g., outdoor play) and/or formal (e.g., swim lessons) recreational activities. Participants received one of three swim sessions, with lessons occurring once weekly in the summer and twice weekly in the other sessions (see Table 1). There were no significant differences between the groups in gender ($F= .172, p=.812$), age ($F= .544, p=.589$), ethnicity ($F= 2.253, p=.124$), autism severity ($F= 1.577, p=.224$), medication use ($F= 1.336, p=.279$), recreation participation ($F= .450, p=.642$), or sensory patterns (seeking $F= .741, p=.487$; avoiding $F= .464, p=.634$; sensitivity $F= 1.570, p=.229$; low registration $F=1.889, p=.172$).

Table 1
Demographic Characteristics of Participants

Characteristics	Number of Participants	Percentage of Participants
Age		
4-6 years old	7	22.6
7-9 years old	16	51.6
10-12 years old	7	22.6
13-17 years old	1	3.2
Gender		
Male	23	74.2
Female	8	25.8
Diagnosis		
Autism	29	93.5
Asperger's	1	3.2
Other (e.g., PDD NOS)	1	3.2
Social Impairment Severity		
Mild	6	19.4
Moderate	11	35.5
Severe	14	45.2
Ethnicity		
Caucasian	17	54.8
African American	4	12.9
Asian	2	6.5
Latino	3	9.7
More than one	5	16.1
Medication		
Yes	17	54.8
No	14	45.2
Recreational Activities		
Formal & Informal	20	64.5
Informal Only	6	19.4
Formal Only	3	9.7
None	2	6.5
Swim Session		
1-Summer	13	41.9
2-October-December	9	29.0
3-January-March	9	29.0

Feasibility

Thirty-five parents completed the CHQ, and only two questionnaires included missing data. Missing data were limited to a few items with no predictability to suggest

items were intentionally skipped. Missing data were from children who were excluded from analysis due to low SRS-2 scores that did not confirm ASD diagnosis. Confidence intervals indicated the Physical Health and Psychosocial Health Summary scores are more precise than scale scores (See Table 2). Several profile scales (General Health, Physical Function, Role/Social Limitations-Physical, Behavior, Mental Health, Self-esteem, and Parent Impact-Time), showed greater variability at post-testing, possibly reflecting changes related to the intervention. Parents of children with ASD report lower scores on the CHQ than the general population (Raat et al., 2005) across all measures, particularly in areas of behavior, mental health and psychosocial health (see Table 3).

Table 2

Children's Health Questionnaire Means, Confidence Intervals and Variance

Profile Scores	Mean	Pre-test		Post Test		
		95% CI	Variance	Mean	95% CI	Variance
General Health Perceptions	75.3226	68.5271 82.1181	343.226	75.000	67.1330 82.8670	460.000
Physical Function	85.6631	76.1227 95.2034	676.490	88.1720	78.5887 97.7553	682.597
Role/Social Limitations-Emotional-Behavioral	53.7634	41.2636 66.2632	1161.290	60.2151	47.4229 73.0072	1161.290
Role/Social Limitations-Physical	86.0215	77.2193 94.8238	575.866	84.9462	75.5607 94.3318	654.719
Bodily Pain/Discomfort	76.1290	66.9625 85.2956	624.516	74.1935	65.2701 83.1170	591.828
Global Behavior	53.6290	48.4425 58.8155	199.933	59.3414	51.3392 67.3436	475.946
Behavior Scale	47.4194	35.7250 59.1137	1016.452	43.5484	32.1815 54.9153	960.323
Mental Health	63.9785	57.2636 70.6933	335.125	58.3333	50.9297 65.7370	407.407
Self-Esteem	65.0538	58.1997 71.9078	349.164	62.3656	54.7598 69.9714	429.958
Change in Health	49.1935	42.1215 56.2656	371.724	40.7258	34.4093 47.0423	296.539
Parental Impact-Emotional	45.5645	35.1393 55.9897	807.796	43.1452	33.6125 52.6778	675.403
Parental Impact-Time	62.9032	53.2101 72.5963	698.327	55.3763	44.9791 65.7735	803.465
Family Activities	43.9516	33.5721 54.3312	800.739	42.3387	33.1170 51.5604	632.056
Family Cohesion	73.5484	65.3438 81.7530	512.225	72.7419	64.5285 80.9554	501.398
Summary Scores						
Physical Health	50.6657	46.0688 55.2627	157.061	44.2178	38.5870 49.8486	235.650
Psychosocial Health	33.4738	28.9500 37.9976	152.104	34.9689	30.7472 39.1906	132.469

