J Autism Dev Disord (2013) 43:1662–1675
DOI 10.1007/s10803-012-1714-6

ORIGINAL PAPER

Logging On: Evaluating an Online Support Group for Parents of Children with Autism Spectrum Disorders

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Abstract Twenty mothers participated in an online support group for parents of children with autism spectrum disorders. Twenty-five unrelated parents participated in a no-treatment control group. The participants completed online questionnaires prior to and following the 4-month support group, to evaluate changes in mood, anxiety, parenting stress, and positive perceptions. No significant differences between the groups or across time were found. However, parents who participated in the group reported being satisfied with the support they received and finding the group helpful. Issues related to participant recruitment and retention are discussed. Further research is required to investigate the efficacy of online support groups for parents of children with ASD.

Keywords Autism · Parents · Support groups · Internet · Online · Well-being

Introduction

Parenting a child with a developmental disability can be a stressful experience. Research shows that in this population the presence of more child behaviour problems is related to increased parental stress (Baker et al. 2003). Children with autism spectrum disorders (ASD) tend to experience more behaviour problems than children with other developmental disabilities, and thus, research shows that parents of children with ASD experience more stress than other parents (Blacher and McIntyre 2006; Dabrowska and Pisula 2010; Eisenhower et al. 2005; Lecavalier et al. 2006). Many behaviours associated with ASD, such as self-injury and some repetitive behaviours, are especially frustrating and upsetting for parents and are associated with daily stress (Bitsika and Sharpley 2004). Furthermore, parents of children with ASD report more symptoms of anxiety and depression compared to parents of children with other disabilities (Hamlyn-Wright et al. 2007) and parents of typically developing children, with the negative effects being especially strong for those parents who do not have support from family members who understand their child's disability (Sharpley et al. 1997).

Despite the large amount of research indicating that parenting a child with ASD is extremely stressful, little research has examined methods of alleviating parental stress for these families. Parent support groups (PSGs) are one way to help parents of children with ASD cope with their stress, meet other parents, and develop a sense of belonging. Support groups for parents are a relatively cost-effective and easily-implemented intervention for supporting the needs of these families (Smith et al. 1994). Few studies have reported rates of support group use in parents of children with ASD or other disabilities; however, Mandell and Salzer (2007) found that two-thirds of parents of children with ASD report having used PSGs at some point, and in another study, we found that 75 % of parents of children with ASD reported using a PSG at some time (Clifford 2011). In addition, 42 % of a sample of parents of children with chronic illness living in households earning under $40,000 annually reported using PSGs (Smith et al. 1994). It is important to note that there is a natural response bias in these studies, such that parents who do not use PSGs

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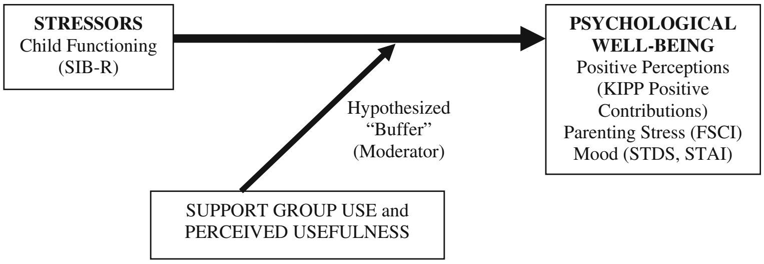

Fig. 1 Stress buffering model: Theoretical framework

are unlikely to participate in studies of PSGs; therefore, it is difficult to know the true rate of PSG use. Clinically, parents report accessing support groups for free on the internet, by invitation from other parents or from agency staff who are aware of community groups, and as part of the services offered while their child is on a wait-list for government-funded intervention. Given the apparent popularity of PSGs for parents of children with ASD, surprisingly little research has evaluated these interventions.

The Stress Buffering Model

The Stress Buffering Model (SBM; Cohen and Wills 1985) suggests that support moderates (or buffers) the effect of stressors on well-being (Cohen and Wills 1985). Specifically, in the presence of support, it is thought that stressors have less impact on psychological well-being (i.e., stress, mood, and positive perceptions of one's child). The SBM was used as a framework for this study (Fig. 1) due to its simplicity compared to other models of stress in describing the relationship between stressors, well-being, and support in a clinically relevant way. Previous research with this model has found mixed results; however, the validity of the model is increased when the specific stressors measured have been found to affect the specific measure of well-being and the support is deemed helpful (Vaux 1988). The SBM was used to investigate the role of online support group involvement in (a) decreasing stress and negative mood and (b) increasing positive perceptions in parents of children with ASD.

Parent Support Groups and Well-Being

Studies have investigated the effects of support groups on the well-being of participants, and in general, findings indicate that support groups tend to have positive effects (e.g., Preyde and Ardal 2003; Singer et al. 1999; Solomon et al. 2001). Mothers of pre-term infants who participated in support groups reported less stress and negative mood than those who did not participate in the support group (Preyde and Ardal 2003). Research with parents of children with developmental disabilities found statistically significant positive changes in parents' reported perceptions of their child with a disability following PSG involvement that were not observed in the control group (Singer et al. 1999). When asked about their experiences in support groups, parents of children with disabilities reported an increased sense of control in the world, an increased sense of belonging or being part of a community, and positive changes in their relationship with and perception of their child (Solomon et al. 2001). In a qualitative study, parents of children with physical disabilities reported that contact with other parents of children with similar disabilities provided emotional, social, and practical support that could not be derived from professionals or family and friends. This contact with other parents also seemed to have a "powerful stress buffering influence" (Kerr and McIntosh 2000, p. 309).

