BSc in Psychology

Stress, anxiety, depression and social constraints in parents of children with autism
Foreword

Submitted in partial fulfillment of the requirements of the BSc Psychology degree, Reykjavik University, this thesis is presented in the style of an article for submission to a peer-reviewed journal.
Abstract
The present study examined parenting stress, anxiety and depression among Icelandic parents of children with autism. In addition, the study examined if having a child with behavior problems and feelings of constraints when talking about the child would be associated with higher parenting stress, anxiety and depression levels. Parents (N=187) of children, 12 years or younger, with autism spectrum disorder completed an online questionnaire. The majority of participants were females (82.9%) and married (56.2%). The findings indicated that parenting stress was high with 79% of parents reporting stress levels within the clinical range. Although the majority of parents reported anxiety and depression within the normal range, 15% and 20% reported severe or extremely severe anxiety and depression respectively. Multiple regression analyses showed that having a child with behavior problems and feelings of constraints when talking about the child to spouse or family and friends was associated with higher levels of parental stress, anxiety, and depression. The results indicate the need to provide parents of children with autism with training and support to manage their child’s behavior problems, access to an intervention to reduce their stress, anxiety and depression levels and help them to talk about their child with autism.

Keywords: autism spectrum disorder, parenting stress, anxiety, depression, behavior problems, social constraints.

Útdráttur
Rannsókuð var foreldrastreita, kvíði og þunglyndi meðal íslenskra foreldra barna með einhverfu. Að auki var athugað hvort hegðunarvandamál barnsins og upplifun á félagslegum hömlum þegar foreldrar töluðu um barnið sitt hefði tengsl við hærri foreldrastreitu, kvíða og þunglyndi. Foreldrar (N=187) barna með einhverfu, 12 ára og yngri svörðu spurningalista á veraldarvefnun. Meirihluti þátttakenda voru giftar (56.2%) konur (82.9%). Niðurstöður rannsóknarinnar gáfu til kynna há foreldrastreitu, en 79% foreldra greindu frá foreldrastreitu yfir klínískum mörkum. Prátt fyrir að meirihluti foreldra hafi greint frá kvíða og þunglyndi innan eðlilegra marka, greindu 15% frá alvarlegum eða virkilega alvarlegum einkennum kvíða og 22% frá alvarlegum eða virkilega alvarlegum einkennum þunglyndis. Niðurstöður margviðrar aðhvarfsgreiningar sýndu að hegðunarvandamál barns og upplifun á félaglegum hömlum þegar foreldrar töluðu um barnið við maka, vini eða fjólskyldu höfðu tengsl við hærri foreldrastreitu, kvíða og þunglyndi. Niðurstöður rannsóknarinnar gefa til kynna að þörf sé á að veita foreldrum barna með einhverfu þjálfinn og stuðning til þess að takast á við hegðunarvandamál barna sinna, aðgengi að hlutun með það að markmiði að minnka streitu, kvíða og þunglyndi og hjálpa þeim og aðstandendum að tala um barnið með einhverfu.

Lykilorð: einhverfa, foreldrastreita, kvíði, þunglyndi, hegðunarvandamál, félagslegar hömlur.
Autism spectrum disorder is a neurodevelopmental disorder that is usually diagnosed in early childhood (American Psychiatric Association (APA), 2013; World Health Organization (WHO), 1993). The essential symptoms of the disorder are qualitative impairment in reciprocal social interaction, communication and stereotyped or repetitive patterns of behavior (WHO, 1993). The symptoms of the disorder limit or impair individual everyday functioning, but functional impairment may vary depending on individuals’ environment and their characteristics (APA, 2013).

The prevalence of autism spectrum disorder has been increasing since 1990 and is estimated around 1% worldwide (Fombonne, 2009; McDonald & Paul, 2010). In Iceland, Saemundsen, Magnússon, Georgsdóttir, Egilsson, & Rafnsson (2013) found that among children born in the years 1994 – 1998 the prevalence of autism was 1,2%. However, the most recent figures in Iceland showed that prevalence has almost doubled to 2,2% (Arnaldsdottir, 2016).

Taking care of a child with autism spectrum disorder can be demanding and several studies have documented elevated levels of parenting stress among parents of children with autism (Davis & Carter, 2008; Hayes & Watson, 2013; Karst & Van Hecke, 2012; Mori, Ujiie, Smith, & Howlin, 2009). Researchers commonly report that parents of children with autism experience more parenting stress compared to parents of typically developing children and compared to parents of children with other disabilities, e.g. Down’s syndrome and intellectual disability (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Duarte, Bordin, Yazigi & Mooney, 2005; Eisenhower, Baker & Blacher, 2005; Gong et al., 2015; Hayes & Watson, 2013; Hoffman, Sweeney, Hodge, Lopez-Wagner & Looney, 2009; Padden & James, 2017).

The most widely used instrument to measure parenting stress among parents of children with autism is the Parenting Stress Index-Short Form (PSI-SF) (Zaidman-Zait et al.,
Davis & Carter (2008) examined parenting stress, using PSI-SF, among 108 parents of children with autism. Results revealed that 33% of parents reported total parenting stress scores in the clinically significant range, with no statistically significant difference between mothers (39%) and fathers (28%). The results also revealed that the most stressful area of parenting for both parents was related to the nature of interactions between the parents and the child, as measured by the Parent-Child Dysfunctional Interaction subscale on PSI-SF, since 50% of mothers and 39% of fathers scored in the clinically significant range on this subscale (Davis & Carter, 2008).

Epstein, Saltzman-Benaiah, O’Hare, Goll, & Tuck (2008) also examined parenting stress among parents of children with autism using PSI-SF. Results revealed that 76% of mothers and 75% of fathers reported parenting stress scores that fell within the clinically significant range, with no statistical difference between mothers and fathers. It is not clear why the stress levels varied between these studies, but one reason could be that the average age in Epstein’s et al., study was nine years while it was two years in Davis & Carter’s. Consistent with this possibility, there is evidence indicating that older children with autism, between the age of 6-12 years old, cause greater stress to parents than children younger than six years old (Gong et al., 2015). In line with the studies above other investigators have found that parenting stress levels between mothers and fathers of children with autism does not differ (Hastings, 2003; Ozturk, Riccadonna, & Venuti, 2014).

Many studies have found anxiety and depression symptoms among parents of children with autism (Davis & Carter, 2008; Eisenhower et al., 2005; Hastings, 2003). In addition to showing higher anxiety and depression symptoms than parents of normally developing children, parents of children with autism show higher symptoms than parents of children with Down’s syndrome (Gong et al., 2015; Hamlyn-Wright, Draghi-Lorenz & Ellis, 2007; Padden & James, 2017). Davis & Carter (2008) found that depression and anxiety symptoms among parents of children with autism were frequent. Their results showed that 33% of mothers and
17% of fathers reported depression symptoms in the clinical range, with significant difference between mothers and fathers. However, no difference was observed in anxiety between parents, with 6% of fathers and 6% of mothers reporting clinically significant anxiety levels. (Davis & Carter, 2008). On the contrary, Hastings (2003) found that mothers and fathers did not differ in their levels of depression, but mothers reported significantly more symptoms of anxiety than the fathers. Gong et al., (2015) found that mothers had both higher anxiety and depression scores than fathers.

