

Research Article

Primary Care Outpatient Treatment Centre for Intellectual Disabilities Helps Prevent Inpatient Psychiatry Treatments

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Abstract: Background: Our qualitative study evaluated the following two questions: For what needs do adults with intellectual disabilities consult a primary care outpatient treatment at a psychiatry department? How have hospitalization rates and experiences evolved for this population over the last 20 years? **Method:** We explored the occurrence and topographies of SBP across different severity levels of ID to inform clinical practice. We then quantified the number of hospitalizations. **Results:** Aggressive-type behaviours were the most frequent. Our study showed that 23% of our sample didn't have any serious behavioural problems but did have psychiatric comorbidities and ambulatory care helped to prevent the need for inpatient hospital admission. **Conclusion:** We attribute the decrease in hospitalisations to the creation of our department of outpatient psychiatric care specialized in the field of ID. This is why improving primary care services is vital in order to create equal treatment.

Keywords: intellectual disabilities; severe behavioural problems; primary care; hospitalizations; inpatient psychiatry treatments; Switzerland.

INTRODUCTION

The care and treatment of severe behavioural problems (SBP) in adults with intellectual disabilities is a complex problem. Numerous studies (Carey, Hosking, *et al.*, 2016; Carey *et al.*, 2017; Carey, Shah, *et al.*, 2016; Hosking *et al.*, 2016; Morin, Valois, Crocker, Robitaille, & Lopes, 2018) have shown that the health needs of individuals with intellectual disabilities are greater and more complicated. In its most recent report on disability, the World Health Organization (2011) suggested that these differences may be attributed to a limited access to services and to a poor quality of care.

Ambulatory care sensitive (ACS) conditions are conditions where effective primary care and health management can help prevent the need for emergency department (ED) visits and inpatient hospital admissions (Hand, Boan, Bradley, Charles, & Carpenter, 2018). It is well-documented that costs associated with ACS admissions exceed costs for non-ACS admissions (Mkanta, Chumbler, Yang, Saigal, & Abdollahi, 2016). Currently, relatively little is known

about the frequency of ACS admissions in ID. A recent study in the adult population found that the proportion of adults with ACS admissions was significantly higher among those with ID relative to those with general population (Mkanta *et al.*, 2016).

Numerous studies have shown a high prevalence of serious behavioural problems (Matlock & Aman, 2014) such as: aggressivity (2-28%), destructive behaviours (10-31%), self-harm (7-30%) (Borthwick-Duffy, 1994) and these serious behaviours have a significant impact on social exclusion and long-term hospitalization (Folch *et al.*, 2018). These are very worrying behaviours as they have real physical, social, educational and economic consequences (Paclawskyj, Kurtz, & O'Connor, 2004). Not only does self-harm and aggression cause physically serious injuries but they can also lead to under stimulation (Paclawskyj *et al.*, 2004).

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Our qualitative study evaluated the following two questions: For what needs do adults with intellectual disabilities consult a primary care outpatient treatment at a psychiatry department. How have hospitalization rates and experiences evolved for this population over the last 20 years?

To do this we use behavioural assessment tool with robust psychometric properties - the French scale EGCP-IIR for quantified why the person consult a psychiatry department (Sabourin, Senécal, & Paquet, 2016).

METHOD

SAMPLE

The 421 patients of this study received regular out-patient treatment at the Department of Psychiatry of Mental Development (SPDM) at the Vaud University Hospital Centre (CHUV). They presented an intellectual disability (according to the CIM-10: F70 mild, F71 moderate, F72 severe, F73 profound) whose severity was determined by the Wechsler Intelligent Scale for Adults (WAIS-IV). The inclusion criteria were as follows: men and women over age 18 and under 65, diagnosed with ID.

These procedures fall under the framework of developing investigative strategies for adult intellectual disabilities and they have been approved by the Ethics Committee for Clinical Research of the University Hospital of Lausanne (protocol 48/08).

INSTRUMENTS AND PROCEDURES

This evaluative research was implemented according to a relatively simple methodological mode, for both data collection (gathering of information to quantitatively and qualitatively describe the problem) and data processing (essentially descriptive statistics) to construct a model of reality most likely corresponding to the actual reality, which cannot be inferred as is from the raw data. We consulted the medical-administrative data of patients who were treated in our service and composed the socio-demographic status and diagnoses. This meant that we investigated the degree of intellectual disability and whether a psychiatric disorder and/or serious behavioural problems were absent or present.

