Depression and Anxiety

in older adults with intellectual disabilities

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The work presented in this thesis was financially supported by:
The Netherlands Organisation for Health Research and Development (ZonMw) (grant number 57000003)

Healthcare organization for people with intellectual disabilities:
Amarant, Tilburg, the Netherlands

Abrona, Huis ter Heide, the Netherlands

Ipse de Bruggen, Zwammerdam, the Netherlands

ISBN: 978-94-6169-232-0
Cover design: Sabine Aarts, www.sarts.nl
Layout and printing: Optima Grafische Communicatie, Rotterdam, the Netherlands

Depression and anxiety in older adults with intellectual disabilities

Depressie en angst bij ouderen met een verstandelijke beperking

Proefschrift

ter verkrijging van de graad van doctor aan de Erasmus Universiteit Rotterdam op gezag van de rector magnificus

Prof. dr. H.G. Schmidt

en volgens besluit van het College voor Promoties.

De openbare verdediging zal plaatsvinden op
Woensdag 30 mei 2012 om 9:30 uur
door

Heidi Hermans
geboren te Breda

PROMOTIECOMMISSIE

Promotor:	Prof. dr. H.M. Evenhuis
Overige leden:	Prof. dr. J.J. van Busschbach
	Prof. dr. A.T.F. Beekman
	Prof. dr. M.J. Jongmans

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Chapter 1

Introduction

GENERAL INTRODUCTION

For years, psychiatric problems in the general population have been hardly studied in epidemiologic research. This was one of the conclusions of the Dutch Advisory Committee on Health Research in a report about research into chronic illness, in the early nineties. Consequently, this committee advised the Dutch Health ministry to invest in epidemiologic studies into depression and anxiety. Based on the outcomes, substantial improvement of healthcare was to be expected. Rationale for the choice of these topics was the relative scarcity of research in this field, compared to the immense emotional and financial burden of psychiatric disorders for patients and society.[1]

The subsequent grant programme has resulted in collaborations of scientific and healthcare organizations and corroboration of existing initiatives. As a result, knowledge about the prevalence, negative consequences and biological, medical and psychosocial risk factors of both disorders has considerably increased. It appeared that depression and anxiety disorders have a negative influence on cognitive functioning, functional abilities and the development and recovery from chronic diseases. It also appeared that both disorders often remained unrecognised and therefore untreated, especially in older people.[2]

People with intellectual disabilities (ID) have been excluded from these studies in the general population and these results can not be merely translated to people with ID due to substantial differences between both populations. People with ID suffer from longstanding disability, have co-morbid health problems, live in group homes and use more often psychotropic drugs than the general population.[3, 4] Therefore, research in people with ID is important.

In the last decade, research among people with ID has increased. In 2005, the Dutch Advisory Committee on Health Research advised to support health research among people with ID.[5] Focus of this new research should be, among other things, on ageing, because the prolonged lifespan of people with ID led to an increasing number of older people.[6-8] In people with ID, ageing comes often with health problems, motor disabilities and functional decline.[9, 10] These age-related co-morbidities are primary a burden for older people with ID, but ID services also face the problem of an increasing number of older clients with age-related co-morbidities resulting in additional costs, while ID care already accounts for 8.2% of the total Dutch healthcare costs.[11] This increasing group of older people with ID may require substantial differences in their care or support needs. Knowledge about diagnostics, prevalence rates and associated factors of problems is necessary to arrange high-quality, efficient care.

This need of knowledge led to the founding of a consort, consisting of three ID care providers, Amarant, Abrona and Ipse de Bruggen, and the department of Intellectual

Disability Medicine of the Erasmus University Medical Centre Rotterdam. The main goals of this consort were to increase knowledge of health of older people with ID, to enhance effective participation of clients in healthcare policies and research, and to increase specific expertise and scientific attitude of staff. In 2008, the first step to reach these goals has been made by starting an epidemiologic study, titled 'Healthy Ageing and Intellectual Disability'.

THE HEALTHY AGEING AND INTELLECTUAL DISABILITY STUDY

The 'Healthy Ageing and Intellectual Disability' (HA-ID) study is a large-scale, cross-sectional epidemiologic study with three sub-themes: physical activity and fitness, nutrition and nutritional state, and depression and anxiety. The selection of studied health topics has been based on consultations of client groups and professionals, next to the scientific literature about age-related health problems in the general population. The aims of this study were 1) to perform baseline assessments of prevalence rates and secondary health effects for each sub-theme, 2) to identify risk groups, 3) to select and evaluate diagnostic tools to assess health problems.[12]

At the start of the study, the consort provided support or care to 2322 clients aged 50 years or over, which was 10% of the total Dutch client population aged 50 years or over of formal ID services.[7] Of them, 1050 clients participated in the HA-ID study. Experts in project organization, managers of the involved care organizations and professionals working in clinical practice have been involved in the organization of a broad selection of measurements. Professionals (e.g. psychologists, behavioural therapists, physiotherapists, speech therapists) performed almost all measurements, which required their enduring commitment and enthusiasm. To minimize burden for participants and their caregivers, all measurements were organized per care unit and performed on-site in a period of two weeks. Detailed information about recruitment and design of the HA-ID study have been described in Hilgenkamp et al. (2011) (appendix I).[12]

In the HA-ID study, for mental health the main focus was on depression and anxiety, because of the high prevalence rates of depression and anxiety and their negative consequences in the general population as well as clinical experience of professionals in ID care. Furthermore, knowledge of depression and anxiety and associated factors is lacking for older people with ID. Internationally, the prevalence of depression and anxiety has been studied in large samples of adults with ID,[13-15] but not specifically in older adults with ID. Prevalence rates might be different in older people with ID, e.g. because of age-related physical, mental and functional decline.[6] The few published studies in older adults with ID were small and lack information on associated factors.[16, 17] There-

fore, depression and anxiety have been studied in the HA-ID study. The characteristics of these psychiatric disorders are described in the next section.

DEFINING CONCEPTS: DEPRESSION AND ANXIETY DISORDERS

Depression and anxiety disorders are both psychiatric disorders and are diagnosed according to specific diagnostic criteria. There are two general diagnostic systems, the Diagnostic and Statistical manual of Mental disorders (DSM-IV) and the Internal Classification of Diseases (ICD-10),[18, 19] and two adapted versions of these systems for people with ID, the Diagnostic Manual-Intellectual Disability (DM-ID) and Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation (DC-LD).[20, 21] The symptoms described in these diagnostic systems are very much alike, but the number of symptoms required for a depressive or anxiety disorder varies. In the following two paragraphs, the characteristics of both disorders and the main differences in diagnostic systems will be discussed.

Depression is a mood disorder and is characterised by depressed mood or loss of interest or pleasure in daily activities. Other symptoms which may appear are reduced energy, significant weight change or change of appetite, disturbed sleep/sleep problems, psychomotor agitation or retardation, feelings of worthlessness or guilt, lowered self-esteem, difficulties concentrating and recurrent thoughts of death. A DSM-IV diagnosis of depression requires the presence of at least five of the above symptoms (including depressed mood or loss of interest), whereas ICD-10, DC-LD and DM-ID require three or four of these symptoms.

Anxiety disorder is a generic term covering several specific disorders which are all characterized by feelings of anxiety. The anxiety disorders covered in the HA-ID study are: panic disorders, agoraphobia, specific phobia, social phobia and generalized anxiety disorders. Anxiety, especially panic attacks, is characterized by physical symptoms, such as accelerated heart rate, sweating, trembling, chest pain, nausea, choking sensation and dizziness. Anxiety can trigger feelings of unreality (depersonalisation or derealisation) and fears of dying or losing control may appear. Someone with an anxiety disorder finds it difficult to control the anxiety and worrying. Panic disorders can occur solely or co-occur with phobia. Phobias are characterized by anxiety for being in specific places or situations, for presence of specific objects, or for exposure to social interactions. Generalized anxiety disorder is characterized by excessive anxiety and worries about a number of events or activities. ICD-10 and DSM-IV require three or four of the physical anxiety symptoms. The main difference in the DM-ID and DC-LD systems is that observation of anxiety symptoms by others instead of self-report is allowed. Other differences mainly concern indication of which criteria may be unobservable or inapplicable (e.g.

avoidance of situations, worries, and depersonalisation) and complex symptoms have been replaced by observable features of anxiety.

The consequences of these different classification systems for the diagnosis have been studied by Cooper et al. (2007). They found that usage of DSM-IV criteria resulted in the lowest number of diagnoses of affective and anxiety disorders, ICD-10 criteria in slightly more diagnoses, and application of DC-LD criteria resulted in the highest number of diagnoses. Assessment by an experienced psychiatrist using all available criteria resulted in even more diagnoses.[22] The use of general diagnostic criteria in people with ID may lead to fewer diagnoses, because of inapplicable diagnostic criteria and unobservable symptoms. Although adapted systems contain additional information to support diagnostics in this group, their application in research is hampered by the lack of modified, standardized psychiatric diagnostic instruments.

STUDY AIMS

Diagnosing psychiatric disorders is challenging and time-consuming in people with ID. Therefore, we have used a two-step procedure in which all participants were screened with questionnaires, but only a selection of the participants were further examined with a psychiatric diagnostic interview, based on their screening outcome. Diagnostic instruments used in the HA-ID study had to be suitable for use in large-scale research as well as in clinical practice and should be reliable and valid. Besides, to compare our outcomes with those in the general population, instruments used in epidemiologic studies in the general older population should be included. The selection process of these instruments will be described in Chapter 2. Chapter 3 and 4 will give an overview of internationally available instruments for depression and anxiety which have been studied for their psychometric properties in adults with ID. Chapter 5 presents the reliability and validity of the Dutch translation of a Scottish self-report instrument for anxiety, whereas Chapter 6 presents the feasibility, reliability and validity of the Dutch translation of an American informant-report instrument for depression and anxiety.

To improve detection and prevention of depression and anxiety, knowledge about prevalence rates of both disorders and risk groups is necessary. Therefore, occurrence of increased depressive and anxiety symptoms and an estimate of the prevalence of depression and anxiety disorders were studied and will be presented in Chapter 7. In Chapter 7 and 8, the prevalence rates of symptoms and disorders will be compared with rates in the general older population.

Defining risk groups in a cross-sectional study is only possible for fixed factors, such as age or syndromes. By studying associated factors, it is possible to describe groups in which increased depressive and anxiety symptoms and disorders are more prevalent.

Factors associated with depression and anxiety have been described in Chapter 9. Several studies have shown that adults with ID may be exposed to a high number of life events and that this is associated with depression and anxiety.[23-26] Therefore the occurrence of life events and its association with depression and anxiety in older adults with ID is described in Chapter 10.

The level of accomplishment of the study aims has been described in the general discussion (Chapter 11). In this final chapter, the implications for clinical practice and future research will also be discussed.

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Part I

Chapter 2

Diagnostics of depression and anxiety

Depression or anxiety disorders can only be diagnosed with a diagnostic assessment performed by a skilled diagnostic investigator. In a diagnostic assessment, the criteria of diagnostic systems, such as DSM-IV or ICD-10,[1, 2] for depressive or anxiety disorders are used as a guideline. In large-scale research, structured diagnostic interviews are usually applied to make psychiatric diagnoses.

In the general population, diagnostic assessment of depression and anxiety is regularly done by means of psychiatric anamnesis. In the population with intellectual disabilities (ID), psychiatric assessment is only possible for people with sufficient cognitive and verbal skills whereas hetero-anamnesis (informant-report) is used for people with insufficient cognitive or verbal skills. In several studies, it has been established that people with mild or moderate ID are able to report reliably about depression and anxiety,[3-6] but it is important that the content and wording of the questions are concrete.[7] Self-report enables questions about cognition and feelings, whereas informant-report only allows questions about observable behaviour. Therefore, self-report, if possible, is preferred over informant-report.

Because of the size of the 'Healthy Ageing and Intellectual Disability' (HA-ID) study (n=1050), depressive and anxiety disorders have been diagnosed with a two-step procedure. All participants have been screened with questionnaires for depression and anxiety symptoms. Participants with a screening score above one or more of the pre-set cut-offs were further examined with a structured psychiatric diagnostic interview.

SCREENING INSTRUMENTS

We aimed to select good screening instruments suitable for both this large-scale study and for clinical practice; with the advantage that professionals in the consort would obtain experience with evidence-based diagnostics of depression and anxiety and with the selected instruments. Furthermore, we aimed to select instruments which have been used in research in the general population, if feasible for older persons with ID too, because the use of such instruments would enable comparison with the general population and increase the status of our research.

Selection procedure

To comply with the aims, four selection criteria have been formulated. The applied selection criteria concerned psychometric properties, content of the questionnaire, feasibility of the questionnaire for clinical practice, and application in earlier research in the general population.

To select the most suitable screening instruments for this study, we first made an overview of all nationally and internationally available screening instruments for depressive or anxiety symptoms, developed for children or adults with ID or for children, adults or older people with normal intelligence, used in research or clinical practice.

A first selection has been made based on the instruments' reliability and validity, judged according to several guidelines for psychological instruments.[8-11] Because of the novelty of the intellectual disability research field, instruments developed for people with ID were not excluded directly if only reliability had been studied.

The second selection has been based on the content of the questionnaire. Content was further specified into length of the instruments and the applicability and comprehensiveness of the instruments' items. Questionnaires with more than 30 items have been excluded, because they would be too time-consuming. Instruments with items inapplicable to most adults with ID have been excluded too. Examples of inapplicable items were items about school or raising children. Comprehensiveness of items has been evaluated by the number of standardized diagnostic criteria from DSM-IV, ICD-10, DM-LD and DC-LD[12, 13] and additional behavioural symptoms, found in earlier research in this population,[14-19] covered by the instruments. This list with criteria and behavioural symptoms consisted of 22 criteria/symptoms for depresSubsequently, experts in assessing psychopathology in adults with ID judged the instruments' feasibility in clinical practice by evaluating the difficulty of the wording and response format. Taking their expertise into account this resulted in instruments practicable for use in clinical practice.

Finally, an expert in epidemiological psychiatric research advised about the international status of instruments, developed for the general (older) population.

Selection outcome

Search of the literature resulted in 78 screening instruments (Figure 1), 20 for depression, 38 for anxiety and 20 for both. Fifty-six of these instruments have been developed for the general population and 22 for people with ID. Evaluation of the reliability, and if available, validity resulted in a first selection of 8 instruments for depression, 16 for anxiety and 7 for both.

Evaluation of the content of the instruments resulted in a second selection of nine instruments for depression covering 3 to 14 criteria/symptoms and eight instruments for anxiety covering 3 to 10 criteria/symptoms. In this step, all questionnaires for anxiety developed for children have been eliminated, because they contain questions inapplicable to older people with ID.

The evaluation of the expert-group resulted in five instruments: one self-report questionnaire for depression developed for the general population, the Inventory of Depressive Symptomatology Self Report,[20] two self-report questionnaires for anxiety, the Glasgow Anxiety Scale for people with an Intellectual Disability[21] and the Anxiety

subscale of the Hospital Anxiety and Depression Scale[22] which has been developed for the general population, one informant-report questionnaire for depression, the Dutch Signalizing Depression List for people with Intellectual Disabilities[23] and one informant-report questionnaire screening for both anxiety and depression, the Anxiety, Depression, And Mood Scale.[24] The Glasgow Anxiety Scale and the Anxiety, Depression And Mood Scale had to be translated into Dutch by us. A detailed description of the selection procedure is presented in Figure 1.

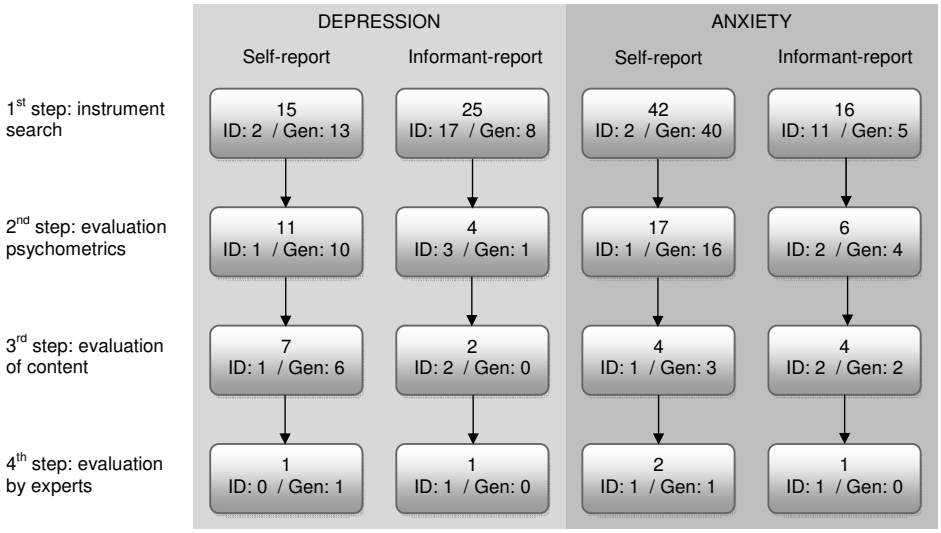

Figure 1: Flow-chart of the selection procedure of screening instruments for depression and anxiety *(ID= instruments developed for people with intellectual disability; Gen= instruments developed for the general population)*

Description of the selected screening instruments

Depression

The Inventory of Depressive Symptomatology Self Report (IDS-SR)[20] consists of 30 items and has been developed for the general population. In the HA-ID study, the IDS-SR has been used to interview participants capable of self-report. Its phrasing has been adapted to make the instrument suitable for interviewing instead of written completion. The IDS-SR covers 14 of the 22 diagnostic criteria and behavioural symptoms of depression used in the selection procedure. At the start of the study, the IDS-SR had not been studied for its psychometric properties in adults with ID, but reliability and validity are fair to good in the general population.[25-28] A recent master thesis showed that its internal consistency and test-retest reliability are good (α= 0.89 and ICC= 0.91) and the

validity satisfactory (sensitivity 71% and specificity 54%) in Dutch adults with ID.[29] Its score ranges from 0 to 84. We used a cut-off score of ≥18.[25]

The Dutch Signalizing Depression List for people with Intellectual Disabilities (SDL-ID)[23] has been developed for people with ID and has to be completed by informants. The SDL-ID consists of 18 items and covers 11 of the diagnostic criteria and additional symptoms of depression. The SDL-ID's internal consistency and interrater reliability in older people with ID are good (α= 0.77 and *r*= 0.87).[30] The score on the SDL-ID ranges from 18 to 72. We used a cut-off score of ≥35.[31]

Anxiety

Participants capable of self-report were screened with the Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID).[21] The GAS-ID has been developed for people with ID and consists of 27 items. These items cover 10 of the diagnostic criteria and symptoms for anxiety. The internal consistency, reliability and validity of the original version are good (α= 0.86, ICC= 0.89, sensitivity 100% and specificity 100%).[21] The psychometric properties of the Dutch translation of the GAS-ID have been evaluated by us in older people with ID (Chapter 5). Its score ranges from 0 to 54. We used a cut-off score of ≥17 (Chapter 5).

Participants capable of self-report were also screened with the Anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A).[22] The HADS-A has been developed for the general population and consists of seven items which cover 4 of the 24 diagnostic criteria or symptoms for anxiety. Based on the feasibility results of a pilot-study, standardized explanatory information was added to four items (2, 3, 6 and 7) for better comprehension. Its internal consistency (α= 0.96) and sensitivity and specificity against psychiatric diagnosis based on a structured interview (94% and 85%) are good in the general population[32-35] but have not been studied in people with ID. Its score ranges from 0 to 21. We used a cut-off score of ≥8, as recommended for the Dutch population.[36]

All participants have been screened with the Anxiety, Depression, And Mood Scale (ADAMS).[24] The ADAMS is an informant-report instrument, specifically developed for adults with ID, consisting of five subscales. In the HA-ID study, the total ADAMS was completed, but only the General anxiety subscale has been used. This subscale consists of seven items which cover five of the diagnostic criteria or symptoms of anxiety. The internal consistency of the subscales of the original version varied from α= 0.75 to 0.83, the test-retest reliability of the total ADAMS and subscale scores from ICC= 0.72 to 0.83 and the interrater reliability from ICC= 0.37 to 0.62[24] and those of the Dutch version have been evaluated by us (Chapter 6). The score on the General anxiety subscale ranges from 0 to 21. We used the cut-off scores of ≥10 for participants without autism and ≥14 for those with an autism-spectrum disorder (Chapter 6).

PSYCHIATRIC DIAGNOSTIC INTERVIEW

Several structured psychiatric diagnostic interviews have been developed for the general population, but these interviews require self-report, while the questions' wording is often too difficult. The Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD)[37] is the only structured psychiatric interview developed for adults with ID with satisfactory psychometric properties. Therefore, we have selected this interview for the HA-ID study.

The PAS-ADD interview is a semi-structured, diagnostic interview including a heteroanamnesis. It focuses on the more common axis I disorders, and has been based on the Schedules for Clinical Assessment in Neuropsychiatry (SCAN).[38] Current diagnoses of Major Depressive Disorder (MDD), general anxiety disorder, panic disorder, agoraphobia, social phobia and specific phobia based on ICD-10 criteria can be made with the PAS-ADD. Inapplicable items or incomplete answers can be separately scored and are excluded from the final diagnostic decision. The test-retest reliability for depression and anxiety is good (ICC of respectively 0.91 and 0.79), the interrater agreement is large (kappa between 0.66 and 0.83) and the criterion validity against expert psychiatric diagnosis is satisfying (sensitivity 63% and specificity 84%).[39-41]

In the HA-ID study, professional caregivers were interviewed with the PAS-ADD interview and, if possible, the participants with ID themselves were interviewed as well. The interviews were applied by psychologists or behavioural therapists, experienced in working with older people with ID, who were additionally trained in recognizing psychiatric disorders and the PAS-ADD interview's system.

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Chapter 3

Characteristics of instruments screening for depression in adults with intellectual disabilities: A systematic review

Based on:
H. Hermans and H. M. Evenhuis, Characteristics of instruments screening for depression in adults with intellectual disabilities: Systematic review. Research in Developmental Disabilities, 31: p. 1109-1120, 2010.

ABSTRACT

Background: Multiple screening questionnaires for depression developed for the general population or specifically for people with intellectual disabilities (ID) are available.

Aim: To obtain information on feasibility, reliability and validity of internationally available instruments screening for depression applied in people with ID.

Method: Systematic review of the literature.

Results: For self-report, the Glasgow Depression scale for people with a Learning Disability appears most promising (internal consistency α= 0.90, test-retest reliability *r*= 0.97, sensitivity 96% and specificity 90%). For informant-report three instruments seem promising: the Assessment of Dual Diagnosis (internal consistency α= 0.77 and α= 0.91, test-retest reliability *r*= 0.94, interrater reliability *r*= 0.98), the Reiss Screen for Maladaptive Behaviour (internal consistency α=0.58-0.83, interrater reliability *r*= 0.61-0.84, sensitivity 80%, specificity 83%), and the Children's Depression Inventory (internal consistency α= 0.86, sensitivity 83%, specificity 93%).

Conclusions: Although three instruments seem promising, none of them have been studied satisfactorily in this group, yet. More research on psychometric properties, especially sensitivity and specificity in the ID population, is needed.

INTRODUCTION

The prevalence of depression in adults with intellectual disabilities (ID) ranges between 2.2% and 8.9%,[1-4] showing that depression is a common psychiatric disorder in this group. If caregivers suspect psychiatric problems, a general practitioner or psychologist is often the first person they contact. Even if these professionals are aware of the psychiatric problems people with ID can have, diagnosing depression is often complicated in this population. The depressive symptoms listed in diagnostic manuals such as DSM-IV[5] or ICD-10[6] are not always identifiable in people with ID, and especially not in people with a severe or profound ID.[7] For instance, cognitive depressive symptoms, such as loss of confidence or unreasonable feelings of guilt may not be presented as such by people with ID.[7] Moreover, behaviour equivalents such as expressions of irritability, which are not mentioned in standard diagnostic manuals, may reflect depression in this group.[7-11] As a result, an accurate diagnosis may require specific expertise and time-consuming assessment.

To make efficient use of such expertise, identification of persons with possible depressive symptoms through screening is recommendable. Such screening does not require specific expertise. It can be done using standardized questionnaires, of which the outcome indicates whether further diagnostic assessment for depression is recommendable. A range of screening questionnaires developed for the general population or specifically for people with ID are available internationally. Those developed for people with ID are based on self-report or on report by caregivers.

Professionals may have difficulties selecting a screening instrument for depression and judging its quality. They need to know which instruments are suitable for screening people with ID, and what the merits and demerits are of a certain instrument. Therefore, the objective of this study is to review currently available instruments screening for depression in individuals with ID and to describe their feasibility, reliability and validity.

METHOD

Literature search

Literature was searched via PubMed, PsychInfo and Embase. In order to be included, all studies had to be published between January 1980 and December 2008, in English, and focus on the feasibility, reliability or validity of the measurement instrument used for depression in people with ID. The participants of the studies had to be teenagers, adolescents or adults (14 years and older) with ID. All severities of ID and all kinds of residential setting were included. In different search combinations, the following key terms were used: 'Intellectual disability', 'mental retardation', 'Down syndrome', 'learning disability', 'developmental disability', 'depression', 'mood', 'depressed', 'assessment', 'measurement', 'screening', 'diagnosis'

and 'questionnaire'. Relevant articles were selected for further examination. Other relevant articles were found through the references of articles we had already selected.

Outcome measures

Outcome measures were feasibility, internal consistency, test-retest reliability, interrater reliability, sensitivity, specificity and correlation with other instruments, which is called convergent validity. In this study, feasibility was operationalized as assessment time or percentage of successful completion. Sensitivity and specificity are chosen as outcome measures, because it is important to make an efficient and correct decision for further diagnostic assessment based on the screening.

Methodological quality

To judge the methodological quality of the studies reviewed, we have made a quality system based on five criteria: size and characteristics of study population, distribution of people with and without depression, what was defined as gold standard, and report on measures of variability (Table 1). For size of the study population, a cut-off of 30 participants was chosen, because a study population of 30 or more participants is less vulnerable for the influence of a non-standard distributed study population.[12] A normal distribution of the study population is relevant for most statistical techniques. Sample size is also of influence on the estimate of the power of a test, whereas Stevens (1996) stated that with a sample size of 100 or more participants, power "is not an issue".[12]

Table 1: Evaluating methodological quality of studies

Item	Criteria	Score
Number of participants	> 100	2
	> 30 – 100	1
	≤ 30	0
Characteristics of participants	Group representing the target population of the instrument	0/1
Psychopathology of participants	>20% - 50% of the participants had a depression	2
	≥ 10% - 20% or > 50%- 90% of the participants had a depression	1
	< 10% or > 90% of the participants had a depression	0
	Unclear	0
Gold standard	Clinical diagnosis by a psychiatrist or psychologist based on a standard diagnostic system	2
	Clinical diagnosis by a psychiatrist or psychologist	1
	Other depression screening instrument used as reference standard	1
	All other	0
	Not applicable	0
Report on measures of variability	Standard deviation or standard error, or confidence interval is reported	0/1

The second and third criteria, 'characteristics of participants' and 'psychopathology of participants', evaluate whether the studied population is representative for the people who will receive the test in practice. For the second criterion, distribution of levels of ID was of most importance. Furthermore residential setting should be defined: the study population had to consist of more than institutionalized participants. The fourth criterion judges the quality of the gold standard with which the validity of the questionnaire is studied. The last criterion judges the completeness of the report. Standard deviations and standard estimated errors are illustrative for the distribution of scores within the study population. Confidence intervals are informative to compare studies of different size with each other and to estimate how reliable and valid the questionnaire will be in another study population. The scoring system is shown in Table 1. The total quality score of a study could range from 0 to 8. We considered a score of 2 or less low, a score of 3 - 5 moderate, and a score of 6 or over high quality.

Interpretation of the psychometric properties

We have calculated 95% confidence intervals of all reported correlation coefficients and of the sensitivity and specificity rates. This gives a more reliable view of the reliability and validity of each instrument in the population. To interpret the internal consistency and correlation coefficients we applied three guidelines for psychological tests, which are presented in Table 2. After an overview of the quality of the studies, characteristics, feasibility and psychometric properties of each instrument will be discussed separately.

Table 2: Guidelines to interpret internal consistency and correlation coefficients

Internal consistency[13]	**Interpretation**
< 0.70	Unacceptable
0.70-0.79	Fair
0.80-0.89	Good
≥ 0.90	Excellent
Pearson product-moment correlation coefficient[14]	**Interpretation**
< 0.29	Little or no correlation
0.30-0.49	Low correlation
0.50-0.69	Moderate correlation
0.70-0.89	High correlation
≥ 0.90	Very high correlation
Intraclass correlation coefficient[15]	**Interpretation**
< 0.40	Poor
0.40-0.59	Fair
0.60-0.74	Good
≥ 0.75	Excellent

RESULTS

General results

Fifteen instruments, which had been studied for their reliability, were identified.[11, 16-17, 20-21, 25, 30, 34, 37, 39-40, 43, 50-61] Of four instruments, one out of two feasibility points was reported. For 13 of these 15 instruments, validity was also studied. Sensitivity and specificity were estimated for seven instruments. Quality of the reviewed studies as judged by our quality system is shown in Table 3. Three studies had a high quality score, whereas the quality of fourteen studies was moderate, and of seven studies low. Psychometric properties are presented in Table 4 and 5. In case of instruments for a wider range of psychiatric conditions, all results in Table 4 and 5 apply to depression subscales and not to the total scale.

Table 3: Quality of reviewed studies

	Instrument	n used for reliability or validity	Characteristics: Residential setting and severity ID	Depression distribution	Gold standard	Report on measures of variability	Quality
Cuthill et al. (2003)	GDS-LD GDS-CS	65	Unclear; 38 mild or moderate ID, 27 no ID	70.8% depression	Clinical diagnosis (DSM-IV criteria)	1	5
Esbensen et al. (2005)	SRDQ	73[a]	Institutionalised, staffed accommodation, living with family, independent living; mild or moderate ID	unclear	Diagnosis by psychiatrist	1	4
Reynolds & Baker (1988)	SRDQ	89	Staffed accommodation; borderline, mild or moderate ID	Unclear	Not applicable	1	3
Rojahn et al. (1994)	RSMB SRDQ	38	Unclear; mild or moderate ID	23.7% depression	Diagnosis by experienced psychiatrist	1	5
Minnen van et al. (1995)	RSMB	89	Institutionalised, staffed accommodation; borderline or mild ID	6.7% affective disorder	Psychiatric diagnosis based on institutional records	1	3
Gustafsson & Sonnander (2002)	RSMB	155	Institutionalised, staffed accommodation, living with family, independent living; all levels of ID	6.5% depression	Sub-sample (n=42) diagnosis by psychiatrist (DSM-IV criteria)	1	6
Sturmey & Bertman (1994)	RSMB PIMRA	81	Unclear, all levels of ID	Unclear	Unclear	0	1

Table 3: Quality of reviewed studies (continued)

	Instrument	n used for reliability or validity	Characteristics: Residential setting and severity ID	Depression distribution	Gold standard	Report on measures of variability	Quality
Myrbakk & Von Tetzchner (2008)	RSMB DASH-II Mini PAS-ADD ADD	181[b]	Staffed accommodation, living with family, independent living; all levels of ID, most severe or profound ID	Unclear	Psychiatric diagnosis by specialists from case files	1	5
Esbensen et al. (2003)	ADAMS	61	Institutionalised, staffed accommodation, living with family, independent living; all levels of ID	Unclear	Not applicable	1	3
Prosser er al. (1998)	Mini PAS-ADD	68	Unclear, moderate, severe and profound ID	12.0% depression	Diagnosis by psychiatrist (ICD-10 criteria)	0	4
Sturmey et al. (2005)	PAS-ADD Checklist	226	Institutionalised, staffed accommodation, living with family, independent living; mild, moderate and severe ID	12.0% depression	Diagnosis by psychiatrist	1	6
Moss et al. (1998)	PAS-ADD Checklist	66[c]	Staffed accommodation, living with family, independent living; moderate, severe and profound ID	24.0% depression	Diagnosis by psychiatrist specialized in ID	0	5
Matson et al (1999)	DASH-II	57	Institutionalised; severe or profound ID	32.0% depression	Diagnosis by psychiatrist or psychologist (DSM-IV criteria)	0	5
Matson et al. (1984)	PIMRA	110	Unclear; 88% mild or moderate ID, 12% borderline or severe ID	3.6 % depression	Not applicable	0	2
Senatore et al. (1985)	PIMRA	110	Institutionalised, staffed accommodation; mild, moderate and severe ID	5.0% depression	PIMRA	0	3
Minnen van et al. (1994)	PIMRA	89	Institutionalised, staffed accommodation; mild ID	7.0%	Diagnosis by psychiatrist	0	2
Matson & Bamburg (1998)	ADD	67[d]	Institutionalised, staffed accommodation; mild or moderate ID	Unclear	Not applicable	0	2

Table 3: Quality of reviewed studies (continued)

	Instrument	n used for reliability or validity	Characteristics: Residential setting and severity ID	Depression distribution	Gold standard	Report on measures of variability	Quality
Charlot et al. (2007)	MASS Interview	93	Psychiatric inpatients, all levels of ID	44.0% depression	Diagnosis by psychiatrist	0	4
Ross & Oliver (2003)	MIPQ	23[e]	Unclear, severe or profound ID	Unclear	Not applicable	1	1
Kazdin et al. (1983)	BDI Zung PIMRA	110	Independent living; borderline, mild, moderate and severe ID	5.5 % depression	Not applicable	0	3
Powell (2003)	BDI & Zung	120	Institutionalised, staffed accommodation, independent living; all levels of ID	28.0% mood disorder	Not applicable	0	5
Prout & Schaefer (1985)	Zung BDI	21	Staffed accommodation; mild ID	Unclear	Not applicable	1	2
Meins (1993)	CDI	798	Institutionalised, staffed accommodation; all levels of ID	Unclear	Psychiatric diagnosis (DSM-III-R)	1	6
Dagnan et al. (2008)	HADS	187[f]	Both unclear	Unclear	Not applicable	0	2

GDS-LD, Glasgow Depression Scale for people with a Learning Disability; GDS-CS, Glasgow Depression Scale Carer Supplement; SRDQ, Self-Report Depression Questionnaire; RSMB, Reiss Screen for Maladaptive Behavior; PIMRA, Psychopathology Instrument for Mentally Retarded Adults; DASH-II, Diagnostic Assessment for the Severely Handicapped-II; Mini PAS-ADD, Mini Psychiatric Assessment Schedule for Adults with a Developmental Disability; ADD, Assessment of Dual Diagnosis; ADAMS, Anxiety, Depression, And Mood Scale; PAS-ADD Checklist, Psychiatric Assessment Schedule for Adults with a Developmental Disability Checklist; MASS, Mood and Anxiety Semi-Structured; MIPQ, Mood, Interest, and Pleasure Questionnaire; BDI, Beck Depression Inventory; Zung, Zung Self-Rating Depression Scale; CDI, Children's Depression Inventory; HADS, Hospital Anxiety and Depression Scale.

