
ORIGINAL PAPER

**The Brief Family Distress Scale: A Measure of Crisis in Caregivers of Individuals with Autism
Spectrum Disorders**

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Abstract

Parents of individuals with autism spectrum disorders (ASD) often experience stressors associated with caring for their child. These stressors can cause considerable distress for families, which at times can develop into full blown crisis, and it is important that professionals be able to quickly identify when families are approaching or are in crisis to respond appropriately. The current study presents an initial attempt to measure the subjective experience of crisis in 164 caregivers of people with ASD through a single item instrument, the Brief Family Distress Scale. The BFDS was negatively correlated with helpful coping mechanisms (family hardiness, and parent empowerment), and positive adjustment (caregiver quality of life and positive parenting experiences), and positively correlated with known stressors (severity of aggressive behavior, negative life events) and problematic coping and outcomes (caregiver burden, worry, mental health problems). As expected, caregivers at Marked levels of distress (approaching or in crisis) were significantly different from caregivers at lower levels of distress in nearly all of the dependent variables. Having a quick way of measuring where families are in terms of distress and crisis can be helpful for researchers and clinicians alike.

Keywords: Autism spectrum disorders; Parents; Stress; Crisis; Measurement

Introduction

Parents of individuals with autism spectrum disorders (ASD) often experience stressors and distress associated with caring for their child. Approximately .9% of the population is thought to have an ASD (Centre for Disease Control, 2009), and share a common triad of impairments in communication, socialization and behavior/interests (American Psychiatric Association, 2000). Symptoms of ASD can range in severity from having minimal communicative and social skills (with associated intellectual disability) to having Asperger syndrome (and sometimes above average intellectual ability). Although the diagnosis of ASD usually occurs in childhood, caring for an individual with ASD is a lifelong endeavour (Seltzer et al., 2004), and this care can place additional stressors on the family and primary caregivers at any stage of the lifespan. These stressors can cause considerable distress for families which at times can develop into full blown crisis, and it is important that researchers and clinicians be able to quickly identify when families are approaching or are in crisis to respond appropriately.

In this context, stressors are variables that place additional demands upon the caregiver or family unit. Frequently occurring child-related stressors among parents of children with ASD or other developmental disabilities include the severity of a child's disability (Bristol, 1987; Krauss, 1993), the child's caretaking demands (Minnes, 1988), and most notably, the child's problem behaviors (internalizing and externalizing problem behaviors; Hastings, 2002; Hodapp et al., 1997). Caregiver variables such as education, financial resources, and health, have also been identified as stressors (Hauser-Cram et al., 2001; Minnes et al., 2007). Understandably, there is a great deal of interest by researchers and clinicians on how families cope with these stressors and their impact on the well-being of the family. Common outcomes of stressors can include increased parent stress (Saloviita et al., 2003), depression (Hastings & Brown, 2002), marital discord and poor sibling adjustment (Prince, 2007) and quality of life (Lee, 2009), reflecting an impact on the entire family. There are known processes that mediate the relation between stressor and outcome, which include coping styles (Hastings et al., 2005), psychological acceptance (MacDonald et al., 2010), and self-efficacy (Hastings & Brown, 2002). We also know that targeting the psychological processes that act as mediators, through interventions like mindfulness training, can have a substantial impact on the child and parent (e.g., Blackledge & Hayes, 2006; Singh et al., 2010).

One impact of stressors that is highly relevant to supporting these families, but has yet to be examined, is crisis. Within the context of adjustment to stressors, crisis can be considered both an event (the phenomenon of a crisis) and a response to the phenomenon (Gilliland & James, 1993, as cited in Lewis & Roberts, 2001). Crisis is defined as

“An acute disruption of psychological homeostasis in which one’s usual coping mechanisms fail and there exists evidence of distress and functional impairment. The subjective reaction to a stressful life experience that comprises the individual’s stability and ability to cope or function. The main cause of a crisis is an intensely stressful, traumatic, or hazardous event...” (Roberts, 2000, p. 516).

