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## **Dietary supplements for aggressive behavior: studies in people with intellectual disability**

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# *Chapter 3*

## **ADOPTION OF DIETARY SUPPLEMENTS TO REDUCE CHALLENGING BEHAVIOR IN PEOPLE WITH INTELLECTUAL DISABILITY: A QUALITATIVE STUDY**

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D.A.A. Gast, E.J. Giltay, A.J.C. van der Slot, J.K. de Wit, J. Heijstek-van Grootheest, A.M. van Hemert, R. Didden. Adoption of Dietary Supplements to Reduce Challenging Behavior in People with Intellectual Disability: A qualitative study

## **ABSTRACT**

**Introduction:** Dietary supplements may improve challenging behavior in people with intellectual disability, but it is unclear to what extent these people and their caregivers, are open to this intervention. In this focus group study, we aimed to explore which factors influence the adoption of a dietary supplement intervention.

**Methods:** We conducted seven focus group sessions with people with intellectual disabilities, professionals and client representatives. The focus groups were analysed following the steps of 'constant comparison analysis.'

**Results:** Five topics emerged from the data: (1) relationship with other interventions, (2) professional roles, (3) characteristics of the intervention, (4) being informed (5) supplements and healthy diet.

**Conclusion:** Adoption of an intervention with dietary supplements can be facilitated by clarifying the professional roles, a prerequisite is evidence about the effectiveness and safety of the intervention. Adoption by people with intellectual disabilities can be facilitated by involving them in assessing the attractiveness of the intervention.

## INTRODUCTION

Implementation of a new intervention for challenging behavior in people with intellectual disability can be challenging, even if there is evidence of effectiveness (Lloyd and Kennedy, 2014). This is known as the research-to-practice gap (Proctor et al., 2009), often caused by a mismatch between the intervention and the potential users' needs and capacities (Dingfelder and Mandell, 2011). Involving users in the implementation and assessing their perspectives on the intervention's acceptability may help facilitate successful adoption of the intervention (Greenhalgh et al., 2004).

Challenging behavior is common among people with intellectual disabilities. The most common types of such behaviors are aggressive and self-injurious behavior (Emerson et al., 2001), with a prevalence of up to 50%-80% within specific subpopulations (Bowring et al., 2019). A range of interventions is used to treat challenging behavior, such as anger management, applied behavior analysis, mindfulness-based therapy, and psychotropic medication among others (Didden et al., 2016). Despite these efforts, challenging behavior often persists and there remains a need for additional effective, minimally invasive, safe, and cost-effective ways to reduce challenging behavior (Campbell et al., 2014; Sheehan and Hassiotis, 2017). Dietary supplements may complement the repertoire of approaches.

The effect of multivitamin, mineral, and omega-3 fatty acid supplements on behavior has been studied among prisoners and children with problem behaviors (Benton, 2007; Frensham et al., 2012; Rucklidge and Kaplan, 2013). Studies have shown that daily doses of supplements may have a small to moderate effect on aggression and antisocial behavior (Adams, 2015; Gesch et al., 2002; Raine et al., 2016; Rucklidge et al., 2018; Schoenthaler et al., 1997; Zaalberg et al., 2010). Besides, an intervention with dietary supplements could well fit the needs of people with intellectual disabilities since their nutritional status on average has been found to be suboptimal (Humphries et al., 2009) and their ability to implement a healthier food intake has been found to be relatively unsuccessful (Heller et al., 2011).

According to the "diffusion of innovations" model, transferring an effective intervention into daily clinical practice is a complex process in which four phases can be distinguished (Rogers, 2002; Durlak and DuPre, 2008). The first "dissemination phase" comprises the

information supply to the users. In the second "adoption phase," users decide whether they agree with using the intervention. The third "implementation phase" is the start of practical use. The final "sustainability phase" is the maintenance of the use of the intervention. The present study seeks to facilitate the adoption phase. Qualitative research can be used to support the process of adoption (Palinkas, 2014). We are not aware of other studies on the adoption of interventions for challenging behavior in people with intellectual disabilities.

