Diagnostic aid

dementia in people with SPI(M)D

Manual

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1.Introduction

People with severe/profound intellectual (and multiple) disabilities (abbreviated to SPI(M)D) are growing older. Because age is the most important risk factor for dementia, dementia is increasingly common in this group. It also plays a role that individuals with Down syndrome (trisomy 21), 20-30% of whom have severe/ profound intellectual disabilities, have a high genetically determined risk of developing dementia due to Alzheimer's disease.

Identifying and diagnosing dementia in individuals with SPI(M)D is complex. In order to diagnose dementia, there must be cognitive decline that impacts daily functioning. Distinguishing deterioration due to dementia from pre-existing severe limitations in functioning in individuals with SPI(M)D is challenging.

In individuals without intellectual disabilities, neuropsychological tests are used to determine dementia-related cognitive decline. These tests are unsuitable for individuals with SPI(M)D due to their limited understanding of the test instructions and limitations in verbal skills. Available dementia screening instruments for individuals with intellectual disabilities also appear not to be entirely useful for individuals with SPI(M)D (Wissing, Dijkstra et al., 2022).

This diagnostic aid has been developed to identify dementia-related changes in individuals with SPI(M)D to support the diagnostic process of dementia.

2. Contents

The diagnostic aid consists of two parts: general details and dementia-related changes.

2.1. General details

The first part contains general data from the interviewer, informant(s), and client and is structured as follows:

- **Interviewer:** profession and care organisation
- **Informant(s):** gender, relationship to client, and duration of involvement (years and number of hours per week)
- **Client:** date of birth, age, sex, living situation, daycare centre, level and cause of intellectual disability, intellectual/adaptive/social-emotional functioning, presence of dementia, verbal skills, walking skills

Level of intellectual disability and intellectual, adaptive functioning and social-emotional functioning
People are asked about the *original level* of functioning before deterioration occurred.

Presence of dementia
The question is whether dementia has previously been diagnosed, with three response options:

- No evidence of dementia
- Questionable dementia
  There is slight deterioration, but not yet to such an extent that the diagnostic dementia criteria are met. The suspicion is that the decline is due to an early dementia process, but 'normal ageing', possibly in combination with the reinforcing effect of other old age conditions, cannot yet be ruled out.
- Clinically diagnosed dementia
  Based on clinical evaluation and multidisciplinary dementia diagnosis. Differential diagnosis has been performed, and other conditions have been excluded as a cause of the deterioration (or have had a minimal influence).

Verbal skills
The client is asked whether they can typically express themselves verbally (in words). This concerns the presence of these skills before there was a decline.
N.B.! 2.1 and 2.2 are only completed if the client can typically express themselves verbally.

Walking skills
The client is asked whether they are typically able to walk. This concerns the presence of these skills before there was a decline.
N.B.! 6.7 and 6.8 are only completed when the client is typically able to walk.

2.2. Dementia-related changes

The second part of the diagnostic aid contains 42 items concerning dementia-related changes, divided into seven symptom domains. The diagnostic aid provides additional explanations or examples for a number of items.

- **1. Changes in cognition**
  - 1.1 Recognizing everyday activities
  - 1.2 Making simple choices
  - 1.3 Recognizing people
  - 1.4 Recognizing objects
  - 1.5 Preference for objects
  - 1.6 Losing objects
  - 1.7 Perceiving distances
  - 1.8 Finding the way
  - 1.9 Recognizing daily rhythm
  - 1.10 Recognizing day and night

- **2. Changes in language and speech**
  - 2.1 Number of words used
  - 2.2 Speaking intelligibly

    N.B.! 2.1 and 2.2 are only completed if the client typically had verbal skills before there was any decline.

- **3. Behavioural changes**
  - 3.1 Anxiety
  - 3.2 Sadness
  - 3.3 Interest in the direct living environment
  - 3.4 Withdrawing
  - 3.5 Waking up during the night
  - 3.6 Daytime sleeping
  - 3.7 Irritable behaviour
  - 3.8 Resisting help that is needed
  - 3.9 Physical aggression
  - 3.10 Restless behaviour
  - 3.11 Stereotypical behaviour
  - 3.12 Compulsive behaviour
  - 3.13 Disinhibited behaviour
  - 3.14 Mood swings
  - 3.15 Hallucinations/delusions

- **4. Changes in eating and drinking**
  - 4.1 Eating/drinking skills
  - 4.2 Eating/drinking appetite
  - 4.3 Choking
  - 4.4 Chewing
  - 4.5 Body weight

- **5. Changes in personal care**
  - 5.1 Personal care

- **6. Changes in motor skills**
  - 6.1 Mobility/transfers
  - 6.2 Balance
  - 6.3 Fall frequency
  - 6.4 Wheelchair use
  - 6.5 Stiffness
  - 6.6 Muscle strength
  - 6.7 Gait
  - 6.8 Walking distance

    N.B.! 6.7 and 6.8 are only completed if the client had typical walking skills, i.e. before there was any decline.

