

2024-03

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<https://pearl.plymouth.ac.uk/handle/10026.1/21766>

10.1111/jir.13108

Journal of Intellectual Disability Research

Wiley

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Brief Report

Clinical characteristics of people with intellectual disability admitted to hospital with constipation: identifying possible specific high-risk factors

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Abstract

Background People with intellectual disabilities (ID) die on an average 20 years earlier to the general population. They have higher rates of multimorbidity and polypharmacy. Around 25% of people with ID report chronic constipation. The England Learning Disabilities Mortality Review found that nearly 25% of deaths identified constipation as a long-term health problem. However, the likely risk factors for constipation related harm are poorly enumerated. We sought to identify possible specific high-risk factors by examining the clinical characteristics of people with ID admitted to hospital with constipation.

Methods Data of people with ID admitted with constipation in two general hospitals covering a population of 1.3 million from 2017 to 2022 were reported using the STROBE guideline for cohort studies. Collected data included age, gender,

intellectual disability severity, recorded medication, presenting complaint and co-morbidities. The medication anticholinergic burden was calculated using the anticholinergic burden scale. Continuous variables were summarised by mean and standard deviation if normally distributed, with categorical variables summarised by the number and percentage in each category.

Results Of 46 admissions (males 52%), 57% had moderate to profound ID, 37% had epilepsy, 41% prescribed antiseizure medication (ASM) and 45% were on laxatives. Average age was 46 years. The anticholinergic burden score mean was 2.3 and median, one.

Conclusions We can hypothesise that people with more severe ID, suffering from epilepsy and on ASM may be more at risk of developing severe constipation. Some admissions may be avoided with earlier use of laxatives in the community.

Keywords Anti-seizure medication, Constipation, Developmental disorder, Gastrointestinal problems, Laxatives

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Introduction

Just over 2% of people in England have an intellectual disability (ID; <https://www.the-health-improvement-network.com/> 2023). This population is defined by a high prevalence of multimorbidity across the entire life course attenuated by challenges in comprehension, social understanding and communication (American Psychiatric Association 2013; Kinnear *et al.* 2018).

People with intellectual disability suffer from constipation more than the general population (Robertson *et al.* 2018; Maslen *et al.* 2022). A whole population study using data from the Second Dutch National Survey of General Practice showed constipation is diagnosed in 45 people with ID per 1000 people, compared with nine in the general population highlighting five times higher rates of concern (Straetmans *et al.* 2007). The rate of regular laxative use in a 12-month period is 25% for people with ID compared with 0.1% for general population (Straetmans *et al.* 2007). A European study of 1253 people with ID reported 26.5% of their sample to have constipation, and this was not age related (Haveman *et al.* 2011). There is evidence that patients with more severe intellectual disability and those with reduced mobility are at more risk of constipation (4, 5).

The probable causes of this greater prevalence of constipation in children and adults with ID include neurological deficits such as cerebral palsy, poor mobility, sedentary lifestyle, dysphagia, poor diet, poor fluid intake and difficulty communicating symptoms (Del Giudice *et al.* 1999; Chadwick & Jolliffe 2009). Anticholinergic side effects are causative of constipation, particularly psychotropics and anti-seizure medication (ASM) (Coleman & Spurling 2010; O'Dwyer *et al.* 2016; Robertson *et al.* 2018). Those people with more severe intellectual disability are non-verbal and may have difficulties in communicating the nature of the distress caused by constipation. Therefore, detection may depend upon the vigilance of care staff.

In England, the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) reviewed the deaths of 247 people with ID over the 2-year period in 2010–2012 and found 37% in the study cohort had chronic constipation (Confidential Inquiry into premature deaths of people

with learning disabilities (CIPOLD) 2023). The authors also recognised that in those who died, significantly more were given medication for constipation and epilepsy (Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) 2023). Following CIPOLD, the Learning Disabilities Mortality Review (LeDeR) was established to annually report on all deaths between the age of four and 74 in people with ID in England (The Learning Disabilities Mortality Review (LeDeR) Programme, University of Bristol 2020; <https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf> 2023). In 2018, 2019 and 2020 of 2362, 2473 and 1940 deaths reported to LeDeR, 46%, 55% and 55% had constipation as a long-term health condition (<https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf> 2023). Over a third of people with ID who died prematurely were prescribed laxatives (<https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf> 2023).

