Emergency Psychiatric Services for Individuals With Intellectual Disabilities: Perspectives of Hospital Staff

Yona Lunsky, Carolyn Gracey, and Sara Gelfand

Abstract

Strains on the mainstream mental health system can result in inaccessible services that force individuals with intellectual disabilities into the emergency room (ER) when in psychiatric crisis. The purpose of this study was to identify clinical and systemic issues surrounding emergency psychiatry services for people with intellectual disabilities, from the perspective of hospital staff. Focus groups were conducted with emergency psychiatry staff from 6 hospitals in Toronto, Canada. Hospital staff reported a lack of knowledge regarding intellectual disabilities and a shortage of available community resources. Hospital staff argued that caregivers need more community and respite support to feel better equipped to deal with the crisis before it escalates to the ER and that hospital staff feel ill prepared to provide the necessary care when the ER is the last resort. Input from hospital staff pointed to deficiencies in the system that lead caregivers to use the ER when other options have been exhausted. Both staff and caregivers need support and access to appropriate services if the system is to become more effective at serving the psychiatric needs of this complex population.

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In Canada and other parts of the world, psychiatric services were once provided through state institutions for individuals with intellectual disabilities. In the 1970s, plans to downsize and close these institutions were initiated, and, since then, individuals with intellectual disabilities have been directed to the mainstream mental health system for their psychiatric needs (Lunsky, Garcin, Morin, Cobigo, & Bradley, 2007; Ouellette-Kuntz et al., 2005). As many as 40% of adults with intellectual disabilities living in the community are believed to have mental health issues (Bouras & Drummond, 1992; Reiss, 1990), and psychiatric issues account for a considerable proportion of their hospital admissions in Ontario, Canada (Balogh, Hunter, & Ouellette-Kuntz, 2005). Researchers have suggested that the inability of individuals with intellectual disabilities to access appropriate mental health services in a timely manner leads to crises resulting in visits to hospital emergency rooms (ERs; Bradley & Lofchy, 2005). A more in-depth study of what leads to ER visits by people with intellectual disabilities and what occurs in the ER is vital if we are to begin to understand and intervene to correct deficiencies at both the clinical and systems levels.

“A psychiatric emergency is any behaviour that cannot be dealt with as rapidly as needed by the ordinary mental health, social service, or criminal justice system in a community” (Hillard, 1994, p. 541). Understanding what occurs in the ER is an indication of how other components of the system of care delivery are functioning (Dawe, 2004; Hillard, 1994; Spurrell, Hatfield, & Perry, 2003). High rates of ER visits by individuals with intellectual disabilities may be caused, in part, by insufficient primary and mental health care and poor links between health and social services (Bradley & Lofchy, 2005; Lunsky, Garcin, Morin, Cobigo, & Bradley, 2007). Although about half of all adults with intellectual disabilities are taking psychotropic medication (Lunsky, Emery, & Benson, 2002; Molyneux, Emerson, & Caine, 1999; Robertson et al., 2000), many do not have access to psychiatrists. As a result, these adults’ mental health care is often man-
managed by general practitioners who feel ill equipped to provide psychiatric care for this population (Lennox, Diggens, & Ugioni, 2000; Lunsky et al., 2007). In addition to a lack of health services, many adults with intellectual disabilities lack more basic services such as housing, meaningful daytime activities, and case management (Lunsky & Puddicombe, 2005). A lack of basic supports can lead to coping difficulties and crisis, which can ultimately lead to ER visits (Morris, Bradley, Gitta, Nugent, & Summers, 2004).

Emergency physicians and allied health staff have limited expertise in serving individuals with intellectual disabilities (Bradley & Lofchcy, 2005; Grossman, Richards, Anglin, & Hutson, 2000; Iacono & Davis, 2003; Sowney & Barr, 2006; Sullivan et al., 2000). In a recent Toronto study (Mitchell et al., 2005), ER physicians were asked how confident they felt in recognizing and diagnosing psychiatric disorders. They listed developmental disorders as one of the three disorders they felt least comfortable diagnosing. This is not surprising given that intellectual disabilities are minimally addressed in training for family medicine (Special Olympics, 2005; U.S. Department of Health and Human Services, 2002), internal medicine (Grossman et al., 2000), and psychiatry (Lunsky & Bradley, 2001), as well as in nursing (Ailey, 2003; Haut & Hull, 2000; Sowney & Barr, 2006; Summers et al., 2005) and social work (Burge, Druick, Caron, Ouellette-Kuntz, & Paquette, 1999).