[a] n=12 for criterion validity

[b] n= 54 for ADD

[c] n= 201 for internal consistency

[d] n= 101 for internal consistency

[e] n= 53 for internal consistency

[f] n= 32 for Zung, n= 44 for GDS-LD

Self-report instruments

Six instruments have been developed for self-report by people with mild or moderate ID. Two of these instruments also have an informant-report version. Three of six have been developed for the general population.

The Glasgow Depression Scale for people with a Learning Disability (GDS-LD)[16] and its version for informants: The Glasgow Depression Scale Carer Supplement (GDS-CS), measure depressive symptoms in people with mild or moderate ID. The GDS-LD contains 20 items which are based on DC-LD[8], DSM-IV[5], and ICD-10[6] criteria and on established depression questionnaires. The GDS-CS contains 16 items, which are the observable items of the GDS-LD. The answering scale of both versions is a 3-point rating scale. Assessment time is 10 to 15 minutes for the GDS-LD and 5 minutes for the GDS-CS.[16] The correlation between the GDS-LD and GDS-CS was $r = 0.93$.[16]

The Self-Report Depression Questionnaire (SRDQ)[17] is a structured interview designed for measurement of depressive symptoms in adults with mild ID. The SRDQ has 32 items, which are based on DSM-III[18] criteria and the Research Diagnostic Criteria symptoms[19] of major and minor depression. The first 31 items are to be scored on a 3-point rating scale, item 32 is scored with smileys. The SRDQ can be used by trained interviewers.[17]

The Psychopathology Instrument for Mentally Retarded Adults-Self-Report (PIMRA-SR) and its informant version (PIMRA-I)[20] both assess psychopathology on basis of DSM-III criteria in people with ID. Both versions have 56 items distributed over seven subscales. One of these subscales is the affective disorders subscale, which has 7 items. Each item is answered with 'yes' or 'no'. The PIMRA exists for many years now and has therefore been studied relatively often. Van Minnen et al. (1994) and Kazdin et al. (1983) found that both versions can distinguish well between people with and without psychopathology[21][20] but they did not calculate the sensitivity or specificity.

The Beck Depression Inventory (BDI)[22] is a screening instrument for the adult population without ID. It measures the severity of depressive symptoms with 13 items. These items are based on descriptions of patients with depression and DSM-III criteria. According to McGillivray & McCabe (2005) the wording of the items of the BDI is simple enough to understand by people with a mild or moderate ID.[23] Nevertheless Kazdin et al. (1983) used a version with modified language.[20]

The Zung Self-Rating Depression Scale (Zung)[24] measures frequency of depressive symptoms in adults without ID and has 20 items. One study used the Zung modified by Kazdin et al. (1983)[25] but another study did not have any trouble with completion of the original version by people with mild or moderate ID.[26]

The Hospital Anxiety and Depression Scale (HADS)[27] measures depression and anxiety symptoms. Both subscales contain 7 items and can be used independently from each other. The HADS is developed for non-psychiatric adult hospital patients without ID but is often used for other populations and also for people with ID. The items of the

depression subscale focus on the loss of interest and pleasure in activities. Dagnan et al. (2008) have adapted the HADS by simplifying its language.[25]

In conclusion, for self-report, the Glasgow Depression Scale for people with a learning disability seems most promising, because of its good reliability, convergent validity and sensitivity and specificity. The reliability of the Self-Report Depression Questionnaire was also good. However, the convergent validity was contradictory and the sensitivity and specificity were studied in a too small group. All other instruments were studied insufficiently for their psychometric properties in people with ID.

Table 4: Psychometric properties of self-report screening instruments for depression

Instruments	Internal consistency	Reliability	Decision analysis	Convergent validity (instrument)
GDS-LD				
Cuthill et al. (2003)	0.90	Test-retest (period): r = 0.97, p< 0.001, CI[a]: 0.96-0.99 (within one session)	Cut-off 15: SEN[b] 90%, CI: 77-95%, SPE[d] 100%, CI: 83-100% Cut-off 13: SEN 96%, CI: 85-99%, SPE 90% CI: 69-97%	r= 0.94, p< 0.001, CI: 0.91-0.97 (BDI-II[22])
GDS-CS				
Cuthill et al. (2003)	0.88	Test-retest (period): r= 0.98, CI: 0.97-1.00 (2 days) Interrater: r= 0.98, CI: 0.97-1.00	-	-
SRDQ				
Rojahn et al. (1994)	-	-	-	No sig correlation (RSMB[28] and DICA[29])
Esbensen et al. (2005)	0.89	Test-retest (period): r= 0.71, CI: 0.58-0.81 (16 weeks)	SEN 75%, CI: 47-91% SPE 92%, CI: 65-99%	r= 0.25, p< 0.05 (ADD[30]), CI: 0.02-0.46
Reynolds & Baker (1988)	0.90	Test-retest (period): r= 0.63, CI: 0.49-0.75 (11 weeks)	-	r= 0.65, p< 0.0001, CI: 0.51-0.77 (HRSD[31])
PIMRA-SR				
Kazdin et al. (1983)	-	-	-	r= 0.33, p< 0.05, CI: 0.15-0.49 (BDI) No sig correlation (Zung[24] and MMPI[32])
Matson et al. (1984) and Senatore et al. (1985)	0.85	Test-retest (period): r= 0.69, p< 0.001, CI: 0.58-0.78 (22-23 weeks)	-	-

Table 4: Psychometric properties of self-report screening instruments for depression (continued)

Instruments	Internal consistency	Reliability	Decision analysis	Convergent validity (instrument)
Minnen van et al. (1994)	0.68	-	-	-
BDI				
Powell (2003)	0.86		-	*r*= 0.34, *p*< 0.001, CI: 0.17-0.50 (Zung[24])

Kazdin et al. (1983)	-		-	*r*= 0.59, *p*< 0.05, CI: 0.49-0.71 (Zung[24]);
				r= 0.25, *p*< 0.05, CI : 0.07-0.42 (MMPI Depression subscale[32]);
				r= 0.33, *p*< 0.05, CI: 0.15-0.49 (PIMRA-SR[20])

Prout & Schaefer (1985)	-		-	*r*= 0.73, *p*< 0.05, CI: 0.44-0.89 (Zung[24]); *r*= 0.74, *p*< 0.05, CI: 0.46-0.89 (Depressive Adjective Checklist[33])
Zung				
Powell (2003)	0.58		-	*r*= 0.34, *p*< 0.001, CI: 0.17-0.50 (BDI[22])
Kazdin et al. (1983)	-		-	*r*= 0.59, *p*< 0.05, CI: 0.46-0.71 (BDI[22]); No sig correlation with MMPI Depression subscale[32] and PIMRA-SR[20]
Prout & Schaefer (1985)	-		-	*r*= 0.73, *p*< 0.05, CI: 0.44-0.89 (BDI[22]); *r*= 0.79, *p*< 0.05, CI: 0.55-0.92 (Depressive Adjective Checklist[33])
HADS				
Dagnan et al. (2008)	0.60		-	*r*= 0.53, *p*< 0.05, CI: 0.23-0.75 (Zung[24]); *r*= 0.40, *p*< 0.05, CI: 0.12-0.63 (GDS-LD[16])

GDS-LD, Glasgow Depression Scale for people with a Learning Disability; BDI, Beck Depression Inventory; GDS-CS, Glasgow Depression Scale Carer Supplement; SRDQ, Self-Report Depression Questionnaire; DICA, Diagnostic Interview in Children and Adolescents; HRSD, Hamilton Rating Scale for Depression; PIMRA, Psychopathology Instrument for Mentally Retarded Adults; Zung, Zung Self-Rating Depression Scale; MMPI, Minnesota Multiphasic Personality Inventory; HADS, Hospital Anxiety and Depression Scale

[a] CI= 95% confidence interval

[b] SEN= sensitivity

[c] SPE= specificity

Informant-report instruments

Ten instruments have been developed for completion by informants. Two instruments screen exclusively for depression, the other seven have a depression subscale.

The Psychiatric Assessment Schedule for Adults with a Developmental Disability Checklist (PAS-ADD Checklist)[34] is a broad screening for mental health problems in people with ID. The affective/neurotic subscale has 25 items, which are based on the most predictive items of the PAS-ADD interview.[35]

The Assessment of Dual Diagnosis (ADD)[30] screens for psychiatric disorders in people with mild or moderate ID. The 79 items are based on DSM-IV criteria and previously published studies about depression in people with ID. One of the 13 subscales is the depression subscale. Administration time of the ADD is approximately 20 minutes.[30]

The Reiss Screen for Maladaptive Behaviour (RSMB)[28] has been developed to help care staff identify people who are expected to need a mental health service and consists of 38 items. It has two subscales measuring depression: Depression Behavioural Signs (RSMB BS) and Depression Physical Signs (RSMB PS). Each subscale consists of five items.

The Mini Psychiatric Assessment Schedule for Adults with a Developmental Disability (Mini PAS-ADD)[36] provides care staff with a framework for observing possible psychiatric symptoms. Training of care staff to use this scale is necessary. It contains 86 psychiatric symptoms, which are extracted from the PAS-ADD interview. One of the seven subscales is the depression subscale with 17 items.

The Anxiety, Depression, And Mood Scale (ADAMS)[37] measures symptoms of anxiety and depression in people with ID. It has 28 items distributed over five subscales. The depression subscale has seven items. The items are based on DSM-IV criteria, other instruments and clinical assessments.

The Diagnostic Assessment for the Severely Handicapped-II (DASH-II)[38] measures behavioural and psychiatric symptoms in people with severe or profound ID. The 84 items are distributed over 13 subscales, the depression subscale is one of them and has 15 items. Completion time is 25 minutes.[11]

The Psychopathology Instrument for Mentally Retarded Adults-Informant (PIMRA-I)[20] is described in detail in the section of the PIMRA-SR.

The Mood and Anxiety Semi-Structured (MASS) interview[39] measures mood and anxiety in people with ID. It contains 35 symptoms, which are behavioural descriptions of the DSM-IV criteria.

The goal of the Mood, Interest, and Pleasure Questionnaire (MIPQ)[40] is detecting symptoms of depression. The target group concerns people with severe or profound ID. It has 25 items, which are based on DSM-IV criteria and symptomatic behaviours as defined by Lowry (1998).[41]

The Children's Depression Inventory (CDI)[42] measures presence and severity of depressive symptoms in children (7-17 years) without ID. The 27 items are based on

the BDI. There is a self-report and informant-report version. Only the informant-report version was studied in people with ID. The CDI was studied for its reliability in adults with ID. Meins (1993) deleted three items for which attending school was necessary. The adapted CDI with 24 items could be completed for 81.2% of the subjects, completion was significantly ($p < 0.001$) more difficult if level of ID was more severe.[43]

In conclusion, for informant-report, the Assessment of Dual Diagnosis (ADD), the Reiss Screen for Maladaptive Behaviour (RSMB) and the Children's Depression Inventory (CDI) seem most promising. The ADD had good reliability and convergent validity. Overall the reliability and convergent validity of the RSMB were moderate, however its depression subscales have not been studied sufficiently yet. The CDI had a good internal consistency and moderate sensitivity and specificity, which perhaps can be improved by choosing a different cut-off point. On the other hand, it appeared less suitable for people with a more severe level of ID. Hence, all three instruments seem promising, but should be studied more extensively. All other instruments were studied insufficiently or had low reliability or convergent validity.

Table 5: Psychometric properties of informant-report screening instruments for depression

Instruments	Internal consistency	Reliability	Decision analysis	Convergent validity (instrument)
ADD				
Myrbakk & Von Tetzchner (2008)	0.77	-	-	r= 0.61, p< 0.01, CI[a]: 0.41-0.76 (RSMB PS[b][28]); r= 0.64, p< 0.01, CI: 0.45-0.78 (RSMB BS[c][28]); r= 0.78, p< 0.01, CI : 0.65-0.87 (Mini PAS-ADD[36])
Matson & Bamburg (1998)	0.91	Test-retest: r= 0.94, p< 0.005, CI: 0.91-0.97 (2 weeks) Interrater: r= 0.98, p< 0.005, CI: 0.97-1.00	-	-
RSMB				
Gustafsson & Sonnander (2002)	BS: 0.76 PS: 0.60	Interrater: BS: r= 0.65, CI: 0.56-0.74 PS: r= 0.61, CI: 0.50-0.71	Total RSMB: SEN[d] 80%, CI: 55-93% SPE[e] 83%, CI: 44-97%	-

Table 5: Psychometric properties of informant-report screening instruments for depression (continued)

Instruments	Internal consistency	Reliability	Decision analysis	Convergent validity (instrument)
Myrbakk & Von Tetzchner (2008)	BS: 0.70 PS: 0.63	-	-	BS/ PS: *r*= 0.60/ 0.60, *p*< 0.01, CI : 0.50-0.69 (Mini PAS-ADD[36]) ; *r* = 0.64/ 0.61, *p*< 0.01, CI: 0.45-0.78 / CI: 0.41-0.76 (ADD[30]); *r*= 0.48/ 0.61, *p*< 0.01, CI: 0.37-0.59/ CI: 0.51-0.70 (DASH-II[38])
Rojahn et al. (1994)	-	-	-	No sig correlation (SRDQ[17] and DICA[29])
Minnen van et al. (1995)	BS: 0.83 PS: 0.76	Interrater: BS: *r*= 0.64, *p*< 0.001, CI: 0.50-0.76 PS: *r*= 0.84, *p*< 0.001, CI: 0.77-0.90	-	-
Sturmey & Bertman (1994)	BS: 0.58 PS: 0.69	-	-	BS/ PS: *r*= 0.26/ 0.53, *p*< 0.01, CI: 0.04-0.46/ CI: 0.36-0.67 (PIMRA-I[20]) ; *r*= 0.26/ 0.14, *p*< 0.01, CI : 0.04-0.46/ -0.08-0.35 (psychiatric diagnosis)
PAS-ADD Checklist				
Sturmey et al. (2005)	0.80	-	Total PAS-ADD checklist: SEN 66%, CI: 57-74% SPE 70%, CI: 61-78%	-
Moss et al. (1998)	0.84	Interrater: *r*= 0.76, CI: 0.64-0.85	-	-
Mini PAS-ADD				

Myrbakk & Von Tetzchner (2008)	0.84	-	-	*r*= 0.60, *p*< 0.01, CI: 0.50-0.69 (RSMB PS[28]);
				r= 0.60, *p*< 0.01, CI: 0.50-0.69 (RSMB BS[28]);
				r= 0.63, *p*< 0.01, CI: 0.53-0.72 (DASH-II[38])

Prosser et al. (1998)	0.86	Interrater: *r*= 0.62, CI: 0.45-0.76	-	-
ADAMS				
Esbensen et al. (2003)	0.80	Test-retest (period): ICC= 0.76, CI: 0.64-0.85 (14-90 days) Interrater: ICC = 0.39, CI: 0.15-0.59	-	-

Table 5: Psychometric properties of informant-report screening instruments for depression (continued)

Instruments	Internal consistency	Reliability	Decision analysis	Convergent validity (instrument)
DASH-II				
Myrbakk & Von Tetzchner (2008)	0.70	-	-	*r*= 0.61, *p*< 0.01, CI: 0.51-0.70 (RSMB PS[28]); *r*= 0.48, *p*< 0.01, CI: 0.37-0.59 (RSMB BS[28]); *r*= 0.63, *p*< 0.01, CI : 0.53-0.72 (Mini PAS-ADD[36])
Matson et al. (1999)	-	-	SEN 73.3%, CI: 61-83%	-
PIMRA-I				
Minnen van et al. (1994)	0.70	-	-	*r*= 0.74, *p*< 0.001, CI: 0.64-0.83 (RSMB PS[28]); *r*= 0.70, *p*< 0.001, CI: 0.58-0.80 (RSMB BS[28])
Matson et al. (1984) and Senatore et al. (1985)	0.83	Test-retest (period): *r*= 0.74, *p*< 0.001, CI: 0.65-0.82 (22-23 weeks)	-	-
Sturmey & Bertman (1994)	0.48	-	-	*r*= 0.53, *p*< 0.01, CI: 0.36-0.67 (RSMB PS[28]); *r*= 0.26, *p*< 0.01, CI: 0.04-0.46 (RSMB BS[28])
MASS				
Charlot et al. (2007)	-	-	Compared to clinical diagnosis: SEN 93%, CI: 81-97% SPE 67%, CI: 54-78% Compared to HRSD [31]): SEN 92%, CI: 78-97% SPE 73%, CI: 43-90%	-
MIPQ				
Ross & Oliver (2003)	0.94	Test-retest (period): *r*= 0.87, CI: 0.72-0.95 (1 week) Interrater: *r*= 0.76, CI: 0.51-0.90	-	-

Table 5: Psychometric properties of informant-report screening instruments for depression (continued)

Instruments	Internal consistency	Reliability	Decision analysis	Convergent validity (instrument)
CDI (informant-report)				
Meins (1993)	0.86		Cut-off 13: SEN 83%, CI: 44-97%, SPE 93%, CI : 88-96% Cut-off 17: SEN 75%, CI: 36-94%, SPE 98%, CI: 95-100%	

ADD, Assessment of Dual Diagnosis; RSMB, Reiss Screen for Maladaptive Behaviour; Mini PAS-ADD, Mini Psychiatric Assessment Schedule for Adults with a Developmental Disability; SRDQ, Self-Report Depression Questionnaire; DICA, Diagnostic Interview in Children and Adolescents; PIMRA, Psychopathology Instrument for Mentally Retarded Adults; PAS-ADD Checklist, Psychiatric Assessment Schedule for Adults with a Developmental Disability Checklist; DASH-II, Diagnostic Assessment for the Severely Handicapped-II; ADAMS, Anxiety, Depression, And Mood Scale; MASS, Mood and Anxiety Semi-Structured; HRSD, Hamilton Rating Scale for Depression; MIPQ, Mood, Interest, and Pleasure Questionnaire; CDI, Children's Depression Inventory

[a] CI= 95% confidence interval

[b] PS= Depression-Physical Signs

[c] BS= Depression-Behavioural Signs

[d] SEN= sensitivity

[e] SPE= specificity

Other depression instruments

Four other studies reported about the development of depression instruments, however, reliability or validity data are lacking. The characteristics of these instruments will be shortly discussed below.

The Marston 30 symptoms checklist[7] measures changes in behaviour or symptoms, which can be a sign of depression in people with ID. It is completed by the person with ID and an informant. The symptoms are based on ICD-10 criteria and the Disability Assessment Schedule.

The Mental Retardation Depression Scale (MRDS)[44] measures depression with nine items, which were selected from the Comprehensive Psychopathological Rating Scale.[45]

The Checklist for general practitioners[46] is a guide for general practitioners in diagnosing depression in people with ID. It exists of a carer and a general practitioner checklist. The items are based on DSM-IV, ICD-10 and DC-LD criteria as well as observable features of depression in people with ID reported in literature.

The Multi-dimensional Observation Scale for Elderly Subjects (MOSES)[47] is a 40-item screening instrument for maladaptive behaviour including depression.[48] There exists a modified version for people with Down syndrome.[47]

DISCUSSION

This review gives an overview of the currently available screening instruments for depression which have been studied for their psychometric properties in people with ID. The Glasgow Depression Scale for people with a Learning Disability (GDS-LD) seems the most promising self-report instrument. Three informant-report instruments seem promising: the Assessment of Dual Diagnosis (ADD), the Reiss Screen for Maladaptive Behaviour (RSMB) and the Children's Depression Inventory (CDI). However, none of these four instruments has been studied completely for its capability in measuring depression in this population.

When comparing our findings with those of a review by Perez-Achiaga et al. (2009),[49] we agree that the GDS-LD and the Self-Report Depression Questionnaire (SRDQ) are both relatively good instruments for self-report. However, we have a strong preference for the GDS-LD because of its higher reliability, convergent validity, sensitivity and specificity rates than the SRDQ. Although the GDS-LD was only studied once and the retest period in this study was very short, it was of moderate methodological quality with a study population with a good depression distribution of 70.8% depressed and 29.8% non-depressed participants. In contrast, the SRDQ has been studied three times but sensitivity and specificity results are based on only 12 participants, which shows in the large 95% confidence intervals of its sensitivity and specificity rates. Furthermore, the additional informant-report version of the Glasgow Depression Scale is useful for clinical use.

We disagree with Perez-Achiaga et al. (2009) on the utility of the PAS-ADD Checklist and the RSMB for screening for depression, because sensitivity and specificity for the particular subscales have not been studied. Furthermore, at this stage, some key DSM-IV symptoms, such as pervasive loss of pleasure in activities, feelings of worthlessness and guilt, lack of concentration, and suicidal ideation, are not represented in the RSMB.[50] Therefore, at this stage we do not rate the RSMB as the best instrument to screen for depression in clinical practice, although psychometric properties for the total instrument are promising. In contrast with Perez-Achiaga et al. (2009), we consider the ADD and CDI both promising based on their reliability, convergent validity or sensitivity and specificity. However, reliability research in larger samples and research on sensitivity and specificity is still needed.

We have three constructive recommendations for future research. The first is to report more completely about characteristics of the study population, study procedure and results. Moderate or low quality as judged by our quality system was often caused by incomplete or unclear data presentation or unclear report of sample characteristics. The second recommendation is, to use Intraclass Correlation Coefficient (ICC) instead of Pearson correlation to compute interrater reliability. The advantage of ICC over Pearson

correlation is, that in case of a systematic disagreement between two or more raters, Pearson correlation can still be high, while ICC controls for this effect.[1] The relative novelty of the ICC can explain why it has not been used in older studies. Our third recommendation is to report useful information for practical application, such as assessment time and percentage of successful completion in specific groups. Furthermore, outcome measures, such as sensitivity and specificity, which are informative to judge an instrument's value for clinical use, are often lacking. The latter can be explained by practical barriers to study sensitivity and specificity, because you need a good distribution of participants with and without depression and an expert to independently diagnose depression based on DSM or ICD criteria. Especially outside the UK, psychiatrists with specific experience with people with ID are scarce. However the use of a standardised diagnostic instrument, such as the PAS-ADD Interview, enables specifically trained professionals, such as psychologists, to diagnose depression in people with ID.

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Chapter 4

Instruments assessing anxiety in adults with intellectual disabilities: A systematic review

Based on:
H. Hermans, F.H. van der Pas and H. M. Evenhuis, Instruments assessing anxiety in adults with intellectual disabilities: A systematic review. Research in Developmental Disabilities, 32: p. 861-870, 2011.

ABSTRACT

Background: In the last decades several instruments measuring anxiety in adults with intellectual disabilities have been developed.

Aim: To give an overview of the characteristics and psychometric properties of self-report and informant-report instruments measuring anxiety in this group.

Method: Systematic review of the literature.

Results: Seventeen studies studying 14 different instruments were found. Methodological quality as measured with the Quality Assessment of Diagnostic Accuracy Studies checklist was insufficient for four studies, sufficient for seven, and good for six. For self-report, the Glasgow Anxiety Scale for people with a Learning Disability appears most promising, with good internal consistency (α= 0.96), high test-retest reliability (*r*= 0.95), sensitivity (100%) and specificity (100%). For informant-report, the General anxiety subscale of the Anxiety, Depression And Mood Scale may be promising, with good internal consistency (α= 0.83 and α= 0.84) and excellent test-retest reliability (ICC= 0.78 and ICC= 0.92), but poor interrater reliability (ICC= 0.39).

Conclusions: Three instruments appear promising. However, these instruments have only been studied once or twice, whereas the methodological quality of these studies was varying.

INTRODUCTION

The increasing attention for psychiatric disorders in people with intellectual disabilities (ID) has resulted in the development of numerous standardised questionnaires and interviews, measuring a diversity of psychiatric problems. These instruments can be divided in screening versus diagnostic instruments and in self-report versus informant-report instruments. In addition, instruments may vary in target population, origin of the items, length of assessment and psychometric quality. This variety makes it, both in research and clinical practice, difficult and time-consuming to choose the most suitable instrument. A critical overview of available instruments can be of assistance. For several psychiatric disorders, such as depression, dementia, autism and psychopathology in general, a more or less comprehensive overview of available instruments already exists.[1-10] However, a systematic overview of anxiety instruments is lacking, though several studies showed that anxiety is common in people with ID.[11-13] Therefore, the objective of this review is to give an overview of characteristics and psychometric properties of currently available instruments which measure anxiety in people with ID.

METHOD

Literature search and selection

Literature was searched via Embase, PubMed and PsychInfo. The following key terms were used: "Intellectual disability or mental retardation or Down syndrome or learning disability or developmental disability" and "anxiety or phobia or fear or panic disorder" and "assessment or measurement or questionnaire or screening or diagnosis" and "validity or reliability or feasibility or psychometric or sensitivity or specificity". Studies were included if psychometric properties were separately studied for the anxiety subscale and if a majority (> 50%) of the study population had ID and was 16 years or older. The following psychometric properties should have been studied: Test-retest reliability or interrater reliability or convergent validity or predictive validity (preferably sensitivity and specificity). Excluded were reviews and case studies, studies not published in English, Dutch, French, Spanish or German. Other relevant articles were sought through the references of articles we had already selected. Selection was done independently by two researchers (HH and FP). For every selected article consensus had to be reached.

Methodological quality

Methodological quality of the selected studies was judged with a modified version of the Quality Assessment of Diagnostic Accuracy Studies (QUADAS) criteria, as developed by a Cochrane working group.[14] This is an evidence-based quality checklist for

use in systematic reviews of diagnostic accuracy studies. We have slightly adapted the QUADAS checklist:[14] item 1 was specified, and a new item about test-retest period was added (Table 1). For size of study population, a cut-off of 30 participants was chosen, because a study population of 30 or more participants is less vulnerable for the influence of a non-standard distributed study population.[15] Methodological quality was judged independently by two researchers (HH and FP). Items were scored "yes", "no", "unclear" or "not applicable". Not applicable items were not included in the final quality judgement. QUADAS does not provide a scoring. However, to give insight into the relative methodological quality of the studies, we have divided the studies in five categories: Inferior, Insufficient, Sufficient, Good, Excellent. For studies using a reference standard for validity assessment, we considered more than 12 out of 15 items answered with "yes" as excellent, 10-12 items as good, 8-9 items as sufficient, 3-8 items as insufficient and less than 3 items as inferior methodological quality. For studies without a validity assessment, we considered more than 6 out of 7 applicable items answered with "yes" as excellent, 5-6 items as good, 4 items as sufficient, 2-3 items as insufficient and less than

Table 1: Items of the modified QUADAS

Items	
1	Was the spectrum of patients representative of the patients who will receive the test in practice:
	a) More than 30 participants for all statistical calculations?
	b) Levels of ID representing the target population?
2	Were selection criteria clearly described?
3	Is the reference standard likely to correctly classify?
4	Is the time period between reference standard and index test short enough to be reasonably sure that the target condition did not change between the two tests?
5	Did the whole sample or a random selection of the sample, receive verification using a reference standard or diagnosis?
6	Did patients receive the same reference standard regardless of the index test result?
7	Was the reference standard independent of the index test (i.e. the index test did not form part of the reference standard)?
8	Was the execution of the index test described in sufficient detail to permit replication of the test?
9	Was the execution of the reference standard described in sufficient detail to permit its replication?
10	Were the index test results interpreted without knowledge of the results of the reference standard?
11	Were the reference standard results interpreted without knowledge of the results of the index test?
12	Were the same clinical data available when test results were interpreted as would be available when the test is used in practice?
13	Were uninterpretable/ intermediate test results reported?
14	Were withdrawals from the study explained?
15	Was the test-retest period minimal 14 days?

2 items as inferior methodological quality. Studies including test-retest reliability should have one item more answered with "yes" for each category of quality described above.

Interpretation of the psychometric properties

If not given by the authors, we have calculated 95% confidence intervals of sensitivity and specificity rates and of all reported correlation coefficients, except the Spearman's rank correlation coefficient. This gives a more reliable view of the reliability and validity of each instrument in the studied population. It was not possible to calculate 95% confidence intervals for Spearman's rank without raw data. To interpret the internal consistency and correlation coefficients, we applied four guidelines for psychological tests, which are presented in Table 2.

Table 2: Guidelines to interpret internal consistency and correlation coefficients

Internal consistency[16]	**Interpretation**
< 0.70	Unacceptable
0.70-0.79	Fair
0.80-0.89	Good
≥ 0.90	Excellent
Pearson product-moment and Spearman's Rank correlation coefficient[17]	**Interpretation**
< 0.29	Little or no correlation
0.30-0.49	Low correlation
0.50-0.69	Moderate correlation
0.70-0.89	High correlation
≥ 0.90	Very high correlation
Intraclass correlation coefficient[18]	**Interpretation**
< 0.40	Poor
0.40-0.59	Fair
0.60-0.74	Good
≥ 0.75	Excellent
Kappa statistic[19]	**Interpretation**
< 0.00	Poor
0.00-0.20	Slight
0.21-0.40	Fair
0.41-0.60	Moderate
0.61-0.80	Substantial
0.81-1.00	Almost perfect

RESULTS

General results

We found 369 unique studies. Of those, 352 studies were excluded: 312 did not study psychometric properties of an instrument measuring anxiety, 13 did not study people with ID, five studied only children and adolescents, one studied only internal consistency, five studied only factor structure and seven did not study the anxiety subscale separately for its psychometric properties, but only the total scale. Finally, 17 studies were selected to review.[20, 24-25, 28, 30-31, 35-36, 38-39, 41-47] Four studies had insufficient methodological quality, seven sufficient, and six good. None of the studies had excellent or inferior methodological quality (Table 3). The selected studies included eleven screening instruments, four for self-report and seven for informant-report, and three diagnostic instruments.

Screening instruments

Self-report instruments

The Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID)[20] has been developed for people with ID. It has 27 items with a 3-point answering scale. The items are based on experiences of people with ID, clinical judgement and eight already available self-report scales for people with and without ID. Assessment time is 5-10 minutes.

The Psychopathology Instrument for Mentally Retarded Adults-Self-Report (PIMRA-SR)[21] has been developed for people with ID. It has 56 items with a 2-point answering scale, which are based on DSM-III criteria.[22] The Anxiety disorder subscale (7 items) is one of PIMRA's eight subscales.

