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Research article

Towards criteria and symptoms of constipation in people with severe or profound intellectual and multiple disabilities: A Delphi study

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ABSTRACT

Background: Chronic constipation is common in people with intellectual disabilities, and seems to be highly prevalent in people with severe or profound intellectual and multiple disabilities (SPIMD). However, there is no current widely accepted definition for the constipation experienced by these individuals.

Aim: This Delphi study aims to compile a list of operationalized criteria and symptoms of constipation in people with SPIMD based on practical experiences of and consensus between experts supporting them.

Methods: A two-round Delphi study with an intermediate evaluation and analyses was conducted. Parents and relatives of persons with SPIMD and support professionals were included. The panel answered statements and open questions about symptoms and criteria of constipation. They were also requested to provide their opinion about classifying criteria and symptoms into domains. Answers to statements were analysed separately after both rounds with regard to consensus rate and displayed qualitatively; answers to open questions were analysed deductively.

Results: In the first Delphi round (n = 47), consensus was achieved on criteria within the domains 'Defecation' and 'Physical features', that were assigned to broader categories. Symptoms retrieved within the domain 'Behavioural/Emotional' were brought back to the panel as statements. After the second Delphi round (n = 38), consensus was reached on questions about domains, and for eight criteria (domain 'Defecation' n = 5; domain 'Physical features' n = 3). Within the domain 'Behavioural/Emotional', consensus was achieved for five symptoms. Criteria and symptoms with consensus >70% were considered 'generic' and <70% as 'personal'. Symptoms mentioned in the text boxes were used to operationalize categories.

Discussion and conclusion: It was possible to compile a list of generic criteria related to the domains 'Defecation' (n = 5) and 'Physical features' (n = 3) supplemented with generic symptoms related to the domain 'Behavioural/Emotional' (n = 5). We propose using both generic as well as personal criteria and symptoms resulting in a personal profile for an individual with SPIMD. Based on the current results, we recommend follow-up research to develop a screening tool to be used by

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relatives and professional caregivers, and a definition of constipation. This may support reciprocal collaboration and lead to timely identification of constipation in people with SPIMD.

1. Introduction

People with SPIMD have severe or profound intellectual disabilities, severe or profound motor disabilities, and usually also sensory disabilities [1,2]. Furthermore, they frequently experience additional health problems such as epilepsy, reflux, dysphagia, and constipation [3]. Their disabilities and health problems are often interrelated, and consequently, they need extensive support from their direct support persons, parents, family, or other support professionals for almost every aspect of their lives [2]. People with SPIMD are also dependent on their direct support persons for signalling and recognizing the onset or aggravation of health problems [4]. However, they often communicate physical discomfort or pain in an unconventional manner [1] and so direct support persons may find it difficult to interpret their communication properly.

Chronic constipation is common in people with intellectual disabilities, and prevalence rates increase for people with SPIMD [5]. According to support plans and medical records, 94% of the target group have constipation [3]. This is considered to be a collection of symptoms, generally within the bowel, consisting of difficult or infrequent passage of stool, hardness of stool, or a feeling of incomplete evacuation [6,7], and is usually caused by multiple factors [8]. It is important to identify constipation promptly because missed clinical symptoms can create serious problems that could result in fatal intestinal obstruction [9–11]. Moreover, other medical problems can arise from chronic constipation, such as rectal prolapse, diverticula of colon, intestinal obstruction, megacolon, and haemorrhoids [12]. Importantly, in addition to physical discomfort, unrecognized constipation may lead to behavioural changes [13], increased frequency of epileptic convulsions [14], and a decrease in quality of life. Therefore, it is important to properly signal and diagnose constipation. However, clarifying a definition to do so is difficult because the symptoms can manifest in different forms [15].

A range of criteria and symptoms of constipation in persons with intellectual disabilities have been ascertained in literature. However, a substantiated definition specifically for persons with SPIMD has not been identified [16,17]. The studies that were found used: Rome Diagnostic Criteria [18,19], ICD-10 criteria [20], criteria of the Bristol Stool Scale [21–23], criteria of the proposed definition of Veugelers *et al.* [16], signs and symptoms from another reference, or self-composed definitions [17]. However, people with SPIMD are not able to express that they are experiencing some of the criteria and symptoms. These criteria, for example, the feeling of incomplete defecation or of anorectal obstruction or blockage, cannot be easily determined by their family or professional caregivers [24].

Personal and professional experiences may contribute to the criteria and symptoms found in literature. If experts supporting persons with SPIMD in daily life, *i.e.*, relatives and direct support persons, nurses, and intellectual disability physicians, reflect on those found in literature, they may gain important new knowledge and insights. Additionally, criteria and symptoms may be operationalized based on experiences in practice. Therefore, the aim of this Delphi study is to compile a list of criteria and symptoms experienced by people with SPIMD based on the practical experiences of and consensus between family carers, paid carers, and professionals who support them.

2. Methods and materials

2.1. Design

In order to compile a list of criteria and symptoms of constipation in persons with SPIMD, a two-round Delphi study with intermediate evaluation and analyses was conducted. This method is considered to be appropriate for health-promotion research in ‘new’ areas with only a small knowledge base [25–27]. Consensus for the criteria and symptoms of constipation in persons with SPIMD was sought from the groups of experts who support people with severe profound intellectual disabilities.

The Delphi study was conducted between August 2020 and February 2021 in the Netherlands. The first round was open for six weeks, and a reminder was sent after three weeks. After the analyses of Delphi round 1 and designing round 2, the list was sent to the same group of participants of the first Delphi round. The second round was open for eight weeks, including two weeks over the Christmas holidays. A reminder was sent after five weeks. Round 2 was closed when there was an even distribution over the professional groups, and data saturation was present regarding consensus.