Effects of Support Groups for Parents of Children with ASD

The research that has focused on outcomes of support groups for parents of children with ASD is exploratory and qualitative (Bitsika and Sharpley 1999, 2000; Carter 2009). Bitsika and Sharpley (1999) completed a small ($n = 14$) exploratory study of outcomes associated with participation in an informational counseling group for parents of children with ASD. These participants chose to attend one of three in-person support groups held every second week for 75 min sessions. At the end of each session, parents chose the theme for the upcoming session, and generally, the focus of the sessions was on providing support, rather than discussing specific strategies for dealing with personal stress. Following each session, the participants completed a brief questionnaire that was developed by the authors for the study, which examined participants' comfort and connection with group members, perceptions of themselves, self-efficacy, and well-being. The exploratory analyses indicated trends towards an increase in positive self-concept and decreased distress over time. Both group cohesion and self-efficacy increased gradually until about the half way point of the intervention and then decreased gradually; the authors were unsure of the explanation for this finding, especially in light of reports that participants valued the opportunity to connect with other parents. When asked to rate their experience with the group at follow-up, the parents indicated that they very much enjoyed participating, they found the group very valuable, and they would recommend that other parents participate. Compared to these ratings, parents had lower, but still positive ratings of the helpfulness of the group in dealing with a series of problems. When asked about the major benefits of participating in the group, almost all of the parents indicated that receiving support and understanding from the other group members was the best outcome; whereas one parent stated that the major benefit for her was providing assistance to other group members. Overall, the authors concluded that the group was of value and was helpful to the participants, but the methodological limitations of the study, such as small sample size and the use of unstandardized measures that the participants found difficult to answer, may have reduced the effects seen on standardized measures of well-being. The authors recommended that further research be conducted to examine the benefits of support groups for parents of children with ASD.

In a second study, Bitsika and Sharpley (2000) evaluated the effects of a parent support program with a psycho-educational focus on learning stress management techniques that included time in each session to discuss parents' current concerns. The groups were scheduled for eight weekly 75-min sessions, and parents completed questionnaires after each session and pre- and post-group. There were no significant changes in stress, anxiety, or depression symptoms following participation in this group. The lack of reported change may have occurred because the pre-group assessment showed that neither the mean anxiety nor mean depression scores of participants fell outside the normal range prior to participation in the group. Parents reported that they enjoyed the sessions and found them helpful. This study was also limited by a small sample size ($n = 11$), and therefore the authors reported that it lacked sufficient power to detect differences in the outcome measures, although they were able to detect a significant increase in group cohesion from pre- to post-group. The authors concluded that the parents were especially satisfied with the focus on learning strategies for coping with stress, and the parents emphasized the value of learning with other parents with whom they could relate. Bitsika and Sharpley also suggested that assisting parents in learning to cope with their stresses could improve their ability to learn strategies for managing their child's behaviour problems. However, this suggestion is in contrast to the recommendations of other researchers (Smith et al. 1994; Solomon et al. 2001) who have found that parents prefer groups that focus on emotional support and developing a sense of belonging, rather than sharing information.

Carter's (2009) qualitative study of parents' experiences with online support appears to be the only study that examined outcomes of online support groups for parents of children with ASD. Parents were asked about the positive and negative experiences they had when using "the Internet for self-help group support and advocacy" (p. 47). Twenty-two parents were interviewed about their experiences with using the internet. These parents had not necessarily participated in a formal online support group; they needed only to have used the internet for support (e.g., accessing information or resources, participating in a listserv[1]), and/or advocacy. The main themes that emerged in the parents' responses about the positive aspects of using the internet for support included receiving access to information and services, connecting with others, and increasing advocacy. At the same time, the disadvantages of accessing support through the internet were that it provided inaccurate, confusing, or overly negative information and parents sacrificed time with family for advocacy that was not always effective. The author concluded that online support groups for parents of children with ASD have many potential benefits, but efforts should be made to ensure that parents receive accurate and useful information. She recommended that further research was required to evaluate the outcomes of online PSGs specifically.

Limitations of Previous Research

Previous research on support groups for parents of children with ASD is sparse and predominantly exploratory (Bitsika and Sharpley 1999; Carter 2009). Those studies that have examined pre- to post-group changes (Bitsika and Sharpley 1999, 2000) are limited by small sample sizes (ranging from $n = 11$ to $n = 14$) and the use of unstandardized measures. In addition, there has been no published quantitative research examining the effects of online PSGs for this population despite the growing trend for parents to connect in this way. Those studies that have examined the broader group of parents of children with special needs are qualitative (e.g., Kerr and McIntosh 2000) and largely atheoretical (e.g., Singer et al. 1999; Solomon et al. 2001), focusing on a few general variables (e.g., helpfulness, group climate, empowerment) expected to change as a result of support group use. By establishing a theory base to measure the effects of PSGs systematically, we believe that research can better assess the role of PSGs in providing the most appropriate and effective support for parents of children with ASD.

In developing the format for the support groups in this study, the findings from previous research on parents'

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[1] Listservs allow participants to share information by sending messages to the email addresses of subscribers.

preferences for support groups were taken into consideration. Smith et al. (1994) surveyed parents of children with special needs about their experiences with PSGs. Parents reported a preference for the support aspect of the group as opposed to information sharing and teaching from professionals; they enjoyed being able to meet other parents and share feelings. As well, parents reported that child care and transportation were both barriers to using support groups. Taking these findings into consideration, this study examined an online parent support group that was designed as a discussion group for parents focusing on sharing experiences and developing relationships with facilitation from a counselling professional. The online component was expected to reduce some barriers to participation; for example, parents were able to participate from their home and after their child had gone to bed. The topics of discussion for these group sessions were based on parent suggestions, so as to mirror both the approach taken by many community PSGs and previous research on in-person PSGs for parents of children with ASD (Bitsika and Sharpley 1999). Finally, this group design was chosen with a view to providing a model for agencies wishing to implement similar groups to support families of children with ASD.

