

A survey on service users' perspectives about information and shared decision-making in psychotropic drug prescriptions in people with intellectual disabilities

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Abstract

Background: In people with intellectual disabilities and mental disorders and/or challenging behaviours, rates of psychotropic drug prescription are high. In clinical treatments and evaluations, all stakeholders should be involved in a process of shared decision-making (SDM). We aimed to investigate the perspectives of clients and their carers on clients' treatments with psychotropic drugs.

Methods: We conducted a survey among adults with intellectual disabilities in a Dutch mental healthcare centre providing community, outpatient and inpatient care. Data were collected between January and June 2022. Questions focused on experiences with the provision of information, treatment involvement and SDM and participants' wishes in this regard.

Findings: Respondents (57 clients and 21 carers) were largely satisfied with the overall care from their clinicians, and with how information on the pharmacological treatment was provided verbally, but written information was insufficient or not provided. Seventy per cent of clients and 60% of carers reported being involved in medication decision-making. However, over 75% of participants desired greater involvement in SDM and over 60% in medication reviews.

Conclusions: Service users and representatives were satisfied about the treatment and verbal information on their psychotropic drug use. The provision of written information, the SDM process and ongoing evaluation of psychotropic medication use could be improved.

KEYWORDS

intellectual disability, psychotropic drug prescription, shared decision-making, service users' perspectives, survey

Accessible Summaries

- People with intellectual disabilities are often prescribed medication for mental or behavioural disorders.

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- It is important that healthcare professionals listen to the views of people who are prescribed this medication.
- However, people may not be involved enough when decisions are made about their medication. They might not have enough information about their medication in a way that they understand.

We wanted to know the views of clients with intellectual disability about their psychotropic medication use.

We invited clients, their representatives and paid carers of a specialist mental healthcare centre to take part in a survey.

Questions were about:

- (1) The relationship with their doctor.
- (2) If they were given the right information.
- (3) Involvement in medication evaluations.
- (4) Involvement in decisions regarding their medications.

Seventy-eight service users (57 clients and 21 carers) completed the questionnaire.

Answers were that:

- (1) Service users were satisfied with the overall care from their doctor.
- (2) Service users were satisfied with the information about the prescription of medication that was provided verbally.

They were less satisfied about written information that they received about their psychotropic medication.

- (3) Most service users reported being involved in medication decision-making, but fewer than half were completely satisfied with this.
- (4) Most service users wanted to be more involved in decisions about their medication.

Our findings mean that healthcare professionals need to do more to involve service users with learning disabilities in decisions about their medication.

1 | INTRODUCTION

The prevalence of mental disorders in people with intellectual disabilities varies depending on the diagnostic criteria and the study population. In a meta-analysis of 22 studies, a point prevalence of 33% was found, including behavioural disorders and excluding autism (Mazza et al., 2020). Psychotropic drugs are often prescribed in the treatment of mental disorders. The prevalence of psychotropic drug use among people with intellectual disabilities varies from 38% to 90%, depending on the setting and the study population. The prevalence of psychotropic use increases with age (García-Domínguez et al., 2022; Koch et al., 2012; Perry et al., 2018); roughly one in five younger people with intellectual disabilities are prescribed one or more psychotropic drugs (Sullivan & Sadeh, 2015), with the figure rising to 6 in 10 older adults (O'Dwyer et al., 2017). In general, the prevalence is higher in residential facilities than in community populations. Much recent attention has fallen on the long-term prescribing of psychotropic drugs for challenging behaviours in the absence of a psychiatric disorder, as their effectiveness

for this indication has not been proven (Deutsch & Burket, 2021), and psychosocial strategies and environmental modifications are recommended as first-line interventions. Moreover, people with intellectual disabilities appear more vulnerable to adverse side effects of psychotropic drugs. Metabolic side effects like diabetes and obesity are common. Due to health inequalities resulting from social barriers to adhere to a healthy lifestyle, and genetic factors like Down syndrome, people with intellectual disability are at higher risk for these side effects (de Kuijper et al., 2019). Also, they are exposed to increased risks for neurological side effects like movement disorders (Sheehan et al., 2017). Therefore, careful consideration of the advantages and disadvantages of psychotropic drug prescription is necessary, respecting the clients' perspectives in a process of shared decision-making (SDM).

Over the last two decades, SDM has taken on an important place in medical care. SDM implies involvement of two parties, that is, the patient and the healthcare practitioner, who share information on the health issue. Agreement on the treatment plan implies the weighing of all perspectives at the issue, with equal prominence being given to

the medical and scientific expertise of the clinician and the lived experience and goals of the patient (Charles et al., 1997; Stevenson et al., 2000). There may be additional challenges to practicing SDM with people with intellectual disability; for example, it is necessary that the clinician's explanation and communication on the issue is adapted to the client's understanding, and all information materials are accessible. In many countries, SDM in intellectual disability healthcare is not yet commonplace. A recent study (Horner-Johnson et al., 2022) on contraceptive decision-making among women with various disabilities aged 18–45 years identified several barriers to SDM, with inaccessible information and limited opportunities for SDM mentioned especially in women with intellectual disability.