2.2. Participants

2.2.1. | criteria for participants

The Delphi panel consisted of parents or important relatives of persons with SPIMD (further: relatives) and professional caregivers. The inclusion criteria for relatives were ‘having a child, or family member with SPIMD aged 18 and older with constipation problems’. For professional caregivers, *i.e.*, direct support persons (DSPs), nurses, nurse practitioners, and ID physicians, they were ‘being involved in supporting people with SPIMD, having knowledge about constipation, working for different organizations spread over the Netherlands’.

2.2.2. Recruitment of participants

Participants were approached through multiple channels for the Delphi rounds in order to achieve the broadest representation possible through:

- Expert network in the field of individuals with SPIMD;
- Dutch residential care facilities supporting persons with intellectual disabilities; and
- Conferences about constipation in people with intellectual disabilities.

If intended participants were interested in participating in the study, they were asked to send a registration email to the first author.

2.2.3. Ethical approval

Ethical approval for this study was granted by the Hanze Ethical Review Board after a review of the study outline, data management plan, informed consent forms, and procedure (heac.2020.013). Prior to the first round, an information letter was sent to the intended participants after receiving their registration email. They were informed about the background and aims of the study, data management, and privacy aspects. Additionally, it was relayed to them that they would not receive financial compensation but would be informed of the outcomes of the study. In order to provide a one-week reflection period, the link to the online Delphi panel was sent one week after the intended participants received the information letter. After entering the Delphi panel, online informed consent could be given and was received from all participants. For the second Delphi round, the same participants were invited using the same information letter and informed consent procedure.

2.3. Data collection

2.3.1. First Delphi round

In the first round, open questions were asked, and in addition, statements were presented to the panel which they could answer using a 5-point Likert Scale.

General questions about characteristics and constipation were asked first.

The participants were then invited to share their experiences and describe in a text box which criteria and symptoms they see when they suspect that their child or the person they support has constipation. Based on literature [17], questions were presented in different categories: General ('If you suspect your child/the person you support has constipation, what criteria and/or symptoms do you see?'), Defecation ('If you suspect your child/the person you support has constipation, what criteria and/or symptoms with regard to defecation do you see?'), Physical features ('If you suspect your child/the person you support has constipation, what criteria and/or symptoms do you see on a physical level?'), and Behavioural/Emotional ('If you suspect your child/the person you support has constipation, what criteria and/or symptoms do you see in their behaviour and emotions?').

Thirdly, participants could fill in if they recognized criteria and symptoms found in a previous systematic review of literature [17]. Additionally, this list was supplemented with symptoms not described in the studies included in the review but found in textbooks for nurses, concerning, for example, odour and colour [24]. Criteria and symptoms were presented in statements to the participants with the question whether they recognized the criterion or symptom when they suspect their child/the person they support (client) has constipation. They could answer using a 5-point Likert Scale with the options 'always', 'often', 'sometimes', 'rarely', 'never', or 'I can't judge that' (Appendix A).

2.3.2. Intermediate analyses

After the first Delphi round, both recognized and unrecognized consensus of the answers on the statements was calculated. As acceptance criterion, we chose consensus of 70% or above in consultation with the research team based on levels of consensus used in other Delphi studies [28,29]. The criteria with consensus of 70% or above were assimilated into larger categories and again brought back to the panel as results. Criteria and symptoms that could not be classified into the categories as well as those retrieved from the text box on the domain Behavioural/Emotional, were brought back to the second Delphi round. These intermediate analyses were used for designing the second Delphi round.

2.3.3. Second Delphi round

In the second Delphi round, a factsheet with the preliminary results from the first round was shown to the panel. Based on this information, the following statements were presented to the panel which they could answer with yes/no/I can't judge that:

- If they recognized symptoms and criteria for which no consensus was reached in the first round and could not be clustered within the larger categories (two statements).
- If they recognized symptoms and criteria retrieved from the text boxes in the first Delphi round.

In addition, their opinion was asked about the domains which they could answer with yes/no/different, namely, ..:

- If they agreed with the domains Defecation, Physical features, and Behavioural/Emotional
- If they agreed with classifying answers into 'criteria' for the domains Defecation and Physical features and 'symptoms' for the Behavioural/Emotional domain.

Lastly, one open question was asked which they could answer in a text box:

- Which specific symptom do they believe is categorically related to constipation.

After the second Delphi round, an email was sent out to inform the participants that the Delphi study was finished. The second factsheet with preliminary results was drawn up accordingly and sent out to the Delphi panel.

2.4. Data analyses

2.4.1. Characteristics and questions about constipation

Characteristics and questions about constipation were analysed descriptively.

2.4.2. First Delphi round

After the first round, the Delphi panel's answers on the criteria and symptoms that were found using the 5-point Likert scale were analysed regarding consensus. We considered 70% or above as consensus for recognized criteria and symptoms [28,29]; less than 30% as consensus for not recognized criteria and symptoms; and between 30 and 70% as no consensus for recognizable criteria and symptoms. The statements were assimilated into larger categories, i.e.:

- Domain Defecation: frequency, deviation of frequency, consistency of stool, amount of stool, and passage of stool; and- Domain Physical features: Fuller or round belly, abdominal pain.

All criteria and symptoms retrieved from the text boxes in the first round were analysed deductively, i.e. first within the three domains Defecation, Physical features, Behavioural/Emotional; and, secondly, in the abovementioned categories. These analyses were performed with the research team (MW, CS, AP, and AW).

2.4.3. Second Delphi round

In the second round, in consultation with the research team, 70% consensus of criteria/symptoms was considered sufficient. Subsequently, the proposed criteria and symptoms were assimilated into one list, divided into the domains of Defecation, Physical features, and Behavioural/Emotional. Qualitative data obtained in the text box with the question 'Which specific symptom is categorically related to constipation based on your experience?' were displayed descriptively.