Although research has highlighted some of the processes that lead families of individuals with ASD or other developmental disabilities to poor adjustment, none have examined the process of what leads them to crisis, how families in crisis differ from those approaching crisis, or what families are like following a crisis. To date, researchers and clinicians lack a quick assessment instrument to gauge the magnitude of a crisis experience from the perspective of the individuals in or approaching crisis (Lewis & Roberts, 2001). While excellent measures of stress and coping in families exist, our clinical experience suggests that families with significant levels of crisis need assistance to quickly convey information at service intake that can be meaningful to them and to clinicians.

The current study presents an initial attempt at measuring the subjective experience of crisis in families of people with ASD. Our instrument, the Brief Family Distress Scale (BFDS), was designed with specific criteria in mind. Given Roberts’ (2000) definition of crisis, the measure was meant to assess the experience from the perspective of the caregiver, and was placed along a continuum of distress, from mild stress to qualitatively distinct and immediate periods of crisis. The continuum was inspired by Myer et al. (1992) Triage Assessment Form, which aids clinicians to measure the type and severity of crisis experienced by college students on a 10-point scale. The BFDS was also meant to be brief, so that even families in severe distress could complete it with ease.

In this study, we present descriptive data on the BFDS and evaluate its construct validity by studying its correlation with related constructs. Findings are based on an online survey of caregivers of people with ASD, where we inquired into commonly known stressors, mediators, and outcomes that have been highlighted in the literature. We hypothesised that the caregiver responses on the BFDS would be negatively correlated to helpful coping mechanisms (family hardiness, and parent empowerment), and positive adjustment (caregiver quality of life and positive parenting experiences), and positively correlated with known stressors (severity of aggressive behavior, socioeconomic status, negative life events) and problematic coping and outcomes (caregiver burden, worry, mental health problems).

Method

Participants

Participants included 164 parents of individuals with ASD from Canada, with 91% of the sample being mothers. Only one caregiver per family was able to participate in the survey. Parents were 26 – 71 years of age (M age = 44.96, SD = 7.93), and children were 2 – 46 years of age (83% male; M age = 13.68, SD = 7.62). Diagnoses as reported by parents included Asperger Syndrome (26%), Autism (53%), and PDD-NOS (20%). Sixty percent of parents noted their children had below average intellectual functioning. The vast majority of individuals with ASD were living at home (96%).

Socioeconomic status was estimated based on the average income associated with participants' forward sortation area of postal codes (first three digits), using Statistics Canada's 2006 Canadian Census (Statistics Canada, 2006). Participants' average income ranged from \$41,678 to \$230,740 CAD, with an overall average of approximately \$81,762 CAD (Median = \$77,084; SD = \$25,855). Most participants lived in Ontario (78%), followed by Saskatchewan (9%) and British Columbia (5%). English was the first language for 92% of the sample. With respect to ethnicity, 89% of participants identified as European Canadian, 1.2% identified as Middle Eastern, 2% identified as African/West-Indian, 1.6% as South Asian, 2.4% identified as Asian, 2.4% identified as Native Canadian, and .6% identified as Latin/South American. Approximately 6% of the participants identified as more than one ethnicity.

Measures

Crisis experience. Parents completed the Brief Family Distress Scale, by rating where they and their families were in terms of crisis, on a 10-point scale. Each point was grounded in a statement describing a point along the continuum from no stress to complete crisis, shown in Appendix A. The statements were adapted from qualitative interviews with parents of individuals with developmental disabilities and mental health problems (Weiss & Lunsky, 2010). Figure 1 portrays the histogram of the sample that acknowledged each level of distress. The distribution was normally distributed around a mean of 4.28 (SD = 1.65), median of 4, and mode of approximately 4.5, reflecting what might be expected from a non-referred community sample's level of distress ("Things are often stressful, but we are managing to deal with problems when they arise"). An important minority (11%) of the sample indicated being close to crisis by rating themselves as a 6 or 7 ("We have to work extremely hard every moment of every day to avoid having a crisis" or "We won't be able to handle things soon. If one more thing goes wrong - we will be in crisis"). Five percent of the sample noted a score of 8 or above, acknowledging currently being in crisis.

