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Research report

Prevalence of depression and anxiety in older users of formal Dutch intellectual disability services

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ABSTRACT

Background: Little is known about the prevalence of depression and anxiety among older people with intellectual disabilities (ID). Therefore, the aim of this study was to study the prevalence of depression and anxiety in this population.
Method: This study is a cross-sectional epidemiologic multicentre study which was part of the "Healthy Ageing and Intellectual Disabilities" study. The study population consisted of 990 participants aged ≥50 years with borderline to profound ID which were screened with self-report and informant-report instruments; 290 of them were assessed with a standardized diagnostic interview.
Results: Depressive symptoms were prevalent in 16.8% (95% CI: 14.4–19.1) and significantly associated with higher age. Anxiety symptoms were prevalent in 16.3% (95% CI: 14.0–18.6) and significantly associated with female gender and borderline to mild ID. Major depressive disorder was prevalent in 7.6% (95% CI: 5.2–11.0), anxiety disorders in 4.4% (95% CI: 2.6–7.0) and both in 0.7% (95% CI: 0.2–1.6). There was no relationship with gender, age or level of ID.
Limitations: For most participants, informant-report instruments have been used instead of self-report to overcome communication difficulties or inabilities. Also, a standardized psychiatric diagnostic interview has been used instead of psychiatric diagnoses made by an experienced psychiatrist.
Conclusion: Prevalence of major depressive disorder is higher and of anxiety disorders lower than in the Dutch general older community-dwelling population.

1. Background

In contrast to other research areas, comparatively little research has focused on the prevalence of common Axis I psychiatric disorders among older people with intellectual disabilities (ID). Life expectancy of this population is increasing, implying a growing number of older people with ID with age-related physical and mental health problems (Woittiez and Crone, 2005; Perkins and Moran, 2010). In the community-dwelling older population (55+ years), depression and anxiety are common, with increased depressive symptoms in 13.5–14.9%, increased anxiety symptoms in 14.9–18.5%, major depression in 1.8–4.0% and anxiety disorders in 10.2–11.6% (Beekman et al., 1995; Beekman et al., 1998, 1999; Mehta et al., 2003; Byers et al., 2010). In smaller groups of older people with ID (aged ≥50 years), prevalence rates of 4.8–5.4% for depression and 2.8–5.7% for anxiety disorders have been found (Cooper, 1997; Patel et al., 1993; Reid et al., 2011). Results from the general population cannot be directly translated to older people with ID, because of substantial differences between both populations. In older people with ID, the prevalence of depression and anxiety may be expected to be high, given their longstanding disability, associated impairment and multiple co-morbid health problems (Pope and Tarlov, 1991). On the other hand, group-home living and higher psychotropic drug use may reduce depression and anxiety (Stolker et al., 2002). In addition, people with ID may present psychiatric symptoms differently and have limited or no abilities to report symptoms (Einfeld and Tonge, 1999). These diagnostic problems may limit the number of ICD-10 depression and anxiety diagnoses in people with ID (Reid et al., 2011). Because such diagnostic problems increase with severity of ID (Marston et al., 1997), lower prevalence rates of psychiatric disorders, diagnosed according to standardized diagnostic criteria, are to be expected in people with more severe ID.

The aims of this study were to examine prevalence rates of increased depressive and anxiety symptoms, major depression, and anxiety disorders in older adults with ID, as well as their associations with gender, age and level of ID and compare the

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prevalence of major depression and anxiety disorders with data from the general Dutch older population.

2. Method

2.1. Design and study population

This study was part of the cross-sectional 'Healthy Ageing and Intellectual Disabilities' (HA-ID) study, performed in a consort of three large formal ID services in the south–west of The Netherlands. These services provide care to a broad spectrum of clients, covering different levels of support needs: centralized residential accommodations, community-based homes, day activity centres and supported independent living. The distribution of clients primarily receiving care (35%) and clients primarily receiving support (65%) is similar as in the total Dutch population using formal ID services (Hilgenkamp et al., 2011). People with ID unknown to formal ID-services are not part of our study population.