- **7. Additional health problems**
  - 7.1 Incontinence

3. Interview

The diagnostic aid is administered as an interview. Completion by a caregiver or family member is strongly discouraged.

3.1. Interviewer

- The interview is preferably conducted by a psychologist (or a person with a rather similar profession expertise) with experience in administration of evaluation scales.
- Prior to the interview, the interviewer explains the purpose, design, and scoring system to the informant(s).
- The interviewer then presents each item to the informant(s), following the given order of the symptom domains and the items within them.
- The interviewer provides an explanation and examples of an item in order to obtain a picture of that item that is as valid as possible from the informant(s).
- It is also important that the interviewer asks for relevant examples regarding the client for each item.
- If the informants give different answers, the interviewer asks them to reach a consensus.
- For each item, the interviewer can record relevant comments from informants in the note box.

3.2. Informant(s)

The diagnostic aid is preferably conducted with two informants. If this is not possible, one informant can suffice. Informants can be caregivers from the residential facility or daycare centre and family members. A condition is that they can describe changes in the last six months compared to the typical functioning and behaviour of the client. Informants should have known the client for at least two years.

3.3. Client

The client is not present during the interview given the evaluating nature and to encourage honest answers from informants.

4. Scoring

4.1. Score per item

For each item, the interviewer asks whether there has been a observable change in the last six months compared to the typical functioning or behaviour. This is functioning or behaviour that is typical of the client and that they exhibited during adult life before deterioration occurred. The scoring options assume a decline in functioning because this is typical of dementia (American Psychiatric Association, 2022; McKhann et al., 2011; Ries, 2018; World Health Organization, 2018). Items can be scored as:

- Yes, less (score 1)
- No change (score 0)

For each observed change in the last six months, the item score is 1.

For the fifteen behavioural items (3.1 to 3.15) and the item concerning appetite/wanting to drink/drinking (4.2), both an increase and a decrease can be scored because behavioural changes in dementia can take place in both directions. (Dekker et al., 2018; Dekker, Ulgiati, et al., 2021). The same applies to the items concerning preference for objects (1.5) and body weight (4.5). The scoring options for these items are:

- Yes, more (score 1)
- Yes, less (score 1)
- No change (score 0)

If a change has been observed in the last six months, the item score is 1, regardless of the direction of the change (increase or decrease).

Please note!

- A change that has been visible for more than six months while it is not typical is scored as a change.
- Progress in functioning is scored as ‘no change’. When the client uses more words than before, for example, this is not seen as a dementia-related change and is therefore scored as ‘no change’.
- If the behaviour is not present at the time of completion or if the behaviour is present but has not changed, then ‘no change’ is scored.

Because informants do not always have insight into the client’s sleeping habits, there is an additional scoring option for the item awake at night (3.5): ‘unknown, no insight into sleeping habits’, with a score of 0.

For the ten items on cognitive functions (1.1 to 1.10) and the item on eating/drinking skills (4.1), chewing (4.4) and care (5.1), there is the option to score 'not applicable, skill never developed'. 'Not applicable' is only scored if the client has never developed the skill, so it cannot deteriorate and therefore cannot be a symptom of dementia. The item on incontinence (7.1) is scored as 'not applicable' if the client has always been incontinent. This means no score will be assigned to this item.

The items concerning verbal skills (2.1 and 2.2) and walking skills (6.7 and 6.8) are only completed when the client typically possessed these skills before deterioration occurred. Therefore, this is not the case if the client has never developed these skills. These items are only assigned a score in the first case.

4.2. Scores per symptomdomain

The change score per symptom domain is calculated by adding all observed changes within a symptom domain in the last six months. The number of items where a change could be visible is calculated by subtracting the items scored as 'not applicable' from the total number of items within a domain. When an item is scored as 'not applicable', no deterioration can be observed, and it cannot be a dementia symptom. If the items concerning verbal skills and walking skills are not presented to the informant(s) because the client has never developed these skills, they will be included in the calculation as 'not applicable'.

