Adults with Dual Diagnosis in the Emergency Department: Why do they go and what happens once they are there?

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CNSC Presentation

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Introduction

- ED a barometer of the status of entire health system
- It is linked to primary care, outpatient care and psychiatric hospitalizations
- Limited expertise inside and outside ED when it comes to serving patients ID

Ontario Tertiary Hospitals Study

- 1 in 8 patients has dual diagnosis
- 20% being served in specialized dual diagnosis programs; 80% being served in generic programs
- 37% of inpatients with dual diagnosis have been in hospital for 5+ years
- They have been more severe symptoms, fewer resources & require a higher level of care than other patients

Lunsky et al., (2006) Psychiatric Services

Canadian Hospitalization Study

- 2% of mental health hospitalizations by those with developmental disability
- 42% of developmental disability hospitalizations were for mental health issues
- 36% of hospitalizations in adults btwn 16 and 24 (compared to 16% of hospitalizations in non-DD)
- Same length of stay but more rehospitalizations (36% rehospitalized within the year versus 21%)

Lunsky & Balogh (2010) Canadian Journal of Psychiatry

ED FOCUS GROUPS PROJECT

- Lack of knowledge
- Medication and restraint
- Respect and compassion
- Lack of resources in hospital and community

(Lunsky, Gracey & Gelfand, 2008)
(Weiss, Lunsky, Gracey, Canrinus, & Morris, 2009)
(Lunsky & Gracey, 2009)

- We needed to understand more about the unique characteristics of those who visit the ED in crisis
- 2007 we launched a 3 year study on crisis and ID

GOAL OF PROJECT

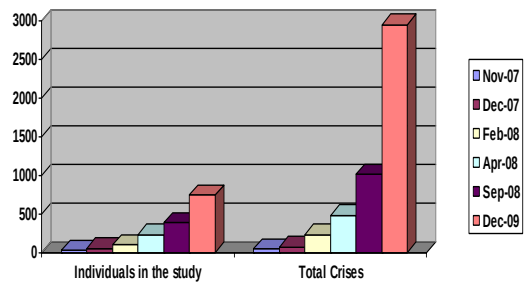
- To follow as many people with ID as possible to see:

1. **Who** has a crisis
2. **Which** crises lead to ED visits
3. **What** happens in the ED

Method

- Staff from participating agencies were trained to complete forms on clients who had experienced crisis
- They provided detailed info on the crisis, as well as client background information
- If crisis resulted in ED visit, a form describing ED visit was also completed
- With consent, hospital chart describing ED visit was reviewed

WHAT WE FOUND….



BREAKDOWN OF CRISES

3451 **Crises** in Total

↓

570 **ER** Visits

↓

165 **Admissions** to hospital

Now looking at those who have had at least one behavioural crisis…

AGE INFORMATION

AGE	# of INDIVIDUALS	%
20 and under	131	17%
21-30	174	23%
31-40	153	20%
41-50	156	21%
51+	133	18%
Unknown	4	<1%

Where do people live?

- Group Homes: 386 clients (51%)
- Family: 199 clients (26%)
- Minimal support: 162 clients (22%)
  - SIL: 72 clients (10%)
  - Independent living: 40 clients (5%)
  - Shelter: 16 clients (2%)
  - Boarding Home: 12 clients (2%)
  - Transitional housing: 15 clients (2%)
  - Correctional Facility 4 clients (<1%)
  - Street 3 clients (<1%)

Severity of Aggression

- 5 point scale ranging from not serious to extremely serious
  - Not serious: 639 crises (19%)
  - Slightly serious: 634 crises (18%)
  - Moderately Serious: 522 crises (15%)
  - Very Serious: 696 crises (20%)
  - Extremely Serious: 102 crises (3%)