For the HA-ID study, all clients aged 50 years or over were invited to participate. The age-limit of 50 years was chosen, because it is generally accepted, though not proven, that people with ID, and not only people with Down syndrome, show signs of premature ageing (Patel et al., 1993; Perkins and Moran, 2010). Of the general Dutch population aged ≥ 50 years, 0.5% is known to formal ID services (Woittiez and Crone, 2005) of which 10% receives care or support from one of the services participating in this study. Recruitment and the informed consent-procedure have been described in more detail elsewhere (Hilgenkamp et al., 2011). In short, all clients receiving care or support on the 1st of September 2008 have been invited to participate in the HA-ID study. Except for ages ≥ 50 years, no exclusion criteria have been used. Of the total number invited, 49.7% of the clients or their legal representatives gave informed consent to participate of which 98.2% actually participated. Inclusion and participation of the current study population are described in Fig. 1. This study has been approved by the Medical Ethical Testing Committee of the Erasmus University Medical Centre at Rotterdam, The Netherlands (MEC nr: 2008-234).

2.2. Procedure

Because psychiatric diagnostic assessment of all participants is too time consuming in large-scale epidemiologic research, depression and anxiety disorders were diagnosed with a two-step diagnostic procedure. To evaluate increased depressive and anxiety symptoms, three self-report and two informant-report screening instruments for depression and anxiety were selected after a review of the literature, evaluation of psychometric properties, and consultation of experts on applicability for large-scale assessment of adults with ID. Participants who have borderline, mild or moderate ID were considered capable of self-report if they used comprehensible speech and could oversee the time-frame of at least one week. Self-report instruments were applied by eight trained interviewers. All interviewers had a background in psychological testing and have been additionally trained in applying the instruments used in this study. Informant-report instruments were completed in writing by professional caregivers who knew the participant for at least three months. Increased depressive or anxiety symptoms were defined as a score above the cut-off of at least one depression or anxiety screening instrument respectively. Cut-off scores were based on published guidelines by the questionnaires' developers or results of earlier studies.

All participants with at least one score above the cut-off of one of the screening instruments were further examined with a standardized psychiatric interview within two weeks. Because published sensitivities of the screening questionnaires vary between 71% and 84% and specificities between 52% and 78%, and because at the start of the study, criterion validity for the translated instruments still had to be evaluated by us, we also performed the psychiatric interview in an additional random sample of participants with scores below all cut-off scores. This procedure made it necessary, to extrapolate the results of participants assessed with the diagnostic interview to all other participants, taking their screening results into account, in order to estimate prevalence rates of major depression and anxiety disorders. To illustrate this, the extrapolation procedure for major depression is presented in Fig. 2. The 95% confidence intervals of the prevalence rates were calculated with a Bayesian method (Lunn et al., 2000).

Gender, age, level of ID, mobility, genetic syndromes, autism spectrum disorder and psychotropic medication use (Anatomical Therapeutic Chemical (ATC) classification: N05B and N06A) were retrieved from the participants' files. The ATC classification system is an international system of the WHO which classifies drugs in groups according to the organ or system on which they act and their chemical, pharmacological and therapeutic properties (WHO Collaborating Centre for Drug Statistics Methodology, 2011). Data on psychotropic medication and genetic syndromes were obtained through the participant's physician and data on level of ID and autism spectrum disorders through the participant's psychologist or behavioural therapist. In The Netherlands, level of ID is assessed with IQ-testing, using varying tests according to the abilities of the person with ID.

2.3. Measures

For depression, participants capable of self-report were screened with the Inventory of Depressive Symptomatology Self Report (IDS-SR) (Rush et al., 1986) and participants incapable of self-report with the Dutch informant-report Signalizing Depression List for people with Intellectual Disabilities (SDL-ID) (Roeden, 1989b). The IDS-SR has been developed for the general population and we adapted its phrasing for better applicability. In people with ID, its internal consistency and test–retest reliability are good ($\alpha=0.89$ and $ICC=0.91$) and the validity is satisfactory (sensitivity 71% and specificity 54%) (Bassa, 2011). Its score ranges from 0 to 84. We used a cut-off score of ≥ 18 (Rush et al., 1996). The SDL-ID's internal consistency and interrater reliability in older people with ID are good ($\alpha=0.77$ and $r=0.87$) (Roeden, 1989a). The score on the SDL-ID ranges from 18 to 72. We used a cut-off score of ≥ 35 (Schoonhoven, 2001). In a pilot study, the IDS-SR and SDL-ID were completed both for 23 participants, showing 100% correspondence for the used cut-off scores.