Performing ER assessments of patients with intellectual disabilities is very challenging (Houghton, 2001; Lunsky & Bradley, 2001). In making a diagnosis, the psychiatrist must differentiate among underlying medical disorders that may appear psychiatric, reactions to emotional upsets (e.g., grief or trauma), and psychiatric disorders (Bradley et al., 2002, 2007). The stressful and unfamiliar environment of a hospital emergency department can intensify the patient’s communication problems, attentional difficulties, memory impairments, and sometimes challenging behavior that are common in individuals with an intellectual disability and mental health problems (Bradley & Lofchy, 2005; Grossman et al., 2000; Houghton, 2001; Sullivan et al., 2000). To complicate matters, many of these individuals are prescribed multiple psychotropic medications that can play a role in triggering or exacerbating the psychiatric crisis (Robertson et al., 2000; Valdivinos, Caruso, Roberts, Kim, & Kennedy, 2005), and their capacity to provide consent to treatment is often unclear (Heng & Sullivan, 2003; Sowney & Barr, 2007). Research is required to determine the assistance that clinicians require during such challenging assessments.

A handful of studies have considered the experiences of individuals with intellectual disabilities in a hospital or in the ER, from their perspective (Hart, 1998; Iacono & Davis, 2003; Parkes, Samuels, Hassiotis, Lyngaard, & Hall, 2007) or the perspective of their caregivers (Fox & Wilson, 1999; Iacono & Davis, 2003; Slevin & Sines, 1996; Sowney & Barr, 2007). These studies have demonstrated that the experience is stressful for patients and caregivers and that hospital staff display negative attitudes (Slevin & Sines, 1996) and a lack of knowledge that impacts patient care (Barr, 2004). It is as important to examine the perspective of hospital staff who serve individuals with intellectual disabilities as it is to know about the perspective of the service user. More needs to be learned about the experiences, challenges, and potential solutions of hospital staff, if the ER interface is to be improved. Only with information from both groups (i.e., ER users and ER staff) can change be made.

In our review of the literature, we found only one project that solicited emergency nursing staff perspectives on treating patients with intellectual disabilities from five hospitals in Ireland (Sowney & Barr, 2006, 2007). The main themes nurses spoke about were lack of knowledge about intellectual disability, nurses’ dependence on caregivers, consent issues, and communication problems. However, from the quotes in the two articles, it appears that nursing staff focused on patients treated for physical rather than mental health issues and on admitted patients rather than patients at the emergency assessment phase. This Irish study was also limited by its exclusive focus on the perspectives of nurses, when ER assessments typically involve an interdisciplinary team of individuals.

The purpose of our research was to identify issues and concerns raised by interdisciplinary emergency psychiatry–crisis-response teams at six hospitals in an urban setting in Canada, when dealing with patients with intellectual disabilities and mental health or behavioral issues (i.e., dual diagnosis). In particular, we wanted to understand the typical clinical presentation, barriers in the health system that contribute to ER visits, challenges encountered in the ER, and suggestions for improvement and prevention.
Emergency psychiatric services

Method

Focus groups were conducted with emergency psychiatry staff from six high-volume general hospitals in Toronto, a large, urban setting with an ethnically diverse population of approximately 2.5 million. These six hospitals were selected because they were known to be frequently used by individuals with intellectual disabilities. Initial contact was made with the hospital psychiatrist responsible for emergency psychiatry services, who was informed of the study and invited to select suitable emergency psychiatry staff to participate. In total, 44 hospital staff members, including psychiatrists and psychiatry residents, nurses, social workers, and other crisis workers—allied health professionals and managers, participated in the focus groups. The makeup of each group varied by hospital, with the three teaching hospitals having more psychiatrists (n = 4) and psychiatry residents (n = 2) present than the three community hospitals (n = 2 psychiatrists and no psychiatry residents).

