Perceptions of support staff with respect to discontinuation of long-term used antipsychotics for residential individuals with intellectual disability; a mixed method study

Student:	B. Kleijwegt, 3952096
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Lecturer:	Dr. Harmieke van Os-Medendorp
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Utrecht University, Master Clinical Health Sciences,
Nursing Science, UMC Utrecht

1. Introduction

Antipsychotics are the most used psychotropic drugs by individuals with intellectual disability (ID) in residential facilities.[1–4] A large American study showed that 45% of adults with ID used antipsychotics.[5] In the Netherlands the prevalence of use of antipsychotics in residential care for individuals with ID is estimated at 32%.[2]

Antipsychotics can have neurological, metabolic, cardiovascular, haematological, gastro-intestinal and sexo-urinary side effects.[2,6,7]

Antipsychotics are used for registered indications as schizophrenia and psychotic episodes in persons with ID, but also for behavioural symptoms without psychotic components, such as aggression or automutilation. This is called off-label use.[8] A recent study showed that 58% of the residential individuals with ID on antipsychotics used this for behavioural problems (also referred to as challenging behaviour (CB)) without psychotic components. This same study revealed that 78% of these residential individuals with ID used antipsychotics for more than ten years.[2]

CB can be defined as “culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities”.[9] Although antipsychotics are frequently prescribed for persons with ID with CB, its efficacy is questioned. A Cochrane review concluded on the basis of three randomized controlled trials, that there is no evidence, that antipsychotics are helpful for adults with ID in reducing CB.[10]

Given the limited evidence on the efficacy of antipsychotic medication for CB in persons with ID, in combination with the (sometimes serious) side effects, the possibilities for discontinuation are discussed in the scientific literature. A recent study showed it was possible to discontinue antipsychotics in 44% of residential persons with ID.[11] Twelve weeks after discontinuation 84 % of this group was still not taking antipsychotics. From the individuals with ID who did not achieve complete discontinuation the mean daily dose was reduced between 15% and 20%.[11] Behavioural functioning measured with the aberrant behaviour checklist[12] overall improved. The measurement of individual target behaviour with visual analogue scale showed worsening at the point of withdrawal or maximum dose reduction, returning to baseline at follow up. In the same study the effects from discontinuation or reduction of antipsychotics resulted in a decrease of weight, waist circumference, BMI and systolic blood pressure.[13]

In order to effectively discontinue or reduce antipsychotics, the cooperation of the professionals who are providing daily care and support of persons with ID (support staff)

is important. The support staff can observe and report signals from persons with ID on which decisions will be based whether or not to start or continue the process of reducing antipsychotics. They are also the first to be confronted with the consequences of the discontinuation in terms of symptomatic deterioration or behavioural disturbances.

From clinical experience it is known that the topic of discontinuation or reduction of psychotropic medication calls for restraint, concern or fear in support staff. However, more specific knowledge about the perceptions of support staff with respect to discontinuation of antipsychotic medication is lacking in the scientific literature. Some older studies are conducted on perceptions of support staff concerning the use of psychotropic medication in general in persons with ID.[14–16] None of these studies were directed specifically at discontinuation of antipsychotics.

Given the central position of support staff in caring for clients with ID, insights into their perceptions concerning discontinuation of antipsychotic medication is crucial. It offers the opportunity to determine in which way these perceptions influence the process of discontinuation of antipsychotics in both positive and negative ways. Based on these insights discussion can take place within their own discipline and the multidisciplinary team about the application of successful strategies for discontinuation of antipsychotics in persons with ID, thus reducing unnecessary exposure of side effects of antipsychotics and retaining client's quality of life.

The aim of this study is to gain insight in the perceptions of support staff about discontinuation of long-term used antipsychotics in residential individuals with ID.

2. Methods

2.1 Design

To investigate the perceptions of support staff regarding discontinuation of antipsychotics in residential persons with ID, an mixed methods design was carried out.[17] The first phase of the study consisted of a qualitative exploration of the perceptions of support staff by means of focus groups. The use of focus groups, as a method of qualitative data collection, is appropriate to gain insight in "attitudes, perceptions and opinions of participants".[18] The group setting offers opportunities for group discussion concerning controversial issues, and hence it has added value over individual interviews.[19] Strength of focus groups is its capacity to discuss matters extensively and to provide insights in the different perspectives of the

members of the focus group.

After inventorying the prevalent perceptions about discontinuing antipsychotics, a survey was developed to quantify these perceptions in a larger sample of support staff members.

Insert figure 1.

2.2 Focus groups

To investigate the perceptions of support staff on discontinuation of antipsychotic medication, four focus groups were conducted at three organisations providing residential care for persons with ID in the Netherlands. Inclusion criteria were that participants had to work as support staff on a ward where over 30% of the clients used antipsychotics. All participants received an information letter and signed an informed consent form.
The number of participants varied from three to nine per focus group. Mean age was 43 years, with a range from nineteen years to 62 years. Working experience varied between two and 32 years, with a mean of sixteen years.