For anxiety, all participants were screened with the Anxiety, Depression, And Mood Scale (ADAMS) (Esbensen et al., 2003). The ADAMS is an informant-report instrument, specifically developed for adults with ID, consisting of five subscales developed for adults with ID. The total ADAMS was completed, but the general anxiety subscale was used for this study. This subscale's internal consistency, test–retest reliability and interrater reliability are good ($\alpha=0.88$, $ICC=0.86$ and $ICC=0.74$) and its validity is satisfactory (sensitivity 80–82% and specificity 65–78%) in older people with ID (Hermans et al., 2012). The score on the general anxiety subscale ranges from 0 to 21. We used the cut-off scores recommended by Hermans et al. (2012): ≥ 10 for participants without autism and ≥ 14 for those with an autism-spectrum disorder. Participants capable of self-report were also screened with the Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID) (Mindham and Espie, 2003) and the

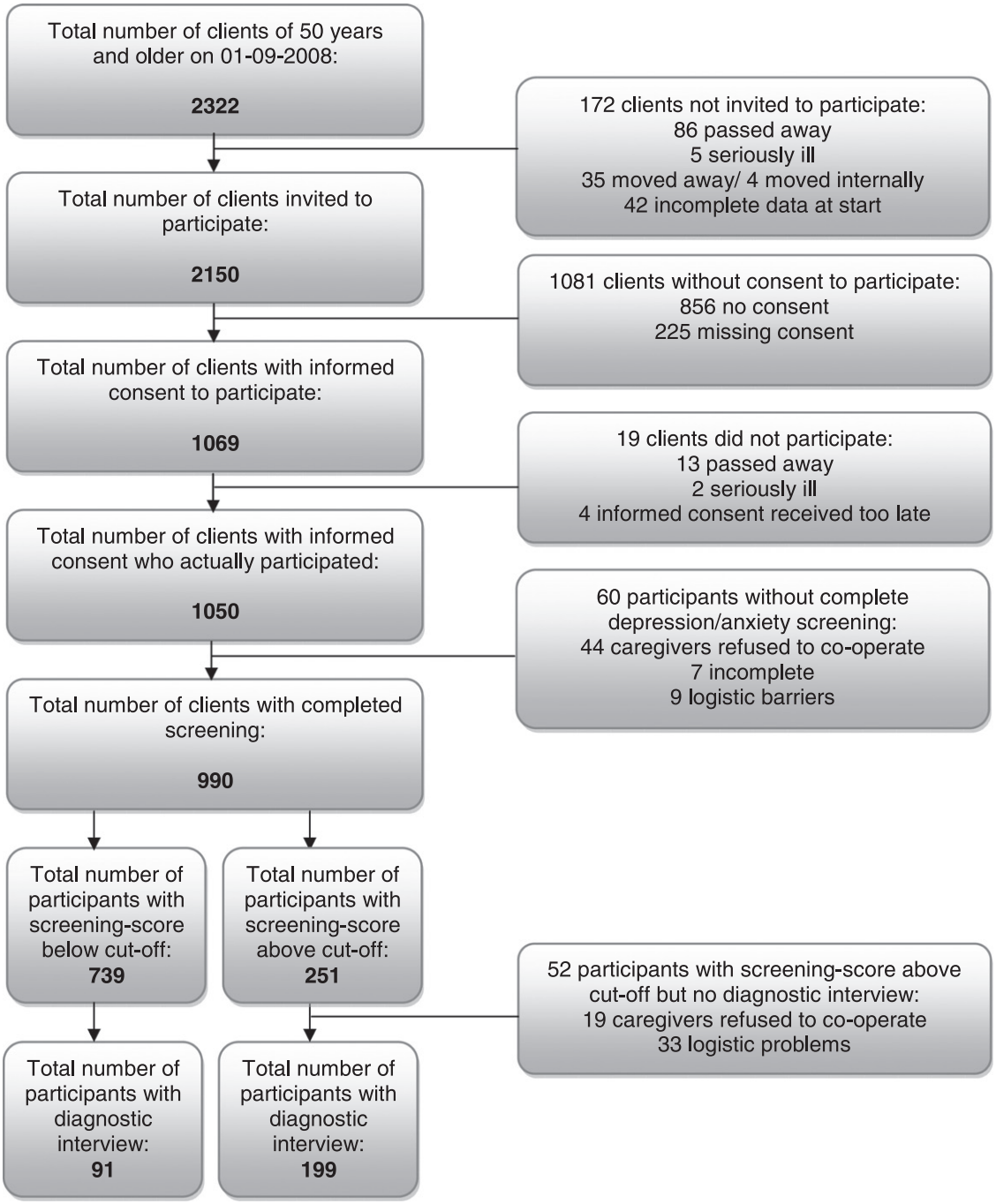

Fig. 1. Flow-chart inclusion of study population.

Anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A) (Zigmond and Snaith, 1983), in addition to the ADAMS. The GAS-ID has been developed for people with ID and its internal consistency and reliability are good ($\alpha = 0.86$ and $ICC = 0.89$) and its validity is sufficient (sensitivity 84% and specificity 52%) (Mindham and Espie, 2003). Its score ranges from 0 to 54. We used a cut-off score of ≥ 17 (Hermans et al., in press). The HADS-A has been developed for the general population. Standardized explanatory information was added to four items (2, 3, 6 and 7) for better comprehension. Psychometric properties are fair to good in the general older population (Spinhoven et al., 1997; Croon et al., 2005). Its score ranges from 0 to 21. We used a cut-off score of ≥ 8, as recommended for the Dutch population (Croon et al., 2005).

Psychiatric diagnoses were made using the Dutch version of the Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD) (Moss et al., 1994). The PAS-ADD is a semi-structured, diagnostic interview which focuses on the more common axis I disorders, and has been based on the Schedules for Clinical Assessment in Neuropsychiatry (SCAN) (World Health Organization, 1992). Current diagnoses of Major Depressive Disorder (MDD), general anxiety disorder, panic disorder, agoraphobia, social phobia and specific phobia based on ICD-10 criteria (World Health Organization, 1994) can be made with the PAS-ADD. Its psychometric properties are satisfactory (Costello et al., 1997; Moss et al., 1997). It has been validated in people with ID against expert psychiatric diagnosis. The questions of the PAS-ADD interview can be answered