It is established in the literature that children with autism have a high incidence of behavior problems and show more intense behavior problems than children with no developmental disorder (Brobst, Clopton, & Hendrick, 2009; Eisenhower et al., 2005). Studies have found a strong association between behavior problems and parenting stress, with the strongest association between conduct problems and parenting stress (Lecavalier, Leone, & Wiltz, 2006; Manning, Wainwright, & Bennett, 2011). Studies also show, that behavior problems are among the main factors that predict parenting stress (Davis & Carter, 2008; Gong et al., 2015). In addition, studies have documented that the magnitude and severity of behavioral problems predicted greater maternal depressive symptoms (Abbeduto et al., 2004). According to Sharpley, Bitsika, & Efremidis (1997) parents of children with autism reported that behavior problems were the greatest contributor to feelings of anxiety and depression.

Social constraints on expressing emotions and concern about the child with autism may also exacerbate parenting stress, anxiety and depression among parents of children with autism. Although social constraints have not been examined among parents of children with autism, several studies have shown that individuals undergoing various life stressors (e.g., bereavement, cancer), who experience social constraints regarding the stressor, report high levels of depression and anxiety (Agustsdottir et al., 2010; Lepore & Revenson, 2007). Findings from a qualitative analysis that revealed that parents of children with autism often
report a lack of understanding among friends and family, support the possibility that social constraints on expressing concerns about the child with autism can cause frustrated social interactions with those without a child with autism (Phelps, Hodgson, McCammon, & Lamson, 2009). Further support comes from the literature demonstrating that lacking social support is associated with increased parenting stress, anxiety and depression among parents raising a child with autism (Bishop, Richler, Cain, & Lord, 2007; Ekas, Lickenbrock, & Whitman, 2010; Gable, Reis, Impett, & Asher, 2004; Manning et al., 2011).

To date no published study has examined parenting stress, anxiety, depression and social constraints among Icelandic parents of children with autism. Therefore, the overarching goal of the present study was to identify the prevalence of parenting stress, anxiety and depression among Icelandic parents and to examine the impact of child’s behavioral problems and the parents’ social constraints on parenting stress, anxiety and depression.

More specifically based on the above literature the following aims will be examined: Aim 1: To determine levels of parenting stress among mothers and fathers of children with autism and examine differences in parenting stress among mothers and fathers. It is hypothesized that there will be no significant differences in mothers and fathers parenting stress scores. Aim 2: To determine levels of anxiety and depression among mothers and fathers of children with autism and examine if fathers and mothers differ on anxiety and depression. Given the inconsistent findings in the literature, no hypothesis is specified. Aim 3: To examine if there is a relationship between child’s behavior problems and parenting stress, anxiety and depression. It is hypothesized that behavior problems will be significant related to higher levels of parenting stress, anxiety and depression. Aim 4: To determine if social constraints on expressing emotions regarding the child with autism is related to parenting stress, anxiety and depression. It is hypothesized that parents who feel constrained
in expressing their emotions regarding their child will have higher levels of parenting stress, anxiety and depression.

**Method**

**Participants**

A total of 187 parents of children with autism spectrum disorder chose to participate in this study, 141 mothers and 29 fathers with 17 participants not revealing their gender. To be eligible for the study, participants had to be parents or guardians of a child diagnosed with autism spectrum disorder, 12 years old or younger. The most common age range of participants was 31-40 years (55.9%) and the majority were married (56.2%). Participants answered questions about their child with autism. The majority of children were boys (82.5%), the most frequent age range was 6-8 years (39.9%) and most of the children got their diagnosis between the ages of 3-5 years (45.6%).

**Instruments and Measurements**

*Demographic information* was assessed with questions considering both demographic information about participants and their children with autism (e.g. parent age, marital status, child age, child age when diagnosed).

*Parenting stress* was measured using Parenting Stress Index-Short Form (PSI-SF) (Abidin, 1990). PSI-SF consists of 36 questions that were derived from the 101-item Parenting Stress Index (Abidin, 1983). In present study Icelandic version of PSI-SF, translated to Icelandic by Marga Thome, was used (Appendix A). PSI-SF was designed to identify perceived stress related to the role of parenting among parents of children between the ages of 1 month to 12 years. PSI-SF has three subscales, 12 item each. The subscales are: Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI) and Difficult Child Characteristics (DCC). The Parental Distress subscale consists of items relating to the distress parents experience in their roles as parents, such as “Since having a child I feel that I am
almost never able to do things I like to do”. The Parent-Child Dysfunctional Interaction subscale assesses parents’ perception of the nature of the interactional system between parent and child, such as “Most times I feel that my child does not like me and does not want to be close to me”. The Difficult Child Characteristics subscale assesses parents’ perception about their child that makes them easy or difficult to manage, such as “My child turned out to be more of a problem than I had expected”. Participants rated their agreement with each item on a 5 point Likert scale, ranging from 1 (strongly agree) to 5 (strongly disagree). The possible range was 36-180 for total sum score, and 12-60 for each subscale. Total score ≥90 on PSI-SF and ≥30 on each subscale, is an indication of risk for the wellbeing of the parent and the child (Abidin, 1990). Good internal consistency, validity and test-retest reliability have been demonstrated (Abidin, 1995). In present study, excellent internal reliability was found for PSI-SF (Cronbach’s α = .94). For the subscales, the internal reliability was good or α = .90 for the Parental Distress subscale, α = .87 for the Parent-Child Dysfunctional Interaction subscale and α = .89 for the Difficult Child Characteristics subscale.

Anxiety and depression was measured by using the short form of the Depression, Anxiety, and Stress Scale (DASS-21), which is a short version of the 42-item DASS (Lovibond & Lovibond, 1995). In present study Icelandic version, translated to Icelandic by Petur Tyrflipsson, was used (Appendix B). DASS-21 is a self-report scale, which comprises three seven-item scales measuring depression, anxiety and stress. In present study, the stress scale on DASS-21 was not used as a part of the results. DASS-21 comprises a four-point Likert scale, ranging from 0 (did not apply to me at all) to 3 (applied to me much, or most of the time). The possible range for each seven-item scale is 0-42 (i.e. scores from DASS-21 are multiplied by two to make scores comparable to DASS-42). Total scores on depression scale ranging from 0-9 are considered normal, scores ranging from 10-13 are considered mild, scores from 14-20 are considered moderate, scores from 21-27 are considered severe and
scores ≥28 are considered extremely severe. Total scores on anxiety scale ranging from 0-7 are considered normal, scores ranging from 8-9 are considered mild, scores from 10-14 are considered moderate, scores from 15-19 are considered severe and scores ≥20 are considered extremely severe (Lovibond & Lovibond, 1995). In present study, excellent internal reliability was found for DASS-21 (Cronbach’s α = .94). For depression scale, good internal reliability was found (Cronbach’s α = .89) and for anxiety good internal reliability was found (Cronbach’s α = .84).

