

Research: Care Delivery

Characteristics of diabetes medication-taking in people with mild to moderate intellectual disability compared to those without: a mixed-methods study

R. E. Paterson¹ , L. Taggart² , L. Hoyle³ and M. Brown⁴

¹School of Health and Social Care, Edinburgh Napier University, Edinburgh, ²School of Nursing, University of Ulster, Belfast, ³School of Health Sciences, University of Stirling, Stirling and ⁴School of Nursing and Midwifery, Queens University, Belfast, UK

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Abstract

Aim To compare the frequency and factors associated with diabetes medication-taking (depression, perceived side effects, self-efficacy and social support) in people with mild to moderate intellectual disability and those without intellectual disability.

Methods In stage 1 of this study, we collated information on diabetes medication-taking and associated factors in 111 people with diabetes: 33 adults with mild to moderate intellectual disability and 78 adults without intellectual disability. Validated instruments measuring medicine-taking, self efficacy, depressive symptoms, perceived level of social support and perceived side effects were administered in both groups. In stage 2, we used an abductive qualitative approach to triangulate stage 1 findings with carers responses ($n = 12$).

Results The instruments showed good internal reliability (Cronbach's $\alpha = 0.7$ – 0.9). Comparisons between people with intellectual disabilities and those without revealed similar frequency of medication-taking (70% vs 62%; $P = 0.41$). People with intellectual disabilities and diabetes had significantly higher depressive symptoms, as measured by the Glasgow Depression Scale for people with a Learning Disability ($P = 0.04$), higher levels of perceived side effects ($P = 0.01$), and lower confidence levels, as measured by the Perceived Confidence Scale ($P = 0.01$). The results of stage 2 showed how carers of people with intellectual disabilities and diabetes optimized medication-taking yet infrequently discussed the side effects of medicines.

Conclusions Further investigation of medication-taking and side effects may result in the development of an evidence-informed intervention to improve medicines safety in people with intellectual disabilities.

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Introduction

Globally, the WHO has suggested that improving adherence to medicines may have a greater impact on chronic disease management than any other scientific advancements [1]. Medication adherence occurs when the patient's actions match the prescribed regimen, with optimum adherence achieved when medicines are taken as prescribed 80–95% of the time [2]. Adherence maximizes therapeutic effect, improves quality of life, alleviates clinical symptoms and minimizes adverse drug events. Despite these benefits, it is

estimated that up to 50% of medicines are not taken as prescribed [1], and medication-taking in people with diabetes is amongst the poorest [2]. Comparing diabetes to hypertension and asthma, diabetes medication-taking was estimated at 66% [3]. Furthermore, a systematic review of 45 studies concluded that non-adherence to diabetes medication was one of the most common reasons for hospitalization [4], and significant correlations between non-adherence to medication and poor glycaemic control are evident [5]. The long-term consequences of poor glycaemic control include hypoglycaemia or hyperglycaemia, cardiovascular disease, limb amputation, renal and visual impairment, and premature death [6]. Thus, medication-taking is a crucial factor in optimizing health in people with diabetes.

Correspondence to: Ruth Paterson. E-mail: r.paterson@napier.ac.uk

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What's new?

- Approximately 30–50% of medicines are not taken as prescribed, with a paucity of research on medication-taking specific to people with intellectual disability.
- The frequency of medication-taking in adults with diabetes with and without intellectual disabilities is similar. People with intellectual disabilities and diabetes had perceived side effects to be greater compared to people without intellectual disabilities and diabetes.
- People with intellectual disabilities and diabetes may benefit from increased pharmacovigilance and screening for side effects by family, paid carers and healthcare professionals.