Objectives

This study aimed to determine whether involvement in an online parent support group affects parent reported perceived stress, symptoms of anxiety, symptoms of depression, and positive perceptions of their child. Consistent with the effects of support group involvement in previous research, it was hypothesized that parents involved in the online support groups would report less perceived stress, fewer symptoms of current (state) anxiety and depression, and more positive perceptions of their child than the control group following participation in the group, and that the two groups (control and treatment) would not significantly differ in these measures of well-being before participation in the group. In addition, the Stress Buffering Model was used as a framework to assess whether support group use for parents who perceive the support group to be useful moderated (or "buffered") the effect of child functioning on parent psychological well-being. It was hypothesized that for parents who perceived the support group to be useful, involvement in the support group would moderate the effect of child functioning on psychological well-being. Specifically, it was expected that when comparing parents who have children with similar severity of behaviour problems, parents who participated in a PSG they perceived to be useful would report less stress, anxiety, and depression, and more positive perceptions than parents who do not participate in the PSG. Finally, this study provides new documentation about how to develop and implement an online support group for parents of children with ASD. Recommendations for future implementation of the protocol employed in this study may be useful to clinicians working with these families. Findings from this study on outcomes associated with involvement in an online PSG provide information for future research and the development of supports for families.

Method

Participants

Parents of children with ASD were recruited from the larger sample of participants ($n = 178$) who completed a study examining predictors of involvement in PSGs (Clifford 2011). Parents were required to have access to a computer with an internet connection in order to participate. Those parents who indicated an interest in participating in a new online parent support group were invited to participate ($n = 119$). Thirty-six of these parents registered for the online support groups, 30 attended at least one of the sessions, and 20 completed all of the post-group measures. Parents who did not participate in the online support group ($n = 142$) were invited to participate in the control group and 25 of them completed all of the post-group measures.

Measures

Demographic information, including the child's gender and date of birth, the parent's gender and date of birth, household income, and parental education and employment, was collected as part of the pre-group questionnaires.

The following measures were used to assess parent well-being and included in the pre-and post-group questionnaires:

Family Stress and Coping Interview (FSCI; Nachshen et al. 2003)

The FSCI measures perceived stress and coping in caregivers of individuals with developmental disabilities, including ASD. For this study, only the questions measuring perceived stress were used. Parents rate the stressfulness of 23 issues (e.g., "The diagnosis of your child as having a disability" and "Deciding on the best level of integration for your child") on a 4-point scale from 0 (*Not Stressful*) to 3 (*Extremely Stressful*). Total scores are calculated by summing individual scores and higher scores indicate higher levels of perceived stress. Previous research with the FSCI found high internal consistency ($\alpha = .89$), high test–retest reliability ($r = .80$), and face validity (Nachshen et al. 2003). In the current study there was also good internal consistency ($\alpha = .87$) and high test–retest reliability ($\alpha = .77$).

State Trait Anxiety Inventory (STAI; Spielberger 1983)

The STAI measures both current (state) and general (trait) anxiety using two scales with 20 items each. Participants rate how much each item describes them, currently or in general, on a scale from 1 (*not at all/almost never*) to 4 (*very much so/almost always*) for both the state and trait subscales, respectively. The scale provides total scores for both state and trait anxiety and higher scores reflect more symptoms of anxiety. In previous research, inter-item reliability for both the trait subscale (ranging from $\alpha = .72$ to $\alpha = .96$) and state subscale (ranging from $\alpha = .65$ to $\alpha = .96$) was quite good (Barnes et al. 2002). Reliability was also good in the current study for both the trait ($\alpha = .79$) and state ($\alpha = .91$) scales.

State-Trait Depression Scales (STDS; Spielberger et al. 2003)

The STDS measures current (state) and general (trait) symptoms of depression using 40 items, 20 from each scale (state and trait). Participants rate how much a given characteristic describes them, currently or in general, on a scale from 1 (*not at all/almost never*) to 4 (*very much so/almost always*) for the state and trait scales, respectively. Relevant items are reverse scored, and two total scores (state and trait) are calculated with higher scores reflecting more symptoms of depression. Previous research (Spielberger et al. 2003; ranging from $\alpha = .91$ to $\alpha = .96$) and the current study ($\alpha = .92$ to $\alpha = .94$) have found high internal consistency for both scales.

Kansas Inventory of Parental Perceptions (KIPP; Behr et al. 1992)

The KIPP measures parents' perceptions of the contributions their child has made to their family (Positive Contributions), how their child compares to others around them (Social Comparisons), the causes of their child's disability (Causal Attributions), and the control they have over their child's disability (Mastery/Control). For the current study, the Positive Contributions domain, which includes nine subscales, was used to measure positive perceptions of the child with ASD. The other domains were not included. Parents are asked to rate each item in terms of how much they agree or disagree on a scale from 1 (*strongly disagree*) to 4 (*strongly agree*). The resulting score indicates how positively the parent perceives the effect of their child on their life, with higher scores indicating more positive perceptions. Each subscale on the KIPP had adequate to good internal consistency in the standardization sample (ranging from $\alpha = .66$ to $\alpha = .87$; Behr et al. 1992). In the current study, internal consistency of the subscales ranged from acceptable ($\alpha = .60$) to excellent ($\alpha = .92$). The subscale scores have not been found to be stable over time, and rather they tend to reflect the current cognitions of the individual.

The following measures were used to assess various characteristics of the participants' children, including adaptive functioning, maladaptive behaviours, and symptoms of ASD.

Scales of Independent Behavior-Revised Short Form (SIB-R; Bruininks et al. 1996)

The SIB-R measures adaptive behaviour by parent ratings of the child's ability on 40 different skills. Parents rate the child's ability to complete each task on a 4-point scale ranging from 0 (*never or rarely*) to 3 (*does very well-always or almost always-without being asked*). Adaptive behaviour and age equivalent scores are obtained, on which higher scores indicate more abilities or adaptive behaviour. Parents are also asked to report whether the child engages in any of 8 different types of problem behaviour, and rate the frequency and severity of the behaviour. General, internalized, asocial, and externalized maladaptive behaviour scores can be calculated with lower maladaptive behaviour scores being more problematic. Scores ranging from 10 to −10 fall within the "normal range", scores from −11 to −20 are "marginally serious", −21 to −30 are "moderately serious", −31 to −40 are "serious", and scores lower than −41 are "very serious". The SIB-R was standardized on a population that included a sample of individuals with intellectual disabilities, and is reported to have good to excellent internal consistency, high test–retest reliability, and good inter-rater reliability (Bruininks et al. 1996).

