

EXPERIENCES OF CRISIS IN FAMILY CAREGIVERS OF PEOPLE WITH DEVELOPMENTAL DISABILITIES

DR. JONATHAN WEISS

CNSC March 6, 2012

Learning objectives

- Learn about how families understand crisis
- Identify how crisis severity is related to family caregiver experiences
- Discuss common barriers that precede crisis

Families MATTER

- In Ontario, 94% of youth with intellectual disability live with family members (Roebuck, 2008)
- Family caregivers are playing an increasingly important role across the lifespan
 - Percent of ADULTS with ID receiving Medicaid in the US living with parents (Lakin, Prouty, & Coucouvanis, 2007):
 - 1992: 6.3%
 - 1999: 22%
 - 2006: 38.8%

Families care

Families get others to provide care:
Gateway Provider Model (Stiffman, Pescosolido, & Cabassa, 2004)

```

    graph TD
      SI[Systemic issues] <--> CN[Clinical need]
      CN <--> PI[Predisposing issues]
      SI <--> C[Caregivers]
      CN <--> C
      PI <--> C
      C <--> A[Access to health care]
      SI <--> A
      CN <--> A
      PI <--> A
  
```

- Many people with developmental disabilities, and their families, experience crises
 - But what is a crisis?
 - Using emergency rooms for behaviour problems
 - Requiring time-limited treatment beds or crisis specific services
 - Having police get involved
 - Attacking a parent or sibling, or themselves?
 - Destroying someone's property when feeling angry?

□ Is this family in crisis?

□ *At the moment we are in a situation of nowhere. We have a son at 22 and we don't know anything about his future. And my wife has Lupus and all these problems, and now she has depression herself. Nearly two months she has been on disability leave... Tremendous stress. And we are nervous about my son. I am in a very difficult situation with the two of them, with no light at the end of the tunnel.*

Weiss & Lunsky, NADD 2009

□ Is this family in crisis?

□ *My daughter needs support too, the rest of the family needs support. My husband has depression and I'm sure that it would be different if his life wasn't so stressful. And I feel like I'm an Atlas holding up the world ... I am holding the family together and I need a break but I can't. I need to be strong enough until what? Never ends.*

Weiss & Lunsky, NADD 2009

Crisis Definitions – What is crisis?

9

□ Roberts (2000)

- 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 disruptive life event
- The **disruptive** event is
 - **stressful, traumatic, or hazardous,**
 - **perceived** by the caregiver as the cause of considerable distress
 - **not resolved** by previously used coping methods

Is crisis the same thing as stress?

10

□ McCubbin & Patterson (1983)

- **Stress** is a demand capability imbalance
- **Crisis** is an inability to restore stability and by the continuous pressure to make changes in the family structure and patterns of interaction

Purpose of study

□ Understanding when families are approaching a point of crisis is important

- We need clarity on what the term 'crisis' means
- We need a quick way of measuring the severity of a family's crisis experience.
 - Something useful to families and meaningful to clinicians so they know what kind of support to provide

Research questions

□ Better understand of what a crisis represents to families of individuals with developmental disabilities

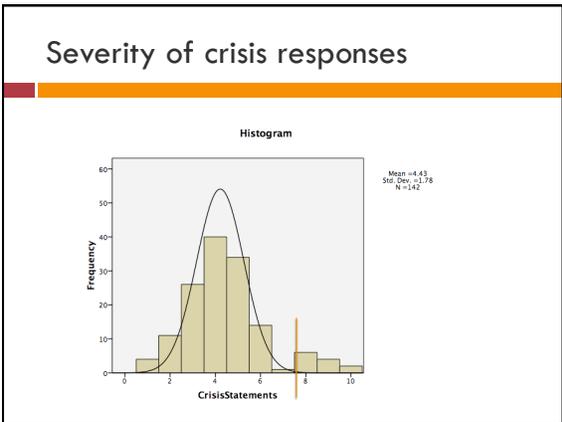
- Do families' examples of crisis support Roberts' view?
- Can families convey the severity of their crisis experience in a quick way that is meaningful to them and to clinicians responding to their situation?

Emerging themes

- Increases in stressors or severity of problem behaviour
 - “Significant change in his behaviours or ability to perform activities in of daily living”
 - “Her having a meltdown... beating, us, kicking, punching, hitting, pinching, pushing, slapping”
- Sudden event
 - “Death of a parent/grandparent, death of in-law, great grandparent, sudden loss of earnings, separation with pending divorce; having to move from hometown to large city”

Crisis Definitions – What is Crisis?