2.4.4. Final weighting of the criteria and symptoms

Summarizing results from both rounds, we provided the lists of criteria within the domains of Defecation and Physical features, and the list of symptoms within the domain Behavioural/Emotional. We displayed both the criteria and symptoms with more and less consensus than 70%. In doing so, we considered criteria and symptoms with consensus of more than 70% as 'generic criteria or symptoms', indicating that these may apply to most persons with SPIMD. Criteria and symptoms with consensus of less than 70% were considered as 'personal criteria or symptoms', indicating that these may be useful for specific individuals with SPIMD.

3. Results

3.1. Participants

A total of 54 participants started the first Delphi round; there were eight relatives and 46 professional caregivers. The characteristics of two children did not meet the inclusion criterion, and two relatives did not complete the questions. Of the professional caregivers, five stopped answering the questions in the text boxes. In total, answers of six relatives and 41 professional caregivers from 24 organizations were included. In the second Delphi round, answers of 37 participants could be included in the analyses. The characteristics of the participants are described in [Table 1](#).

3.2. Results of Delphi round 1

Results for the criteria and symptoms retrieved from the text boxes and statements with consensus are described in [Fig. 1](#). Consensus was achieved in the domain Defecation for six criteria and in the domain Physical features for three criteria, which the authors subsequently assigned to the following categories: Domain Defecation - 1) frequency, 2) deviation of frequency, 3) consistency

Table 1
Characteristics of participants of the panel and the persons they support

	Participants round 1 n=47		Participants round 2 n=37	
	n	%	n	%
Relation to the person with SPIMD				
Family member	6	15	6	16
Professional	41	85	31	84
Total	47	100	38	100
Professionals				
Direct support person	13	28	9	28
Nurse	8	17	5	15
Nurse Practitioner	9	20	6	19
ID Physician	16	35	12	38
Total	46*	100	32**	100
Working experience				
≤5 yrs	8	17		
5-9 yrs	10	22		
10-19 yrs	17	37		
≥20 yrs	8	17		
Missing	3	7		
Total	46*	100		
Prevalence constipation persons with SPIMD				
Always	4	9		
Often	26	56		
Regularly	15	33		
Sometimes	1	2		
Never	-			
Gender differences prevalence constipation according to professionals				
Yes	8	18		
No	36	82		
Total	44	100		
Age range persons with SPIMD and constipation (year)***				
0 - 11	12	9		
12-18	18	14		
19-30	28	21		
31-49	37	28		
≥50	36	28		
Age range with highest prevalence of constipation***				
0 - 11	3	9		
12-18	2	14		
19-30	10	21		
31-49	20	27		
≥50	23	31		
No differences in age categorie	16	22		

ID Physician: Intellectual Disability Physician

* After filling out profession and working experience, five persons stopped during the other questions.

** One person stopped during the questions about criteria and symptoms.

*** Multiple options could be chosen.

of stool, 4) amount of stool, 5) passage of stool; Domain Physical features - 1) fuller or round belly, and 2) abdominal pain.

As indicated by the arrows in Fig. 1, the criteria with a consensus rate lower than 70% were also assigned to one of the categories as well as most of the criteria and symptoms found in the text boxes of domains Defecation and Physical features. Criteria and symptoms that could not be assigned to a category as well as the criteria and symptoms retrieved from the text box for the domain Behavioural/Emotional were brought back to the second Delphi round.

3.3. Results Delphi round 2

Based on information about the preliminary results from the first round, the participants of the Delphi panel were asked if they agreed with the domains Defecation, Physical features, and Behavioural/Emotional. A total of 97% of the participants (n = 35) agreed and 3% disagreed (n = 1). Additionally, 97% of the participants (n = 35) agreed with classifying answers into 'criteria' for the domains Defecation and Physical features and 'symptoms' for the Behavioural/Emotional domain. One participant (3%) checked the box 'other', stating, 'I think that a fuller, round belly and decreased appetite are important and, in addition, behavioural symptoms such as: irritability, general malaise, withdrawn behaviour, and loss of pleasure'.

Results for consensus on criteria and symptoms in the second Delphi round are shown in Table 2, which indicates that within the domains Physical features and Behavioural/Emotional, consensus was found for one criterion (Not feeling well, general malaise) and