The use of dietary supplements to reduce challenging behavior is a new type of intervention that is currently tested in a pragmatic randomized controlled trial (clinicalTrials.gov, NCT03212092). It is unclear to what extent people with intellectual disabilities, as well as their representatives and caregivers, are open to using supplements as an intervention for challenging behavior. Therefore, in this focus group study, we aimed to explore which factors influence the adoption of a dietary supplement intervention.

## **METHODS**

The group process may help participants form and express their ideas and opinions. That is why focus groups are suitable for dealing with topics, even if not all participants have prior opinions on the matter (Morgan and Krueger, 1993). Since no studies have been conducted on the adoption of dietary supplements for challenging behavior, we chose to set up the study according to the "Grounded Theory Approach", in which concepts from the data emerge in an interactive process of data collection and theory formation (Strauss and Corbin, 1994).

All participants provided written informed consent, which included permission to make a video recording of the session. Anonymity was achieved by giving each participant a random code used in the transcription of the recordings. Participants with intellectual disabilities received a gift voucher worth €5 for attending the focus group meetings. Professional caregivers and client representatives could claim their travel allowance.

### **Recruitment and Participants**

We recruited participants with and without intellectual disabilities from an organization for the care of people with intellectual disabilities located in the western part of the

Netherlands. The participants with mild intellectual disabilities / borderline intellectual functioning came from three pre-selected locations. Inclusion criteria were: living in a care facility for people with intellectual disabilities, legally competent to give informed consent and the ability to participate in a focus group discussion. To create a safe environment, we invited people with intellectual disabilities who knew each other beforehand, and the focus groups took place in their living/working environment (Barr et al., 2003). The recruitment of professionals started with an in-company email with an open invitation. The theoretical sampling method was used for the groups that followed (Breckenridge and Jones, 2009). This meant that after coding and analysing the initial data, we looked for professionals and representatives who could provide an extra perspective on the topic and emailed them an invitation. The final sample size resulted from the data saturation principle, which was achieved when new data entries no longer yielded new information or insights (Khan, 2014).

### **Procedure**

We developed separate moderator guides for moderating the groups with participants with intellectual disabilities and for the professionals and client representatives. Each moderator guide included a questioning route based on guidelines (Krueger and Casey, 2002), with questions about the adoption of the intervention (Appendix 3.1). We adapted the questions to the cognitive abilities of the participants. In focus group sessions with individuals with intellectual disabilities, illustrations and objects were used to support comprehension. Each of the seven focus groups lasted 45-90 minutes and was led by a trained focus group moderator (fourth author), who has extensive experience working as a psychologist with people with intellectual disabilities.

### **Data analysis**

The sessions were transcribed from the video recordings. Due to a technical problem, focus group session number two (see Table 3.1) has not been recorded, but the reporting has been done using notes. Analyses were conducted after each focus group and were done by the first five authors who discussed their findings in regular meetings. If concepts remained unclear, we introduced these themes as questions in the next focus group. Meaningful units were distinguished in the text and were given an open code, using the constant comparative method (Corbin and Strauss, 1990). The open codes were combined in more general categories by axial coding. Finally, concluding themes that emerged from the categories were defined (Appendix 3.2). We used the software

program Atlas.ti (version 8, Scientific software development GmbH, Berlin, Germany) for the analysis.

## RESULTS

### Participants

Seven focus groups were held between February 2019 and May 2019, ranging from three to nine participants (total  $n = 35$ ) (see Table 3.1). The participants with intellectual disabilities had an average age of 26.7 years ( $SD = 12.0$ ), and 69% were female. The average age of the other participants was 46.4 years ( $SD = 14.3$ ), and 91% was female.

**Table 3.1.** Distribution of the participants across the seven focus groups

Session Number	Participants	Representatives	Support staff	Psychologists	Medical staff	Managers	Total
1	3						3
2	6						6
3			4				4
4	4						4
5		1	3	3		2	9
6		1			4	1	6
7					1	2	3
<b>Total</b>	13	2	7	3	5	5	35

Note. Participants = participants with mild intellectual disabilities, or borderline intellectual functioning

The results will be discussed per topic and themes. The supporting quotes are listed in Appendix 3.3. We have identified the following five topics related to the adoption of the nutritional supplement intervention: (1) relationship with other interventions, (2) professional roles, (3) characteristics of the intervention, (4) being informed, and (5) supplements and healthy diet.