In another study, the provision of information on health issues by GPs and nurses during health check consultations with clients with intellectual disability was observed (Chinn & Homeyard, 2017). Although the participating professionals were experienced in working with people with intellectual disabilities, they often did not communicate in an understandable way. Moreover, even though they knew that accessible information was available, they often did not utilise these materials or used them inappropriately.

Generally, depending on the client's wishes and abilities, relatives and/or paid carers are also involved in SDM. Webb et al. (2020) investigated experiences of service users with intellectual disability and mental health problems in this so-called supported decision-making. Service users indicated that their difficulties in SDM were related to the treatment options, the kind and outcomes of the decision and the roles of significant others in decision-making. They needed practical support, including accessible information, emotional support of peers, families and professionals and enough time to think about the decision. They had negative experiences regarding not being involved in treatment decisions, especially those regarding pharmacological treatments. On the other hand, they stated that medication use and/or severe mental illness could hinder their capabilities regarding SDM (Webb et al., 2020). Several studies have shown that clients with intellectual disability, their families and/or paid carers are insufficiently informed on the effects and potential side effects of their medication (Crossley & Withers, 2009; Fish et al., 2017; Huneke et al., 2012; Sheehan et al., 2018). Another study on service users' experiences with specialist mental healthcare showed that especially black service users with intellectual disability indicated that they were not satisfied with their pharmacological treatments; they were not heard in medication decisions and not involved in treatments (Bonell et al., 2012). Service users, their families and paid carers often feel insufficiently involved in treatment decisions of mental disorders, including psychotropic drug prescribing (Sheehan et al., 2019). Yet, studies investigating service users' and their representatives' wishes regarding drug treatments revealed that they would like to contribute their experiences and views on treatments and be involved in decision-making (de Kuijper et al., 2023; Sheehan et al., 2019; Smith et al., 2019).

With the present study, we aimed to add to the body of knowledge regarding service users' views on their psychotropic drug

treatments and find starting points for improvement in SDM and authentic involvement in treatment decisions. We investigated the experiences and wishes of clients, their representatives and paid carers on the pharmacological treatment clients received from a leading intellectual disability specialist mental healthcare centre in the north-east region of the Netherlands. The focus was on the information that clients, their caregivers and representatives had received about clients' prescribed medication, their involvement in treatment decisions and monitoring and their satisfaction with the extent to which they were involved in decisions.

2 | METHODS

2.1 | Design, participants and setting

We conducted a cross-sectional survey among adult clients with intellectual disability of a regional specialised mental healthcare centre, providing community, outpatient and inpatient care in the north-east region of the Netherlands, who were prescribed psychotropic drugs, and among their paid carers and representatives. Outpatients of the centre living on their own receive their pharmaceutical care from community pharmacy, and those outpatients in living facilities of service providers and inpatients receive their pharmaceutical care from hospital pharmacy. Those who receive pharmaceutical care by hospital pharmacy are supported in medication adherence by the provision of information materials to paid carers. Here, a pharmacist is also available for annual medication evaluations and questions from prescribers. The study is the first step in a project 'SDM in medication use', which aims to increase clients' and/or representatives' involvement in pharmacological treatments and SDM in intellectual disability mental healthcare (UMCG research register number 2021100684). The delivery of this project is monitored and evaluated by a project group consisting of the researchers, nurses, a behavioural scientist, a psychiatrist, a pharmacist, a parent and a mentor.

2.2 | Ethics and consent statement

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation, that is, Dutch legal Acts, Data protection rules and Codes of conduct, and with the Helsinki Declaration of 1975, as revised in 2008. All procedures were approved by the medical Ethics Review Board of the University Medical Centre Groningen (METc 2021/591) and judged as not a clinical research project with human subjects.

Written informed consent was obtained from all subjects. In case a client lacked capacity to consent, their legal representative provided informed consent in line with the specific legislation in the Netherlands.

2.3 | Procedures

Recruitment took place by sending an information letter to all receiving care from the service who were prescribed psychotropics at the reference date of 25 October 2021. In case a client had a legal representative, the letter was sent to them. In the Netherlands, a legal representative, e.g., a family member or an independent (healthcare) professional, is appointed when a person with intellectual disability is not able to represent their own interests regarding health and/or social matters. The letter and all other materials for the clients were presented in an accessible (easy read) format developed in consultation with the project group. The letter consisted of information about the whole project 'SDM in medication use' and specific information about the survey and the questionnaire that a participant should complete. Clients and legal representatives were invited to participate in the survey and send their informed consent.