Social constraints were measured by using the Social Constraints Scale (SCS) (Lepore, Silver, Wortman, & Wayment, 1996). SCS comprises five questions rated on a four-item Likert scale, from 1(never) to four (always). In the current study, a four-question modified Icelandic version of the SCS was used (Ragnarsdottir, 2012) (Appendix C). Three questions were applied from Lepore et al., (1996) and following question added “how often did your (spouse or friend/relative) change the subject when you tried to discuss your child?” Participants rated these four questions, first regarding spouse and then regarding friends/family. In present study, good internal reliability was found for SCS-spouse (Cronbach’s α = .85) and for SCS-friends/family (Cronbach’s α = .82). In addition, two questions were added, one regarding spouse and one regarding friends and family: “I would like to talk more to my spouse/friends/family about my child with autism” (Appendix C). Parents rated their agreement on a 5 point Likert scale, ranging from 1 (highly agree) to 5 (highly disagree).

Behavior problems information was assessed with one question: “Does your child have behavioral problems?”. Parents rated their agreement on a 4 point Likert scale, ranging from 1 (never) to 4 (frequently).
Procedure

The study was approved by the Icelandic National Bioethics Committee (no: 17-078-S1). The internet survey was posted on a closed page on Facebook (Einhverfa), where parents and guardians of children diagnosed with autism spectrum disorder, 12 years and younger, were asked to participate. Before the internet survey was posted on the Facebook page an approval was obtained from Autism organization in Iceland. The data collection took place from March 27th to April 5th 2017. Before the parents/guardians accessed the questionnaire, they read an information sheet where the purpose of the study was explained in detail as well as risks and benefits of participating in the study and participants right to discontinue at any time (Appendix D). Researchers’ contact information was provided should participants have any questions regarding the research. In addition, the phone number of a developmental therapist was provided should participants experience some distress when answering the questions. By accessing the questionnaires participants agreed to participate in the study.

Design and Data Analysis

This study employed a cross-sectional survey design to assess parenting stress, anxiety, depression and social constraints among parents of children with autism spectrum disorder, 12 years and younger. There were three dependent variables (i.e. parenting stress, anxiety and depression) and two independent variables (i.e. behavior problems and social constraints). Descriptive statistics were calculated to provide information about participants’ demographic characteristics and their child’s characteristics. Descriptive statistics for dependent variables (i.e. parenting stress, anxiety and depression) and independent variables (i.e. behavior problems and social constraints) were also conducted. Percentages of participants in clinical range on scales measuring parenting stress, anxiety and depression were also conducted. One-way ANOVA was carried out to determine if there was statistically difference between mothers and fathers scores on scales measuring parenting stress, anxiety
and depression. A repeated measures ANOVA and Bonferroni post-hoc test was carried out to determine if there was statistical difference between parental score on subscales measuring parenting stress and where. Next, correlation matrix was executed to assess the association between dependent and independent variables. Finally, hierarchical regression was executed to determine if behavior problems and social constraints (independent variables) might explain the variance in parenting stress, anxiety and depression (dependent variables). Before the regression analysis were conducted one-way ANOVA was used to determine significant relationships between dependent variables and demographic characteristics. Characteristics with significant relationship were used as control variables in regression analysis. Finally, assumptions of the regression analysis were tested for each dependent variable. All data analysis was carried out with the SPSS 20.

Results

Demographic characteristics

Demographic characteristics of the participants and their children are shown in table 1. The majority of the participants were women, a little over half of the sample were married and the most frequent age range was 31 – 40 years. The majority of children were boys, the most frequent age range was 6 – 8 years and most of the children received their diagnosis between the ages of 3 – 5 years.

To determine if any of the parents and children’s demographic characteristics needed to be included as control variables in the final regression model, the relationship between the demographic characteristics of the parents and the children and the dependent variables (i.e. parenting stress, anxiety and depression) were examined using one-way ANOVA.

For parenting stress, one-way ANOVA revealed that age of child when diagnosed with autism was associated with stress among parents ($F(3, 155) = 3.013, p = .032$). A Bonferroni post-hoc test ($p = .050$) showed that parents of children diagnosed at the age of 9-
12 years ($M = 120.72, SD = 25.98$) showed higher stress levels than parents of children that got their diagnosis at the age of 0-2 years ($M = 100.77, SD = 27.42$). Pairwise comparisons for the age groups 3-5 years ($M = 109.93, SD = 24.88$) and 6-8 years ($M = 115.36, SD = 25.68$) were non-significant.

Table 1

*Demographic characteristics of the parents and their children*

<table>
<thead>
<tr>
<th>Parents</th>
<th>Frequency (%)</th>
<th>Children</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>29 (17.1)</td>
<td>Boys</td>
<td>137 (82.5)</td>
</tr>
<tr>
<td>Women</td>
<td>141 (82.9)</td>
<td>Girls</td>
<td>29 (17.5)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>21 – 30 years</td>
<td>15 (8.8)</td>
<td>2 – 5 years</td>
<td>24 (14.3)</td>
</tr>
<tr>
<td>31 – 40 years</td>
<td>95 (55.9)</td>
<td>6 – 8 years</td>
<td>67 (39.9)</td>
</tr>
<tr>
<td>41 – 50 years</td>
<td>54 (31.8)</td>
<td>9 – 11 years</td>
<td>54 (32.1)</td>
</tr>
<tr>
<td>50 ≥</td>
<td>6 (3.5)</td>
<td>12 years</td>
<td>23 (13.7)</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married</td>
<td>95 (56.2)</td>
<td>0 – 2 years</td>
</tr>
<tr>
<td></td>
<td>Cohabitation</td>
<td>46 (27.2)</td>
<td>3 – 5 years</td>
</tr>
<tr>
<td></td>
<td>Single</td>
<td>18 (10.7)</td>
<td>6 – 8 years</td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>10 (5.9)</td>
<td>9 – 12 years</td>
</tr>
</tbody>
</table>

For anxiety, one-way ANOVA revealed a difference between mothers and fathers ($F(1, 163) = 4.369, p = .038$). Mothers showed higher levels of anxiety ($M = 7.57, SD = 8.13$) than fathers ($M = 4.28, SD = 5.23$). One-way ANOVA also revealed that marital status was associated with level of anxiety among parents ($F(1, 162) = 6.977, p = .009$). Parents that were single or divorced ($M = 10.50, SD = 8.75$) showed higher anxiety levels than parents that were married or in cohabitation ($M = 6.29, SD = 7.44$). Lastly, age of child had association with level of anxiety among parents ($F(3, 159) = 3.586, p = .015$). A Bonferroni
post-hoc test \( (p = .050) \) showed that parents of 12 years old children showed the highest anxiety levels \((M = 12, SD = 9.95)\). However, pairwise comparison for children between 2-5 years \((M = 5.22, SD = 5.49)\), 6-8 years \((M = 6.48, SD = 8.45)\) and 9-11 years \((M = 6.30, SD = 5.97)\) were non-significant.