#### Topic 1: Relationship with other interventions

There was consensus among professionals that the approach to challenging behavior requires a wide range of interventions such as care methodologies, psychotropic medication, emotion regulation, and other behavioral therapies, not only dietary supplements.

## **Topic 2: Professional roles**

Because the intervention with nutritional supplements is new, it is not yet embedded in the facilities' usual care for people with intellectual disabilities. Two themes were distinguished within this topic: the physician's role and the role of other professionals.

### *The physician's role*

In several groups, the issue was brought up that it was not clear who would be in charge of this new intervention. Various options were discussed, such as a potential leading role for a dietitian because it concerns an intervention with dietary supplements or a psychologist because it concerns challenging behavior. Ultimately, most participants agreed that the physician should be responsible for prescribing and evaluating the intervention with supplements. Many professionals and people with intellectual disabilities considered an intervention with dietary supplements as a medical intervention, which should therefore take place under a physician's responsibility.

### *The role of other professionals*

The intervention was not seen as solely a matter for the physician. Psychologists mentioned that preferably the start and evaluation of the intervention is discussed in a multidisciplinary team consisting of the client/representative, a support staff member, a dietitian, and a psychologist, and a physician. Support staff discussed that their role is to motivate the client and facilitate daily supplement intake.

## **Topic 3: Characteristics of the intervention**

The participants with intellectual disabilities were the largest contributors to this topic on the characteristics of the intervention. Two themes emerged from the data: the swallowability and the costs of the supplements.

### *Swallowability*

Most people with intellectual disabilities had some experience with the use of nutritional supplements. They agreed that many of the supplements were difficult to swallow due to their large size and that this was made worse by an unpleasant smell and taste. They discussed how taking the supplements could be made easier and suggested making the supplements smaller, with a better taste. They also wondered if frequency of intake over the day could be reduced.

### *Costs*

Both professionals and people with intellectual disabilities debated the question of who should pay for the supplements. Several support staff members suggested that the



supplements should be paid from the client's budget. However, the people with intellectual disabilities in the focus groups suggested that health insurance should cover these costs.

#### **Topic 4: Being informed**

On the one hand, this topic was about the information and opinions on the use of supplements that people already had, and on the other hand, about the information they lacked. The following themes were discussed: opinions about the intervention's efficacy and safety and the need for reliable information.

##### *Opinions about the efficacy and safety*

In all seven groups, the benefits of supplements were thought to comprise general health and resistance against the flu, while a minority believed it could positively affect challenging behavior. The low risk of side effects, relative to for example psychoactive medication, was often mentioned as a positive aspect of supplements. Still, many also expressed concerns about the intervention, including possible drug interactions, potential side effects, and the risk of excessive levels of micronutrients.

##### *Lack of unambiguous, understandable, and evidence-based information*

The support staff pointed out that they came across different and conflicting information about dietary supplements' efficacy and safety and were no longer sure what to believe. Several professionals agreed that the use of supplements had not been part of their formal education and that further training would be necessary. The medical staff and psychologists stressed the importance of scientific evidence of the intervention. For the physicians, the information about effectiveness and safety had to be endorsed by the guidelines of their professional associations. People with intellectual disabilities said they wanted to be informed about the intervention and indicated that the information should be understandable.

#### **Topic 5: Supplements and a healthy diet**

Although it was explained that the intervention aimed at reducing challenging behavior and not replace a healthy diet, animated discussions arose in all focus groups about the relationship between supplementation and a healthy diet.

Several professionals expressed concern that support staff's motivation to improve diet quality would decrease if they began prescribing nutritional supplements within the organization. For them, dietary supplements would only be an option if other attempts to improve diet quality had failed. Other professionals argued that providing healthy food

did not necessarily guarantee healthier diet for people with intellectual disabilities. Some people with intellectual disabilities preferred a healthy diet over supplements. Others made clear that they did not care at all about a healthy diet. Opinions differed about the extent to which professionals should try to control the client's eating habits. Some professionals emphasized that a healthy diet should always be a goal, while others said they consider freedom of choice as an equally important principle.