The Zung Anxiety Scale (ZAS)[23] has been developed for the general population. Lindsey et al. (1994) have adapted the ZAS for use in people with ID.[24] The 20 items were rephrased and the response-format was simplified to presence or absence of the symptoms.

The Fear Survey for Adults with Mental Retardation (FSAMR) has been developed for adults with ID.[25] It has 73 items about fear stimuli, six items to assess acquiescence response set and six open ended questions. The items are based on interviews with adults with ID and their caregivers, interviews with youth with and without ID, the Fear Survey Schedule[26] and the Fear Survey for Children with and without Mental Retardation.[27] Most respondents answered consistently on the items to assess acquiescence response set and could complete 66-100% of the items.[25]

Psychometric properties of the self-report anxiety instruments or the anxiety subscale of the instruments are given in Table 4.

Table 3: Quality of reviewed studies

Author (year)	Studied instruments	Items of the modified QUADAS																Quality
		1a	1b	2	3	4	5	6	7	8	9	10	11	12	13	14	15	
Helverschou et al. (2009)	PAC	y	y	y	na	na	na	na	na	y	na	na	na	y	u	u	na	Good
Hove & Havik (2008)	P-AID	y	y	y	y	u	n	y	y	y	n	u	y	y	y	u	na	Good
Myrbakk & Von Tetzchner (2008)	Mini PAS-ADD, DASH-II, ADD	y	y	n	n	y	y	y	y	y	y	n	n	y	u	u	na	Sufficient
Charlot et al. (2007)	MASS	y	y	n	y	u	y	y	y	y	y	u	y	y	u	u	na	Good
Ramirez & Lukenbill (2007)	FSAMR	y	u	y	n	y	y	y	y	y	y	n	n	y	y	n	na	Good
Methot & Morin (2004)	ADAMS[a]	y	y	n	na	na	na	na	na	y	na	na	na	y	u	u	y	Sufficient
Esbensen et al. (2003)	ADAMS	y	y	y	na	na	na	na	na	y	na	na	na	y	u	u	y	Good
Mindham & Espie (2003)	GAS-ID	n	y	y	y	u	y	y	y	y	n	u	u	y	u	u	y	Sufficient
Gonzalez-Gordon et al. (2002)	PAS-ADD Interview[b]	y	y	y	y	u	y	y	y	y	y	y	y	y	n	u	n	Good
Matson & Bamburg (1998)	ADD	y	y	n	na	na	na	na	na	y	na	na	na	y	u	u	y	Sufficient
Moss et al. (1998)	PAS-ADD checklist	y	y	u	na	na	na	na	na	u	na	na	na	y	u	u	na	Insufficient
Prosser et al. (1998)	Mini PAS-ADD	y	y	y	na	na	na	na	na	n	na	na	na	u	u	u	na	Insufficient
Costello et al. (1997)	PAS-ADD Interview	y	y	y	na	na	na	na	na	y	na	na	na	n	u	u	na	Sufficient
Moss et al. (1997)	PAS-ADD Interview	n	y	y	y	u	y	y	y	y	n	n	y	u	u	u	na	Sufficient
Lindsay et al. (1994)	ZAS	y	y	n	n	y	y	y	y	y	y	u	u	y	u	u	na	Sufficient
Matson et al. (1991)	DASH	n	y	u	na	na	na	na	na	y	na	na	na	n	u	u	na	Insufficient
Senatore et al. (1985)	PIMRA	n	u	n	na	na	na	na	na	y	na	na	na	y	u	u	y	Insufficient

y= yes; n= no; u= unclear; na= not applicable

[a] French version

[b] Spanish version

Table 4: Psychometric properties of self-report screening instruments measuring anxiety

Instrument	Quality of the study	Internal consistency	Reliability	Convergent validity (instrument)	Predictive validity
GAS-ID					
Mindham & Espie (2003)	Sufficient	0.96	Test-retest (period): r= 0.95, p<0.0001, CI[a]: 0.87-0.99 (4 weeks)	ρ= 0.75, p<0.001, (Beck Anxiety Scale)[b]	Cut-off 13-15: SEN[c] 100%, CI: 83-100%, SPE[d] 100%, CI: 82-100%
PIMRA-SR					
Ramirez & Lukenbill (2007)	Good	-	-	r= 0.32, p< 0.001, CI: 0.16-0.46 (FSAMR)	-
Senatore et al. (1985)	In-sufficient	-	Test-retest (period): r= 0.54, p< 0.01, CI: 0.15-0.79 (23 weeks, SD 4.3)	-	-
ZAS					
Ramirez & Lukenbill (2007)	Good	-	-	r= 0.40, p< 0.001, CI: 0.25-0.53 (FSAMR)	-
Lindsay et al. (1994)	Sufficient	-	-	r= 0.59, p< 0.05, CI: 0.41-0.73 (GHQ anxiety subscale)	-
FSAMR					
Ramirez & Lukenbill (2007)	Good	0.97	-	r= 0.40, p< 0.001, CI: 0.25-0.53 (ZAS), r= 0.32, p< 0.001, CI: 0.16-0.46 (PIMRA-SR)	-

GAS-ID, Glasgow Anxiety Scale for people with an Intellectual Disability; PIMRA-SR, Psychopathology Instrument for Mentally Retarded Adults-Self-report, ZAS, Zung Anxiety Scale; FSAMR, Fear survey for adults with mental retardation

[a] CI= 95% confidence interval

[d] studied in people without ID

[c] SEN= sensitivity

[d] SPE= specificity

Informant-report instruments

The Anxiety, Depression And Mood Scale (ADAMS)[28] has been developed for people with ID. It consists of 28 items with a 4-point answering scale. The items are based on DSM-IV criteria,[29] other instruments and clinical assessments. The General anxiety subscale (7 items) is one of ADAMS' five subscales.

The Assessment of Dual Diagnosis (ADD)[30] has been developed for adults with mild or moderate ID. It has 79 items of which severity, duration and frequency are rated on a

3-point scale. The items are based on DSM-IV criteria and previously published studies. The Anxiety subscale is one of the 13 subscales.

The Psychiatric Assessment Schedule for Adults with a Developmental Disability Checklist (PAS-ADD Checklist)[31] has been developed for people with ID. It consists of 29 items with a 4-point answering scale and a life events checklist. The items are based on the most predictive items of the PAS-ADD interview.[32] The items are divided in three clusters, anxiety is covered in the Affective/neurotic cluster (20 items).

The Mini Psychiatric Assessment Schedule for Adults with a Developmental Disability (Mini PAS-ADD)[33] has been developed for people with ID. It consists of 86 psychiatric symptoms which are rated on a 4-point severity scale. The items are based on the PAS-ADD interview. The Anxiety and phobias subscale is one of the seven subscales.

The Diagnostic Assessment for the Severely Handicapped-II (DASH-II)[34] is the revision of the Diagnostic Assessment for the Severely Handicapped (DASH).[35] The DASH-II has been developed for people with severe or profound ID. It consists of 84 symptoms of which severity, duration and frequency are rated on a 3-point scale. The items are based on DSM-III-R. The Anxiety subscale (8 items) is one of the 13 subscales.

The Psychopathology in Autism Checklist (PAC)[36] has been developed for people with ID and autism. It has 42 items with a 4-point answering scale. The items are based on ICD-10[37] and DSM-IV criteria. The Anxiety subscale (6 items) is one of PAC's five subscales. The Anxiety subscale does not differentiate between different psychiatric diagnoses.[36]

Psychometric properties of the informant-report anxiety instruments or the anxiety subscale of the instruments are given in Table 5.

Table 5: Psychometric properties of informant-report screening instruments measuring anxiety

Instruments	Quality of the study	Internal consistency	Reliability	Convergent validity (instrument)
ADAMS				
Methot & Morin (2004)	Sufficient	General anxiety (5 factors): 0.84 Anxiety (3 factors) [a]: 0.83	Test-retest (period): General anxiety (5- factors): ICC= 0.92, CI[b]: 0.85-0.96 Anxiety (3- factors): ICC: 0.92, CI: 0.85-0.96, (2 weeks)	-
Esbensen et al. (2003)	Good	0.83	Test-retest (period): ICC= 0.78, CI: 0.67-0.86, (14-90 days), Interrater: 0.39, CI: 0.13-0.61	-
ADD				
Myrbakk & Von Tetzchner (2008)	Sufficient	0.74	-	ρ= 0.72, p< 0.01, (Mini PAS-ADD)
Matson & Bamburg (1998)	Sufficient	0.79	Test-retest (period): r= 0.82, CI: 0.73-0.89 (2 weeks) Interrater: r= 0.83, CI: 0.74-0.90	-

Table 5: Psychometric properties of informant-report screening instruments measuring anxiety

Instruments	Quality of the study	Internal consistency	Reliability	Convergent validity (instrument)
PAS-ADD Checklist				
Moss et al. (1998)	In-sufficient	Affective /neurotic subscale: 0.84, Anxiety subscale[c]: 0.77	Interrater: Affective/ Neurotic subscale: r= 0.76, p< 0.001, CI: 0.64-0.85, Anxiety subscale: r= 0.57, p< 0.001, CI: 0.38-0.72	-
Mini PAS-ADD				
Myrbakk & Von Tetzchner (2008)	Sufficient	0.73	-	ρ= 0.43, p< 0.01, (DASH-II), ρ= 0.72, p< 0.01, (ADD)
Prosser et al. (1998)	In-suffient	0.76	Interrater: r= 0.36, CI: 0.13-0.56	-
DASH				
Matson et al. (1991)	In-sufficient	0.62	Interrater proportion of agreement= 0.98	-
DASH-II				
Myrbakk & Von Tetzchner (2008)	Sufficient	0.54	-	ρ= 0.43, p< 0.01, (Mini PAS-ADD)
PIMRA-I				
Senatore et al. (1985)	In-sufficient	-	Test-retest (period): r= 0.85, p< 0.001, CI: 0.67-0.94 (22 weeks, SD:5.3)	-
PAC				
Helverschou et al. (2009)	Good	0.78	Interrater: κ= 0.58	-

ADAMS, Anxiety, Depression And Mood Scale; ADD, Assessment of Dual Diagnosis; PAS-ADD Checklist, Psychiatric Assessment Schedule for Adults with a Developmental Disability Checklist, Mini PAS-ADD, Mini Psychiatric Assessment Schedule for Adults with a Developmental Disability; DASH, Diagnostic Assessment for the Severely Handicapped; PIMRA-I, Psychopathology Instrument for Mentally Retarded Adults-Informant; PAC, Psychopathology in Autism Checklist

[a] After factor analysis, Méthot & Morin (2004) preferred a three-factor structure over the original five-factor structure

[b] CI= 95% confidence interval

[c] the anxiety subscale is one of the subscales based on a 'a priory' factor analysis

Diagnostic instruments

The Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD) Interview[32] has been developed for assessment with people with ID (respondents) and their caregivers (informants). It is a semi-structured interview and focuses on the more common axis I disorders. The PAS-ADD interview consists of sections about schizophrenia, depression, phobic anxiety disorders and other anxiety disorders. Average

assessment time is 32.4 minutes (s.d. 9.2) for respondents and 31.2 minutes (s.d. 2.5) for informants. Assessment has to be done by clinicians with a background in psychopathology and expertise in interviewing people with ID. After training other professionals with an adequate background in mental health can use it too. Good training in interviewing and coding is essential.[32]

Table 6: Psychometric properties of diagnostic instruments measuring anxiety

Instruments	Quality of the study	Internal consistency	Reliability	Predictive validity
PAS-ADD Interview				
Gonzalez-Gordon et al. (2002)	Good	-	Test-retest (period) neurotic symptoms : ICC= 0.79, CI[a]: 0.69-0.88 (7-15 days), Interrater: ICC= 0.89, CI: 0.82-0.96[b]	-
Costello et al. (1997)	Sufficient	-	Interrater: specific phobia κ= 0.82, agora phobia κ= 0.66, nervous tension κ= 0.50, autonomic anxiety κ=0.47, panic κ= 0.47	-
Moss et al. (1997)	Sufficient	-	-	SEN[c]: 100%, CI: 44-100%, SPE[d]: 97%, CI: 91-99%
MASS Interview				
Charlot et al. (2007)	Good	-	-	GAD[e]: SEN 73%, CI: 0.59-0.84, SPE: 69%, CI: 0.55-0.80, any anxiety disorder (GAD, Panic, OCD[e] anxiety NOS[f]): SEN 96%, CI: 0.87-0.99, SPE 81%, CI: 0.67-0.90
P-AID				
Hove & Havik (2008)	Good	Social phobia: 0.85, specific phobia 0.83, agoraphobia: 0.87, generalized anxiety[c] 0.89, panic disorder: 0.89	Interrater: Social phobia: ICC= 0.65 (0.45-0.78), specific phobia: ICC= 0.66 (0.45-0.78), agoraphobia: ICC= 0.75 (0.61-0.74), generalized anxiety: ICC= 0.55 (0.28-0.72), panic disorder: ICC= 0.49 (0.19-0.68)	-

PAS-ADD, Psychiatric Assessment Schedule for Adults with a Developmental Disability; MASS, Mood and Anxiety Semi-Structured; P-AID, Psychopathology checklists for Adults with Intellectual Disability

[a] CI= 95% confidence interval

[b] test-retest and interrater reliability only for the respondent interview

[c] SEN= sensitivity

[d] SPE= specificity

[e] GAD= generalised anxiety disorder

[f] OCD= obsessive compulsive disorder

[g] NOS= not otherwise specified

The Mood and Anxiety Semi-Structured (MASS) interview[38] has been developed for assessment with caregivers of people with ID. Presence or absence in the last month is assessed for 35 symptoms which are based on behavioural descriptions of DSM-IV-TR criteria. Assessment time is 30-60 minutes. The interview can be used by mental health clinicians with experience with people with ID with minimal training.

The Psychopathology checklists for Adults with Intellectual Disability (P-AID)[39] have been developed for completion by informants and consist of 18 different checklists: Eight for problem behaviours and ten for psychiatric disorders. Five of these checklists measure anxiety: Agoraphobia, social phobia, specific phobia, generalised anxiety, and panic disorder. The 92 anxiety items are about characteristics of the content of the anxiety reaction, time, place, generality and bodily reactions. The items are based on the diagnostic criteria of the DC-LD.[40]

Psychometric properties are given in Table 6.

DISCUSSION

This review gives an overview of the psychometric properties of fourteen currently available instruments which have been studied for their psychometric properties in adults with ID. The Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID) is the most promising self-report instrument, whereas the Anxiety, Depression And Mood Scale (ADAMS) appears the most promising informant-report instrument. The Assessment of Dual Diagnosis (ADD) also seems promising, but the test-retest and interrater reliability of the ADD were high but not significant at the $p< 0.005$ level. It is unknown if these reliability coefficients are significant at a higher level. The PAS-ADD Checklist has also good reliability results, but this study is of insufficient methodological quality. The PAS-ADD Interview seems the most robust diagnostic instrument.

The methodological quality of the studies, as judged with a slightly modified version of the QUADAS checklist, is varying, but most studies have at least sufficient methodological quality. Insufficient quality was most often caused by incomplete reporting. Over the years, the methodological quality of studies, especially clarity of reporting, improved.

Although a good predictive validity is the most relevant characteristic of a screening or diagnostic instrument, sensitivity and specificity against a psychiatric expert diagnosis have only been studied for the GAS-ID and two diagnostic interviews. While it may be hard obtaining individual psychiatric diagnoses for outpatient study populations, such validity assessment is of vital importance. The expert diagnosis might be replaced by PAS-ADD interviews done by trained psychologists. However, Moss et al. (1997) and Costello et al. (1997) state that especially anxiety disorders are difficult to accurately diagnose with the PAS-ADD interview.[41, 42]

In conclusion, this review showed that quite a few instruments assessing anxiety do exist for people with ID, but in most cases their psychometric properties are insufficiently studied. Therefore, we would recommend for future research to further study the psychometric properties of already existing, promising instruments, instead of developing more new instruments. For clinical practice, it is recommendable to be careful with interpreting results of an instrument of which reliability and especially validity have not been studied completely.

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Chapter 5

Reliability and validity of the Dutch version of the Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID)

Based on:
H. Hermans, J. Wieland, N. Jelluma, F.H. van der Pas and H. M. Evenhuis, Reliability and validity of the Dutch version of the Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID). Submitted.

ABSTRACT

Background: In the Netherlands, no self-report questionnaire screening for anxiety in people with intellectual disabilities (ID) was available yet. Therefore, we have translated the Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID) into Dutch and studied its reliability and validity in adults with borderline, mild or moderate ID.

Method: Test-retest reliability was studied in 66 participants, convergent validity against the Anxiety subscale of the Hospital, Anxiety and Depression Scale in 96, and criterion validity against psychiatric diagnosis in 195 participants.

Results: Internal consistency was α= 0.86, test-retest reliability ICC= 0.89 (95% CI: 0.82-0.93), correlation with the HADS-A *r*= 0.61 (95% CI: 0.47-0.72) and sensitivity and specificity were 83.9% (95% CI: 72.2-91.2) and 51.8% (95% CI: 43.6-59.9) using a cut-off score of 17. Missed diagnoses (false-negatives) were mostly specific phobias. Of the false-positives, 38 participants (58%) had another psychiatric diagnosis.

Conclusions: The Dutch version of the GAS-ID seems a reliable instrument for clinical practice with satisfactory sensitivity, but moderate specificity. Although specificity for anxiety disorders is only moderate, high scores seem to be indicative of other psychiatric problems.

INTRODUCTION

Symptoms of anxiety are more prevalent in people with mild or moderate intellectual disabilities (ID) than in people with severe or profound ID.[1, 2] The symptoms of anxiety disorders are partly internal symptoms, which are seldom observable. This makes it hard for informants to recognize and evaluate the frequency and intensity of these symptoms.[3-5] Nevertheless, detecting anxiety disorders in people with ID is important, because they can be effectively treated with medication or cognitive behavioural therapy.[6, 7] Because of the internalizing symptoms, diagnostic assessment based on self-report is strongly recommended,[3, 8] and many adults with mild or moderate ID are well able to report about their feelings.[4, 9-11] It has been shown that in this group, reported symptoms generally correspond with the diagnostic criteria of the DSM-IV[12] or ICD-10.[13] [10, 14, 15] However, anxiety questionnaires developed for the general population can be too difficult for this group and simplified language and a clear response format are necessary for reliable outcomes.[16]

A recent review of the literature shows that the psychometric properties of four self-report instruments measuring anxiety have been evaluated in adults with ID: the Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID),[17] the Psychopathology Instrument for Mentally Retarded Adults-Self-Report,[18] the Zung Self-Rating Anxiety Scale,[19] and the Fear Survey for Adults with Mental Retardation.[20] In the Netherlands, no self-report anxiety instrument for adults with ID is available with satisfactory reliability and validity, according to guidelines for psychological tests.[21-23] Therefore, we have translated the GAS-ID into Dutch. We have selected this instrument, because of its short, concrete questions concerning both cognitive and physical symptoms of anxiety. Furthermore, of the four evaluated instruments, the GAS-ID currently has the best psychometric properties.[24] Our aim was to study the reliability, convergent validity, and criterion validity of the Dutch translation of the GAS-ID.

METHOD

Setting and study population

Data collection was performed in three settings during February 2009 to April 2011. Part of the data collection was done as part of the epidemiologic study 'Healthy Ageing and Intellectual Disability' (HA-ID)[25] in which physical and mental health of adults with ID of 50 years and older are being studied. Data of adults younger than 50 years were collected through a service organization for people with ID, providing care and support in residential settings and day-care settings, and through an outpatient mental health clinic for people with ID. The test-retest sample was part of the total sample (Table 1).

The HA-ID study and the additional study in the ID service organization have been approved by the Medical Ethical Testing Committee of the Erasmus University Medical Center at Rotterdam, the Netherlands. Written informed consent was obtained from the participants or their legal guardians. Recruitment, inclusion, and informed consent procedures have been described in detail in Hilgenkamp et al. (2011). In the mental health clinic, it is part of the general policy to routinely monitor treatment outcomes (Routine Outcome Monitoring).[26] It has its own form of Routine Outcome Monitoring, using instruments especially developed for people with ID, but also instruments used in regular psychiatry, such as the Brief Symptom Inventory.[27, 28] Patients are informed at the beginning of the assessment that if data are used for research purposes, this is done in anonymous form. If people object to such use, their data are removed. A comprehensive protocol safeguards anonymity of the patients and ensures proper handling of the data. The Medical Ethical Committee of the Leiden University Medical Centre approved the regulations and agreed with this policy.[26]

Measures and procedure

The Glasgow Anxiety Scale

The Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID)[17] is a self-report questionnaire that consists of 27 items about worries, specific fears, and physiological symptoms of anxiety. The total score ranges from 0 to 54. The authors studied its reliability and validity in 35 adults with ID, finding an internal consistency of $\alpha = 0.96$, test-retest reliability of $r = 0.95$, and sensitivity and specificity rates of respectively 100% (95% CI: 83-100) and 100% (95% CI: 82-100) that were identical for the cut-off scores of 13, 14 and 15.[17] The GAS-ID was administered in an assisted fashion, depending on health care setting and level of intellectual disability. For participants of the HA-ID study and the ID service organization for people with ID this means that the GAS-ID was administered by trained interviewers. To study test-retest reliability, the GAS-ID was administered twice by the same interviewer. In the mental health clinic, participants completed the GAS-ID in written form with support from a psychologist. In other self-report measures, assisted completion did not influence respondents' ratings of symptoms excessively.[29, 30] In both settings, the comprehensibility of the questions was carefully verified for each participant. The GAS-ID was completed before any treatment was started.

Translation of the GAS-ID

The GAS-ID was independently translated into Dutch by three members of the research team, after which the three translated versions were discussed and consensus was reached about the final draft. A native English speaker translated the Dutch version back to English. It appeared that the phrasing of his translation was different for several questions, but the content of all items corresponded completely. We first tested feasibility of

this Dutch translation in a pilot study of 26 participants with a mild or moderate ID. As a result, the item 'Are you scared of spiders?' was placed first, because this question made the concept of anxiety clear and several participants indicated this as a recognizable kind of anxiety.

Other measures

To study the convergent validity of the Dutch GAS-ID, participants of the HA-ID study also completed the Anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A).[31] The HADS-A is a screening instrument that consists of seven items. It has been developed for the general hospital population, but its psychometric properties are sufficient in community and primary care settings as well.[31-34] The HADS-A has been used in adults with ID, but its reliability and validity have not been studied in this group yet.[35] For better comprehension, we added a standardized explanation of difficult concepts, such as restless feelings, to four items (2, 3, 6 and 7). The HADS-A was administered by trained interviewers.

The criterion validity of the Dutch GAS-ID was assessed by evaluating the outcome of the GAS-ID against a gold standard. We used the outcome of a psychiatric diagnostic interview as gold standard. All participants assessed in the HA-ID study or in the ID service organization were interviewed with the Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD) Interview.[36] The PAS-ADD Interview is a semi-structured diagnostic interview based on ICD-10 criteria that consists of sections about schizophrenia, depression, phobic anxiety disorders, and other anxiety disorders. The psychometric properties of the PAS-ADD Interview are fair to good in adults with ID.[37-39] All PAS-ADD Interviews were performed by specially trained behavioural therapists and psychologists with experience in working with people with ID. Both the participant and a professional caregiver were independently interviewed. The professional caregivers had to know the participant for at least three months and provided support or care in the residential setting. All participants assessed in the mental health clinic underwent multidisciplinary assessment, including an interview by a psychiatrist, specialized in working with people with ID. The psychiatrists, behavioural therapists and psychologists were blind to the outcome of the GAS-ID.

Personal characteristics and residential setting were retrieved from the participants' files. Data on level of ID and Autism Spectrum Disorders were obtained through the participant's psychologist or behavioural therapist.

Analysis

All analyses were done with the Statistical Package for the Social Sciences 17.0. Internal consistency was examined with Cronbach's alpha. Test-retest reliability was studied with Intraclass Correlation Coefficients (ICC). Correlation of the GAS-ID with the HADS-A

was studied with Pearson's product-moment coefficient. To study differences between subgroups on the total score of the GAS-ID, the association of gender, age, level of ID (borderline, mild, moderate), and presence or absence of an Autism Spectrum Disorder with the GAS-ID's total score was studied with a linear regression analysis. Characteristics with a significant association with the GAS-ID's total score were used to define subgroups for which sensitivity and specificity of GAS-ID scores against psychiatric diagnosis were determined using ROC curves.

Convergent validity was studied by comparing the baseline-scores on the GAS-ID with those on the HADS-A. Criterion validity (sensitivity and specificity) was studied in the total sample by comparing the GAS-ID score with the psychiatric diagnoses based on the psychiatric diagnostic interviews. The concept of sensitivity and specificity has been developed to facilitate diagnostic decision-making by clinicians based on different cut-off values.[40] Sensitivity reflects to what extent a diagnostic instrument correctly identifies people with a pathological disorder (true-positives) and specificity reflects its ability to correctly recognize people as not having a pathological disorder (true-negatives).

To study the GAS-ID's suitability for use in studies about ageing, the reliability and validity were studied for the total sample and for subgroups aged younger than 50 years and aged 50 years or older. All correlation coefficients, sensitivity, and specificity rates are presented with 95% confidence intervals. Published guidelines for psychological tests were used to interpret Cronbach's alpha, ICC's, and Pearson's product-moment coefficients.[22, 23, 41]

RESULTS

The total study population consisted of 195 participants, 98 participating in the HA-ID study, 35 from the ID service organization and 62 from the mental health clinic. Characteristics of the total sample and reliability sample are presented in Table 1.

Internal consistency of the GAS-ID was 0.86 for the total sample, 0.88 for the sample aged <50 years and 0.81 for the sample aged ≥50 years. Test-retest reliability was ICC= 0.89 (95% CI: 0.82-0.93) for the total reliability sample, ICC= 0.89 (95% CI: 0.76-0.95) for the sample aged <50 years and ICC = 0.88 (95% CI: 0.78-0.93) for the sample aged ≥50 years. The mean test-retest period was 23 days (mode: 14; range 14-37 days). The correlation of the GAS-ID with the HADS-A was r= 0.61 (95% CI: 0.47-0.72), p< 0.01 (n= 96).

Linear regression analysis revealed a significant association of gender and age with the score on the GAS-ID, and no significant association with level of ID or autism (data not shown). Therefore, subgroups of participants according to gender and age or combinations of those were made, for which ROC curves were determined and cut-off scores with the best criterion validity defined. It appeared that subgroups based on gender or

Table 1: Characteristics of the study population

	Sample test-retest reliability			**Total sample**		
	<50 years	≥50 years	Total	<50 years	≥50 years	Total
n	23	43	66	75	120	195
Gender (male/female)	13/10	22/21	35/31	27/48	47/73	74/121
Age						
Mean (s.d.)	33.8 (8.7)	61.7 (7.8)	51.9 (15.6)	31.3 (9.3)	62.2 (8.9)	50.3 (17.6)
Range	19.2-48.4	50.7-80.5	19.2-80.5	16.3-49.6	50.6-86.6	16.3-86.6
Residential setting (%)						
Central setting	0 (0.0)	2 (4.7)	2 (3.0)	0 (0.0)	25 (20.8)	25 (12.8)
Community home	16 (69.6)	34 (79.1)	50 (75.8)	26 (34.7)	74 (61.7)	100 (51.3)
Independent living with ambulatory support	7 (30.4)	7 (16.3)	14 (21.2)	21 (28.0)	16 (13.3)	37 (19.0)
Independent living without support	0 (0.0)	0 (0.0)	0 (0.0)	12 (16.0)	5 (4.2)	17 (8.7)
With relatives	0 (0.0)	0 (0.0)	0 (0.0)	16 (21.3)	0 (0.0)	16 (8.2)
Level of ID[a] (%)						
Borderline (IQ = 70-84)	1 (4.3)	4 (9.3)	5 (7.6)	31 (41.3)	15 (12.5)	46 (23.6)
Mild ID (IQ = 50-69)	21 (91.3)	22 (51.2)	43 (65.2)	40 (53.3)	70 (58.3)	110 (56.4)
Moderate ID (IQ =35-49)	1 (4.3)	10 (23.3)	11 (16.7)	4 (5.3)	27 (22.5)	31 (15.9)
Unknown[b]	0 (0.0)	7 (16.3)	7 (10.6)	0 (0.0)	8 (6.7)	8 (4.1)
Psychiatric diagnoses (%)						
Depression	6 (26.1)	4 (9.3)	10 (15.2)	14 (18.7)	14 (11.7)	28 (14.4)
Anxiety disorder	9 (39.1)	4 (9.3)	13 (19.7)	36 (48.0)	20 (16.7)	56 (28.7)
GAD[c]	0 (0.0)	1 (2.3)	1 (1.5)	1 (1.3)	3 (2.5)	4 (2.1)
Panic disorder	1 (4.3)	3 (7.0)	1 (1.5)	5 (6.7)	3 (2.5)	8 (4.1)
Phobia	8 (34.8)	0 (0.0)	11 (16.7)	9 (12.0)	9 (7.5)	18 (9.2)
PTSD[d]	0 (0.0)	0 (0.0)	0 (0.0)	19 (25.3)	5 (4.2)	24 (12.3)
Anxiety disorder NOS[e]	0 (0.0)	0 (0.0)	0 (0.0)	2 (2.7)	0 (0.0)	2 (1.0)
Autism Spectrum Disorder	6 (26.1)	1 (2.3)	7 (10.6)	8 (10.7)	4 (3.3)	12 (6.2)
Other[f]	6 (26.1)	5 (11.6)	11 (16.7)	24 (32.0)	23 (19.2)	47 (24.1)
Mean score GAS-ID (s.d.)	18.2 (9.9)	13.3 (7.4)	15.0 (8.6)	21.2 (9.3)	16.2 (7.5)	18.1 (8.6)
Mean score GAS-ID T2[g] (s.d.)	16.7 (9.7)	13.9 (8.1)	14.9 (8.7)	-	-	-

[a] ID = intellectual disability
[b] No official level of ID was administered
[c] GAD = generalized anxiety disorder
[d] PTSD = post-traumatic stress disorder
[e] Not otherwise specified
[f] Mania, psychosis, ADHD, personality disorders
[g] T2 = second completion

on gender and age combined did not result in different, more valid cut-off scores than subgroups based on age alone. In Table 2, the criterion validity of varying cut-off scores for the sample of participants younger than 50 years, of 50 years and over, and the total sample are presented with 95% confidence intervals.

A cut-off score of 17 seems most valid for the whole sample (Table 2). Further inspection of this cut-off score showed that in the total sample, four of nine missed diagnoses (false-negatives) concerned specific phobias and three of them were missed in the older group. In the younger group, five diagnoses were missed, of which two concerned a post-traumatic stress disorder (PTSD). In the total sample, 38 of 66 of the false-positives had another psychiatric disorder, such as depression, psychosis or personality disorder. This applies to all 25 false positives in the younger group and to 13 of 41 in the older group.

Table 2: Criterion validity of the GAS-ID for different cut-off scores

	<50 years		**≥50 years**		**Total study population**	
Score	Sensitivity (95% CI)	Specificity (95% CI)	Sensitivity (95% CI)	Specificity (95% CI)	Sensitivity (95% CI)	Specificity (95% CI)
13	91.7% (78.2-97.1)	17.9% (9.0-32.7)	90.0% (69.9-97.2)	36.0% (27.3-45.8)	91.1% (80.7-96.1)	30.9% (23.9-39.1)
14	91.7% (78.2-97.1)	25.6% (14.6-41.2)	90.0% (69.9-97.2)	41.0% (31.9-50.8)	91.1% (80.7-96.1)	36.7% (29.1-45.0)
15	86.1% (71.3-94.0)	28.2% (16.5-43.8)	85.0% (64.0-94.8)	45.0% (35.6-54.8)	85.7% (74.3-92.6)	40.3% (32.5-48.6)
16	86.1% (71.3-94.0)	30.8% (18.6-46.4)	80.0% (58.4-91.9)	50.0% (40.4-59.6)	83.9% (72.2-91.3)	44.6% (36.6-52.9)
17	86.1% (71.3-94.0)	37.9% (22.7-51.6)	80.0% (58.4-91.9)	58.0% (48.2-67.2)	83.9% (72.2-91.3)	51.8% (43.6-59.9)
18	77.8% (61.9-88.3)	48.7% (33.9-63.8)	65.0% (43.3-81.9)	64.0% (54.2-72.7)	73.2% (60.4-83.0)	59.7% (51.4-67.5)

DISCUSSION

This study of the reliability and validity of the Dutch translation of the GAS-ID in 195 adult participants shows that the reliability is good, with an internal consistency of 0.86 and test-retest reliability of 0.89. The validity is moderate, with a correlation with the HADS-A of r= 0.61 and a sensitivity and specificity of respectively 83.9% and 51.8%, using a cut-off score of 17.