Insert Figure 1 here

Child problem behavior. Problem behavior was measured by the 10-item Aggressive/Destructive Behavior subscale of the short form of the Behavior Problem Inventory (Rojahn et al., 2001, 2010). Each item is scored on two scales, a five-point frequency scale (Never = 0, Monthly = 1, Weekly = 2, Daily = 3, Hourly = 4) and a four-point severity scale (No problem = 0, Slight problem = 1, Moderate problem = 2, and Severe problem = 3). A general definition of aggressive behavior is also given: “Offensive actions or deliberate overt attacks directed towards other individuals or objects”. A frequency-severity score for each problem behavior was calculated as the product of each item’s severity and frequency ratings, with higher scores reflecting greater overall problem behavior. Cronbach’s alpha for the frequency-severity scores with the current sample was .85. A mean frequency-severity score was then taken across items to reflect overall aggressive-destructive behavior.

Negative life events. Parents were provided with a list of negative life events, based on the list used for the Psychiatric Assessment Schedule for Adults with Developmental Disability (Moss et al., 1998). We asked parents to note the life events that occurred for them in the past year. The events provided were as follows: Death or illness in family member or friend (39%), serious problem with a close friend (28%), unemployment (14%), serious illness or injury (16%), retirement or laid off from work (13%), change in residence (9%), something valuable lost or stolen (4%), problems with police or other authority (2%), break up of steady relationship (5%), major financial crisis (17%), separation or divorce (10%), sexual problem (4%), alcohol problem (4%), drug problem (1%), recent trauma/abuse (4%), and loss of staff (3%). Parents received one point for each life event they experienced. Three quarters of the sample reported at least one negative life event, and 13% reported at least three negative life events ($M = 1.70$, $SD = 1.78$). Parents were also asked to rate on a four-point scale if they have difficulty paying their monthly bills, from “No difficulty” (1) to “Great deal of difficulty” (4).

Family hardiness. Family hardiness was measured by the four-item Compensating Experiences subscale of the Inventory for Family Protective Factors (Gardner et al., 2008). Parents rate their experiences of mastery within the context of adversity on a five-point Likert scale, ranging from “Not At All Like My Family” to “Almost Always Like My Family”. The subscale is correlated with longer measures of family hardiness (e.g., Family Hardiness Index, McCubbin, 1987). Higher scores reflect greater hardiness, and Cronbach’s alpha in the current sample was .84.

Parent empowerment. Parent empowerment was measured by the Family subscale of the Family Empowerment Scale (FES; Koren et al., 1992), a parent-report scale that assesses empowerment in relation to parenting a child with disability. The Family subscale measures a parent's feelings of personal control and self-efficacy in relation to their child with disability, as expressed through their personal attitudes as a parent (sense of self), knowledge of their child's disability, and empowering behaviors (ability to act to obtain goals for their family and child). Responses are indicated on a five-point Likert scale ranging from "Very Untrue" (1) to "Very True" (5), with higher scores representing more empowerment. Internal reliability (alpha coefficient = .88), and test-retest reliability are reported to be strong ($r = .83$). This scale exhibited high internal consistency in the current study (Cronbach's alpha = .87).

Caregiving worry. We measured level of worry with a four-item five-point Likert scale developed by Pruchno and McMullen (2004) to assess concerns about caring for an adult child in the future, and which was adapted for the current study by removing the adult focus (e.g., "I am concerned about the physical strain of caring for my child in the future"). Responses range from "Strongly Disagree" (0) to "Strongly Agree" (4), with higher scores reflecting greater worry. Cronbach's alpha in the current study was .86. Using Pruchno and McMullen's ordinal recording for severity of worry, 12% of the sample had low levels of worry (< 9), 50% had moderate levels of worry (9-13), and 38% had high levels of worry (>13).

Quality of life. Quality of life was measured by asking participants to rate their quality of life on a four-point scale (Poor, Fair, Good, or Excellent). Other researchers have measured subjective overall quality of life or health in caregivers using single item scales (Cunny & Perri, 1991; Minnes et al., 2007), suggesting that using a single-item global rating can be helpful to reflect the values and preferences of the respondents without constricting the experience in specific domains (Gill & Feinstein, 1994, as cited in Minnes & Nachshen, 1997).

