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Rohit Shankar *Peninsula Medical School*

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Shankar, Rohit

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Brief Report

Comparing self-report medication data from a longitudinal study on intellectual disability and national dispensing records

A. Gorman,[1,2] M. Odalović,[1,2] P. McCallion,[3] A. Paul,[2] É. Burke,[2] M. MacLachlan,[4] M. McCarron,[2] M. C. Henman,[1] M. Moran,[5] J. O'Connell,[1] R. Shankar,[6] C. Ryan[1] & M. O'Dwyer[1,2]

1 *School of Pharmacy and Pharmaceutical Sciences, Trinity College Dublin, Dublin, Ireland*
2 *School of Nursing and Midwifery, Trinity Centre for Ageing and Intellectual Disability, Trinity College Dublin, Dublin, Ireland*
3 *School of Social Work, College of Public Health, Temple University, Philadelphia, PA, USA*
4 *Assisting Living & Learning Institute and Psychology Department, Maynooth University, Maynooth, Ireland*
5 *Faculty of Learning Disability Psychiatry, College of Psychiatrists of Ireland, Dublin, Ireland*
6 *Peninsula Medical School, University of Plymouth, Plymouth, UK*

Abstract

Background Medication data are a valuable resource in epidemiological studies. As the most common data collection method of medication data is self-report, it is important to understand the accuracy of this in comparison with other methods such as dispensing records. The aim of this study was to compare the agreement between two different sources of medication data of older adults with intellectual disability (ID).

Methods Self-report medication data were gathered from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing and linked to national pharmacy dispensing records. The kappa statistic was used to measure agreement between the two data sources for psychotropic medication.

Results The lowest agreement level was 'moderate' for the number of anxiolytics reported (kappa 0.56). The highest level of agreement was 'almost perfect' for the binary variable of antipsychotics (kappa 0.91). Other agreement results were 'substantial' or 'almost perfect'.

Conclusions Good agreement was found between the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing medication dataset and national dispensing records. Self-report medication data appear to be a valid method of data collection in psychotropic medication use in adults with ID.

Keywords agreement, intellectual disabilities, intellectual disability, pharmacoepidemiology, psychotropic medication, psychotropics

Introduction

As medication use is an important factor in epidemiological studies, it is important to understand

Correspondence: Dr Ashleigh Gorman, School of Pharmacy and Pharmaceutical Sciences, Trinity College Dublin, Dublin 2, Ireland (e-mail: gormanas@tcd.ie).

the accuracy of the medication data collected. Self-report and dispensing records are the most common data collection methods of medication. Comparison between self-report and dispensing records can help to enrich the validity of the findings and assist in translating findings into practice as greater confidence can be attributed to the results (Sinnott *et al.* 2017a). Comparisons between self-report and dispensing records have been made for a variety of populations including older adults (Rikala *et al.* 2010; Richardson *et al.* 2013), pregnant women (Sarangarm *et al.* 2012; Van der Hoven *et al.* 2022), fathers (Cohen *et al.* 2018) and people with coronary heart disease (Pedersen *et al.* 2021). Most have found strong concurrence between self-report and dispensing records (Sarangarm *et al.* 2012; Cohen *et al.* 2018; Pedersen *et al.* 2021). To the author's knowledge, there has been no investigation into the comparison of self-report and dispensing records of psychotropics in older adults with intellectual disability (ID).

The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) is a longitudinal study on ageing that collects a large range of data including physical health, cognition, psychological, behavioural and social on adults with ID aged ≥40 years in Ireland. Medication data are collected, and a wide range of medication research has utilised these data to investigate psychotropic use (Odalović *et al.* 2024), anticholinergic burden (O'Dwyer *et al.* 2016a), anti-epileptic drugs (Monaghan *et al.* 2021), medication burden and frailty (O'Connell *et al.* 2020), and laxative use (Al *et al.* 2019; Fitzpatrick *et al.* 2023). However, to date, the accuracy of the data collected has not been investigated.

The aim of this study was to compare the agreement of IDS-TILDA self-reported medication data and national dispensing records.