Data collection was conducted with two instruments: EGCP-IIR (in English, PBSS-II) and the global assessment of functioning. The comorbidities were assessed by the experienced psychiatrists of our department. The PBSS-II scale measures the frequency of behaviours using Likert-type rating scales per item – a 6-point frequency scale (never = 0; rarely = 1; monthly = 2; weekly = 3; daily = 4; hourly = 5)

The following variables were measured to identify the potential risk factors of serious

behavioural problems: sex, age, ID, dual diagnosis, GAF, and place of residence.

The nine serious behavioural problems were documented using the PBSS-II scale (Sabourin *et al.*, 2016), meaning :

- Stereotypical behaviours
- Sexually perverse behaviours
- Disturbing social behaviours
- Physically aggressive behaviours toward others
- Socially offensive behaviours
- Withdrawal behaviours
- Behaviours that are materially destructive
- Self-harm behaviours
- Non-cooperative and provocative behaviours

After describing the ID population who were treated in our service, we compared this to the 2007 population, the date that our psychiatric liaison service was created. We also compared the number of hospitalisations documented over the last 20 years.

STATISTICAL ANALYSES

Marginal comparisons were made between all covariates and group (the presence or absence of SBP). To compare any associations between categorical variables and the group we constructed corresponding cross-tables and used the Chi-squared test of independence to detect any dependence between these variables and the group. In the case, the expected frequency in at least 20% of cells of a cross-table fell below five; the chi-squared test of independence, which is not reliable anymore, was replaced by the Fisher Exact test, as the later remains valid in such a situation.

Comparisons between means values of continuous variables like age and GAF versus groups were performed using the Student t-test.

These comparisons were followed-up by comparing potential factors of SBP only among patients with ASD.

Using a logistics regression model with SBP as the response, we aimed to assess the effect of age, diagnostic, GAF and ID simultaneously. We chose these variables due to their clinical relevance and importance and not based on any statistical model construction strategy. To fit this model, we used the glm function of R (R Core Team Austria, 2018). The statistical significance level was fixed at 0.05 at the beginning of the study.

RESULTS

The final sample included 421 subjects with ID, aged between 18 and 64 (average: 37.59; SD: 0.59). For patient gender, there were 37% men and 63% women. 60% of the subjects had a mild intellectual handicap, 17% had a moderate intellectual

handicap, 22% had a severe intellectual handicap, and 1% had a profound intellectual handicap. Only 22% of our sample had a dual diagnosis of intellectual handicap and ASD. For place of residence, 73% lived in specialised residential facilities and 27% in the community.

Serious behavioural problems were present in 77% of our sample. The average GAF score in our total sample was 50.62 (+/- 0.83) but there was a great difference between the score of those who did not have SBP (66.44+/-1.21) and those who did (45.88 +/- 0.85).

TABLE 1: Descriptive statistics and between-group analyses

Variables	Total sample <i>n</i> = 421	Non-SBP <i>n</i> = 97	SBP <i>n</i> = 324	<i>P</i>
Age (years) (mean; SD)	37.59 (0.59)	35.61 (1.17)	38.18 (0.68)	=.0587
18-30 (<i>n</i> ;%)	123 (29%)			
31-40 (<i>n</i> ;%)	133 (32%)			
41-50 (<i>n</i> ;%)	66 (16%)			
51-64 (<i>n</i> ;%)	98 (23%)			
Sex (<i>n</i> ;%)				NS
Women	156 (37%)	31 (31.96%)	125 (38.58%)	
Men	265 (63%)	66 (68.04%)	199 (61.42%)	
Intellectual disability level (<i>n</i> ;%)				
Mild	252 (60%)	58 (23%)	194 (77%)	
Moderate	74 (17%)	16 (22%)	58 (78%)	
Severe	91 (22%)	22 (24%)	69 (76%)	
Profound	3 (1%)	1 (33%)	2 (67%)	
Place of residence (<i>n</i> ;%)				NS ‡
Residential facility	305 (72.6%)			
Community	115 (27.4%)			
Dual diagnosis ID+ASD (<i>n</i> ;%)	92 (22%)	24 (26%)	68 (74%)	NS
GAF (mean, SD)	50.62 (0.83)	66.44 (1.21)	45.88 (0.85)	<.0001

Analysis of risk factors for SBP

Binary logistic regression was used to predict an outcome of SBP occurrence in a sample of 421 participants. We included in the model those variables whose significance level was below 0.05 in the between-group analyses.