## **DISCUSSION**

This qualitative study aimed to identify factors influencing the adoption of an intervention with nutritional supplements to reduce challenging behavior in people with intellectual disabilities. The analysis of the input of people with intellectual disabilities, their representatives, and professionals revealed five relevant topics. First, there was a broad consensus that treatment for challenging behavior should consist of combining different approaches and not a monotherapy with nutritional supplements. Second, professionals agreed that there must be clarity about their roles in the intervention. Third, concerning the intervention's characteristics, people with intellectual disabilities stressed the importance of easy-to-swallow supplements of limited size and with no unpleasant odour and taste, or high costs. Fourth, there was a need for more reliable information about the intervention's effectiveness and safety for all groups, and the different groups had different information needs. Finally, it was discussed whether it would be better or not to provide the micronutrients by improving the diet than taking supplements.

We will further discuss the results in order of the five topics that had emerged (1-5). (1) The intervention with supplements can be combined with other interventions and therefore fits into the multi-component approach often used in the treatment of challenging behavior (Embregts et al., 2019; Gore et al., 2013; Tanwar et al., 2017). (2) Physicians could play a key role in the adoption by the multidisciplinary teams, because the other professionals expect them to be in charge of the intervention. Awareness of the therapeutic potential and risks of dietary supplements has grown over the past decades in various medical fields (DiMaria-Ghalili et al., 2014; Eussen et al., 2011; Rittenhouse et al., 2020). Incorporation in evidence-based guideline is required to enable large-scale

adoption of the intervention by physicians, which should be endorsed by their professional association. (3) People with intellectual disabilities find it important to be involved in choosing an intervention for challenging behavior (Wolkorte et al., 2019). In order to increase the acceptance of the supplements by people with intellectual disabilities, details such as how they experience the taste and swallowability of the supplements should be assessed. Pill properties such as smell, taste and size are important to the acceptance of drug therapy in general (Liu et al., 2014). A wide range of nutritional supplements are available with approximately the same content but different dosage forms. People with intellectual disabilities should be involved assessing the characteristics of specific supplements on properties such as taste and swallowability. (4) Support from the caregiver is needed to integrate the information about the intervention into the daily lives of people with intellectual disabilities (Codling and McDonald, 2010). Thereby, positive wording of the indication is a concern so that the implementation of the intervention does not contribute to a negative label in a population already suffering from stigmatization (Ali et al., 2012). (5) The attitude towards the intervention could affect opinions about the relationship between supplement use and a healthy diet. A positive attitude of the caregiver could motivate the client to adopt the intervention (Sundblom et al., 2015), this is a point to consider for communication to the support staff.

### **Beyond adoption**

Adoption by individuals is a necessary step in the diffusion of an innovation, but more is needed for a sustainable use of the intervention in an organization (Greenhalgh et al., 2004). Further research is needed in the political, economic, regulatory, professional, and sociocultural context of the intervention and the embedding and adaptation over time (Greenhalgh et al., 2017).

### **Strengths and limitations**

We can note several strengths of our study. The focus groups were joined by all different professionals who had to deal with challenging behavior. The moderator was trained in leading focus groups and had extensive experience working with people with intellectual disabilities, which facilitated a pleasant and open atmosphere during the focus groups, and participants could speak up freely. A balanced interpretation of the data was promoted as five researchers analysed the data and discussed their findings in regular meetings until they reached consensus.

There are also several potential limitations that need to be discussed. Firstly, participants with profound to severe intellectual disabilities could not participate in the focus group for obvious reasons, although two client representatives participated to represent them. Secondly, when analysing focus group session 2, the notes taken during the session had to be used because the video recordings had failed, causing information to be lost. Thirdly, the participants were not a random sample, as most of the professionals who responded to our initial invitation had special interest in the subject, which was likely greater than the people who did not respond. This is a desirable characteristic to ensure richer content, but it remains unclear to what extent this selection may have resulted in missing topics that may be of concern to less interested parties.