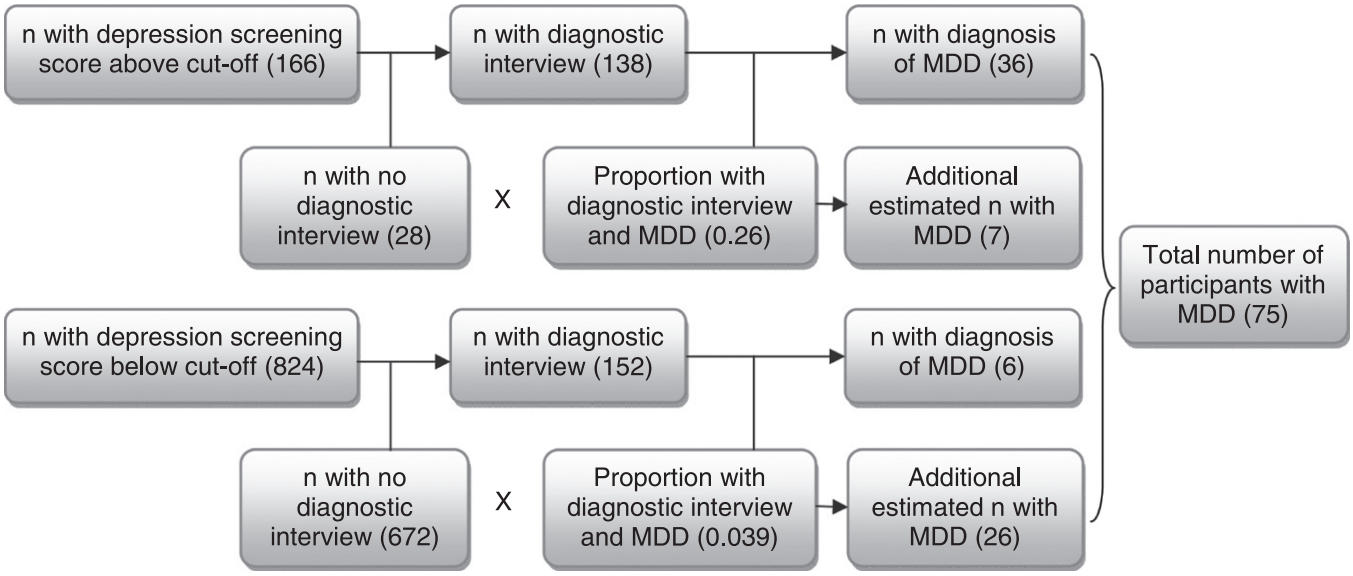

Fig. 2. Extrapolation procedure of major depressive disorder (MDD).

by people with ID, their caregivers or both. The interviews were applied by eighteen psychologists and behavioural therapists, experienced in working with older people with ID, who were additionally trained in recognizing psychiatric disorders and the interview's system. These interviewers were blind for the result of the screening and had no prior knowledge of the participants, except for some exceptional cases in which the interviewer was involved in the participant's usual care. The PAS-ADD interview does not include a differential diagnosis of dementia, but all trained psychologists and behavioural therapists were instructed to score 'uncertain' if a symptom was impossible to score due to confounding factors, such as dementia. Items have only been scored as 'uncertain' if there were considerable doubts of the justifiability to score the symptom as present even after extensive exploration of the symptom. 'Uncertain' symptoms were excluded from the final diagnostic decision.

2.4. Statistical procedure

All analyses were done with the Statistical Package for the Social Sciences 17.0. First, non-response analyses were done using a *t*-test for age and X^2-tests for gender and residential setting.

To enable comparison with other studies, point prevalence rates of increased depressive and anxiety symptoms, major depression and anxiety disorders were calculated for the total study population, as well as for subgroups aged 55 years or over, aged from 50 to 65 years, and participants aged 65 years or over. Prevalence rates will be presented with 95% confidence intervals. The prevalence rates of major depression and anxiety disorders were compared to findings of the Longitudinal Aging Study Amsterdam in the general Dutch older population, aged 55–85 years, by calculating Standardized Morbidity Ratios (SMR) taking age and gender distribution into account (Liddell, 1984). SMR is a ratio between the observed and expected numbers of individuals with poor health. An SMR (observed/expected) of 1 means similar prevalence rates.