For depression, One-way ANOVA showed that marital status was associated with level of depression among parents \((F(1, 165) = 7.759, p = .006)\). Parents that were single or divorced \((M = 17.57, SD = 10.40)\) showed higher depression levels than parents that were married or in cohabitation \((M = 12.14, SD = 9.20)\). In addition, age of child when diagnosed with autism was associated with depression level among parents \((F(3, 163) = 3.438, p = .018)\). A Bonferroni post-hoc test \((p = .050)\) showed that parents of children diagnosed at the age of 9-12 years \((M = 17.05, SD = 12.28)\) showed higher depression levels than parents of children that got their diagnosis at the age of 0-2 years \((M = 9.11, SD = 6.72)\). Pairwise comparisons for the age groups 3-5 years \((M = 13.79, SD = 9.68)\) and 6-8 years \((M = 13.22, SD = 9.25)\) were non-significant.

**Parenting stress**

The one-way repeated measures ANOVA showed significant differences in parents’ mean scores on Parental Distress (PD) subscale, Parent-Child Dysfunctional Interaction (P-CDI) subscale and Difficult Child Characteristics (DCC) subscale \((F(2, 350) = 120.736, p < .001)\). A Bonferroni post-hoc test showed differences in all pairwise comparisons between the three subscales \((p < .001)\)

Mothers and fathers had similar scores on PSI-SF, including every one of its subscales; Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI) and Difficult Child Characteristics (DCC) (Table 2). One-way ANOVA showed no significant difference between mothers and fathers on PSI-SF \((F(1, 158) = 0.155, p = .695)\) nor any of its subscales; Parental Distress subscale \((F(1, 165) = 0.968, p = .327)\), Parent-Child
Dysfunctional Interaction subscale \(F(1, 162) = 0.440, p = .508\) and Difficult Child Characteristics subscale \(F(1, 164) = 0.355, p = .552\).

Table 2

Mean scores and standard deviations on Parenting Stress Index-Short Form (PSI-SF)

<table>
<thead>
<tr>
<th></th>
<th>Parents</th>
<th></th>
<th>Mothers</th>
<th></th>
<th>Fathers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Mean (SD)</td>
<td>N</td>
<td>Mean (SD)</td>
<td>N</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>PSI-SF total</td>
<td>160</td>
<td>110.31 (26.15)</td>
<td>134</td>
<td>110.67 (26.69)</td>
<td>26</td>
<td>108.46 (23.56)</td>
</tr>
<tr>
<td>PD</td>
<td>167</td>
<td>36.69 (10.62)</td>
<td>139</td>
<td>37.06 (10.82)</td>
<td>28</td>
<td>34.89 (9.54)</td>
</tr>
<tr>
<td>P-CDI</td>
<td>164</td>
<td>31.66 (9.87)</td>
<td>136</td>
<td>31.90 (10.01)</td>
<td>28</td>
<td>30.54 (9.22)</td>
</tr>
<tr>
<td>DCC</td>
<td>166</td>
<td>41.77 (9.99)</td>
<td>139</td>
<td>41.56 (10.20)</td>
<td>27</td>
<td>42.81 (8.91)</td>
</tr>
</tbody>
</table>

Note: The possible range for total scores on PSI-SF was 36-180. For subscales, the possible range was 12-60.

As shown in table 3 majority of the parents (79%) reported clinically elevated scores on PSI-SF total scale. Highest percentages were found in relation to Difficult Child Characteristics subscale (86%) with no difference between mothers (87%) and fathers (85%). Lowest percentages were found in relation to Parent-Child Dysfunctional Interaction (53%), with mothers (55%) and fathers (50%) reporting similar clinically elevated scores.

Table 3

Percentages in clinical range among parents on Parenting Stress Index-Short Form (PSI-SF)

<table>
<thead>
<tr>
<th></th>
<th>Parents</th>
<th></th>
<th>Mothers</th>
<th></th>
<th>Fathers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>% Clinical range</td>
<td>N</td>
<td>% Clinical range</td>
<td>N</td>
<td>% Clinical range</td>
</tr>
<tr>
<td>PSI-SF total</td>
<td>176</td>
<td>79</td>
<td>134</td>
<td>81</td>
<td>26</td>
<td>77</td>
</tr>
<tr>
<td>PD</td>
<td>183</td>
<td>73</td>
<td>139</td>
<td>75</td>
<td>28</td>
<td>68</td>
</tr>
<tr>
<td>P-CDI</td>
<td>180</td>
<td>53</td>
<td>136</td>
<td>55</td>
<td>28</td>
<td>50</td>
</tr>
<tr>
<td>DCC</td>
<td>182</td>
<td>86</td>
<td>139</td>
<td>87</td>
<td>27</td>
<td>85</td>
</tr>
</tbody>
</table>

Note: Parents in clinical range was determined using normative guidelines in PSI-SF manual.
Anxiety and depression

Table 4 presents descriptive statistics for anxiety and depression scores among parents on DASS-21. A one-way ANOVA revealed that mothers had significantly higher levels of anxiety than fathers \((F(1,163) = 4.369, p = .038)\) while there were no differences in depression scores between mothers and fathers \((F(1, 166) = 1.739, p = .189)\).

Table 4

Mean scores and standard deviations on DASS-21

<table>
<thead>
<tr>
<th></th>
<th>Parents</th>
<th></th>
<th>Mothers</th>
<th></th>
<th>Fathers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Mean (SD)</td>
<td>N</td>
<td>Mean (SD)</td>
<td>N</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>173</td>
<td>6.80 (7.72)</td>
<td>136</td>
<td>7.57 (8.13)</td>
<td>29</td>
<td>4.28 (5.23)</td>
</tr>
<tr>
<td>Depression</td>
<td>176</td>
<td>12.83 (9.52)</td>
<td>139</td>
<td>13.53 (9.71)</td>
<td>29</td>
<td>10.97 (8.78)</td>
</tr>
</tbody>
</table>

Note: The possible range for measures of anxiety and depression was 0-42

Table 5 presents cut-off scores for anxiety and depression among parents. Although the majority of parents reported depression and anxiety within the normal range, 14% and 25% of the parents reported moderate levels of anxiety and depression respectively and 15% and 20% of parents reported severe or extremely severe anxiety and depression respectively.

Table 5

Percentages for anxiety and depression cut-off scores among parents on DASS-21.

<table>
<thead>
<tr>
<th></th>
<th>% Anxiety</th>
<th></th>
<th>% Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Parents</td>
<td>Mothers</td>
<td>Fathers</td>
</tr>
<tr>
<td></td>
<td>N = 165</td>
<td>N = 136</td>
<td>N = 29</td>
</tr>
<tr>
<td>Normal</td>
<td>64</td>
<td>61</td>
<td>72</td>
</tr>
<tr>
<td>Mild</td>
<td>8</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Moderate</td>
<td>14</td>
<td>15</td>
<td>7</td>
</tr>
<tr>
<td>Severe</td>
<td>6</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Ext severe</td>
<td>9</td>
<td>11</td>
<td>0</td>
</tr>
</tbody>
</table>

Note: Recommended cut-off scores were determined using DASS-21 manual
Social constraints and behavior problems

Descriptive statistics for social constraints measured with Social constraints scale (SCS) revealed total mean score, $M = 13.86$ and standard deviation, $SD = 4.84$ among parents. The social constraints subscale regarding spouse revealed mean score, $M = 6.28$ and standard deviation, $SD = 2.87$. The subscale regarding family and friends revealed mean score, $M = 7.61$ and standard deviation, $SD = 3.07$.