Clients and legal representatives were also asked permission to send an invitation for participation in the survey to clients' paid carers. In case legal representatives judged that the client they represented was competent in this respect, this client was also sent the information letter and invited to participate. In case there was no legal representative, clients themselves could suggest a representative to invite for participation.

When clients and legal representatives consented to contact the support professional or nonlegal representative (when applicable), these persons were also sent the information and invitation letter by mail and requested to send back their informed consent when they were willing to participate in the survey.

All potential participants could call or email the research assistant when they needed explanation or more information about the project and questionnaire.

Participants who had sent their informed consent received a letter with a request to complete the questionnaire online (by providing a QR code to the questionnaire) or on paper. Letters were sent between 27 January 2022 and 16 June 2022. A reminder letter was sent after three to 6 weeks in the event that the questionnaire was not returned.

2.4 | Measures

We developed three similar questionnaires for the three groups of participants, based on the literature (Campbell, 2012; Crossley & Withers, 2009; Fish et al., 2017; Sheehan et al., 2019). Drafts were reviewed by the project group and discussed and adapted during meetings of the project group and researchers.

Respondents were asked to evaluate their experiences of being given information on the psychotropics that they were prescribed, their satisfaction with this information, their satisfaction on their involvement in treatment decisions and of the effect of the medication that they were prescribed. We also asked about their wishes regarding their involvement in treatment decisions and medication monitoring.

Each question was rated on a Likert scale between 1 (*totally disagree*) and 5 (*totally agree*). For the clients, the questionnaire was provided in an accessible manner using easy-to-read language, emoji faces and colours. Respondents were able to add comments to some questions in open text fields. Hard copy or electronic versions of questionnaires could be completed by multiple respondents regarding the same client (i.e., client with intellectual disability and/or paid carer and/or representative).

Participants with intellectual disability could complete the questionnaire along with their paid carers, if they wished.

2.5 | Data collection

Data were collected on demographic variables, psychotropic drug use, experiences regarding the content and process of providing information of this medication (e.g., reason for prescription, administration, dose, side effects, warnings, written information), the quality of contact with their doctor, the perceived effect of the medication and engagement in decision-making/SDM, including asking consent for the prescribing and wishes concerning SDM. Furthermore, the opinion of paid carers and representatives about clients' advocacy in treatments was asked.

2.6 | Statistical analyses

SPSS version 26 was used to analyse data. We calculated frequencies of demographic categorical variables by participant group, categories of medication use and scores on Likert scales. We summed the scores of Likert scales for the eight questions about the providing of information and computed the means and SDs by participant group.

3 | RESULTS

3.1 | Respondents

All 196 eligible clients were invited to take part, of whom 57 (29%) gave informed consent to participate in the study. Of the invited 61 legal and invited representatives, 13 (21%) participated. Nine (38%) of the 24 paid carers who were invited by their client or the legal representative of their client returned questionnaires. Two paid carers completed a questionnaire about their participating client and two representatives about one participating client. Figure 1 shows the flow of participants through the study.

3.2 | Demographic characteristics

Table 1 shows the demographic characteristics of the three groups of participants.

Of the clients who responded, more than half indicated that they had legal representatives, that is, a mentor, a representative who is