Logistic regression analyses were used to study the association between gender, age, level of ID (borderline/mild, moderate, severe/profound) and Down syndrome (independent variables) and increased depressive symptoms, increased anxiety symptoms, MDD and anxiety disorders (dependent variables). All independent variables were simultaneously entered into the regression to control for their influence on other independent variables in the regression.

Table 1
Characteristics of the study population (n=990).

Characteristic	*n*	%	Median (IQR)
Gender			
Male	508	51.3	
Female	482	48.7	
Age (yrs)			
50–65	685	69.2	
≥65	305	30.8	
Level of ID			
Borderline (IQ=70–84)	31	3.1	
Mild (IQ=50–69)	211	21.3	
Moderate (IQ=35–49)	471	47.6	
Severe (IQ=20–34)	165	16.7	
Profound (IQ<20)	89	9.0	
Unknown	23	2.3	
Accommodation			
Central location[a]	536	54.1	
Community home	403	40.7	
Living with family	7	0.7	
Independent living	44	4.4	
AEtiology of ID[b]			
None	617	62.3	
Down syndrome	142	14.3	
Other syndromes	67	6.8	
Unknown	46	4.6	
Psychotropic drug use[c]			
Antidepressants	99	10.0	
Anxiolytics	97	9.8	
Screening questionnaires completed			
SDL-ID	789	79.7	27.00 (9.00)
General anxiety (ADAMS)	975	98.5	4.00 (6.00)
IDS-SR	215	21.7	7.00 (9.00)
GAS-ID	215	21.7	10.00 (8.00)
HADS-A	217	21.9	3.00 (4.00)

ADAMS, Anxiety, Depression, And Mood Scale; SDL-ID, Signalizing Depression List for people with Intellectual Disabilities; IDS-SR, Inventory of Depressive Symptomatology Self Report; GAS-ID, Glasgow Anxiety Scale for people with an Intellectual Disability; HADS-A, Anxiety subscale of the Hospital Anxiety and Depression Scale

[a] Central location refers to accommodations in a sheltered environment with surrounding health facilities (e.g., physician, dentist, movement therapy centre)

[b] 118 missing.