Social Communication Questionnaire (SCQ; Rutter et al. 2003)

The SCQ is a parent-report measure used for screening children who may have ASD. Parents are asked to answer 40 yes–no questions regarding the child's social and communication skills. The Current Form, which was used for this study, asks about the child's functioning over the last 3 months. The SCQ has good sensitivity, ranging from .71 to .90, and specificity, ranging from .71 to .86 (Chandler et al. 2007; Corsello et al. 2007). For this study, the SCQ was primarily used for screening participants' children for inclusion. Consistent with the literature (Corsello et al.

2007), a cut-off score of 15 was used for children 8 years and older, whereas a cut-off score of 11 was used for children under 8 years.

Post-Session and Post-Group Evaluations of the Parent Support Group

Participants in the online support group were asked to complete brief post-session surveys after each of the support group meetings. They rated their satisfaction with the support they received and with the topic discussed during the session on a 5-point scale from 1 (*Very Dissatisfied*) to 5 (*Very Satisfied*). The participants also reported the most and least helpful aspects of the session and provided suggestions for future topics.

In addition, parents who participated in the support group were asked questions about the group in their post-treatment questionnaires. Specifically, parents were asked to indicate how many of the sessions they had attended, their reason(s) for missing sessions, and whether they thought it was important to change something about the group in order to improve attendance. Parents also used a 10-point scale ranging from 1 (*Very Dissatisfied*) to 10 (*Very Satisfied*) to rate their overall satisfaction with the support received during the group, and they reported qualitatively the most and least useful aspects of the group.

Procedure

Participants were initially recruited to participate in a larger study on support group use among parents of children with ASD through multiple sources including postings on websites and online forums, mailings through research labs and agencies in several Ontario cities, flyers in agency waiting rooms, and ads in newsletters. Parents were invited to complete a series of questionnaires in a secure online survey program. If participants did not complete all of the questionnaires at once they received a reminder via email to return and complete the remaining questionnaires. It took about 1 h to complete the questionnaires, which served as the pre-group time point in this study. At the end of the 8-session support group, participants completed a post-group survey, which consisted of a subset of the measures they had completed during the pre-group survey that were required to measure change in the current study (see above) and took about 30 min to complete online. Parents who did not participate in the online support group and who had completed the pre-group survey were invited to be part of the control group for this study and were also asked to complete the post-group survey.

Online Parent Support Group

Participants who indicated an interest in participating in the online PSG were invited to participate and were asked to select from several possible meeting times for the PSG. Meeting times were chosen based on the preference of the parents with 5–10 parents registered in each of the groups, although on average 3 parents attended each session. Four of the five groups were held from 9:00 pm until 10:00 pm on weekday evenings, whereas the fifth was held from noon until 1:00 pm on a weekday. Parents also chose the frequency of meetings, with 4 of the 5 groups being held bi-weekly and one held weekly. Most groups ran for 8 sessions, except for one that ran for 7 sessions because of a statutory holiday on the day of one of the sessions.

Each parent was assigned an account with a pseudoname and a private password to be used during the real-time online chat sessions. The facilitator also invited the parents to post comments and questions on an online discussion board that could be checked at their convenience. Following each session, the parents completed a short survey regarding their experience during that session and provided recommendations regarding changes to the format and structure for future sessions. The participants also recommended topics for future group sessions. The facilitator looked for common themes in the recommendations incorporating them into future sessions as possible and choosing topics that could apply to parents at various stages in parenting a child with ASD. The topics included: treatment issues, the impact of ASD on families, managing behaviour problems, coping with stress, advocacy, dealing with schools and the community, useful resources, and transitions. The topics for each group varied based on the interests of the members; however, most of these topics were covered in each group. In general the group sessions focused on providing mutual support and a sense of belonging among the participants, with specific topics structuring the discussion.

Facilitator

The facilitator was a Master's level clinician (doctoral student in Clinical Psychology) who was experienced in working with families of children with ASD and in facilitating psycho-educational groups. In addition to assigning the topics for discussion, the facilitator's roles during each session included coordinating the beginning of the session (e.g., inviting each participant to join the group chat and ensuring their technology was functioning so that they could participate); monitoring the session; occasionally providing information or clarification; redirecting the conversation when the discussion moved away from the topic; introducing subtopics to keep the discussion flowing; drawing participants' attention to a question or comment that had not been addressed; and reminding the participants when it was time to wrap up the session. The facilitator sent emails to the participants reminding them of the upcoming meetings 3 days prior to the session, the morning of the session, and, for those who had not logged in, 5 min after the session began. She also sent emails after each session reminding the parents to complete the post-session survey and to share any resources that were discussed during the group.

Data Analyses

Changes in the well-being of the parents in the treatment and control groups were evaluated using a multivariate mixed model analysis of variance (MANOVA). Specifically, differences in parenting stress, state anxiety, state depression, and positive perceptions were examined between groups (treatment and control) and over time (pre- and post-treatment). A series of multiple regression analyses was planned to evaluate the relationship between PSG use, child functioning and parent psychological well-being, in accordance with Baron and Kenny's (1986) guidelines for assessing moderators. The multiple regressions included; (1) child functioning as a predictor and psychological well-being as the outcome variable, (2) support group use as the predictor and psychological well-being as the outcome variable, and (3) child functioning and support group use as predictors and psychological well-being as the outcome variable.

Previous studies examining the outcome of participation in PSGs have been limited by insufficient power due to small sample sizes (ranging from $N = 10$ to $N = 14$; Bitsika and Sharpley 1999, 2000; Fontana et al. 1988; Troester 2000). For the purposes of the current study, we had proposed to recruit 60 participants in order to have the power to detect a medium effect size ($\eta^2 = .06$) in the overall result of a MANOVA 80 % of the time ($\alpha = .05$). However, we were only able to recruit 45 participants, therefore had the power to detect a medium effect size ($\eta^2 = .06$) in the overall result of a MANOVA 71 % of the time ($\alpha = .05$) or a significant interaction (i.e., moderator) 24 % of the time (Faul et al. 2007). This study had the power to detect a Pearson correlation with a medium effect size ($r = .36$) 80 % of the time (Faul et al. 2009).