Examples:

Summary section 4: changes in eating and drinking

	Change score	Number of items	Not applicable
Item 4.1: Not applicable, skills never developed	-	-	1
Item 4.2: No change	0	1	-
Item 4.3: Yes, choking ***more often***	1	1	-
Item 4.4: Yes, not chewing ***as well***	1	1	-
Item 4.5: No change	0	1	-
Symptom domain score	**2**	**4**	**1**

Summary section 6: changes in motor skills

	Change score	Number of items	Not applicable
Answer selection question: Client is typically unable to walk.			
Item 6.1: Yes, **decline** in mobility/transfers	1	1	-
Item 6.2: No change	0	1	-
Item 6.3: No change	0	1	-
Item 6.4: No change	0	1	-
Item 6.5: Yes, **more** stiffness in muscles/joints	1	1	-
Item 6.6: Yes, **less** muscle power	1	1	-
Item 6.7: Item not presented and completed because the client never developed walking skills.	-	-	1
Item 6.8: Item not presented and completed because the client never developed walking skills.	-	-	1
Symptom domain score	**3**	**6**	**2**

4.3. Total scores

The total change score is calculated by adding up the change scores per symptom domain. The total number of items in which a change could be visible is also calculated by adding up the number of items per symptom domain. The total number of items scored as 'not applicable' is calculated by adding up all non-applicable items per symptom domain.

Example:

Total scores

	Change score	Number of items	Not applicable
Symptom domain 1. Changes in cognition	3	9	1
Symptom domain 2. Changes in language and speech	-	-	2
Symptom domain 3. Behavioural changes	8	15	-
Symptom domain 4. Changes in eating and drinking habits	2	4	1
Symptom domain 5. Changes in personal care	1	1	-
Symptom domain 6. Changes in motor skills	4	6	2
Symptom domain 7. Additional health problems	0	1	-
Total score	**18**	**36**	**6**

In total, a change was scored for 18 items. Of the 42 items in total, six are not applicable. The total number of items on which a decline could be scored is 36. The following applies: if a client has never developed a skill, it cannot deteriorate and therefore cannot be a dementia symptom. In conclusion, a change was scored for 18 of the 36 items.

4.4. Total percentage change score

The total percentage change score is calculated by dividing the total change score by the total number of items on which a decline could be scored and multiplying the result by 100%.

Example:

Total percentage change score

Formula: total change score/total number of items on which change could be scored x 100%

In the example above, the change score is 18, and the total number of items is 36. By entering this information into the formula (18/36 x 100%), the total percentage score is calculated to be 50%.

4.5. Interpretation

This diagnostic aid identifies dementia-related changes in individuals with SPI(M)D to support the diagnostic process in case of questionable dementia or diagnosed dementia. A dementia diagnosis cannot be made *only* on the basis of the results of the diagnostic aid. Other conditions with dementia-like symptoms can also cause changes. These potential differential diagnoses must be excluded, such as:

- cerebrovascular accident (stroke)
- delirium
- depression
- epilepsy
- hearing problems
- hypothyroidism (underactive thyroid)
- side effects of or poisoning from medication
- pain
- sleep apnea
- vision problems
- vitamin B12 deficiency
- recent life events that affect functioning or behaviour

5. Development

The diagnostic aid was developed within a large-scale study conducted by a multidisciplinary collaboration (see credits). The development of the new diagnostic aid consisted of four steps:

- **Step 1: Identifying observable dementia symptoms in indiviudals with SPI(M)D using five different research methods.**

  1. Literature review
  Only eight studies were found describing dementia symptoms in individuals with SPI(M)D (Wissing, Ulgiati et al., 2022).

  2. Focus groups
  During four focus groups , care professionals and family members discussed how dementia manifests itself in individuals with SPI(M)D. They often observe dementia symptoms in specific daily situations, such as during care, eating and drinking, mobility and transfers, communication, and leisure activities. (Dekker, Wissing et al., 2021).

  3. Survey
  Care professionals and family members indicated in a survey which symptoms they observed in individuals with SPI(M)D and questionable dementia or diagnosed dementia (Wissing, Fokkens et al., 2022).
  In particular, decline in daily living activities and behavioural changes were frequently observed (Wissing, Fokkens et al., 2022).

