Experiences of crisis in family caregivers of people with developmental disabilities

Dr. Jonathan Weiss
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, & Coucovanis, 2007):
    - 1992: 6.3%
    - 1999: 22%
    - 2006: 38.8%
Families care

What will happen to him when we are gone?
Families get others to provide care:

*Gateway Provider Model (Stiffman, Pescosolido, & Cabassa, 2004)*
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.
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.
Crisis Definitions – What is crisis?

  - 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?

- 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?
### Severity of Crisis

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

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<th>Score</th>
<th>Description</th>
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<td>We are currently in crisis, and have asked for help from crisis services (Emergency room, hospital, community crisis supports)</td>
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<td>10</td>
<td>We are currently in crisis, and it could not get any worse</td>
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Participant Demographics

- 142 participants recruited across Canada, through an online survey
  - Age of interviewee: $M = 45.4$ years, $SD = 8.6$
  - Age of family member with DD: $M = 16.2$ years, $SD = 8.9$
- Relationship to family member
  - 90% mother, 9% father, 1% sibling
- Ethnicity
  - 93% Caucasian; 91% spoke English as first language
- Gender of family member with DD: 80% male
- 95% of family members with DD lived with parents
Crisis Definitions – What is crisis?

- People have different ideas of what a crisis is. In your own words, what would a crisis look like for you?

- 144 comments

- Comments were analyzed using qualitative methods adapted from Ground Theory (Cresswell, 1994; Patton, 1990)

- 127 (88.2%) consistent with Roberts (2000) definition of crisis

*Many thanks to Carly McMorris for her analysis of the comments*
Word cluster of crisis
Emerging themes

- Lack of coping
  - "We would no longer be able to manage at least one key area of our lives (e.g., employment, relationships, etc.,)"

- “We would lose control of our more challenging emotions, and cause damage to another person/relationship”
- **Breakdown**
  
  "When too many things need to be 'fixed' or redirected to avoid tantrums, outbursts, sadness"

- **Loss of resources**
  
  "Right now crisis is financial - I home schooled my son and found him to be gaining extremely well - I have had to file bankruptcy and am very afraid of losing our home which would be a huge detriment to our entire family and would throw my son in total upheaval"
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 responses
# Severity of Crisis

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

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Collapsed 6-7 items
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

* p < .01
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
Barriers prior to crisis

- Negative experiences with professional help
- Not knowing where to find help
- Distance too far to get help
- Having difficulty describing the problem
- Considered problem temporary
- Steps to seek help were overwhelming
- No trust in professional help
- Wanted to handle the problems themselves
- Believed that the problem was not so serious

[Bar chart showing percentages of individuals with barriers before crisis]
Barriers to services

- < 21: Perceptions of the problem
  - Considered problem temporary and not serious
  - Steps to seeking help overwhelming

- > 21: Perceptions of the system
  - Negative experiences and lack of trust in professionals
  - Not knowing where to find help

For both groups: physical distance to help
Summary

- When families speak of crisis
  - Stressor that is associated with high levels of distress/stress, + loss of internal and/or external resources
  - And hopelessness?

- When considered on a continuum of stress-crisis
  - Logical relations to stressors, family resources (hardiness, empowerment), and constructs reflecting negative impact (burden, worry, mental health problems, quality of life)
  - But small relations on all factors... how do these factors relate to each other and combine to explain greater variance?
Implications

- Perhaps a quick measure of where family carers are at when coming in for service
- Improvements might not be reflected in crisis vs. no crisis, but instead in a reduction of crisis severity
- Until now, the sample is a self-referred community sample, and a correlational study
- Future work assessing families referred for crisis or tertiary service is needed
  - How is the scale associated with service utilization in the moment (ER use, hospitalization, crisis services, community activity involvement, etc.)?
Thank you!
Questions?

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