

BRIEF REPORT: Experiences of Families of Individuals with Intellectual Disability and Psychiatric Disorder

Abstract

Caring for individuals with intellectual disability often results in stressful experiences for family caregivers, even leading to crisis in some cases. This paper uses the Brief Family Distress Scale (BFDS) to assess the subjective experience of crisis in a clinical sample of 29 families of individuals with intellectual disability and psychiatric disorder. Our analyses determined that 58% of the families rated themselves as 6 or above on the BFDS, indicative of approaching crisis or worse. An analysis of the BFDS' correlation with related constructs and stressors, and families' need for certain resources and services are further discussed.

Families of individuals with intellectual disability (ID) often experience stress in relation to caring for their family member. Previous research has determined that parents of children with ID experience greater stress compared to parents of children without disabilities (Hassall, Rose, & McDonald, 2005). Stressors include the added caregiving demands required to manage problem behaviours, and the lack of financial resources, when the focus is on caregiving rather than working (Hastings, 2002; [Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001](#)).

Stressors associated with taking care of a family member with ID can have a significant negative impact on families, and in some cases, lead to crisis ([Weiss & Lunskey, 2011](#)). It is crucial for health care professionals to quickly identify when families are either approaching or experiencing crisis so that they can respond to them appropriately. [Weiss and Lunskey \(2011\)](#) assessed the subjective experience of crisis in parents raising their child with autism spectrum disorder in the community using the Brief Family Distress Scale (BFDS); the BFDS was found to be positively correlated with problematic coping mechanisms and outcomes and negatively correlated with helpful coping mechanisms and positive adjustment.

The present study extends this work by examining the BFDS in a specialized mental health program for adults with ID. All families in this study have a family member with ID and psychiatric disorder. This study presents descriptive data on the families, their distress levels, and the correlation among family distress and related constructs (family empowerment, family hardiness, compassion fatigue, and impact of supporting their family member).

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Keywords

Brief Family Distress Scale
(BFDS),
crisis,
intellectual disability,
psychiatric disorder

Method

Participants

The sample consisted of 29 relatives (parent or sibling) of individuals referred to a hospital-based mental health service for adults with ID. Individuals with ID were 18-56 of age ($M = 28.97$, $SD = 11.23$), 66% were male and 76% were living with their family at the time of the study.

Measures

Perceived Level of Crisis

The Brief Family Distress Scale (BFDS) (Weiss & Lunsky, 2011) was used by caregivers to rate how close their family was to being in crisis. The BFDS is a one-item, 10-point scale. According to Weiss and Lunsky (2011), scores of 1-3 indicate no distress; 4-5 indicate moderate distress; and scores of 6 or more reflect marked distress (i.e., families are close to or experiencing a crisis).

Family Empowerment

The Family Subscale of the Family Empowerment Scale (Koren, DeChillo, & Friesen, 1992) was used to assess caregivers' personal control, confidence, self efficacy and their ability to attain family goals. It includes twelve-items rated on a five-point Likert scale, "Not True At All" (1) to "Very True" (5); higher scores indicate greater empowerment.

Family Hardiness

The Compensating Experiences subscale of the Inventory for Family Protective Factors (Gardner, Huber, Steiner, Vasquez, & Savage, 2008) was used to assess families' ability to resolve and cope with problems and major life stressors. It is a four-item measure on a five-point Likert scale, "Strongly Disagree" (1) to "Strongly Agree" (5), with higher scores indicating greater hardiness.

Worry

The Caregiver Worry Scale (Pruchno & McMullen, 2004) was used to assess caregivers' concern for taking care of a family member

with ID. It includes four items rated on a five-point Likert scale, from "Strongly Disagree" (1) to "Strongly Agree" (5); higher scores reflect greater worry.

Compassion Fatigue

The Caregiver Burden Scale (Lawton, Moss, Hoffman, & Perkinson, 2000) was administered to assess caregivers' fatigue in relation to caring for a family member with ID. It is a nine-item scale rated on a five-point scale, from "Never" (1) to "Nearly Always" (5), with higher scores reflecting higher levels of fatigue (after reverse coding for two items).

Caregivers' Employment Difficulty

A single binary item (yes/no) was used to determine whether caregivers had quit their job or reduced their hours of work to care for their family member with ID.

Caregivers' Financial Difficulty

A single item was used to see whether caregivers had any difficulty paying their monthly bills. Responses were rated on a four point scale, ranging from "No Difficulty" (1) to "A great deal of difficulty" (5).

Caregivers' Needs for Information and Support

Families used a 22-item checklist to identify any information and support needs related to the family member's mental health, general health, social care and community involvement, and also the type of skills needed to care for their family member.