Positive caregiving experiences. Positive parenting experiences were measured using the seven-item Positive Gain Scale (PGS: Pit-ten Cate, 2003) developed originally to assess positive aspects of raising a child with intellectual disability, on a five-point Likert scale. Five items reflect the perceived benefits of raising a child (e.g., "Since having this child I have a greater understanding of other people"), and two reflect positive gains for the family (e.g., "Since having this child, my family has become more tolerant and accepting"). The current study asked parents to consider their child with ASD. The current study showed good internal consistency (Cronbach's alpha = .87), similar to a recent study of fathers of individuals with ASD that used the scale (Cronbach's alpha = .80;

MacDonald et al., 2010).

Caregiving burden. Burden was measured using the Caregiving Burden subscale of the Revised Caregiving Appraisal Scales (Lawton et al., 2000). Responses are noted on a five-point Likert scale, with higher scores reflecting greater burden. A previous study of family caregivers of adults with developmental disability reported good internal consistency (Cronbach's alpha = .87; Pruchno & McMullen, 2004). In the current study, Cronbach's alpha was .77. Pruchno & McMullen (2004) also suggested a recoding of the continuous score to reflect three categories of burden (< 22, 22-27, > 27), and in the current sample, 24% had low (< 22, 24.0%), 39% had moderate (22 - 27, 33.0%), and 37% had high (> 27, 33.9%) levels of burden.

Mental health problems. Mental health problems were measured by the Kessler 6-Item Psychological Distress Scale (K6; Kessler et al., 2003), a screening tool for non-specific psychological distress that asks about the frequency of symptoms (e.g. nervousness, hopelessness, etc.) on a five-point Likert scale ranging from "None of the time" (0) to "All of the time" (4). The K6 is a core measure in the annual US National Health Interview Survey, the US National Household Survey of Drug Abuse, and the Canadian National Health Interview Survey. The K6 has high internal consistency (Cronbach's alpha = .89) and construct validity when compared to other mental health screening tools (Furukawa et al., 2003; Kessler et al., 2002), and shows good agreement with widely used epidemiological diagnostic interviews (Kessler & Ustun, 2004; Wittchen, 1994). Cronbach's alpha in the current study was = .87. A cut-off of 8-12 has been suggested for screening for mild-moderate mental health problems, and a score of 13+ reflective of serious mental illness (Kessler et al., 2003). Twenty percent of the current sample obtained a score suggestive of mild-moderate mental health problems, and 14% of the current sample met the clinical cut-off for serious mental illness. Parents were also asked to rate the degree to which their mental health got worse as a result of caring for their child with ASD, on a four-point scale from "Not at all" (1) to "A lot" (4). Parents who noted "Not Sure" were recorded as "Not at All".

Procedure

Parents were recruited through convenience sampling from July 2009 to July 2010. An invitation to participate in an online survey was posted on several Canadian Asperger and Autism advocacy websites (e.g., Autism Ontario, Asperger Society of Ontario) and circulated through email lists associated with these organizations. Parents were able to access the survey by clicking on a link in the body of the invitation. Parents were also able to send the invitation to other parents of children with ASD. If they wished to fill out a hardcopy questionnaire, a

mailing address was provided. The York University and Centre for Addiction and Mental Health Research Ethics Boards approved this research. We obtained informed consent from all participants online. The survey took approximately 30 min to complete.

Results

Pearson's product moment correlations and Spearman's *rho* were calculated among stressor (problem behavior, negative life events, SES, difficulty paying bills), coping (family hardiness, parent empowerment, worry), and positive and negative adjustment variables (caregiver quality of life, positive parenting experiences, burden, and mental health problems). Given the large number of analyses, alpha was set at .01 to reduce the likelihood of Type I error (Perneger, 1998). As shown in Table 1, significant moderate-sized correlations were found between all the variables and crisis severity (magnitudes: .29 - .45; Cohen, 1988), except for positive parenting experiences ($p = .08$) and SES ($p = .88$). Crisis level was not related to child age, $r = .06, p = .45$, parent age, $r = -.06, p = .43$, or child gender, $t(163) = -1.10, p = .27$. Table 1 also indicates how the stressor, coping, and adjustment variables were related to each other, in expected directions.