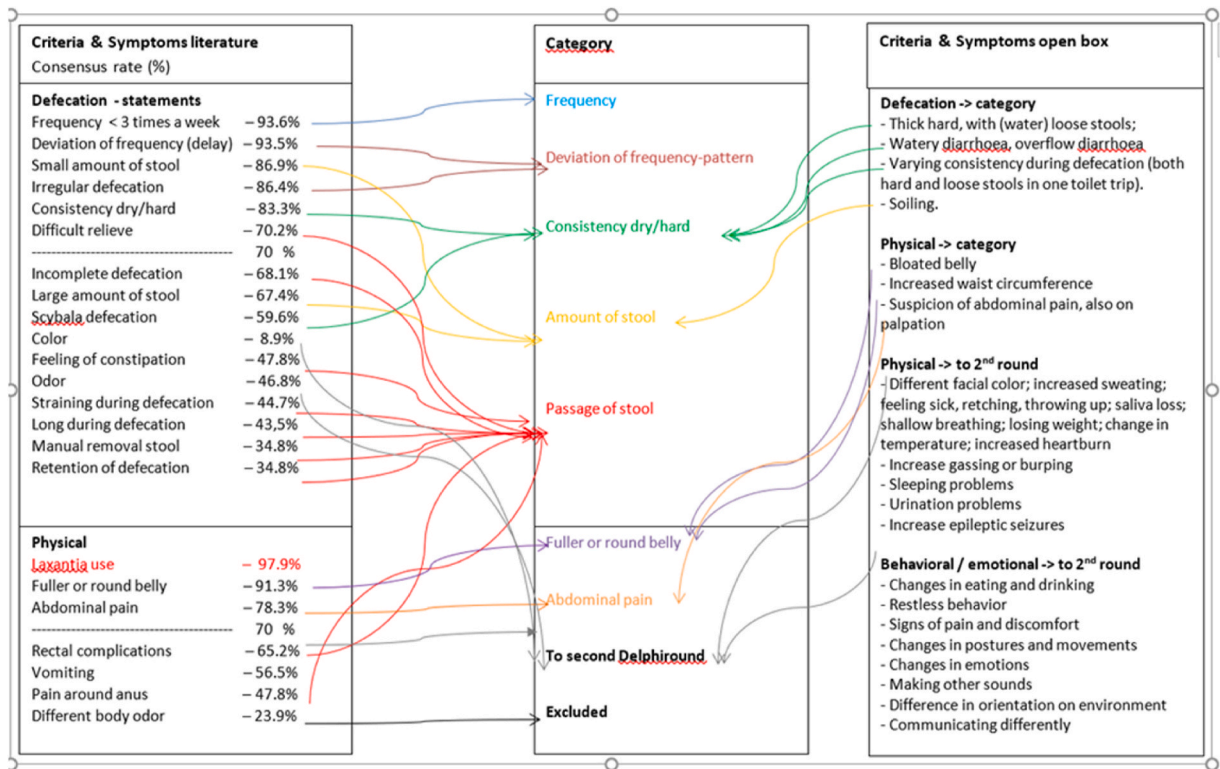


Fig. 1. Results consensus about statements, criteria, and symptoms from the open boxes, and categorization.

five symptoms (Changes in eating and drinking, Restless behaviour, Signs of pain and discomfort, Changes in postures and movements, and Changes in emotions).

Moreover, the percentage ‘not able to judge’ was relatively high for several criteria and symptoms. An analysis of which participants filled out ‘not able to judge’ showed that the majority were ID physicians, nurses, and nurse practitioners within the domains Behavioural/Emotional and Defecation; in the domain Physical features, mainly relatives and DSPs were not able to judge criteria and symptoms.

Tables 3–5 show a summary of category, proposed criteria/symptoms per domain, and consensus results from both rounds. Additionally, qualitative data obtained in the text box with the question ‘Which specific symptom is categorically related to constipation based on your experience?’ are displayed descriptively in this table. Criteria and symptoms with consensus above 70% are described as ‘generic criteria or symptoms’. Criteria and symptoms with consensus of less than 70% are described as ‘personal criteria or symptoms’.

In addition to Tables 3–5, the answers below were also given to the question, ‘Which specific symptom is categorically related to constipation based on your experience?’:

‘.. I found it difficult to answer these questions because the way the client indicates he/she is constipated can vary greatly ... ’

‘..But besides the behaviour, I always want to know what the client’s defecation pattern is before I can say it’s constipation ... ’

‘..No, as ID Physician AVG, I find that difficult to discern ... ’

‘.. I don’t know of any behaviour that only corresponds to constipation..’

‘.. No, the patient population is too diverse in age and developmental age for that ... ’

‘.. I think that such behaviour may also be noticeable through other discomfort ... ’

Table 2
Results consensus about criteria and symptoms Delphi round 2.

Criteria and symptoms	Yes (%)	No (%)	Not able to judge (%)	Details not able to judge regarding participant background
Defecation	34	37	27	<i>90 % ID phys/nurse/NP</i>
Color stool darker	38	35	27	<i>80 % ID phys/nurse/NP</i>
Odor stool different				
Physical	95	2.5	2.5	<i>71% ID phys/nurse/NP</i>
- Not feeling well, general malaise (different facial color; increased sweating; feeling sick, retching, throwing up; saliva loss; shallow breathing; losing weight; change in temperature; increased heartburn)	62	19	19	<i>57% DSPs/nurse</i>
- Increase gassing or burping	60	22	19	<i>100% parents/DSPs</i>
- Sleeping problems	57	35	8	<i>63% parents/DSPs</i>
- Urination problems	54	24	22	
- Increase epileptic seizures				
Behavioral / emotional	100	0	0	<i>75% ID phys/nurse – 25% DSP</i>
- Changes in eating and drinking (less or no appetite; wanting to drink less or not wanting to drink at all; refusing medication)	100	0	0	<i>71% ID phys/nurse</i>
- Restless behavior (calms down less quickly, seems more tense, can no longer enjoy things that are normally relaxing)	97	0	3	<i>67% ID phys/nurse/NP – 33% parents/DSPs</i>
- Signs of pain and discomfort (grimacing, frowning, verbally expressing pain)	89	3	8	<i>75% ID phys/nurse/NP-25% DSP</i>
- Changes in postures and movements (more physical restlessness; greater urge to move/ make extreme movements; remains lying/sitting in one position, tries to find another position, adopts a crooked position, has increased muscle tension)	89	0	11	
- Changes in emotions (less cheerful, more easily angry or agitated, sad (more often), seems anxious or more anxious, less able to tolerate stimuli or changes)	68	13	19	
- Making other sounds (noises that may be related to discontent, such as moaning, whining, groaning, crying)	68	16	16	
- Difference in orientation on environment (less or more; exhibits withdrawn behavior; seems focused or more focused on internal stimuli, needs motivation or more motivation when doing an activity, is less alert, tries to get more in touch with their surroundings, seems to be demanding attention for something, seeks out extreme stimuli or more extreme stimuli, masturbates more, hurts themselves more often)	49	19	32	
- Communicating differently (less or not communicating at all)				