4. Interviews

Care professionals with extensive experience with individuals with SPI(M)D and dementia were interviewed about observable dementia symptoms in this group. Behavioural changes were the most commonly observed symptoms. Furthermore, the interviewees observed cognitive symptoms mainly in clients with verbal skills and walking skills (Wissing, Fokkens et al., 2022).

5. Clinical records

Data on dementia-related changes were collected from clinical records of individuals with SPI(M)D with and without questionable dementia or diagnosed dementia (Wissing, Hobbelen et al., 2023).

- **Step 2: Identifying relevant items for individuals with SPI(M)D in four existing dementia lists for ID**
  1. Dutch version of the Dementia Scale for Down Syndrome (DSVH)
  2. Behavioural and Psychological Symptoms of Dementia in Down Syndrome (BPSD-DS-2) evaluation scale
  3. Dementia Questionnaire for persons with Mental Retardation (DMR/DLD)
  4. Social competence Rating scale for people with intellectual disabilities (SRZ)

  Of the 193 items in total, 101 appeared to describe relevant symptoms for individuals with SPI(M)D (Wissing, Dijkstra et al., 2022).

- **Step 3: Merging the results from steps 1 and 2**

  Table 1 shows an overview of retrieved symptom categories (step 1) and identified applicable relevant items from existing dementia screening instruments for individuals with ID (step 2). Items were developed for the diagnostic aid for symptom categories found in 4 or 5 research methods. If relevant items for these symptom categories were identified in existing dementia screening instruments, these were used as inspiration for developing the items for the diagnostic aid.

Table 1. Overview (triangulation) of dementia symptoms in individuals with SPI(M)D obtained by five research methods with identified applicable items from existing dementia lists for individuals with ID.

Symptom domains and categories		Research methods					
		Literature[1]	Focus groups[2]	Survey[3]	Interviews[3]	Files[4]	ID-dementiascreening instruments[5]
Changes in cognition	↓ Memory (amnesia)	✔	✔	✔	✔	✔	✔
	↓ Orientation in place	✔	✔	✔	✔	✔	✔
	↓ Performing actions (apraxia)	✔	✔	✔	✔	✔	✔
	↓ Language skills (aphasia)	✔	✔	✔	✔	✔	✔*
	↑ Losing objects	-	✔	✔	✔	✔	✔
	↓ Orientation in time	-	✔	✔	✔	✔	✔
	↓ Understanding visual images/ spatial relationships	-	✔	✔	✔	✔	✔
	↓ Recognition of people/objects/ sounds (agnosia)	-	✔	✔	✔	✔	✔
	↓ Responsiveness	-	✔	✔	✔	✔	✔
	↓ Preference for (favorite) objects	-	✔	✔	✔	✔	-
	↓ Awareness of proper order	-	✔	✔	✔	✔	-

Changes in cognition	↑ Confusion	✔	✔	-	-	-	-
	↓ Concentration	-	-	✔	✔	-	-
	↑ Sensory sensitivity	-	-	✔	✔	-	-
	↓ Social skills	✔	-	-	-	-	-
	↓ Personal habits	✔	-	-	-	-	-
	↓ Planning	-	-	✔	-	-	-
	↓ Problem solving	-	-	✔	-	-	-
	↓ Judgment	-	-	✔	-	-	-
Changes in ADL	↓ ADL	✔	✔	✔**	✔	✔	-
	↓ Eating/drinking skills	✔	✔	-	✔	✔	✔
	↓ Care	✔	✔	-	✔	✔	✔
	↓ Leisure activities	-	✔	-	✔	-	-
	↓ Housework	-	-	-	✔	-	✔
	↓ Climbing stairs	-	-	-	✔	✔	-
Behavioural changes	↑ Irritable behaviour	✔	✔	✔	✔	✔	✔
	↑ Sleeping problems	✔	✔	✔	✔	✔	✔
	↑ Restless and stereotypical behaviour	✔	✔	✔	✔	✔	✔
	↑ Aggressive behaviour	✔	✔	✔	✔	✔	✔
	↑ Apathetic behaviour	✔	✔	✔	✔	✔	✔
	↓ Eating and drinking behaviour	✔	✔	✔	✔	✔	✔
	↑ Anxious behaviour	-	✔	✔	✔	✔	✔
	↑ Obstinate behaviour	-	✔	✔	✔	✔	✔
	↑ Depressive behaviour	-	✔	✔	✔	✔	✔
	↑ Disinhibited behaviour	✔	✔	-	✔	✔	✔
	↑ Psychotic behaviour	-	✔	✔	✔	✔	-
Changes in motor skills	↓ Walking skills	✔	✔	✔	✔	✔	✔
	↑ Wheelchair use	✔	✔	✔	✔	✔	✔
	↑ Muscle cramps	✔	✔	✔	✔	✔	-
	↓ Transfers/mobility	✔	✔	-	✔	✔	✔
	↓ Balance	-	✔	✔	✔	✔	✔
	↑ Fall frequency	-	✔	✔	✔	✔	✔
	↓ Chewing/swallowing	-	✔	✔	✔	✔	✔
	↑ Stiffness	-	✔	✔	✔	✔	-
	↓ Muscle strength	-	✔	✔	✔	✔	-
	↓ Movement speed/quality	-	-	✔	✔	✔	✔
Medical comorbidities	↑ Epilepsy	✔	✔	✔	✔	✔	✔
	↑ Incontinence	-	✔	✔	✔	✔	-
	↓ Weight	-	✔	✔	✔	✔	-