Insert table 1.

Focus groups were conducted based on a topic list. The topic list was constructed based on findings from literature and input of members of an expert group which was composed in preparation for this study. The expert group consisted of an ID physician, a manager of a ward with persons with ID and CB, a senior researcher specialised in anxiety in persons with ID,and a manager of the (para)medical staff and psychologists. The found topics are presented in table 2.

Insert table 2.

The third author of this article (KH), nurse and Master of Nursing Science, moderated all focus groups. He is experienced in moderating focus groups and has extensively worked with persons with ID and CB. The moderator was an outsider for the participants of the focus groups. The focus groups were audio-recorded and transcribed ad verbatim. A thematic analysis according to Braun[20] was conducted, making use of the qualitative software program NVIVO10. The first focus group was coded independently by two researchers (BK,LdJ) and relevant themes were determined. Participants confirmed the themes. The focus groups lasted approximately 1,5 hours.

2.3 Survey

Based on the identified themes and their elaboration, referring to the perceptions of support staff members concerning discontinuation of antipsychotics, an item pool was generated. This item pool was first discussed with the research team and the expert group, making a first selection of items for the survey. Next a first draft of the questionnaire was constructed, with 29 statements to be scored on a 5-point Likert scale. Five professionals, not participating in the actual survey, tested the feasibility of the questionnaire through the method of cognitive reviewing.[21] The definitive questionnaire was distributed, as a paper version or a digital version and is included in appendix 1.

3. Results

3.1 Focus groups

3.1.1 Indications for the use of antipsychotics

Participants of the focus groups described the indications predominantly in terms of behaviour or emotion, and less in terms of the psychiatric diagnosis. The use of antipsychotics is perceived helpful in reducing anxiety, agitation, compulsive behaviour and automutilation in persons with ID.

3.1.2 Reasons for discontinuation

Support staff was motivated to contribute to reducing the dosage of antipsychotics, because they frequently perceive persons with ID as taking too much antipsychotics, causing severe side effects. All kind of side effects were summoned, but emotional indifference was perceived as the most serious one, because of its perceived impact on quality of life. From the idea that all medications have side effects, the overall thesis emerged: “less medication is always better”, whereas serious behavioural deterioration was seen as threshold for discontinuation. Severe medical problems like medication-intoxication or severe fall risk were seen as definite indications for reducing or discontinuation of antipsychotics.

Another reason for discontinuation was that in some persons with ID the indication for antipsychotics was unknown and in their current behaviour there were no need for prolonged use of antipsychotics.

Some participants of the focus groups were aware of the alleged inefficacy of antipsychotics regarding regulation of CB in persons with ID, without psychotic disorders.

Support staff assumed when persons with ID and CB get older, their CB would decrease, therefore considering discontinuation was appropriate.

3.1.3 *Attitude towards discontinuation*

Support staff formulated a general attitude towards discontinuation based on their previous experiences. The participants in the focus groups were in the opinion that, in a few cases, complete discontinuation of antipsychotic medication was possible and that in some of these cases behavioural improvements could be achieved. In a larger part of clients, not complete discontinuation but a substantial reduction of antipsychotic drugs is among the possibilities. The limit of reduction is reached when the occurrence of CB increases. In unstable clients, with persistent CB, reduction of antipsychotics was considered not appropriate.

A few participants explicitly stated that they expected a temporary increase in CB during the period of withdrawal. Some participants were optimistic about the opportunities for reduction and did not see significant risks, while others were cautious because of expected risks for the clients themselves (like an increase in automutilation), risks for other clients or support staff in the facility (e.g. due to an increase of aggressive behaviour).
Some participants considered the discontinuation of antipsychotics as a risk for the person with ID due to expected severe, irreversible behavioural deterioration, even with the original dose of antipsychotics reinstated. They considered this as an insurmountable barrier to experiment with discontinuation of antipsychotics.

3.1.4 Conditions needed for discontinuation

According to the participants antipsychotics were considered effective for reducing overreaction of persons with ID on different stimuli they are confronted with. Therefore an environment with lots of unpredictable or threatening stimuli are perceived as unfavourable for discontinuing antipsychotics. Examples are a too large total amount of support staff the person with ID is confronted with, which makes a clear approach difficult, or too little time support staff can spend with one person to provide support in regulating stressful events and social interactions.

Working with a positive approach, aiming at support instead of control, is seen as a condition which reduces anxiety and stress, leading to decreased prevalence of CB, and therefore increases the possibilities for discontinuation of antipsychotics.

Restraint towards discontinuation is present regarding persons with ID with a history of serious aggression incidents. Knowledge of these incidents originates from own working experience or from the client's files. The perceived intensity of the aggression causes restraint, and also the absence of possibilities to prevent or control this aggression.