Results

Descriptive Data

Support Group Participants

All of the parents who participated in the online PSG ($n = 20$) were mothers and their mean age was 43 years (SD = 5.61 years), though these participants ranged in age from 33 to 53 years. The majority of these parents were in a relationship (80 %) with most being married ($n = 15$) and one living in a common-law relationship ($n = 1$), whereas few were single ($n = 3$) or divorced ($n = 1$). Most of the parents who participated in the online PSG had attended college or university (90 %, $n = 18$); 20 % had a college diploma (two year or associates' degree; $n = 4$), 30 % had a university degree ($n = 6$), and another 30 % had a professional or graduate degree ($n = 6$). The parents' reported annual household incomes ranged from $19,000 to $600,000, with the median income being $83,000. Fourteen of the parents lived in Canada (70 %) and the remaining 6 lived in the United States (30 %). Prior to participating in the online PSG, the parents reported experiencing mild to moderate parenting stress ($M = 38.50$, SD = 14.49), and few symptoms of state anxiety ($M = 20.80$, SD = 8.65) or depression ($M = 19.65$, SD = 7.65). They also reported that in some aspects of their life their child with ASD had made positive contributions and in other aspects they had not, thus their mean score on the measure of positive perceptions was between "agree" and "disagree" ($M = 137.80$, SD = 22.98). None of the variables measuring well-being showed significant skewness or kurtosis.

The children (17 boys and 3 girls) of the parents who participated in the online PSG ranged in age from 2 to 22 years with a mean age of 9 years (SD = 4.83 years), and they had a variety of diagnoses. The parents reported that half of the children ($n = 10$) had a diagnosis of Autistic Disorder or Autism, 30 % had PDD-NOS ($n = 6$) and 20 % had Asperger's Syndrome ($n = 4$). One of the children had a co-morbid diagnosis of intellectual disability. The children also varied in their functioning level and their mean adaptive behaviour score had an age equivalent of about 3 years, 10 months ($M = 65.25$, SD = 20.19), which is significantly lower than their mean chronological age, and ranged from 9 months to 14 years, 6 months. Overall, these parents reported that their children had some behaviour problems with the mean general maladaptive behaviour score falling within the Moderately Serious range ($M = -21.05$, SD = 16.64).

Control Group

The majority of the parents who participated in the control group were mothers ($n = 23$); however, there were also 2 fathers in this group. These parents ranged in age from 26 to 65 years with a mean age of 43 years (SD = 8.42 years). Most of the parents were married ($n = 20$, 80 %), two were in common-law relationships ($n = 2$), two were single ($n = 2$), and one was divorced ($n = 1$). This was also a highly educated group with 96 % having completed some college or university ($n = 24$). Sixteen percent ($n = 4$) had a college diploma, 20 % had an undergraduate degree ($n = 5$), and 36 % had a professional or graduate degree ($n = 9$). The parents in the control group reported that their household incomes ranged from \$17,000 to \$200,000 with a mean income of \$89,541 (SD = \$48,538). Most of the parents ($n = 19$) lived in Canada, and the others were in the United States ($n = 6$). The parents in the control group reported experiencing mild to moderate parenting stress ($M = 37.00$, SD = 11.27), and few symptoms of state anxiety ($M = 21.45$, SD = 6.02) or depression ($M = 20.38$, SD = 8.34). In some aspects of their life, their child with ASD had made positive contributions and in other aspects they had not, thus their mean score on the scale measuring positive perceptions was between "agree" and "disagree" ($M = 129.12$, SD = 26.82). None of the variables measuring well-being showed significant skewness or kurtosis.

The parents in the control group had children (24 boys and 1 girl) ranging in age from 3 to 17 years with a mean age of 10 years old (SD = 4.14 years). They reported that their children had a variety of diagnoses within the autism spectrum, with the majority having a diagnosis of Autistic Disorder or Autism ($n = 13$), 40 % with Autism Spectrum Disorder ($n = 10$), 24 % with Asperger's Syndrome ($n = 6$), and one with PDD-NOS ($n = 1$).[2] Two of the children also had co-morbid intellectual disabilities. These children were reported to have a range of adaptive behaviour with the mean score at the age equivalent of 5 years, 2 months ($M = 71.08$, SD = 16.09), which is considerably lower than the mean chronological age for this group, and ranging from 1 year, 6 months to 11 years, 8 months. In addition, these children were described as having few behaviour problems ($M = -16.64$, SD = 12.28).

The parents who participated in the online PSG did not differ significantly from the parents who participated in the control group on any of the demographic variables, nor did either group of parents differ significantly from the parents who were invited, but did not participate in this study (Table 1).

Group Attendance

As outlined above, 119 parents were invited to participate in the PSG; 30 % ($n = 36$) of the invited parents registered for a group, and 25 % ($n = 30$) of the invited parents attended at least one session. Sixty-four percent ($n = 23$) of the parents who initially registered attended 3 or more of the support group sessions, whereas 25 % attended 6 or more sessions ($n = 9$), and only 1 parent attended all of the sessions in her group. Despite numerous reminders, only 56 % ($n = 20$) of the parents who initially registered for the groups completed the post-group survey. The most common reasons that parents who had participated in at least one session reported for not attending the meetings were scheduling conflicts ($n = 10$), problems with computer or internet access ($n = 6$), illness ($n = 4$), forgetting to login ($n = 4$), and being too busy ($n = 3$). One parent indicated that the group was not useful to her and that she did not receive enough support from the group, so she chose to stop attending. None of the other parents chose these latter two options as the reasons they did not attend the sessions. When asked specifically, 75 % ($n = 15$) of the parents who had participated in at least one session said they would not recommend changing anything about the group in order to increase attendance.