Bold: consensus 'yes' > 70% *Italics:* not able to judge > 10% ID phys: Intellectual disability physician; NP: Nurse Practitioner; DSP: Direct Support Person

Table 3
Results domain Defecation regarding criteria of constipation for people with SPIMD

Defecation – generic criteria (<i>consensus >70%</i>)				
No.	Category	Symptom / Criterion	Consensus (%)	Specifically related to constipation (Round 2)
1.	Frequency	Frequency < 3 times a week	93.6	
2.	Deviation of frequency-pattern	Deviation of frequency (delay)	93.5	<i>A period of no stool</i> <i>Has to strain for an awfully long time</i>
3.	Amount of stool	Irregular defecation	86.4	
		Small amount of stool	86.9	<i>Soiling</i> <i>Small amount</i>
4.	Consistency dry/hard	Consistency dry/hard	83.3	<i>Varying stool consistency</i> <i>Dry</i>
5.	Passage of stool	Difficult relieve	70.2	<i>Going to the toilet takes longer</i>
Defecation – personal criteria (<i>consensus < 70%</i>)				
3.	Amount of stool	Large amount of stool	67.4	<i>Very large amount</i>
4.	Consistency dry/hard	Scybala defecation	59.6	
5.	Passage of stool	Incomplete defecation	68.1	
		Rectal complications	65.2	
		Feeling of constipation	47.8	
		Straining during defecation	44.7	
		Long during defecation	43.5	
		Manual removal stool	34.8	
		Retention of defecation	34.8	

No: number

Italics: qualitative data obtained in the open box with the question 'Which specific symptom is specifically related to obstipation based on your experience?'

Table 4
Results domain Physical features regarding criteria of constipation for people with SPIMD

Physical – generic criteria (<i>consensus >70%</i>)				
No.	Category	Symptom / Criterion	Consensus (%)	Specifically related to constipation (Round 2)
1.	Not feeling well, general malaise	Laxantia use	97.9 94	<i>Different facial color Increased sweating Feeling sick, retching, throwing up Saliva loss Shallow breathing Losing weight Change in temperature Increased heartburn Vomiting Cramping and more vomiting (a lot!) Fecal vomiting. Vomiting more than usual Fainting Losing consciousness Bringing up mouthfuls of food Vomiting Pale complexion Vasovagal collapse/syncope vomiting Gagging PEG probe not flowing that well/fast enough Bringing up food Vomiting small pieces Losing saliva Bloating belly Increased waist circumference Lots of air Palpation Hard belly that can be very sensitive to the touch. or tense, painful (tight) belly. Expressing abdominal pain Abdominal pain Cramps but nothing coming out</i>
2.	Fuller or round belly	Fuller or round belly (Q5)	91.3	
3.	Abdominal pain	Abdominal pain	78.3	
Physical – personal criteria (<i>consensus < 70%</i>)				
		Increase gassing or burping	62	
		Sleeping problems	60	<i>Not sleeping</i>
		Urination problems	57	<i>Urine retention</i>
		Vomiting	56.5	
		Increase epileptic seizures	54	<i>More epileptic seizures</i>
		Pain around anus	47.8	
		Odor	46.8 -38	
		Color	8.9 -34	

No: number

Italics: qualitative data obtained in the open box with the question ‘Which specific symptom is specifically related to obstipation based on your experience?’

Table 5
Results domain Behavioral / emotional regarding symptoms of constipation

Behavioral / emotional – generic criteria (<i>consensus >70%</i>)				
No.	Category	Symptom open box (Round 1)	Consensus (%)	Specifically related to constipation (Round 2)
1.	Changes in eating and drinking	<i>Less or no appetite; wanting to drink less or not wanting to drink at all; refusing medication</i>	100	<i>Not wanting to eat Poor appetite and drinking poorly. Poorer appetite but mainly drinking poorly. Not eating, or poor appetite Decreased appetite Not wanting to eat Decreased appetite Not wanting to eat or drink She does not feel like doing anything</i>
2.	Restless behavior	<i>Calms down less quickly, seems more tense, can no longer enjoy things that are normally relaxing</i>	100	<i>His behavior is restless. Restless behavior Tense posture. Hyper and active at night Restless</i>

(continued on next page)

Table 5 (continued)

Behavioral / emotional – generic criteria (consensus >70%)				
3.	Signs of pain and discomfort	<i>Grimacing, frowning, verbally expressing pain</i>	97	<p><i>Pressing on belly and introverted, difficult to get through to.</i> <i>Is very restless</i> <i>Very active behavior, agitated</i> <i>Startles more easily, startled by sensations in her body.</i> <i>The behavioral repertoire appropriate for indicating pain</i> <i>Discomfort</i> <i>Non-verbal signs of pain, grimacing, corners of the mouth raised, frowning.</i> <i>Facial expressions showing he is in pain</i> <i>Shaking legs</i></p>
4.	Changes in postures and movements	<i>More physical restlessness; has greater urge to move/make extreme movements; lies/sits in one position. tries to find a different position. adopts a crooked position. has increased muscle tension</i>	89	<p><i>Restless movements</i> <i>Tense fetal position</i> <i>Less cooperative with ADL</i> <i>Not sitting or standing but just lying down.</i> <i>Restless motion</i> <i>Curling up, large eyes</i> <i>Hunched over, crouching posture</i> <i>Increase in spasms</i></p>
5.	Changes in emotions	<i>Less cheerful, more easily angry or agitated, sad or sad more often, seems anxious or more anxious, less able to tolerate stimuli or changes</i>	89	<p><i>Irritable, restless behavior and very easily angry.</i> <i>Self-mutilation</i> <i>Unusually naughty behavior/ seriously pushing boundaries</i> <i>Behavior difficult to understand (angry moods, head-banging)</i> <i>Less able to tolerate stimuli and other clients</i> <i>Angry</i> <i>Wanting to hurt himself or others</i> <i>Exhibits different behavior.</i></p>
Behavioral / emotional – personal criteria (consensus < 70%)				
6.	Making other sounds	<i>Noises that may be related to discontent, such as moaning, whining, groaning, crying</i>	68	<p><i>Dissatisfied noises;</i></p> <p><i>Groaning</i> <i>Crying</i> <i>Making sounds of displeasure.</i> <i>Shouting</i> <i>Crying</i> <i>Whimpering a lot</i> <i>Loud noises, whimpering</i> <i>Crying</i> <i>Starts crying loudly.</i> <i>Shouting</i></p>
7.	Difference in orientation on environment	<i>less or more; exhibits withdrawn behavior; (more) focused on internal stimuli, (more) motivation needed when doing an activity, less alert, tries to get more in touch with their surroundings, seems to be asking attention for something, looking for extreme or more extreme stimuli, masturbating more, hurting themselves more often</i>	68	<p><i>Masturbation behavior is increasing</i></p> <p><i>Touching himself rectally.</i> <i>Inalert more quickly</i> <i>Less able to self-manage</i> <i>Lots of introverted behavior.</i> <i>More withdrawn behavior, avoiding people and stimuli. Less initiative.</i> <i>Very introverted.</i> <i>Banging</i></p>
8.	Communicating differently	<i>less or not communicating at all</i>	49	