Some participants stated explicitly that a thorough plan for the discontinuation of AP would be helpful, while others mentioned topics, which could probably be seen as components of a plan. First, according to participants, the positive outcome(s) that can be achieved by discontinuation or reduction from antipsychotics needs to be clearly formulated. Secondly, before discontinuation starts alternative physical and/or psychological approaches for the management of CB must be investigated, for example in case of pain or stressful interactions with fellow clients. Thirdly, before discontinuation, an assessment needs to be made whether support staff will be able to handle possible (temporary) deterioration. So an elaboration of different ways in which a client could react on discontinuation of antipsychotics is important, accompanied by different intervention strategies. The availability of emergency medication is considered helpful, as is the possibility for support staff to call for support by a professional from outside the team but with knowledge of the client, capable of advising about the most suitable behavioural approach in case of crises. Some participants stated that a person with a more distant perspective could help them look at the behaviour of the client overcoming negative emotions, caused by an increase of CB, like anger or fear.
In a team of support staff it must be clear who communicates with physicians. Otherwise, in case of unclear communication there is a risk of ad hoc decisions, with the risk that more sceptical or fearful co-workers stop or reverse the discontinuation. A client's personal early recognition plan is perceived as an adequate instrument to monitor behavioural changes of clients that might occur during discontinuation of antipsychotics in a diagnostic way.

Participants seemed to regard the physician as the leading discipline in case of discontinuation of antipsychotics. The role of the psychologist was mentioned by participants, but not very prominent. The client's relatives could have a role in stimulating or discouraging discontinuation.

Participants noticed that the opinion of relatives weighed heavily in decisions on whether to reduce antipsychotics or not. Participants expected the same weight for the opinion of a team because they felt that they are the most designated profession to monitor the quality of life of clients and to assess if it is still safe and feasible to handle possible CB of clients in case of discontinuation of antipsychotics. They expressed that this role is not always acknowledged by other professionals, like a physician or a psychologist.

Some participants stated that they have not enough knowledge about phenomena that can occur during discontinuation of antipsychotics. No other knowledge or skills deficits were reported by support staff.

3.2 Survey

3.2.1 Characteristics of survey respondents

A total of 347 surveys was distributed, in three organisations, whereof 141 surveys were returned (41%). Mean age of the respondents was 38 years and mean working experience was 13 years. Seventy percent of the respondents was female. Characteristics of the respondents are presented in Table 3.

Insert Table 3.

3.2.2 Findings of the survey

3.2.2.1 Indications for the use of antipsychotics

Related to the subject of off-label use, a huge majority (78%) felt that they knew whether the clients who used antipsychotics had a diagnosis of a psychotic disorder or not.

3.2.2.2 Reasons for discontinuation

Five percent of the respondents disagreed with the statement that side effects of antipsychotics are very stressful for clients, a large part (48%) neither agreed or disagreed while 47% perceived the side effects as very stressful.

A minority questions the efficacy of antipsychotics, as is shown by twelve percent of the respondents disagreeing with the statement that antipsychotics are effective in controlling CB and 21% of the respondents agreeing with the statement that antipsychotics are used by clients while having almost no benefit.

A large part of the respondents (46%) neither agreed or disagreed on the statement that the dosage of antipsychotics is too high in a considerable part of the clients.

3.2.2.3 Attitude towards discontinuation

A majority of support staff (68%) perceived themselves as motivated to contribute to discontinuation of antipsychotics with a part of the clients.

A minority (22%) considered their own team as too reserved concerning discontinuation of antipsychotics. A large part of the respondents disagreed (41%) with the statement that antipsychotics can be discontinued in a considerable part of the clients, while 35% neither agreed or disagreed and 24% agreed. The reactions to the statement that discontinuation can only be reached in exceptional cases show that 47 percent agreed with this statement, 30percent disagreed and 23% neither agreed or disagreed. Only five percent of the respondents agreed with the statement that more clients should be prescribed antipsychotics. Thirty-nine percent of the respondents agreed with the statement that discontinuation is not possible at their own working place, while 36 percent disagreed. A majority of 68% of the respondents agreed with the statement that the dosage of

antipsychotics can be lowered in a considerable part of the clients.

Almost similar parts agreed (26%) and disagreed (22%) on the statement that discontinuation is a huge risk for clients, while fifty-three percent neither agreed or disagreed. A minority of 27 percent agreed with the statement that decreasing antipsychotics is almost always causing deterioration in clients. Twenty-two percent of the respondents agreed with the statement that the discontinuation of antipsychotics is causing more unsafety than can be justified, while 38% didn't agree.