Procedure

Participating families completed all measures as part of the intake procedure to help clinicians determine what sort of treatment was required for both individuals with ID and their families. A retrospective review of the data collected over a two-year period was conducted. This project received Research Ethics Board (REB) approval from the hospital.

Table 1. Top Prioritized Needs of Families of Individuals with Intellectual Disability and Psychiatric Disorder

Need/Support	Percentage (%) of Caregivers
Information for the family member's treatment progress	81
Counselling for how to cope with the family member's symptoms and behaviours	78
Information on available treatment options	78
More activities for the family member to get involved in	75
Residential support for the family member	72
Information on medication and their side effects prescribed to the family member	69
Information on more mental health care	66
Future planning for the family member	63
Finding a psychiatrist/therapist for the family member	56
Community support and services for the family member	56
Employment support for the family member	50

Table 2. Correlations of Crisis, Helpful Coping Mechanisms, and Problematic Coping Mechanisms and Outcomes

	Crisis (BFDS)	1	2	3	4
Empowerment	-0.49*				
Hardiness	-0.52*	0.56*			
Compassion fatigue	0.46*	-0.33	-0.30		
Worry	0.29	-0.17	0.13	0.65*	
Difficulty paying bills (<i>rho</i>)	0.62*	-0.21	-0.50*	0.07	-0.04

* $p < 0.05$

Results

Families identified a number of stressors related to caring for their family member with ID. In particular, more than 50% of caregivers had to quit their job or reduced hours of work, and 54% of them also faced difficulties paying monthly bills in the process. Table 1 shows that top priorities among caregivers included information on the family member's treatment progress (81%), counselling for coping with symptoms and behaviours (78%), information on treatment options (78%), and activities for their family member (75%).

Using the categories suggested by Weiss and Lunsky (2011) for the BFDS, 26% of caregivers experienced no distress (score 1–3), 16% were moderately distressed (score 4–5), and 58% experienced marked distress (score 6–10). Further, the sample's mean score on the BFDS fell above the cut-point for marked distress ($M = 6.06$, $SD = 2.42$).

Pearson's product moment correlations were also computed between the BFDS and several family constructs (Table 2). Significant moderate-sized correlations were obtained between the BFDS and family empowerment, hardiness and compassion fatigue in the expected direc-

tion. Spearman's rank correlation also revealed a significant strong correlation with financial difficulties. Furthermore, an independent samples *t* test found significant difference in BFDS ratings between the families who either faced no or little difficulty ($M = 4.92, SD = 2.15$), or a great deal of difficulty ($M = 8.12, SD = 1.08$) paying their monthly bills, $t = 4.53, p < .001$.

Discussion

Most families referred to the specialized mental health service for adults with ID were close to being or were in crisis. This distress is associated with low levels of empowerment and hardiness, and high levels of compassion fatigue. Many families reported difficulties with their finances, inability to work, and that caregiving responsibilities made it difficult to function day to day.

One of the goals of the present study was to determine whether the BFDS could accurately capture the distress level of families of individuals with ID and psychiatric disorder. The findings of this study replicated those of Weiss and Lunsy (2011) and demonstrate that the BFDS provides useful information regarding family distress in a clinical sample. In comparison to their community sample, we found greater level of marked distress among families receiving tertiary level of mental services. This was expected given the extent and complexity of difficulties inherent in a clinical sample of individuals with ID and psychiatric disorder.

Financial and employment troubles were significant stressors for families in the current study, as has been reported elsewhere (Davenport & Eidelman, 2008; Perry, 2004). Our findings also highlight the types of services and information prioritized by caregivers, namely information for their family member's treatment options and progress, counselling programs for coping with the family member's symptoms and behaviours, and more activities for the family member. This suggests that both mental health services and developmental services such as support for financial planning and respite services may help families to better cope with ongoing stressors reduce the likelihood of crisis. Preventative efforts, therefore, should consider a broad range of services and facilitate service navigation. The existing siloed approach to service does not fully address family needs.

Some of the limitations of the study include small sample size and the lack of demographic information on the caregivers. Future research should assess larger samples of caregivers to see if the experiences of caring for a family member with ID and psychiatric disorders are dependent on factors such as the family member's age, severity of their ID and mental illness, and socio-economic status. It would also be interesting to see whether the stress associated with caring for a family member with ID and psychiatric disorder is experienced differently by different caregivers (i.e., parents vs. siblings).

Key Messages from This Article

People with disabilities: When you are having a hard time, this can be difficult for your family too. You and your family need support to help you when you have a mental health problem.

Professionals: The Brief Family Distress Scale can be administered to quickly determine how close families of individuals with ID and mental health issues are to being in crisis. Families can indicate what type of supports would be most helpful to them at such times.

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