An English study looked into factors and conditions influencing 'avoidable' emergency attendance and admissions for people with ID between 2005 and 2009 using four years of Hospital Episode Statistics (HES) data (Glover & Evison 2013). The authors estimated a five times higher rate of emergency admissions than the general population (Glover & Evison 2013). Following epilepsy (>40%), one of the most obvious differences between people with ID and general population in the proportions of emergency ACSC admissions was constipation (Glover & Evison 2013).

However, there is a surprising lack of research on the serious consequences of constipation in this group and potential modifiable risk factors (Maslen *et al.* 2022). This study looked to identify the demographic and clinical characteristics of people with ID admitted to a general hospital with constipation or complications of constipation to enumerate likely specific risk factors.

Methods

The STROBE guidance for observational studies was used (Data S1) to design and report this retrospective cohort study.

Study setting and design

Hospital data were examined in two district general secondary hospitals in southwest England - Truro in Cornwall (pop: 538 000) and Exeter in Devon (pop: 800 000). We obtained a list of patients admitted over a 5-year period (2017–2022) who had both intellectual (learning) disability and were admitted with a diagnosis of constipation. The latter required a primary diagnosis code under ICD-10 of K59.0. Therefore, we were reliant on the diagnosis of constipation by the admitting or discharging clinician. Both variables needed to be recorded in routine hospital data. Each admission was considered a single episode.

Data on demographics including age, gender, ethnicity, severity of intellectual disabilities, presenting complaint and relevant co-morbidities were collected. Clinical records data on regular medication prescribed at any point of their inpatient pathway were collected and used to calculate the anticholinergic burden (ACB) of their medication using the ACB scale (O'Dwyer *et al.* 2016).

Analysis

Statistical analysis focused on summarising the data from the cohort of patients. Continuous variables were summarised by mean and standard deviation if normally distributed, with categorical variables summarised by the number and percentage in each category.

Ethics and governance

The two NHS centres registered the project as an internal audit/service evaluation, conducted a Data Protection Impact Assessment (DPIA) and gained approval from their Information Governance (IG) leads to submit anonymous data to a MS Excel sheet. Data were collected in compliance with the General Data Protection Regulation (GDPR). As per the NHS Health Research Authority tool (<http://www.hra-decisiontools.org.uk/research/index.html>), no formal ethical approval was necessary for this study (Health Research Authority 2022) (Data S2). No patient identifiable data was collected. Individual patient data was compiled into a single dataset prior to analysis. No author outside the respective study institution had access to personalised data. Data were

anonymised to share with the statistician.

Deidentified participant data and data dictionary were made available along with the study protocol to the statistician and other authors.

Results

During the 5-year period (2017–2022), in Exeter, there were 20 admissions identified of 19 different people with ID. In Truro, there were 26 admissions of 24 people with ID. The total number of admissions were 46 which included three patients having two admissions.

Data on the patient demographics is summarised in Table 1. Patients had a mean age of 47 years on admission, with an approximately equal number of males ($n = 24$, 52%) and females ($n = 22$, 48%). Of the 39 with recorded ID severity, 57% ($n = 22$) had moderate to profound ID. The most common causes for presentation were constipation ($n = 22$, 48%) and abdominal pain ($n = 20$, 43%). Patients also presented with vomiting, abdominal distension, and seizures. Of note, 13% ($n = 6$) of patients were admitted for elective procedures when constipation was identified as a major concern. Just over a third, ($n = 16$, 37%) of the study cohort had epilepsy. In our

Table 1 Demographics

Factor	No. of admissions	Category	Summary
Area	46	Devon	20 (43%)
		Cornwall	26 (57%)
Age	46	-	46.8 ± 21.8
Gender	46	Female	22 (48%)
		Male	24 (52%)
Severity of ID	39	Mild	17 (44%)
		Moderate	8 (21%)
		Severe- profound	14 (36%)
Presentation ^a	46	Constipation	22 (48%)
		Abdominal pain	20 (43%)
		Abdo distention	7 (15%)
		Vomiting	11 (24%)
		Seizures	1 (2%)
		Planned procedure	6 (13%)
Epilepsy	43	No	27 (63%)
		Yes	16 (37%)

Summary statistics are mean ± standard deviation or number (percentage).

^aPatients may have more than one presentation. Percentages may not add up to 100%.

study cohort, 13 of the 16 people with epilepsy (81%) were associated with moderate to profound ID ($n = 22$; 57%). The association of epilepsy in those with constipation issues with moderate to profound ID was thus 59%.