Table 3*Comparison of ASD and General Population Responses on CHQ*

	Population	Mean (SD)	Range
Physical Functioning	ASD Sample	75.32 (18.5)	30-100
	General Population	95.1 (15.4)	0-100
Role/Social Limitations- Emotional-Behavioral	ASD Sample	53.76 (34.1)	0-100
	General Population	96.7 (13.2)	0-100
Role/Social Limitations- Physical	ASD Sample	86.0 (24.0)	33-100
	General Population	95.3 (16.6)	0-100
Bodily Pain/Discomfort	ASD Sample	76.1 (25.0)	20-100
	General Population	85.5 (19.6)	0-100
Behavior Scale	ASD Sample	47.4 (31.9)	0-100
	General Population	70.3 (15.9)	0-100
Mental Health	ASD Sample	64.0 (18.3)	25-92
	General Population	81.8 (16.2)	8-100
Self-Esteem	ASD Sample	65.1 (18.7)	33-100
	General Population	79.6 (13.9)	0-100
Change in Health	ASD Sample	49.2 (19.3)	13-81
	General Population	52.5 (7.2)	13-75
Parental Impact-Emotional	ASD Sample	45.6 (28.4)	0-100
	General Population	89.9 (15.5)	0-100
Parental Impact-Time	ASD Sample	62.9 (26.4)	17-100
	General Population	92.4 (19.8)	0-100
Family Activities	ASD Sample	44.0 (28.3)	0-100
	General Population	90.7 (16.3)	0-100
Family Cohesion	ASD Sample	73.5 (22.4)	30-100
	General Population	74.9 (18.1)	0-100
Physical Health	ASD Sample	50.7 (12.5)	15-64
	General Population	56.1 (7.9)	0-68
Psychosocial Health	ASD Sample	33.5 (12.3)	4-60
	General Population	52.5 (7.2)	13-75

* General population means are not available for General Health or Global Behavior; general population means are published in Raat et al., 2005.

Discussion

Applied research to develop, evaluate, or improve interventions treating core symptoms and co-occurring conditions in individuals with ASD is a priority of the autism organization and stakeholders (Frazier et al., 2018; IACC, 2017). Current research is hindered by lack of measures, particularly health related quality of life measures, validated for use with ASD populations. Measuring health-related quality of life in children with ASD in clinical trials can complement efficacy measures, offering a complete picture of the impact of disorder and treatment on overall well-being. The purpose of this study was to estimate rates and variability of responses of parents of children with ASD on the Children's Health Questionnaire (CHQ) to inform future recreational therapy intervention research with this population. Our findings show consistency with emerging health-related quality of life research using other measures, as well as advantages of the CHQ for children with ASD.

Results showed summary scores for physical health and psychosocial health were more precise than profile scores. This is consistent with the CHQ manual reporting small standard deviations and high reliability of summary scales leading to confidence intervals of 1/2 to 1/5 that of profile scales (Landgraf et al., 1996). Additionally, re-

search has shown CHQ physical and psychosocial health summary scores to have adequate internal consistency when used with typically developing children and children with other health concerns (e.g., asthma, headaches, hearing problems) (Raat et al., 2005). The CHQ manual reports Cronbach's alpha of five of the eight multi-item profile scales exceed .74 (Landgraf et al., 1996), indicating self-esteem, mental health, and behavior have "good" and physical function and family activity domains have "exceptionally high" internal consistency. These profile scales also have the lowest confidence intervals indicating better precision. Results of our study, manual reliability estimates, and previous research suggest some CHQ profile scales are adequate measures of specific health-related quality of life constructs, while CHQ physical and psychosocial summary scales are best for monitoring children in clinical practice or clinical trials.