Bandura's social cognitive theory [9] conceptualizes the complexity of medication-taking as an interwoven process between cognitive, psychological and environmental factors. Psychological well-being, confidence or self-efficacy, medication beliefs and level of social support play an important role in mediating whether or not people with diabetes take their medicines [7–10]. A systematic review and meta-analysis of 47 independent samples demonstrated that depression had a moderate effect on treatment and medication-taking in people with type 1 and type 2 diabetes [7]. Moreover, a meta-analysis of 48 studies concluded that, when measured against depression, low self-efficacy may be a more significant indicator of poor medication-taking than depressive symptoms [8]. Perceptions of medication side effects have a significant impact on health-related quality of life and medication adherence [9]. Environmental factors (such as social support) may also influence medication-taking. A mixed-methods study [13] found that presence of social networks was a strong predictor of diabetes medication adherence in people with diabetes, a finding corroborated by Gherman *et al.* [8].

Whilst social cognitive theory has provided some clarity on factors associated with medication-taking in the general population with diabetes, it not known how those factors translate to people with intellectual disabilities and diabetes. Adults with intellectual disabilities are two to three times more likely to develop diabetes [11] and to have suboptimal glycaemic control [12]. Given the cognitive impairments, communication difficulties, greater reliance on family or paid carers and lack of engagement with primary healthcare professionals [13] in this population, it is hypothesized that such individuals are at greater risk of suboptimal medication-taking.

The aim of the present study was to apply social cognitive theory in a prospective mixed-methods study to investigate the key characteristics, depressive symptoms, self-efficacy, perceived side effects and social support with regard to diabetes medication-taking in adults with diabetes with and without intellectual disabilities.

Methods

We conducted a two-stage mixed-methods study comparing and contrasting adults with type 1 or 2 diabetes with and without intellectual disability, who were taking prescribed diabetes medication, in a single health board in Scotland. The study was completed in November 2017.

Stage 1**Participants**

The target sample size was 109 and was derived from a power analysis using G*Power 3.1.5 with $\alpha = 0.05$ and power = 0.80, and assuming an estimated effect size of $f^2 = 0.15$. Information about the study was distributed to regional general practices ($n = 124$), diabetes outpatient clinics ($n = 2$), a diabetic clinical research facility ($n = 1$), specialist community intellectual disability services ($n = 3$) and a social care department ($n = 1$). The named informants were two general practitioners, three diabetes research nurses and three intellectual disability specialists. During the recruitment phase, potential participants were approached via the named informants, then contacted by the researcher and, if eligible, recruited to the study. Eligible participants were aged >18 years, able to provide voluntary consent, diagnosed with type 1 or 2 diabetes and prescribed glucose-lowering medicines. Intellectual disability was defined according to the International Classification of Diseases (ICD)-10 which categorizes intellectual disability as borderline, mild, moderate, severe and profound [14]. Given that in previous research classification of intellectual disability was rarely formally documented [15] and given the absence of a regional database, a pragmatic approach to identification of participants was adopted. This involved named informants identifying people with mild to moderate intellectual disability and diabetes, corroborating the results with medical records and verifying diagnosis during recruitment.

Data collection

Demographic, dependent and independent variable data, numbers and types of prescribed diabetes medication, and insulin vs glucose-lowering agent data, were self-reported and these reports were corroborated with a medicines chart or repeat prescription information. Diabetes medication was defined as any prescribed first-, second- or third-line glucose-lowering agents [17]. HbA_{1c} data were extracted from electronic medical records and the value reported within 6 months of the interview was recorded. Demographic data recorded were: age; level of intellectual disability; diabetes duration; level of education; living situation; prescribed medicines; and whether or not the participant was receiving insulin therapy.

Measurements. The five validated instruments described below were used to collate data from participants with diabetes with and without intellectual disability.