It is not remarkable that the specificity of the GAS-ID is lower than its sensitivity. Anxiety is a very common psychiatric symptom not only indicative for an anxiety disorder. Of the false positives, indeed 38 participants (58%) had other psychiatric diagnoses, justify-

ing referral for psychiatric assessment. In the age group younger than 50 years, this was the case in all false-positives, but this may have been caused by an overrepresentation of participants, referred to the outpatient mental health clinic. The false negatives show that specific phobias may be harder to detect with the GAS-ID, perhaps because they only cause anxiety in very specific situations. Indeed Moss et al. (1997) found that people with ID find it hard to describe panic attacks and phobias, which may explain detection only after more extensive psychiatric assessment. Specific phobias can be easier detected with semi-structured questions, which allow a first determination of anxiety provoking situations. In addition to this, self-report measures of anxiety are known to be difficult to complete, even for the general population.[42]

Comparison of our results to those of Mindham and Espie (2003) shows that our reliability coefficients are lower, though still good. The original sensitivity and specificity rates were much better, with optimal cut-off values between 13 and 15, while specificity became reasonable in our group only with cut-off values of 17 and higher. Compared to the English study population, our sample was larger but older, and less participants had an anxiety disorder, but more participants were diagnosed with other psychiatric disorders.

A limitation of our study is that we used the HADS-A to examine convergent validity, while its psychometric properties have not been evaluated in the population with ID. However, no other anxiety instruments validated for this population were available. Another limitation is that, although all psychiatric diagnoses were made by trained professionals, different procedures have been followed in the different settings. For part of the sample this was done using the PAS-ADD interview. Since this interview does not include all psychiatric diagnoses (for instance, there is no PTSD-section), this influenced the diagnostic procedure. On the other hand, it is a reflection of daily practice.

In conclusion, the GAS-ID seems a reliable screening instrument both for research and clinical practice, with a satisfactory sensitivity, but moderate specificity, resulting in false-positive cases. Probably, this is partly caused by the high prevalence of other psychiatric disorders in this population. Replication of the study in a larger sample may clarify this further, and moreover enable assessment of the underlying factor structure of the GAS-ID. Users of the GAS-ID should be aware of its limitations. The relatively low specificity might be problematic for research or screening procedures aimed specifically at anxiety disorders. This is less problematic for general psychiatric assessment, because high anxiety scores are often indicative of other psychiatric disorders. In clinical practice, extra attention should be paid to specific phobias, because four of these diagnoses (27%) were not detected with the GAS-ID. Even though this makes the GAS-ID less helpful in diagnosing specific anxiety disorders or making treatment decisions, it is a useful and reliable screening instrument for the detection of symptoms of anxiety in general.

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Chapter 6

Feasibility, reliability and validity of the Dutch translation of the Anxiety, Depression And Mood Scale in older adults with intellectual disabilities

Based on:
H. Hermans, N. Jelluma, F.H. van der Pas and H. M. Evenhuis, Feasibility, reliability and validity of the Dutch translation of the Anxiety, Depression And Mood Scale in older adults with intellectual disabilities. Research in Developmental Disabilities, 33: p. 315-323, 2012.

ABSTRACT

Background: The informant-based Anxiety, Depression And Mood Scale was translated into Dutch and its feasibility, reliability and validity in older adults (aged ≥ 50 years) with intellectual disabilities (ID) was studied.

Method: Test-retest (n=93) and interrater reliability (n=83), and convergent (n=202 and n=787), discriminant (n=288) and criterion validity (n=288) were studied. Convergent and criterion validity were studied for the Depressed mood and General anxiety subscales. Subgroups based on level of ID and autism have been made to study the criterion validity. Psychiatric diagnoses based on the PAS-ADD Interview were used as gold standard.

Results: All subscales had good internal consistency (α≥ 0.80), excellent test-retest reliability (ICC≥ 0.75) and good interrater reliability (ICC≥ 0.74), except for the Social avoidance subscale (ICC= 0.57). The Depressed mood subscale showed low correlation (*r*= 0.44) with the self-report Inventory of Depressive Symptomatology, high correlation with the informant-report Signalizing Depression List for people with ID (*r*= 0.71) and no correlation with the PAS-ADD's sleep disorders subscale (*r*= 0.15). Its sensitivity ranged from 73 to 80%, and its specificity from 71 to 79%. The General anxiety subscale showed low correlation with the self-report scales: Glasgow Anxiety Scale (*r*= 0.37) and Hospital Anxiety and Depression Scale (*r*= 0.41), and no correlation with the sleep disorder subscale (*r*= 0.02). Its sensitivity ranged from 67 to 100%, and its specificity from 48 to 81%.

Conclusions: The Dutch translation of the ADAMS is reliable and sufficiently valid to screen for anxiety and depression in older people with ID.

INTRODUCTION

Life expectancy of people with intellectual disabilities (ID) is increasing.[1] The increasing age combined with complex physical and mental health problems makes it complicated to provide good quality care for older people with ID.[2] To study the health status of older people with ID in the Netherlands, a large epidemiological study, titled 'Healthy Ageing and Intellectual Disability', is in progress. One of the themes addressed in this study is 'Depression and Anxiety'. In adults with ID, the prevalence of depression ranges from 2.2 to 8.0%[3-6] and of anxiety disorders from 2.2 to 14.0%.[3-5, 7] In the general ageing population, it is known that depression and anxiety are strongly related and often co-occurring.[8] Furthermore, occurrence of depression and anxiety symptoms increases with higher age.[9-13] Both depression and anxiety symptoms have a negative influence on physical health, daily functioning and quality of life.[13-19]

Prevalence rates, co-occurrence and associations have not been studied in ageing people with ID yet. Therefore, all participants of the 'Healthy Ageing and Intellectual Disability' (HA-ID) study have been screened with questionnaires measuring depression and anxiety. It is important to use reliable and valid screening instruments. Therefore, the screening instruments used in the HA-ID study were chosen after a thorough selection procedure. In this selection process, first all available questionnaires measuring depression or anxiety in children or adults with or without ID were explored. Second, the psychometric properties in adults with ID or in the general population were reviewed and instruments with at least fair psychometric properties were selected. Then, coverage of diagnostic criteria for depression and anxiety of these questionnaires was evaluated. Finally, several experts were consulted to discuss feasibility for both epidemiological research and clinical practice in older people with ID. The instruments which were most suitable according to the above criteria, were selected to screen for depression and anxiety. The selected instruments for depression are: The Inventory of Depressive Symptomatology Self Report (IDS-SR)[20] and the Dutch Signalizing Depression List for people with Intellectual Disabilities (SDL-ID).[21] The selected instruments for anxiety are: The Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID)[22], the Anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A)[23] and the Anxiety, Depression And Mood Scale (ADAMS).[24] The ADAMS and GAS-ID had to be translated by us, after which their psychometric properties had to be evaluated. In the current report evaluation outcomes of the ADAMS will be presented. The ADAMS was selected because a review of the literature concerning reliability and validity of instruments measuring anxiety in adults with ID showed that this instrument had relatively good psychometric properties compared to other informant-report instruments.[25] Furthermore, the ADAMS is the most comprehensive informant-report instrument screening for anxiety in terms of coverage of standard diagnostic criteria for anxiety. Besides, an instrument

which measures both depression and anxiety may be convenient for clinical practice, because of their relatedness and co-occurrence. This report describes the results of our study about the feasibility, reliability and validity of the ADAMS in older people with ID.

METHOD

Study population

In the 'Healthy Ageing and Intellectual Disability' (HA-ID) study, 1050 clients aged 50 years or older in a consort of three large ID care providers in the south and west of the Netherlands have been included. Clients live independently with regular support from a professional caregiver, visit day activity centers, live in community-based settings primarily offering support of independence and participation, or in centralized or community-based settings primarily offering care. Level of ID, residential setting, Down syndrome and current psychiatric diagnoses were retrieved from the participants' files.

The HA-ID study has been approved by the Medical Ethical Testing Committee of the Erasmus University Medical Center in Rotterdam, the Netherlands (MEC nr: 2008-234). Written informed consent was obtained from the participants or their legal guardians. Recruitment and informed consent procedure have been described in detail by Hilgenkamp et al. (2011).[26]

Based on published Intraclass Correlation Coefficients for test-retest and interrater reliability[24] and our minimal acceptable 95% confidence interval, we calculated that the sample for the present reliability study should consist of at least 39 participants.[27] More participants were included to enable us to study subgroups. Participants for the reliability study were included during the first three months of data collection (February-April, 2009). Validity was studied in the total sample of the HA-ID study (data collection from February 2009 to July 2010). Except for age under 50 years, there were no exclusion criteria. All informants were professional caregivers who knew the participant for at least three months and provided support or care in the residential settings.

Instrument characteristics

The Anxiety, Depression, And Mood Scale (ADAMS)[24] is an informant-report screening instrument with 28 items that have to be answered on a 4-point answering scale. It consists of five subscales: Manic/hyperactive behaviour (5 items), Depressed mood (7 items), Social avoidance (7 items), General anxiety (7 items) and Obsessive/compulsive behaviour (3 items). The questions are based on DSM-IV criteria,[28] other instruments and clinical experience. The authors studied its reliability in 50 to 61 participants with borderline to profound ID: the internal consistency of the subscales varied from $\alpha = 0.75$ to 0.83, the test-retest reliability of the total ADAMS and subscale scores from ICC= 0.72

to 0.83 and the interrater reliability from ICC= 0.37 to 0.62.[24] Methot and Morin (2004) evaluated a French translation in adults with mild to profound ID: the internal consistency of the subscales varied from α= 0.69 to 0.84 and the test-retest reliability from ICC= 0.63 to 0.96.[29] Criterion validity of the ADAMS has not been studied and no cut-off values were available. Therefore, in the HA-ID study a preliminary cut-off score of 11 for the ADAMS' General anxiety subscale was used, based on the results of a pilot-study with 38 participants, showing that the sensitivity was 100% and the specificity 86% with this cut-off score.

Procedure

Three members of the research team independently translated the ADAMS into Dutch, after which consensus was reached about the final draft. A native English speaker translated the Dutch version back to English. It appeared that the phrasing of his translation was different for several questions and the response format, but the purport of both versions corresponded for all questions and responses.

In addition to the ADAMS, participants with sufficient cognitive and verbal capacities were interviewed with a self-report questionnaire about depression (IDS-SR) and two self-report questionnaires about anxiety (GAS-ID and HADS-A). For self-report, a participant should have a borderline, mild or moderate ID, use comprehensible speech and oversee the time-frame of at least one week. This was reported by the legal guardian or main professional caregiver. The IDS-SR consists of 30 items based on DSM-IV criteria for major depression and has been developed for the general population in which it has good internal consistency (α= 0.79-0.94), moderate test-retest reliability (*r*= 0.66) and good sensitivity and specificity against psychiatric diagnosis made with a structured interview (100% and 94%).[30-33] The GAS-ID consists of 27 items and has been developed for people with ID. Its internal consistency (α= 0.96), test-retest reliability (*r*= 0.95) and sensitivity and specificity against psychiatric diagnosis made with a semi-structured interview (both 100%) are good.[22] The HADS-A has been developed for the general population, but has been used in people with ID before.[34] Its internal consistency (α= 0.96) and sensitivity and specificity against psychiatric diagnosis made with a structured interview (94% and 85%) are good in the general older population.[35, 36] The self-report instruments were verbally administered by trained interviewers.

In addition to the ADAMS, for participants unable to provide self-report data, the Signalizing Depression List for people with Intellectual Disabilities (SDL-ID)[21] was applied. This is a Dutch instrument with good interrater reliability (*r*= 0.87) in older people with ID.[37]

Due to the size of the total HA-ID study, complete psychiatric diagnosis in all participants was too time-consuming and expensive, therefore only participants with a score above the cut-off score of the IDS-SR (≥ 18), GAS-ID (≥ 15), HADS-A (≥ 8), SDL-ID (≥ 35) [22, 30, 37, 38] or above the preliminary cut-off score of the ADAMS' General anxiety subscale

(≥ 11) were interviewed with the Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD) Interview.[39] To examine the specificity of the ADAMS, an additional random sample with scores below the cut-off score of the ADAMS was assessed with the PAS-ADD Interview. To obtain sufficient power, this random sample should consist of at least 100 participants. The PAS-ADD Interview is a semi-structured interview and focuses on the more common axis I disorders: major depression, phobic anxiety disorders, panic disorder, generalised anxiety disorder and mania. All PAS-ADD Interviews were performed by specifically trained behavioural therapists or psychologists with experience in working with people with ID. They were blind to the outcome of the screening instruments.

Personal characteristics, level of ID, residential setting and diagnosis of an autism spectrum disorder were retrieved from the participants' files. Data on level of ID and autism spectrum disorders were obtained through the participant's psychologist or behavioural therapist.

Feasibility

Feasibility was operationalized as: 1. Duration of completion, and 2. Comprehensibility of the items of the questionnaire as judged by informants. Comprehensibility of the total set of questions was scored with 'yes' or 'no'. Beforehand, we had decided that completion should not take more than 15 minutes and that at least 90% of the informants should rate the questions as comprehensible.

Reliability

Internal consistency of all subscales was calculated. To study test-retest reliability, the ADAMS was completed by the same informant at baseline (T1) and after approximately two weeks (T2) on the condition that no major changes occurred in between. Major changes were events with a substantial influence on the mood of a participant, such as disease or moving to a new home, and were checked before second completion. To study interrater reliability, a second professional caregiver was asked to complete the ADAMS independently from the first. Test-retest and interrater reliability were studied for the total sample and for subgroups with borderline or mild ID, moderate ID, and severe or profound ID.

Validity

Convergent validity was studied by comparing scores at T1 on the Depressed mood subscale of the ADAMS to the scores on the IDS-SR and SDL-ID and by comparing scores on the General anxiety subscale of the ADAMS to the scores on the GAS-ID and HADS-A.

Discriminant validity was studied by comparing scores at T1 on the Depressed mood subscale and the General anxiety subscale with the outcome on the Non-organic sleep

disorder subscale of the PAS-ADD. This subscale is chosen because both depression and anxiety are differential diagnoses for sleep disorders[28] and have some shared symptoms with sleep disorders (e.g. disturbed sleep pattern), but are different concepts.

Criterion validity of the Depressed mood and General anxiety subscales was studied by sensitivity and specificity rates, against PAS-ADD diagnosis of depression and anxiety as the gold standard. The other subscales were not studied for their validity, because we did not expect a substantial number of people suffering from obsessive-compulsive disorder and mania diagnoses.

Statistical procedure

All analyses were done with the Statistical Package for the Social Sciences (SPSS) version 15.0. Differences of age, gender, and residential setting between participants with a completed ADAMS and without a completed ADAMS were studied with a t-test for age and chi-square for gender and residential setting. Differences of age, gender, and level of ID between participants assessed and not-assessed with a PAS-ADD Interview were studied with a t-test for age and chi-square for gender and level of ID.

Internal consistency was examined with Cronbach's alpha. Test-retest reliability and interrater reliability were both studied with Intraclass Correlation Coefficients (ICC). Correlations of the ADAMS' subscales with the other instruments were analyzed with Pearson's product-moment correlation coefficient. A Bonferroni correction ($\alpha/6$) was applied to adjust for the increased risk of Type 1 errors caused by the multiple analyses.

Means on the subscales were compared for gender, age, presence or absence of autism and Down syndrome with t-tests and for level of ID with One-way ANOVA. A Bonferroni correction ($\alpha/4$) was applied to adjust for multiple comparisons. Significant differences on mean scores for these characteristics were used to define subgroups for which cut-off scores with optimal sensitivity and specificity were defined. The sensitivity and specificity for different subgroups and different cut-off scores were studied using Receiver Operator Characteristic (ROC) curves.

All correlation coefficients, sensitivity and specificity rates are presented with a 95% confidence interval. Published guidelines for psychological tests were used to interpret Cronbach's alpha, ICC's and Pearson's product-moment coefficients.[40-42]

RESULTS

During the first three months of the HA-ID study, 230 people were invited to participate in this study, 127 of whom (55.2%) provided informed consent. This sample was included in the reliability study. In total, informed consent was received for 1069 (49.7%) of the 2150 persons invited to participate in the HA-ID study. Nineteen persons with informed

consent did not participate due to severe illness, death or returning the consent-form too late.[26] In the total sample, people who live independently and people aged 80 to 84 years were slightly underrepresented.[26] The ADAMS was completed for 975 participants (92.9%); missing data was caused by caregivers' refusal to co-operate or incomplete co-operation. Of the 975 participants, 106 had a score above the cut-off score of the ADAMS' General Anxiety subscale and were interviewed with the PAS-ADD Interview,

Table 1: Characteristics of the study population

	Reliability sample[a]	Criterion validity sample[a]	Total sample
n	127	288	975
Gender (male/female)	39/88	137/151	501/474
Mean age (s.d.)	63.6 (8.4)	62.8 (8.2)	62.2 (8.1)
Residential setting (%)			
Central location	53 (41.7)	166 (57.6)	534 (54.8)
Community home	67 (52.8)	114 (39.6)	385 (39.5)
Independent living	7 (5.5)	8 (2.8)	41 (4.2)
Level of ID[b] (%)			
Borderline	23 (18.1)	12 (4.2)	31 (3.2)
Mild ID	26 (20.5)	74 (25.7)	201 (20.6)
Moderate ID	50 (39.4)	133 (46.2)	467 (47.9)
Severe ID	15 (11.8)	37 (12.8)	165 (16.9)
Profound ID	13 (10.2)	14 (4.9)	89 (9.1)
Syndromes (%)			
None	83 (65.4)	175 (60.8)	611 (62.7)
Down syndrome	16 (12.6)	35 (12.2)	142 (14.6)
Fragile X syndrome	1 (0.8)	0 (0.0)	8 (0.8)
Prader Willi syndrome	0 (0.0)	0 (0.0)	1 (0.1)
Rett syndrome	0 (0.0)	0 (0.0)	2 (0.2)
Angelmann syndrome	0 (0.0)	0 (0.0)	3 (0.3)
Other syndromes	6 (4.7)	16 (5.6)	51 (5.2)
Unknown	21 (16.5)	62 (21.5)	157 (16.1)
Current psychiatric diagnoses[c] (%)			
Depression	8 (6.3)	28 (9.7)	49 (5.0)
Anxiety disorders	3 (2.4)	16 (5.5)	28 (2.9)
Other psychiatric disorders	5 (3.9)	49 (17.0)	110 (11.3)
Autism	5 (3.9)	46 (16.0)	166 (17.0)
Dementia	10 (7.9)	30 (10.4)	73 (7.5)
Suspicion of dementia	11 (8.7)	28 (9.7)	76 (7.8)

[a] Part of the total sample

[b] ID= intellectual disabilities

[c] Diagnosis retrieved from participant's files

whereas 182 participants with a score below the cut-off score were also interviewed. Participants assessed with the PAS-ADD Interview were not significantly different from those who were not assessed with the PAS-ADD Interview for gender, age and level of ID. The characteristics of the reliability sample, criterion validity sample and the total sample are described in Table 1.

Feasibility

Sixty-five informants evaluated the feasibility of the ADAMS for 34 participants. Mean completion time was 10.7 minutes (s.d.= 4.0). The total set of questions was judged as comprehensible by 63 of the 65 informants (96.9%).

Reliability

There were no significant differences between participants and non-participants for gender, age and residential setting for the reliability sample (data not shown). The ADAMS was completed twice by the same professional caregiver for 93 of the 127 participants. Missing data were caused by caregivers who did not return the second questionnaire. No participants had to be excluded because of the occurrence of major changes in the interval period. The mean time interval between first and second completion was 19.5 days, range: 6 to 47 days.

The ADAMS was completed by a second professional caregiver for 83 participants. Missing data were caused by the unavailability of a second caregiver who knew the participant for at least three months or the second caregiver did not complete the questionnaire in time. Test-retest and interrater reliability of the total ADAMS and subscale scores are presented in Table 2, together with published results of Esbensen et al. (2003).[24] Internal consistency, test-retest and interrater reliability of total and subscale scores according to level of ID are presented in Table 3.

Table 2: Reliability of the ADAMS of the total group in comparison with results of Esbensen et al. (2003)

	ICC Test-retest (95% CI)		**ICC Interrater (95% CI)**	
	Our study (n=93)	Esbensen et al. (2003) (n=61)	Our study (n=83)	Esbensen et al. (2003) (n=50)
Manic/ hyperactive behaviour	0.79 (0.69-0.86)	0.72 (0.58-0.83)	0.78 (0.68-0.85)	0.37(0.10-0.59)
Depressed mood	0.75 (0.65-0.83)	0.76 (0.64-0.85)	0.75 (0.64-0.83)	0.39 (0.13-0.61)
Social avoidance	0.75 (0.65-0.83)	0.83 (0.74-0.90)	0.57 (0.40-0.70)	0.61 (0.40-0.77)
General Anxiety	0.86 (0.78-0.90)	0.78 (0.67-0.86)	0.74 (0.63-0.82)	0.39 (0.13-0.61)
Obsessive/ compulsive behaviour	0.78 (0.68-0.85)	0.82 (0.72-0.89)	0.75 (0.64-0.83)	0.62 (0.42-0.77)
Total ADAMS	0.83 (0.75-0.89)	0.81 (0.71-0.89)	0.76 (0.65-0.84)	0.48 (0.24-0.67)

Table 3: Reliability of the ADAMS according to level of ID

	Manic/ hyperactive behaviour	Depressed mood	Social avoidance	General Anxiety	Obsessive/ compulsive behaviour	Total ADAMS
Cronbachs alpha (n=127)	0.80	0.84	0.85	0.88	0.83	
Test-retest reliability (95% CI)						
Borderline/ mild ID[a] (n=37)	0.83 (0.70-0.91)	0.78 (0.61-0.88)	0.75 (0.57-0.86)	0.89 (0.78-0.95)	0.79 (0.62-0.88)	0.87 (0.79-0.94)
Moderate ID (n=37)	0.80 (0.65-0.89)	0.78 (0.61-0.88)	0.85 (0.72-0.92)	0.81 (0.67-0.90)	0.75 (0.57-0.87)	0.80 (0.63-0.89)
Severe/ profound ID (n=19)	0.67 (0.33-0.86)	0.67 (0.34-0.86)	0.52 (0.11-0.78)	0.84 (0.64-0.94)	0.78 (0.53-0.91)	0.77 (0.49-0.91)
Interrater reliability (95% CI)						
Borderline/ mild ID (n=28)	0.81 (0.64-0.91)	0.72 (0.48-0.86)	0.38 (0.02-0.66)	0.83 (0.67-0.92)	0.80 (0.61-0.90)	0.71 (0.47-0.86)
Moderate ID (n=36)	0.62 (0.37-0.78)	0.78 (0.62-0.88)	0.48 (0.19-0.70)	0.48 (0.19-0.70)	0.64 (0.41-0.80)	0.58 (0.32-0.76)
Severe/ profound ID (n=19)	0.85 (0.65-0.94)	0.74 (0.44-0.89)	0.84 (0.64-0.93)	0.84 (0.64-0.94)	0.83 (0.61-0.93)	0.86 (0.67-0.94)

[a] ID= intellectual disabilities

Validity

Of the total sample, 202 participants had sufficient cognitive and verbal capacities to be interviewed with the self-report questionnaires: IDS-SR, GAS-ID and HADS-A. The SDL-ID was completed by a professional caregiver for 787 participants who were not capable to complete one or all of the self-report questionnaires. There was a low positive correlation between the ADAMS' Depressed mood subscale and the IDS-SR, r= 0.44 (95% CI: 0.32-0.55), and a high positive correlation with the SDL-ID, r= 0.71 (95% CI: 0.68-0.75). There was a low positive correlation between the ADAMS' General anxiety subscale and the GAS-ID, r= 0.37 (95% CI: 0.25-0.49) and HADS-A, r= 0.41 (95% CI: 0.29-0.52). All correlations were significant (p< 0.001).

Discriminant validity was determined for 288 participants. There was little correlation between the sleep disorders subscale of the PAS-ADD and the ADAMS' Depressed mood subscale, r= 0.15 (95% CI: 0.03-0.26) and no correlation with the ADAMS's General anxiety subscale, r= 0.02 (95% CI: -0.10-0.14). Both correlations were not significant.

Criterion validity was determined for 288 participants. The score on the General anxiety subscale was significantly associated with level of intellectual disability and autism, and the score on the Depressed mood subscale with gender, level of intellectual disability and autism. Therefore, subgroups of participants with these characteristics or combinations of those were made, for which ROC-curves were determined and cut-off scores with best criterion validity defined. For the General anxiety subscale, this has resulted

in a cut-off score of ≥ 10 for people without autism and of ≥ 14 for people with autism, regardless of the level of ID. For the Depressive mood subscale, the optimal cut-off score was ≥ 11 for people with borderline or mild ID and ≥ 9 for people with moderate, severe or profound ID. For the Depressed mood subscale, defining subgroups based on gender, autism or combination of these characteristics with level of ID did not result in different, more valid cut-off scores.

Information about presence or absence of autism was lacking for 34 participants. These participants were excluded for sensitivity and specificity calculations. Sensitivity and specificity rates are presented in Tables 4 and 5.

Table 4: Criterion validity of the ADAMS' General anxiety subscale

	Without autism			**With autism**		
	n (anxiety diagnosis)[a]	Sensitivity (95% CI)	Specificity (95% CI)	n (anxiety diagnosis)[a]	Sensitivity (95% CI)	Specificity (95% CI)
Total group	208 (11)	82% (0.52-0.95)	65% (0.58-0.71)	46 (5)	80% (0.38-0.96)	78% (0.63-0.88)
Borderline/mild ID[b]	67 (3)	100% (0.44-1.00)	48% (0.37-0.60)	10 (1)	100% (0.21-1.00)	78% (0.45-0.94)
Moderate ID	109 (7)	71% (0.36-0.92)	73% (0.63-0.80)	17 (1)	100% (0.21-1.00)	75% (0.51-0.90)
Severe/profound ID	32 (1)	100% (0.21-1.00)	74% (0.57-0.86)	19 (3)	67% (0.21-0.94)	81% (0.57-0.93)

[a] Anxiety disorder diagnosis made with the PAS-ADD Interview

[b] ID= intellectual disabilities

Table 5: Criterion validity of the ADAMS' Depressive mood subscale

	n (depression diagnosis)[a]	**Sensitivity (95% CI)**	**Specificity (95% CI)**
Borderline/mild ID[b]	82 (10)	80% (0.49-0.94)	79% (0.68-0.87)
Moderate ID	129 (22)	73% (0.52-0.87)	71% (0.62-0.79)
Severe/profound ID	51 (8)	75% (0.41-0.93)	77% (0.62-0.87)

[a] Depression diagnosis made with the PAS-ADD Interview

[b] ID= intellectual disabilities

DISCUSSION

Overall, our results suggest that the Dutch translation of the informant-based ADAMS is a promising instrument to screen for anxiety and depression in older adults with ID. Feasibility is good, with both duration and comprehensibility of the questionnaire within preset limits. The internal consistency of all subscales is good.[41] According to the guidelines of Cicchetti and Sparrow (1981), the test-retest reliability is good for the total group and all ID level subgroups, except for the Social avoidance subscale, which

has only fair reliability in the group with severe/profound ID.[42] Interrater reliability is good or fair[42] for all subscales in all subgroups, except for the Social avoidance subscale, which has poor reliability in the group with borderline/mild ID. Correlation between the informant-based ADAMS and self-report questionnaires for depression and anxiety is low, whereas the correlation of the Depressed mood scale with the other informant-report depression instrument is high. Correlations of the ADAMS's Depressive mood and General anxiety subscales with the Non-organic sleep disorder subscale of the PAS-ADD Interview were low, implying good discriminant validity. Sensitivity and specificity against semi-structured psychiatric diagnosis are good or sufficient for most subgroups.

Comparison of our reliability findings with those of Esbensen et al. (2003) (Table 2) shows that our internal consistency is slightly higher, our test-retest reliability results are similar, but with smaller confidence intervals, and our interrater reliability results are comparable for the Social avoidance subscale and higher for the other subscales. The difference in interrater reliability may have been caused by differences in informants: our informants were all professional caregivers, whereas the informants in the study of Esbensen et al. (2003) were professional caregivers, teachers and family members.[24]

In line with several earlier studies,[43-46] we find large discrepancies between outcomes of self-report and informant-report, reflecting differences between the judgement of participants and their professional caregivers. An explanation may be that self-report instruments contain items about internal symptoms, whereas informant-report instruments are based upon observable behaviour.

A remarkable finding is that informants disagree on the presence of symptoms of social avoidance, specifically for the group with borderline/mild ID. An explanation could be that social avoidance varies with social context,[47] which may cause informants to score differently. Otherwise, the questions of this subscale might be less clearly phrased, causing interpretation difficulties. Another remarkable finding is that personal characteristics (level of ID, gender or autism) have a significant relationship with scores on the subscales, which partly resulted in different cut-off scores to optimize the criterion validity of the ADAMS.

Strengths of our study are the systematic selection process to select instruments measuring depression and anxiety and the extensive set of psychometric properties we have studied. Limitations of our study are the relatively small sub-sample sizes which cause large confidence intervals of the correlation coefficients for test-retest and interrater reliability and the sensitivity and specificity rates, whose intervals are even more enlarged by the low number of depression or anxiety diagnoses in the subgroups. Another limitation is that we have determined comprehensibility of the questions with one question while it would have been better if we had judged comprehensibility separately for every question. A third limitation is the preliminary cut-off score for the General anxiety subscale which was too high for people without autism. As a result, we have missed 11

participants for further diagnostics with the PAS-ADD Interview. A final limitation is the as yet limited knowledge about the psychometric properties of some of the instruments used to examine convergent validity. In principle, instruments with good psychometric properties should be used. However, other anxiety or depression instruments validated for our study population were not available.

Though the Dutch translation of the ADAMS seems to be a reliable and valid instrument for clinical practice and future research, it is important to stress that these results can not be generalized to the complete adult population. Moreover, cut-off scores should be used for screening only, not to diagnose depression or anxiety or to make treatment decisions. For future research we recommend to study criterion validity of the ADAMS in adults with ID younger than 50 years, because the instrument can be useful for the whole adult population and not only for older people. Furthermore, we recommend studying sensitivity to change, because this is important to evaluate effectiveness of interventions.

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Part II

Chapter 7

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

Based on:
H. Hermans, A.T.F. Beekman, H.M. Evenhuis, Prevalence of depression and anxiety in older users of formal Dutch intellectual disability services. Submitted.

ABSTRACT

Background: Little is known about the prevalence of depression and anxiety among older adults with intellectual disabilities (ID).

Aim: To study the prevalence and associations of depression and anxiety in older users of formal ID services and to compare with data from the general population.

Method: Depression and anxiety were studied in 990 participants aged ≥ 50 years with ID using self-report and informant-report instruments. Prevalence of Major Depressive Disorder (MDD) and anxiety disorders was estimated using a two-stage diagnostic design.

Results: The prevalence of increased depressive symptoms was 16.8% and associated with higher age, while the prevalence of increased anxiety symptoms was 16.3% and associated with mild ID. The prevalence of MDD was 7.6% and of anxiety disorders 4.4%. Compared to the Dutch general population, the standardized morbidity ratio of MDD was 5.15 and of anxiety disorders 0.59.

Conclusion: MDD was much more prevalent and anxiety disorders were less prevalent than in the general population.

INTRODUCTION

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.[1, 2] In the community-dwelling older population (55+ years), depression and anxiety are common, with increased depressive symptoms in 13.5 to 14.9%, increased anxiety symptoms in 14.9 to 18.5%, major depression in 1.8 to 4.0% and anxiety disorders in 10.2 to 11.6%.[3-7] In smaller groups of older people with ID (aged ≥ 50 years), prevalence rates of 4.8 to 5.4% for depression and 2.8 to 5.7% for anxiety disorders have been found.[8-10] Results from the general population can not 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.[11] On the other hand, group-home living and higher psychotropic drug use may reduce depression and anxiety.[12] In addition, people with ID may present psychiatric symptoms differently and have limited or no abilities to report symptoms.[13] These diagnostic problems may limit the number of ICD-10 depression and anxiety diagnoses in people with ID.[10] Because such diagnostic problems increase with severity of ID,[14] lower prevalence rates 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 to compare the prevalence of major depression and anxiety disorders with data from the general Dutch older population.