Material and methods

Design and procedure

This study is a comparison of two different sources of medication data – self-reported medication data collected as part of IDS-TILDA and pharmacy-dispensed medications via the Health Services Executive Primary Care Reimbursement Service (HSE-PCRS) for those who consented to this linkage. Comparing self-report IDS-TILDA data and pharmacy dispensing records will determine IDS-TILDA data as an acceptable proxy to conduct analysis with a larger group of data. This work is part of a larger study, Examining Quality, Use and Impact of Psychotropic (Use) in older adults with intellectual disabilities (EQUIP), with study protocol published (Gorman *et al.* 2022).

Participants

Those who participated in Wave 4 of IDS-TILDA and who provided medication data were eligible to participate in this study. Wave 4 involved 739 participants; the exclusion of those who did not provide medication data (n = 20) yielded 719 participants in Wave 4. Of these, 314 participants (43.7%) provided consent and a medical card number (a medical card number is provided to patients who qualify for free health services, including prescription medicines), and 292 of these were valid numbers [40.6% (verified using the Health Service Executive Eligibility Status Check n.d.)] (Fig. 1).

Demographics for the 292 participants with data linkage at Wave 4 (2019/2020) are presented in

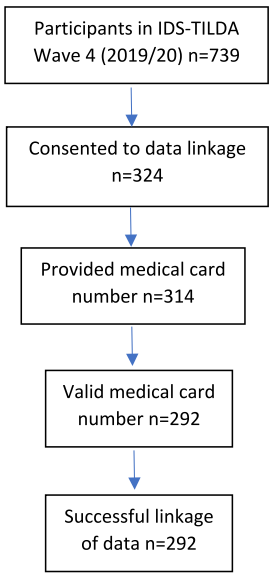

Figure 1. Selection of participants with Health Services Executive Primary Care Reimbursement Service data linkage. IDS-TILDA, Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing.

Table 1. There was a significantly higher report of behaviours of concern in IDS-TILDA participants who were not data-linked as compared with those with data linkage. No other characteristic was significantly different.

Health status demographics investigated included epilepsy, mental health condition, dementia, functional status and behaviours of concern. Epilepsy was measured by a doctor's diagnosis as reported by the participant or their proxy. Mental health condition was measured by a doctor's diagnosis (e.g. psychiatrist, general practitioner and geriatrician) of an emotional, nervous or psychiatric condition (hallucinations, anxiety, depression, emotional problems, schizophrenia, psychosis, mood swings, manic depression, post-traumatic stress disorder, etc.), as reported by the participant or their proxy. Dementia was measured by a doctor's diagnosis of Alzheimer's disease, dementia, organic brain syndrome or senility and serious memory impairment, as reported by the participant or proxy, or reporting of any anti-dementia drug [identified using the World Health Organization's Anatomical Therapeutic Chemical (ATC) code N06D]. Functional status was assessed by the Barthel index scores: total dependence (0–4), severe dependence

Table 1 Demographics of participants with data linkage (n = 292) compared with those with only IDS-TILDA data (n = 427)

	Dispensing data provided, *N* = 292[†], *n*, %	**Dispensing data not provided, *N* = 427[†], *n*, %**	***P* value**
Age (years)			>0.05
40–49	61, 20.9	67, 15.7	
50–64	162, 55.5	234, 54.8	
65+	69, 23.6	126, 29.5	
Gender			>0.05
Male	136, 46.6	196, 45.9	
Female	156, 53.4	231, 54.1	
Residence			>0.05
Independent/family	58, 20.1	66, 15.6	
Community group home	142, 49.3	202, 47.8	
Residential care	88, 30.6	155, 36.6	
Level of intellectual disability			>0.05
Mild	74, 26.9	115, 28.5	
Moderate	126, 45.8	179, 44.4	
Severe/profound	75, 27.3	109, 27.0	
Epilepsy			>0.05
No	207, 70.9	293, 68.9	
Yes	85, 29.1	132, 31.1	
Any mental health condition			>0.05
No	157, 54.0	225, 52.6	
Yes	134, 46.0	203, 47.4	
Dementia and Alzheimer's disease			>0.05
No	279, 95.5	403, 94.4	
Yes	13, 4.5	24, 5.6	
Barthel index (functional status)			>0.05
Mild dependence/total independence	75, 26.6	93, 23.4	
Moderate/severe/total dependence	207, 73.4	304, 76.6	
Behaviours of concern[†]			**<0.05**
No	132, 45.7	151, 37.1	
Yes	157, 54.3	156, 62.9	

Bold emphasis indicates significance <0.05.