No: number

Italics: qualitative data obtained in the open boxes Round 1, and Round 2 (with the question ‘Which specific symptom is specifically related to obstipation based on your experience?’)

4. Discussion

The objective of this Delphi study was to compile a list of criteria and symptoms of constipation in people with SPIMD. Based on practical experiences of and consensus between experts of the Delphi panel, we were able to compile a list of generic criteria within the domains Defecation ($n = 5$) and Physical features ($n = 3$), supplemented with generic symptoms related to the domain 'Behavioural/Emotional' ($n = 5$). Criteria and symptoms with consensus $<70\%$ were considered as 'personal'. Those could be operationalized by assimilating the criteria and symptoms from the statements and the text boxes into categories as well as by using the quotations of the experts found in both Delphi rounds with regard to the three domains.

In the second Delphi round, we asked the panel if they agreed with classifying symptoms and criteria in the domains Defecation, Physical features, and Behavioural/Emotional. Based on consensus, we propose using these domains in practice and in follow-up research on persons with SPIMD. Until now, existing criteria have indeed used features for defecation and physical domain, but have not allocated these criteria into specific domains and have not used Behavioural/Emotional symptoms [16,18–22]. Neither Behavioural/Emotional symptoms are used within the paediatric Rome IV criteria for diagnosing constipation in young children [30]. The reason for this might be that 'it is essential that symptom-based diagnostic criteria are accurate, clear, and unambiguous' [30]. Since persons with SPIMD cannot report symptoms accurately and the diagnosis of constipation is mainly based on reports from relatives and/or professionals and their interpretations of the person's symptoms, the symptoms found within the domain Behavioural/Emotional seem to be valuable to use for people with SPIMD.

Of the symptoms found in the domain 'Behavioural/emotional', 'Changes in eating and drinking' may be specifically related to constipation. However, the question is if the other Behavioural/Emotional symptoms are related more so to physical discomfort and/or pain in general, as one of the participants stated. To answer this question, further research in practice with relatives and professional caregivers will be necessary as well as comparison with pain assessment scales. Additionally, within the domain of 'Physical features', the highest consensus rate was determined for laxative use; this seems to be confirmation that constipation is present. However, as laxatives are used to treat constipation, it does not seem logical to use it as a criterion.

Most participants agreed with using the term 'criteria' for the domains Defecation and Physical features and 'symptoms' for the Behavioural/Emotional domain. In the future, 'criteria' may be used to create a definition of constipation for persons with SPIMD when 'symptoms' do not seem to be specifically associated with the diagnosis of constipation but are more indicative that something is wrong, comparable to, for example, behaviour related to pain [31]. In addition to this, criteria and symptoms with a consensus rate lower than 70% may be important for specific persons with SPIMD. We therefore feel that we cannot disregard or refrain from using these criteria and symptoms. For this reason, we proposed dividing the criteria and symptoms that were found into generic and personal categories based on a consensus rate above or below 70% respectively. Adding the personal criteria and symptoms to the generic criteria and symptoms, a personal profile of constipation may be compiled for which the domains of constipation may be monitored over time. In addition, although the criteria we found within the domains Defecation and Physical features are comparable to those of existing criteria of constipation [16,18–22], in the present study, they are more specified and detailed and hence these criteria seem to be suitable for better interpretation by caregivers. Consequently, caregivers will be able to better report about the presence of these criteria in the person with SPIMD that they support, which will contribute to properly identifying constipation.

4.1. Strengths and limitations

Despite our efforts to involve relatives in this Delphi panel, more professional caregivers participated. The relatives who did participate reported that their child was younger than 20, and professional caregivers reported that prevalence of constipation increased in persons older than 20. Relatives of persons with SPIMD older than 20 may have already found solutions for constipation, or their family member may live in a residential facility meaning they have less insight into their constipation symptoms. Additionally, for relatives and professional caregivers, the COVID-19 pandemic may have impeded the participation in the second Delphi round. Moreover, the second round was performed between the first week of December 2020 to February 2021, which coincided with a peak in the pandemic in the Netherlands. This meant relatives and professionals were busy with care tasks, nurses, for example, were busy with administering vaccinations. These circumstances may have impacted the results of our study. Nevertheless, we found consensus on criteria and symptoms as well as on the other questions. As a result, this study could be closed after two rounds. During follow-up research, we hope that the circumstances will be improved.