[c] 115 missing.

All independent variables should be continuous or dichotomous; therefore dummy variables were constructed for the level of ID. Participants with a diagnosis of dementia, made by both their physician and their psychologist or behavioural therapist, were excluded from the regression analysis with increased depressive symptoms ($n=41$), because of the resemblances of depression and dementia symptoms and the high prevalence of dementia in Down syndrome. The magnitude of association of the independent variables with increased depressive and anxiety symptoms and disorders were compared by calculating odd's ratios. Multicollinearity refers to a high correlation between independent variables, which is not preferred in regression analysis, and was checked for all independent variables with the variance inflation factor (VIF) of linear regression analysis (Craney and Surles, 2007). The proportion of the dependent variable which is explained by the factors in the model was calculated with R^2 of Hosmer and Lemeshow (1989).

3. Results

The screening questionnaires were completed for 990 participants (Fig. 1) with a mean age of 61.1 years (S.D.=8.2). Non-participants ($n=1332$) and participants were not significantly different for age ($t=0.27$, $p=0.79$), but men ($X^2=4.72$, $p<0.05$) and people living independently ($X^2=44.22$, $p<0.05$) were slightly underrepresented in the sample. The diagnostic interview was applied to 199 participants with at least one score above the cut-off and 91 participants with low screening scores (Fig. 1). These 290 participants did not significantly differ on age, gender or level of ID from the other participants with screening scores above or below the cut-off (data not shown). Time between screening and diagnostic interview was four weeks on average. Characteristics of the study population are described in Table 1. In the regression analyses, there was no multicollinearity; VIFs were between 1.01 and 1.79.

3.1. Increased depressive and anxiety symptoms

The prevalence rates of increased depressive and increased anxiety symptoms are presented in Table 2. Higher age was significantly associated with depressive symptoms and borderline/mild ID with anxiety symptoms (Table 3).

3.2. Major depressive disorder (MDD) and anxiety disorder

The point prevalence of MDD was 7.6% and anxiety disorders 4.4% (Table 2). For the total population, the prevalence rates of the specific anxiety disorders were generalized anxiety disorder (GAD): 0.5% (CI: 0.2–1.1), phobia: 3.3% (CI: 1.8–5.7) and panic disorder: 1.8% (CI: 0.7–3.6). Age, gender, level of ID and Down syndrome were not significantly associated with depression or anxiety disorders (Table 3). Compared to the Dutch general older community-dwelling population (Table 4), the SMR of MDD was 5.15 (CI: 3.93–6.63) and of anxiety disorders 0.59 (CI: 0.42–0.80).

MDD, as diagnosed during the study, had also been reported by the participant's psychologist or behavioural therapist in 37.5% and anxiety disorder in 26.3%. Comparison with drug treatment was not possible, because prescription indications have not been scored, whereas psychotropic drugs can be prescribed for different indications, including epilepsy and challenging behaviour.

Table 2
Prevalence rates (95% CI) of increased depressive and anxiety symptoms and disorders.

	Age groups			
	≥ 50 years	≥ 55 years	50–65 years	≥ 65 years
n (*n* with diagnostic interview)	990 (290)	732 (221)	685 (183)	305 (107)
Symptoms				
Depressive symptoms	16.8% (14.4–19.1)	17.4% (14.7–20.3)	15.5% (12.8–18.4)	19.7% (15.4–24.6)
Anxiety symptoms	16.3% (14.0–18.6)	16.5% (13.9–19.4)	15.6% (13.0–18.6)	17.7% (13.6–22.5)
Co-occurring depressive and anxiety symptoms	7.7% (6.1–9.5)	8.1% (6.2–10.3)	7.5% (5.6–9.7)	8.2% (5.4–11.9)
Disorders				
Depression (MDD)[a]	7.6% (5.2–11.0)	8.1% (5.2–12.0)	7.5% (4.3–11.8)	8.9% (4.5–13.7)
Anxiety disorders	4.4% (2.6–7.0)	5.2% (2.9–8.5)	3.8% (1.8–6.8)	5.6% (2.6–10.8)
Co-occurring MDD and anxiety disorders	0.8% (0.3–1.5)	0.8% (0.3–1.9)	0.7% (0.2–1.7)	1.0% (0.1–2.4)

[a] MDD=major depressive disorder.

