



Psychiatry of Intellectual Disability in the Elderly: A Baseline Audit

Ayomipo Amiola · Phil Temple · Ashok Singh · Manilka Brahmana · Meghana Rayala · Ignatius Gunaratna

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Abstract Intellectual disabilities (ID) are lifelong conditions characterized by deficits in general intellectual functioning and adaptive skills with onset in the developmental period. Globally, the prevalence of ID varies by age and the prevalence in older adults is considerably lower than that in the general population indicating that people with ID (PWID) may have shorter life spans. Despite the substantially increased mean life expectancy compared to the past, PWID continue to experience poor care often dying twenty years earlier than others. Higher rates of mental illnesses, increased risk of physical health morbidity and mortality and advancing age worsen their health disadvantage. There is very limited evidence that the treatment needs of the elderly patient group with ID and a mental illness have either been described or addressed. We aimed to conduct a baseline audit and service evaluation describing the sociodemographic, clinical and treatment variables of elderly patients (aged over 65 years) attending a specialist out-patient psychiatry clinic for PWID, compliance with the suggested audit standards for this group, and make

recommendations for future clinical practice. Results are presented in tabular form, with extensive psychiatric and physical health morbidity highlighted. Compliance with audit scores also suggested significant gaps in physical health care and monitoring. There is a need for close working relationships between the patient, carers, health and social care professionals at all levels to mitigate these issues and larger scale audits involving multiple centres are needed to further improve quality of service offered to this patient group.

Keywords Elderly · Intellectual disability · Baseline audit · Physical health · PWID

Introduction

Intellectual disabilities (ID) are lifelong conditions characterized by deficits in general intellectual functioning and adaptive skills with onset in the developmental period (World Health Organisation, 2019). Globally, the prevalence of ID has been reported to vary between 1 and 3% (Harris, 2006). This prevalence varies by age (Linehan, 2019). In addition, only a smaller proportion of people with ID contact specialist health or social services. This is because many adults with ID (especially mild) may not feel the ‘need’ for this input, may wish to avoid the perceived stigma of being labelled or may be considered ‘ineligible’ for various reasons by specialist care services.

A. Amiola (✉) · P. Temple · A. Singh · M. Brahmana · I. Gunaratna
Hertfordshire Partnership University NHS Foundation Trust, Little Plumstead Hospital, Norfolk NR13 5EW, UK
e-mail: a.amiola@nhs.net

M. Rayala
Norfolk and Suffolk NHS Foundation Trust, Drayton High Road, Hellesdon NR6 5BE, UK

The prevalence of ID in older adults (i.e., aged 60 or more) was estimated to be about 0.35% of the general population in England (Emerson & Hatton, 2008). This rate is considerably lower than the 1–3% rate in the general population. It therefore gives an indication that people with ID may have shorter life spans. When it comes to the number of people over 60 who are in contact with specialist ID services, it is estimated to be about 26,000. (Emerson & Hatton, 2008).

Although people with ID now have a substantially increased mean life- expectancy compared to the earlier part of the twentieth century (Coppus, 2013), they continue to experience poor health and social care. Their life expectancy is still 20 years lower than general population (O’Leary et al., 2018). On average, males with ID die 22 years and females 26 years earlier than the general population (White et al. 2022). The cause for this premature and higher mortality is multifactorial. The ageing process starts earlier in people with ID with a consequent increase in significant physical health challenges (World Health Organisation, 2001; Evenhuis et al., 2012). Genetic factors and psycho-social variables such as adverse early life circumstances, discrimination and housing problems affect the ability to access timely, appropriate, and effective health care (Emerson et al., 2011). Even after adjusting for these known risk factors, people with ID were still 3 to 4 times more likely to die from an avoidable medical cause of death. Most of these avoidable deaths were because timely and effective treatment was not given (NICE, 2021).

People with ID have higher rates of mental illnesses and other psychiatric morbidity (Cooper, 2020). The life expectancy for people with severe mental illnesses (e.g., schizophrenia, bipolar affective

disorder, or non-organic psychosis) is about 20 years shorter than the general population (Das-Munshi et al., 2021; Chesney et al., 2014; NICE 2021). Therefore, this combination of ID and mental illness increases the risk of physical health morbidity and mortality (Chauhan et al., 2020). Advancing age then becomes the third element in this cascade of health disadvantage. There is very limited evidence that the treatment needs of the elderly patient group with ID and a mental illness have either been described or addressed.