In the second Delphi round, the percentage 'not able to judge' was relatively high for several criteria and symptoms. Within the domains Behavioural/Emotional and Defecation, the majority of ID physicians, nurses, and nurse practitioners felt that they were not able to make statements about those symptoms or criteria whereas in the domain Physical features mainly relatives and DSPs were not able to judge criteria and symptoms. This is important information because this may indicate that both groups of caregivers need each other to be able to either signal or diagnose constipation: ID physicians, nurses, and nurse practitioners need the reports of relatives and DSPs to inform them about the Behavioural/Emotional and Defecation features while relatives and DSPs need the ID physicians, nurses, and nurse practitioners to reflect on the Physical features. Developing a definition with criteria to be used by ID physicians, nurses, and nurse practitioners and a screening list to be used by relatives and DSPs may help to support their collaboration.

4.2. Recommendations

In order to properly identify constipation, it is important that relatives and DSPs can use the criteria and symptoms in an efficient manner and report them adequately to the ID physician and nurses involved. Therefore, we propose exploring the following avenues to

continue this research. The lists of symptoms and criteria that were determined can be developed into a screening tool. Some of the criteria can be further operationalized, for example, by using the Bristol Stool Scale to score the consistency of defecation. Subsequently, with data generated by relatives and DSPs using the screening tool in practice, its psychometric properties can be determined. In addition, the symptoms and criteria within the screening tool can be evaluated by physicians specialized in gastrointestinal disorders and used to create a definition or a framework for constipation in persons with SPIMD.

5. Conclusion

In conclusion, in this Delphi study on constipation in people with SPIMD, a list of criteria within the domains Defecation and Physical features supplemented with symptoms in the domain Behavioural/Emotional could be compiled based on practical experiences of and consensus between experts of the Delphi panel. We propose using both generic as well as personal criteria and symptoms resulting in a personal and individual profile for a person with SPIMD. Continuing this research, the list of symptoms and criteria that were determined can be developed into a screening tool to be used by relatives and DSPs. Secondly, symptoms and criteria that were found can be evaluated by physicians specialized in gastrointestinal disorders. These two avenues may support reciprocal collaboration and lead to identifying constipation quickly in people with SPIMD.

Author contribution statement

Aly Waning: Conceived and designed the experiments; Performed the experiments; Analysed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

M.C. Wagenaar: Conceived and designed the experiments; Performed the experiments; Contributed reagents, materials, analysis tools or data; Wrote the paper.

A.A.J. van der Putten; C.P. van der Schans: Conceived and designed the experiments; Performed the experiments; Analysed and interpreted the data; Wrote the paper.

Data availability statement

The data that has been used is confidential.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Statements and consensus Delphi-round 1

Defecation.

Number	Parents or relatives	Professionals	Consensus	Ronde 1 Delphi
	If you suspect your child/the person you support (client) has constipation, what criteria and/or symptoms do you see?			Recognized or no consensus
1.	... my child passes stools less than three times a week. 100%	... my client passes stools less than three times a week. (1) 92.7%	93,6%	Recognized
2.	... the colour of the stool changes. 100%	... the colour of the stool changes. (2) 41.5%	48,9%	No consensus
3.	... the odour of the stool changes. 100%	... the odour of the stool changes. (3) 39.0%	46,8%	No consensus

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Number	Parents or relatives	Professionals	Consensus	Ronde 1 Delphi
4.	... my child is straining at least 25% of the time while defecating. 66.7%	... my client is straining at least 25% of the time while defecating. (4) 41.5%	44,7%	No consensus
5.	... the stool is dry and hard in consistency (shape). 83.3%	... the stool is dry and hard in consistency (the shape of the stool is hard and looks dry). (5) 87.8%	87,2%	Recognized
6.	... passing the stool seems to be difficult. 83.3%	... passing the stool seems to be difficult. (6) 68.3	70,2%	Recognized
7.	... the shape of the stool looks like pebbles/marbles and is very hard (scybalia stool). 16.7%	... the shape of the stool looks like pebbles/marbles and is very hard (scybalia stool). (7) 65.8%	59,6%	No consensus
8.	... my child will be prescribed laxatives for defecation. 100%	... my client will be prescribed laxatives for defecation. (8) 97.6%	97,9%	Recognized
9.	... my child does not seem to have had a full bowel movement. 83.3%	... my client does not seem to have had a full bowel movement. (9) 65.8%	68,1%	No consensus
10.	... my child seems to have a feeling of blockage in the intestines. 50%	... my client seems to have a feeling of blockage in the intestines. (10) 47.5%	47,8%	No consensus
11.	... my child has a large amount of stool. 83.3%	... my client has a large amount of stool. (11) 65%	67,4%	No consensus
12.	... my child has a small amount of stool. 83.3%	... my client has a small amount of stool. (12) 87.5%	86,9%	Recognized
13.	... my child has to sit longer on the toilet/potty/commode wheelchair to be able to fully relieve themselves. 50%	... my client has to sit longer on the toilet/potty/commode wheelchair to be able to fully relieve themselves. (13) 42.5%	43,5%	No consensus
14.	... defecation is delayed, it takes a few days before my child has a bowel movement again. 100%	... defecation is delayed, it takes a few days before my client has a bowel movement again. (14) 92.5%	93,5	Recognized
15.	... my child has irregular bowel movements. 100%	... my client has irregular bowel movements. (15) 85%	86,4%	Recognized
16.	... I have to remove stool from my child manually. 50%	... I have to remove stool from my client manually. (16) 32.5%	34,8%	No consensus
17.	... my child seems to have stopped passing stools. 16.7%	... my client seems to have stopped passing stools. (17) 37.5%	34,8%	No consensus