[†]Numbers may not total *N* number in column due to missing data.

IDS-TILDA, Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing.

(5–12), moderate dependence (13–18), mild dependence (19) and total independence (20) (Wade & Collin 1988). A binary variable was created for statistical purposes, with the following categories: 'mild dependence/total independence' and 'moderate/severe/total dependence'. Behaviours of concern were assessed by the Behaviour Problems Inventory (BPI) – Short Form (Rojahn *et al.* 2012). The BPI contains 30 items divided into three categories of behaviour [self-injurious behaviours (8 items), aggressive/destructive behaviours (10 items) and stereotyped behaviours (12 items)]. The BPI was included in the pre-interview questionnaire (PIQ) and completed by the participant's care/key worker/support worker on their behalf. They were asked to indicate which behaviours have been observed in the participant during the past 2 months. The BPI – Short Form is a validated tool (Rojahn *et al.* 2012; Mascitelli *et al.* 2015) and has been used successfully in other studies (Painter *et al.* 2016; Bowring *et al.* 2018; Gandía-Abellán *et al.* 2023). A binary variable was created for each of the three categories of behaviour. A participant was recorded as having a behaviour of concern if they reported 'yes' for at least one of the 30 items on the BPI, regardless of frequency or severity of the behaviour.

Medication data

Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing medication data

Prior to the main interview (which was conducted face-to-face), IDS-TILDA participants received a PIQ to complete in their own time, independently or supported by carer. The PIQ includes questions that may require participants or their proxy to review medical records or other material to complete. The main interview consists of additional questions where reviewing of records is unlikely. Participants were asked to record 'all medications that you take on a regular basis, take every day or every week' as part of the PIQ. This included prescription and non-prescription medications, over-the-counter medicines, vitamins, and herbal and alternative medicines. These answers were then confirmed in a face-to-face interview. Medications were recorded as brand or generic name and were subsequently classified based on their ATC codes. Two pharmacists independently reviewed and confirmed ATC classifications as follows: antipsychotics (N05A), anxiolytics (N05B), sedatives/hypnotics (N05C), antidepressants (N06A) and mood-stabilising agents [anti-seizure medications (N03A) reported by people without a diagnosis of epilepsy, lithium (N05AN01)]. Psychotropic medications were analysed in line with their licensed indication; however, some reclassifications were undertaken to reflect main clinical use, as seen in other psychotropic medication research (O'Dwyer *et al.* 2017; Odalović *et al.* 2024). Lithium was reclassified as a mood-stabilising agent; prochlorperazine was reclassified as an antiemetic/antinauseant; clonazepam was reclassified as an anxiolytic in participants who had no diagnosis of epilepsy but reported a diagnosis of a mental health condition; clobazam and rectal diazepam were removed from anxiolytics; and midazolam was removed from the sedative/hypnotic subclass.

Following reclassifications, 12 variables were created. Six binary variables report the use of (1) antipsychotics, (2) anxiolytics, (3) sedatives/hypnotics, (4) antidepressants, (5) mood-stabilising agents and (6) any psychotropic. Six numerical variables report the total number of subclass medications per person: (1) antipsychotics, (2) anxiolytics, (3) sedatives/hypnotics, (4) antidepressants, (5) mood-stabilising agents and (6) any psychotropic.

Primary Care Reimbursement Service medication data

Prescription claims in the Primary Care Reimbursement Service (PCRS) database are coded using the ATC classification system. Only relevant recorded information from the PCRS data was analysed, which included age category and gender (to confirm data of IDS-TILDA participants), brand name, defined daily doses, strength, quantity and unit of administration of each drug dispensed. PCRS data were extracted for the 2 months either side of the participant's IDS-TILDA Wave 4 interview date to ensure that all medications prescribed were captured. PCRS medication data followed the same method of classification as detailed earlier.