Predictors of visits to ED

- Level of disability (more mild)
- Younger age
- **Less supported residential setting**
- No daytime activities
- Dual diagnosis
- **Previous ER visits**
- Severity of aggression
- **Number of life events in past year**
- Receiving clinical services
- **Crisis Plan**

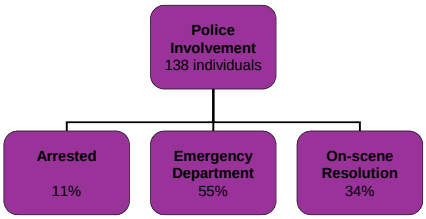
Suicidality

- Small subgroup of individuals but does occur
- Suicide attempters were younger, more likely to be female, under supported, with mild ID
- Attempters had more life events in previous year than non- attempters
- Most who attempted had been to hospital before
- Similar rates of therapy to other individuals

Autism

- More SIB, property destruction and physical aggression
- Severity of aggression ratings were higher
- HOWEVER, no more likely to visit ER (19-20%)
- Two subgroups:
  - Asperger Syndrome and very severe ASD
- Multiple Crises
- ED is extra stressful, complicated for this group
- However, can manage crisis outside of ER with support (80% did successfully)

Police intervention



Police intervention with adults with ID can happen for different reasons. Only 1 in 10 such visits resulted in arrest in this study. Both individual and situational predictors can explain this outcome.

Life Events

- More life events in past year for those that visit ED
- Many common life events are preventable
- Sometimes life event is a direct trigger of crisis and sometimes the link is less obvious
- Life events are a bigger issue for people who visit ED for behavioural reasons and not medical

Life Events	ER visit (N=143)	no ER visit (N=604)
Death of first degree relative	9.8 %	6.0 %
Death of a close family friend, relative, etc	7.0 %	5.0 %
Serious illness or injury	13.3 %	10.1 %
Serious illness of close relative*	**13.3 %**	**7.6 %**
Move of house or residence*	**35.7 %**	**18.5 %**
Change in roommates	21.7%	19.4%
Breakup of steady relationship	4.9%	3.6%
Separation or Divorce	1.4%	1.0%
Alcohol Problem*	**5.6%**	**0.7%**
Drug Problem*	**7.0%**	**1.3%**
Serious problem with family friend, caregiver*	**27.3%**	**9.9%**
Unemployed for more than one month*	**15.4%**	**3.1%**
Retirement from work	0.0%	0.7%
Laid off or fired from work	4.9%	2.2%
Something valuable lost or stolen	3.5%	1.7%
Problems with police or other authority*	**14.7%**	**7.5%**
Major financial Crisis	4.9%	2.0%
Sexual Problem	4.2%	3.6%
Change in client's primary staff/worker	30.1%	28.8%
Recent trauma/abuse*	**12.6%**	**3.1%**

Crisis Study: Proportion of Individuals Taking Psychotropic Medications (n=748)

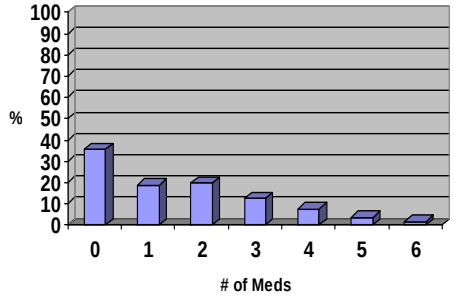


Chart Audits of visits to ED

We completed audits of 225 ER Visits
(based on 119 individuals visiting 18 hospitals)

Documentation of Intellectual Disability

- The presence of ID was noted in the chart for 57% of visits
- The level of ID was recorded for 24% of these visits

Consulting with an informant

- In 69 visits (31%), ER staff spoke to a professional caregiver
- In 46 visits (20%), ER staff spoke to a familial caregiver
- In 13 visits (6%), ER staff spoke to both a professional caregiver and a familial caregiver
- In the remaining 123 visits (55%), there was no indication in chart that any informants were consulted