Five predictors were included in the model (sex, age, ID, GAF, dual diagnosis), using the Enter method. Except the GAF, no other factor was significantly associated with the occurrence of SBP.

The GAF on the other hand is negatively associated with the SBP with an Odds-Ratio of 0.9.

Regarding topographies of SBP in the PBSS-IIR scale, SBP was not significantly more frequent in participants with ID and ASD. More precisely, differences were found for specific topographies of SBP in individuals with ASD such as Stereotypical behaviours (1) and Self-harm behaviours (8) and other unspecified SBP forms were not different between groups.

TABLE 2: DEVELOPMENT OF THE SITUATION OVER TIME

Comparison of outpatient treatments between 2007 and 2017

Reasons for Mental Development Psychiatry Service (SPDM) intervention	% in 2007	% in 2017
→ Critical event with acute exacerbation of ID manifestations (major communication and behavioural disorder)	70%	77%
→ Psychiatric comorbidity associating a particular psychopathological affection with ID (psychological disorder entangled in the manifestation of intellectual disability)	30%	23%

Amongst the cases of comorbidity that our service was brought to investigate and treat, especially when the degree of severity of disability was relatively high, the SPDM noted a predominance of psychotic disorders.

However, regardless the degree of disability, episodes of anxiety or depressive disorders were relatively frequent.

When there is a moderate degree of disability, the comorbidity constituted a syndrome that frequently involved personality disorder indicators. This type of disorder incites specific relationship-based difficulties, which means that the socio-educational context must be adapted and kept under consideration in order to avoid a lack of understanding or a bad interpretation of the reactions of the ID person affected. This is to avoid an unsuitable relational approach and inadequate interactions.

Finally, when the intellectual handicap is mild and the individual's place of residence is not or hardly subject to any institutional socio-educational supervision, in certain cases, we have documented

evidence of addiction – most often alcohol or cannabis – in the extent that the patients are independent enough to have access to one or another form of the drug in the naturally surrounding social community.