Data analysis

Kappa statistics were used to measure the agreement between IDS-TILDA self-report medication data and

HSE-PCRS data at Wave 4 (2019/2020). The kappa result was interpreted as follows: no agreement (≤0), slight (0.01–0.20), fair (0.21–0.40), moderate (0.41–0.60), substantial (0.61–0.80) and almost perfect agreement (0.81–1.00) (McHugh 2012). Confidence intervals were calculated at 95%. A study using The Irish Longitudinal Study on Ageing (TILDA) data completed similar statistical analysis (Richardson *et al.* 2013). As dispensed data are considered to be accurately recorded (Richardson *et al.* 2013), comparing IDS-TILDA self-report medication data with the HSE-PCRS dispensed data allows for the strength of IDS-TILDA medication data to be determined.

Results

For the 292 data-linked participants, five subclasses of psychotropic medications were examined, as well as the psychotropic total. Table 2 shows the results of kappa statistics. The agreement of the subclasses differed between their continuous and binary variables. Kappa statistics differed for each subclass but were in the same grouping of level of agreement, with the exception of anxiolytics. For example, the total number of antipsychotics resulted in a kappa statistic of 0.86 and the binary variable of this with a kappa statistic of 0.91; that is, both kappa statistics showed an agreement level of 'almost perfect', as shown in Table 2. For anxiolytics, the total number has a kappa statistic of 0.56 ('moderate'), but the binary variable has a kappa statistic of 0.62 ('substantial').

Table 2 Agreement between Wave 4 (2019/2020) medication data in IDS-TILDA and pharmacy dispensing records

Medication class	Kappa	*P* value	95% CI
Mood-stabilising agents			
Total number	0.74	<0.001	(0.63–0.85)
Binary	0.78	<0.001	(0.68–0.89)
Antipsychotics			
Total number	0.86	0.000	(0.80–0.92)
Binary	0.91	0.000	(0.86–0.96)
Anxiolytics			
Total number	0.56	<0.001	(0.42–0.70)
Binary	0.62	<0.001	(0.48–0.76)
Sedatives/hypnotics			
Total number	0.65	<0.001	(0.46–0.84)
Binary	0.72	<0.001	(0.53–0.91)
Antidepressants			
Total number	0.91	<0.001	(0.86–0.96)
Binary	0.88	<0.001	(0.82–0.94)
Psychotropics			
Total number	0.66	<0.001	(0.60–0.73)
Binary	0.66	<0.001	(0.62–0.74)

CI, confidence interval; IDS-TILDA, Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing.

Discussion

Pharmacy dispensing data are believed to be more accurate, compared with self-reported data, as it is required to be correct and up-to-date and has been used frequently in pharmacoepidemiology research (McGowan *et al.* 2013; Moriarty *et al.* 2015; Sinnott *et al.* 2017b; Conlan *et al.* 2023). In general, good agreement was found between self-report medication data in IDS-TILDA and the pharmacy dispensing records, with most resulting in a substantial agreement or almost perfect agreement. This shows that the method to collect medication data in IDS-TILDA provides accurate data. A similar study, comparing the agreement of self-report medication data collected as part of another longitudinal study in Ireland, TILDA, and pharmacy data on prescription medications also showed a good level of agreement (Richardson *et al.* 2013). Whilst they did not focus solely on psychotropic medication nor group medications in the same manner, two therapeutic groups are relevant to this paper: psycholeptics (ATC code N05) and psychoanaleptics (ATC code N06). Psycholeptics (incorporating antipsychotics) had a moderate kappa statistic of 0.59, whilst this study showed an almost perfect kappa statistic of 0.91. Psychoanaleptics had a substantial kappa statistic of 0.69 (antidepressants in IDS-TILDA had agreement of 0.88). Given the therapeutic groups of psycholeptics and psychoanaleptics cover a wider range of medications than just antipsychotics, the results are not directly comparable but worth noting.