These groups were organized within the emergency psychiatry programs at a time convenient to staff (e.g., during monthly educational rounds) between June and July 2005 and held on-site at the hospitals. Focus groups were 1 hr in length and were facilitated by the first author (Y.L.), a clinical psychologist with experience conducting focus groups. Focus groups were selected for this study rather than individual interviews to capitalize on the interactions among participants (Owen, 2001).

Hospital staff were asked to discuss the most common presenting problems they encountered in patients with intellectual disabilities, their comfort level treating these patients, common challenges encountered in the ER, and supports or services required by ER staff. In addition, hospital staff were asked to suggest potential resources as well as prevention and intervention strategies. Each group was asked the same set of questions, in the same order (see the Appendix). Questions were developed based on input from a panel with expertise in health research and intellectual disability (Lunsky et al., 2005–2008). Responses were recorded in writing simultaneously by the first author and a research assistant. Notes from the two research team members were synthesized immediately after each focus group met and were reviewed again after all the group interviews had been conducted. When inconsistencies arose, the notes were discussed until a consensus was reached. In addition, the records were reviewed by a third researcher who did not participate in the focus groups. The narrative data were analyzed and emerging themes were identified.

This study received ethics approval from the Research Ethics Board at the Centre for Addiction and Mental Health. Hospital staff understood that participation was voluntary and responses remained confidential. Staff signed written consent forms prior to starting the focus groups. No one declined to participate or ended the focus group early. Staff were offered refreshments during the group session, and after the group session they were given a booklet on managing individuals with intellectual disabilities in the ER (Bradley et al., 2002), along with a CD of helpful resources for their emergency room.

Results

Findings from the focus groups revealed a number of themes that centered on a lack of knowledge, training, support, and resources for both hospital staff and caregivers. The findings are organized below by study question rather than by theme and are substantiated by quotations from the focus groups.

Description of Client Population

When staff were asked about the typical presentation of individuals with intellectual disabilities and mental health issues (i.e., dual diagnosis) and the frequency with which they visited the ER, they reported that one or two people with a dual diagnosis would use the ER each week. When asked about the level of disability, hospital staff reported that individuals with both mild and severe disabilities visited the ER. There was agreement that, although they saw very few people with intellectual disabilities compared with other populations, serving these individuals required a great deal of effort.

We don’t see a lot, but when we do, they are time consuming and difficult. Sometimes the same person comes 3 to 4 times in a row.

When asked how patients arrived at the ER, hospital staff reported that some patients arrived alone, but most were accompanied by either a paid or unpaid caregiver, and, in some situations, they were accompanied by police due to safety concerns.

When questioned about the main reasons that individuals with intellectual disabilities come to the ER, staff from five of the six hospitals said that the primary reason was behavior/aggression (see Table 1). Staff from four of the same hospitals reported
Table 1  Hospital Staff Responses Regarding the Main Reasons for ER Visits

<table>
<thead>
<tr>
<th>Responses</th>
<th>No. of hospitals (N = 6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aggression/behavioral issues</td>
<td>5</td>
</tr>
<tr>
<td>Burn out/respite/last resort</td>
<td>4</td>
</tr>
<tr>
<td>Housing crisis</td>
<td>2</td>
</tr>
<tr>
<td>Food/social contact</td>
<td>2</td>
</tr>
</tbody>
</table>

*Note.* ER = emergency room.

that many individuals were brought to the ER because caregivers did not have the professional support needed to adequately deal with the crisis and were unable to cope with the situation on their own.

They bring the patient to the ER looking for a miracle pill or wanting the hospital because they can’t cope.

It is more about the staff’s difficulties and burn out and less about the behaviour of the person.

We are more likely to admit this population for respite—more than any other type of population. We don’t like doing that, but the bottom line is that there is no other option and everyone is burnt out.

Staff from two hospitals said that a lack of adequate housing and an inability to place a client were often reasons that patients came to the ER.