METHOD

Design and study population

This study was part of the '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: central 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.[15] 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 lower 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.[2, 9] Of the general Dutch population aged ≥ 50 years, 0.5% is known to formal ID services of which 10% receives care or support from one of the participating services.[1] Recruitment and the informed consent-procedure have been described in more detail elsewhere.[15] Inclusion and participation of the current study population

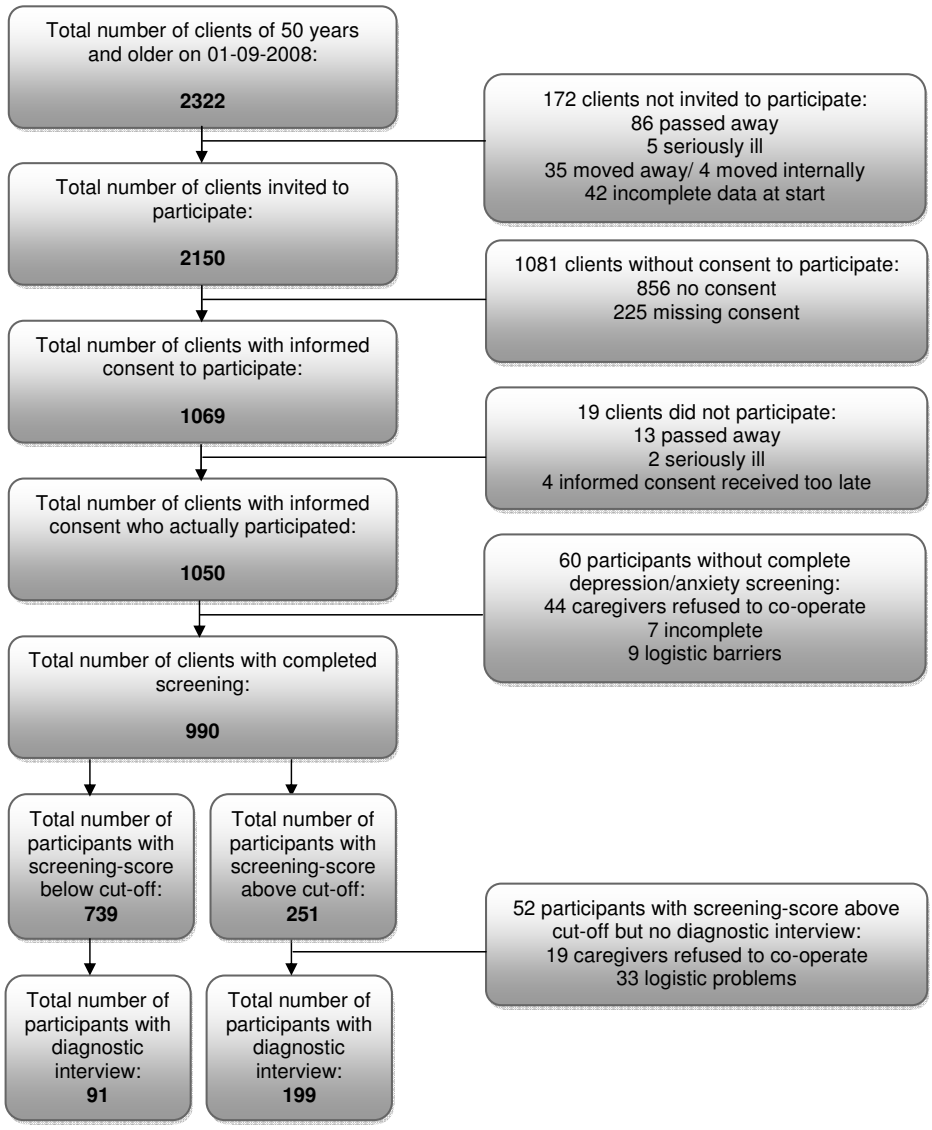

Figure 1: Flow-chart inclusion of study population

are described in Figure 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).

Procedure and measures

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, evaluating 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 trained interviewers. 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.

For depression, participants capable of self-report were screened with the Inventory of Depressive Symptomatology Self Report (IDS-SR)[16] and participants incapable of self-report with the Dutch informant-report Signalizing Depression List for people with Intellectual Disabilities (SDL-ID).[17] 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 (α= 0.89 and ICC= 0.91) and the validity satisfactory (sensitivity 71% and specificity 54%).[18] Its score ranges from 0 to 84. We used a cut-off score of ≥18.[19] The SDL-ID's internal consistency and interrater reliability in older people with ID are good (α= 0.77 and *r*= 0.87).[20] The score on the SDL-ID ranges from 18 to 72. We used a cut-off score of ≥35.[21] 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).[22] 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 (α= 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.[23] 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)[24] and the Anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A),[25] in addition to the ADAMS. The GAS-ID has been developed for people with ID and its internal consistency and reliability are good (α= 0.86 and ICC= 0.89) and its validity sufficient (sensitivity 84% and specificity 52%).[24] Its score ranges from 0 to 54. We used a cut-off score of ≥17.[26] 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.[27, 28] Its score ranges from 0 to 21. We used a cut-off score of ≥8, as recommended for the Dutch population.[28]

Depression and anxiety disorders

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. All participants with at least one score above the cut-off of one of the screening instruments, were further examined with a standardised psychiatric interview within two weeks. Because published sensitivities of the screening questionnaires vary between 71-84% and specificities between 52-78% (see above), and because at the start of the study, criterion validity for the translated ADAMS and GAS-ID 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 outcomes of participants assessed with the diagnostic interview to all other participants, taking their screening outcomes 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 Figure 2. The 95% confidence intervals of the prevalence rates were calculated with a Bayesian method.[29]

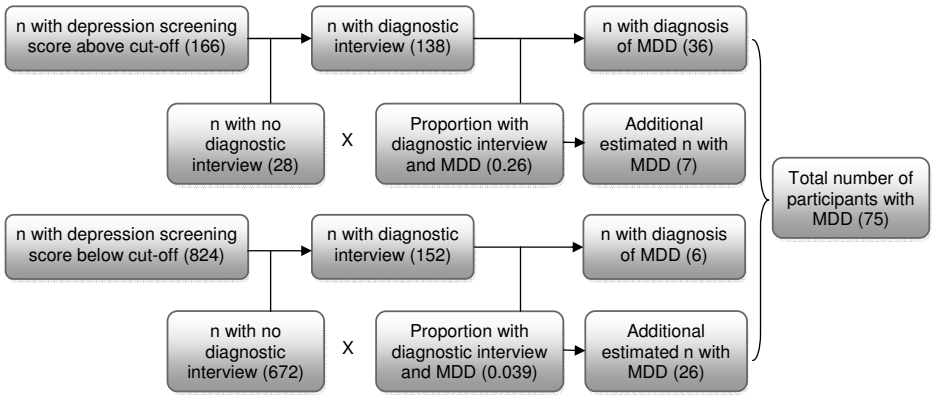

Figure 2: Extrapolation procedure major depressive disorder (MDD)

Psychiatric diagnoses were made using the Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD).[30] 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).[31] Current diagnoses of Major Depressive Disorder (MDD), general anxiety disorder, panic disorder, agoraphobia, social phobia and specific phobia based on ICD-10 criteria[32] can be made with the PAS-ADD. Its psychometric properties are satisfactory.[33, 34] It has been validated in people with ID against expert psychiatric diagnosis. The questions of the PAS-ADD Interview can be answered by people with ID, their caregivers or both. The interviews were applied by psychologists or 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 outcome 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 scored as 'uncertain' were excluded from the final diagnostic decision.

Other variables

Gender, age, level of ID, residential setting, mobility, genetic syndromes, autism spectrum disorder and psychotropic medication use (ATC classification: N05B and N06A) were retrieved from the participants' files. The Anatomical Therapeutic Chemical (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.[35] 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.

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 chi-square 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 population, participants aged 55 years or over, aged 50 to 65 years, and participants aged 65 years or over. The prevalence rates of major depression and anxiety disorders were compared to outcomes 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.[36] 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), controlled for the other independent variables. All independent variables should be continuous or dichotomous, therefore dummy variables were constructed for 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 relatively 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.

RESULTS

The screening questionnaires were completed for 990 participants (Figure 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 to 91 participants with low screening scores (Figure 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 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.

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).

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	536	54.1	
Community home	403	40.7	
Living with family	7	0.7	
Independent living	44	4.4	
Etiology of ID[a]			
None	617	62.3	
Down syndrome	142	14.3	
Other syndromes	67	6.8	
Unknown	46	4.6	
Psychotropic drug use[b]			
Antidepressants	99	10.0	
Anxiolytics	97	9.8	
Screening questionnaires completed			
SDL-ID	789	79.7	27.0 (9.0)
General anxiety (ADAMS)	975	98.5	4.0 (6.0)
IDS-SR	215	21.7	7.0 (9.0)
GAS-ID	215	21.7	10.0 (8.0)
HADS-A	217	21.9	3.0 (4.0)

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] 118 missing

[b] 115 missing

Major depressive disorder and anxiety disorder

The point prevalence of MDD was 7.6% and of anxiety disorders 4.4% (Table 2). For the total population, the prevalence rates of the specific anxiety disorders were: generalised anxiety disorder (GAD): 0.5% (95% CI: 0.2-1.1), phobia: 3.3% (95% CI: 1.8-5.7) and panic

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: Associations (Odds ratios (95% CI)) with depression and anxiety for the total population

	Increased depressive symptoms	**Increased anxiety symptoms**	**Major depressive disorder**	**Anxiety disorders**
n	820	862	241	241
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)

*$p < 0.05$, **$p < 0.01$

disorder: 1.8% (95% 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 (95% CI: 3.93-6.63) and of anxiety disorders 0.59 (95% 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 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) and Beekman et al. (1998)

[b] HA-ID= Healthy Ageing and Intellectual Disability

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 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 previously in smaller samples of older people with ID. Reid et al. (2011) studied anxiety in a large group of adults using the Present Psychiatric State for Adults with Learning Disabilities. The prevalence of anxiety disorders in the subgroup aged ≥ 50 years (n=364) was 2.7% (95% CI 1.5-5.0), which is similar to our outcome. Cooper et al. (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% (95% CI 3.1-11.3), which is similar to

our outcome, and GAD in 9.0% (95% 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% (95% CI 2.1-10.7), overlapping our study outcome, and anxiety disorders in 5.7% (95% CI 2.6-11.9), which also overlaps our 4% prevalence. The differences in used diagnostic instruments and in 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 by earlier studies in older people with ID, except for generalized anxiety disorders, which is less prevalent in our study population.

As described in the introduction, we had expected to find higher levels of depression and anxiety among older people with ID than are found in the general population. Considering major depressive disorder, this was indeed what we found.[3] The prevalence is almost comparable to that in the general nursing-home population aged ≥ 55 years,[37] which is a frail population with multiple health problems. This may imply an increased vulnerability of older people with ID. For anxiety disorders, we found lower prevalence rates.[4] Remarkably, this trend has also been found in nursing-home residents.[38] Smalbrugge and colleagues (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,[38] which is also applicable to most people with ID receiving formal services. The lower prevalence could also be explained by the high psychotropic and anti-epileptic drug use by people with ID,[12, 39] 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) 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.[40]

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 treatment in clinical practice should be stimulated, providing well-evaluated screening instruments and training professionals in optimal diagnosis. Professionals working in clinical practice should realise 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 was carefully prepared, it still had some limitations, related to the large scale of the study on the one hand, and to 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.[10] 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. However, it is important to realise, that these limitations may have resulted in an underestimation rather than an overestimation of the prevalence rates. In conclusion, this epidemiologic study led to relevant insights into mental health of older people with ID.

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Chapter 8

Comparison of anxiety reported by older people with intellectual disabilities and by older people with normal intelligence

Based on:
H. Hermans, A.T.F. Beekman and H. M. Evenhuis, Comparison of anxiety reported by older people with intellectual disabilities and by older people with normal intelligence. Submitted.

ABSTRACT

Background: Older people with intellectual disabilities (ID) may experience more anxiety than older people with normal intelligence. Study questions: 1) Is the reported severity of anxiety in this group similar to that in the general older population? 2) Are specific anxiety symptoms reported as frequently by both groups?

Method: Outcomes on the General anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A) of 172 participants of the 'Healthy Ageing and Intellectual Disability' (HA-ID) study with borderline to moderate ID, aged 55-85 years, were compared with outcomes of 2917 participants of the Longitudinal Aging Study Amsterdam (LASA) with normal intelligence, using age-adjusted ratios.

Results: Mean HADS-A total score of people with ID was significantly higher than that of people with normal intelligence (3.51 versus 2.53, $p < 0.01$), whereas the percentage of scores above cut-off in both groups was similar. Four out of seven items were more often reported as present by people with ID: 'tense or wound up feelings', 'frightened feelings', 'worrying thoughts', and 'sudden feelings of panic'.

Conclusion: Although the prevalence of clinically relevant anxiety seems similar in both populations, caregivers or professionals in clinical practice should be aware that the level of sub-clinical anxiety reported by older people with ID is higher than that reported by other older people with normal intelligence.

INTRODUCTION

There are several reasons why older people with intellectual disabilities (ID) may experience more and different symptoms of anxiety compared with elderly with normal intelligence. Anxiety symptoms reported by people with mild or moderate ID generally correspond to standard diagnostic criteria,[1] but it is unknown if the severity of these symptoms is similar to that in the general population. People with ID may be more anxious, because of their limited autonomy and less effective coping styles.[2] Furthermore, they are exposed to more negative life events and have less social support which may also increase anxiety.[3, 4] In old age, the number and impact of life events increases and independency decreases due to cognitive and functional decline.[5, 6] On the other hand, the higher use of psychotropic medication and supported living conditions may prevent anxiety.[7-9]

With this study, we wanted to answer the following study questions: 1) Is the severity of anxiety in older people with ID similar to that in older people with normal intelligence? 2) Are specific anxiety symptoms reported as frequently by older people with ID as by older people with normal intelligence?

METHOD

Setting and study population

This study was based on two large-scale studies in the Netherlands: the 'Healthy Ageing and Intellectual Disability' study (HA-ID) and the 'Longitudinal Aging Study Amsterdam' (LASA).

HA-ID is an epidemiological study to investigate healthy ageing in older people with ID. HA-ID has included 1050 persons, aged 50 years and over, recruited through three formal ID services which provide care and support in residential and day-care settings.[10] Of these 1050 participants, 215 participants were included for self-report. Participants with borderline, mild or moderate ID who use comprehensible speech and are able to oversee the time-frame of at least one week, as reported by their legal guardian or main professional caregiver, have been included for self-report. Of those 215 participants, 172 had an age between 55 and 85 years and have been included in the current study. Of these participants, 19 had a borderline (IQ= 70-84), 110 a mild (IQ= 50-69) and 43 a moderate ID (IQ= 35-49), as established by their psychologist or behavioural therapist. The study protocol of HA-ID has been approved by the Medical Ethical Testing Committee of the Erasmus University Medical Center at Rotterdam, the Netherlands. Written informed consent was obtained from the participants or their legal guardians. Ethical issues and recruitment procedure have been described in detail elsewhere.[10]

LASA is an on-going longitudinal study on ageing. The study population consists of a cohort based on a nationally representative sample aged 55 to 85 years. Random samples, in which men and older-old have been oversampled, have been drawn from population registers in three different regions in the Netherlands. Sampling and non-response have been described in detail elsewhere.[11] In this study, data of the first cycle has been used. Of the total LASA population that participated at the first cycle of LASA (n=3107), 2917 (94%) participants had a completed HADS-A. All participants to the LASA study provided informed consent in accordance with Dutch law and the LASA study was approved by the Medical Ethical Committee of the VUmc University Medical Centre.

Procedure and measures

In both studies, anxiety has been assessed using the General anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A).[12] The HADS-A is a screening instrument which consists of seven items with a 4-point rating scale (from 0 if symptom is absent to 3 if symptom is present all the time), resulting in a total score ranging from 0 to 21. Its internal consistency (α= 0.96), test-retest reliability (r= 0.64) and sensitivity and specificity against psychiatric diagnosis made with a structured interview (82% and 56%) are satisfying in the general Dutch population.[13, 14] In older people with ID, the correlation of the HADS-A with a self-report anxiety instrument specifically developed and validated for this group, is moderate (r= 0.61).[15] The HADS-A was completed in written by the participants with normal intelligence, whereas participants with ID were interviewed by a trained interviewer. Standardized clarifying information was added to four items (2, 3, 6 and 7) for better comprehension.

Statistical analyses

All analyses were performed with the Statistical Package for the Social Sciences 17.0. Age of participants of HA-ID and LASA was compared with a t-test, and gender, antidepressant and anxiolytic drug use with chi-square tests.

HADS-A total scores of both groups were compared with a t-test and with an ANCOVA, while controlling for differences in age. To compare numbers of participants with a score above the HADS-A cut-off of ≥8,[16] we divided both samples in three age-strata (55-64 years, 65-74 years, and 75-85 years), and calculated how many participants with a score above cut-off would be expected in the HA-ID population if the outcomes were similar to those in the LASA population, applying age-related outcomes. This expected number was compared to the actually observed number of HA-ID participants with a score above cut-off by calculating the ratio. A ratio of 1 means, that there is no difference between both populations.[17] The strength of the association between ID and an anxiety score above cut-off has been defined by calculating the odds ratio.

To compare frequencies of reported individual items, all scores were recoded into absent (score 0) or present (score 1, 2 or 3). Numbers of participants reporting an item as present were compared by calculating the same observed/expected ratio as described above.

RESULTS

The HA-ID and LASA population did not differ significantly on gender distribution, but the HA-ID population was significantly younger and used significantly more antidepressant and anxiolytic drugs (Table 1).

Table 1: Characteristics of the study population

	HA-ID	LASA	Difference
n	172	2917	
Male/Female	80/92	1409/1508	X^2= 0.21
Age (s.d)	64.3 (7.2)	70.4 (8.7)	*t*= -10.59**
Antidepressant drug use (%)	28[a] (16.3)	44[b] (1.5)	X^2= 172.54**
Anxiolytic drug use (%)	15[a] (8.7)	147[b] (5.0)	X^2= 5.79*

[a] Data of 33 (19%) participants is missing
[b] Data of 355 (12%) participants is missing
*p< 0.05, **p< 0.01

Figure 1 shows the distribution of total scores in both populations. The mean total score of the HA-ID population was 3.51 (s.d.= 3.19), whereas that of the LASA population was 2.53 (s.d.= 3.30). Univariate comparison of these means showed that they were significantly different (t= 3.79, p< 0.01). Controlling for the difference in age, the HA-ID population scored significantly higher on the HADS-A (F(2, 3087)= 7.28, p< 0.01).

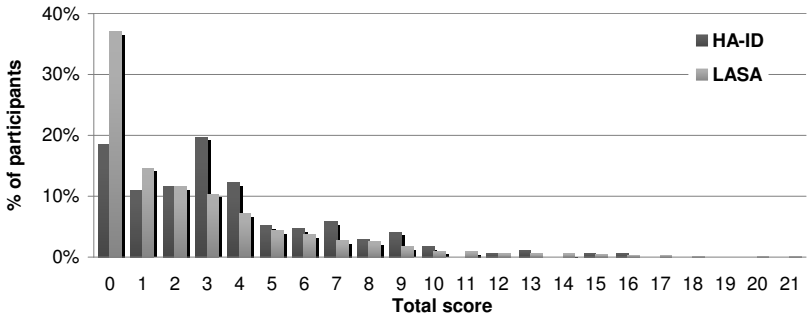

Figure 1: Total scores of HA-ID and LASA population

The ratio between observed and expected cases with a score above cut-off in the group with ID, against numbers found in the general population was 1.36 (95% CI: 0.83-2.10) (Table 2). The odds ratio was 1.39 (95% CI: 0.85-2.25). According to the age-adjusted ratio and odds ratio, the number of people scoring above cut-off in both groups was not significantly different.

Adjusted for age, people with ID reported significantly more often 'tense or wound up feelings', 'frightened feelings', 'worrying thoughts', and 'sudden feelings of panic' (Table 2).

Table 2: Percentages of participants with score below or above HADS-A cut-off and percentages of participants with item reported as present for different age-strata

	55-64 years		**65-74 years**		**75-85 years**		**Ratio[a] (95%CI)**
	HA-ID	LASA	HA-ID	LASA	HA-ID	LASA	
Total n	97	938	57	929	18	1050	
Total score < 8	90.7%	91.7%	86.0%	91.0%	83.3%	91.3%	0.97 (0.82-1.13)
Total score ≥ 8	9.3%	8.3%	14.0%	9.0%	16.7%	8.7%	1.36 (0.83-2.09)
Items							
1. Tense or wound up feelings	48.5%	38.1%	54.4%	36.2%	66.7%	35.3%	1.46 (1.18-1.78)
2. Frightened feelings	17.5%	12.5%	24.6%	15.7%	38.9%	14.5%	1.61 (1.14-2.20)
3. Worrying thoughts	43.3%	31.7%	57.9%	33.7%	66.7%	33.1%	1.56 (1.25-1.92)
4. Relaxed feelings	36.1%	42.9%	47.4%	38.1%	50.0%	32.1%	1.03 (0.81-1.30)
5. Frightened feeling in stomach	16.5%	14.5%	15.8%	14.4%	27.8%	13.8%	1.21 (0.82-1.73)
6. Restless feelings	26.8%	27.3%	33.3%	28.2%	38.9%	25.3%	1.10 (0.82-1.45)
7. Sudden feelings of panic	17.5%	8.6%	17.5%	9.7%	27.8%	9.8%	2.04 (1.40-2.89)

[a] observed/expected

DISCUSSION

This is a study of reported anxiety symptoms in two Dutch population-based older study cohorts, one in the general population and one in the population with ID, using an internationally applied self-report screening instrument for anxiety. The outcomes show that older adults with borderline to moderate ID report significantly more anxiety, but do not score significantly more often above the cut-off score. Specifically, worrying, frightened feelings, tension, and feelings of panic are reported significantly more often than in the general older population. These outcomes confirm our expectation that older persons with ID are more prone to anxiety than older people with normal intelligence.

Psychotropic drug use is significantly higher in the population with ID, but we had no information about indications for anxiolytic and antidepressant drug prescriptions. Prescriptions may have included epilepsy, behavioural and sleeping problems, which

are common in people with ID.[18-20] We did not control for this difference. However, it is likely that the higher level of psychotropics among the HA-ID cohort has led to an underestimation of the prevalence of anxiety in older people with ID and therefore also into an underestimation of the difference between HA-ID and LASA.

The existence of anxiety in older people with ID should receive more attention, because it is higher than in the general population regardless of higher psychotropic drug use. Professionals in clinical practice should be aware that the limited abilities and autonomy of people with ID combined with age-related decline may result in excessive worrying and tense feelings. They should encourage clients to discuss their anxious feelings and to label anxiety provoking situations, which may lead to less anxiety.

A limitation of this study is the relatively small sample of people with ID, which is caused by the low participation in self-report of HA-ID participants due to their limited cognitive abilities. This has limited the power of the study. The incomplete knowledge about the psychometric properties of the HADS-A in people with ID may be a limitation, because it has not been verified that it indeed measures anxiety in this population. However, the symptoms of anxiety in people with ID as reported in this population seem to be similar to those the general population.[1, 21] Furthermore, of the anxiety instruments developed for the general population, only the Zung Anxiety Scale has been studied for its validity in people with ID, with disappointing results.[22] The different completion procedure of the HADS-A of both studies may also seem a limitation, but completion in written by participants with ID would have resulted in unreliable outcomes. Hence, the different completion procedures, written and verbal, are a reflection of clinical practice for both samples.

In conclusion, the report of sub-clinical anxiety by older people with ID is higher than in the general older population. Consequently, more attention for anxiety and support of caregivers is necessary.

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Chapter 9

Factors associated with depression and anxiety in older adults with intellectual disabilities

Based on:
H. Hermans and H. M. Evenhuis, Factors associated with depression and anxiety in older adults with intellectual disabilities: Results of the Healthy Ageing and Intellectual Disabilities study. Submitted.

ABSTRACT

Aim: To study which factors are associated with depression and anxiety in older adults with intellectual disabilities (ID).

Method: Increased depressive and anxiety symptoms were studied in 990 participants, with borderline to profound ID, aged ≥ 50 years, using self-report and informant-report screening questionnaires. In 290 participants, major depression as well as anxiety disorders were assessed with a standardised psychiatric interview. Associations with personal, medical, and psychosocial factors, which were collected through informant-report questionnaires and participants' medical and psychological records, were studied using multiple logistic regression analysis.

Results: Increased depressive symptoms were positively associated with increased anxiety symptoms, number of life events during the past year, and chronic diseases (heart failure, cerebrovascular accident, chronic obstructive pulmonary disease, coronary artery disease, diabetes mellitus and malignity in the previous five years) and negatively with instrumental activities of daily living (IADL)-abilities. Major depression was positively associated with chronic diseases and negatively with IADL-abilities. Increased anxiety symptoms were positively associated with borderline or mild ID and increased depressive symptoms and negatively associated with Down syndrome, epilepsy, and social contacts. Anxiety disorders showed no significant associations.

Conclusions: Also in older people with ID, depression and anxiety are strongly associated with each other and with personal, physical and psychosocial factors. To develop effective prevention and treatment policies, factors associated with depression and anxiety should be further examined in future longitudinal research.

INTRODUCTION

Life expectancy of people with intellectual disabilities (ID) is increasing, implying a growing number of older people with ID with age-related physical and mental health problems.[1, 2] Although studies of depression and anxiety disorders in older adults with ID are scarce, it seems that both depression and anxiety are more prevalent in this group than in younger adults with ID.[3] However, risk factors for depression and anxiety have not been studied yet.

In large-scale Dutch research in the general older population, the following risk factors for depression, anxiety or both have been identified: female gender, higher age, chronic diseases, cognitive impairment, functional limitations, educational level, a family history of depression or anxiety disorders, impaired vision or hearing, pain, smoking, feelings of loneliness, few social contacts, and negative life events.[4-11] In adults with ID, risk factors for depression have been studied incidentally, showing overlap with those in the general population.[12, 13] Additional risk factors found in this group are Down syndrome and epilepsy.[14, 15] Risk factors for anxiety have hardly been studied in adults with ID; autism spectrum disorders, epilepsy, lack of day-time occupation, and life events were found to be associated with anxiety.[15-17]

These outcomes can not be merely translated to older adults with ID. Factors associated with depression and anxiety in older adults with ID may differ from those in the general older population, because of a different lifestyle, higher psychotropic medication use,[18-20] and more physical disabilities, such as visual impairment,[21] partially from an earlier age on.[2] Associated factors in older adults with ID may differ from those in younger adults with ID, because of age-related chronic diseases and increasing functional impairment.[2, 22] Insight into factors associated with depression and anxiety in older adults with ID is needed to enable development of successful preventive interventions in clinical practice. In this first explorative study, we determined which factors are associated with depression and anxiety in older adults with ID.

METHODS

Study design and study population

This study was part of the '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: central 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.[23] People with ID unknown to formal ID services are not part of our study population.

Of the general Dutch population aged ≥ 50 years, 0.5% is known to formal ID services of which 10% receives care or support from one of the services participating in this study.[1] All their clients aged 50 years or over (n=2322) were invited to participate. For 1050 participants, written informed consent was obtained from the participants or their legal guardians. The lower 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.[2, 24] A more extensive description of the study population, recruitment and informed consent procedure is given in Hilgenkamp et al. (2011). This study has been approved by the Medical Ethical Testing Committee of the Erasmus University Medical Center at Rotterdam, the Netherlands (MEC nr: 2008-234).

Procedure and measures

Increased depressive and anxiety symptoms

Depressive and anxiety symptoms were measured with self-report and informant-report questionnaires. Increased depressive and anxiety symptoms were defined as a score above the cut-off of one or more of the depression or anxiety questionnaires. Self-report questionnaires were verbally applied by trained interviewers in participants who had borderline, mild or moderate ID, used comprehensible speech and were able to oversee the time-frame of at least one week. Informant-report instruments were completed in written by professional caregivers who knew the participant for at least three months.

Depressive symptoms were measured with the Dutch informant-report Signalizing Depression List for people with Intellectual Disabilities (SDL-ID)[25] and the Inventory of Depressive Symptomatology Self Report (IDS-SR).[26] The SDL-ID was used for participants with insufficient cognitive or verbal capacities to complete self-report. Its internal consistency and interrater reliability in older people with ID is good (α= 0.77 and *r*= 0.87).[27] We used the cut-off score of ≥ 35 which has been recommended by the author.[28] For participants capable of self-report, the IDS-SR was used instead of the SDL-ID. The phrasing of the IDS-SR was adapted to improve applicability. The internal consistency and test-retest reliability of this adapted version are good (α= 0.89 and ICC= 0.91) and its validity is sufficient (sensitivity 71% and specificity 54%) in adults with ID.[29] Based on published results, we used the cut-off score of ≥ 18.[30]

Anxiety symptoms were measured with the Anxiety, Depression, And Mood Scale (ADAMS),[31] the Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID),[32] and the anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A).[33] The ADAMS is an informant-report questionnaire with sufficient to good reliability and validity in older people with ID.[34] The five subscales of the ADAMS were completed for all participants, but only the score on the General anxiety subscale has been used.

We used the cut-off score of ≥10 for participants with no autism and ≥14 for participants with an autistic spectrum disorder, as recommended by Hermans et al. (2012). In addition to the ADAMS, participants who were capable of self-report were interviewed with the GAS-ID and the HADS-A. The GAS-ID has been developed for people with ID and has good psychometric properties.[32, 35] We used a cut-off score of ≥17 which was valid in older adults with ID (sensitivity= 80% and specificity= 58%).[35] The HADS-A has been developed for the general population and we have added standardised information to four items (2, 3, 6, 7) to increase comprehension. Psychometric properties are fair to good in the general population.[33, 36, 37] Based on published results, we used a cut-off score of ≥ 8.[36]

Diagnosis of depression and anxiety disorders

Because psychiatric diagnostic assessment of all HA-ID participants was too time consuming, depression and anxiety disorders were diagnosed with a two-step diagnostic procedure. All participants with at least one score above the cut-off of one of the screening instruments were further examined with a standardised psychiatric interview within two weeks. Because published sensitivities of the screening questionnaires vary between 71-84% (see above), and because at the start of the study, criterion validity for the translated ADAMS and GAS-ID 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.

Current psychiatric diagnoses (major depressive disorder, generalised anxiety disorder, panic disorder, phobia) were made using the Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD) Interview.[38] The PAS-ADD is a semi-structured interview developed for adults with ID and has been based on the Schedules for Clinical Assessment in Neuropsychiatry (SCAN).[39] Its psychometric properties are satisfactory.[40-42] The questions of the PAS-ADD Interview can be answered by people with ID, their caregivers or both. The interviews were applied by psychologists or behavioural therapists, experienced in working with older people with ID, who were additionally trained in recognizing psychiatric disorders and the interview's system. Symptoms impossible to score, due to confounding factors such as severity of ID or dementia, were scored as 'uncertain'. Items scored as 'uncertain' were excluded from the final diagnostic decision.

Associated factors

Potential associated factors have been chosen, based on associations found in earlier studies in adults with ID or the general older population. Some risk factors, such as family history and loneliness, were not examined, because these data have not been collected in this study, whereas educational level was replaced by level of ID.

Gender, age, level of ID, Down syndrome, autistic spectrum disorder, chronic diseases, epilepsy, sensory impairment, mobility, functional ability, number of life events, smoking, and frequency of social contacts were chosen as possible associated factors for depression and anxiety. Gender, age, level of ID, smoking, presence of an autistic spectrum disorder, Down syndrome, visual and hearing impairment, epilepsy, and chronic diseases (heart failure, cerebrovascular accident, chronic obstructive pulmonary disease, coronary artery disease, diabetes mellitus and malignancy in the previous five years) were retrieved from the participants' files based on diagnoses made by psychologists, behavioural therapists, or physicians. Frequency of social contacts was assessed with three questions about number and type of social contacts, with a total score ranging from 0 to 12. Number of life events during the past year was assessed with a checklist of 28 life events of which appearance in the last 12 months must be rated. This checklist was based on other life event checklists[38, 43] and experiences of professionals in clinical practice. Activities of daily living (ADL), instrumental activities of daily living (IADL) and wheelchair dependency were used as indicators of functional ability. ADL was assessed with the Barthel Index[44] of which the total score ranges from 0 to 20 and IADL with the Lawton IADL scale,[45] with a total score ranging from 8 to 24.

Statistical analysis

All analyses were performed with the Statistical Package for the Social Sciences 17.0. Non-response analyses were done using a t-test for age and chi-square tests for gender and residential setting.