Aim

This paper describes a baseline audit and service evaluation that had the following aims.

1. Describe the socio-demographic, clinical and treatment variables of elderly patients (aged 65 or above) who attended a specialist out-patient psychiatry clinic for people with ID.
2. Describe the compliance with the suggested audit standards for this group.
3. Refine the audit standards and make recommendations for future clinical practice.

Methods

Potential audit standards were identified by consensus following three focus group discussions that involved seven psychiatrists who were part of a continuing professional development (CPD) peer group. They were discussed further with multi-disciplinary health and

Box 1 Preliminary audit standards

1. All patients had a full diagnostic evaluation^a
2. For all patients prescribed psychotropic medications, the indications and rationale for prescribing was clearly stated
3. There was at least a 6 monthly review of psychotropic medication
4. These minimum 6 monthly reviews included an account of any side effects
5. These minimum 6 monthly reviews evaluated the need for continuation or discontinuation of medication
6. All patients had annual physical health checks that was referenced/ documented in the psychiatry case records
7. The quality of the annual health checks was referenced/ documented in the psychiatry case records
8. The annual health check led to a clear health action plan that was referenced/ documented in the psychiatry case records

^aCovering the degree of intellectual disability, the cause of intellectual disability, other developmental disorders, mental illness, personality disorder, substance-use related disorders, physical health disorders, trauma, and types of challenging behaviours

Table 1 West Norfolk outpatient clinic population by age

	Number (n)	Percentage (%)
Aged 18–59 years	102	80
Aged 60–64 years	11	9
Aged 65–74 years	15	11
Aged 75 years or above	0	0

social care professionals within the community and hospital-based teams. A list of 8 preliminary baseline audit standards were finalised (See Box 1).

The baseline audit and service evaluation were carried out within the psychiatry team providing out-patient services for adults with an ID in West Norfolk, UK. All patients on the out-patient case-load between 04/01/2021 and 04/10/2021 were included. Information on the socio-demographic, clinical and treatment variables and adherence to audit standards were collected retrospectively from case records by the clinicians providing the service.

The results were presented at two multi-disciplinary CPD meetings attended by a total of around 110 delegates. Suggestions to improve clinical practice were refined using verbal and written feedback from these meetings.

The study utilised routinely collected data from the admissions diagnostic assessment process. In accordance with NHS guidance on research, audit, and service evaluation (NHS Health Research Authority, 2020), the project fulfilled criteria for service evaluation and hence did not require approval from an NHS Research Ethics Committee.

Results

During the baseline audit and service evaluation period, the West Norfolk psychiatry of ID adult out-patient clinic had a total of 128 patients, of which 15 (11%) were over the age of 65 years and 26 over 60 (20%).

Tables 1, 2, 3, 4, 5 and 6 below list the socio-demographic, clinical and treatment variables that were identified.

Table 2 65 and above group (n = 15): Accommodation

	Number (n)	Percentage (%)
Own home	4	27
Supported living	2	13
Residential care	9	60

Table 3 65 and above group (n = 15): Clinical Diagnosis

	Number (n)	Percentage (%)
Mild ID	3	20
Moderate ID	4	27
Severe ID	1	7
ID (degree not stated)	7	47
Autistic Spectrum Disorder	2	13.3
Dementia	1	6.6
Psychoses	5	33.3
Bipolar Affective Disorder	5	33.3
Depressive Disorders	4	26.6

Table 4 65 and above group: Co-morbid physical illnesses

	Number (n)	Percentage (%)
Type 2 Diabetes Mellitus	6	40
Epilepsy	2	13
Hyperthyroidism	2	13
Vitamin D deficiency	2	13
Hypertension	1	7
Cardiovascular Disease	1	7
Obstructive Sleep Apnoea	1	7
Hypothyroidism	1	7

Table 5 65 and above group: Psychotropic Medication Prescription

	Number (n)	Percentage (%)
Antipsychotics	12	80
Mood Stabiliser	7	47
Antidepressant	5	33
Benzodiazepines	2	13
Antidementia medications	1	7