3.2.2.4 Conditions needed for discontinuation

A majority (55%) of the respondents perceived their contribution is sufficiently taken into account concerning decisions of discontinuation or reduction of AP medication. Two-thirds (67%) agreed with the statement that they can influence decisions whether discontinuation should be prolonged or not in case of safety issues or in case of issues of quality of life of a client (67%). Almost two-third (64%) of the respondents disagreed with the statement that decisions according to discontinuation are taken too unilaterally by a physician.

A large majority (85%) perceived the expertise of the psychologist as indispensable in discontinuation of antipsychotics. A large part (60%) considered consultation from outside the team as necessary. Forty-five percent agreed with the statement that opinions of relatives should weigh heavily concerning decisions of discontinuation, while twelve percent disagreed, leaving 43 percent undecided.

A large majority agreed on the statement that discontinuation needs a clear plan (97%). Ninety-four percent considered scenarios in which the clients can react on discontinuation as supportive.

A large part of the respondents perceived themselves as having sufficient knowledge for taking part in multidisciplinary deliberation (49%), being able to recognize side effects of antipsychotics (67%), and being aware of the possible harmful long-term side effects of antipsychotics (66%). Eighty-two percent perceived themselves as able to determine when to consult a physician concerning side effects and 79 percent felt that they were aware of phenomena that may occur during discontinuation.

Insert table 4.

4. Discussion

Four focus groups were conducted in this mixed methods study, followed by a survey to gain insights in the perception of support staff about discontinuation of antipsychotics regarding residential individuals with ID.

Support staff perceive antipsychotics as effective in decreasing anxiety, automutilation, agitation and aggression. Not all side effects of antipsychotics are perceived as having significant effects in decreasing quality of life. Although support staff perceives themselves as motivated to contribute to discontinuation of antipsychotics there is a clear difference in opinions between the perceptions of complete discontinuation of antipsychotics and reduction of antipsychotics. A larger part of support staff believes that reduction is possible compared to the part that believes that complete discontinuation is possible. It seems like a serious increase in CB is interpreted in a way that the limits of reduction are reached and not as temporary deterioration. A clear plan with a description of responsibilities for all members of the multidisciplinary team is perceived as indispensable. Support staff perceive themselves as able to contribute to multidisciplinary deliberation about discontinuation of antipsychotics, as having enough knowledge of (long-term) side effects, knowing when to consult a physician regarding side effects and aware of phenomena that could occur during discontinuation.

This is the first study directed at perceptions of support staff about discontinuation of antipsychotics in persons with ID. Striking about the results is that the support staff perceive antipsychotics are effective in reducing CB and there is no expectation that discontinuation will be successful in a considerable part of the clients but that they are also willing to contribute to discontinuation of antipsychotics in general. Perhaps support staff is motivated to contribute to discontinuation of antipsychotics because of the expectation that the dosage can be decreased in a considerable group of clients and that a lower dosage is a positive result because of less side effects (in particular emotional indifference) leading to an improved quality of life.

Two-thirds of the respondents judged their knowledge and skills concerning antipsychotics, side effects and phenomena regarding discontinuation as sufficient. This is not in line with the outcomes of a small study[22] aiming at identification of staff (n=25) knowledge of antipsychotics and their associated side effects. In this study a small majority was only able to identify three or less potential side effects and only a minority of staff respondents felt that they had sufficient information on antipsychotic medication and side effects. Also in a study about knowledge of antipsychotic medication and side effects in

nursing homes a lack of knowledge was found on direct care staff.[23]

Outcomes of focus groups and survey showed that a large majority of support staff believed that a thorough plan is supportive, just like having an idea in the ways in which the client can react on discontinuation of antipsychotics. An explicit methodical plan of the discontinuation is recommended, to strengthen the efforts of the multidisciplinary team regarding discontinuation of antipsychotics. In order to create tailor-made plans, matching with the needs of the client and procedures of the multidisciplinary teams a decision guide must be developed. This decision guide must address the expected gain, a screening on physical problems causing CB, options to optimize the behavioural approach of the client, and an assessment whether the team has the capacity to cope with possible deterioration. An overview of the expected ways the client can possibly react and matching intervention strategies for support staff, the availability of emergency medication and the opportunity to call for support should be addressed by the decision guide as well. Furthermore arrangements must be made with the team of support staff if they need help by holding proper perspective, in which way behaviour of the client, safety and quality of life of the client and safety of support staff are monitored. Also a time limit must be determined to distinguish possible temporary behavioural deterioration from permanent deterioration.

Strength of this study is the combined approach of focus groups and survey, in which the combination of qualitative and quantitative data contributes to a better understanding of the perception of support staff regarding discontinuation of antipsychotics. Another strength of this study is that data collection through focus groups and questionnaires took place in three organisations, which increases generalisability.

The impact of side effects on clients is an important factor in the consideration whether to reduce or discontinue antipsychotics. Limitation of this study is that survey questions only asked about side effects in general and not about specific side effects. Another limitation is that the perceived knowledge of side effects could not be compared with actual knowledge of side effects.