Descriptive statistics for behavior problems information showed that 40% of parents reported that behavior problems happened frequently, 33% reported that behavior problems happened occasionally, 23% reported behavior problems happened seldom and only 4% never.

In addition results revealed that 46% of parents reported that they would like to talk more to family and friends about their child with autism and 32% reported that they would like to talk more to their spouse about their child.

Correlational analysis

Table 7, displays Pearson’s correlational analysis for PSI-SF (i.e. total score and three subscales), anxiety, depression, social constraints (i.e. total score and two subscales) and behavior problems.

As shown in table 7, higher levels of total scores on PSI-SF were associated with higher levels of social constraints (i.e. total score, family/friend’s subscale and spouse subscale) and behavior problems. Higher levels of anxiety were also associated with behavior problems and higher levels of social constraints, except the SC-spouse subscale. Depression was found to be associated with significantly higher levels of social constraints (i.e. total score and two subscales) and behavior problems.
Table 7

Correlation statistics for PSI-SF, anxiety, depression, social constraints and behavior problems

<table>
<thead>
<tr>
<th></th>
<th>SC-total</th>
<th>SC-family and friends</th>
<th>SC-spouse</th>
<th>Behavior problems</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$r$</td>
<td>$r$</td>
<td>$r$</td>
<td>$r$</td>
</tr>
<tr>
<td>PSI-SF total</td>
<td>.41**</td>
<td>.47**</td>
<td>.25**</td>
<td>.45**</td>
</tr>
<tr>
<td>PD</td>
<td>.50**</td>
<td>.52**</td>
<td>.33**</td>
<td>.35**</td>
</tr>
<tr>
<td>P-CDI</td>
<td>.32**</td>
<td>.41**</td>
<td>.16</td>
<td>.34**</td>
</tr>
<tr>
<td>DCC</td>
<td>.24**</td>
<td>.31**</td>
<td>.14</td>
<td>.47**</td>
</tr>
<tr>
<td>Anxiety</td>
<td>.27**</td>
<td>.34**</td>
<td>.13</td>
<td>.22**</td>
</tr>
<tr>
<td>Depression</td>
<td>.40**</td>
<td>.45**</td>
<td>.19*</td>
<td>.27**</td>
</tr>
</tbody>
</table>

Note: * $p<.05$ ** $p<.001$

Regression analysis

Hierarchical multiple regression was used to determine to what extent social constraints and behavior problems contributed to parenting stress, anxiety and depression.

As shown in table 8, three separate regression models were conducted for each dependent variable (i.e. parenting stress, anxiety and depression). In step 1, the demographic characteristics of parents and children that had significant association with each dependent variable were entered as control variables. In step 2, social constraints and behavior problems were entered as independent variables.

As can be seen in table 8, the explanatory power (Adjusted $R^2$) increased to 39% by adding social constraints and behavior problems to step 2 in model 1. Similarly, by adding social constraints and behavior problems to step 2 in model 2 and 3, the explanatory power increased to 15% and to 20% respectively. However, this increase in explanatory power for model 2 and 3 can mainly be due to social constraints variable since problem behaviors did not significantly relate to anxiety and depression.
Table 8

Hierarchal multiple regression for parenting stress, anxiety and depression

<table>
<thead>
<tr>
<th>Model</th>
<th>Parenting stress</th>
<th>Anxiety</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>β</td>
<td>B</td>
</tr>
<tr>
<td>Step 1</td>
<td>Control variables</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents -gender</td>
<td>3.02</td>
<td>.16</td>
<td></td>
</tr>
<tr>
<td>Parents - Marital status</td>
<td>-6.97*</td>
<td>-.19*</td>
<td>-9.11*</td>
</tr>
<tr>
<td>Children - Age</td>
<td>1.44*</td>
<td>.17*</td>
<td></td>
</tr>
<tr>
<td>Children - Age diagnosed</td>
<td>3.78</td>
<td>.14</td>
<td>1.00</td>
</tr>
<tr>
<td>Adjusted R²</td>
<td>.01</td>
<td>.08</td>
<td>.04</td>
</tr>
<tr>
<td>Step 2</td>
<td>Independent variables</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social constraints</td>
<td>14.58**</td>
<td>.30**</td>
<td>0.37**</td>
</tr>
<tr>
<td>Problem behavior</td>
<td>27.59**</td>
<td>.49**</td>
<td>1.70</td>
</tr>
<tr>
<td>Adjusted R²</td>
<td>.39</td>
<td>.15</td>
<td>.20</td>
</tr>
</tbody>
</table>

Note: * p<.05 ** p<.01

Discussion

The main aim of the present study was to examine parenting stress, anxiety and depression among Icelandic parents of children with autism. In addition, to examine if the child’s behavior problems and parents’ social constraints in expressing their emotions regarding their child, would be associated with higher parenting stress, anxiety and depression among parents.

The results from present study indicated that Icelandic parents of children with autism report elevated levels of parenting stress, with 79% of parents reporting clinically elevated total stress score, as measured by the PSI-SF. These results are in line with the results from Epstein et al., (2008) which revealed that 76% of mothers and 75% of fathers reported parenting stress scores in the clinical significant range on PSI-SF. However, in Davis & Carter’s (2008) research, 33% of parents reported parenting stress scores in the clinical
significant range on PSI-SF. One potential reason for these inconsistent findings could be that the age of autism diagnosis varied between these studies. The children in Davis & Carter’s study were diagnosed young, or around the age of two, while the children in Epstein et al., study were diagnosed when they were around seven years old. Consistent with this potential reason for inconsistency, is finding from present study which revealed that parents of children diagnosed at the age of 9-12 years showed higher stress levels than parents of children that got their diagnosis at the age of 0-2 years. It is not clear why diagnosis at a later age is associated with higher stress levels among the parents. A potential reason is that early intensive behavior therapy program based on applied behavior analysis (ABA) greatly improves prognosis among children with autism, as associations between parenting stress and child progress have been identified, (Hillman, 2006; Grandin, 2014; Robbins, Dunlap, & Plienis, 1991).

The most stressful area of parenting in present study was related to the Difficult Child Characteristics subscale, with 86% of parents scoring in the clinically significant range on that subscale, 87% of mothers and 85% of fathers. This finding contrasts with Davis & Carter’s (2008) finding that the most stressful area of parenting was related to the Parent-Child Dysfunctional Interaction subscale. Potential reason for this difference is that the Parent-Child Dysfunctional Interaction subscale focuses more on the children’s ability to socially engage with the parent, but the children in Davis & Carter’s (2008) study were very young (M = 2.24 years). In present study, however, the most common age range of children was 6-8 years (39.9%), so their ability to socially engage with their parents might have improved. The results from present study also revealed no statistically significant differences between mothers’ and fathers’ parenting stress scores on PSI-SF, nor any of its subscales. That is consistent with our hypothesis and with findings from previous studies documenting
no significant difference between mothers and fathers total scores on PSI-SF, nor any of its subscales (Davis & Carter, 2008; Epstein et al., 2008; Ozturk et al., 2014).