The use of psychiatry in ED

- According to chart reviews, 142 visits had no medical issue and were 'behavioural' in nature
- Of those, 70 visits (49%) were triaged to psychiatry and/or crisis team
- REMAINDER were discharged PRIOR to psychiatric assessment

Most common behav. presentations (n=123)

1. **Physical aggression (32.5%)**
   - pushed mom against wall and hit her head
2. **Suicidal ideation or attempt (20.3%)**
   - threatened to run into traffic after accusation
   -took a bottle of pills after argument with brother
3. **Other psychiatric symptoms (13.0%)**
   - anxious, depressed, hallucinations
4. **Verbal aggression (7.3%)**
   - calling staff names, threatened to hurt roommate

Most common medical presentations (n=98)

1. **Injury/Poisonings (41.8%)**
   - wrong medication taken
   - too much medication taken
   - slipped and fell down on ice
2. **Ill defined symptom/signs (11.2%)**
   - client felt dizzy and weak
3. **Nervous system/sense organs (10.2%)**
4. **Digestive (9.2%)**
5. **Infectious/Parasitic (7.1%)**

Medical visits sometimes have an emotional or behavioural component…

- Injury due to fight
- Injury due to fire setting
- Fall due to medications
- Poisoning due to being upset

Sometimes medical issues can become behavioural…

- Restraints during laceration
- Increased agitation while waiting overnight
- Long visit with no administration of medications

Comparison of two types of visits

- Younger individuals, with psychiatric diagnoses and history of recent life events more likely to have behavioural presentations (not medical)
- Individuals with behavioural presentations more likely to come back compared to medical presentations
- Behavioural more likely admitted (47% versus 26%)
- Satisfaction rates lower for behavioural visits

Individuals Living with Family who visited ED

- Chart audit of 20 individuals with a total of 44 visits
- 35% of individuals made repeat visits to the EDAggression was the most common presenting problem
- Patients received psychiatric consult 64% of the time
- 43% ED visits resulted in admission
- 36% of the time, ED staff sent patients home with no recorded follow up plans
- No differences were found between hospitalized and non-hospitalized visits in terms of client characteristics or crisis severity

What people who visited the ED had to say about it.....

What doesn't work

- This lady said to me "you come in here all the time and this and that… She argued with me. I was upset about it so I just left and went to another hospital
- They don't understand that it is hard to be cooperative when I am agitated
- Sometimes I get sent home from the ER even though I am suicidal. It is as if they are angry at me for trying to commit suicide. They don't understand what a serious problem it is for me
- When I got handcuffed by police: It scared the heck out of me
- I had to wait a long time… Then I was with all these people with mental problems. Like one guy was kicking the door and a lot of people were making noises…It wasn't a good experience

What works

- Nurse makes me feel like I don't have to worry about why I am here. I just have to get better
- Being admitted makes me feel safe but then leaving I feel suicidal all over again
- When the ER staff talk to me and the doctor gives me medication

Waiting in the ED

- It was a bit difficult because the more people came in with other problems, the more anxious she got. Its not like a regular individual who could understand the wait
- We got there at 6 and got through around midnight. Then we waited until 7 in the morning to see the psych doctor.

Being sent home too early

- They said they couldn't keep her anymore so they sent her home. The same day they sent her home, she ran away. She has never taken the bus on her own but that day she took herself to another hospital.

Summary of Findings

- Best predictor of ED use is past ED use
- Life events are important to think about
- Aggression to others is most common issue
- Self harm is also a serious concern
- Polypharmacy is common
- Not everyone at ED is seen by psychiatry
- Assessments in ED may not be comprehensive
- Decisions in ED are not just based on clinical issues
- ED users and caregivers are less satisfied with treatment for behavioural issues than medical ones

WHAT NEXT?