All separate anxiety disorders (general anxiety disorder, phobic anxiety disorder and panic disorder) were recoded as 'anxiety disorder'. The association of increased depressive and anxiety symptoms, major depression and anxiety disorder with all potential associated factors was analyzed with point-biserial correlation coefficients for continuous variables and phi coefficients for dichotomous variables. Personal characteristics (gender, age, level of ID, and Down syndrome) and variables significantly associated with anxiety or depression were included in multiple logistic regression analysis. Personal characteristics were added to the regression analysis independently from their association with the dependent variable, because of their potential influence on other independent variables. All independent variables were simultaneously entered into the regression to control for their influence on other independent variables in the regression. People with a diagnosis of dementia, made by both their physician and their psychologist or behavioural therapist, were excluded from the regression analysis of increased depressive symptoms (n=41, of which 31 had Down syndrome), because of the overlap of depressive and dementia symptoms. Including them would specifically confound the association between Down syndrome and depressive symptoms, because dementia is highly prevalent in older people with Down syndrome. Autism was excluded

beforehand as independent variable from the regression analysis of increased anxiety symptoms, because the cut-off score of the ADAMS's General anxiety subscale is based on having autism or not. Dummy variables were constructed for level of ID, because all independent variables should be continuous or dichotomous. The magnitude of association of the independent variables with depression and anxiety can be compared by calculating odd's ratios identified by the regression analyses. The proportion of the dependent variable which is explained by the factors in the model was calculated with R^2 of Hosmer and Lemeshow.[46] Multicollinearity, which refers to a high correlation between independent variables in one model, which is undesirable in regression analysis, was checked with the variance inflation factor.[47]

RESULTS

The screening questionnaires were completed for 990 of the 1050 participants, of who 166 had increased depressive symptoms and 161 increased anxiety symptoms. Missing data were caused by caregivers' refusal to co-operate (n=44), logistic reasons (n=9) and incompleteness (n=7). Non-participants (people without consent and participants with incomplete data; 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 participants living independently (X^2= 44.22, p< 0.05) were significantly underrepresented in the sample. The PAS-ADD interview was completed for 290 of the 990 participants. The total study population and the sub-sample of participants with a completed PAS-ADD interview are described in Table 1, as is the occurrence of significantly correlated factors.

Increased depressive symptoms were significantly positively correlated (p< 0.05) with age, increased anxiety symptoms, number of life events and chronic diseases, and significantly negatively correlated with frequency of social contacts, ADL, and IADL. Of these, frequency of social contacts, IADL, and chronic diseases were significantly correlated with major depression. Increased anxiety symptoms were significantly positively correlated with gender, smoking, increased depressive symptoms, number of life events and chronic diseases, and significantly negatively correlated with level of ID, Down syndrome, epilepsy, frequency of social contacts, IADL, visual impairment and hearing impairment. None of the factors was significantly correlated with anxiety disorders; therefore no regression analysis was performed with anxiety disorders as dependent variable.

The regression analyses showed that increased depressive symptoms remained significantly positively associated with increased anxiety symptoms, number of life events and chronic diseases, and negatively with IADL-abilities (Table 2). These variables explained 23.0% of the variance in increased depressive symptoms. Major depression

Table 1: Characteristics of the study population

Characteristic	Total sample	Sample with PAS-ADD interview[a]
n	990	290
Personal characteristics		
Male/female	508/482	137/153
Mean age (s.d.)	61.1 (8.2)	61.9 (8.3)
Down syndrome (%)	142 (14.3)[b]	35 (12.1)[k]
Level of ID (%)		
Borderline & mild	242 (24.2)	89 (30.7)
Moderate	471 (47.6)	138 (47.6)
Severe & profound	254 (25.7)	53 (18.3)
Unknown	23 (2.3)	10 (3.4)
Depression and anxiety (%)		
Increased depressive symptoms	166 (16.8)	138 (47.6)
Increased anxiety symptoms	161 (16.3)	128 (44.1)
Major depression	-[c]	42 (14.5)
Anxiety disorders	-[c]	23 (7.9)
Medical factors (%)		
Visual impairment	210 (21.2)[d]	58 (20.0)[l]
Hearing impairment	259 (26.2)[e]	68 (23.4)[m]
Chronic diseases	223 (22.5)[f]	77 (26.6)[n]
Epilepsy	177 (17.9)[g]	44 (15.2)[o]
Other factors		
Autism spectrum disorder (%)	168 (17.0)[h]	46 (15.9)[p]
Smokers (%)	194 (19.6)	72 (25.5)
Wheelchair dependency (%)	107 (10.9)	25 (8.6)
Mean social contacts score (s.d.)	5.82 (2.64)	5.60 (2.61)
Mean number of life events (s.d.)	5.88 (3.13)	6.41 (3.17)
Mean ADL-score (s.d.)	13.84 (5.77)	13.67 (5.58)
Mean IADL-score (s.d.)	11.85 (4.69)	12.03 (4.69)

PAS-ADD, Psychiatric Assessment Schedule for Adults with a Developmental; ADL, activities of daily living; IADL, instrumental activities of daily living

[a] part of the total sample

[b] 118 missing; [c] studied in 290 participants only; [d] 152 missing; [e] 157 missing; [f] 130 missing; [g] 167 missing; [h] 61 missing; [k] 43 missing; [l] 54 missing; [m] 52 missing; [n] 47 missing; [o] 56 missing; [p] 24 missing

remained significantly positively associated with chronic diseases and negatively with IADL-abilities (Table 3). These variables explained 10.9% of the variance. Increased anxiety symptoms remained significantly positively associated with borderline or mild ID and increased depressive symptoms, and negatively with Down syndrome, epilepsy, and social contacts (Table 4). These variables explained 24.7% of the variance.

Table 2: Outcomes of the regression analysis of increased depressive symptoms (n=693)[a]

Independent variable	B (unadjusted)	S.E.	Wald	OR (95% CI)
Gender	-0.09	0.23	0.14	0.92 (0.59-1.44)
Age	0.01	0.02	0.73	1.01 (0.98-1.04)
ID: borderline/mild	-0.12	0.43	0.09	0.88 (0.38-2.03)
ID moderate	0.15	0.30	0.27	1.17 (0.65-2.09)
Down syndrome	0.44	0.34	1,70	1.55 (0.80-3.02)
Increased anxiety symptoms	2.55	0.28	85.93	12.75 (7.44-21.84)**
Life events	0.12	0.04	12.60	1.13 (1.06-1.21)**
Social contacts	-0.06	0.05	1.82	0.94 (0.86-1.03)
ADL	-0.04	0.02	2.69	0.96 (0.92-1.01)
IADL	-0.15	0.05	10.98	0.86 (0.79-0.94)**
Chronic diseases	0.55	0.26	4.55	1.74 (1.05-2.89)*

[a] Less than 990 participants in the regression analyses has been caused by missing medical information and excluded participants with dementia (n=41)
*p< 0.05, **p< 0.01

Table 3: Outcomes of the regression analysis of major depression (n=198)[a]

Independent variable	B (unadjusted)	S.E.	Wald	OR (95% CI)
Gender	0.20	0.41	0.24	1.22 (0.55-2.75)
Age	-0.01	0.03	0.22	0.99 (0.94-1.04)
ID: borderline/mild	0.13	0.67	0.04	1.13 (0.31-4.20)
ID moderate	0.34	0.54	0.41	1.41 (0.49-4.03)
Down syndrome	-1.17	0.80	2.16	0.31 (0.07-1.48)
Social contacts	-0.15	0.08	3.40	0.86 (0.74-1.01)
IADL	-0.14	0.07	4.12	0.87 (0.76-0.99)*
Chronic diseases	1.01	0.43	5.49	2.74 (1.18-6.36)*

[a] Less than 290 participants in the regression analyses has been caused by missing medical information
*p< 0.05

Table 4: Outcomes of the regression analysis of increased anxiety symptoms (n=764)[a]

Independent variable	B (unadjusted)	S.E.	Wald	OR (95% CI)
Gender	0.21	0.24	0.73	1.23 (0.77-1.98)
Age	-0.01	0.02	0.53	0.99 (0.96-1.02)
ID: borderline/mild	1.57	0.42	13.92	4.82 (2.11-11.01)**
ID moderate	0.66	0.36	3.42	1.93 (0.96-3.89)
Down syndrome	-0.94	0.45	4.31	0.39 (0.16-0.95)*
Smoking	0.27	0.28	0.95	1.31 (0.76-2.27)
Epilepsy	-0.76	0.34	4.86	0.47 (0.24-0.92)*
Increased depressive symptoms	2.60	0.28	83.67	13.41 (7.69-23.39)**
Life events	0.03	0.04	0.57	1.03 (0.95-1.11)
Social contacts	-0.11	0.05	5.28	0.90 (0.82-0.98)*
IADL	0.04	0.032	1,39	1.04 (0.98-1.11)
Visual impairment	0.01	0.338	0.01	1.01 (0.52-1.96)
Hearing impairment	-0.39	0.294	1.74	0.68 (0.38-1.21)
Chronic diseases	0.17	0.269	0.41	1.19 (0.70-2.01)

[a] Less than 990 participants in the regression analyses has been caused by missing medical information
*p< 0.05, **p< 0.01

DISCUSSION

This large-scale study gives a first overview of the association of personal, physical, psychiatric and social factors with depression and anxiety in older adults with ID. Older adults with increased depressive symptoms are exposed to more life events, have more often increased anxiety symptoms, suffer more often from chronic diseases, and perform worse on IADL-abilities. Those diagnosed with a major depression also have more often chronic diseases and perform worse on IADL-abilities. Older adults with increased anxiety symptoms have more often borderline or mild ID, increased depressive symptoms and few social contacts, whereas those with Down syndrome or epilepsy have less often increased anxiety symptoms.

Except for the association of life events with depressive symptoms, none of the factors associated with depression identified by previous studies in adults with ID (e.g. female gender) was confirmed by our results. Factors associated with anxiety have been hardly studied in adults with ID and the few factors found by previous studies (e.g. life events) were not confirmed by our results as well. Moreover, the association of epilepsy was the other way around, which may be caused by the anxiety-diminishing effect of anti-epileptic drugs.[48, 49] The low occurrence of anxiety symptoms in older adults with Down syndrome correspond with the relatively low incidence of psychiatric disorders in younger adults with Down syndrome, reported by previous studies.[50-52] The differ-

ences in found associated factors may be partly explained by different study designs, exploring psychiatric problems in specific populations (e.g. with epilepsy or autism) [15, 16] instead of exploring factors associated with psychiatric problems like we did, and partly by different statistical analyses, using multivariate analyses of variance[13] instead of multiple regression analyses in which it is possible to control for the confounding effect of other factors.

The strong association between depressive and anxiety symptoms is similar to findings in the general population.[7, 53, 54] For depression, factors identified in the general population which were confirmed by our study are: chronic diseases, functional limitations and life events. Other factors repeatedly found in the general population, such as age or visual impairment, were not confirmed by our results. The lack of a significant association with age in older adults with ID may be explained by their longstanding or early-onset of limitations and diseases which may result in less age-related health problems.

The relatively low proportions of variance explained by the independent variables suggest that other, unidentified, factors contribute to depression or anxiety. For example, biological factors, such as inflammation markers and neurotropic factors, are known to be associated with depression in the general older population,[55-57] but were not included in our study. Further research should explore the association of these factors with depression and anxiety in older adults with ID.

The main limitation of this study is the cross-sectional study design, hindering conclusions about causality for most associations. For example, the association of anxiety with the number of social contacts can be two-fold: less social contacts may increase anxiety, but anxiety can also limit social contacts. In the same way may poor functional abilities cause depression, but depression can also cause a decline in functional abilities.[58] In the current study, causal relationships can only be assumed for fixed independent variables, such as gender, age or Down syndrome. Another limitation is that factors associated with major depression or anxiety disorders have only been studied in part of the total study population, reducing the power of these analyses.

Nevertheless, this first exploratory study gives direction to future research and guidance to prevention in clinical practice. Several factors are associated with depression and anxiety and legitimate further evaluation in longitudinal studies, to draw conclusions about causality. Our results also show that depression and anxiety are more prevalent in specific groups. For example, people with mild ID, who often live in a less protective living environment, report more anxiety. In clinical practice, prevention procedures should focus on these vulnerable groups. Besides, when developing prevention or treatment policies, it should be considered that depression and anxiety are not isolated conditions, but that they are strongly associated with each other and with personal (e.g. level of ID), physical (e.g. chronic diseases), and social (e.g. life events) factors.

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Chapter 10

Life events and their associations with depression and anxiety in older people with intellectual disabilities

Based on:
H. Hermans and H. M. Evenhuis, Life events and their associations with depression and anxiety in older people with intellectual disabilities: Results of the HA-ID study. Journal of Affective Disorders, 138: p. 79-85, 2012.

ABSTRACT

Background: People with intellectual disabilities (ID) may be exposed to more life events due to different living circumstances and limited coping abilities. The frequency of life events may increase with age due to age-related decline, loss of significant others and forced relocations. We studied the occurrence of life events in adults with mild to profound ID aged ≥ 50 years and their association with depression and anxiety.

Methods: Occurrence and burden of life events were assessed with a checklist of 28 items, completed by professional caregivers. Depression and anxiety were assessed with self-report and informant-report screening instruments (n=988) and with a psychiatric interview (n=286). Associations with depression and anxiety were studied for life events in general and for specific life events.

Results: 97% of the participants had been exposed to multiple life events during the preceding year and 72% had been exposed to one or more negative life events. The frequency was significantly higher in participants aged 65 years or over, in participants with mild or moderate ID and in participants with depression or anxiety. Minor physical illness and problems with a fellow resident were significantly associated with depression and anxiety, decline or loss of mobility and loss of leisure-time activities with depression and change at work or from work with anxiety.

Conclusions: Given the high prevalence of life events and their association with depression and anxiety, life events should be better monitored and, if possible, prevented.

INTRODUCTION

In people with intellectual disabilities (ID), the occurrence of life events is high and they are associated with psychiatric and behavioural problems.[1-4] Life events can be positive (e.g. marriage) or negative (e.g. death of close relative) and some life events (e.g. relocation) may be positive for one person, but negative for another.[5] It is likely that people with ID are exposed to different and more life events than the general population, because of different living circumstances, limited coping skills, and less control over their lives.[6, 7] Similarly, the frequency of life events may be lower for people with mild ID than for people with more severe ID, because of independent living and better coping abilities.[8] We expected that life events may occur even more often in older people with ID, because of age-related physical and cognitive decline, co-morbid health problems, loss of significant others and forced relocations.[9, 10] Given the relationship of life events with all kinds of psychiatric problems, older people with ID may have an increased risk of psychiatric problems due to more life events.

Therefore, we studied life events in older adults with ID and their association with depression and anxiety. To that end, we have developed a checklist with a broad variety of life events. Because of the subjective character of life events, we also investigated the experienced burden of life events. Therefore, not only occurrence but also burden of each reported life event had to be rated. With this study, we want to answer the following questions: How frequent are older adults with ID exposed to life events and how often are these events experienced as negative? How accurate is observers' judgement of burden of life events? Are life events associated with age, level of ID, residential setting, depression and anxiety?

METHOD

Setting and study population

This study was part of the 'Healthy Ageing and Intellectual Disabilities' (HA-ID) study, performed in a consort of three large service organizations in the south-west of the Netherlands. These organizations provide care and support of varying intensity at residential settings and day-care settings. All clients aged 50 years or over were invited to participate (n=2322). Informed consent was received from the participants or their legal guardians for 1069 persons. Nineteen persons who gave informed consent failed to participate due to severe illness, death or returning the consent form too late. Of another 62 participants, data on life events were missing, due to informants' refusal to complete the questionnaire (n=57), logistic problems (n=4), and one unfinished questionnaire, which resulted in a study population of 988 participants. Recruitment and ethical issues

are described in more detail elsewhere.[11] This study has been approved by the Medical Ethical Testing Committee of the Erasmus University Medical Center at Rotterdam, the Netherlands (MEC nr: 2008-234).

Measures and procedure

Gender, age, level of ID, residential setting and a history of depression or anxiety disorder were retrieved from the participants' files. Level of ID and a history of depression or anxiety disorder were requested from the participants' psychologist or behavioural therapist.

Life events

Life events were assessed with a checklist of 28 life events, of which appearance and burden during the last 12 months had to be rated (yes/no). This checklist has been developed for the HA-ID study and was based on the Brugha life events checklist, the life events checklist of the PAS-ADD Interview, frequent life events mentioned in other studies,[5, 12-14] and experiences of professionals (physicians, psychologists and caregivers) working with people with ID. The internal consistency is good (α= 0.81). The checklist was completed by informants, because a time-frame of 12 months is too long to oversee for many people with ID.[15] Informants were stimulated to ask participants about the experienced burden of the reported life events, if possible.

Depression and anxiety

Increased depressive and anxiety symptoms were assessed using self-report and informant-report screening instruments and were defined as a score above the cut-off of at least one of these screening instruments. Participants with a borderline, mild or moderate ID, who use comprehensible speech and are able to oversee the time-frame of at least one week, were considered capable of self-report. Self-report instruments were applied by trained interviewers. Informant-report instruments were completed in written by professional caregivers who knew the participant for at least three months.

Depressive symptoms were assessed with the Inventory of Depressive Symptomatology Self Report (IDS-SR)[16] for self-report and the Dutch informant-report Signalizing Depression List for people with Intellectual Disabilities (SDL-ID)[17] for participant incapable of self-report. The IDS-SR has been developed for the general population, but its psychometric properties are good in adults with ID: internal consistency of α= 0.89, test-retest reliability of ICC= 0.91, sensitivity of 71% and specificity of 54%.[18] Its score ranges from 0 to 84. Based on published results, we used a cut-off score of ≥18.[19] The SDL-ID's internal consistency and interrater reliability in older people with ID are good (α= 0.77 and *r*= 0.87).[20] The score on the SDL-ID can range from 18 to 72. We used a cut-off score of ≥35 which has been recommended by the author of the questionnaire.[21]

Anxiety symptoms were assessed with the Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID)[22] and the Anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A)[23] for participants capable of self-report and with the General anxiety subscale of the Anxiety, Depression, And Mood Scale (ADAMS)[24] for all participants. The GAS-ID has been developed for people with ID and has good psychometric properties.[22] Its score ranges from 0 to 54. We used a cut-off score of ≥17 which has been recommended by Hermans et al. (submitted) for older adults with ID.[25] The HADS-A has been developed for the general population in which its psychometric properties are fair to good.[23, 26, 27] Standardized explanatory information was added to four items (2, 3, 6 and 7) for better comprehension. Its score ranges from 0 to 21. Based on published results, we applied a cut-off score of ≥8.[26] The ADAMS is an informant-report instrument and was applied in total to avoid violation of the questionnaire's structure. The General anxiety subscale has sufficient to good psychometric properties in older adults with ID.[28] The score on the General anxiety subscale ranges from 0 to 21. We applied the cut-off scores recommended by Hermans et al. (2012): ≥10 for participants without autism and ≥14 for those with an autism-spectrum disorder. The presence of an autism spectrum disorder was requested from the participants' psychologist or behavioural therapist.

Diagnoses of major depression and anxiety disorders (generalised anxiety disorder, panic disorder, phobia) were made with the Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD) Interview.[12] The PAS-ADD is a semi-structured interview with satisfactory psychometric properties.[29-31] Interviews were done by behavioural therapists experienced in working with people with ID, who had been trained in using the PAS-ADD Interview. The PAS-ADD interview has been applied to a subsample of the total study population.

Statistical analyses

All analyses were done with the Statistical Package for the Social Sciences 17.0. Non-response analyses were done using a t-test for age and chi-square tests for gender and residential setting. Non-response analysis for level of ID was not possible, because this was unknown for non-participants. We verified the accuracy of report of burden by informants by comparing the correlation of depressive and anxiety symptoms with both total number of life events and total number of negative life events, using Point-biserial correlation coefficients. Reliable report should result in a higher correlation of depressive and anxiety symptoms with negative life events than with total life events. For this specific analysis, depressive and anxiety symptoms were recoded to one variable: scores below cut-off scores on all depression and anxiety questionnaires versus one or more scores above the questionnaires' cut-off scores.

Differences in frequency of total and negative life events for age (50-64 years versus ≥ 65 years), increased depressive and anxiety symptoms, major depression and anxiety disorders were analysed with t-tests and for level of ID, residential setting and the different anxiety disorders (generalized anxiety disorder, phobia and panic disorder) with a one-way ANOVA. To control for the increased vulnerability of people with a history of depression or anxiety disorders, significant differences in frequency of total and negative life events for increased depressive and anxiety symptoms, major depression and anxiety disorders were also analysed with an ANCOVA (with history of depression or anxiety disorder as covariate).

The relationship of individual life events with increased depressive and anxiety symptoms was explored with a logistic regression analysis using items of the life events checklist, gender, age and level of ID as the independent variables and increased depressive and anxiety symptoms as dependent variables. Life events which were prevalent in less than 5% (n<50) of the study population were excluded from the regression analysis to increase statistical power. Multicollinearity is an undesirable strong relation between the independent variables and was checked for all independent variables with the variance inflation factor.[32] The relationship of individual negative life events with increased depressive and anxiety symptoms has not been studied, because we wanted to study the objective relationship of life events and depression and anxiety. The relationship of individual life events with major depression and anxiety disorders has not been studied, because the sample with a diagnosis was too small to use in regression analysis.

RESULTS

The study population consisted of 509 men and 479 women with a mean age of 61.1 (s.d.= 8.2). Non-response analyses showed that men (X^2= 3.99, p< 0.05) and people living independently were significantly underrepresented (X^2= 47.69, p< 0.05). The diagnostic interview was applied to 286 participants, 195 with at least one score above the cut-off and 91 participants with screening scores below all cut-off scores.

Frequency of life events

Of the total sample, 979 (99.1%) participants had been exposed to one or more life events during the preceding year, 953 (96.5%) to two or more, and 889 (90.0%) to three or more (Table 1). The most frequently reported life events were: change of staff in residential setting/day care (85.0%), holidays (65.3%), new fellow resident (55.1%), mild physical illness (47.2%) and change of main professional caregiver (39.5%) (Table 2). Concerning the number of life events rated as negative, 707 (71.6%) participants had been exposed to one or more negative life events, 503 (50.9%) to two or more and 331 (33.5%) to three

Table 1: Frequency of multiple life events (n=988)

Number of life events	n (%)	Number of negative life events	n (%)
0	9 (0.9)	0	281 (28.4)
1	26 (2.6)	1	204 (20.6)
2	64 (6.5)	2	172 (17.4)
3	117 (11.8)	3	109 (11.0)
4	143 (14.5)	4	85 (8.6)
5	142 (13.5)	5	49 (5.0)
6	128 (13.0)	6	26 (2.6)
≥7	359 (36.3)	≥7	62 (6.3)

Table 2: Frequency of each life event

Life event	Total: n (%)	Negative: n (%)
Change of staff in residential setting or day-care	835 (84.5)	265 (26.8)
Holiday	645 (65.3)	49 (5.0)
New resident moved in	545 (55.2)	94 (9.5)
Minor illness or injury	468 (47.4)	235 (23.8)
Change of key-worker	391 (39.6)	71 (7.2)
Problems with fellow resident	372 (37.6)	275 (27.8)
Change at or from work or day-care	353 (35.7)	91 (9.2)
Death of relative or friend	274 (27.7)	111 (11.2)
Decline or loss of mobility	257 (26.0)	154 (15.6)
Major illness of a relative, caregiver or friend	253 (25.6	130 (13.2)
Death of significant other (other than relative or friend)	213 (21.6)	75 (7.6)
Change in frequency of visits from or to family/friends	193 (19.5)	84 (8.5)
Moving within service organization	184 (18.6)	41 (4.2)
Major illness or injury	178 (18.0)	126 (12.8)
Loss of leisure time activities	113 (11.4)	52 (5.3)
Rapid loss of vision or hearing	109 (11.0)	57 (5.8)
Problems with relative, friend or staff	96 (9.7)	81 (8.2)
Menopause	80 (8.1)	22 (2.2)
Loss of something valuable	55 (5.6)	45 (4.6)
Moving from independent living or living with family to service organization	50 (5.1)	11 (1.1)
Stopped working/ day-care	40 (4.0)	8 (0.8)
Sexual problem	38 (3.8)	29 (2.9)
Divorce/ break up of steady relationship	28 (2.8)	12 (1.2)
Alcohol or drug related problems	26 (2.6)	6 (0.6)
Burglary	20 (2.0)	8 (0.8)
Financial problems	17 (1.7)	14 (1.4)
Problems with justice and/or authorities	11 (1.1)	5 (0.5)
Fired from work/unemployment	6 (0.6)	4 (0.4)

or more (Table 1). The most frequently reported negative life events were: problems with a fellow resident (27.8%), change of staff (26.8%), mild physical illness (23.8%), decline or loss of mobility (15.6%) and severe illness of relative, carer or friend (13.2%) (Table 2).

Participants aged 65 years or over had been exposed to significantly more life events than younger participants (Table 3). People with mild or moderate ID had been exposed to significantly more total and negative life events during the preceding year than people with severe or profound ID (Table 3).

Accuracy of report of burden by observers

The correlation of total number of life events with increased depressive or anxiety symptoms (r_{pb}= 0.17 (95% CI: 0.11-0.23), p< 0.01) was lower than the correlation of number of negative life events with increased depressive or anxiety symptoms (r_{pb}= 0.29 (95% CI: 0.23-0.34), p< 0.01), suggesting that observers' judgement of burden of life events is adequate.

Association of life events with depression and anxiety

Participants with increased depressive or anxiety symptoms had been exposed to significantly more total and negative life events during the past year, which remained significant after controlling for a history of depression or anxiety disorders (Table 3). Figure 1 shows the association of multiple exposure to total and negative life events with depressive and anxiety symptoms. Participants with major depression had been

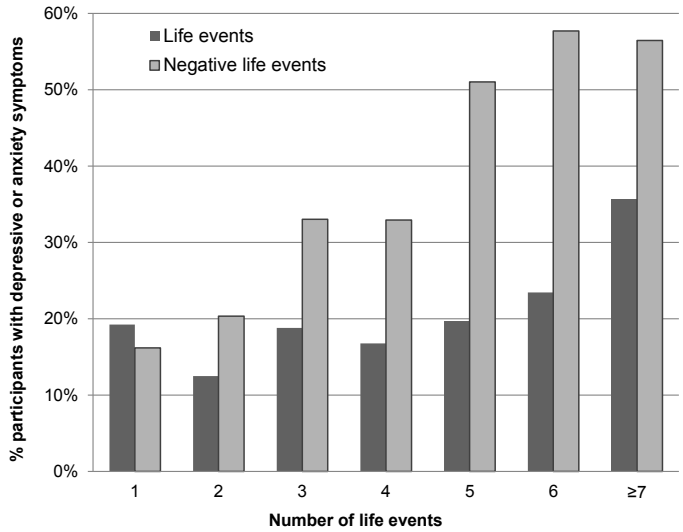

Figure 1: Association of multiple life events and depressive and anxiety symptoms

exposed to significantly more negative life events, which remained significant after controlling for a history of depression (Table 3). Participants with a generalized anxiety disorder have been exposed to significantly more life events and those with a panic

Table 3: Characteristics of study population and differences in number of life events

Characteristics	n	Mean number of life events (s.d.)	Mean number of negative life events (s.d.)
Gender		*t*= 1.35	*t*= -0.19
Male	509	6.05 (3.20)	2.18 (2.44)
Female	479	5.78 (3.04)	2.21 (2.43)
Age		*t*= -2.12*	*t*=-1.86
<65 years	682	5.78 (3.10)	2.10 (2.38)
≥65 years	306	6.24 (3.18)	2.42 (2.54)
Level of ID		F(3, 962)= 9.02**	F(3,962)= 10.52**
Borderline/Mild	241	6.34 (3.15)	2.61 (2.59)
Moderate	471	6.15 (3.25)	2.36 (2.62)
Severe	165	5.31 (2.90)	1.46 (1.78)
Profound	89	4.71 (2.34)	1.53 (1.62)
Accommodation		F(2,986)= 2.04	F(2,986)= 0.12
Independent living	43	5.67 (3.52)	2.35 (2.26)
Community-based home	412	6.16 (3.12)	2.21 (2.46)
Central location	533	5.76 (3.12)	2.17 (2.43)
Depression screening		*t*= -4.61**; F(2,900)= 9.13**[a]	*t*= -6.73**; F(2,900)= 30.88**[a]
Score below cut-off	818	5.70 (3.03)	1.92 (2.22)
Score above cut-off	165	6.92 (3.31)	3.56 (2.97)
Major depression diagnosis		*t*= -1.71	*t*= -2.97**; F(2,258)= 3.77*[a]
No major depression	245	6.31 (3.13)	2.76 (2.66)
Major depression	41	7.22 (3.42)	4.10 (2.81)
Anxiety screening		*t*= -3.26**; F(2,896)= 3.03*[b]	*t*= -6.54**; F(2,896)= 21.98**[b]
Score below cut-off	827	5.76 (3.11)	1.94 (2.28)
Score above cut-off	157	6.64 (3.00)	3.50 (2.81)
Anxiety disorders diagnosis		*t*= -0.27	*t*= -0.50
No anxiety disorders	263	6.42 (3.20)	2.92 (2.72)
Anxiety disorders	23	6.61 (3.10)	3.22 (2.65)
Specific anxiety disorders[c]		F(2,21)= 5.72*	F(2,21)= 5.22*
Generalized anxiety disorder	4	9.50 (4.80)	2.75 (1.26)
Phobia	11	4.82 (2.14)	1.91 (2.34)
Panic disorder	8	7.63 (1.69)	5.25 (2.44)

[a] Controlled for a history of depression

[b] Controlled for a history of anxiety disorders

[c] Participants with ≥ 1 anxiety disorder were classified according to their most severe anxiety disorder

*p< 0.05, **p< 0.01

disorder to significantly more negative life events than participants with phobia (Table 3).

Table 4 shows the association of each life event with increased depressive and anxiety symptoms by means of odds ratios (OR). A higher OR represents a stronger association of a life event with depression or anxiety. 'Problems with a fellow resident' and 'minor physical illness or injury' were significantly associated with both increased depressive and anxiety symptoms, 'decline or loss of mobility' and 'loss of leisure-time activities' with increased depressive symptoms, and 'change at work or from work/day-care' with

Table 4: Association of each life event with depression and anxiety expressed in Odds ratio (95% CI)

Life event	Increased depressive symptoms	Increased anxiety symptoms
n	961	962
Gender	1.08 (0.73-1.59)	1.52 (1.02-2.26)*
Age	1.00 (0.98-1.03)	1.00 (0.98-1.02)
Borderline/mild ID[a]	0.68 (0.39-1.18)	3.40 (1.95-5.91)
Moderate ID[b]	1.01 (0.65-1.58)	1.45 (0.85-2.48)
Change of staff in residential setting or day-care	1.04 (0.60-1.82)	1.01 (0.59-1.74)
Holiday	0.47 (0.32-0.68)**	0.53 (0.36-0.78)**
New resident moved in	1.21 (0.82-1.79)	1.15 (0.78-1.70)
Minor illness or injury	1.58 (1.07-2.32)*	1.49 (1.01-2.20)*
Change of key-worker	0.94 (0.63-1.39)	0.81 (0.54-1.22)
Problems with fellow resident	1.61 (1.10-2.36)*	1.85 (1.25-2.72)**
Change at or from work or day-care	1.29 (0.87-1.91)	1.65 (1.11-2.46)*
Death of relative or friend	1.05 (0.66-1.66)	1.16 (0.73-1.83)
Decline or loss of mobility	1.75 (1.16-2.65)**	1.02 (0.65-1.61)
Major illness of a relative, caregiver or friend	0.84 (0.52-1.36)	1.23 (0.78-1.95)
Death of significant other (other than relative or friend)	1.40 (0.90-2.19)	0.75 (0.46-1.23)
Change in frequency of visits from or to family/friends	1.13 (0.71-1.79)	0.99 (0.62-1.61)
Moving within service organization	0.83 (0.49-1.40)	1.27 (0.77-2.09)
Major illness or injury	1.16 (0.74-1.82)	1.06 (0.65-1.72)
Loss of leisure time activities	2.92 (1.75-4.86)**	1.64 (0.92-2.93)
Rapid loss of vision or hearing	0.92 (0.52-1.63)	0.45 (0.21-0.98)*
Problems with relative, friend or staff	0.66 (0.34-1.28)	1.50 (0.86-2.64)
Menopause	0.79 (0.37-1.69)	0.87 (0.44-1.72)
Loss of something valuable	1.58 (0.79-3.19)	0.96 (0.44-2.06)
Moving from independent/with relatives living to an ID living facility	0.61 (0.23-1.64)	0.32 (0.10-1.07)

[a] Versus moderate and severe/profound ID

[b] Versus borderline/mild and severe/profound ID

*$p < 0.05$, **$p < 0.01$

increased anxiety symptoms. 'Holiday' was significantly associated with absence of depressive and anxiety symptoms and 'rapid loss of vision or hearing' with absence of anxiety symptoms.