Table 6 65 and above group: Preliminary Audit Findings (n = 15)

Audit standard	Compliant number (%)
1. All patients had a full diagnostic evaluation	14 (93%)
2. For all patients prescribed psychotropic medications, the indications or rationale for prescribing was clearly stated	14 (93%)
3. There was at least a 6 monthly review of psychotropic medication	11 (73%)
4. These minimum 6 monthly reviews included an account of any side effects	9 (60%)
5. These minimum 6 monthly reviews evaluated the need for continuation or discontinuation of medication	15 (100%)
6. All patients had annual physical health checks that was referenced/ documented in the psychiatry case records	0 (0%)
7. The quality of the annual health checks was referenced/ documented in the psychiatry case records	0 (0%)
8. The annual health check led to a clear health action plan that was referenced/ documented in the psychiatry case records	0 (0%)

The compliance with the preliminary audit standards is summarised in Table 6 below.

Discussion

This exploratory baseline audit and service evaluation was done within one service and hence the findings cannot necessarily be generalised to the whole elderly ID population. Nevertheless, as far as we know, this is the first description of a clinically relevant issue that affects a vulnerable population of those with ID and mental illnesses accessing a psychiatry clinic. About a tenth of the clinic population is aged over 65years, a proportion that doubles when one includes those aged 60years and above.

In the demographic spread, it is notable that there were no patients aged over 75 years, and this is reflective of trends in terms of life expectancy both for patients with ID and for those with enduring mental illnesses. This is also in keeping with the finding from literature about a significantly lower life expectancy than the general population for this group.

In terms of compliance with audit scores, although a full diagnostic evaluation had been completed for almost all, the level of ID was not stated in about half the group. This may be due to the difficulty of administering appropriately normed and standardized tests of intellectual and adaptive functioning in this age group. It may also be indicative of clinical practice 30–40 years ago when psychometric assessments were not routinely done, and ID was diagnosed based on clinical opinions.

Psychotropic medication prescribing appears to be in line with current guidelines (NICE 2016; Royal College of Psychiatrists, 2016; Branford et al., 2019). Regular reviews to consider the rationale for prescribing and the need to continue/ discontinue were being offered. Attendance at these reviews by patients, appeared to be lower with some not attending. To adhere to current guidance, both in letter and spirit, there needs to be careful thought on how to improve the attendance of patients at these reviews. This applies to physical health issues too, as set out below.

The evidence of annual physical health checks, its quality and the health care plans that followed were not available in the psychiatry case-notes. In England, annual health checks are carried out in primary care within GP surgeries. It is entirely possible that these had indeed happened, and the poor audit score merely reflected a lack of communication between primary care and secondary care i.e., psychiatry services). The situation may have been further complicated because specialist community learning disability services in this geographical area were provided by one organisation while psychiatry services came from another. This is an issue that needs addressing. Those prescribing psychotropic medication, do need to have a full understanding of the patient's physical health status. The LeDer report (University of Bristol Norah Fry centre for disability studies, 2020) noted that not having an annual health check is found to be significantly associated with dying before 50 years. Annual health checks when properly done can promote healthy lifestyles, support wellbeing, and enable

early access to additional healthcare support when needed. During these reviews, clinicians can spot the early signs of cancer, diabetes, respiratory and heart disease thus initiating treatment earlier and hence better health outcomes are achieved. They also provide opportunities to discuss vaccinations, manage and monitor known chronic health conditions, and to discuss end-of-life care issues.

Concerning physical health conditions, multi-morbidity increases with age in people with ID; however, the pattern of chronic conditions differs from the general population. There is a higher prevalence of neurological conditions, and leading causes of death include this and circulatory conditions (McCarron et al., 2013; White et al., 2022). Other conditions significantly prevalent in older adults with ID include thyroid disorders, epilepsy (both present in this group), hearing loss, eczema, dyspepsia, and parkinsonism. van Schrojenstein Lantman-de et al. (2008) categorises these conditions as *ID-related* (epilepsy, mobility or visual problems), *syndrome-related* (hypothyroidism in Down's syndrome, congenital heart disease in William's syndrome) or as a *secondary health condition* (constipation, obesity). Interestingly, some conditions such as coronary heart disease and chronic obstructive pulmonary disease appear to be less prevalent in people with ID.