Medication usage data were not available for two admissions, and thus, data were based on 44 admissions. Data summaries are shown in Table 2. There was a high prevalence of ASM use ($n = 18$, 41%) and a low prevalence of the use of antipsychotics ($n = 2$, 5%) and opiates ($n = 2$, 5%). In the study population, 45% of people with ID were on any laxatives at any point of their admission. Osmotic ($n = 16$, 36%) and stimulant ($n = 14$, 32%) were the most common types of laxatives prescribed. The observed range of ACB scores was from 0 to 10. The mean score was 2.3, with a median score of 1. Of those with medication data reported ($n = 44$), in approximately a third of admissions ($n = 14$, 32%), the ACB score was zero.

Discussion

This is the first ‘deep dive’ examination of data of people with ID who have been admitted to a general hospital with a diagnosis of constipation that we are aware of. There are some interesting observations.

Our sample had a high prevalence of moderate-profound ID (57%) which is much higher than the proportion of the ID population with moderate-profound ID, which is around 15%. In our study, more than a third of admitted patients had epilepsy and 41% were on ASM. Only one patient presented with seizures. Epilepsy was over-represented in those with moderate-profound ID. There was a high rate of use of anti-seizure

medication and epilepsy. Considering the recognition of constipation being a significant morbidity, it is surprising that only 45% of patients were prescribed laxatives during their hospitalisation. Other commonly prescribed medications for people with ID which have a side effect of constipation such as antipsychotics and opiates were only present in 5% of admissions respectively which is reassuring.

Higher constipation rates are known to be associated with increasing severity of ID (2, 5), and our findings suggest this increased prevalence can lead to an increase rate of severe complications requiring hospitalisation. This population has significant multimorbidity and polypharmacy when compared with their peers with a milder disability (Sun *et al.* 2022). These patients have a higher prevalence of several likely risk factors including more physical comorbidities, poorer mobility, poorer fluid intake and diet and more medications.

A particular association is with epilepsy where moderate-profound ID is associated with 30–50% prevalence of seizures (Watkins *et al.* 2020; Watkins *et al.* 2022a). Epilepsy in general and ASMs in particular are associated with higher rates of constipation (Gabrielsson *et al.* 2023). There is a lack of clear national and international integrated focus on managing epilepsy in people with ID (Shankar *et al.* 2020; Watkins *et al.* 2020; Snoeijen-Schouwenaars *et al.* 2021; Watkins *et al.* 2022a; Gabrielsson *et al.* 2023; Sun *et al.* 2023). An extension of this issue is the ASM prescribing. Significant concerns are emerging of the use and monitoring of ASMs in people with ID for both seizure and non-seizure management, i.e., for behavioural issues and particularly those over 40 years of age (Watkins *et al.* 2022b; Branford *et al.* 2023a; Branford *et al.* 2023b). This raises concerns of who is monitoring physical health issues such as epilepsy and the associated prescribing in particular, the ASMs in this vulnerable population in a timely, holistic and person centred manner (O’Dwyer *et al.* 2021). It is possible that we need greater awareness that ASMs can have the significant side effect of constipation. Failure to do so, especially in this population with limited cognitive and communicative abilities, can give rise to issues of diagnostic overshadowing where patient distress is attributed to emotional and psychological antecedents rather than investigating further for physical health concerns and

Table 2 Medications of $N = 44$ admissions

Medication type	Medication, n (%)
Antipsychotics	2 (5%)
Antiseizure medication	18 (41%)
Opiates	2 (5%)
Laxatives – Stool softener	0 (0%)
Laxatives – Bulk forming	2 (5%)
Laxatives – Osmotic	16 (36%)
Laxatives – Stimulant	14 (32%)
Laxatives – Any	20 (45%)

complications (Kinney *et al.* 2020; Shankar *et al.* 2020; Maslen *et al.* 2022; Watkins *et al.* 2022a).

In our study the mean ACB score was 2.3 on the ACB scale although the scores were not normally distributed, and the median score was 1. In Scotland, in a data-linkage retrospective matched study, a sample of people with ID ($n = 4305$) were compared with the general population ($n = 12915$) and found to have a much higher ACB (OR = 1.48 [1.33–1.66], $P < 0.001$) and were more likely to be on ASMs (OR = 2.57 [2.22–2.99], $P < 0.001$) and gastrointestinal medications (Ward *et al.* 2022). In a sample of 736 people with ID in Ireland over 40 years of age, the median score was 4, and 29% were on no anticholinergics compared with 32% of our cohort (O'Dwyer *et al.* 2016). This would suggest the ACB score is not particularly high in our cohort compared with a general sample of people with ID, although it is worth considering that prescribing in Ireland and Scotland may be different to that in England. There has been a campaign to reduce prescribing of anti-psychotic medications (which have a high ACB) for people with ID in England in recent years (Boustani *et al.* 2008; Shankar *et al.* 2019; Deb *et al.* 2020; Branford & Shankar 2022). However, as people age it is important to recognise the impact of anticholinergic side effects on the ageing mind (Andrews & Storr 2011).