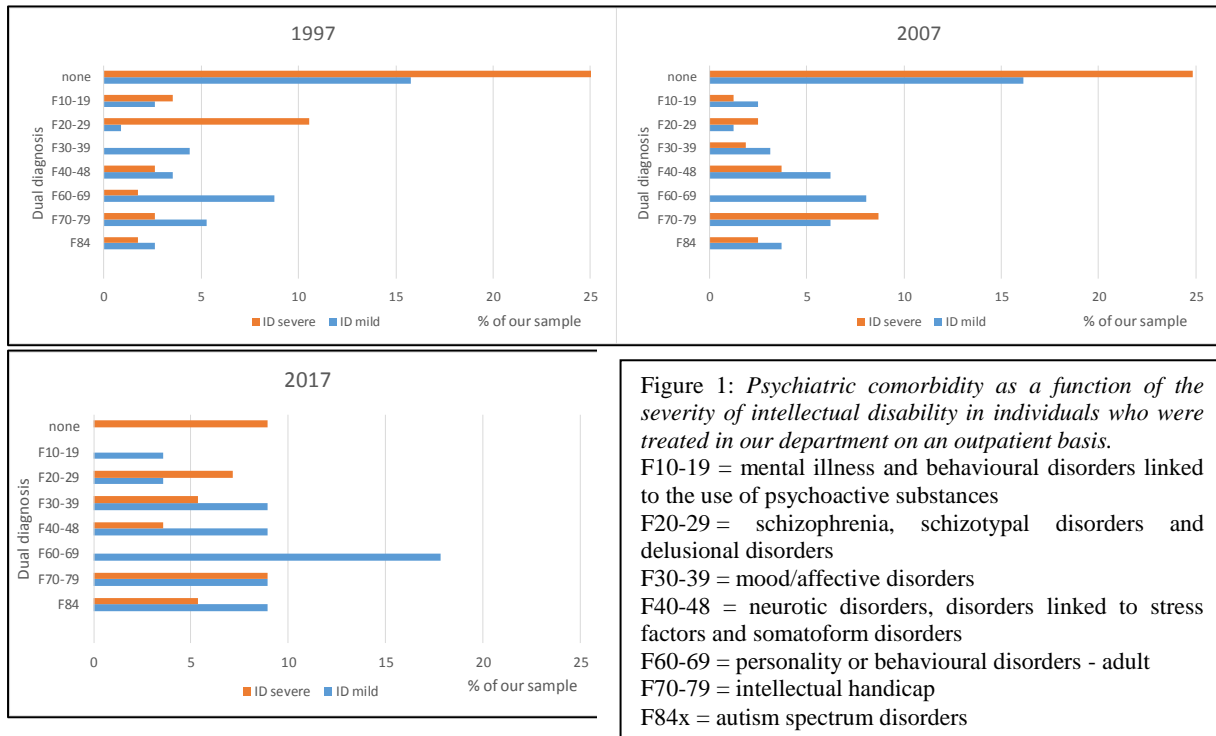


Figure 1: *Psychiatric comorbidity as a function of the severity of intellectual disability in individuals who were treated in our department on an outpatient basis.*
 F10-19 = mental illness and behavioural disorders linked to the use of psychoactive substances
 F20-29 = schizophrenia, schizotypal disorders and delusional disorders
 F30-39 = mood/affective disorders
 F40-48 = neurotic disorders, disorders linked to stress factors and somatoform disorders
 F60-69 = personality or behavioural disorders - adult
 F70-79 = intellectual handicap
 F84x = autism spectrum disorders

TABLE 3: DEVELOPMENT OF HOSPITALISATIONS

Comparison	1997	2007	2017
No of ID patients hospitalised	114	161	56

Development of hospitalisations

In the canton of Vaud, the first successive descriptive studies (Grasset *et al.*, 2008; Spagnoli, Favrod, & Grasset, 2003) show that the use of psychiatric hospitalisations progressively increased between 1997 and 2007. Yet, the last ten years has seen that number decrease again and we attribute this decrease in hospitalisations to the creation of our department of outpatient psychiatric care specialized in the field of ID.

A significant percentage of hospitalised individuals did not receive a diagnosis during their hospitalisation, meaning that the only diagnosis reported was that of their intellectual disability. This situation involves a majority of individuals in the category « moderate/severe intellectual disability or autism ».

In terms of the typical psychiatric comorbidities ((F10 → F69) they are less represented since they only involve 30% of hospitalised individuals in 2007, meaning 46% of the « mild intellectual disability » category and 15.6% of the « moderate/severe intellectual disability or autism ». In 2017, the percentage dropped to 23%. These results

match the data reported in the international literature, according to which between 20 and 35% of the ID population present a psychiatric comorbidity. This also means that in 2007, 70% of the ID individuals were hospitalised in psychiatry even if they did not suffer from a psychiatric comorbidity. It should be noted that the situation hasn't improved much in 10 years since, in 2017, only 23% of the individuals hospitalised in psychiatry received a psychiatric diagnosis.

DISCUSSION

Summary

- Our study showed that 23% of our sample do not have any serious behavioural problems but do have psychiatric comorbidities. 320 adults with intellectual disabilities, meaning 77% of the sample, did present serious behavioural problems. For this category we reported a majority of aggressive-type behaviours (aggressive, destructive, provocative, sexual, offensive and disturbing (70%); self-harm and stereotypical (19%) behaviours, as well as withdrawal behaviours (11%) were a minority.
- The trend between 1997 and 2007 was an increase in psychiatric hospital admissions for ID

individuals. Given that psychiatric hospitals were oversaturated, and the ineffectiveness reported in certain hospitalisations, this was an alarming situation.

- Psychiatric diagnosis remains a significant problem within the hospital context. Our study showed that for the 2007 hospitalisations, only 30% of the hospitalised ID individuals received a psychiatric diagnosis; in 2017, only 23%. Efforts must be made to improve psychiatrist training in terms of establishing more suitable diagnostic criteria.
- Our retrospective analysis made it possible for us to show that the creation of an outpatient psychiatry service specializing in this population reduced the number of hospitalisations in 2017.