1. Medication adherence was measured using the self-reported, eight-item Morisky Medication Adherence Scale (MMAS-8) [16]. This instrument asks the participant to state 'yes' or 'no' to a series of questions, and one point is received for each answer aligned to the expected response. Scores of ≥ 6 are defined as good adherence, and scores < 6 as poor adherence. Results were corroborated with HbA_{1c} values, and suboptimal diabetes control was defined as HbA_{1c} > 58 mmol/mol ($> 7.5\%$) [17].
2. Depressive symptoms were measured using the Glasgow Depression Scale for people with a Learning Disability (GDS-LD), a 20-item scale which has been psychometrically tested for use in adults with mild to moderate intellectual disability [18]. In the present study a score of ≥ 10 indicated depressive symptoms.
3. Self-efficacy was measured using the four-item Perceived Competence in Diabetes Scale (PCS). For each of the four components, perceived competence is rated on a scale of 1 (not at all true) to 7 (very true) and the score is transformed to a scale 0 to 100. Higher score indicates greater self-efficacy [19].
4. The Perceived Sensitivity to Medicines scale (PSM) [20] is a short five-item instrument. Individual item scores are summed to provide a total PSM score ranging from 5 to 25. Higher scores indicate greater perceived medicine side effects.
5. Perceived level of social support was assessed using the eight-item modified Medical Outcomes Study Social Support survey (mMOS-SS) [21]. Participants rate items across a five-point Likert scale, and the score is totalled and transformed to a scale of 0–100. The higher the score the greater the perceived level of social support.

With the exception of the GDS-LD, the instruments had not previously been used or validated in adults with intellectual disabilities. To optimize comprehension of items in the instruments, minor linguistic modifications and further explanation using illustrations from Boardmaker[®], were made. Boardmaker is a software package of standardized picture symbols commonly used with people who are strong visual learners, which includes people with intellectual disabilities. The amended scales were reviewed for comprehension and time needed to complete by people with intellectual disability and intellectual disability clinicians. All instruments were completed within an hour, with minimal support from the researcher.

Data analysis. Data were analysed using SPSS 22 statistical package. Cronbach's α measured the reliability of instruments, with a score of 0.7–1.0 demonstrating good internal reliability. Comparisons of medication-taking, demographic data and factors previously associated with adherence were made between the intellectual disability and non-intellectual

disability groups using the chi-squared test (for binary data) and the Mann–Whitney *U*-test for data measured on the ordinal scale (as these data had outliers and were considered non-normal). Statistical significance was determined at the 5% level. No allowance was made for the multiplicity of tests. There was no imputation of missing data.

Stage 2

Participants

In stage 2, qualitative semi-structured interviews were conducted with a sample of family and paid carers of stage 1 participants. The primary research question of interest was whether the frequency of, and factors associated with, medication-taking were consistent with the views of carers supporting diabetes medication-taking in stage 1 participants? Thus, the aim was to triangulate stage 1 findings and explore enablers and barriers to medication-taking. Carers were eligible to participate if they had supported stage 1 participants with medication-taking for more than 1 year and they agreed to participation. The target number of carer participants was between 10 and 15.

Table 1 Topic guide for stage 2 interviews

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1. Can you just tell me what relationship (if any) you are to this person?
 2. How do you help them take their diabetic medicines?
 3. Part of the study was to look at how well the patient felt they took their medication, can you give me some information about how you believe (participant's name) takes their medicine.
 4. What do you see as the barriers to (participants name) taking medicines and what do you see as the things that help (him or her) to take insulin and/or oral medicines?
 5. Can you talk a bit about how you think mood affects how well they take their medicine,
 6. Does this affect how you support him or her taking medications?
 7. Can you tell me a bit about how confident he or she feels in managing his or her medication?
 8. Do you feel confident in supporting him or her managing treatment – if yes why? /if no why?
 9. We asked whether worries about side effects from the medications or whether they felt the medications are doing them any good. Can you talk a bit about whether you think has any worries about side effects or whether they feel the medicines help them control their diabetes?
 10. Do you have any views about the diabetes medicines that your patient takes (insulin or pills)? Side effects/do they work?
 11. We asked service users what they thought about their level of social support, what is your impression of how this impacts on taking their diabetic medicines.
 12. There are three main parts to diabetes self care: 1) medicines; 2) exercise; 3) diet. In your view what do you think is the most challenging for Stage 1 participant? Can you explain to me why that is?
-

Methods

Following preliminary analysis of stage 1 data, a topic guide was designed and used in the semi-structured interviews in stage 2 (Table 1). To ensure that carers' views reflected their own perspective of stage 1 participants' medication-taking, results relating to the person they cared for were not discussed. On completion, data were matched to the respective stage 1 participant results, integrated and aligned.