Table 1 Demographics for participants in the treatment and control groups, and parents who did not participate

Demographic variable	Treatment ($n = 20$) Mean (SD)	Control ($n = 25$) Mean (SD)	Non-participant ($n = 107$) Mean (SD)	*F*
Household income	\$113,444	\$89,541	\$121,419	0.11
	(\$133,466)	(\$48,538)	(\$348,661)	
Parent age (years)	42.70	42.82	41.08	0.89
	(5.61)	(8.42)	(7.08)	
Child age (years)	9.32	9.81	9.10	0.26
	(4.83)	(4.14)	(4.67)	
Child adaptive behaviour	65.25	71.08	68.80	0.56
	(20.19)	(16.09)	(18.68)	
Child maladaptive behaviour	−21.05	−16.64	−18.35	0.73
	(16.64)	(12.28)	(11.20)	
Child ASD symptoms	22.40	20.00	19.80	1.88
	(5.00)	(8.11)	(4.88)	

Effects of Online Parent Support Group

Changes in the well-being of the parents (i.e., parenting stress, anxiety, depression, and positive perceptions) were examined between the treatment and control groups and over time (pre- and post-treatment). Neither the main effects of group, nor the main effects of time, nor the group by time interaction were significant, and the observed power for these analyses was low (i.e., .31, .21, and .09, respectively). As discussed above, the participants had relatively high pre-group well-being scores (Table 2).

Perceived usefulness of support group participation was hypothesized to be a predictor of parental well-being and a moderator of the relationship between child problem behaviours and parental well-being. Overall the parents

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[2] These categories were not mutually exclusive; some parents indicated that their child had both Autism and Autism Spectrum Disorder.

Table 2 Well-being scores for parents in the treatment and control groups pre- and post-parent support group

Variable	Treatment ($n = 20$)		Control ($n = 25$)		Interaction *F*
	Pre-PSG Mean (SD)	Post-PSG Mean (SD)	Pre-PSG Mean (SD)	Post-PSG Mean (SD)	
Parenting stress	38.50	37.10	37.00	33.52	0.42
	(14.49)	(12.67)	(11.28)	(10.53)	
Positive perceptions	139.84	138.74	129.58	133.25	0.83
	(29.67)	(15.81)	(27.29)	(17.24)	
Anxiety symptoms	20.80	21.75	21.46	21.63	0.21
	(8.64)	(7.36)	(6.02)	(7.81)	
Depression symptoms	19.65	19.20	20.38	20.04	0.01
	(7.65)	(6.13)	(8.34)	(6.80)	

rated the group as useful ($M = 7.35$, $SD = 2.21$); however, there was not a significant relationship between perceived usefulness of the PSG and parenting stress ($r = .36$, $p = .12$), state anxiety ($r = .25$, $p = .30$), state depression ($r = .14$, $p = .57$), or positive perceptions ($r = .01$, $p = .99$) among the support group users post-group. Child maladaptive behaviour (SIB-R General Maladaptive Index, $M = -21.30$, $SD = 14.02$, Moderately Serious Range) was significantly correlated with parenting stress ($r = .64$, $p < .01$), state anxiety ($r = .76$, $p < .001$), and state depression ($r = .74$, $p < .001$), but not with positive perceptions ($r = .21$, $p = .37$). Child adaptive behaviour was significantly correlated with positive perceptions ($r = .49$, $p < .05$), but not with the other measures of well-being, and child age was not correlated with any of the variables measuring well-being. Due to the small sample size and the lack of significant correlations between the variables (Table 3), the proposed multiple regression analyses to investigate moderation were not calculated.

Table 3 Pearson correlations between child characteristics and parent well-being in online support group users

Parent well-being	Child characteristics			
	Maladaptive behaviour	Adaptive behaviour	Autism symptoms	Child age
Parenting stress	−.64**	−.18	.38	−.25
Positive perceptions	.21	.49*	−.40	.13
State anxiety symptoms	−.76**	−.05	.38	−.36
State depression symptoms	−.74**	−.24	.34	−.29

* $p < .05$; ** $p < .01$

Satisfaction with the Online Parent Support Group

Parents who participated in the PSG were asked to rate their satisfaction with the support they received during each session and with the topics of discussion for each session on a 5-point scale. Overall, parents reported being "Satisfied" with both the support received ($M = 4.10$, $SD = 0.93$) and the topics discussed ($M = 4.12$, $SD = 0.90$) in the sessions. This was the general finding for each of the sessions (see Fig. 2). Following the completion of the group, when asked to rate the usefulness of the support group overall on a 10-point scale, parents reported that the group was useful ($M = 7.35$, $SD = 2.21$), and they reported receiving a moderate amount of support from the group ($M = 6.85$, $SD = 2.30$).

When asked to report qualitatively about the most and least useful aspects of the group, while the participants tended to have similar beliefs about the most useful aspects of participating in the PSG; there was more variability in their reports of the least useful aspects. Many parents reported that the most useful aspect of the group was the opportunity to connect with other parents ($n = 8$) and to gain information about resources ($n = 5$). In addition, a few of the participants ($n = 3$) reported that the facilitation provided was the most useful aspect of the group, and one parent reported that helping with a research project was useful. In terms of the least useful aspects of the group, some parents reported issues with the online format, such as the delay in receiving responses ($n = 2$) or participants typing at the same time ($n = 1$). Other parents reported that the differences in experiences of the parents, such as age of child ($n = 1$) or geographic location ($n = 2$) made the group less useful. A couple of parents were concerned with attendance ($n = 2$), one found that other parents' complaints were not useful, a couple ($n = 2$) reported that some of the topics were difficult to chat about, and one reported that she wanted more resources from the facilitator.