Table 3
Results of the logistic regression analyses with depression and anxiety for the total population.

	Increased depressive symptoms	Increased anxiety symptoms	Major depressive disorder	Anxiety disorders
n	820	862	241	241
Model fit				
Chi-square	12.66*	39.01**	6.27	5.61
Degrees of freedom	5	5	5	5
R^2	1.8%	5.2%	3.3%	4.4%
Odds ratios (95% CI) of independent variables				
Female	0.98 (0.67–1.44)	1.46 (0.99–2.14)	0.79 (0.52–2.34)	1.84 (0.66–5.16)
Age in years	1.04* (1.02–1.06)	1.00 (0.98–1.02)	1.02 (0.97–1.07)	1.01 (0.95–1.07)
Borderline/mild ID (versus moderate-profound ID)	0.66 (0.38–1.17)	3.73** (2.14–6.52)	0.54 (0.17–1.67)	1.45 (0.41–5.19)
Moderate ID (versus borderline-profound ID)	0.87 (0.56–1.37)	1.62 (0.95–2.76)	1.16 (0.45–3.01)	0.47 (0.12–1.86)
Down syndrome	1.10 (0.60–2.00)	0.59 (0.31–1.13)	0.33 (0.07–1.53)	1.02 (0.20–5.24)

* $p<0.05$.
** $p<0.01$.

Table 4
Comparison with the Dutch older general community-dwelling population.

		55–64 years			65–74 years			75–85 years		
		Male	Female	All	Male	Female	All	Male	Female	All
LASA[a]	*n*	465	499	964	442	512	954	571	567	1138
	Major depression (%)	1.1	1.6	1.6	0.9	2.9	2.0	2.1	3.2	2.6
	Anxiety disorders (%)	4.2	9.1	6.9	10.3	16.6	13.9	7.4	13.7	10.4
HA-ID[b]	*n*	237	208	445	111	104	215	30	35	65
	Major depression (%)	10.6	5.8	8.3	7.2	5.8	6.5	10.0	17.1	13.8
	Anxiety disorders (%)	6.3	3.4	4.9	5.4	6.7	6.0	3.3	5.7	4.6

[a] LASA = Longitudinal Aging Study Amsterdam, data retrieved from Beekman et al. (1995, 1998).
[b] HA-ID = Health Ageing and Intellectual Disability.

4. Discussion

This is the first large-scale study into increased depressive and anxiety symptoms and diagnoses of major depressive disorder and anxiety disorders among older people with ID, showing prevalence rates of 17% for increased depressive symptoms, 16% for increased anxiety symptoms, 8% for major depressive disorder (MDD), 4% for total anxiety disorders and 1% for co-morbid depression and anxiety disorders. The prevalence of MDD is higher than that in the Dutch general older population (SMR 5.15), but the prevalence of anxiety disorders is lower (SMR 0.59). Symptoms as well as disorders seem to increase with age, but this is only significant for depressive symptoms, whereas increased anxiety symptoms are associated with borderline or mild ID. A majority of depression and anxiety disorders were unknown to the participants' psychologists or behavioural therapists.

Both depression and anxiety disorders have been studied in smaller samples of older people with ID. Reid et al. (2011) studied anxiety in 364 adults aged ≥ 50 years using the Present Psychiatric State for Adults with Learning Disabilities. The prevalence of anxiety disorders was 2.7% (CI: 1.5–5.0), which is similar to our findings. Cooper (1997) studied 134 adults aged ≥ 65 years, also with the Present Psychiatric State for Adults with Learning Disabilities, and found that depression was prevalent in 6.0% (CI: 3.1–11.3), which is similar to our findings, and generalized anxiety disorder (GAD) in 9.0% (CI: 5.2–15.0), which is much higher than our 0.5% prevalence. Patel et al. (1993) studied 105 adults aged ≥ 50 years using the PAS-ADD and found that depression was prevalent in 4.8% (CI: 2.1–10.7), overlapping our study findings, and anxiety disorders in 5.7% (CI: 2.6–11.9), which also overlaps our 4% prevalence. The differences in used diagnostic instruments and characteristics of the study populations require cautious comparison, but it seems that our prevalence rates of major depression and anxiety disorders are similar to those found in earlier studies, except for GAD, which is less prevalent in our study.