Data analysis

Interviews were digitally recorded, transcribed verbatim and analysed using NVIVO software. Stage 1 and 2 data were matched and analysed to create an in-depth explanation and verification of stage 1 results. An abductive, six-stage-approach thematic analysis was then conducted. This involved familiarization with the data by reading them, listening to audio recordings, coding and categorizing them into relevant data extracts and, where necessary verifying meaning with research participants. Themes were then created from meaningful patterns in the data, and aligned to stage 1 data. These themes were then checked by a second qualitative researcher with the original dataset. Validity and robustness of themes were confirmed when both researchers (R.P., L.H.) agreed themes and verified that they were coherent, consistent and distinctive.

Study ethics

Ethical approval for the study was granted by the Integrated Research Approval System (IRAS no 14-NS-0060), Health Service and University committees in the region. All study participants, provided informed written consent prior to study enrollment.

Results

Stage 1

Sample characteristics

Of 164 invited participants, 50 (31%) were people with intellectual disability. A total of 111 participants (68%)

were included in the analysis: 33 (30%) in the intellectual disability group and 78 (70%) in the non-intellectual disability group. All datasets were complete and instruments showed good internal reliability (Table 2; Cronbach's $\alpha = 0.7-0.9$). Demographic characteristics (Table 3) showed that 81% of participants had a diabetes duration of >6 years, and 75% had a diagnosis of type 2 diabetes. Comparisons between the intellectual disability and non-intellectual disability groups showed that the male:female ratio was similar, and the intellectual disability group had a lower median age (51 vs 64 years; $P = 0.05$) and a lower level of secondary school education ($P = 0.008$). A higher proportion of the intellectual disability group was employed (45% vs 3%; $P = 0.001$), lived alone (52% vs 23%; $P = 0.005$) and received support with medicines (70% vs 5%; $P = 0.05$). A lower proportion of the intellectual disability group with type 2 diabetes was prescribed insulin (11% vs 57%; $P = 0.05$). The intellectual disability group had a significantly higher median GDS-LD depression score (11 vs 8; $P = 0.04$), higher PSM scores (side effects; 14 vs 11; $P = 0.01$) and lower median PCS (self-efficacy) scores (75 vs 93; $P = 0.01$). Perceived levels of social support were similar in both groups.

Comparisons of frequency of medication adherence in intellectual disability and non-intellectual disability groups

Table 4 shows the frequency of medication adherence data, as measured by the MMAS-8. A higher proportion of the intellectual disability group reported good or excellent adherence (MMAS-8 score ≥ 6) compared to the non-intellectual disability group (70% vs 62%, respectively). There was no statistically significant difference in glycaemic control ($P = 0.82$), frequency of adherence ($P = 0.41$) or mean adherence score ($P = 0.65$) across the two groups. According to the MMAS-8, the most common reason for non-adherence was 'forgetting' in the group overall, and the second most common reason in the intellectual disability group was because 'medicines made them feel worse' (18% vs 8%; $P = 0.17$), which was corroborated by the overall

Table 2 Internal reliability of dependent (eight-item Morisky Medication Adherence Scale) and independent (depression, medication side effects, self-efficacy and social support) measurement instruments

Scale	Group overall	Diabetes and intellectual disability group, Cronbach's α	Diabetes without intellectual disability group, Cronbach's α
Medication adherence (MMAS-8; eight-item scale)	0.7	0.7	0.7
Depression (GDS-LD; 20-item scale)	0.8	0.8	0.8
Medication side effects (PSM; five-item scale)	0.9	0.8	0.9
Self-Efficacy (PCS; four-item scale)	0.9	0.9	0.9
Social support (mMOS-SS; eight-item scale)	0.9	0.9	0.9

GDS-LD, Glasgow Depression Scale for people with a Learning Disability; MMAS-8, eight-item Morisky Medication Adherence Scale; mMOS-SS, modified Medical Outcomes Study Social Support Survey; PCS, Perceived Competence in Diabetes Scale; PSM, Perceived Sensitivity to Medicines.