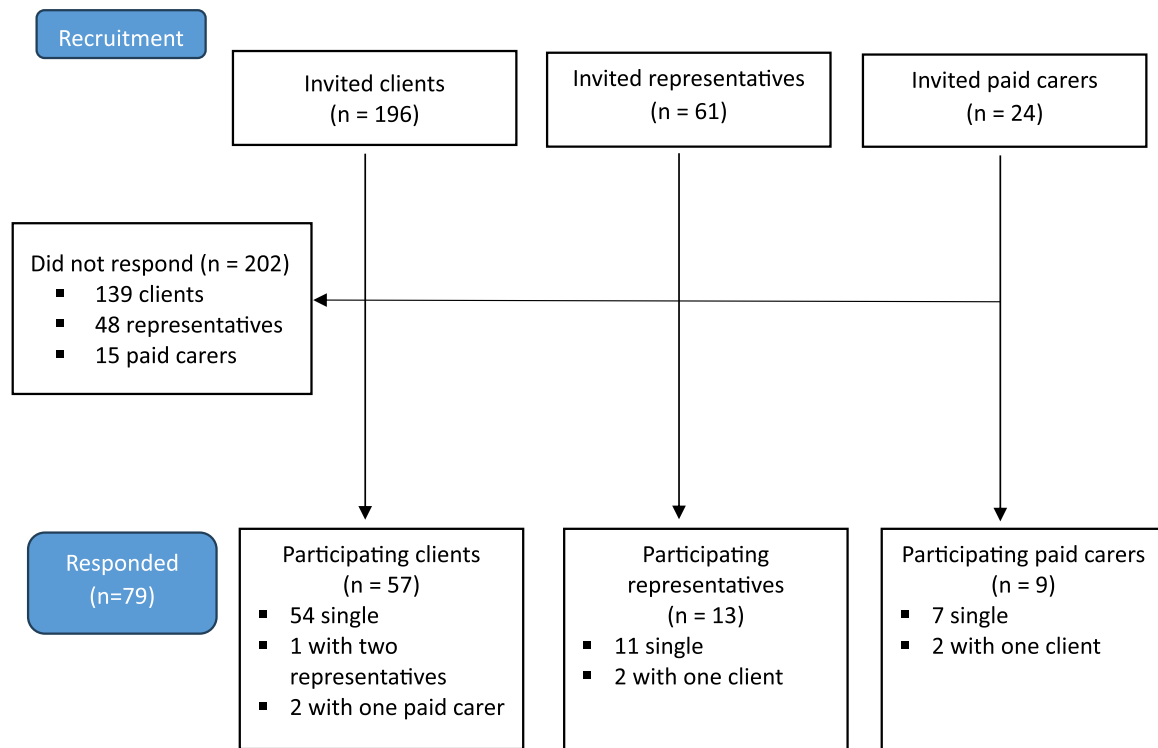


FIGURE 1 Flow diagram of participants. [Color figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/bhd.12823)]

legally appointed when a person is not competent to represent their own interests and/or to decide in health and/or social matters, or a curator, a representative who is legally appointed when a person is not competent to represent their own interests and/or to decide in financial matters, or a legal administrator, a representative who is legally appointed when a person is not competent to represent their own interests and/or to decide in health, social and financial matters. Because a person should request that a legal representative is appointed to advocate their interests, it may happen that, although a person is not competent in health, social and/or financial matters, there is no legal representative. In that case, a parent, adult child, partner, brother or sister may take this position.

There were no data on the level of intellectual functioning of the 57 clients who were competent to complete the questionnaires by themselves. Forty percent of the 13 responding representatives indicated that they represented a client with a mild intellectual disability, 23% a client with a moderate intellectual disability, and 8% a client with a severe intellectual disability.

3.3 | Psychotropic drug use

Three of the participating clients had recently stopped their psychotropic drug. Of the remaining 54 clients, 69% were prescribed antipsychotics, 44% antidepressants, 15% medication for ADHD, 13% mood-stabilisers, 7% short-acting benzodiazepines and 28% middle- or long-acting benzodiazepines. Sixty-nine per cent were prescribed two or more psychotropic drugs. Participants in higher age

groups used multiple psychotropic drugs more often (age group >60 years 100%, age group 41–60 years 95% and age group 18–40 years 55%, $p = 0.008$).

Table 2 shows the use of psychotropics as indicated by the participants with intellectual disability. Participants were asked to provide the name of the drug(s), the reason(s) for prescription and the duration of use. Behavioural symptoms like temper tantrums, irritability, worrying and stress were often mentioned as reasons for use, especially in case of antipsychotic drug use, next to indications such as low mood for antidepressants, anxiety for benzodiazepines and suspiciousness, hearing voices and psychosis for antipsychotics.

Twenty-seven of the 57 participating clients indicated that they managed their own medication, while 22 received help from their caregivers (data not shown). Of the remaining eight clients, two indicated that they would like to manage their own medication, one received digital support and five participants did not respond. The nine participating paid carers indicated that 22% of their clients managed their own medication, and 78% received help from them or family. The 13 representatives indicated that 45% of their represented managed their own medication and 55% received help.

3.4 | Provision of information

The satisfaction regarding the providing of verbal and written information about the type of psychotropics prescribed and its

TABLE 1 Demographic characteristics of the three groups of participants in a survey on psychotropic drug use by individuals with intellectual disability.

Characteristics	Clients (n = 57)	Paid carers (n = 9)	Representatives (n = 13)
Age category (years)			
18–40	33 (59%)	3 (33%)	7 (54%)
41–60	21 (37%)	5 (56%)	5 (39%)
>60	2 (4%)	1 (11%)	1 (7%)
Missing	1		
Gender			
Man	26 (46%)	1 (11%)	4 (31%)
Woman	29 (52%)	8 (89%)	9 (69%)
Other	1 (2%)		
Missing	1		
Representative			
Mentor ^a	13 (23%)		
Curator ^b	4 (7%)		
Legal administrator ^c	14 (25%)		
Other (not legally appointed)	23 (40%)		
Don't know	3 (5%)		
Living situation		Living situation represented client	
Independent living/not supported	3 (5%)		
Independent living/with support of paid carer	23 (40%)		2 (15%)
With family	10 (18%)		3 (23%)
Group home	20 (35%)		8 (62%)
Other	1 (2%)		
Education			
High school qualification		2 (22%)	
Middle-level applied education		4 (45%)	
University of applied sciences		3 (33%)	
Relationship with client			
Partner			2 (15%)
Family member			4 (31%)
Mentor ^a			5 (39%)
Curator ^b			2 (15%)

^aA representative who is legally appointed when a person is not competent to represent their own interests and/or to decide in health and/or social matters.