Respondents were also categorized into crisis groups: No impairment (1-3; 34%), Moderate impairment (4-5; 50%), or Marked impairment (6-10; 16%). One-way ANOVAs confirmed significant differences based on crisis groups across all of the variables, except for positive parenting experiences and SES, listed in Table 2. Post hoc analyses indicated that parents at the Marked level of impairment had significantly more negative events, mental health problems, and burden compared to parents at No or Moderate levels of impairment (all p 's $\leq .01$). Parents at the Marked level also reported significantly lower levels of quality of life and family hardiness compared to parents at both other levels (both $p \leq .001$).

Discussion

The purpose of this study was to pilot a brief measure of crisis, which could be used by clinicians and researchers to quickly ascertain a family's level of distress along a full continuum, from little distress to an experience of crisis. We also examined whether the scale could validly categorize families into groups who differ on a number of relevant positive and negative constructs in expected directions. Given the community sample used in the current research and that the study was voluntary and online, it is not surprising that only 16% of our sample reported what we view as a Marked level of impairment (being close to or in crisis), reflected by a score of 6 or greater on the scale, and that the majority of our sample experienced a 'Moderate' level of impairment (50%). It

should be noted that what we refer to as ‘Moderate’ impairment constitutes an experience of stress in a family that is managing with significant effort (e.g., “Things are very stressful, but we are getting by with a lot of effort”). Such a large percentage of Moderate impairment suggests that even in a community sample, many families of individuals with ASD experience significant distress (Baker-Ericzén et al., 2005). If data were collected from tertiary-level or crisis-related services, we might expect to find a higher percentage of Marked impairment (Weiss & Lunskey, 2010).

The correlations reported in the current study are in the expected directions, and appear to be of moderate strength, with *p*-values that surpass a conservative alpha, even with a convenience sample of families able and willing to complete an online survey. It is important to note that the relations are not close to being perfectly linear, with intercorrelations among variables varying considerably. Together, this suggests that the crisis measure is not redundant with any other measure and that there is not just one latent variable underlying the pattern of findings. It is likely that stressors have an additive and interactional effect upon a family’s failure to cope and resultant crisis (McCubbin & McCubbin, 1987), and that a combination of predictors would account for more of the variance in a family’s crisis rating on the BFDS than any single variable. That is, a family’s experience of crisis is related to the combination of demands placed upon the family, balanced by the capabilities of the family system to adjust to those demands and the meaning that the family places on their situation (Patterson, 1988).

Our findings have a number of limitations. As with all cross-sectional research, it is not clear whether the various stressors lead to crisis, or if the crisis itself offers a lens that makes life appear more stressful and less positive. Similarly, it is not clear whether crisis leads to lower quality of life and more mental health issues or if mental health issues and low quality of life are what make some families in difficult situations rate themselves as feeling as though they are in crisis. Future research should examine prospectively whether stressors will predict greater crisis severity longitudinally, and whether coping mechanisms and context mediate or moderate the effect of stressors. As well, parents self-referred to the study, and we have no way of independently verifying the diagnoses they provided or in measuring the severity of autism symptoms in their children. It is also unknown whether the scale can be used successfully with parents of other clinical populations, although the general nature of the questions and the correlations with a number of non-ASD specific measures suggests that it is applicable for use with other groups.

Some clinicians support families in order to prevent crisis, while other clinicians work specifically with families in response to crisis. Both groups of clinicians would benefit from a brief measure of how close families

consider themselves to be in crisis. Measuring crisis is important to understand the nature of the crisis state with greater accuracy, to determine the severity of crisis and the most appropriate interventions for crisis, and to monitor progress from various perspectives (Lewis & Roberts, 2001). Future research could extend this measure to capture the perspective of different family members, and also the clinician perspective. Given the subjective nature of crisis (Roberts, 2000), there may be some situations where the clinician view and the family view are not the same, and such a discrepancy can lead to difficulty. Having a common scale can help provide shared language to communicate about a family's experience in times of severe distress.

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