Discussion

This study faced many of the same challenges that other studies of PSGs have encountered (Bitsika and Sharpley

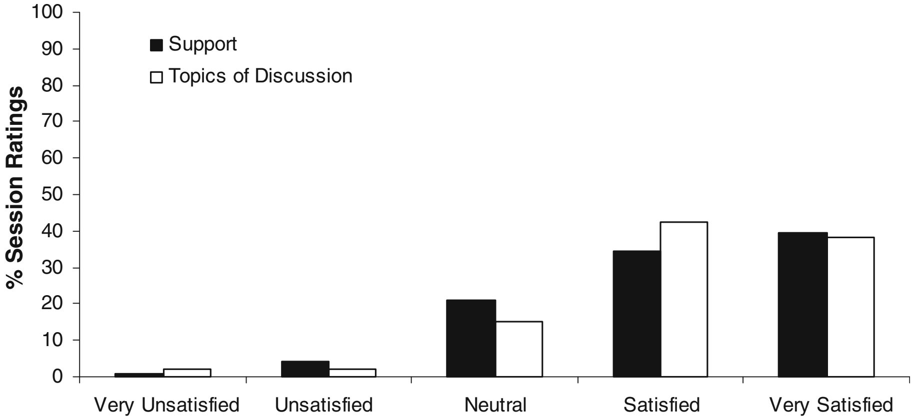

Fig. 2 *Bar graph* of satisfaction with support received and topics discussed during parent support group sessions

1999, 2000; Fontana et al. 1988; Troester 2000) and unfortunately it was not possible to answer the main research questions concerning the effects of participating in an online support group for parents of children with ASD. Previous studies had sample sizes ranging from 10 to 14 participants in the PSG (Bitsika and Sharpley 1999, 2000; Fontana et al. 1988; Troester 2000), and used exploratory data analyses (e.g., regression line of best fit) and underpowered (.43) multivariate analysis of variance (MANOVA) to analyze differences across time (Bitsika and Sharpley 1999, 2000). The current study had a sample size of 45 and the power to detect a medium effect ($r = .36$) 71 % of the time, therefore, it would appear that the effect size for the relationship between perceived usefulness of the PSG and parental well-being was below this level. The power to detect moderator effects is generally very low, because the test is in the interaction term. This study only had the power to detect a medium effect ($\eta^2 = .06$) of the interaction between time and treatment group on well-being 24 % of the time, and no such effect was detected. It is possible that because the parents had relatively few symptoms of anxiety and depression, and little parenting stress, as in a previous study (Bitsika and Sharpley 2000), there was little room for change in their well-being scores.

This study did provide some descriptive information that will be useful for replicating this online PSG, and it provided information about parents' reports of their experiences while participating in this group. Similar to the research on in-person PSGs (Bitsika and Sharpley 1999, 2000), the parents who participated in the online support group reported being satisfied with the support they received and the topics discussed during each session of the support group. In general, the parents reported that the group was useful and that they received some support from it. They especially enjoyed the opportunity to connect with other parents and share information about resources. It will be important, however, to replicate this study with a larger sample before firm conclusions can be made. In addition, future studies may consider including long-term follow-up, which may provide additional information about the outcomes for participants, particularly related to ongoing contact following the PSG.

Theoretical Implications

Consistent with previous research (Bitsika and Sharpley 2004; Blacher and McIntyre 2006; Dabrowska and Pisula 2010; Eisenhower et al. 2005; Hamlyn-Wright et al. 2007; Lecavalier et al. 2006; Sharpley et al. 1997), parents reported that their children displayed behaviour problems and the severity of behaviour problems was correlated with parental well-being. Unfortunately, we were not able to assess the merits of the Stress Buffering Model in understanding the impact of an online support group for parents of children with ASD. Although this study did meet the criteria outlined by Vaux (1988)—the stressor (child functioning) was related to the outcome (perceived stress) and the buffer (support group use) was deemed useful by participants—there was not enough power to assess the moderation. Further research examining this model as it applies to this population is warranted as this study was largely inconclusive, and the model has been successfully applied in other populations and has promise for use with parents of children with disabilities who experience considerable stress in their lives.

Clinical Implications

The development of this online support group for parents of children with ASD is a first step in developing accessible, cost-effective, and efficient means of supporting parents of children with ASD. To these authors' knowledge, no other online support programs for this population have been developed and researched in a systematic way (i.e., with pre- and post-group data collection, and post-session data collection). The online nature of the group offers the potential to reach parents who may not participate in traditional support groups because of geographic location, lack of child care, or inconvenience. Further development of online support groups should continue in order to find ways to support as many parents as possible.

For parents of children with disabilities, connecting with other parents is seen as an excellent way to enhance well-being (Kerr and McIntosh 2000; Solomon et al. 2001). Although Bitsika and Sharpley (1999) also failed to find many statistically significant changes over time, their parents reported that the in-person PSG was helpful, especially because of the opportunity to connect with other parents. The same was true in the current study, despite the fact that these parents had never met face-to-face. For most parents, having even one other parent to chat with was helpful, and they did not need a large group in order to feel supported or heard. This sentiment was captured in the qualitative responses of the participants, many of whom reported that the support, understanding, and validation received from other parents were the most useful aspects of participating in the group. Furthermore, many participants valued the experience as it made them feel as though they were not alone. The second most commonly reported benefit of the group in the current study was access to information about resources and services, which is also an important reason to connect parents with each other.

Clearly, further research is needed to determine the true effectiveness of online support groups for parents of children with ASD. However, based on the experience of the author in this study, the following recommendations are made to clinicians who are interested in implementing this type of group: (1) ensure that the facilitator is experienced and comfortable working with families of children with ASD and is able to think quickly to intervene effectively during group sessions; (2) clearly outline the format and expectations of the group at the beginning of the group to ensure that parents understand that it is a mutual parent support group, rather than a facilitator-led psycho-educational group; (3) find ways to encourage regular attendance in order to obtain the most benefit for the parents involved; (4) if numbers permit, consider dividing parents into groups based on the age of the children and/or geographic location; (5) encourage parents to take a role in deciding the focus and direction of the group, including the frequency of meeting times and the topics of discussion; and (6) encourage the development of relationships among the parents.

Limitations and Directions for Future Research

It is difficult to know whether the lack of differences over time and between groups was due to relatively high well-being scores among the participants prior to participation in the group or one of the following possible limitations: small sample size, an ineffective intervention, the variables chosen to measure change over time, the measurement tools chosen, or some other problem. Future research with this population should focus on ruling out these potential problems when examining the effectiveness of support groups for parents of children with ASD.