Symptom categories and applicable items are classified into five domains according to diagnostic dementia criteria (American Psychiatric Association, 2022; McKhann et al., 2011; World Health Organization, 2018) and scientific literature (Dekker et al., 2018, Dekker, Ulgiati et al., 2021; Ries, 2018; Strydom et al., 2010). Behaviour can either increase or decrease; only the most prominent change is shown in the table. ✔ indicates that a symptom category has been found with the relevant research method and/or that one or more applicable items in existing dementia lists for individuals with intellectual disabilities (ID) have been identified. If a symptom category was found using 4 or 5 of the research methods, a new item was developed for this (symptom categories marked white). Symbols: ↑, increase compared to typical functioning; ↓, decrease compared to typical functioning; *, applicable items identified for individuals with verbal skills (typical); **, changes in activities of daily living (ADL) were not broken down in the survey. References: 1, Wissing, Ulgiati, et al., 2022; 2, Dekker, Wissing, et al., 2021; 3, Wissing, Fokkens, et al., 2022; 4, Wissing, Hobbelen et al., 2023; 5, Wissing, Dijkstra, et al., 2022.

- **Step 4: Developing new items**
  Based on the combined results from steps 1 and 2 and after a pilot with a draft version, 45 items were included in the diagnostic aid for dementia in individuals with SPI(M)D. This has been included in the other items because a decline in memory is difficult to determine in individuals with SPI(M)D.
  A decline in the performance of daily activities (apraxia) is asked about in the items concerning eating/ drinking skills and care, because the focus groups showed that this symptom is mainly observed during these specific daily situations. A change in responsiveness is asked about in the items concerning behavioural changes.

Recognizing people

Observable dementia symptoms in SPI(M)D

- *Focus groups*
  ↓ recognition of supervisors
- *Interviews*
  ↓ recognition of supervisors
  ↓ recognition of family members
- *Survey*
  ↓ recognition of persons
- *Literature review*

Relevant items from existing lists

- Recognizing family/friends (DSVH)
- Recognizing staff (DMR)
- Recognizing persons (DMR)

Newly developed item:

1.3 **Recognizing people**
Examples: caregivers, family members, other clients
Has there been a change in recognizing people in the last six months?

O Yes, less recognition of people
o No change
o Not applicable, skill never developed

Notes:

- **Step 5: First practical test**
  The first version of the diagnostic aid, consisting of 45 items, was subjected to an initial practical test (Wissing, Koudenberg et al., 2023). Interviews were conducted with informants for individuals with SPI(M)D without dementia (n=18), with questionable dementia (n=10), and with a diagnosis of dementia (n=8). Validity and reliability results of the practical test were very promising. With regard to the discriminatory capacity, a trend was found for the item, domain, and total scores, with individuals with a dementia diagnosis scoring the most changes and individuals without dementia the least. Practical experiences with the diagnostic aid were mainly positive. Following this practical test, three items (panic, muscle cramps, epilepsy) were removed because almost all participants in the questionable dementia group and dementia diagnosis group showed no change. The improved version of the diagnostic aid with 42 items can be used in practice. However, further research is needed to investigate the reliability and discriminative ability further.

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Credits

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