^bA representative who is legally appointed when a person is not competent to represent their own interests and/or to decide in financial matters.

^cA representative who is legally appointed when a person is not competent to represent their own interests and/or to decide in health, social and financial matters.

reason, the dosage and way of taking this medication, potential side effects and interactions was rated as a total score of the Likert scales of eight questions (range 5–40). The mean score of client responses was 30 (range 8–40, SD = 7.7), that of paid carers was 32 (range 15–39, SD = 7.9) and that of representatives was 31 (range 9–40,

SD = 10.1). In all groups, the ratings were highest for verbal explanation and lowest for the availability of written information. In all groups, more than half (55%–85% of respondents) rated the highest (5) with the contact and accessibility of the prescribing doctor.

TABLE 2 Psychotropic drug use as indicated by participants with intellectual disability ($n = 54$).

Kind of psychotropic drug	AP ($n = 37$)	AD ($n = 24$)	ADHD ($n = 8$)	MS ($n = 7$)	BS ($n = 4$)	BL ($n = 17$)
Reason for use is known.						
Yes	34 (92%)	23 (96%)	7 (88%)	6 (86%)	4 (100%)	15 (88%)
No	3 (8%)	1 (4%)	1 (12%)	1 (14%)		2 (12%)
Duration of use (year)						
<1	1 (3%)	4 (16%)	1 (17%)	1 (14%)	1 (50%)	
1–5	16 (50%)	6 (24%)	2 (33%)	2 (29%)	1 (50%)	8 (47%)
5–10	5 (16%)	3 (12%)	1 (17%)	1 (14%)		3 (18%)
>10	6 (19%)	7 (28%)	2 (33%)	2 (29%)		4 (23%)
Unknown	3 (9%)	4 (16%)		1 (14%)		2 (12%)
Missing	6		2		2	

Abbreviations: AD, antidepressants; ADHD, medication for ADHD; AP, antipsychotics; BL, benzodiazepine (middle)/long-acting; BS, benzodiazepine short-acting; MS, mood-stabilisers and anti-epileptics.

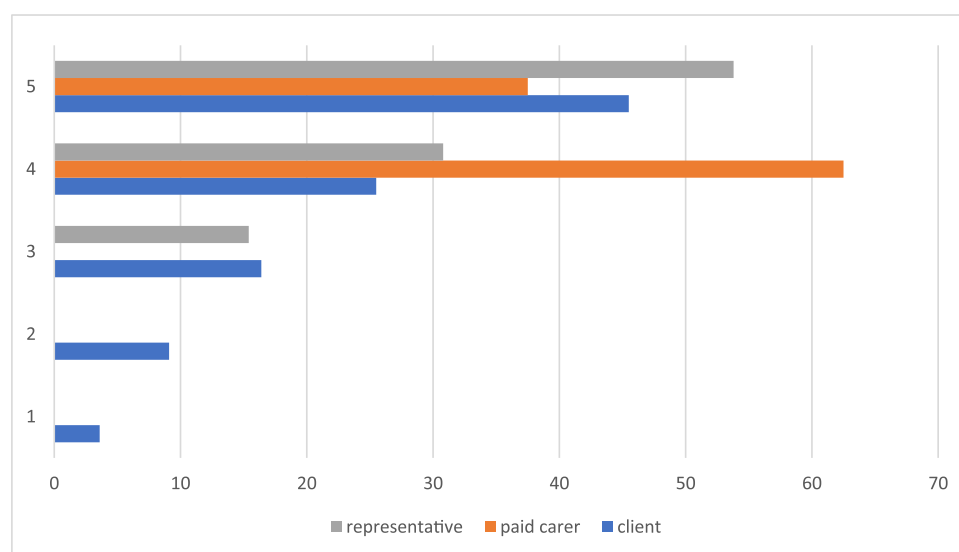


FIGURE 2 Satisfaction about the effect of psychotropic drugs on symptoms of mental or behavioural disorders of individuals with intellectual disability rated at Likert scales (score 1–5 = completely dissatisfied–completely satisfied) according to participants in a survey among adult clients of a specialised mental healthcare centre. [Color figure can be viewed at wileyonlinelibrary.com]

3.5 | Experiences and wishes regarding treatment and decision-making

Many participants, that is, 56% of clients, 56% of paid carers and 44% of representatives, reported that they were not informed about or did not receive consultations to evaluate the effect of their medication or to monitor adverse side effects. Yet, 55% of clients and paid carers, and 90% of representatives stressed the importance of such an evaluation by rating the highest agreement at Likert scales regarding statements on this issue. None of the participants disagreed with those statements. Other findings were that 70% of clients were asked to consent to the prescription of their psychotropic, 13% were not and 17% did not know. Of the legal representatives, these figures were 61%, 8% and 31%, respectively.