Table 3 Descriptive statistics of the group overall and comparisons between people with diabetes with and without intellectual disability

Socio demographics	Group overall, N = 111	Diabetes and intellectual disability, n = 33	Diabetes without intellectual disability, n = 78	P
Median age, years	62	51	64	0.05*
Intellectual disability, n (%)	33 (30)	-	-	
Women, n (%)	55 (50)	15 (45)	40 (51)	0.58 [‡]
Lower than secondary school education level, n (%)	82 (74)	30 (91)	52 (66)	0.008*
Employed, n (%)	17 (15)	15 (45)	2 (3)	0.001*
Living alone, n (%)	35 (31)	17 (51)	18 (23)	0.003*
Type 2 diabetes, n (%)	83 (75)	27 (82)	56 (72)	0.266 [‡]
Type 1 diabetes, n (%)	28 (25)	6 (18)	22 (28)	0.266 [‡]
Prescribed insulin, n (%)	63 (57)	9 (27)	54 (69)	0.05*
Type 2 diabetes prescribed insulin, n (%)	35 (42)	3 (11)	32 (57)	0.05*
Support with diabetes medications, n (%)	27 (24)	23 (70)	4 (5)	0.05*
>4 medicines prescribed, n (%)	93 (84)	28 (85)	65 (83)	0.84 [‡]
Diabetes >6 years, n (%)	90 (81)	24 (73)	66 (85)	0.14 [‡]
Median (IQR) GDS-LD score	8	11 (5–16)	8 (5–10.2)	0.04*
Median (IQR) PSM score	11	14 (10–17)	11 (8–14)	0.01*
Median (IQR) self-efficacy (PCS) score	93	75 (57–93)	93 (83–100)	0.01*
Median (IQR) perceived level of social support (mMOS-SS) score	85	78 (67–96)	88 (75–100)	0.09 [†]

GDS-LD, Glasgow Depression Scale for people with a Learning Disability; IQR, interquartile range; mMOS-SS, modified Medical Outcomes Study Social Support Survey; PCS, Perceived Competence in Diabetes Scale; PSM, Perceived Sensitivity to Medicines.

*Statistically significant difference between the group with diabetes and intellectual disability and the group with diabetes without intellectual disability.

[†]Non-parametric Mann–Whitney U-test as outliers detected continuous data.

[‡]Chi squared test for significance (ordinal variable).

Table 4 Comparison of dependent variables (medicines adherence and HbA_{1c}) in the group overall, and in people with and without intellectual disability

Variable	Group overall, N = 111	Diabetes and intellectual disability, n = 33	Diabetes without intellectual disability, n = 78	P
Suboptimal glycaemic control*, n (%)	67 (60)	18 (55)	49 (63)	0.42 [†]
Median HbA _{1c} , mmol/mol	61	60	61	0.82 [‡]
MMAS-8 ≥6 (good adherence), n (%)	71 (63)	23 (70)	48 (62)	0.41 [†]
Mean (SD) medicines adherence score	6.4 (1.7)	6.5 (1.6)	6.3 (1.7)	0.65 [§]

MMAS-8, eight-item Morisky Medication Adherence Scale.

*HbA_{1c} >58 mmol/mol (7.5%). MMAS-8 score ≥6.

[†]Chi-squared test for significance (ordinal variable).

[‡]Non-parametric Mann–Whitney U-test as outliers detected in continuous data.

[§]Independent t-test as parametric continuous data.

higher median PSM scores (14 vs 10) in people with intellectual disability (Table 5).