Further research is needed about the impact of different side effects of antipsychotics on persons with ID (according to persons with ID themselves or by proxy) on quality of life and compare this with the perceptions of support staff about the impact of side effects on quality of life. In case of discrepancies, targeted education can be deployed.

References

1. Tsiouris J, Kim S-Y, Brown W, Pettinger J, Cohen I. Prevalence of Psychotropic Drug Use in Adults with Intellectual Disability: Positive and Negative Findings from a Large Scale Study... [corrected][published erratum appears in J AUTISM DEV DISORD 2013 Mar; 43(3): 732]. J Autism Dev Disord. 2013;43(3):719–31.

2. De Kuijper G, Hoekstra P, Visser F, et al. Use of Antipsychotic Drugs in Individuals with Intellectual Disability (ID) in the Netherlands: Prevalence and Reasons for Prescription. J Intellect Disabil Res. 2010 Jul;54(7):659–67.

3. Stolker JJ, Koedoot PJ, Heerdink ER, Leufkens HGM, Nolen WA. Psychotropic drug use in intellectually disabled group-home residents with behavioural problems. Pharmacopsychiatry. 35(1):19–23.

4. Deb S, Kwok H, Bertelli M, et al. International guide to prescribing psychotropic medication for the management of problem behaviours in adults with intellectual disabilities. World Psychiatry. 2009;8:181–6.

5. Tsiouris J a., Kim S-Y, Brown WT, Pettinger J, Cohen IL. Prevalence of Psychotropic Drug Use in Adults with Intellectual Disability: Positive and Negative Findings from a Large Scale Study. J Autism Dev Disord. 2012;719–31.

6. Cahn W, Ramlal D, Bruggeman L, et al. Prevention and treatment of somatic complications of the use of antipsychotics. Tijdschr Psychiatr [Internet]. 2008;50(9):579. Available from: http://www.tijdschriftvoorpsychiatrie.nl/assets/articles/articles_1795pdf.pdf

7. De Leon J, Greenlee B, Barber J, Sabaawi M, Singh NN. Practical guidelines for the use of new generation antipsychotic drugs (except clozapine) in adult individuals with intellectual disabilities. Res Dev Disabil. 2009;30(4):613.

8. De Kuijper G, Van Loon Y, Steegemans H, Ewals F. Prescription of psychotropic medication to people with intellectual disability NVAVG Guideline [Internet]. 2007. Available from: http://www.nvavg.nl/upload/standaarden/standaard---2008-01-psychofarmaca.pdf

9. Emerson C. Challenging behaviour: Analysis and intervention in people with learning difficulties. Cambridge: Cambridge University Press; 1995.

10. Brylewski J, Duggan L. Antipsychotic medication for challenging behaviour in people with learning disability. Cochrane Database Syst Rev. 2004;

11. De Kuijper H. G :Evenhuis, Minderaa R, Hoekstra P. Effects of controlled discontinuation of long-term used antipsychotics for behavioural symptoms in individuals with intellectual disability. J Intellect Disabil Res. 2014;58(1):71.

12. Aman M, Singh NN, Stewart A, Field C. The aberrant behavior checklist; a behavior rating scale for the assessment of treatment effects. Am J Ment Defic. 1985;89(5):485–91.

13. De Kuijper G, Mulder H, Evenhuis H, Visser F, Hoekstra P. Effects of discontinuation of long-term used antipsychotics on prolactin and bone turnover markers in patienst with intellectual disability. J Clin Psychopharmacol. 2014;34(1):157.

14. Aman MG, Singh NN, White AJ. Caregiver perceptions of psychotropic medication in residential facilities. Res Dev Disabil. 1987;8(3):449.

15. Christian L, Snycerski SM, Singh NN, Poling A. Direct service staff and their perceptions of psychotropic medication in non-institutional settings for people with intellectual disability. J Intellect Disabil Res. 1999 Apr;43 (Pt 2)(Pt 2):88–93.

16. Singh NN, Ellis CR, Donatelli LS, et al. Professionals perceptions of psychotropic medication in residential facilities for individuals with mental retardation. J Intellect Disabil Res. 1996;40(1):1.

17. Creswell J, Clark V. Designing and conducting mixed methods research. Thousand Oaks, California: SAGE Publications, Inc.; 2011.

18. Krueger R. Focus Groups A Practical Guide for Applied Research. New Delhi: Sage Publications; 1994.

19. Ketelaar P, Hentenaar F, Kooter M. Groups in focus. The Hague: Boom Lemma; 2011.

20. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(1):77.

21. Beatty P, Willis GB. Research synthesis; the practice of cognitive interviewing. Public Opin Q. 2007;71(2):287.

22. Fretwell C, Felce D. Staff knowledge of the side effects of anti-psychotic medication. J Appl Res Intellect Disabil. 2007;20(6):580–5.