The present study also examined anxiety and depression among Icelandic parents of children with autism. Although the majority of parents reported anxiety and depression scores within the normal range, 15% of the participants reported severe or extremely severe anxiety scores and 20% reported severe or extremely severe depression scores. These scores are higher than have been observed in the general population. For example, in general adult UK population, 5.2% reported severe or extremely severe anxiety scores and 5.8% reported severe or extremely severe depression scores (Crawford & Henry, 2003). Consistent with findings from Hastings (2003), the present study found that there were no significant differences between mothers’ and fathers’ depression scores, while mothers reported significantly higher levels of anxiety that fathers. Results from present study also revealed that demographic characteristics were related to higher level of anxiety and depression among parents of children with autism. Parents that were single or divorced showed significantly higher level of anxiety and depression than parents that were married or in cohabitation. In addition, parents of 12 year old children with autism showed the highest anxiety level and parents of children that got their autism diagnosis at the age between 9-12 years showed the highest depression level.

Our hypotheses that behavior problems would be significantly related to higher levels of parenting stress, anxiety and depression was confirmed, with the strongest association being between behavior problems and Difficult Child Characteristics subscale and PSI-SF total score. This finding is in line with previous studies which have reported association between behavior problems and parenting stress (Lecavalier et al., 2006; Manning et al., 2011). Also, behavior problems have been found to be the main contributor to feelings of anxiety and depression among parents (Abbeduto et al., 2004; Sharpley et al., 1997).
Our hypothesis that parents who feel constrained in expressing their emotions regarding their child will have higher levels of parental stress, anxiety and depression was confirmed, with the strongest significant association between SC-family and friends’ subscale and Parental Distress subscale. These findings indicate that if parents of children with autism feel that their friends, family or spouse are not helpful or supportive when they talk about their child they will be more likely to feel parenting stress, anxiety and depression. In addition, results also indicated that parents wanted to talk more about their child with their spouse, family and friends, with 46% of parents reporting that they would like to talk more to family and friends about their child with autism and 32% reporting that they would like to talk more to their spouse about their child. These findings indicate that parents of children with autism feel isolated and want to be able to express their emotions and talk about their child with their partner, friends and family. As this is the first study to examine social constraints in emotional expression among parents of children with autism the findings can only be compared with those that have examined social constrains and distress among other populations. Findings from a study among prostate cancer patients in Iceland reveal that those who perceived higher levels of constraints in expressing their emotions and cancer concerns had higher levels of distress (Agustsdottir et al., 2010).

The present study has some limitations. Firstly, the gender distribution was not equal with only 17.1% of male participants, which limits the external validity of the study. Also, the study used a convenience sample which is also a threat to external validity. Parents that chose to participate might have been different in any way from those parents who did not chose to participate. In addition, the findings in present study relied on parental self-reports which are subject to potential bias. As this study is cross-sectional it is not possible to determine the direction of the relationship between dependent variables (i.e. parenting stress, anxiety and depression) and independent variables (i.e. social constraints and behavior.
problems), the relationship might even be bidirectional. In addition, information about other diagnosis that the child might have were not obtained. Lastly, it is also important do consider that feelings of distress among parents may arise from other factors (e.g. pre-existing pathology or social problems) that are not related to having a child with autism. Above mentioned limitations should be kept in mind when interpreting the findings.

Findings from present study have both theoretical and practical implications. From a theoretical perspective, the results of the current study add to a body of researches documenting elevated levels of parenting stress among parents of children with autism and to studies showing anxiety and depression symptoms among those parents. This is the first study to demonstrate that feelings of constraints in talking about the child with autism with spouse, family or friends is associated with higher levels of parenting stress, anxiety and depression. Lastly, to the author’s knowledge, this is the first study that examines parenting stress, anxiety, depression and social constraints among parents of children with autism in Iceland. From a practical perspective, findings provide important information about parenting stress, anxiety, depression among Icelandic parents of children with autism. Results show that parents show elevated levels of parenting stress, anxiety and depression. There is clearly a pressing need to provide parents of children with autism with training and support to manage their child’s behavior problems and access to an intervention to reduce their stress, anxiety and depression levels and help them to talk about their child with autism. Single parents, parents whose child received diagnosis after the age of nine, parents of a child with behavior problems and parents who feel that they cannot talk to friends and family are in particular need for support.

Future researches should use longitudinal investigation to further understand the dynamic processes that take place over time and therefore enable further understanding of the causal relationship and obtain information about other diagnosis that the children might have.
References


Appendix A
Parenting stress index-short form (PSI-SF)

Þegar þú svarar spurningunum hér á eftir, hugsðu þá um barnið þitt með einhverfu/röskun á einhverfurófi og miðaðu svörin við ástand dagsins í dag.

Fyrstu viðbrögð þín við hverri spurningu ættu að vera svar þitt.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>alveg</td>
<td>frekar</td>
<td>ekki viss</td>
<td>frekar</td>
<td>alveg</td>
</tr>
<tr>
<td>sammála</td>
<td>sammála</td>
<td>ósammála</td>
<td>ósammála</td>
<td></td>
</tr>
</tbody>
</table>

1. Oft finnst mér að ég ráði ekki nógu vel fram úr hlutunum ........................................ 1 2 3 4 5
2. Mér finnst ég fórna meiru af tíma mínun fyrir barnið en ég átti nokkurn tímann von á .............. 1 2 3 4 5
3. Mér finnst foreldralutverkið setja mér stólinn fyrir dyrnar ................................................................. 1 2 3 4 5
4. Frá því að ég eignaðist þetta barn hef ég ekki getað sinn不锈钢 og öðrum viðfangsefnum ...................... 1 2 3 4 5
5. Frá því að ég eignaðist barn finnst mér ég næstum aldrei hafa tíma til að sinna hlutum sem mig sjálfa(n) hefur langað til ................................................................. 1 2 3 4 5
6. Ég er óánægð(ur) með síðustu fóti sem ég keypti á mig ................................................................. 1 2 3 4 5
7. Það er heilmargt í lífi mínu sem angrar mig ...................... 1 2 3 4 5
8. Að eiga barn hefur valdið meiri erfiðleikum í sambandi mínu við maka (barnsföður/-móður) mín/mína en ég átti von á ................................................................. 1 2 3 4 5
9. Mér finnst ég vera ein(n) og vinalaus ........................................... 1 2 3 4 5
10. Þegar ég fer í samkvæmi býst ég venjulega ekki við að skemmta mér ................................................................. 1 2 3 4 5
11. Ég hef ekki sama áhuga á fólki og ég hafði áður ...................... 1 2 3 4 5
12. Ýmislegt sem áður vakti ánægju mína gerir það ekki lengur .............. 1 2 3 4 5
13. Það er sjaldan sem barnið mitt gerir eitthvað fyrir mig sem vekur hjá mér ánægju ........................................ 1 2 3 4 5