Stage 2

In stage 2, all eligible carers ($n = 27$) were contacted by letter and invited to participate. Of those, eight declined, four were uncontactable and three did not attend the scheduled interview. Thus, an opportunistic sample of 12 carers comprising nine with intellectual disability and three without intellectual disability was obtained. Interviews were 15–35 min in duration. In the intellectual disability group, four

were paid carers and five unpaid. In people without intellectual disability, all were family members. With regard to triangulation, stage 1 and 2 results were aligned to medication adherence and depressive symptoms, but not perceptions of side effects. Thematic analysis of the data identified two main themes: 1) optimization and 2) barriers. Samples of coding and definitions of themes are outlined in Table 6.

Triangulation

Eleven carers' reports of medication-taking were matched with stage 1 participant reports, and carers across the intellectual disability and non-intellectual disability sample

Table 5 Frequency and chi-squared comparisons of unfavourable responses to the eight-item Morisky Medication Adherence Scale questionnaire in the group overall, intellectual disability and non intellectual disability groups

Morisky MMAS-8 adherence scale (favourable answer*)	Group overall, N = 111	Diabetes and intellectual disability, n = 33	Diabetes without intellectual disability, n = 78	Chi squared test P value
1. Do you sometimes forget to take your diabetes medication? (N)	51 (46)	12 (36)	39 (50)	0.19
2. Over the past 2 weeks, were there any days when you did not take your diabetes medication? (N)	27 (24)	7 (21)	20 (26)	0.62
3. Have you ever cut back or stopped taking your diabetes medication without telling your doctor because you felt worse when you took it? (N)	12 (10)	6 (18)	6 (8)	0.17 [‡]
4. When you travel, or leave home, do you sometimes forget to bring along your diabetes medications? (N)	18 (16)	1 (3)	17 (22)	0.02 [†]
5. Did you take your diabetes medication yesterday? (Y)	3 (3)	0 (0)	3 (4)	0.55
6. When you feel like your diabetes is under control, do you sometimes stop taking your medications? (N)	3 (3)	2 (6)	1 (1)	0.21 [‡]
7. Do you ever feel hassled about sticking to your diabetes treatment plan (N)	26 (23)	11 (33)	15 (19)	0.11
8. How often do you have difficulty remembering to take all your diabetes medications (never, sometimes, always)	43 (39)	12 (36)	31 (40)	0.73

MMAS-8, eight-item Morisky Medication Adherence Scale.

*Possible responses: yes/no; correct response = 1 point; incorrect response = 0 points. Possible responses: never (1 point); almost never, sometimes, quite often, always (0 points). Possible scale range = 0–8. Poor adherence: MMAS-8 score <6; medium adherence: MMAS-8 score 6 and 7; good adherence MMAS-8 score = 8.

[†]Statistically significant, $P < 0.05$.

[‡]Expected count <5 so exact test was selected for Pearson's chi-square.

Table 6 Themes and definitions from stage 2 data analysis

Theme	Theme descriptor
1. Optimization	Optimization strategies were defined as any type of psychological or physical assistance which the carer interpreted as support for the person with or without intellectual disability in taking prescribed diabetes medicines. Prescribed diabetes medication was defined as a pharmacological treatment regimen recommended by a prescriber or other healthcare professional (e.g. diabetes specialist nurses, district nurse or pharmacist) designed to optimize glycaemic control
2. Barriers	How carers of individuals with or without intellectual disability interpreted the influence that depression side effects, self-efficacy and social support had on adherence of the participants in stage 1 to their prescribed diabetes medicines

reported that those with MMAS-8 scores ≥ 6 used medications as prescribed (response: 'fine') and that they were 'used to it'. Others with sub-optimal adherence and poor glycaemic control reported that participants were frequently 'distracted' or 'forgetful'. One paid carer of a participant with intellectual disability reported:

'... if something comes up, he's very good at going away and not taking his insulin stuff with him' (MMAS-8 score 5, HbA_{1c} 100 mmol/mol).

Carers of people with intellectual disability and diabetes perceived a link between mood and medication-taking. Those with elevated depression scores (GDS-LD score >10) reported a negative relationship between depressive symptoms and medication-taking, mitigated by the support offered by the carer.

'...if she's depressed, I think she'd just say, "Well, I'm not taking it, there's no point". I quite firmly believe that.'