23. Lemay C a., Mazor KM, Field TS, et al. Knowledge of and perceived need for evidence-based education about antipsychotic medications among nursing home leadership and staff. J Am Med Dir Assoc. Elsevier Ltd; 2013;14(12):895–900.

Tables and figures

Table 1. Characteristics of the focus groups and participants

	Total of four focus groups	First focus group	Second focusgroup	Third focus group	Fourth focus group
Number of participants	29	9	9	3	8
Mean age in yrs (min-max)	44 (19-62)	45 (25-61)	43 (27-62)	47 (43-52)	44 (19-62)
Yrs of working experience (min-max)	16 (2-32)	12 (3-25)	19 (8-30)	19 (8-28)	16 (2-32)
Female/Male	22/7	5/4	8/1	3/0	6/2
Nurse/Social workers	13/16	2/7	6/3	3/0	2/6
Duration per focus groups in minutes	-	99	103	88	93

Max= maximum, min=minimum, yrs = years

Table 2. Topic List

Indications for the use of antipsychotics *In which cases or situations are antipsychotics used? How do they help? From perspective of support staff? From perspective of client with ID?*
Reasons for discontinuation *What are the reasons for considering discontinuation of antipsychotics?*
Expectations towards the course of discontinuation *What do you expect in a positive or negative way in case of discontinuation from antipsychotics? This expectation is based on?*
Attitude towards discontinuation *How is your attitude towards discontinuation of antipsychotics? Which factors influence this attitude? What is the weight of each factor? In which situation is discontinuation a success or a failure?*
Conditions needed for discontinuation *Which conditions are important? In which way do these conditions influence the considerations about discontinuation? What is the weight of the conditions?*

Table 3. Characteristics of survey respondents

	Total amount of respondents
Number of respondents (response in %)	141 (41%)
Mean age in yrs (range)	38 (19-63)
Yrs of working experience (range)	13 (0-40)
Percentage female/male	70%/30%

Yrs = years

Table 4. Agreement in percentage on survey statements

	strongly disagree	disagree	neither agree or disagree	agree	strongly agree
Indications for the use of antipsychotics					
I know whether the clients using antipsychotics are diagnosed with a psychotic disorder or not.	0%	8%	14%	69%	9%
Reasons for discontinuation of antipsychotics					
The side effects of antipsychotics are very stressful for clients.	0%	5%	48%	43%	4%
Antipsychotics are effective in controlling challenging behaviour.	1%	11%	30%	55%	3%
A considerable part† uses antipsychotics while having almost no benefits from it.	3%	34%	42%	20%	1%
The dosage of antipsychotics for a considerable part† of the clients is too high.	1%	24%	46%	28%	1%
Attitude towards discontinuation of antipsychotics					
I am motivated to contribute to discontinuation of antipsychotics with a part of the clients.	2%	16%	14%	60%	8%
My team is too reserved according to discontinuation of antipsychotics.	9%	40%	29%	21%	1%
Antipsychotics can be discontinued with a considerable part† of the clients.	3%	38%	35%	23%	1%
Discontinuation of antipsychotics can only be realised in exceptional cases.	1%	29%	23%	44%	3%
More clients should be prescribed antipsychotics.	6%	60%	29%	4%	1%
Discontinuation is not possible at my working place.	6%	30%	24%	33%	7%
The dosage of antipsychotics can be decreased in a considerable par† t of the clients.	1%	8%	23%	62%	6%
Discontinuation of antipsychotics is a huge risk for clients.	1%	22%	53%	23%	3%
Decreasing antipsychotics is almost always causing a deterioration of behaviour.	0%	37%	36%	25%	2%
Decreasing antipsychotics is causing more unsafety than can be justified.	1%	37%	40%	21%	1%
Conditions needed for discontinuation of antipsychotics					
My contribution is sufficiently taken into account concerning discontinuation of antipsychotics	2%	15%	28%	51%	4%
I can influence decisions whether discontinuation of antipsychotics should be stopped or prolonged in case of safety issues.	4%	13%	16%	63%	4%
I can influence decisions whether discontinuation of antipsychotics should be stopped or prolonged in case of clients QoL.	3%	12%	19%	63%	4%
Decisions according to discontinuation are taken too unilaterally by a physician.	6%	58%	22%	11%	4%
The expertise of the psychologist is indispensable in discontinuation of antipsychotics.	0%	4%	11%	70%	15%
As a team of support staff we need consultation from outside the team for discontinuation of antipsychotics.	1%	16%	23%	53%	7%
The opinion of relatives of the client should weigh heavily concerning decisions of discontinuation of antipsychotics.	0%	12%	43%	41%	4%
Discontinuation of antipsychotics is only possible with a clear plan and description of responsibilities.	0%	0%	3%	72%	25%
Knowing in which ways a client can react on discontinuation of antipsychotics is supportive in guiding clients.	0%	2%	4%	78%	16%