"When all is said and done,
a lot more is said than done"

"When we see our kids treated this way and it's difficult not that I would do it but sometimes when you see people do some weird stuff with themselves and their kids, it takes situations like these when you reach out to people and they're looking at you as if you're piece of garbage or what you're saying doesn't matter. …You just put the person there or you give them some medication.

It takes more than that. You wouldn't like to see your family member going through that and no one is there to help. Show a little bit more kindness. Have a heart because the profession you're in you vowed to help people so that's what we expect from you. Help, that's what we want."

- The first visit is an emergency but recurrent visits are a failure of the system
  - Proactive crisis planning should be triggered by first visit
  - Include person with ID, caregivers, hospital, primary care, and other clinicians in the planning
  - Get that plan into the ED

- Consider emotional or behavioural aspects to “medical emergencies”
- Do we lower the bar and triage more frequently to psychiatry or crisis worker?
- How closely to we need to understand the contribution of multiple medications to presentation?

- Screening around life events should be standard practice in understanding the crisis
  - Recent life events may not be so “recent”
  - Cumulative impact of interpersonal stressors
  - Need to ask person with ID and informants

- Needed supports to people with ID when in ED
  - Supports to caregivers
  - Reminders to take medications
  - Finding a way to include the person with ID in process
  - Environmental considerations to make it less stressful

2011 Primary Care Guidelines

- Primary care guidelines and tools that apply to ED
  - Guide to understanding behaviour
  - Medication audit
  - Hospital information sheet
  - Guidance to caregivers if visiting ED
  - Crisis planning tool

Resources for families and staff

- Hospital information sheet
- Guide to prepare for and cope with crises
- Importance of debriefing after first crisis
- Documentation to take from ED
- Follow-up visit after ED with physician

Tools for individuals with ID

- Hospital passport
- Social stories about ED
- ED care package

- Awareness of local resources in ED
  - Community Networks of Specialized Care
  - Local clinical services for individuals with ID
  - Local developmental services
  - Relevant websites accessible to ED staff
  - Liason person who can provide information
  - Champion within each hospital who can find information

Participating Agencies

Toronto – 21 (Community Living Etobicoke, Community Living Central Toronto, Community Living North York, Community Living Scarborough, CORE, COTA, DDRS, Griffin Centre, Kerry's Place, L'Arche, Mary's Centre, Meta, Muki Baum, New Leaf, Operation Springboard, Reena, Salvation Army, Surex Community Services, Surrey Place, Vita Community Living, Woodgreen Community Services, York Community Services)

Peel – 5 (Community Living Mississauga, Brampton Caledon Community Living, Peel Crisis Capacity Network, Central West Specialized Developmental Services, Peel CAMH)

Kingston - 5 (Ongwanada, Community Living Kingston, DDCOT, MHT, APSW)

Participating Hospitals

- **Toronto** (CAMH, Humber River Regional, Mt. Sinai, North York General, Rouge Valley Health System, St. Josephs Health Centre, St. Michaels, Sunnybrook Health Science Centre, The Scarborough Hospital, Toronto East General, Toronto General, Toronto Western)
- **Peel** (Credit Valley, William Osler Health Centre, Peel Memorial, Trillium)
- **Kingston** (Kingston General Hospital, Hotel Dieu)

Websites and Resources

- Surrey Place Centre Primary Care Guidelines (http://www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx)
- CAMH ER Guidelines (http://www.camh.net/Publications/CAMH_Publications/guide_manageclient_inteldisorder.html)
- Hospital passports (search hospital passport and learning disability)
- Books Beyond Words Series (Sheila Hollins)
- Dual Diagnosis Program, CAMH

Related Research Studies

- Aggression and impact on Staff (Work and Well Being Research and Evaluation Program, CAMH)
- Autism Spectrum Disorders and Health Service Use
  - The Family Study
  - The Asperger Syndrome Study

  (For more information go to www.familyprojects.ca)

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THANK YOU

Centre for Addiction and Mental Health
Centre de toxicomanie et de santé mentale