(GDS-LD score 12, MMAS-8 score 8, HbA_{1c} 46 mmol/mol)

A paid carer of a participant with intellectual disability reported how low mood manifested in a reluctance to take medications, which was overcome with persuasion, resulting in high MMAS-8 scores:

'...if her mood is low... if something has happened she's reluctant to take her medication. But then, she always will come around and she will take it.' (GDS-LD score 21, MMAS-8 score 8)

Theme 1: Optimization

Carers of participants adopted a dynamic and proportionate approach to optimizing medication-taking, such as 'reminding', 'persuading' and 'physical support'. This proportionality was evident across all medicines regimens. For example, when a participant with intellectual disability and type 2 diabetes required insulin therapy, care shifted from self-

management to the carer and healthcare professional. A needle phobia resulted in insulin injections being managed by the carer and district nurse:

‘...it took us about a year...there is always a staff member in with him when the nurses come in to give him his injections because he requested it, so yeah that’s what we did.’ (MMAS-8 score 8, HbA_{1c} 102 mmol/mol).

In another case, a paid carer’s account of supporting a person with intellectual disability and type 2 diabetes included attempts to give full autonomy when managing medicines. However, support shifted back to carers following accidental overdose:

‘When she had her medication in a cabinet in her bedroom, she opened it and she took an overdose of her medication, so that’s why we hold onto it... we hand her the blister pack and she always knows which day, which time it is.’

Ongoing attempts by the carer to shift self-management to the person with intellectual disability were also evident:

‘We’ve been starting to get her to count how many she has each time as well, so she knows in the afternoon there’s three tablets, so she knows that, she knows which ones, so she’s getting to know what she’s taking and what time she’s taking them at.’ (MMAS-8 score 8, HbA_{1c} 46 mmol/mol).

Theme 2: Barriers

A barrier to medication-taking in the majority of cases was side effects not being discussed, with half of carers not aware of perceived side effects even when high PSM and low MMAS-8 scores were reported. A family carer of a person with intellectual disability and diabetes, lacked insights into the side effects of metformin..

‘...he’s been on the metformin for a year/18 months maybe... I think he realises they are doing him good...cause if he doesn’t take them his blood sugar is sky high.’ (PSM score 22, MMAS-8 score 5)

In a minority of cases ($n = 3$) common side effects were reported by carers of people with an intellectual disability and, if sufficiently intolerable, medicines were reviewed and PSM scores lowered.

‘... he was having diarrhoea...and we took that information back to the doctor and obviously, they changed his medication.’ (PSM score 9, MMAS-8 score 8).

This suggests that, infrequently, carers of people with intellectual disability and diabetes took appropriate action by shifting care back to the healthcare professional for a review of medications.

Discussion

As far as the authors are aware, this is the first study to compare the characteristics of diabetes medication-taking in

adults with and without intellectual disability and has provided a preliminary insight into the frequency of medication-taking and associated factors in this vulnerable group living with diabetes.

The findings suggest that people with intellectual disability and diabetes have similar rates of medication-taking to those without intellectual disability. This finding was corroborated in stage 2 when carers of people with intellectual disability optimized medication-taking using verbal reminders, persuasion and professional support. Moreover, carers were cognisant of the impact that depressive symptoms had on medication-taking, with those with high levels of anxiety or depression having support increased. Although the link between mood and adherence has been inferred previously in the intellectual disability literature [22], this is the first study to describe how carers facilitate medication-taking in people with depressive symptoms and intellectual disability. Carer support may explain similar rates of medication-taking in the two groups, and frequency of adherence is similar to previous published research [3], but continues to fall short of recommended rates of optimum adherence [2]. Thus, there is a need for further research to establish effective person-centred, evidence-based interventions targeted at optimizing medication-taking in people with intellectual disabilities and diabetes. One area that may warrant further investigation is the impact of side effects on medication-taking in people with intellectual disability.