Strengths and limitations

There were four main limitations to this study. First, the results of our study do not apply to the entire Swiss population of individuals with ID, but only to the adults with ID who were treated in our specialized psychiatry department in a defined geographical area

Furthermore, the patients whom we treat are precisely those who have a complicated situation: both physical health and mental health problems.

The third limit is that this was a cross-sectional analysis of a primary care database. This made it possible to identify the factors actually associated with SBP for the entire cohort, but these variables did not enable us to define the level of risk of developing or maintaining a SBP over time. Finally, it's impossible for the list of potential risk factors studied to be exhaustive. Other factors, such as socio-economic level, traumatic life events, quality of the environment, and other psychosocial factors may also contribute.

Finally, the last limitation is that there are very few studies based upon this population and they all have many differences in terms of population, sample size, age, definitions of serious behavioural problems, and research tools used. There is not yet a clear method of systematically evaluating the impact of these different methodologies on the prevalence data (for example, meta-analysis) simply because of the small number of studies.

Comparison with existing literature

Our results are in line with several other studies (Carey, Shah, *et al.*, 2016; Folch *et al.*, 2018; Morin *et al.*, 2018). Our prevalence rate of 77% serious behavioural problems was higher than the prevalence rate reported in earlier studies (Folch *et al.*, 2018). Our results are in line with different studies which show that the seriousness of SBP is correlated with the severity of ID (Folch *et al.*, 2018; Furniss &

Biswas, 2012), with concomitant psychiatric disorders (Einfeld *et al.*, 2006) and with autism (Minshawi *et al.*, 2014).

Like the study conducted by Holden & Gitlesen, we did not find any difference between the genders (Holden & Gitlesen, 2006). It is clear that the 77% prevalence rate of SBP in our cohort is linked to the fact that the ID patients whom we treat have poor mental health. Indeed, the prevalence of SBP in the overall adult ID population is usually around 18% (Holden & Gitlesen, 2006; Lunqvist, 2013). As mentioned by Holden & Gitlesen, the prevalence of various serious behavioural problems is rarely reported in samples of the general adult ID population. In their study, the most frequently cited behavioural problems were stereotypical behaviours (10.9%), followed by destructive-aggressive (8.3%), and self-harm behaviours (7.5%). In our study, we found that only 22% of the patients had both ID and ASD. We can reasonably hypothesise that this is the reason why both stereotypical behaviours and self-harm behaviours were a minority in our sample, because they are often associated with Autism Spectrum Disorders. 48.3 % of our patients had aggressive-type SBP (including aggressive, destructive, provocative, offensive, and disturbing); 14.3% had stereotypical behaviours and self-harm; 8.1% had withdrawal behaviours and 5.2% had inappropriate sexual behaviours. Other studies have shown aggressive-destructive behaviours to be the most common (Bowring, Totsika, Hastings, Toogood, & Griffith, 2017; Lunqvist, 2013).

Implications for research and/or practice

One of the strengths of this study was being able to show that our primary care outpatient treatment centre dedicated to ID individuals helped prevent inpatient treatments.

We can report that in Switzerland, like other countries, a large majority of health professionals are hesitant to treat individuals with intellectual disabilities (Morin *et al.*, 2018; Werner, Stawski, Polakiewicz, & Levav, 2013) but we try to change this (Giuliani & Baudat, 2019).

Their health needs are greater and more complex and their socio-economic disadvantages explain, in part, this difference in health care (Carey, Hosking, *et al.*, 2016; Carey *et al.*, 2017; Carey, Shah, *et al.*, 2016; Morin *et al.*, 2018).

Establishing the effect of multiple risk factors is likely to identify people who are priority for interventions. Addressing multiple, rather than singular risks, is likely to be more efficacious

Insufficient training (Phillips, Morrison, & Davis, 2004; Trollor *et al.*, 2016), a lack of time on behalf of health care professionals (Tuffrey-Wijne *et*

al., 2014) and poor access to services may explain the decline in mental health of the population of adults with intellectual disabilities.