- 17 comments did not fit with Robert’s (2000) definition
- Emerging theme of Hopelessness
- Examples
 - “No hope for improvement or change for the better in a circumstance”
 - “Everybody feels helpless, child and parents”
 - “Loss of hope for the future”

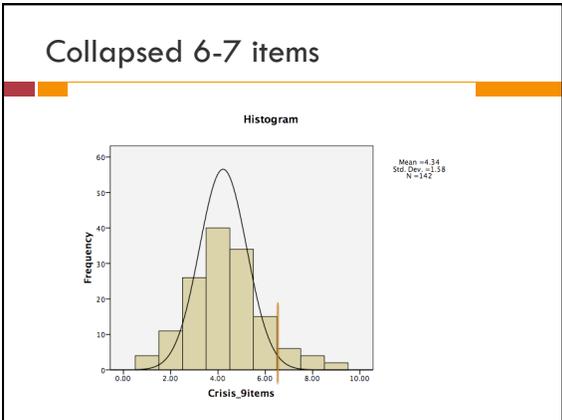


Severity of Crisis

Crisis as dimensional: Family Crisis Scale (Weiss & Lunsky)

1 Everything is fine, my family and I are not in crisis at all
2 Everything is fine, but sometimes we have our difficulties
3 Things are sometimes stressful, but we can deal with problems if they arise
4 Things are often stressful, but we are managing to deal with problems when they arise
5 Things are very stressful, but we are getting by with a lot of effort
6 We have to work extremely hard every moment of every day to avoid having a crisis
7 We won't be able to handle things soon. If one more thing goes wrong - we will be in crisis
8 We are currently in crisis, but are dealing with it ourselves
9 We are currently in crisis, and have asked for help from crisis services (Emergency room, hospital, community crisis supports)
10 We are currently in crisis, and it could not get any worse

22



Severity of Crisis: Bivariate

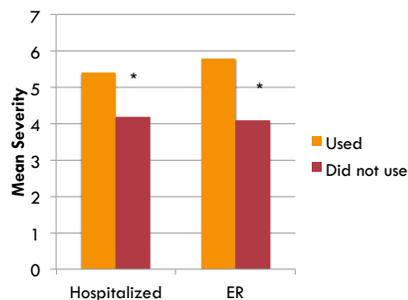
- Severity of crisis is positively related to
 - 4-item caregiver **worry** scale (Pruchno & McMullen, 2004)
 - $r = .32$
 - Frequency of **Aggressive Behaviour** (Behavior Problems Inventory– Short Form; Rojahn, unpublished measure)
 - $r = .43$
 - Caregiver **psychological distress** / mental health problems (Kessler 6)
 - $r = .38$
 - Caregiving **burden** (Revised Caregiving Appraisal Scales, Burden subscale; Lawton et al., 2000)
 - $r = .36$
 - Total **negative life events** (PASSAD life events checklist)
 - $r = .34$

* All $p < .001$

Severity of Crisis: Bivariate

- Severity of crisis is negatively related to
 - 1-item **quality of life** 4-point scale "How is your quality of life?" Poor to Excellent:
 - $r = -.38$
 - **Family empowerment** (Family Empowerment Scale; Family subscale; Koren et al. 1996):
 - $r = -.35$
 - **Family hardiness** (Inventory of Family Protective Factors, Compensating Experiences subscale; Gardner et al., 2008):
 - $r = -.42$
- * All $p < .001$

Severity of Crisis: Service Use



What do families need?

(Gratsa et al. 2007)

- **Information**
 - **Mental health**
 - Types: Description of mental illness and prescribed interventions and ways of doing assessments
 - Symptoms: Descriptions, ways of recognizing
 - Medication: Side effects, interactions, reasons, ways of seeing change
 - **Professionals and services**
 - Roles: Descriptions
 - Expectations
 - Who to call and how long to wait

What do families need?

(Gratsa et al. 2007)

- **Information**
 - **Practical issues**
 - Finances
 - Complaint procedures: Rights
 - Legislation
 - **Crisis planning**

What do families need?

(Gratsa et al. 2007)

- **Support and skill**
 - Working with professionals: Finding the right help, having the right attitude, advocacy
 - Working with society: Coping with negative social life experiences with acceptance and understanding
 - Problem solving & seeking alternatives
 - Self-care
 - New carers
- **Recognition of**
 - Experience of stigma / prejudice, isolation
 - Positive and negative past experiences

Ways to Foster Resilience

- **PREVENTION**
- Increase opportunities for success in work/ leisure
- Increase opportunities for satisfying social/ life experiences
- Ensure ability to communicate and make choices
- Encourage expression & validation of emotions
- Offer medical help when needed
- Offer skills training on coping
- Ensure social and other supports meet individual's needs