In the present study in people with intellectual disability and diabetes, the PSM scores were higher and, in responses to the MMAS-8, reports of feeling worse after taking medicines in were noted. Associations between side effects and medication-taking have previously been reported in people with diabetes [9], but evidence of the influence in people with intellectual disability and diabetes is novel. Comparing number of medicines prescribed in the intellectual disability group with that in the non-intellectual disability group revealed no difference, suggesting type, rather than number, account for higher PSM scores in people with intellectual disability and diabetes. Significantly fewer people with intellectual disability and type 2 diabetes were prescribed insulin. As an alternative they were prescribed oral hypoglycaemic medication, known to have significant gastric side effects [23] and a negative impact on medication-taking [9]. That said, insulin treatment carries the risk of hypoglycaemia, a serious, potentially fatal and avoidable complication of diabetes [24] and links between hypoglycaemia, cognitive impairment and dementia have also been reported [25]. Furthermore, a qualitative study of 29 healthcare providers caring for people with intellectual disability and diabetes expressed concern about hypoglycaemia and effective support for insulin management, citing them as barriers to commencing insulin in people with intellectual disability [26]. Intensifying treatment from twice-daily oral therapy to a minimum of three-times-daily insulin therapy may also affect a person’s quality of life as a result of

increased support, loss of independence and confidence [27]. Therefore, the lower rates of insulin-prescribing in people with intellectual disability and type 2 diabetes may be a pragmatic choice made with people with intellectual disabilities.

Although well-meaning, decisions not to prescribe insulin may reduce the opportunity for optimum glycaemic control, increasing risk of long-term diabetes complications in people with intellectual disabilities [28]. The present study suggests that, with support, people with intellectual disability and diabetes may achieve similar rates of medication-taking to those without intellectual disability. Given the higher rates of hospitalization, shorter life expectancy and poorer overall health among people with intellectual disability [29], it may be advisable to discuss the suitability of insulin therapy with these individuals and their carers. Although the sample size was small, the mismatch between people with intellectual disability reporting high perceived side effects and carers' limited awareness of side effects warrants further exploration. Raising awareness in the carer population of pharmacovigilance and the consequences of side effects of diabetes medication-taking may increase prescriber-led medicines review, treatment and dose adjustments. This may reduce perceived side effects and improve medication-taking in people with intellectual disability and diabetes.

The present study has some important limitations, which affect the generalizability of its findings. Identifying eligible participants to attain a sufficiently powered sample of people with intellectual disability was challenging. We attribute this to recruiting from a single health service area, the absence of a database identifying people with intellectual disability and diabetes, and the need for named informants to identify potential participants. Underpowered studies in vulnerable groups are common, and a recent systematic review of 53 studies reported a median sample size of 48 participants with cognitive impairment and only 26% of studies met their target sample size [30]. To optimize participation from people with intellectual disabilities, significant investment is required for multicentre studies, longer recruitment phases and additional resources to support carer and gatekeeper co-participation. A second limitation was the heterogeneous study population which limited between-group comparisons and generalizability. Age and employment differences between people with and without intellectual disability may have been mitigated by utilising case-control methodology. Additionally, recruiting equal numbers of people with and without intellectual disability is a consideration for future research design. Finally, sequencing of stages may also be considered a limitation; however, the chosen mixed-methods design, quantitative before qualitative, obtained an unbiased view of medication-taking. Reversing the stages may have resulted in carers reflecting on their behaviour and adjusting how they supported medication-taking, thus skewing quantitative results.

Despite these limitations, this study is important as it provides new insights into the similarities and differences in medication-taking in people with and without intellectual disability. A further study with a larger sample, longer recruitment period and case-control design, focusing on the predictive value of side effects and medication-taking in people with intellectual disability and diabetes is recommended. In the interim, clinician-led interventions and regular medicines review, with emphasis on exploring side effects, may develop a greater shared understanding between the prescriber, carer and person with intellectual disabilities relating to the risks, benefits and treatment alternatives. This may improve medication-taking and glycaemic control and reduce morbidity and mortality in people with intellectual disability and diabetes.

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Competing interests

None declared.

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