Physical features

Number	Parents or relatives	Professionals	Consensus	
	If you suspect your child/the person you support (client) has constipation, what criteria and/or symptoms do you see?			Recognized or no consensus
1.	... my child vomits more often or has a tendency to vomit. 50%	... my client vomits more often or has a tendency to vomit. (1) 57.5%	56,5%	No consensus
2.	... my child indicates/seems to indicate abdominal pain during defecation. 50%	... my client indicates/seems to indicate abdominal pain during defecation. (2) 82.5%	78,3%	Recognized
3.	... they soil themselves faster/have fecal incontinence. 50%	... they soil themselves faster/have fecal incontinences. (3) 57.5%	56,5	No consensus
4.	... my child indicates/seems to have pain around the anus while defecating. 50%	... my client indicates/seems to have pain around the anus while defecating. (4) 47.5%	47,8	No consensus
5.	... my child's belly seems fuller/fatter. 83.3%	... my client's belly seems fuller/fatter. (5) 92.5%	91,3%	Recognized
6.	... my child seems to be bloated. 83.3%	... my client seems to be reporting bloating. (6) 50%	54,3%	No consensus
7.	... my child has rectal complications (haemorrhoids, fissures, blood, etc.). 33.3%	... my client has rectal complications (haemorrhoids, fissures, blood, etc.) (7) 70%	65,2%	No consensus
8.	... my child's body odour is 'different'. 50%	... my client's body odour is 'different'. (8) 20%	23,9%	No consensus

Appendix B. Questions Delphi round 2

On this and the following pages, we explain the signs and symptoms that you and other participants indicated in the first round. We would like to know to what extent you recognize these in the event of suspected constipation in persons with extremely severe intellectual and multiple disabilities.

If you suspect your child/the person you support has constipation, what criteria and/or symptoms of the defecation do you see?

Number	Statement	Yes, I recognize this	No, I do not recognize this	I am not able to judge this
1.	... the stool is darker in colour.			
2.	... the smell of the stool is stronger.			
Number	Statement	Yes, I recognize this	No, I do not recognize this	I am not able to judge this
1.	... my child/client is not feeling well, there is general malaise, e.g. my child/client has a different complexion and seems to perspire more. e.g. gags more often, is nauseous or has to vomit more often, my child/client is losing more saliva. e.g. my child/client is losing weight. e.g. my child/client's breathing seems to be shallower. e.g. my child/client is exhibiting a change in body temperature. e.g. my child/client appears to be suffering from heartburn (reflux).			
2.	... my child/client has problems urinating, there is little or no urine and/or there is a bladder infection.			
3.	... my child/client is having an increase in seizures.			
4.	... my child/client suffers more from gas formation, e.g. more belching, passing wind.			
5.	... my child/client has sleeping problems, e.g. sleeps a lot during the day or lies awake more often at night.			
Number	Statement	Yes, I recognize this	No, I do not recognize this	I am not able to judge this
1.	... my child/client exhibits changes in posture and movement, e.g. more physical restlessness. e.g. greater urge to move, extreme movement. e.g. remains lying/sitting in one position. e.g. tries to find a different position. e.g. adopts a crooked position. e.g. has increased muscle tension.			
3.	... my child/client exhibits changes around food and drink, e.g. less or no appetite. e.g. wanting to drink less or not at all. e.g. refusing medication.			
4.	... my child/client exhibits signs of discomfort or pain, e.g. grimacing, frowning. e.g. verbally expressing pain.			
5.	... my child/client exhibits changes in emotions, e.g. being less cheerful. e.g. getting angry or agitated more quickly. e.g. being sad (more often). e.g. seeming anxious or more anxious. e.g. less able to tolerate stimuli or changes.			
6.	... my child/client exhibits restless behaviour, e.g. calms down less quickly. e.g. seems more tense. e.g. is no longer able to enjoy things that are normally relaxing.			
7.	... my child/client makes different noises, e.g. noises that may be related to displeasure such as moaning, whining, groaning, crying.			
8.	... my child/client communicates differently, e.g. less often or not communicating.			
9.	... my child/client is focused differently (less or more) on their surroundings, e.g. exhibits withdrawn behaviour. e.g. reacts passively. e.g. seems more focused on internal stimuli. e.g. needs more motivation when doing an activity. e.g. is less alert. e.g. tries to get more in touch with their surroundings, seems to be demanding attention for something.			

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Number	Statement	Yes, I recognize this	No, I do not recognize this	I am not able to judge this
	e.g. is looking for more extreme stimuli. e.g. my child/client masturbates more. e.g. my child/client hurts themself more often.			

From your experience, can you describe specific behaviour of your child/client that you really only see when you suspect constipation?

After analysing the data from the first round, we divided them into three domains for an overview.

1. This is the proposal for domains:

- Domain - Characteristics of the stool such as the stool is dry and hard in consistency (shape).
- Domain - Physical features. This could be ... my child/client reports/seems to have abdominal pain during defecation. Domain – Behavioural/Emotional characteristics such as ... my child/client shows signs of discomfort or pain ... Do you agree with this classification of symptoms in these domains? 0 yes 0 no, because 0 other, because ...

2. In addition to this division into domains, we have also distinguished the following types of symptoms:

- Obvious symptoms, possibly criteria to become part of a preliminary definition
- More general symptoms of discomfort that may indicate that ‘something’ may be wrong with your child or client at that time, possibly caused by constipation, but it could also be something else.

We are now thinking that the specific symptoms could be part of the provisional definition, and that the non-specific symptoms should prompt further investigation into the causes, e.g., constipation, increased epilepsy, hip problems, increased muscle tension, earache, etc.

Do you agree with this? 0 yes, because ... 0 no, because ... 0 other, because ...

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