14. Stundum finnst mér að barninu mínu líði ekki vel í návist mínni ................................................................. 1 2 3 4 5

15. Barnið mitt brosir sjaldnar til mín en ég átti von á .......... 1 2 3 4 5

16. Þegar ég geri eitthvað fyrir barnið mitt finnst mér það ekki mikils metið .......................................................... 1 2 3 4 5

17. Þegar barnið mitt leikur sér flissar það sjaldan eða hlær .................................................................................. 1 2 3 4 5

18. Barnið mitt virðist ekki taka eins vel eftir og flest önnur börn ........................................................................... 1 2 3 4 5

19. Mér virðist barnið mitt brosa sjaldnar en önnur börn ..................................................................................... 1 2 3 4 5

20. Barnið mitt er ekki fært um að gera eins mikil og ég átti von á .......................................................... 1 2 3 4 5

21. Barnið mitt á erfitt með og er lengi að venjast nýjem aðstæðum ................................................................. 1 2 3 4 5

22. Mér finnst (merktu aðeins við eina fullyrðingu):
   - 1) ég ekki vera nógu gott foreldri
   - 2) ég eiga í erfiðleikum með foreldrahlutverkið
   - 3) ég vera í meðallagi gott foreldri
   - 4) ég vera betri en flestir foreldrar
   - 5) ég vera mjög gott foreldri

23. Ég bjóst við að tilfinningar mínar til barnsins yrðu nánari og betri en þær eru og það angrar mig .................. 1 2 3 4 5

24. Mér finnst hegðun barnsins stundum benda til þess að það vilji mig ekki .......................................................... 1 2 3 4 5

25. Barnið mitt virðist gráta eða vera með fyrirgang oftar en flest önnur börn ......................................................... 1 2 3 4 5

26. Barnið mitt vaknar venjulega í þungu skaði .................................................. 1 2 3 4 5

27. Mér finnst barnið mitt skipta oft skapi og lítið þarf til að koma því úr jafnvægi ........................................... 1 2 3 4 5
28. Einstaka hlutir sem barnið mitt gerir angra mig mikil
........................................... 1 2 3 4 5

29. Barnið mitt bregst mjög illa við þegar eitthvað gerist sem því líkar ekki
........................................... 1 2 3 4 5

30. Barnið mitt kemst í uppnám af minnsta tilefni .............. 1 2 3 4 5

31. Það var mun erfiðara en ég bjóst við að koma reglu á svefn- og maturvenjur barnsins .......................... 1 2 3 4 5

32. Þegar ég reyni að fá barnið mitt til að gera eitthvað eða hætta einhverju (merktu aðeins við eina fullyrðingu):

☐ 1) er það miklu erfiðara en ég átti von á
☐ 2) er það erfiðara en ég átti von á
☐ 3) er jafn erfitt og ég átti von á
☐ 4) er það auðveldara en ég átti von á
☐ 5) er það miklu auðveldara en ég átti von á

33. Hugsáðu þig vandlega um og teldu upp fjölda þeirra atriða í fari barns þíns sem helst gera þér gramt í geði. Til að mynda þegar það vill ekki borða, hlustar ekki, er óvört, truflar þig, suðar, öskrar, vælir, lætur illa eða eitthvað annað.

Vinsamlegast merktu við fjölda þeirra atriða sem þú telur eiga við barnið þitt:

☐ 1) fleiri en 10
☐ 2) 8 - 9
☐ 3) 6 - 7
☐ 4) 4 - 5
☐ 5) 1 - 3

34. Sumt af því sem barnið mitt gerir ergir mig verulega ........................................... 1 2 3 4 5

35. Barnið mitt er erfiðara en ég hélt að það yrði .............. 1 2 3 4 5

36. Barnið mitt gerir meiri kröfur til mín en flest önnur börn gera til foreldra sinna ................................ 1 2 3 4 5
Appendix B

Depression, Anxiety, and Stress Scale (DASS-21)

Lestu hverju fullyrðingu og dragðu hring um tölu 0, 1, 2 eða 3 sem segir til um hvor fullyrðing átti við í þinu tilviki *síðustu víkuna*. Það eru engin rétt eða röng svör. Eyddu ekki of miklum tíma í að velta fyrir þér hverri fullyrðingu.

- 0 = Átti alls ekki við mig
- 1 = Átti við mig að einhverju leyti eða stundum
- 2 = Átti töluvert vel við mig eða drjúgan hluta víkunnar
- 3 = Átti mjög vel við mig eða mest allan tímann

1  Mér fannst erfitt að ná mér niður.  
2  Ég fann fyrir munþurri.  
3  Ég virtist alls ekki geta fundið fyrir neinum jákvæðum tilfinningum.  
4  Ég átti í erfðoleikum með að anda (t.d. allt of hröð öndun, mæði án likamlegrar áreynslu).  
5  Mér fannst erfitt að hleypa í mig krafti til að gera hluti.  
6  Ég hafði tilheiningu til að bregðast of harkalega við aðostæðum.  
7  Ég fann fyrir skjálta (t.d. í höndum).  
8  Mér fannst ég eyða mikilli andlegri orku.  
9  Ég hafði áhyggjur af aðstæðum þar sem ég fengi hræðslukast (panik) og gerði mig að fífli.  
10 Mér fannst ég ekki geta hlakkað til neins.  
11 Mér fannst ég vera mjög pirruð/pirraður.  
12 Mér fannst erfitt að slappa af.  
13 Ég var dapur/döpur og niðurdregin(n).  
14 Ég átti erfitt með að umbera truflanir á því sem ég var að gera.  
15 Mér fannst ég nánast gripin(n) skelfingu.  
16 Ég gat ekki fengið brennandi áhuga á neinu.  
17 Mér fannst ég ekki vera mikils virði sem manneskja.  
18 Mér fannst ég frekar hörundssár.  
19 Ég varð var við hjartsláttinn í mér þó ég hefði ekki reynt á mig (t.d. hraðari hjartsláttur, hjartað sleptti úr slagi).  
20 Ég fann fyrir ótta án nokkurra skynsamlegar ástæðu.  
21 Mér fannst lífið vera tilgangslaust.
Appendix C

Social Constraints Scale (SCS)

Stundum, jafnvel þegar fólk vill vel, getur það sagt eða gert eithvað sem kemur manni í uppnám. Hugsaðu um síðustu fjórar vikurnar og gefðu til kynna hversu oft aftirfarandi atriði áttu við.