Psychotropic medications are often prescribed to this population on an 'as required' basis [PRN (Busch *et al.* 2023)]. As such, they would have been recorded in the IDS-TILDA dataset but may not have been dispensed within the 2 months either side of the interview date, providing a possible explanation for less than perfect agreement, but differences were not

statistically significant. Medication dispensed on a medical card scheme is usually dispensed for 1 month, although this is not always the case. The decision to include data from 2 months either side of the interview date aimed to include all medication dispensed to the individual; however, full agreement was not seen in the data. Previous research using dispensing data has noted that the preferred reporting period may vary by drug (Rikala *et al.* 2010), and the time frame of dispensing data should be thoroughly considered (Nielson *et al.* 2008; Richardson *et al.* 2013). Also seen in other studies was a difference in the concordance between datasets regarding medications used chronically compared with those used intermittently (Sarangarm *et al.* 2012; Richardson *et al.* 2013; Cohen *et al.* 2018). Future work will consider how this may affect understanding of prescribing for people with intellectual disability. There was a difference in the kappa statistics between the binary variable and the numerical variable. Intraclass polypharmacy levels are high in IDS-TILDA participants (O'Dwyer *et al.* 2016b; Odalović *et al.* 2024); therefore, the binary variable is likely to have high agreement as medications prescribed PRN may not have been captured within the PCRS data. This may also explain the difference in agreement between the different subclasses of psychotropics. For example, antidepressants are likely to be prescribed for daily intake, whereas anxiolytics are more regularly prescribed PRN within this population. Changes in prescribing trends over study years may reflect changes to recommended guidelines (National Institute for Health and Care Excellence 2015) and frameworks (Health Service Executive 2021), which may also explain the differences in agreement. The Republic of Ireland operates different public healthcare schemes, such as the Long-Term Illness (LTI) Scheme (Health Service Executive n.d.), which may also explain some differences as on this scheme, patients may get medicines for particular long-term illnesses at no cost, for example, epilepsy, cerebral palsy and hydrocephalus. The data collected from the HSE-PCRS did not capture prescriptions for patients under the LTI scheme. Other studies investigating the agreement between two different sources of medication data only focused on if the medication had been reported and not the number of different medications (within the same subclass).

To the author's knowledge, no other study has investigated dispensing records and self-report medication in people with intellectual disability. Further research is required to examine further if there is a connection between particular demographics and providing consent to access dispensing records and if those differences relate to particular diagnoses and types of prescribing. Here, there was one difference identified between the two groups: behaviours of concern. Given that this is an area where there may be off-label prescribing, this deserves further investigation.

In conclusion, there was strong agreement between the IDS-TILDA medication dataset and national dispensing records. The data collection method of self-reported medication has shown to be accurate in IDS-TILDA.

Limitations

Overall, the linkage of IDS-TILDA self-report medication data to HSE-PCRS data showed a strong level of agreement. However, HSE-PCRS data were not available for all IDS-TILDA participants, mainly due to participants not providing their medical card number. It is also noted that some prescribing for participants on the LTI scheme (mentioned earlier) was not captured.

Some services do not use the HSE-PCRS, and so dispensing data would not have been available for these participants. The self-report medication data in the IDS-TILDA survey are often copied from the participant's Kardex (a document containing patient information including prescribed medications with dosing information), if available. As there is no standard Kardex format and there is often a handwritten note stating if a medication has been discontinued, this may not be clear to the person copying the medication information, and so discontinued medication could potentially have been listed in the IDS-TILDA medication list.

It is also important to note that for diagnoses of epilepsy, mental health condition and dementia, participants are asked if they have received a doctor's diagnosis. However, it is not in the scope of IDS-TILDA to check medical records of participants. IDS-TILDA encourages participants or their proxy to review records before completing questions, where possible. If a participant requires assistance to

complete any aspect of IDS-TILDA, it is advised that the person assisting has known the participant for at least 6 months.

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Conflict of Interest

R. S. has received institutional and research support from LivaNova, UCB, Eisai, Veriton Pharma, Bial, Angelini, UNEEG and Jazz/GW Pharmaceuticals outside the submitted work. He holds grants from NIHR AI, SBRI and other funding bodies all outside this work. The remaining authors have no possible conflicts of interest.

Source of Funding

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Ethics Approval Statement

Ethical approval for IDS-TILDA study was granted by the Trinity College Dublin (TCD) Faculty of Health Sciences Research Ethics Committee and the 138 service providers who support the participants with intellectual disability. For national dispensing records, a privacy impact assessment was completed by the Health Service Executive (HSE). A data exchange agreement was in place between TCD and the HSE before transfer of any personal information.

Data Availability Statement

The data are not publicly available because of privacy and ethical restrictions. The data that support the findings of this study are available from the corresponding author upon reasonable request.

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