Figure 2 shows the satisfaction with the effect of the prescribed medication on clients' symptoms among the three groups of participants. Overall, clients were less satisfied with the effect of their medication than either their representatives or paid carers.

Figure 3 shows the satisfaction and wishes (Figure 3a) with involvement in decision-making regarding psychotropic drug prescription for the three groups of participants and the significant people who should be involved in decision-making according to participants' opinions (Figure 3b).

Finally, we asked the views of paid carers and representatives regarding their roles and tasks in advocacy for individuals with intellectual disability receiving mental healthcare. Paid carers and representatives indicated their own role as most important, but half

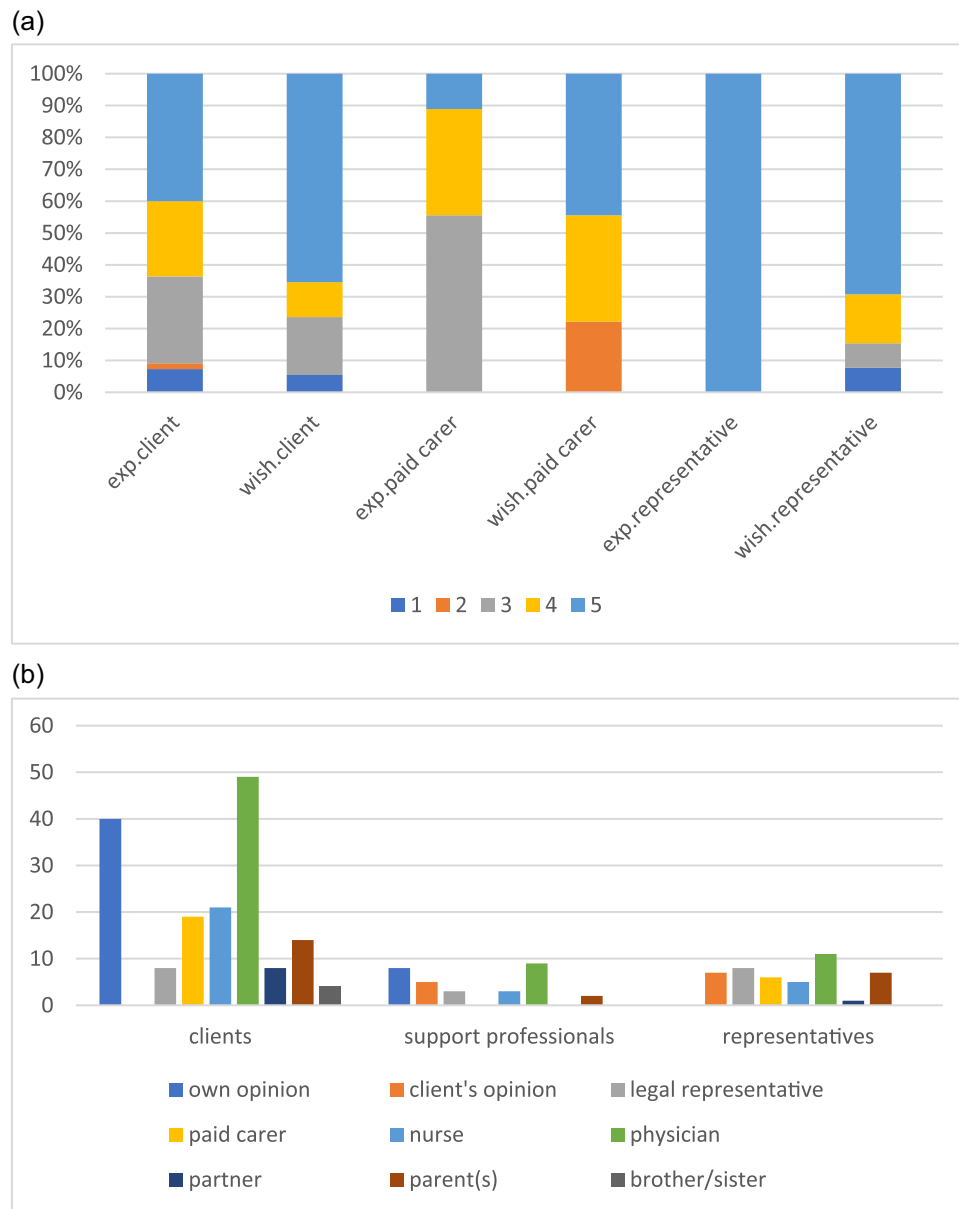


FIGURE 3 Shared decision-making (SDM) in psychotropic drug prescribing to clients with intellectual disability of a specialised mental healthcare centre. (a) Experienced and desired SDM rated at Likert scales (1–5 = completely not-completely involved) of clients with intellectual disability ($n = 55$), paid carers ($n = 9$) and representatives ($n = 13$; 10 missing in experienced SDM). (b) Significant persons who should be involved in SDM in psychotropic drug prescribing according to clients with intellectual disability ($n = 53$), support professionals ($n = 9$) and representatives ($n = 13$). [Color figure can be viewed at wileyonlinelibrary.com]

of them indicated that physicians and representatives/paid carers were also responsible.