I have sufficient knowledge for taking part in multidisciplinary deliberation concerning discontinuation of antipsychotics.	0%	26%	25%	47%	2%
I recognize the side effects of antipsychotics.	0%	6%	28%	64%	3%
I am aware of the possible harmful long-term side effects of antipsychotics.	0%	13%	22%	60%	6%
I know when to consult a physician concerning side effects.	0%	4%	14%	78%	4%
I am aware of the phenomena that may occur during discontinuation of antipsychotics.	0%	9%	12%	75%	4%

QoL= quality of life
† a considerable part was defined as “a quarter or more”

Figure 1. Design of study

Abstract

Title Perceptions of support staff with respect to discontinuation of long-term used antipsychotics for residential individuals with intellectual disability; a mixed method study

Background Antipsychotics are the most used psychotropic drugs by residential intellectually disabled individuals and have harmful side effects. There is limited evidence on the efficacy of antipsychotics on challenging behaviour. Discontinuation is possible for a part of residential individuals with intellectual disability and decreases some harmful side effects. In order to discontinue antipsychotics the cooperation of support staff is important. There is no knowledge on perceptions of support staff with respect to discontinuation of antipsychotic medication in persons with intellectual disability.

Aim This study wants to gain insights in the perceptions of support staff about discontinuation of antipsychotics in residential individuals with intellectual disability.

Method Four focus groups were conducted in this mixed methods study, followed by a survey with 29 Likert items.

Results Support staff perceive antipsychotics as effective in decreasing anxiety, automutilation, agitation and aggression. Support staff perceives themselves as motivated to contribute to discontinuation of antipsychotics. A larger proportion of support staff believes reduction is possible compared with the proportion that believes that complete discontinuation is possible. A clear plan for the multidisciplinary team is perceived indispensable. Support staff has no perceived knowledge deficits on side effects of antipsychotics.

Conclusion In this first study directed at the perceptions of support staff about discontinuation of antipsychotics a combination was found of a positive attitude toward contributing to discontinuation of antipsychotics on one hand and on the other hand the perceived efficacy of antipsychotics in reducing challenging behaviour and an expectation that discontinuation of antipsychotics is almost only possible in exceptional cases.

Recommendations The development of a decision guide is recommended in order to contribute the use of tailor-made discontinuation or reduction plans.

Keywords

Intellectual disability, antipsychotics, challenging behaviour, perceptions, mixed methods

Appendix 1

Enquête over de opvattingen van begeleiders over de afbouw van antipsychotica bij mensen met een verstandelijke beperking

Beste begeleid(st)er,

Ik wil je medewerking vragen aan een onderzoek dat zich richt op het onderwerp antipsychoticagebruik bij mensen met een verstandelijke beperking.

Al langere tijd is het gebruik van antipsychotica binnen de gehandicaptenzorg onderwerp van discussie. Er wordt op dit moment dan ook regelmatig gesproken over de vraag bij wie de antipsychotica kan worden afgebouwd en bij wie niet.

Afbouw van antipsychotica kan (grote) gevolgen hebben voor de begeleiders van cliënten die antipsychotica gebruiken. We willen met dit onderzoek meer inzicht krijgen in de wijze waarop begeleiders tegen de afbouw van antipsychotica aankijken.

We willen je vriendelijk vragen bijgevoegde enquête in te vullen, waarin naar jouw opvattingen over de afbouw van antipsychotica wordt gevraagd. Er zijn dus geen goede of foute antwoorden, het is de bedoeling dat je de vragen zo eerlijk mogelijk invult. Het invullen van de enquête kost ongeveer 10 minuten.

De enquête zal anoniem worden afgenomen, zodat je privacy gewaarborgd blijft.

Het onderzoek wordt vanuit de universiteit begeleid door drs. Addy Pruijssers, dr. Thóra B. Hafsteinsdóttir, dr. Harmieke van Os-Medendorp en prof. dr. Berno van Meijel .

Wij waarderen je medewerking aan dit onderzoek. Wanneer je op de hoogte gehouden wilt worden van de resultaten van het onderzoek of wanneer je vragen hebt, kun je een mail sturen naar: bas.kleijwegt@esdege-reigersdaal.nl

Met vriendelijke groet,

Bas Kleijwegt
Student verplegingswetenschap, Universiteit Utrecht

Achtergrondgegevens

Wat is je geslacht? man / vrouw (doorhalen wat onjuist is)

Wat is je leeftijd? …… jaar

Hoeveel jaar werk je (ongeveer) in de gehandicaptenzorg? …….. jaar

Ben je werkzaam als persoonlijk begeleider/cliëntbegeleider? : ja / nee (doorhalen wat onjuist is)

Bij welke organisatie ben je werkzaam? ……..