### **Conclusion**

This focus group study showed that adopting an intervention as part of a multicomponent treatment for challenging behaviors can be facilitated by clarifying the professional roles. If the intervention is perceived as a medical intervention, the doctor is expected to be in charge and has an important role in the adoption by the other parties involved. A prerequisite is sufficient scientific evidence about the effectiveness and safety of the intervention. The adoption by people with intellectual disabilities can be facilitated by informing them and involving them in assessing the attractiveness of the intervention. Information dissemination should consider the values and sensitivities of both caregivers and people with intellectual disabilities.

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## APPENDIX

**Appendix 3.1.** The questions used in the focus groups

Question topics	People with Intellectual disabilities	Professionals and representatives
About expectations of the intervention	What are the benefits of taking vitamin pills?	What are the benefits of intervention with dietary supplements?
	What are the disadvantages of vitamin pills?	What are the disadvantages of intervention with dietary supplements?
	What do you think about taking vitamins to become less angry/busy/restless?	To what extent do you expect this intervention to work, and why?
Concerning the acceptance of the intervention	Would you take vitamins yourself and why (not)?	What can influence (positive, negative) the effectiveness of the intervention?
	What do your friends/colleagues/parents think of vitamin pills?	What risks do you expect from an intervention with dietary supplements?
	What are the dangers of taking vitamin pills?	What can make this intervention unsuitable or suitable for use in care for the intellectual disabled?
Implementation of the intervention	How can we best tell other people with intellectual disabilities about vitamin pills to reduce aggression?	What special points of interest can you think of that could be important if this intervention is used in healthcare?
	How can we best tell carers about vitamin pills to reduce aggression?	If the intervention is effective, how could we ensure that it will be implemented?
Completion	Did any of you have a question in mind they expected during the interview, but which has not (yet) been asked?	Did any of you expect a question during this focus group that has not (yet) been asked?

**Appendix 3.2.** The Themes, Sub-themes, and Topics that emerged from the data

Topic	Theme	Sub-theme
The relationship with other interventions	Other interventions	Methodologies
	Other interventions	Medications Not only supplements
The professional roles	Who is in charge	Physician Other staff
	Role of other professionals	Role other professionals

Characteristics of supplements	Swallowability	Support staff
		Multidisciplinary consultation
Being informed	Costs	Frequency
		Dosage
	Opinion about efficacy	Swallowing supplements
		Vitamin drink
	Opinion about safety	Odour
		Taste
	Lack of information	Fish oil
		Vitamins
	Understandable information	Supplement costs
		Who pays?
Supplements and a healthy diet	Evidence	Health booster
		Does (not) work on behaviour
	Stigmatizing	Side effects
		Interaction
Healthy diet	Too many vitamins	
	Contradictory information	
Freedom of choice	Too little information	
	Explanation for people with intellectual disabilities	
	Scientific evidence on safety	
	Scientific evidence on the effect	
	Stigma	
	Benefits healthy diet	
	Determination of deficiencies	
	Supplements vs. nutrition	
	Free choice of what to eat	

**Appendix 3.3.** Quotes from the focus groups

Topic	Theme	Participant	Quote
The relationship with other interventions	Other interventions	Sup Fb	It (treatment of challenging behavior) must remain in balance, and not everything has to be dependent on eh eh, for example, a vitamin deficiency ... no ... it must be embedded .. it must not be the only entrance
		Sup Fd	(agrees) it should be complementary and not the only treatment
		Psy Vc	I think there are many more things underlying behavior; ... And that this (nutritional supplements) could be one of those things, with which you could intervene.
The professional roles	Who is in charge	Part Rc	"I think you should discuss the intervention with the doctor. Because what if he says you don't need it?... I think you should consult him."
		Sup Vh	we just said we want it (supplements) on a (medical) prescription anyway, so then you have that extra (motivation) because the doctor says they need to take them