Staff from two of the hospitals also mentioned that many of the individuals who arrived alone often visited the ER looking for food and social contact.

One to two regulars walk in on their own (1/month). [They are] lonely, agitated, and hungry. One client calls 911 and just needs to chat, have some food and then goes home.

When asked what makes hospital staff uncomfortable during these visits, staff from three of the hospitals identified the use of restraints to handle aggressive behavior. Staff from three of the hospitals mentioned that the ER environment was inappropriate for dealing with this type of behaviour.

There is a safety issue—[it's] a small space here. Patients can be confined for days and can be victims of other patients—[they are] easy to be preyed upon.

We will do our best to avoid restraints—try to get them a room on the unit. One-to-one attention helped them get control back, but it’s harder to do in the ER than on the unit.

Barriers—Challenges

Hospital staff were also asked about what they perceived to be the main challenges during ER visits (see Table 2). Staff from all of the hospitals reported that they did not have enough information about potential services to access for these clients, and staff from four of the hospitals reported that they lacked the knowledge and experience to serve the population well.

How can I engage with this person? We don’t have that expertise.

Dual diagnosis is not something mental health staff have skills or experience with.

Staff from four of the six hospitals identified the lack of understanding of the client or the caregiver about procedures and limitations of the hospitals as a significant barrier.

They don’t understand the standard processes that all patients go through.

Coming to emergency is not a ticket to a hospital bed. . . . People have a fantasy that everything will be right if they come to the hospital.

We are limited to medicate, control environment, and send them back. [There’s] not much crises nurses can do.

Everybody expects us to have a solution to a problem that’s been brewing for years.

Staff from four of the six hospitals reported that they were typically provided with very little background information and that it was difficult and time consuming to gather the information that they needed. Even basic information on current medications and psychiatric—medication history were unknown.

Assessments require collateral information, but often there is little, which makes the assessment hard.

It’s a lot of legwork to gather history.

Staff from four of the hospitals were concerned with an inability to find respite and community placements at discharge.

Housing is very difficult. They are often admitted not because of medical [concerns], but because they have no place to go which will take them, especially when they are on the verge of losing housing.

Staff from three of the hospitals mentioned that it was often difficult to communicate effectively and efficiently with other service providers and caregivers.

Sometimes there are complex family dynamics to work through.

[It is] not easy to work with staff from other programs and agencies.

They don’t call back or come in to see the patient.

Staff from two of the hospitals identified care-
Table 2 Hospital Staff Responses Regarding the Main Challenges During ER Visits

<table>
<thead>
<tr>
<th>Response</th>
<th>No. of Hospitals (N = 6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of information on available services</td>
<td>6</td>
</tr>
<tr>
<td>Lack of knowledge and experience with dual diagnosis</td>
<td>4</td>
</tr>
<tr>
<td>Misunderstanding of clients and caregivers about role of ER</td>
<td>4</td>
</tr>
<tr>
<td>Insufficient client background information available</td>
<td>4</td>
</tr>
<tr>
<td>Limited respite and residential placement options</td>
<td>4</td>
</tr>
<tr>
<td>Communication with service providers or caregivers</td>
<td>3</td>
</tr>
<tr>
<td>Caregiver burnout</td>
<td>2</td>
</tr>
<tr>
<td>Time-consuming population</td>
<td>2</td>
</tr>
<tr>
<td>ER an inappropriate environment</td>
<td>2</td>
</tr>
<tr>
<td>Complex medical issues</td>
<td>2</td>
</tr>
</tbody>
</table>

Note. ER = emergency room.

Directions for Intervention

Hospital staff were asked what could be done to prevent individuals with intellectual disabilities from going to the ER in a psychiatric crisis. Staff from five of the six hospitals suggested that more caregiver support and a greater emphasis on respite would help decrease the number of visits. Staff from three of the hospitals mentioned that caregiver training, rapid onsite treatment, and communication with the case manager or management team in the community could all be effective in preventing a crisis from escalating to the point of the person using the ER.