DISCUSSION

This large-scale cross-sectional study in a nearly representative Dutch sample of 988 older people using formal ID services shows, that in the course of one year, up to 72% of the participants has been exposed to one or more negative life events, independent of living conditions. More life events are reported with advancing age and by people with mild or moderate ID. Accumulation of life events, especially negative ones, results in a higher frequency of increased depressive and anxiety symptoms and major depression. The following life events are specifically associated with increased depressive or anxiety symptoms: 'minor illness or injury', 'problems with fellow residents', 'decline or loss of mobility', 'loss of leisure time activities', and 'change at or from work/day-care'.

The development of a life event checklist, based on internationally used checklists for the general population and for adults with ID, with added items characteristic for adults with ID, has certainly yielded a profit: three of the five most frequently reported life events ('change of staff', 'new resident moving in', 'change of key-worker') are typical for adults with ID receiving formal care or support. These three life events were also found to be among the five most frequent life events, as reported by Owen et al. (2004), who also included items typical for this population. Compared to findings of prior studies in younger adults with ID, we found a higher exposure to life events, even compared to findings of Owen et al. (2004) (70% (95% CI: 60-78%) against 90% (95% CI: 88-92%) in our study).[5, 8, 14, 33] These findings confirm our expectation that older people with ID are exposed to more age-related life events than younger adults.

Somewhat remarkable outcomes are the negative associations of 'holiday' with depressive and anxiety symptoms and of 'rapid loss of vision or hearing' with anxiety. The former could imply either that holidays prevent depression and anxiety or that people who have depression or anxiety symptoms go less often on a holiday. The second association might be explained by the fact that, as opposed to slowly progressive sensory losses, rapid losses are usually noticed by clients or caregivers, and subsequently treated.

Although the judgement of impact of life events by observers could only be checked indirectly, the results suggest that this judgement tends to be adequate. This is a relevant finding, because many people with ID are not able to adequately remember past events over a longer time period. However, for three quarters of the sample (those incapable of self-report), one informant completed both the questionnaires about depressive or anxiety symptoms and the life event checklist, which may have resulted in an over-

estimation of the correlation of burden and symptoms. In future research, inter-rater reliability of the life events checklist should be studied to determine the accuracy of judgement by caregivers.

The main limitation of this study is that, like most life event studies, it was cross-sectional and therefore lacks reliable information about causality. Another limitation is that the association of individual life events was studied only for depressive and anxiety symptoms, but not for depression and anxiety disorders, because the prevalence of such disorders is relatively low and therefore hard to study with regression analysis in a non-selected study population. Although symptoms are indicative for psychiatric problems, these results can not be generalised to major depressive disorder and anxiety disorders. The underrepresentation of men and independently living adults has no consequences for the generalizability of this study, because we found no associations of life events with gender or residential setting.

The most important implication for clinical practice is, that ID services should increase their awareness of the occurrence of life events. Especially because accumulation of life events is furthered by the fact that some might trigger others: for example, loss of mobility may lead to relocation which leads to change of key worker. Furthermore, awareness of the impact of certain events should also increase. Events that seem unremarkable to staff or management may have a significant impact on clients' well-being, leading to depression or anxiety. For example, the association of minor physical illness with depression and anxiety may imply increased impact of illness because of limited understanding of the nature of illness. Also, events related to change (e.g. change of staff, change at work, new resident moving in) are rated relatively often as negative. Therefore, a broad spectrum of life events, especially those associated with depression and anxiety, should be actively monitored and, where possible, prevented. Although some life events may be unavoidable, this approach may result in taking into account clients' perspective in care management more often. Besides, the consequences of life events (e.g. depression or anxiety) should also be noticed to ensure adequate support or treatment. Despite the current financial crisis that causes diminishing financial sources for chronic care and leads to multiple policy changes, interventions aimed at limiting preventable life events together with appropriate support to limit the potential negative effect of inevitable life events on psychological well-being should be actively promoted.

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Chapter 11

General discussion

PRINCIPAL FINDINGS

The aims of the 'Healthy Ageing and Intellectual Disability' study were to evaluate diagnostic tools and to quantify health problems and risks in older people with intellectual disabilities (ID), using an approach from the perspective of primary and secondary prevention.

We have established that numerous screening instruments for depression or anxiety have been developed for adults with ID, but none of these instruments has been studied satisfactorily for its psychometric properties. Similarly, the psychometric properties of instruments developed for the general population have been scarcely studied in adults with ID. It also appeared that there was no Dutch screening instrument for anxiety with satisfying reliability and validity. Therefore, we have translated and evaluated the two most promising instruments, a Scottish self-report instrument for anxiety and an American informant-report instrument for anxiety and depression, and found a good reliability and satisfying validity for both.

The screening showed that increased depressive symptoms (screening-score above cut-off) are prevalent in 17% and increased anxiety symptoms in 16% of the older adults with ID and that they are strongly associated with each other. Older people with borderline or mild ID report more often clinically relevant levels of anxiety symptoms than people with more severe ID, but no more frequently than older people with normal intelligence. Furthermore, people with increased depressive or anxiety symptoms appeared to have been exposed to significantly more life events during the preceding year, while up to 97% of the participants had been exposed to more than one life events, of which "structural change of staff", "holiday" and "a new resident moving in" were reported most.

The prevalence of major depression is 8%, which is five times more than in the Dutch general older community-dwelling population, whereas the prevalence of anxiety disorders is 4%, which is nearly half of the prevalence in the general older population. These disorders had not been recognized prior to this study in 62% and 74%, respectively. People diagnosed with major depression have more often limited instrumental activities of daily living-abilities and chronic diseases.

METHODOLOGICAL ISSUES

We have used multiple instruments to screen for depression and anxiety which made the screening procedure complicated. This issue could have been prevented by exclusively using the Anxiety, Depression And Mood Scale for informant-based information. However, at the start of this study, the psychometric properties of its Dutch translation had

not been studied sufficiently. Moreover, we wanted to interview participants themselves whenever possible, especially because several studies have shown that people with mild ID are capable of reliable self-report.[1-3] Besides, we aimed at the use of instruments that are applied in epidemiological studies in the general older population, to enable comparison. An advantage of using multiple instruments was that we have evaluated several instruments.

The selective application of psychiatric diagnostic interviews appeared a methodological limitation, because after data collection we had to adapt the cut-off value of the general anxiety subscale of the Anxiety, Depression And Mood Scale to a lower value, based on our evaluation, resulting in an unknown quantity of underdiagnosis. It also appeared that some participants with scores below cut-off, who had been further examined, were diagnosed with a depressive or anxiety disorder. Consequently, the total number of diagnoses of major depression and anxiety disorders had to be estimated. However we stress that clinically, selective diagnostics based on screening remain a generally accepted approach.

A limitation of the psychiatric diagnostic interview is, that it has been based on a general diagnostic classification system (ICD-10)[4] and therefore lacks adapted criteria for people with ID. This may have resulted in fewer diagnoses than if adapted criteria had been used.[5] Particularly, underdiagnosis of anxiety disorders, which are known to be among the most difficult disorders to diagnose in people with ID,[6] can not be ruled out. The Dutch version of the PAS-ADD interview also lacks a section with symptoms of post-traumatic stress disorders (PTSD). Although PTSD is often excluded in epidemiologic studies of anxiety disorders, it seems to have a high prevalence in adults with ID.[7] The exclusion of PTSD most certainly led to underestimation of anxiety disorders. Although the used interview has some clear limitations, it has been validated in people with ID and remains the method of choice in large-scale research, as long as no valid instrument is available that is based on adapted diagnostic criteria.

A final limitation concerns the study population. The study population lacks older people unknown to formal ID services. Consequently, the results are generalizable to the older population known to formal ID services only. Furthermore, men and people living independently were slightly underrepresented in the sample. The consequences for generalizability of this underrepresentation are harder to define. It seems that the outcomes are still generalizable to the total population known to ID services, because gender and living situation are not significantly related to the main outcomes of this study. Nevertheless, living situation may be partly related to level of ID and this is associated with some of the outcomes. 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.

IMPLICATIONS AND RECOMMENDATIONS FOR CLINICAL PRACTICE

Primary prevention

Primary prevention aims at preventing depression and anxiety in general. Elements of primary prevention can be distilled from effective interventions: sufficient supply of social activities, physical activities, social support[8-10] as well as pro-active support after drastic changes or events (e.g. loss of relatives, retirement, decreased mobility, myocardial infarction).[11, 12] These elements should be at the basis of primary prevention.

Secondary prevention

Secondary prevention aims at early detection and treatment of depression and anxiety symptoms with the objective to prevent full-blown disorders. In general, detection strategies may aim at an entire population or selectively at 'at risk' groups.[13]

Detection

The results of this study show that depression and anxiety often remain unrecognized which is similar to what is found in the general older population.[14] Early detection should be improved, because of the burden of depression and anxiety and their potential negative effect on mental and physical health as well as on cognitive and functional abilities.[15-18]

In the general population, it has been found that universal screening hardly increases recognition.[19] Screening of all older people with ID would be time-consuming and probably not cost-effective.[19] Selective prevention seems to be the most feasible and cost-effective method to detect people who should receive treatment.[11, 19, 20]

Routine screening of 'at risk' groups could be linked to the annual evaluation of clients' individual support plan. Although we did not study risk factors for depression and anxiety, a provisional risk profile for older adults with ID, based on findings of the current study, findings in the general older population, and our own clinical experience, can be proposed. People with a history of depression or anxiety, more than two chronic diseases, little social support and persons who have recently been exposed to two or more negative life events as listed in our checklist, are 'at risk' to develop clinically significant levels of depression or anxiety and should be routinely screened.[21-23]

Based on our own evaluation, both of the literature and the current study, we provisionally recommend the following informant-report screening instruments for use in clinical practice: the Anxiety, Depression And Mood Scale and the Signalizing Depression List. This set can be expanded with the Glasgow Anxiety Scale for people who are capable of self-report. A Dutch self-report screening instrument for depression in people with ID which is easily applicable in clinical practice, is not available yet. The Glasgow Depression Scale is promising; a Dutch translation should be validated. For

those participants with a screening-score above cut-off, multidisciplinary examination and treatment should be performed by their general practitioner or physician for people with intellectual disability and their psychologist or behavioural therapist. Specialist psychiatric health care is indicated for complicated (e.g. multiple psychiatric disorders) or severe cases.

Selective screening only increases detection in part of the population with ID. Detection of depressive and anxiety symptoms in the others can be improved by educating staff. Caregivers and day activity staff should be informed about symptoms of depression and anxiety in this group and educated to recognize these symptoms in daily practice. This should be added to regular professional and postgraduate education programmes. To further support detection by staff, screening instruments should be available in daily practice for direct use when depressive or anxiety symptoms are suspected.[24]

Selective screening does also not apply to the large group of people unknown to formal ID services. It is estimated that around 60% of the people with mild ID do not use care or support from formal ID services and are dependent on general health care services.[25] In primary care, recognition of depression or anxiety disorders is already low for people with normal intelligence[26] and may be even lower for people with ID. Even people with mild or borderline ID may not communicate any symptoms, communicate atypical symptoms, or require more time to formulate their complaints, hampering adequate diagnosis and treatment.[27, 28] Early detection is especially important in this relatively independent group, because they are exposed to more life events and may have less social support than people living in supported settings, which may increase their vulnerability for depression and anxiety.[29] Moreover, untreated psychiatric disorders may lead to absence of work and additional problems, such as addiction.[30-32]

A first step in improving detection could be made by adding specific information about risk factors and symptoms of depression and anxiety in people with ID to clinical guidelines of the Dutch College of General Practitioners and general guidelines of mental health care.[33-36]

A second step to improve detection and treatment is the promotion of multidisciplinary examination and treatment of people with ID. In the Netherlands, for people who according to the General Act on Special Medical Expenses have no indication for specialized healthcare of ID physicians or psychologists, specialized out-patient ID clinics could provide multidisciplinary examination and treatment. During the last decade, 61 of such specialized out-patient ID clinics have been set up by physicians for people with intellectual disability. In almost half of these clinics, specialized psychologists or behavioural therapists are involved. Such multidisciplinary collaboration should be stimulated, because this has shown to be very effective in the treatment of depression

and anxiety disorders in the general population.[37, 38] For enduring implementation of these multidisciplinary ID clinics, structured financial regulations are required.

Treatment

Timely detection is only appropriate and effective if adequate treatment and follow-up is available.[19, 31, 39, 40] Evidence about applicability and effectiveness of treatment of depressive and anxiety symptoms and disorders in people with ID is very limited. In the general older population, psychosocial, pharmaceutical, behavioural interventions and combinations of these interventions are found to be effective in prevention and treatment of depression and anxiety.[8, 41, 42] The few studies concerning treatment in adults with ID focus on depression and show that pharmaceutical treatment and cognitive behavioural therapy are both effective. However, these two methods have not been compared yet.[43-46] Furthermore, cognitive behavioural treatment is only applicable to people with mild ID and to some people with moderate ID. Moreover, therapists have to be creative in adapting the therapy to the abilities of the person with ID.[44] People with more severe ID may be effectively treated with behavioural activation, but the effectiveness of this intervention has only been studied in a pilot.[47] In conclusion, extensive knowledge of treatment of depression and especially anxiety is still lacking. To legitimate screening, the effectiveness of several interventions should be further studied.

RECOMMENDATIONS FOR RESEARCH

Diagnostics of depression and anxiety

In the current study, psychometric properties of the Anxiety, Depression And Mood Scale and the Glasgow Anxiety Scale have been studied. However, sensitivity for change and factorial structure of both instruments still need to be evaluated.

Although we have studied the reliability and validity of those two instruments, one of the main problems remains the clinical use of instruments which have insufficiently been studied for their psychometric properties. New instruments are still being developed, while existing ones are not further studied. International consensus about promising instruments which will be further evaluated would solve this problem. Such consensus about instruments would also enable comparison of the outcomes of different studies concerning depression and anxiety. Furthermore, international application of the same instruments enables international collaboration. International collaboration is important, because the population of people with ID is relatively small which makes it harder to include sufficient numbers of people with particular diseases or genetic syndromes.

Longitudinal research

More knowledge about specific risk factors for depression and anxiety is necessary as a basis for both primary and secondary prevention. Selective screening should be part of clinical practice but requires knowledge about 'at risk' groups. Longitudinal research makes it possible to define risk factors by exploring the causality of the association of personal characteristics, lifestyle (e.g. smoking, physical activity), physical diseases, psychosocial (e.g. life events) and biomedical factors with depression and anxiety. Moreover, it also indicates which factors could be influenced with primary prevention.

Longitudinal research also enables the determination of reinforcing processes. An example of a reinforcing process is the association between heart failure and depression: myocardial infarction causes depression, but depression is also a risk factor for heart failure.[12, 48, 49] Such knowledge supports the development of special preventive programs for people with heart problems. In the current study, it was found that the number of social contacts is negatively associated with increased anxiety symptoms. Knowledge about the causality of this relationship and possible reinforcement give directions for prevention.

Ideally, longitudinal research should follow a cohort of people with ID for at least 20 years (e.g. from 40 to 60 years) to monitor the process of ageing. Such longstanding longitudinal research would make it possible to distinguish general risk factors and age-related risk factors for depression and anxiety. This is important because certain conditions which are mostly age-related in the general population (e.g. impaired mobility, cognitive impairment) may be childhood conditions in people with ID. Knowledge about general risk factors enables prevention since younger age (e.g. stimulating and training motor-development).

Treatment and intervention studies

Interventions should be studied for their effectiveness. The relative newness of research into mental health of people with ID results in less knowledge than in the general population. Next to pharmaceutical and cognitive behavioural therapy, the applicability and effectiveness of interventions aimed at coping styles, social support seeking and activation should be studied in people with ID. Moreover, the feasibility and effectiveness of interventions should be studied for different sub-populations with ID.

Implementation of new methods or processes into routine practice should be evaluated. For example, the contribution of screening and multidisciplinary care on detection and treatment rates should be studied, and factors influencing successful implementation identified (e.g. characteristics of professionals, organizational structure).

Other study populations

The results of this study show that depression and anxiety are substantial problems. People unknown to formal ID services did not participate in this study. This 'hidden' group of people with ID makes recruitment more complicated. Although recruitment of this group is hard, knowledge about psychiatric symptoms and disorders in this group and possible related factors (e.g. number of social contacts, level of social support, number of life events, and physical complaints and diseases) would be of tremendous importance because this group is large[25] and costs of untreated psychiatric disorders are high.[31, 32]

CONCLUDING REMARKS

Depression and anxiety are common disorders and detection should be improved. Improving detection can be done by selective screening and education of staff. Although this study certainly contributes to the knowledge about diagnostics and prevalence of depression and anxiety, more knowledge is still necessary as a basis for evidence-based prevention and treatment in clinical practice.

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Appendix I

Study healthy ageing and intellectual disabilities: Recruitment and design

Based on:
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ABSTRACT

Problems encountered in epidemiologic health research in older adults with intellectual disabilities (ID) are how to recruit a large-scale sample of participants and how to measure a range of health variables in such a group. This cross-sectional study into healthy ageing started with founding a consort of three large care providers with a total client population of 2322 clients of 50 years and over, and two academic institutes. This consort made formal agreements about a research infrastructure and research themes: 1. Physical activity and fitness, 2. Nutrition and nutritional state, and 3. Mood and anxiety. Subsequently, preparation was started by carefully reviewing and selecting instruments to measure a wide set of health variables to answer the research questions. Specific demands of these instruments were that they could be executed efficiently and accurately on-site in a large sample of participants and that the burden of these measurements for participants as well as their caregivers was as minimal as possible. Then, preparation was continued by designing and executing a thorough communication plan for clients, legal representatives and staff of the care providers, preceding the informed consent procedure. In this plan, which had a top-down structure, specific attention was given to personally informing and motivating of key stakeholders: the professional care givers. This preparation led to a recruitment of 1050 participants (45.2%) and to high participation rates in key parts of the assessment. A detailed description is provided about the recruitment and organization and the selected instruments.

INTRODUCTION

Life expectancy of adults with intellectual disabilities (ID) is lengthening towards that of adults without ID, but daily practice indicates that this ageing is relatively often not a healthy ageing. With a higher risk of motor impairments, sensory impairments and epilepsy since earlier in life, these people are prone to develop multiple physical and mental comorbidities at older age.[1-3] 'Frail patients' (multiple diagnoses, complex medical routines, frequent hospitalisation, functional impairment),[4] requiring individualised managed care, are expected to be highly prevalent in this population. Furthermore, functional deterioration is frequent,[5] leading to diagnostic and therapeutic uncertainty, transfers from community-based to central residential settings, and high costs.

With these risks in mind, three Dutch care organizations (Abrona, Huis ter Heide; Amarant,Tilburg; Ipse de Bruggen, Zwammerdam) and two academic departments (Intellectual Disability Medicine, Department of General Practice, Erasmus MC in Rotterdam; Center for Human Movement Sciences, UMCG, Groningen) intended to start a large-scale project to study health in older adults with ID in 2006. Inspired by questions of the care organizations themselves (formulated by client panels and staff panels), three themes were chosen: 1. Physical activity and fitness, 2. Nutrition and nutritional state, and 3. Mood and anxiety. These themes cover a substantial impact on health and quality of life and are supposed to have strong mutual relationships, but have hardly been studied in ageing people with ID. The scientific aims of this project were: a. To perform baseline assessments of prevalence rates and secondary health effects for each theme and to identify risk groups. b. To assess mutual relationships between the themes and their underlying concepts. c. To select and evaluate diagnostic tools to assess each theme.

To meet these aims, an observational cross-sectional design was chosen for this multicentre research project. However, before such a study in this particular and complex target population could be executed, two major obstacles needed to be dealt with.

The first obstacle in the execution of such a study is caused by the specific living circumstances of older adults with ID. Many older adults with ID depend on a care system, involving family and professional caregivers. Lack of involvement, commitment and ultimately support by the care system can be an obstacle to the recruitment of a large, representative sample, as well as to participation in the assessments which will be a part of the study.

The second obstacle is how to measure a range of health characteristics in older adults with ID. In the general population, preventive health checks are used to collect data about certain health characteristics or risk factors, like the Canadian Study of Health and Aging,[6] or the Cardiovascular Health Study.[7] This kind of screening is not applicable to the population of older adults with ID because self-report questionnaires, neuropsycho-

logical tests and often physical tests may require a certain level of cognitive and physical abilities which may not be compatible with those of older adults with ID.

Because of such barriers, most published epidemiological research in adults with ID is based on existing (medical) records or registries, or observations of professional caregivers.[8-13] With this method, underrecognition of certain health problems or risk factors is to be expected,[14] due to communication difficulties of the participants and lack of suitable diagnostic instruments. Another solution is to limit the number of participants.[15] With this solution, extrapolation of the results is hampered since the number of participants is often limited or narrowed by strict exclusion criteria, thus often underestimating the actual problems in this group.[16]

This gives rise to the following research question: How to successfully measure health in older adults with ID in a large, representative sample?

MATERIALS AND METHODS

Before starting the actual study, measures were taken to ensure optimal circumstances for executing a large-scale study. Therefore, the formation of a consort and description of the base population will be presented first. The method section then proceeds with a detailed description of the selection of instruments and organization of measurements, after which the standard informed consent procedure is described. Subsequently, extra activities undertaken to optimize recruitment will be described, such as extra activities in communication and consent procedures. Inclusion, representativeness and participation are described as main outcome measures.

Founding a consort

Former research has shown the importance of cooperation and commitment of different management levels to provide the necessary conditions for a successful execution of a large-scale study in the field.[17][18,19] For this reason, three large care providers and two academic departments joined together in a consort, and preparation of a first large-scale study was started at CEO level in 2006. Formal agreements were made about financing and grant acquisition, responsibilities, communication, project management and infrastructure, involvement of clients and client representatives. Agreement was reached on the following aims of the consort: 1. to increase knowledge on healthy ageing in intellectual disability by means of scientific research, 2. to increase the scientific attitude of staff of care providers by means of participation in research and continuous education, 3. innovation of care by means of implementation of research outcomes. In the preparatory phase and during the execution of the study, the consort discussed about policy, practical issues, results and future directions on three management levels: CEO-level,

level of the boards of directors, and middle-management level, to ensure embedding of and commitment to this project.

The members of this consort cooperated in obtaining a governmental grant for this first research project (granted by the Netherlands Organisation for Health Research and Development, 2007, nr. 57000003).

Base population

The three involved care providers in the consort mentioned above provide financial and organizational support and give access to a large population of older adults with ID receiving any type of care or support from these care organizations.

The care organizations are geographically located in different regions of the Netherlands, both in urban and rural areas and all provide care to a broad spectrum of clients, varying in level of ID, mobility and living arrangements and all including different care settings: central residential settings, community-based homes, day activity centres and supported living. Together they provide care for 8550 persons with ID, which is approximately 10% of the total Dutch client population of specialized care providers.[20] The distribution of clients primarily receiving care (35%) and clients primarily receiving support (65%) is similar as that in the total Dutch client population with ID.[20] Furthermore, the percentage of older adults (50 years and over) in their client population (10%) is similar to that in the total Dutch population with ID.[20] We therefore consider this base population to be representative for the total Dutch client population of older adults with ID.

Materials

The selection of diagnostic methods had to be performed with great care. A detailed description of the selection process of instruments within each subtheme stretches too far for this paper, but has been published elsewhere,[21] or is pending revision.[22]

In general, reliability, validity and feasibility in this specific population were important criteria in the selection of instruments.

As far as feasibility is concerned, the instruments had to be applicable in large-scale research, which means they had to be not too time-consuming and suitable for a large part of this heterogeneous population. Where possible, instruments which were also used in the general (older) population were chosen. This enables comparison between this specific population of older adults with ID and the general population. Furthermore, they had to be executable by a large group of professionals, without high risks of differences between test-observers. Due to the on-site nature of the assessments, instruments had to be ambulatory available, and if possible, non-invasive. The costs of the instruments were also an important factor, considering future use in clinical practice.

For the physical fitness tests and the instruments measuring anxiety and depression, a literature search and evaluation of the retrieved instruments did not result in a definite

evidence-based choice for an instrument. Expert meetings were used to incorporate the clinical experience of scientific and care professionals in the final choice. In some cases English instruments had to be translated into Dutch and tested for feasibility and reliability, for example the questionnaires for anxiety and for eating disorders. A pilot study in November 2008 was used to evaluate those instruments, as well as the feasibility of the entire set of instruments.

The definite selection of instruments is presented in Table 5, with a distinction between measurements requiring active involvement of the participant and measurements without active involvement of the participant.

Procedure

The large-scale nature of an epidemiological study puts three specific demands on the organization of measurements. The organization needs to be efficient, the measures need to be executed accurately and the burden of these measurements for participants as well as their caregivers needs to be as minimal as possible. The burden for participants and their caregivers was considered a central factor in designing the organization of measurements. The feasibility of this organization was also tested in the pilot study and led to minor adjustments in the instruments and organization.

To complete all assessments efficiently, and to comply with one of the aims of the consort as well, the measurements needed to be executed by groups of test administrators, consisting of professionals of the involved care providers. To enhance their commitment and to optimise the organisation, they were informed and consulted in an early stage of the study. Their preferences considering planning and location were followed as much as possible, and interference with existing (medical) routines was avoided as much as possible. To enhance efficiency even further, the particularly time-consuming diagnostic process of psychiatric disorders (through expert interviews) was replaced by a two-step model, with a screening for all participants by self-report or informant-report questionnaires, and only a diagnostic interview for those participants who scored above cut-off points on the questionnaires. Cognitive, social and emotional capabilities determined if a participant could be assessed by self-report questionnaires, administered by a trained test assistant in a screening interview. Therefore, that part of the participants was assessed by self-report questionnaires, the other part by informant-report questionnaires.

To ensure accurate administration of the assessments in this large group of test administrators, they were all trained by the researchers themselves or external experts and regularly checked on correct test assessment and scoring during the entire duration of the study.

Professional caregivers of the clients were informed in an early stage of the study, even before the consent procedure had been started. After consent, involved caregivers were consulted about their preferences and suggestions for the organization of the measure-

ment, to increase their collaboration during the assessments. These preferences were used as input for the final schedule of measurements for individual participants. Involvement and cooperation was thus managed by careful communication and organization.

In order to enhance participation during the assessments, we needed to keep the impact for participants and caregivers as low as possible. All diagnostic assessments needed to be organised at settings nearby participants, preferably locations they were familiar with. Furthermore, all assessments needed to be carried out by trained professionals of the health care organizations themselves, who were familiar to most of the participants. We decided that to decrease the burden of participation even further, all assessments needed to be concentrated in a period of two weeks for a participant, and all participants of the same living facility needed to be clustered together in the same two weeks, to decrease the impact for the involved professional caregivers too. The assessment consisted of parts where active involvement of the participant was necessary (i.e. physical examination) and of parts with no need of active involvement of the participant (i.e. questionnaires for professional caregivers), and the advice of the professional caregiver was followed concerning what parts were too stressful for a specific client.

In these two weeks, the emphasis of the assessment was on the first day, with a physical examination and a physical fitness test for the participants, and questionnaires to be completed by the professional caregivers. In the following two weeks the participants carried a pedometer and an accelerometer, and had appointments for a mealtime observation of swallowing and a short interview structured by self-report questionnaires about anxiety and mood and, if consented to, a venipuncture. Only when a participant scored above cut-off points in this screening for anxiety and/or depression, an in-depth diagnostic interview by trained behavioural therapists with client and/or a professional caregiver took place (all assessments are described in more detail in the Table 5).

After the assessment on the first day, the participant received a medal, and after the whole two weeks, each participant received a certificate of participation. The professional caregiver received a report with a summary of the results of the assessment, with advice whether to consult a physician or behavioural therapist or not.

Standard informed consent procedure

We aimed to include all clients aged 50 years or older receiving care or support by one of the three health care organizations (at the 1st of September 2008). No other exclusion criteria were applied. This selection method is likely to result in a very heterogeneous cohort with regard to aetiology and disabilities, reflecting the heterogeneity in the actual population of older adults with ID. All eligible clients were invited to participate from November 2008 to July 2010.

Separate consent procedures were followed for clients who were capable of understanding the available information and deciding themselves to participate or not in this

research project, and clients who were not capable of doing so. In some health care organizations this distinction was already available from their databases, in others we sought advice from the involved behavioural therapists in this matter, following the guidelines of WGBO,[23] the Dutch law that provides in rights and obligations between patient and health care professionals.

For clients who could make their own decision regarding consent for participation, information consisted of an introductory letter, an information booklet and a consent form, all with adjusted texts and pictograms to be easily readable. For clients who were not able to make this decision themselves, their legal representatives were approached, again with an introductory letter, an information booklet and a consent form. In case of doubt or unavailable information about the capability of the clients to decide for themselves, we first approached the legal representatives, giving them the possibility to forward this decision to the clients.

The study would not interfere with routine medical practice. Ethical approval was obtained (number 2008-234) from the Ethics Committee of the Erasmus University Medical Center. The study followed the guidelines of the Declaration of Helsinki.[24]

Optimizing recruitment

- Extra feature in the organizational structure is that this study was executed by PhD students, who were each employed by one of the health care organizations. This resulted in further strengthening of the connection between research and daily practice and at the same time complying with one of the requirements of the grant organization.
- A time period of around six months was reserved for the communication and practical preparation of the measurements. Extra efforts were made to design a detailed communication plan. Previous projects have shown that the success of a study in ID care depends on the commitment of the professionals in the participating health care organization.[25] Informing and motivating all involved professionals as well as different management levels is essential. Furthermore, information should be adapted to the particular professionals who are informed, for example management versus professional caregivers. Within the three health care organizations, a top-down information route was applied, from top management to the teams of professional caregivers, and this route was extended horizontally to the local ethical committees and client councils. Preceding the study, routine meetings of these groups were used to provide oral and written information. Only after this information route was fully completed, including the level of the professional caregivers, the consent procedure was started.
- Local ethical committees and boards of clients and client representatives of the three involved care organizations were informed as well and they formally consented to

this research project. This created support on different levels of the involved care organizations.
- The invitations to the participants were sent in sequential batches, to limit the time between consent and assessment and therewith minimize the loss of participants due to lack of motivation.
- Extra efforts were made to receive responses of all invited participants. Telephone calls were made to announce the sending of the consent materials, and if not returned in time, telephone reminders were made to obtain the missing consent forms. This offered the opportunity to clients and/or their caregiver to ask remaining questions about the study.
- The consent procedure was accompanied by extra information about the possibility to exclude measurements which were too stressful for a specific participant. This took away expected concerns of legal representatives and/or professional caregivers and was therefore an important extra activity in the consent procedure: After consent, intellectual or physical disabilities of various levels were taken into consideration in the actual participation in different parts of the assessment. Furthermore, the advice of the professional caregiver was to be followed concerning which parts of the assessment would be too stressful or not possible to execute for a specific client and thus be omitted. At all times unusual resistance to (parts of) the assessment by the client was leading.[26]

Outcomes

Inclusion

Numbers of clients in the different phases in the consent procedure will be presented, with a detailed description of non-participants.

Representativeness

To determine if the resulting sample would be representative for the base population, we collected administrative data of all clients aged 50 year and over (gender, age, type of living facility and ZZP-score). ZZP (ZorgZwaartePakket) is the Dutch classification of levels of support, care and/or treatment as a basis for long-term financing[27] (Table 1). ID care and mental health care (MHC) have different ZZP-classifications. A small number of clients may be indicated according to the ZZP classification for mental health care, although having an ID as well. For clients who participate in day activities within the consort and obtained residential care from other care providers, the ZZP score needed to be collected elsewhere.

To determine representativeness of the included sample, we used Pearson's chi-square test for independence, with null hypothesis that the participants and non-participants are similar (i.e. that characteristics are not depending on group).

Participation

To evaluate whether health was successfully measured in this sample of older adults with ID, participation rates are given for four key measurements of the complete health

Table 1: ZZP Classifications ID care[27]

ZZP score	Content of ZZP
1 VG	Residence with minimal support
2 VG	Residence with support
3 VG	Residence with support and care
4 VG	Residence with support and intensive care
5 VG	Residence with support and very intensive care
6 VG	Residence with intensive support, care and regulation of behaviour
7 VG	(Enclosed) Residence with very intensive support, care and regulation of behaviour
Functional indication	Support with no residence (only day care or ambulatory support)

assessment (physical examination, physical fitness test, questionnaires completed by caregivers, interviews) (Table 2). Data on all other measurements will be provided in separate papers concerning those measurements.