Unhealthy dietary choices and low activity levels (often present in this group), including use of psychotropic medications are risk factors for metabolic disorders such as Diabetes Mellitus and cardiovascular disorders which were highly prevalent in our sample. Interestingly, the prevalence of diabetes mellitus in this sample was significantly higher than previously reported values. In a large systematic review conducted by MacRae and colleagues (2015) prevalence rates ranging from 0.4% to 25% was reported for type I and type II Diabetes mellitus in people with intellectual disabilities. However, this over-representation can be explained by the peculiarities of this patient group as a selected population with other risk factors including psychiatric illnesses and psychotropic medication use.

The wide range of co-morbid psychiatric conditions in the elderly ID population has been widely reported (Axmon et al., 2018; Denning & Thomas,

2013). Although the ability to draw definite conclusions are limited, a higher prevalence of problem behaviours, dementia, affective disorders, pervasive developmental disorders, anxiety, and schizophrenia have also been reported in the literature (Cooper, 2019). The West Norfolk clinic sample in this evaluation reported even higher rates than these. The only exception was for dementia where rates of 13% to 20% have been reported elsewhere (Strydom et al., 2020).

Although this evaluation showed that psychotropic medication was being prescribed appropriately, it is worth noting the prevalence of potentially inappropriate prescribing and polypharmacy increases with advancing age and morbidity in all adults, particularly those with ID. This practice is associated with adverse drug reactions and poor outcomes (O'Dwyer et al., 2018). Polypharmacy especially with medications that increase the anticholinergic burden is associated with adverse outcomes, including cardiovascular events, falls, cognitive impairment, and mortality in older people (Cilag et al. 2001). There are unique challenges in providing appropriate pharmacotherapy for older people with ID. They include atypical disease presentations, communication deficits, capacity to consent to medications, age-related changes in pharmacokinetics and pharmacodynamics, comorbid conditions, swallowing difficulties, and other factors associated with frailty. In addition to clinical outcomes, monitoring of medication administration must include careful attention to emergence of side effects and potentially confounding effects of substance use and comorbid medical problems and their treatment (Deutsch & Burket, 2021).

Conclusion

Elderly patients with intellectual disability (ID) who are treated within specialist psychiatry clinics have extensive psychiatric and physical health co-morbidity. The latter may be potentially more problematic because of advancing age, frailty, and prescribed medication. There is a need for close working relationships between the patient, carers, health and

Box 2 Good practice pointers & audit standards

1. The age threshold for psychiatry of the elderly in people with ID should be 60
2. There should be dedicated elderly psychiatry of the ID clinics for this group
3. These clinics should offer longer appointments for a full consideration of the physical health- mental health- psychotropic prescribing interface
4. Patients with capacity should be involved in discussions and decisions about their treatments. Where they lack capacity, there should be adequate documentation of the best interest approaches that are used
5. All patients should have a full diagnostic evaluation^a
6. For all patients prescribed psychotropic medications, the indications and rationale for prescribing should be clearly stated
7. There should be at least a 6 monthly review of psychotropic medication
8. These minimum 6 monthly reviews should include an account of any side effects
9. These minimum 6 monthly reviews should evaluate the need for continuation or discontinuation of medication
10. All patients should have regular physical health monitoring including haematological and biochemical parameters
11. All patients should have annual physical health checks that are referenced/ documented in the psychiatry case records
12. If these are done in primary care or by professionals/ organisations other than the psychiatrist, there should be arrangements for it to be available to the psychiatry team
13. The quality of the annual health checks should be referenced/ documented in the psychiatry case records
14. The health action plan that was drawn up from the annual health check should be referenced/ documented in the psychiatry case records

^aCovering the degree of intellectual disability, the cause of intellectual disability, other developmental disorders, mental illness, personality disorder, substance-use related disorders, physical health disorders, trauma, and types of challenging behaviours

social care professionals at all levels to mitigate these issues. The following good practice recommendations and audit standards (See Box 2) will help in that process. Larger scale audits involving multiple centres and using these standards are needed.

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Declarations

Conflict of interest All authors have no relevant financial or non-financial interests to disclose.

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