4 | DISCUSSION

In this study in a community, outpatient and inpatient specialised mental healthcare provider, we investigated the experiences and wishes of adults with intellectual disabilities, their paid carers and representatives regarding their involvement in treatments with psychotropic drugs. We found that participants in all three of these

groups were satisfied about the verbal information that they had been provided about their psychotropic drug prescriptions, but less satisfied about the written information, which was often lacking and/or not accessible for clients with intellectual disabilities. Also, participants appreciated the contact with their doctor in the consultation. The results of our study show that intellectual disability physicians and psychiatrists affiliated to this Dutch specialised mental healthcare centre are capable in communicating the 'why, what, how and when' of the psychotropics drugs that they prescribe and in responding to questions about the medication use of their clients. This finding is in line with the findings and recommendations of a

qualitative study on views of clients and staff of intellectual disability service providers on the quality of mental health services (Kroese et al., 2013). Here, service users and support staff indicated that mental healthcare service providers should ensure that their staff demonstrate genuine interest in their clients, should have knowledge on issues related to having an intellectual disability and should be trained in communicating with them. Therefore, as compared to previous studies, our results may be encouraging.

Previous studies showed that people with intellectual disabilities are often not well informed about their medication use, do not receive or understand the explanation of their prescribing physicians and lack accessible written information (Crossley & Withers, 2009; Fish et al., 2017; Huneke et al., 2012). Our results indicate that provision of mental healthcare by a specialist mental healthcare centre with trained personnel is a good way to address these shortcomings. However, our results also show that the provision of written information could be improved. However, even when accessible leaflets on psychotropics are provided, the content may be confusing for people with intellectual disabilities (Strydom & Hall, 2001). In addition, a personal approach and verbal explanation from client's carers, nurse or doctor are recommended in helping people with intellectual disability understand their healthcare interventions (Chinn & Homeyard, 2017).

About half of the clients who responded indicated that they managed their own medication; for clients of responding paid carers, this figure was about one-fifth and for clients of responding representatives, this was about half. Unfortunately, we have no data on medication adherence and errors, so we cannot discuss or compare these findings. Yet, studies have shown that people with intellectual disabilities living at home were more likely to have lower adherence (Resciniti et al., 2022) and that education and accessible materials may increase the medication self-management capacities (Sheerin et al., 2021). The educational and information materials that we use in the overall project 'SDM in medication use' will likely contribute to improvement of medication self-management capacities and the quality of support from their caregivers and pharmacists in medication adherence of consumers with intellectual disabilities.

Antipsychotics were the most frequently prescribed kind of psychotropic drugs. A lot of clients reported that they used their antipsychotic for behavioural symptoms. We did not access client medical records to confirm their responses and therefore cannot be sure whether these were also the prescribers' reasons. Yet, this may be a point of concern since off-label prescription is discouraged because of lack of evidence for the effectiveness in this indication and the increased risks for side effects (National Institute for Health and Care Excellence NICE, 2015).

4.1 | Evaluation and monitoring

We also asked about the experiences of participants with the evaluation and monitoring of the effects of the prescribed psychotropics. More than half of the participants reported that they were

not informed about the evaluation and monitoring of the medication use, while more than half of the clients and paid carers and most representatives stressed the importance of such evaluations. Previous studies showed that in UK prescribing practice, the overall quality was sufficient, although the monitoring and treatment of side effects could be improved (Paton et al., 2011). Another study showed that in Dutch specialised mental healthcare settings, medication monitoring was insufficient (Ramerman et al., 2017). Therefore, assuring the evaluation and monitoring of effects of pharmacological treatments should be a starting point for improvement in quality of services and SDM.