A. Hafðu í huga maka þinn þegar þú svarar spurningum 1-4. Ef þú ert einhleyp(ur) þá máttu sleppa spurningum 1-4.

1. Hversu oft fannst þér þú þurfa að halda tilfinningum þínun um barnið þitt út af fyrir þig vegna þess að maka þínun fannst þær óþægilegar?
   a. Aldrei
   b. Sjaldan
   c. Stundum
   d. Alltaf

2. Hversu oft fannst þér þú geta rætt tilfinningar þínar varðandi barnið þitt við maka þinn þegar þú vildir?
   a. Aldrei
   b. Sjaldan
   c. Stundum
   d. Alltaf

3. Þegar þú talaðir um barnið þitt, hversu oft gaf maka þinn það í skyn að hann vildi ekki heyra um það?
   a. Aldrei
   b. Sjaldan
   c. Stundum
   d. Alltaf

4. Hversu oft skipti maka þinn um umræðuefni þegar þú reyndir að tala um barnið þitt?
   a. Aldrei
   b. Sjaldan
   c. Stundum
   d. Alltaf

B. Hafðu í huga vin eða fjölskyldumeðlim (annan en maka) þegar þú svarar spurningum 5-8

5. Hversu oft fannst þér þú þurfa að halda tilfinningum þínun um barnið þitt út af fyrir þig vegna þess að vini eða fjölskyldumeðlim fannst þær óþægilegar?
   a. Aldrei
   b. Sjaldan
c. Stundum
d. Alltaf

6. Hversu oft fannst þér þú geta rætt tilfinningar þínar varðandi barnið þitt við vin eða fjölskyldumeðlim þegar þú vildir?
   a. Aldrei
   b. Sjaldan
   c. Stundum
d. Alltaf

7. Þegar þú talaðir um barnið þitt, hversu oft gaf vinur eða fjölskyldumeðlimur það í skyn að hann vildi ekki heyra um það?
   a. Aldrei
   b. Sjaldan
c. Stundum
d. Alltaf

8. Hversu oft skipti vinur eða fjölskyldumeðlimur um umræðuefni þegar þú reyndir að tala um barnið þitt?
   a. Aldrei
   b. Sjaldan
c. Stundum
d. Alltaf

Um hvern varstu að hugsa þegar þú fyllir út spurningar 5-8
Vin______ Fjölskyldumeðlim______

9. Hversu sammála eða ósammála ertu þessari fullyrðingu: Ég hefði viljað tala meira við maka minn um barnið mitt
   a. Mjög sammála
   b. Frekar sammála
c. Hvorki sammála né ósammála
d. Frekar ósammála
e. Mjög ósammála

10. Hversu sammála eða ósammála ertu þessari fullyrðingu: Ég hefði viljað tala meira við vin/fjölskyldumeðlimi um barnið mitt
    a. Mjög sammála
    b. Frekar sammála
c. Hvorki sammála né ósammála
d. Frekar ósammála
e. Mjög ósammála
Appendix D
Participants information sheet

Streita, kvöði, þunglyndi og félagslegar hömlur foreldra barna með röskun á einhverfurófi

Kæri viðtakandi,

Vinsamlega þugðu neðangreindar upplýsingar vandlega áður en þú ákveður hvort þú viljir taka þátt í þessari rannsókn.

Páttatakendur: Foreldrar eða forsjáraðilar þeirra barna sem fengið hafa greiningu á einhverfurófi/einhverfu og eru á aldursbilinu 0-12 ára eru beðnir um að taka þátt. Sé fleira en eitt barn á heimili á þessu aldursbili með greiningu á einhverfurófi eru foreldrar beðnir um að hafa eitt barn í huga þegar spurningum er svarað.

Ábyrgðarmenn rannsóknarinnar eru Heiðdís B Valdimarsdóttir prófessor við Háskólan í Reykjavík, heiddisb@ru.is og Kristjana Magnúsdóttir sálfræðingur við Greiningar- og ráðgjafarstöð ríkisins, kristjana@greining.is. Meðrannsakandi er Ásta Sigurðardóttir nemi í sálfræði við Háskólan í Reykjavík, astas04@ru.is, s: 8614842. Ef einhverjar spurningar vakna í tengslum við rannsóknina eða þátttöku í henni er velkomið að hafa samband við einhvern af ofangreindum.

Tilgangur rannsóknarinnar er að meta streitu, kvöða, þunglyndi og félagslegar hömlur þeirra foreldra/forsjáraðila sem eiga börn á aldrinum 0-12 ára sem greind hafa verið með röskun á einhverfurófi. Einnig verður leitast eftir að meta hvort greina megi einhver tengsl á milli streitu og líðan foreldra og þeirra einkenna sem barnið súnir. Niðurstöður er erlendra rannsóknna sýna að foreldrar sem eiga börn með röskun á einhverfurófi búa við mikla streitu og sýna einnig einkenni kvöða og þunglyndis. Hér á landi hefur slik rannsókn ekki verið framkvæmd og getur því komið að gagni í þeim tilgangi að meta þann stuðning sem foreldrar þurfa á að halda.

Þátttaka í rannsókninni felur í sér að svara spurningalista á rafrænu formi og gert er ráð fyrir því að það taki þátttakendur 15-20 mín.

Mögulega áhætta er engin í rannsókn þessari. Hins vegar eru spurningar sem snerta líðan þína og spurningar er varða barnið þitt sem í einhverjum tilfellum getu valdið öfægindum. Ef þú vilt tala við einhvern um þessi öfægindi er velkomið að hafa samband við ábyrgarmenn rannsóknarinnar eða meðrannsakanda.

Nafnleyndar og trúnaðar er gætt í rannsókn þessari og eru því svört órekjanleg til foreldra og barna þeirra. Á engu stigi rannsóknarinnar er vitað eða hægt að vita hver svarar. Rannsóknin hefur verið tilkynnt til Persónuverndar og samþykkt af Vísindasiðanefnd.
Réttur til að hætta þátttöku í rannsókn þessari er hvenær sem er, án útskýringa eða eftirmála. Með því að svara spurningalistum samþykkir þú að unnið verði með upplýsingarnar og þær nýttar við gerð niðurstöður rannsóknarinnar. Þér er auðvitað frjálst að sleppa því að svara einstaka spurningum á listanum ef þær valda vanlíðan eða ef svar er óvíst. En æskilegt er vegna rannsóknarinnar að sem flestum spurningum sé svarað eins nákvæmlega og unnt er.

Ef þú hefur einhverjar frekari spurningar tengdar rannsókninni þá er þér velkomið að hafa samband við ábyrgðarmenn eða meðrannsakanda rannsóknarinnar. Ef þáttaka í rannsókninni vekur upp vanlíðan geta þátttakendur haft samband við Sigurlaugu Vilbergsdóttur sigurlaug@greining.is en hún getur veitt þátttakendum eitt viðtal þeim að kostnaðarlausu. Ef þú hefur spurningar um rétt þinn sem þátttakandi í vísindarannsókn eða vilt hætta þátttöku í rannsókninni getur þú einnig snúið þér til Vísindasýðanefndar, Borgartúni 21 – 4 hæð, 105 Reykjavík. Sími: 551-7100, tölvupóstfang: vsn@vsn.is

Með von um góðar undirtektir,
Fyrir hönd rannsóknarhópsins,

Ásta Sigurðardóttir
Heiðdís B Valdimarsdóttir
Kristjana Magnúsdóttir