Opleiding:

	Gevolgde opleiding(en) aankruisen	Diploma behaald: ja/nee
Z-verpleegkundige		
A-verpleegkundige		
B-verpleegkundige		
HBO-V		
Verzorgende (IG)		
MBO-AB		
SPW niveau 3		
SPW niveau 4		
MMZ niveau 3		
HBO-SPH		
HBO-J		
Anders nl		

Invulinstructie

De twee onderstaande blokken leggen uit hoe je deze enquête kunt invullen en hoe je een fout antwoord kunt veranderen.

Keuze ingevuld.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☒	☐	☐	☐	☐

Wanneer u bij een stelling een "fout" antwoord heeft ingevuld, kunt u dit wijzigen door het hele vakje door te kruisen en alsnog het "juiste" keuzevakje aan te kruisen				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☒	☐	☐	☐	☒

Stellingen

In het volgende deel van de enquête krijg je een aantal opvattingen of stellingen te zien.
Geef onder elke opvatting of stelling aan in welke mate je het daarmee eens of oneens bent.

11. Antipsychotica zijn effectief om gedragsproblemen hanteerbaar te houden.				
Zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

12. De bijwerkingen van antipsychotica zijn heel belastend voor cliënten.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

13. Een aanzienlijk deel van de cliënten (*een kwart of meer)* gebruikt antipsychotica terwijl ze daar *(vrijwel)* geen baat bij hebben.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

14. Een aanzienlijk deel van de cliënten (*een kwart of meer)* gebruikt een te hoge dosis antipsychotica.				
Zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

15. Antipsychotica zouden aan meer cliënten voorgeschreven moeten worden.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

16. Bij een aanzienlijk deel (*meer dan een kwart*) van de cliënten kan de antipsychotica totaal worden afgebouwd.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

17. Totale afbouw van antipsychotica is alleen in uitzonderingsgevallen mogelijk.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

18. Bij een aanzienlijk deel van de cliënten (*een kwart of meer)* is het mogelijk de dosis antipsychotica te verlagen.				
Zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

19. Het afbouwen van antipsychotica levert ernstige risico's op voor de cliënt.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

20. Wanneer je antipsychotica gaat afbouwen krijg je vrijwel altijd te maken met een verslechtering van gedrag.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

21. Afbouw van antipsychotica bij cliënten leidt tot meer onveiligheid van begeleiders dan verantwoord is.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

22. Op mijn werkplek is totale afbouw van antipsychotica niet mogelijk.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

23. Ik ben gemotiveerd om bij (een deel van) cliënten mee te werken aan de totale afbouw van antipsychotica .				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

24. Mijn team is te terughoudend als het gaat om het afbouwen van antipsychotica.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

25. Ik heb voldoende kennis om goed deel te nemen aan multidisciplinair overleg over de afbouw van antipsychotica.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

26. Ik herken de bijwerkingen van antipsychotica.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

27. Ik weet van de cliënten die antipsychotica gebruiken of ze de diagnose psychotische stoornis hebben of niet.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

28. Ik weet wanneer ik een arts moet raadplegen in verband met bijwerkingen.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

29. Ik ben op de hoogte van de mogelijke schadelijke lange-termijn gevolgen van antipsychotica.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

30. Ik ben op de hoogte van de verschijnselen die op kunnen treden bij de afbouw van antipsychotica.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

31. Mijn inbreng wordt voldoende meegewogen in besluiten over afbouw van antipsychotica.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

32. Beslissingen tot afbouw worden te eenzijdig door de arts genomen.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

33. Ik heb invloed op besluiten over doorgaan of stoppen van de afbouw van antipsychotica als onveilige situaties optreden.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

34. Ik heb invloed op besluiten over doorgaan of stoppen van de afbouw van antipsychotica als de kwaliteit van leven van de cliënt in het geding is.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

35. De mening van verwanten van de cliënt moet zwaar wegen bij beslissingen over afbouwen van antipsychotica.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

36. De deskundigheid van de gedragswetenschapper is onmisbaar om antipsychotica verantwoord af te bouwen.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

37. Er kan alleen verantwoorde afbouw van antipsychotica plaatsvinden als er een duidelijk plan ligt met een goede taakverdeling van alle betrokkenen.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

38. We hebben als team ondersteuning van buitenaf nodig om antipsychotica verantwoord af te kunnen bouwen.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

39. Het helpt mij in de begeleiding van de cliënt als ik zicht heb op manieren hoe de cliënt zou kunnen reageren op de afbouw van antipsychotica.				
zeer mee oneens	mee oneens	niet mee eens, niet mee oneens	mee eens	zeer mee eens
☐	☐	☐	☐	☐

Ontzettend bedankt voor de tijd en moeite die je in deze enquête hebt gestoken.

Bas Kleijwegt