As described in the introduction, we had expected to find higher levels of depression and anxiety among older people with ID than those found in the general population. Considering major depressive disorder, this was indeed what we found (Beekman et al., 1995). The prevalence is almost comparable to that in the general nursing-home population aged ≥ 55 years (Jongenelis et al., 2004) which is a frail population with considerable health problems. This may imply an increased vulnerability of older people with ID. For anxiety disorders, we found lower prevalence rates while the prevalence of increased anxiety symptoms appears similar (Beekman et al., 1998). Remarkably, this trend has also been found in nursing-home residents (Smalbrugge et al., 2005). Smalbrugge et al. (2005) speculated that this may have been caused by specific characteristics of the nursing-home environment, such as a fixed daily routine and professional care, which is also applicable to most people with ID receiving care or support from formal services. Moreover, professional caregivers in ID services are specialized in limiting stressful situations and the availability of support or care may in itself decrease anxiety as well. The lower prevalence could also be explained by the high psychotropic and anti-epileptic drug use by people with ID (Stolker et al., 2002; Espie et al., 2003), because these drugs may have a calming effect. A final explanation could be that recognition of physical or cognitive symptoms of anxiety (e.g., pounding heart, worrying, etc.) by informants may be difficult and therefore limited, while such symptoms are characteristic for anxiety disorders. This could also explain the higher prevalence of increased anxiety symptoms in people with borderline or mild ID, who are more often capable of self-report. Their comparatively low need of professional support and higher community participation may lead to more exposure to stressful conditions and increase anxiety (Dusseljee et al., 2011).

The low recognition of depression and anxiety in clinical practice is a cause of concern. A low detection rate implies almost certainly also a low treatment rate. Therefore, pro-active detection and intervention should be stimulated by the provision of well-evaluated screening instruments and training of professionals. Professionals working in clinical practice should realize that increased depressive and anxiety symptoms require attention too, because they are common in older people with ID and may be a sign of clinically relevant conditions, which can be relieved with treatment.

Although the diagnostic procedure of this study was carefully prepared, it still had some limitations, connected with the large scale of the study on one hand, and with problems that are typical of research in the ID field, on the other. We had to partially rely on screening to limit the number of complete psychiatric interviews, which made extrapolation inevitable. Moreover, the PAS-ADD interview does not include all psychiatric diagnoses (e.g., obsessive-compulsive disorder) and is based on standard diagnostic criteria for depression and anxiety, while adapted diagnostic criteria may be more suitable to detect psychiatric disorders in people with ID (Reid et al., 2011). Furthermore, minor depression could not be diagnosed, because depressive symptoms were only asked for a preceding period of four weeks. Clinical tasks of locally trained diagnosticians competing with research tasks prolonged the aimed period of two weeks between screening and diagnostic interview, which may have caused a discrepancy because of the natural course of depression and anxiety. Typical for this field is the necessity of reliance on informant-report for most participants, as is the reliance on legal representatives for informed consent, resulting in a relatively low response rate for this extensive health study, in spite of a thorough communication procedure. Despite the low response rate, the study population was an almost representative sample of the entire population of ≥ 50 years receiving care or support from formal Dutch intellectual disability services. Men and people living independently

were slightly underrepresented. It seems that the results are still generalizable to the total population known to ID services, because both characteristics were not related to depression and anxiety. Nevertheless, living situation may be partly related to level of ID and this is associated with increased anxiety symptoms. However, we were not able to compare the level of ID of non-participants with those of participants, because this information was unknown for non-participants.

Nevertheless, it is important to realize, that these limitations may have resulted into an underestimation rather than an overestimation of the prevalence rates. In conclusion, this epidemiologic study led to relevant insights into prevalence of mental health problems of older people with ID.

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Conflict of interest

All authors declare that they have no conflicts of interest.

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