In response to the question of what might be helpful before or during a visit, several suggestions were offered. Staff from four of the hospitals suggested that calling in advance would give them enough time to prepare for the client (e.g., gather information, set up a private space away from the ER) and would provide an opportunity to inform caregivers of what information to bring. This would ultimately help alleviate some of the stress for both hospital staff and clients.

Staff suggested developing a resource list of available services, which could be useful not only for clients and caregivers but for staff in the ER. In terms of format, staff thought both a Website and a 24-hr telephone line would be helpful. Hospital staff wanted to spend less time leaving messages to various agencies, in attempts to get more information or prepare for discharge.

Staff from four of the hospitals also thought that improving interagency communication would be very helpful to communicate about either specific patients or available services. Hospital staff wanted to spend less time leaving messages to various agencies, in attempts to get more information or prepare for discharge.

The system is fragmented. We don’t know what’s out there and it’s hard to navigate—the right arm doesn’t know what the left arm is doing.

Furthermore, staff from four of the hospitals suggested that clients and caregivers receive training on how to provide ER staff with a more comprehensive history (i.e., diagnoses, current treatment plan, crisis plan, baseline, etc.). Staff from four hospitals suggested that hospitals create an alternative, less distressing place to wait during a crisis than the ER waiting area. Staff from two of the
six hospitals suggested that their staff would benefit from more training in dual diagnosis.

**Discussion**

A handful of articles have reported the experiences of nurses or psychiatry staff on working with individuals with intellectual disabilities (Edwards, Lennox, & White, 2007; McConkey & Truesdale, 2000; Slevin & Sines, 1996; Sowney & Barr, 2006, 2007). However, to our knowledge, this is the first article to provide detailed descriptions of the experiences of staff in emergency psychiatry specifically, along with their recommendations on how to improve the situation. Focus groups revealed that, although relatively few individuals with intellectual disabilities and psychiatric issues accessed emergency services in these hospitals, aggressive behaviour and a lack of knowledge, training, and services all contributed to the significant challenges that this complex population posed for hospital staff in the ER.

It is not surprising that the most common issue presenting in the ER is aggression and that hospital staff have discomfort with this. Several studies have reported that the experiences of staff when responding to this behavior are particularly distressing (Fish & Culshaw, 2005, Hawkins, Allen, & Jenkins, 2005; Raccka, 2005; Rose, Horne, Rose, & Hastings, 2004). A number of studies have reported that aggression is one of the most common reasons for referral to any kind of health service (Alexander, Piachaud, & Singh, 2001; Cowley, Newton, Sturme, Bours, & Holt, 2005; Edelstein & Glenwick, 1997). However, other studies on the experiences of hospital staff who treat individuals with intellectual disabilities have focused more on the general discomfort with the population as a result of their lack of knowledge (e.g., McConkey & Truesdale, 2000; Sowney & Barr, 2006, 2007), rather than on their specific discomfort with aggression management.

It is worth noting that, in our study, hospital staff did not identify problems diagnosing and treating psychiatric disorders in people with intellectual disabilities. Perhaps this is because they had an understanding of how to recognize and treat such disorders but less comfort treating aggression, when the cause of the aggression was not clear. It is also possible that hospital staff were not seeing psychiatric disorders without serious aggression because such disturbances are treated outside of the emergency department (see Edelstein & Glenwick, 1997; Lunsky et al., 2006). A final possibility is that hospital staff were not aware of how complex it can be to diagnose a psychiatric disorder in these individuals, and, hence, they did not consider their efforts to do so in the ER to be problematic.

A related concern is that hospital staff did not discuss the possibility that the challenging behavior could have had a medical cause. This could have been because individuals with medical concerns were identified in the triage process and never were assessed by psychiatry. However, numerous articles have stressed the importance of recognizing that medical conditions in this population can result in challenging or aggressive behavior, particularly in individuals with limited communication skills (Bradley et al., 2002; Bradley & Lofchy, 2005; Sullivan et al., 2000, 2006). This issue highlights the concern that a lack of knowledge and experience with this population can result in diagnostic overshadowing, where ER psychiatry staff focus on the behavior or mental health issue and fail to acknowledge the presence of an underlying medical condition. Because of this problem, there is the need for ER psychiatry and triage to work closely together to better distinguish between medical and psychiatric issues, especially with individuals who may not be able to communicate their concerns themselves.