According to Morin *et al.* (2018), the development of social and health policies is necessary in order to cultivate positive and suitable attitudes in health care professionals with respect to adults with ID. Improving primary care services is vital in order to create equal treatment that is why the Swiss Federal Council adopted new health policies (health-2020). On the other hand, we are also convinced that professional training must be improved (Morin *et al.*, 2018; Wilkinson, Dreyfus, Cerreto, & Bokhour, 2012).

Shortfalls in Psychiatric Training

Our results show that there is a lack of training for health care professionals, and especially for psychiatric doctors. This also affects educators in the field of psychiatry, because there is no specific training in the basic curriculum. Existing programs in Switzerland are most often available in the form of occasional modules organized within an institution by exterior animators, and covering such themes as autism, aggressive behaviours, conflict management, sexuality, the therapeutic relationship, non-violent communication, etc. These training sessions are rarely mandatory. Educator demand for psychiatry-related themes (in the larger sense) seems to be great and is not met.

Spagnoli & al (Spagnoli *et al.*, 2003) created a state report on current needs; 57.9% of those queried cited a difficulty in finding a psychiatrist for the treatment and follow-up of individuals with psychiatry/mental handicap comorbidities. The reasons given included: lack of availability, lack of interest in mental handicap, as well as a frequent refusal to undergo institutional treatment (the classic office session is not very useful when a crisis arises). 28 psychiatrists in the canton of Vaud who accept this type of patient were mentioned, and some of them work for several institutions at once.

Criticisms Of Public Psychiatry Can Be Divided Into 5 Categories:

- Constraints linked to access to care, especially for emergencies: no psychiatry services in peripheral regions, and long waiting times to receive a consultation.
- Constraints linked to hospitalisations: refusal to hospitalise, fears by the hospital that the institution might refuse to retake the resident upon discharge, “hospital stays that are so short they require more energy than they give”, no therapeutic pathway upon discharge.
- Problems with continuity of care, especially linked to assistant turnover.
- Problems with treatment: care is too often limited to a modification of medication, without any

consideration of behavioural or environmental factors.

- Problems with recognition: lack of support, even complete misunderstanding of the medical teams when faced with difficulties from the educational teams.

GENERAL CONCLUSION AND RECOMMENDATIONS

The existence of problems linked to a psychiatric comorbidity within the ID population, long highlighted by caregivers and professionals, is confirmed through the data gathered here. The difficulties generated directly affect such a great number of caregivers and professionals that it should no longer be overlooked. We hope that the quantification and description of these problems will make it possible to elaborate certain basic principles of an overall and concerted solution.

The problems that are intrinsic to the comorbidity arise within a difficult context: overburdened psychiatric hospitals, progressive loss of know-how, faulty reciprocal understanding of the worlds of education and psychiatry, etc. Impending budgetary restrictions aren't going to rectify the situation, either. Solutions must be found while considering this difficult context. The situation should improve with the creation of a specialised psychiatric hospital department that is projected for 2021, and mostly, an analysis of the context will lead to a series of possible pathways toward improvement.

- In most cases, interventions that take place where the individual lives make it possible to consider contextual elements as well as avoid the adverse consequences of hospitalisation. This also enables the educational teams to acquire certain specific skills which could be shared more widely and would, in the long run, reduce difficulties.
- These interventions should be led by professionals who have been well-trained in psychiatry and have a good understanding of the educational setting, its culture, and its practices, as well as the intellectual disabilities themselves. It's important to note that good interpersonal connections as well as respect and mutual trust elements that facilitate success and are highly appreciated.
- When hospitalisation is deemed the only possible recourse, it should be negotiated (length of stay, therapeutic goals, specific framework meant to maintain previous progress) between the educational caregivers and the hospital team. This approach should be supported through mediation by the liaison team.
- Team fatigue must be taken into account for the intervention, in the form of team support and supervision. In certain extreme cases, it would be a good idea to improve assistance between institutions.

CONFLICT OF INTEREST

The authors do not report any conflicts of interest.

ETHICAL APPROVAL

These procedures fall under the framework of developing investigative strategies for adult intellectual disabilities and they have been approved by the Ethics Committee for Clinical Research of the University Hospital of Lausanne

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