In our study, parents of children with ASD reported CHQ scores that were lower than scores reported by parents of the general population of children across all profile and summary scales, particularly in areas of behavior, mental health, and psychosocial health. This finding is unique for children with ASD as other disease/disabilities groups had lower scores in most, but not all profile scales (Landgraf et al., 1996). For example, parents report children with ADHD have lower health-related quality of life in areas related to behavior, mental health and self-esteem, but better general health and physical scores (function, roles, and bodily pain) than the general population. Profile scores of children with epilepsy are most like those of children with ASD who have lower scores on all profile scales except bodily pain, in which parents report better scores than the general population. Given that emotional and social impairment are defining characteristics of ASD it is not surprising that children with ASD have lower psychosocial health scores than the general population of children and children with other chronic illnesses/disorders. ASD is not known to substantially impact physical health. However, the Autism Treatment Network investigated health-related quality of life of 286 children and found their physical health scales were like children with chronic conditions and significantly lower than children without conditions (Kuhlthau et al., 2010). The study used the Pediatric Quality of Life Inventory, and also showed significantly poorer parent-reported scores for children with ASD than for the typical population across all domains (Kuhlthau et al., 2010).

Though this study was not designed to investigate intervention effects, changes and variability of reporting at post-test provide insight to areas that may be responsive to intervention (Moore et al., 2011). Results showed greater variability in all physical health scales, suggesting future clinical trials should measure changes in physical health along with commonly measured psychosocial health changes. In the current study, psychosocial health related to behavior, mental health, and self-esteem showed the greatest variability at post-test. Interestingly, scores in these three constructs of psychosocial health were all lower at post-test, while the summary score showed improvement. These constructs may be sensitive to change and provide detail lost in the overall summary score of psychosocial health. The parent impact-time profile score was also lower and showed greater variability at post-test. The intervention for this study required weekly commitment of time as well as long commutes for some families. This construct may be valuable for informing preference-based health-related quality of life in future studies (Payakachat et al., 2012). Currently, there are no preference-based quality of life studies with children with ASD, and these studies are necessary for informing cost effectiveness of interventions. Though some established preference-based

quality of life measures are available, they are not appropriate for children, particularly children with ASD, due to reading and communication demands. The CHQ PF-28 provides the unique advantage of informing preference-based quality of life by measuring impact on parents (e.g., parent time, family activities, etc.)

Strengths and Limitations

Though our sample was small, it was larger than necessary for estimating average values and variability for planning larger subsequent studies. Additionally, it was diverse and included both females and ethnic groups underrepresented in autism research. Our comparisons to the general pediatric population and other conditions are limited to published norms. Additionally, we chose to use the CHQ parent form rather than relying on child self-report of health-related quality of life as this is a validated methodology for children, particularly children who may be unreliable reporters. A child self-report version of the CHQ is available and preferred for children without communication challenges. Due to study pragmatics, we chose to mitigate potential communication barriers by utilizing the parent-report form for all participants.

Recommendations for Research and Practice

Future research should seek to confirm these findings as well as investigate use of child report versions of the CHQ with children with ASD. When the CHQ battery of measures is confirmed for use with children with ASD, recreational therapy researchers might investigate the effects of engaging in different activities (e.g., swimming, dancing, yoga, etc.) on health-related quality of life of children with ASD. Because the form is brief and easily completed by parents, clinicians might consider using the CHQ in addition to progress notes or other measures to monitor response to recreational therapy interventions. The psychosocial and physical summary scores, in particular, may also be helpful for recreational therapists to communicate information about health-related quality of life to families.

Conclusions

From this study, the CHQ PF-28 seems to be an appropriate measure for health-related quality of life of children with ASD. It is easily administered and completed, has adequate precision for reporting specific constructs of physical and psychosocial health, as well as providing summary scores. The CHQ can detect differences in health-related quality of life of children with ASD which differs from the general pediatric population and populations with other chronic conditions. CHQ profile scales related to parent and family impact also have potential to inform preference-based health-related quality of life.

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