## Chapter three

		Ma/Po Kb	if you would like to get this intervention accepted in the care organizations, then you should at least have the doctors with you; otherwise, it will not happen...	
	Role of other professionals	Ma/Po Vf	I do not think you can leave this (the decision for an intervention) to one person. A multidisciplinary consultation should be planned, with at least a doctor, dietician, and psychologist.	
		Sup Fd	... I see clients who take such bad care of themselves ... if they understand that they can get those problems due to vitamin deficiency ... we could motivate them to take those vitamins.	
Characteristics of the intervention	Swallowability	Part Oa	if you have to swallow such large pills, you may choke yourself	
		Part Rb	I don't like the taste of vitamin pills. I am sensitive to certain types of flavors. And I thought they tasted very sour. I got sick of that.	
		Part Od	if you really have to take it every day, you don't want that anymore ... they are not so good ... my home mate had to gag	
		Part Oc	I would prefer chewable tablets with strawberry flavor.	
		Part Oa	It would be better if you only had to take them once a week	
		Costs	Part Ra	I stopped taking supplements ... because they were expensive.
		Part Rc	if your doctor says: this must be paid through the insurance. Wouldn't that just have to be possible?	
		Medic Kc	I think it (the supplements) should be (funded) in the same way as now with clients who receive certain vitamins ... on a prescription from their GP	
		Ma/Po Kb	And in terms of costs, we like to spend our money on things where we see results	
Being informed	Opinion about efficacy	Part Hd	Vitamins keep up your resistance!	
		Repre Vd	(supplements are for) the prevention of diseases because people may not get all nutrients, but that may also be different for everyone; I imagine	
		Ma/Po Nc	You used to learn that when you are sick, you had to take a multivitamin	
		Opinion about safety	Part Hf	They should also write on the package insert what the side effects are
			Psy Vb	I do not see the risks (of supplement use). Well, I have to say that I have not read too much about it, so that is purely my first impression.
		Sup Vk	Well, you may think it is not harmful because it is just a vitamin pill, but maybe the client can get too	

## Focus groups

			much ... we do not know enough about supplements ...
	Lack of information	Sup Fb	(we need more) information, good information that everyone understands, and knows what needs to be done
		Ma/Po Vf	I find it very confusing because one says uh ... you need (supplements) because not everything is in food, and the other says ... um ... you do not need it. I do not know...
	Understandable information	Part Hc	An understandable explanation is important if you want someone to take vitamins...
		Part Ra	you can make a digital guideline with an email address so that people with intellectual disabilities and representatives can ask their questions.
	Evidence	Ma/Po Kb	I think (within the organization) the resistance of the medics (for the introduction of the intervention) is greatest... because they do not know how it works ... or if it works at all ...
		Medic Ne	If there is enough evidence of efficacy, the intervention will also be included in the guideline ... yes if there is enough hard evidence, it will get through to the doctor ... doctor's prescriptions are based on guidelines and advice from the Health Council.
	Stigmatizing	Part Rb	I hated to hear why I had to take those (vitamin) pills. I said, what are you talking about. I am relaxed.
		Moderator	So, you found it especially annoying because they labelled you?
		Part Rb	Yes, absolutely.
Supplements and a healthy diet	Healthy diet	Repre Nb	Basically, I would first look at how we can offer healthy nutrition ... and if more is needed to use nutritional supplements only then ... but administering supplements without proper nutrition, I am not in favor of that.
		Psy Va	With a healthy diet, you also have other benefits. Many of my clients suffer from constipation, for them eating a little fiber would also be nice ... because of constipation, they can be in pain and behave problematically
		Sup Vk	It is also possible that support staff will think that (healthy) food is no longer necessary, we will give them pills instead ... that is a risk.
		Ma/Po Vg	Yes, that is a pitfall!
	Freedom of choice	Ma/Po Ng	we keep talking about how our clients should do it ... how we should do it for the clients... If they do have a choice, they can say ... give me that pill, then I feel better, but then I can eat what I want. You know, I find it problematic to control a lot of things, and I find that with nutrition too. Of course, you offer it (healthy food), and you stimulate it, but to what extent are we going to control (their lives)?

## Chapter three

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Medic Kc	of course, it would be really nice if you offer a perfectly balanced diet on the house, but if a client thinks that is not necessary and walks up to their room, and there are four bags of chips ... they are going to eat that instead of the healthy meal
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Note. Ma/Po = Manager/ policy maker, Medic = medical staff, Part = participant with mild intellectual disabilities, or borderline intellectual functioning, Psy = psychologist, Repr = client representatives, Sup = support staff