Sample Size

Recruitment and participant retention were major concerns in this study and in other studies of PSG use (Bitsika and Sharpley 1999; Fontana et al. 1988; Smith et al. 1994). The majority of parents who indicated an interest in participating in this online parent support group did not, in the end, register for a group. Of those who registered, many did not attend even half of the sessions. Other researchers report similar issues with attendance in their studies of support groups for this population (Bitsika and Sharpley 1999) and for parents of children with other disabilities (Smith et al. 1994) and special needs (Fontana et al. 1988). For example, Troester (2000) invited 200 parents of children in special education to participate in PSGs at the child's school 20 parents registered for the groups, and only 12 of these parents attended a group. Eight more parents were registered with the groups, for a total of 20, with only 10 completing the post-group survey. Troester did not complete any quantitative data analyses. In another study, parents of infants in a neonatal intensive care unit were invited to participate in a PSG ($n = 53$) or a control group ($n = 41$), and 60 % ($n = 32$) and 88 % ($n = 36$) agreed to participate, respectively (Fontana et al. 1988). However, of those who agreed to participate in the PSG, only 12 (38 %) attended at least one session, and the authors were not able to calculate changes over time. Interestingly, most of the parents who completed the post-group survey (75 %) in the current study indicated that the low attendance was not something they would change or consider a problem. Researchers who examine support groups for parents of children with ASD in the future should expect a very low proportion of interested parents to actually register and attend the support group, and thus, efforts should be made to recruit many more parents than are required for sufficient power in the study. Unfortunately, the issue of poor attendance is also a common problem for in-person parent support groups (Smith et al. 1994). Further research should examine whether the online format of the group is able to improve attendance rates by directly comparing online and in-person support groups. Further, the role of individual differences and preferences of parents could be important in optimizing attendance and is worthy of investigation, particularly as it is expected that self-selection bias in these studies can play a role in both attendance and outcomes. This sample includes a heterogeneous group of parents and children, which further limits our ability to assess the outcome of participation in this PSG. Future research may consider examining the role of child diagnosis and co-morbidities, and parents' gender, diagnosis or identification with the broader autism phenotype in choosing appropriate interventions, including PSGs.

Group

This support group had not been implemented before being evaluated in this study; however, parts of its design were based on previously researched groups (Bitsika and Sharpley 1999) and on groups currently available in the clinical community. Any number of variables related to the group design could have affected whether or not significant changes were found post-group. For example, perhaps a greater number of group sessions overall would have yielded more changes in parents' well-being, or perhaps longer sessions or more frequent sessions would have had a different effect. Parents liked the topics of discussion, but it is possible that other topics might have led to more change in well-being. Bitsika and Sharpley (1999, 2000) found that parents seemed to prefer more strategy-focused groups that had the goal of teaching parents to cope with stress rather than groups like those conducted in the current study that had a less direct focus, only connecting parents and allowing them to discuss topics of interest, although this preference is not supported by all researchers (Smith et al. 1994; Solomon et al. 2001). Program evaluation of support groups that are implemented clinically could help to determine which of these variables may be the most important contributors to change in well-being for parents of children with ASD.

Given that expectations for the group and parent needs may have an effect both on outcomes and attendance, it may be particularly useful to ask parents about their expectations and needs. If sample size warrants, it may be helpful to group parents based on their expectations for the group (e.g., share resources, find others like me) in order to best meet the needs of these parents. Monitoring whether expectations are met across the sessions may make it possible to make changes to the group in order to retain more participants and provide the most appropriate support to these participants. Because of the small number of parents who registered for the online support groups, all parents who were available for a given time were included in that session. Some parents indicated that being in groups with others with similar experiences to themselves would have been more useful, especially with respect to parents of older children who were under-represented in this study. In the future, efforts should be made to offer separate groups to parents of younger and older children (or adult children) and to separate groups by geographic location.

Measures

It is important to consider the outcome measures used when examining explanations for the lack of change over time in this study. It is possible that the simplicity of the model chosen for this study also limited the possibility of detecting differences, by reducing the number of variables. Although the measures chosen have sound psychometric properties, it is possible that the constructs measured would not change over relatively short term involvement in an intervention. It could also be possible that only responses to certain items might change over the course of treatment and the subsequent changes in the total score on the measure may not be large enough to yield a noticeable difference given the sample size.

Another possible limitation related to measures is that different variables could change for different parents at different times, which may mean that examining group effects may not demonstrate real changes over time, although individual changes may have occurred. Further investigation of these possible issues is warranted; choosing theoretically important items for examination rather than total scores may provide more sensitive measures of outcome. For example, the parents in this study reported qualitatively that the group was useful in providing connection with other parents, making parents feel less alone, and increasing knowledge of resources. Thus, if parents were specifically asked about these experiences and if changes in their reports were measured over time, group participation might be found to enhance a parent's well-being when measured in this way. In an unpublished study of the effects of a support group for parents of children with Asperger's Syndrome (AS; Viecili et al. 2010), the researchers found that parents reported increases in their empowerment to access services in the community, greater acceptance of their child and their feelings toward their child, and more positive feelings towards having a child with AS. These findings suggest that empowerment, acceptance, and beliefs and feelings about the child are important outcome measures for future studies of parent support groups.

This study relied on parents to describe their own well-being and perceptions of their children, as well as provide information about their child's diagnosis and functioning. In order to support the use of parent reported diagnoses a screening measure of ASD was used to screen participants for inclusion in the study. Recently, others have found that parent reported diagnoses in an online research registry were accurate (Daniels et al. 2012).

Conclusions

This is a unique study, the first known to these authors to investigate changes in parental well-being following involvement in an online support group for parents of children with ASD. Unfortunately, we were not able to detect any changes in parental well-being; however, the parents who participated in this online PSG reported being satisfied with the group and with the support they received. This study provides suggestions for both clinical work and research in the new and innovative area of online support.

Acknowledgments This paper was prepared as part of Tessen Clifford's doctoral dissertation. Special thanks to Dr. Beth Kelley and Dr. Kevin Parker for their support in the development of this project. The first author was supported through a Social Sciences and Humanities Research Council Joseph-Armand Bombardier Canada CGS Doctoral Scholarship [Award # 767-2008-2150] and an Ontario Graduate Scholarship.

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