Most participants were satisfied with the effect of the prescribed psychotropic on their symptoms. However, overall, clients were less satisfied than paid carers and representatives. This finding may be somewhat challenging since we do not have data to explain this difference. Perhaps clients have other preferences in pharmacological treatment outcomes but are not well heard in decisions on ongoing medication use. Also, carers may have asked for medication and persuaded their clients to agree with the medication use. These suggestions may fit with the review of Kohn and Blumenthal (2014), in which the process and outcomes of supported decision-making were critically assessed (Kohn & Blumenthal, 2014). They found little empirical research about the conditions for a good-quality SDM process and stated that the process and outcomes are likely influenced by legal representatives and/or other significant others. Indeed, we found that although most participants felt that primarily the client and the prescribing physician are the most important persons in the decision-making process, also significant others, for example, mentor, family and paid carers, were important in SDM. Moreover, most clients valued their own opinions next to their doctors' as most important in SDM, in contrast with support professionals and representatives, who valued clients' opinions as equally or less important than those of significant others in SDM (Figure 3b). Therefore, doctors asking the client's opinions about the wanted and unwanted effects of the prescribed medication during medication reviews may be another starting point for improvement in SDM. The great satisfaction of caregivers and paid carers with the effect of the prescribed psychotropic drugs may also be related to the positive expectations on the effect of these drugs on the behaviours of their relatives/clients (de Kuijper & van der Putten, 2017). Although guidelines recommend discontinuing the use in this indication, withdrawal attempts may be difficult, for example, because of the reluctance of caregivers. Initiatives like 'Stopping the over-medication of people with an intellectual disability, autism or both' (STOMP) in England may be helpful to reduce over-medication with psychotropic drugs for behaviours that challenge (Branford et al., 2019). In the STOMP project, involvement of all stakeholders in decisions on psychotropic drug use is strongly recommended, so also the opinions of clients themselves should be heard and accounted for.

Other facilitating factors in improvement of SDM are enhancing the health literacy and health self-advocacy of people with intellectual disabilities. This may improve the health information

exchange between doctors and patients, which is necessary in evaluations of medication use and SDM in treatments of mental and behavioural disorders. Good communication skills of both parties are also needed to guarantee that all health information is sufficiently exchanged (Mastebroek et al., 2014). In their interview study among people with intellectual disabilities, paid carers and representatives, Mastebroek et al. (2016) found that the mediating role of carers and good-quality doctor–patient communication were the main factors in the exchange of health information (Mastebroek et al., 2016).

4.2 | SDM

Our results show that participants would like more involvement in SDM on psychotropic drug treatments than they had received. Given the finding that participants were generally satisfied with the verbal information that they were provided with and the contact with their prescribers was of good quality, this gap may lie in the lack of accessible written information and regular structured medication monitoring and reviews, which also provide the opportunity to exchange information about treatment as part of an ongoing dialogue. Indeed, studies have revealed that monitoring and discussing the effects of medication, the providing of accessible materials and information meetings likely increase clients' capacities in SDM regarding pharmacological treatments, including giving informed consent (Ferguson & Murphy, 2014; Huneke et al., 2012; Sheerin et al., 2021). Furthermore, a good relationship with their doctor and emotional support from family members, friend, peers, support staff and care professionals may enhance a client's capacity in SDM (Webb et al., 2020)

4.3 | Limitations

Our study had some limitations. First, the response rate in this survey was low and the sample size (especially the participant groups of paid carers and representatives) was small. Therefore, the participants in this study may not represent all the clients with intellectual disability and their caregivers of this specialised mental healthcare provider. For example, there was just one representative of a person with a severe ID who participated in the study. Also, there were just two participants aged 60 years and over. Unfortunately, we have no data on the mean age or percentages of age groups of all the service users of the mental healthcare centre, so we cannot say anything about the response rate in this age group. However, in the Netherlands, most elderly with intellectual disabilities live in institutions and receive care from intellectual disability physicians and behavioural professionals, and often a consultant psychiatrist. In general, their clinicians will not refer to a specialist mental healthcare centre. Furthermore, in the Netherlands, the average age at death of people with intellectual disability is approximately 65 years. Therefore, these two factors may be an explanation for the very small percentage of elderly participants in our study. Recruitment in the field of intellectual disability research may be

difficult, and our sample size is comparable with other such studies, for example, Horner-Johnson et al. (2022), Webb et al. (2020) and Bonell et al. (2012). Second, the study took place in a single regional specialised mental healthcare centre. Therefore, the results of this study are likely not generalisable to other settings. Another limitation is that we used newly developed questionnaires and do not know the psychometric properties of these instruments.

Future studies could further investigate SDM processes in a wider range of treatment decisions relevant to people with intellectual disability and provide recommendations on aligning the decision-making ability that is offered with that which is desired by patients.

5 | CONCLUSIONS

Clients with intellectual disability, their paid carers and representatives appreciate being involved in decisions about psychotropic drug treatments. Services from a specialist mental healthcare centre may be of benefit in this regard; staff should be well trained and have knowledge about the communication needs of this group of clients.

Starting points for improvement in SDM in decisions about psychotropic medication are the consistent provision of accessible written information, assuring structured medication evaluations and involvement of clients themselves in discussions about their pharmacological treatments in a way that is meaningful.

AUTHOR CONTRIBUTIONS

Gerda de Kuijper was responsible for the conception of the work and design, analyses and interpretation of data, and the drafting and finalising of the work. Josien Jonker was responsible for the conception of the work and design and acquisition of the data, and critically revision of the draft and agreed for submission and publication. Rory Sheehan was responsible for critically revising the draught and agreed for submission and publication. Angela Hassiotis was responsible for critically revising the draught and agreed for submission and publication.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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