Nearly half (45%) of patients in our cohort were prescribed laxatives. Other research suggests 25% of people with ID are prescribed regular laxatives in any 12-month period (Straetmans *et al.* 2007). Those on chronic high-dose stimulant laxative use are at risk of iatrogenic induced slow colonic transit and acquired constipation (Shady *et al.* 2022). It could also be that those not on laxatives became so constipated that they required admission suggesting some of these admissions could be avoided with greater awareness and vigilance of constipation amongst patients, carers and care staff.

In 13% ($n = 6$) of people with ID constipation was identified post-admission for elective procedures. This finding suggests that is important to be vigilant for constipation for all people with ID admitted.

Limitations

As a retrospective cohort study, we report associations and make no conclusion on causations. We were

reliant on the admitting or discharging clinicians diagnosing constipation and recording it. It may be possible that patients with milder constipation were missed resulting in under-reporting of the problem. Underestimation could also have happened due to a lack of relevant history being provided by carers of people with moderate to profound ID. There was no engagement with primary care records of the individual people with ID which might have given better insights to confounders such as nature of diet, presence of genetic conditions etc. Additionally, this study lacks an understanding of the social and environmental factors involved such as the nature of care support, social assistance and patient/carer education which could have had a role in precipitating the admissions. The data collected for this review was collected in part during the Covid-19 pandemic. Therefore, this may have influenced the cause and number of admissions.

An associated issue influencing health outcomes generally in people with ID is communication. This is a bi-directional relationship between care providers and patient stakeholders. This relationship can be influenced by a range of factors ranging from clinician lead factors of time, training etc. to patient factors of health literacy, patient expectation. As communication can rarely be quantified it remains a significant confounder to complex outcomes as outlined in this study (Shady *et al.* 2022).

Implications for clinical practice

There is clear and definitive evidence emerging of cumulative risk issues of intellectual disability severity, age over 40 years, multimorbidity particularly epilepsy, ASMs, ACB, laxative use and chronic constipation leading to harm. Particular focus needs to be on communication and monitoring of these key risk issues and need for regular reviews to patients and/or their carers (Rooney *et al.* 2023). Annual health checks (AHC) of people with ID are recognised to provide improved survival for this vulnerable cohort (Kennedy *et al.* 2022). AHCs could include individual bowel care plans incorporating likely risk factors for chronic constipation (Maslen *et al.* 2022).

Implications for research

The vast majority of those on laxatives were on a stimulant or osmotic laxative. There is a striking lack

of research on laxative prescribing for people with ID as is the case generally (Shankar *et al.* 2018). Research to develop prescribing guidelines on this subject would be helpful (Maslen *et al.* 2022). A national report suggested that nearly 200 people a day are admitted to hospital with constipation in England (The Lancet Gastroenterology Hepatology 2019). This would crudely equate to 1400 to 1500 people with ID being part of this cohort annually. This would be a conservative estimate especially given the greater level of likelihood of constipation affecting people with ID than general population. Considering the 5 years of our study and the geographical population covered the study should have identified 150 to 200 people for the study cohort. However, only a third of the estimate was identified in our study. There is a lack of evidence of prevalence of emergency department attendances for constipation for people with ID. This requires further work using better coding methodologies, better training for coders and using big datasets to enumerate the true estimates of emergency admissions for constipation in people with ID.

Author contributions

All authors satisfy the ICMJE guidance by substantially contributing to the design, analysis and interpretation of the work, drafting of the manuscript, final approval of the manuscript and all agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work is appropriately investigated and resolved.

Acknowledgements

None.

Conflict of interest

No author has any direct disclosure/conflict of interests related to the submitted work. RL has been chief investigator in studies for Janssen and Boehringer-Ingelheim Ltd. RS has received institutional and research support from LivaNova, UCB, Eisai, Veriton Pharma, Bial, Angelini, UnEEG and Jazz/GW pharma outside the submitted work. He holds grants from NIHR AI, SBRI and other funding

bodies all outside this work. No other author has declared any conflict of interest.

Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Accepted 30 October 2023

Supporting Information

Additional Supporting Information may be found online in the supporting information tab for this article.

Data S1. STROBE Statement—checklist of items that should be included in reports of observational studies.

Data S2. Supporting Information.