It is interesting that staff commented on the need for guidelines and resources, given that the study was conducted in a city where published guidelines exist (Bradley et al., 2002), as does a network of crisis and support services for people with intellectual disabilities (Gapen, Dart, & Macdonald, 2007). When Bradley et al.‘s (2002) guidelines were published, they were sent to each of the hospitals surveyed. Similarly, information on the network of services has been made available to hospitals. The lack of awareness of some hospital staff about these resources speaks to the challenge of making information accessible regarding a low-profile, minority population. A similar finding was reported in Sowney and Barr (2007), where nurses did not make use of specialist services and did not know how to access them even though specialist community intellectual disability teams existed across the region. In their study, Sowney and Barr recommended developing inclusive services and strengthening links with community providers and specialists. Any future attempts in Toronto to implement interventions for individuals with intellectual disabilities in the ER must include staff from...
the ER so that resources supplied to the hospitals are accessible and used over the long term. As an example of this, psychiatry residents at the University of Toronto are now educated about resources during a 3-hr, mandatory seminar on treating individuals with intellectual disabilities in the ER, where representatives of the network of services present information on their services. It would be interesting to examine whether such teaching is having an impact in the hospitals. Additional research is needed in this area.

This study has several limitations that should be considered. First, although the focus groups involved a variety of emergency staff, other perspectives (e.g., clients, paid and unpaid caregivers) are needed to fully understand the clinical and systemic issues around visits to the ER for this population. In addition, although having a single facilitator ensured that facilitation was similar across focus groups, there is a possibility that it may have also hindered the diversity of responses from hospital staff. In addition, there is a need for substantive data not only on the characteristics of the individuals the hospitals are serving but on what happens to these individuals in the ER (e.g., information on restraint use, percentage of individuals with intellectual disabilities in hospital). Last, focus groups were conducted within six high-volume hospitals in an urban setting, and findings cannot be generalized to emergency departments in more rural locations or to settings where specialist services and expertise are more readily available than is the situation in Ontario, Canada.

Input from hospital staff in this study points to deficiencies in the system that lead caregivers to use the ER because they believe that all other options for help have been exhausted. If hospital staff is to become more effective in a psychiatric emergency, they need support and access to appropriate services for these clients. Hospital staff offered some very practical suggestions that are relevant to caregivers on how to make a visit to the ER less stressful and more productive. In particular, hospital staff noted that people with intellectual disabilities and their caregivers need guidance on the role of hospitals and how to best prepare for a hospital visit in case an emergency arises. Sowney and Barr (2007) reported similar suggestions made by emergency nurses in regards to medical emergencies. It is our intention to develop such resources in collaboration with hospitals and community agencies in the Toronto region in the near future and then evaluate their effectiveness.

Little is known about what happens when individuals with intellectual disabilities and mental health problems access the ER in a psychiatric crisis. In this study, focus groups among emergency psychiatry staff provided insight into the perspectives and experiences of the hospital providers that were responsible for this care. It is important that staff not only expressed the challenges that they faced but highlighted what anticipatory measures and modifications could be set in place to relieve some of the discomfort and stress for ER staff, caregivers, and clients during these visits. Caregivers and community agencies require more support—respite services to feel better equipped to deal with crises, and hospital staff need more support and training with this population when the ER is the last resort. Furthermore, what seems to be needed is a greater awareness of the services that are available for this population and a more readily accessible and collaborative network of resources. Although research in this area is limited, studies like this into emergency psychiatric services for individuals with intellectual disabilities are critical to our understanding of the mental health needs and systemic issues that exist for this population.

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Appendix

Focus Group Questions

1. How often does someone with a dual diagnosis come to the ER?
2. What are the main reasons why patients with a dual diagnosis come to the ER?
3. What are the main challenges you have encountered during an ER visit?
4. Are there any services within the hospital or outside of the hospital that you think are missing, which would reduce ER visits in the future?
5. Do you have any ideas about what resources might be helpful for you during ER visits or before ER visits?

Note. ER = emergency room.