Table 2 Participation to parts of the health assessment

Measurement	Participation
Physical examination (or part of it)	90%
Physical fitness test (or part of it)	87%
Questionnaires completed by the caregivers	94%
Interviews participants themselves	20%

RESULTS

Inclusion

In figure 1 the results of the recruitment procedure are shown. Although the consent rate (consent/invited) was 1069/2150 (49.7%), the total rate of participants of the total cohort (total number/participants) was 1050/2322 (45.2%).

Representativeness

In Table 3 the numbers are presented for the total population of older adults in all three care organizations, for participants and for non-participants, including the contributing chi-square terms per category. The categories with the largest deviation from the

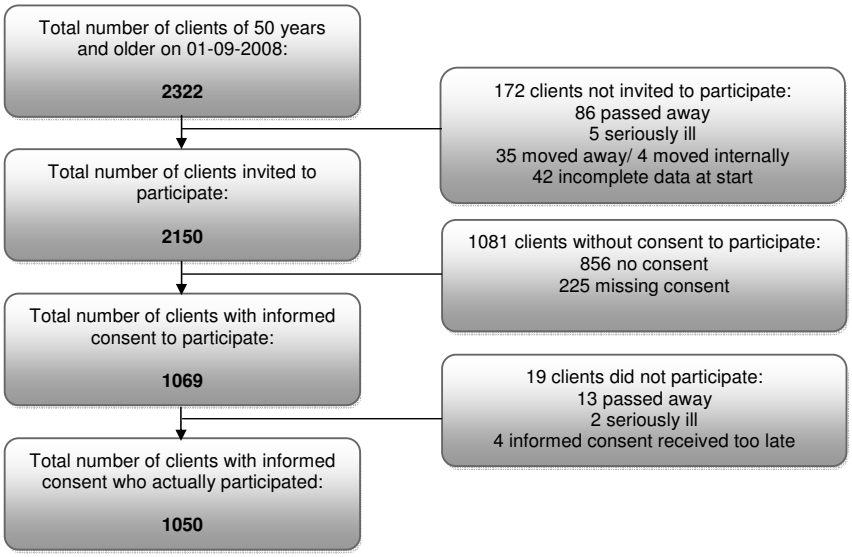

Figure 1. Flow-chart inclusion

Table 3 Representativeness of the study population

	Total population	**Participants**		**Non-participants**	
	N	N	$(X_o-X_e)^2/X_e$	N	$(X_o-X_e)^2/X_e$
Total	2322	1050		1272	
Gender					
Male	1253	539	1.34	714	1.11
Female	1069	511	1.58	558	1.30
Age					
50 – 54 years	638	304	0.83	334	0.69
55 – 59 years	605	246	2.78	359	2.14
60 – 64 years	471	224	0.57	247	0.47
65 – 69 years	235	118	1.29	117	1.06
70 – 74 years	181	90	0.82	91	0.68
75 – 79 years	110	47	0.15	63	0.12
80 – 84 years	56	11	8.08	45	6.66
85 – 89 years	19	8	0.04	11	0.03
90 – 94 years	7	2	0.45	5	0.38
Residential status					
Central setting	1159	557	0.65	602	0.56
Community-based	867	432	2.13	435	1.85
Independent living with ambulatory support	192	43	23.93	149	20.76

Table 3 Representativeness of the study population (continued)

	Total population	Participants		Non-participants	
	N	N	$(X_o\text{-}X_e)^2/X_e$	N	$(X_o\text{-}X_e)^2/X_e$
With relatives	19	7	0.37	12	0.32
Unknown	85	11		74	
Level of care (ZZP-codes)					
Only day-care indication	21	6	1.54	15	1.37
Only indication ambulant care	125	37	8.26	88	7.41
1 VG	23	12	0.11	11	0.10
2 VG	95	39	0.78	56	0.69
3 VG	308	138	0.41	170	0.37
4 VG	366	207	6.64	159	5.86
5 VG	690	325	0.01	365	0.01
6 VG	202	93	0.07	109	0.06
7 VG	278	142	0.84	136	0.75
MHC ZZP scores	8	2	0.85	6	0.77
Unknown	206	49		157	

expected numbers are bold to show which categories cause the significant differences between both groups. Overall chi-square statistics are presented in Table 4.

Table 4 Chi-square statistics

Characteristic	Chi-square (df)	p
Gender	5.3 (1)	0.028
Age	27.41 (8)	0.001
Type of living facility	50.55 (3)	<0.001
Level of care	41.06(9)	<0.001

CONCLUSION AND DISCUSSION

This paper describes how to successfully include a large sample of older adults with ID and to measure their health. A selection of instruments suitable for large-scale health assessment in this group is presented. Involvement of top and middle management in the entire process and a thorough communication plan (with a focus on key groups such as professional caregivers) proved of paramount importance to effectively organize this kind of large-scale research projects.

Not documented in this study, but an important factor in recruitment and measurements, was the actual involvement and cooperation of professional caregivers. Feedback from management of all levels in the care organizations, combined with our personal

experiences in this process, suggest that the professional caregivers reacted positively to the personal communication and cooperativeness of the researcher to follow their preferences in the organization of measurements, leading to widespread cooperation during the consent procedure as well as the measurements themselves.

The actual percentage of clients with informed consent was 49.7%. This percentage seems low, but considering the extensive health screening, which could be seen as a burden for the participant, it might be relatively good. In a multi-centre study with only an assessment of visual and hearing function, the consent percentage was 61%.[19]

The absence of exclusion criteria (except for age) led to a very heterogeneous population. The study population showed significant differences in all categories between participants and non-participants, so it is not a completely representative sample for the total Dutch client population. The significant difference for the category 'gender' was caused by a small overrepresentation of women. For age, the significant difference was caused by an underrepresentation of 80-84 year-olds. This could be explained by the small numbers in the higher age groups, with large consequences for representativeness by small deviations in absolute numbers. Older adults with supported living and often with an indication of ambulant care only, proved hard to reach or to motivate to participate in this study, resulting in an underrepresentation of this group in both the categories 'residential status' and 'ZZP-scores'. One possible explanation might be that they do not recognise themselves as clients of services for people with ID or do not want to be labelled as 'intellectually disabled'. On the other hand, clients with an indication of residence with support and intensive care are overrepresented. Weighting will have to be applied for the results to be generalised to the complete older adult client population with ID in the Netherlands.

Researchers of earlier large-scale studies in populations with ID have reported a number of obstacles, which were avoided in this study by the carefully prepared communication routes and set-up of assessments.[25] Already in 2004, Evenhuis et al. concluded that local coordination, sufficiently supported by the management, was the key factor in a successful organization of an epidemiological study in ID services.[19] Meuwese et al. (2005) concluded that it is not possible to organize a large-scale intervention study without the active cooperation of the management to provide sufficient resources and support.[17] Sjoukes et al. (2006) studied concept-mapping as a method to effectively introduce complex interventions, but concluded this method alone was not sufficient. This method resulted in actions which were primarily operational and ad hoc, instead of changing strategic policies of the care organizations. This resulted in a lack of motivation of the professional caregivers and the middle management.[18] In our study, involvement of top and middle management was secured in the research infrastructure. Next to management involvement in decision-making and policy strategies, they provided necessary conditions and solutions for problems in the execution of this study.

Next to the involvement of top and middle management, this paper provides a few other take home messages for the infrastructure of a large-scale multi-center study for adults with ID. First of all, good preparation of the organization of measurements is as important as designing the research protocol, and requires just as much effort and time. This preparation consists mainly of writing and executing a thorough communication plan, with specific attention for key stakeholders (i.e. professional caregivers). Involved professionals of any kind within the care organizations need to be informed and trained timely and to enhance cooperation they need to have a say in the organization and planning of the assessments. A more detailed description of the research infrastructure and management of involvement and cooperation will be published elsewhere.

Table 5 Measurements with active involvement of the participant

Type	Outcome	Details
Physical assessment	Height	Seca stadiometer, type 214 Body Mass Index calculated: weight divided by squared height
	Knee height	Formulas Chumlea et al.[28] for calculating body height
	Weight	Digital floor scale (Seca robusta type 813) Body Mass Index calculated: weight divided by squared height
	Fat percentage	Formulas Durnin and Womersly[29] for calculating fat percentage from the sum of four skinfolds: triceps, biceps, subscapular and suprailiacal Thickness of skinfolds measured with skinfold caliper (Harpenden).
	Body circumferences	Flexible tape for hip, waist, calf and upper arm circumference Waist-to-hip ratio calculated: waist circumferences divided by hip circumference
	Blood pressure	Omron M7
	Ankle-Arm-Index	Omron M7 (arm) Boso classico and 8-MHz Doppler probe (Huntleigh MD II) (ankle) Ankle-arm-index calculated: systolic blood pressure ankle divided by systolic blood pressure arm
	Bone Quality	Ultrasonometer (Lunar Achilles Insight) for measuring bone stiffness calcaneus
Fitness Assessment	Manual dexterity	Box and block test[30]
	Response time	Response time test
	Balance	Berg Balance Scale[31]
		5 m walking speed (comfortable and fast)
	Muscle strength	Grip strength[32] with Jamar Hand Dynamometer (#5030J1, Sammons Preston Rolyan, USA)
	Muscle endurance	30s Chair stand[33]
	Cardiorespiratory endurance	10m Incremental shuttle walking test[34] Results of this test recalculated to VO2max[35]
	Flexibility	Extended version of Modified back saver sit and reach test[21,36]
Diary	Food intake	3-day food intake diary
Two weeks at home	Rest-activity rhythm	Actiwatch AW 7 (Cambridge Neurotechnologies)
	Physical activity	Pedometer (NL-1000, New Lifestyles, Missouri USA)
Meal time observation	Swallowing problems	Dysphagia Disorders Survey[37]
Interview (if possible)	Self-report depression	Inventory of Depressive Symptomatology Self Report (IDS-SR)[38] Phrasing of the questions adapted to people with ID
	Self-report anxiety	Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID),[39] translated version of the GAS-ID into Dutch
	Self-report anxiety	Hospital Anxiety and Depression Scale (HADS)-anxiety subscale[40] Phrasing of the questions adapted to people with ID
	Social contacts	Checklist about number of contacts with family, friends and peers and visiting leisure-clubs
	Quality of life	Intellectual Disability Quality of Life (IDQOL-16)[41]

Table 5 Measurements with active involvement of the participant (continued)

Type	Outcome	Details
Interview	Diagnostic interview depression and/or anxiety	Participants with scores above the preset cut-off scores on one or more of the depression or anxiety questionnaires have been further examined by behavioural scientists trained in assessing the PAS-ADD-10 interview with participant or his/her caregiver[42]
Venipuncture	Biochemical markers	Fasting plasma levels: glucose, cholesterol, HDL-cholesterol, triglycerides, CRP, Hb and albumin.
Measurements without active involvement of the participant		
History	Medical files	Checklist for general practitioners or ID-physicians
	Psychological files	Checklist for psychologists or behavioral therapists
	Dental files	Checklist for dentists
Questionnaires professional caregiver	Malnutrition	Mini Nutritional Assessment (MNA)[43]
	Eating disorders	Screening Tool of fEeding Problems (STEP)[44] Translated version in Dutch
	Gastro-oesophageal reflux disease (GORD).	GORD Questionnaire: a newly developed questionnaire consisting of 50 items involving risk factors and symptoms of gastro-oesophageal reflux disease
	Informant-report depression and anxiety	Anxiety, Depression, And Mood Scale (ADAMS)[45] Translated version of the ADAMS into Dutch
	Somatic complaints	Somatic complaints subscale of the Symptom Checklist-90 (SCL-90)[46]
	Life-events	Checklist Life Events. Newly developed checklist based on other checklists, earlier life event-studies and experience from professionals working with people with ID
	Social outcome	Checklist about number of contacts with family, friends and peers and visiting leisure-clubs
	Cognitive functioning	Dementia questionnaire for people with intellectual disabilities (DMR) [47]
	Activities of daily life and mobility	Barthel Index[48]
	Instrumental activities of daily Life	Questionnaire based on the Instrumental Activities of Daily Living of Lawton and Brody[49] and the Groningen Activities Restriction Scale[50,51]
	Mobility	Questionnaire based on the Hauser Ambulation Index[52] and the characteristics of the Gross Motor Function Classification Scale.[53]
	Physical activity	Questionnaire about the participants' habitual physical activity
Interview	Diagnostic interview depression and anxiety	Participants with scores above the preset cut-off scores on one or more of the depression or anxiety questionnaires have been further examined by behavioural scientists trained in assessing the PAS-ADD-10 interview with the caregiver[42]

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Summary

SUMMARY

The lifespan of people with intellectual disabilities (ID) is increasing, which results in a growing group of older people with age-related co-morbidities. To explore the health problems of this ageing population, the 'Healthy Ageing and Intellectual Disability' (HA-ID) study has been performed in which 1050 people with ID, aged 50 years and over have participated. The aims of the study were to evaluate diagnostic tools and to quantify health problems and risks in older people with ID. The study focuses on three sub themes: physical activity and fitness, nutrition and nutritional state, and depression and anxiety. Depression and anxiety have been chosen because of the high prevalence in the general older population and clinical experience of professionals in ID care. This thesis gives an overview of diagnostics, prevalence rates and factors associated with depression and anxiety in older people with ID (Chapter 1).

Part I (Chapter 2 – 6) presents the diagnostic methodology of this study, gives an overview of available instruments for depression and anxiety which have been studied for their psychometric properties in adults with ID, and presents the psychometric properties as investigated by us, of two instruments in particular.

In the HA-ID study, depression and anxiety have been diagnosed using a two-step procedure. Firstly, all participants have been screened with self-report and informant-report questionnaires. Secondly, a selection of participants was further examined with a psychiatric diagnostic interview (the PAS-ADD interview), based on their screening outcome. To select the most suitable screening instruments for depression and anxiety, an extensive selection procedure has been followed. First, an overview of nationally and internationally available instruments for depression and anxiety was made. Then, a first selection was made based on their reliability or validity. A second selection was made based on the the content of the questionnaire. A final selection was made based on applicability of the instruments, as judged by experts from clinical practice and an expert in epidemiologic research. The outcomes were: one self-report questionnaire for depression that has been developed for the general adult population (the Inventory of Depressive Symptomatology Self Report), two self-report questionnaires for anxiety of which one has been developed for adults with ID (the Glasgow Anxiety Scale for people with an Intellectual Disability) and one has been developed for the general adult population (the anxiety subscale of the Hospital Anxiety and Depression Scale), one informant-report questionnaire for depression which has been developed for adults with ID (the Signalizing Depression List for people with Intellectual Disabilities) and one informant-report questionnaire screening for both anxiety and depression which has also been developed for adults with ID (the Anxiety, Depression, And Mood Scale).

Chapter 3 and 4 are based on systematic reviews of the literature and give an overview of internationally available instruments for depression and anxiety, which have been

studied for their psychometric properties in adults with ID. For depression, we identified 24 studies of which three were of good quality, fourteen of moderate and seven studies of low quality according to our quality criteria. These studies covered 15 instruments of which four instruments appeared most promising: for self-report, the Glasgow Depression scale for people with a Learning Disability, and for informant-report, the Assessment of Dual Diagnosis, the Reiss Screen for Maladaptive Behaviour, and the Children's Depression Inventory.

For anxiety, we identified 17 different studies of which six were of good quality, seven of sufficient and four of insufficient quality (Chapter 4). These studies covered 14 different instruments of which two appeared most promising: for self-report, the Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID) and for informant-report, the general anxiety subscale of the Anxiety, Depression, And Mood Scale (ADAMS). However, none of these instruments for depression and anxiety had been studied satisfactorily in adults with ID, yet.

In the Netherlands, valid screening instruments for anxiety were lacking. Therefore, we have translated the two most promising instruments for anxiety into Dutch and evaluated their psychometric properties. In chapter 5, the psychometric properties of the Dutch translation of the self-report GAS-ID have been described. Its reliability and validity have been studied in adults with borderline, mild or moderate ID. Internal consistency (n=195) and test-retest reliability (n=66) were good. Convergent validity against the anxiety subscale of the Hospital, Anxiety and Depression Scale (n=96) was moderate and criterion validity against psychiatric diagnosis (n=195) was satisfying.

In chapter 6, the psychometric properties of the Dutch translation of the informant-report ADAMS has been described. Its reliability and validity have been studied in older adults with ID. The internal consistency (n=127) of all subscales (general anxiety, depressed mood, manic/hyperactive behaviour, social avoidance and obsessive/compulsive behaviour) was good. The test-retest reliability (n=93) was excellent and interrater reliability (n=83) good, except for the social avoidance subscale of which interrater reliability was fair. The general anxiety and depressed mood subscales were further studied for their convergent and criterion validity (sensitivity and specificity). Criterion validity has been studied by estimating sensitivity and specificity rates against psychiatric diagnoses of major depression and anxiety disorders made with the PAS-ADD interview. The convergent validity of the depressed mood and general anxiety subscale against self-report instruments (n=202) was low, but the correlation of the depressed mood subscale with another informant-report instrument for depression (n=787) was high. The sensitivity and specificity rates were satisfying. In conclusion, the Dutch translations of the GAS-ID and ADAMS are reliable and their validity is satisfying.

Part II (Chapter 7 – 10) describes the prevalence rates of depression and anxiety and which factors are associated.

In chapter 7, the prevalence rates of increased depressive and anxiety symptoms and disorders are presented. Depression and anxiety were studied in 990 participants with borderline to profound ID using the five selected self-report and informant-report instruments. The prevalence of full blown anxiety and depressive disorders was estimated using a two-stage screening design. It appeared that increased depressive symptoms (a screening-score above cut-off score) were prevalent in 17% while increased anxiety symptoms were prevalent in 16%. The prevalence of major depressive disorder was 8% and of anxiety disorders 4%. The prevalence of major depression was much higher than in the Dutch general older population while the prevalence of anxiety disorders was lower.

In chapter 8, the anxiety symptoms reported by 172 people aged 55-85 years with borderline to moderate ID were compared to those reported by 2917 participants with normal intelligence of the Longitudinal Aging Study Amsterdam. Anxiety symptoms have been studied by comparing their outcomes on the general anxiety subscale of the Hospital Anxiety and Depression Scale, using age-adjusted ratios. It appeared that the prevalence of clinically relevant anxiety is similar in both populations, but the level of sub-clinical anxiety reported by older people with ID is higher than that reported by older people with normal intelligence. In addition, four out of seven items were more often reported as present by people with ID: 'tense or wound up feelings', 'frightened feelings', 'worrying thoughts', and 'sudden feelings of panic'.

In chapter 9, factors associated with depression and anxiety, determined using multiple logistic regression analysis, are described. It appeared that older adults with increased depressive symptoms are exposed to more life events, have more often increased anxiety symptoms, suffer more often from chronic diseases (heart failure, cerebrovascular accident, chronic obstructive pulmonary disease, coronary artery disease, diabetes mellitus and malignity in the previous five years), and perform worse on instrumental activities of daily living (IADL)-abilities. Major depression is associated with chronic diseases and worse IADL-abilities. Older adults with increased anxiety symptoms have more often borderline or mild ID, increased depressive symptoms and few social contacts, whereas those with Down syndrome or epilepsy have less often increased anxiety symptoms. Anxiety disorders showed no significant associations.

The occurrence of life events and association with depression and anxiety is further explored in chapter 10. Occurrence and burden of life events were assessed with a checklist of 28 items, completed by professional caregivers. It appeared that 97% of the participants had been exposed to two or more life events during the preceding year and 72% had been exposed to one or more negative life events. Participants aged 65 years or over, participants with mild or moderate ID and participants with increased depressive

or anxiety symptoms had been exposed to significantly more life events. Minor physical illness and problems with a fellow resident were significantly associated with depression and anxiety, decline or loss of mobility and loss of leisure-time activities with depression and change at work or from work with anxiety.

In the final chapter (Chapter 11), the implications of these results for clinical practice and research are discussed. It is stressed that selective screening of 'at risk' groups and increasing staff's knowledge about depressive and anxiety symptoms is necessary to improve detection. Furthermore, multidisciplinary assessment and treatment should be performed. Specialized out-patient ID clinics can provide this multidisciplinary care, especially for general practitioners' patients with ID. Future longitudinal research should address the causal relationship between personal, physical and psychosocial factors and depression and anxiety. In addition, the effectiveness of different kinds of treat

Samenvatting

SAMENVATTING

Mensen met een verstandelijke beperking worden steeds ouder, waardoor de groep ouderen met een verstandelijke beperking, en daarbij komende leeftijdsgerelateerde gezondheidsproblemen, groeit. Om deze gezondheidsproblemen in kaart te brengen, is het 'Gezond Ouder met een Verstandelijk Beperking' (GOUD) onderzoek gestart. Aan dit onderzoek hebben 1050 mensen met een verstandelijke beperking van 50 jaar en ouder deelgenomen. Het doel van het GOUD onderzoek was om diagnostische instrumenten te beoordelen en gezondheidsproblemen en -risico's te kwantificeren. Het onderzoek bestaat uit drie subthema's: lichamelijke activiteit en fitheid, voeding en voedingstoestand, en depressie en angst. Depressie en angst zijn onderzocht, omdat beide veelvuldig voorkomen in de algemene oudere populatie. Daarnaast vermoedden professionals uit de verstandelijk gehandicapten zorg dat depressie en angst ook bij ouderen met een verstandelijke beperking regelmatig voorkomen. Deze thesis geeft een overzicht van de diagnostische instrumenten, prevalenties en samenhangende factoren van depressie en angst in ouderen met een verstandelijke beperking (Hoofdstuk 1).

In deel 1 van deze thesis (Hoofdstuk 2 – 6) wordt de diagnostische methode van dit onderzoek omschreven en een overzicht gegeven van de beschikbare meetinstrumenten voor depressie en angst waarvan de psychometrische eigenschappen zijn onderzocht bij mensen met een verstandelijke beperking. Daarnaast worden in dit deel the psychometrische eigenschappen van twee door ons vertaalde instrumenten besproken.

In het GOUD onderzoek zijn depressie en angst gediagnosticeerd door middel van een twee-staps procedure. Eerst zijn alle deelnemers gescreend met zelfrapportage en informantenrapportage vragenlijsten. Vervolgens is een selectie van de deelnemers, gebaseerd op hun screeningsuitkomsten, verder onderzocht met een psychiatrisch diagnostisch interview (het PAS-ADD interview). Om de meest geschikte screeningsinstrumenten voor depressie en angst te kiezen, is vooraf een uitvoerige selectieprocedure doorlopen. Eerst is een overzicht gemaakt van alle nationaal en internationaal beschikbare instrumenten voor depressie en angst. Vervolgens is een eerste selectie gemaakt op basis van hun betrouwbaarheid en validiteit. Een tweede selectie is gemaakt op basis van de inhoud van de instrumenten. Een laatste selectie is gemaakt op basis van de praktische toepasbaarheid van de instrumenten welke is beoordeeld door experts uit de praktijk en een expert in epidemiologisch onderzoek. De uitkomst van deze selectieprocedure was: één zelfrapportage vragenlijst voor depressie welke is ontwikkeld voor de algemene populatie (de Zelfinvullijst Depressie), twee zelfrapportage vragenlijsten voor angst waarvan één is ontwikkeld voor volwassenen met een verstandelijke beperking (de Glasgow Angst Schaal voor mensen met een verstandelijke beperking) en de andere is ontwikkeld voor de algemene populatie (de angstschaal van de Hospital Angst en Depressie Schaal), één informantenrapportage vragenlijst voor depressie welke is ont-

wikkeld voor volwassenen met een verstandelijke beperking (de Signaallijst Depressie voor verstandelijk beperkte mensen) en één informantenrapportage vragenlijsten voor zowel angst als depressie die ook is ontwikkeld voor volwassenen met een verstandelijke beperking (de Angst, Depressie En Stemming Schaal).

Hoofdstuk 3 en 4 zijn gebaseerd op twee systematische literatuurstudies en geven een overzicht van de internationaal beschikbare instrumenten voor depressie en angst waarvan de psychometrische eigenschappen zijn onderzocht bij volwassenen met een verstandelijke beperking. Voor depressie hebben we 24 onderzoeken gevonden, waarvan drie van goede kwaliteit waren, veertien van matige kwaliteit en zeven onderzoeken waren van lage kwaliteit beoordeeld volgens onze kwaliteitscriteria (Hoofdstuk 3). Deze onderzoeken bespraken 15 verschillende instrumenten waarvan vier instrumenten het meest veelbelovend leken: voor zelfrapportage was dat de Glasgow Depressie Schaal voor mensen met een verstandelijke beperking en voor informantenrapportage waren dat de Assessment for Dual Diagnosis, de Reiss Screen en de Children's Depression Inventory.

Voor angst hebben we 17 onderzoeken gevonden waarvan zes van goede kwaliteit waren, zeven van voldoende kwaliteit en vier van onvoldoende kwaliteit (Hoofdstuk 4). Deze onderzoeken behandelden 14 verschillende instrumenten waarvan twee het meest veelbelovend leken: voor zelfrapportage was dit de Glasgow Angst Schaal voor mensen met een verstandelijke beperking (GAS-VB) en voor informantenrapportage was dit de Angst, Depressie En Stemming Schaal (ADESS). Echter, geen van deze depressie- en angstinstrumenten zijn al voldoende onderzocht bij volwassenen met een verstandelijke beperking.

In Nederland waren geen valide instrumenten voor angst beschikbaar. Daarom hebben we de twee meest veelbelovende instrumenten voor angst vertaald en hun psychometrische eigenschappen onderzocht. De psychometrische eigenschappen van de Nederlandse vertaling van de zelfrapportage vragenlijst voor angst (de GAS-VB) worden beschreven in Hoofdstuk 5. De betrouwbaarheid en validiteit zijn onderzocht bij volwassenen met een lichte of matige verstandelijke beperking. De interne consistentie (n= 195) en test-hertestbetrouwbaarheid (n= 66) waren goed. De convergente validiteit, uitkomst van de GAS-VB vergeleken met de angstsubschaal van de ADESS (n=96), was matig en de criterium validiteit (sensitiviteit en specificiteit), uitkomst van de GAS-VB vergeleken met de psychiatrische diagnose (n= 195), was voldoende.

In Hoofdstuk 7 worden de psychometrische eigenschappen van de Nederlandse vertaling van de informantenrapportage vragenlijst voor angst (de ADESS) besproken. De betrouwbaarheid en validiteit zijn onderzocht bij ouderen met een verstandelijke beperking. De interne consistentie (n=127) van alle subschalen (algemene angst, depressieve stemming, manisch/hyperactief gedrag, sociale vermijding en obsessief/compulsief gedrag) was goed. De test-hertestbetrouwbaarheid (n=93) was uitstekend

en de interbeoordelaarsbetrouwbaarheid (n=83) was goed, behalve voor de sociale vermijding subschaal waarvan de betrouwbaarheid slechts matig was. De convergente en criterium validiteit van de algemene angstschaal en de depressieve stemmingschaal zijn onderzocht. Criterium validiteit werd geschat op basis van de overeenkomst met de psychiatrische diagnoses depressieve stoornis en angststoornis, gesteld met het PAS-ADD interview. The convergente validiteit van deze beide subschalen, uitkomsten van deze subschalen vergeleken met uitkomsten op zelfrapportage instrumenten (n= 202), was laag, maar de correlatie met een ander informantenrapportage instrument voor depressie (n= 787) was hoog. De sensitiviteit en specificiteit waren voldoende. Concluderend kan gesteld worden dat de Nederlandse vertalingen van de GAS-VB en ADESS betrouwbaar en voldoende valide zijn.

In deel II (Hoofdstuk 7 – 10) wordt de prevalentie van depressie en angst en factoren die daarmee samenhangen beschreven.

In Hoofdstuk 7 worden de prevalenties van verhoogde depressieve en angstige symptomen en van depressieve en angststoornissen beschreven. Depressie en angst zijn bij 990 deelnemers met een lichte tot zeer ernstige verstandelijke beperking onderzocht met de geselecteerde zelfrapportage en informantenrapportage screeningsvragenlijsten. De prevalentie van depressieve en angststoornissen werd geschat met een tweestaps procedure. Verhoogde depressieve symptomen (een screeningsscore boven het afkappunt van één van de depressievragenlijsten) kwamen bij 17% van de deelnemers voor, terwijl verhoogde angstsymptomen bij 16% voorkwamen. De prevalentie van depressieve stoornissen was 8% en van angststoornissen 4%. De prevalentie van depressieve stoornissen was veel hoger dan in de algemene oudere populatie, terwijl de prevalentie van angststoornissen veel lager was.

In Hoofdstuk 8 worden de gerapporteerde angstsymptomen van 172 deelnemers van het GOUD onderzoek met een leeftijd tussen de 55 en 85 jaar die een lichte of matige verstandelijke beperking hebben vergeleken met de angstsymptomen van 2917 deelnemers van de 'Longitudinal Aging Study Amsterdam' zonder verstandelijke beperking. Angstsymptomen zijn vergeleken door de scores op de angstschaal van de Hospital Angst en Depressie Schaal van beide groepen met elkaar te vergelijken door ratio's te berekenen voor verschillende leeftijdsgroepen. Hieruit bleek dat klinisch relevante angstsymptomen even vaak voorkomen in beide groepen, maar subklinische angst wordt vaker gerapporteerd door ouderen met een verstandelijke beperking dan door ouderen zonder een verstandelijke beperking. Daarnaast werden vier van de zeven items ('gespannen gevoelens', 'angstige gevoelens', 'zorgen maken', 'plotselinge gevoelens van paniek') vaker gerapporteerd door ouderen met een verstandelijke beperking.

In Hoofdstuk 9 worden factoren die mogelijk samenhangen met depressie en angst onderzocht met meervoudige logistische regressie-analyse. Hieruit bleek dat ouderen

met een verhoogd aantal depressieve symptomen meer life events hebben meegemaakt, vaker een verhoogd aantal angstige symptomen hebben, vaker chronische ziekten hebben (hartfalen, cerebrovasculaire aandoeningen, chronische obstructieve longaandoeningen, coronair vaatlijden, diabetes mellitus en maligniteiten in de afgelopen 5 jaar) en beperkte instrumentele activiteiten van het dagelijks leven (IADL)-vaardigheden hebben. Ook depressieve stoornissen hangen samen met chronische ziekten en beperkte IADL-vaardigheden. Ouderen met een verhoogd aantal angstsymptomen hebben vaker een lichte verstandelijke beperking, een verhoogd aantal depressieve symptomen en weinig sociale contacten, terwijl mensen met epilepsie of het Down syndroom juist minder vaak een verhoogd aantal angstsymptomen hebben. Er waren geen factoren die significant samenhingen met angststoornissen.

In Hoofdstuk 10 is het voorkomen van life events en hun associatie met depressie en angst verder onderzocht. Voorkomen en belasting van life events is in kaart gebracht met een checklist van 28 life events welke is ingevuld door begeleiders. Hieruit bleek dat 97% van de deelnemers twee of meer life events had meegemaakt in het voorafgaande jaar en 72% was blootgesteld aan één of meer negatieve life events. Deelnemers van 65 jaar of ouder, deelnemers met een lichte of matige verstandelijke beperking en deelnemers met een verhoogd aantal depressie- of angstsymptomen hadden significant meer life events meegemaakt. Lichte lichamelijke ziekte en problemen met een medebewoner hingen significant samen met depressie en angst, vermindering of verlies van mobiliteit en verlies van vrijetijdsbesteding met depressie en verandering op of van werk met angst.

In het laatste hoofdstuk (Hoofdstuk 11) worden de implicaties van deze resultaten voor de dagelijkse praktijk en voor onderzoek besproken. Er wordt benadrukt dat selectieve screening van risicogroepen en verbetering van de kennis van medewerkers over depressieve- en angstsymptomen noodzakelijk is om de herkenning te verbeteren. Verder is multidisciplinaire diagnostiek en behandeling noodzakelijk. Gespecialiseerde poliklinieken voor mensen met een verstandelijke beperking (AVG-poli's) leveren deze multidisciplinaire zorg, wat vooral voor huisartspatiënten met een verstandelijke beperking een uitkomst is. Toekomstig longitudinaal onderzoek moet zicht richten op de causaliteit van het verband tussen persoonlijke, lichamelijke en psychosociale factoren enerzijds en depressie en angst anderzijds. Daarnaast moet de effectiviteit van verschillende soorten behandelingen worden onderzocht.

Dankwoord

DANKWOORD

Aan dit proefschrift zijn vier intensieve jaren van onderzoek (en alles wat daarbij hoort) vooraf gegaan. Dankzij allerlei mensen zijn dit leuke, uitdagende, gezellige en leerzame jaren geweest. Op deze plaats wil ik alle mensen die aan dit onderzoek hebben bijgedragen op wat voor manier dan ook (dus van deelnemer tot morele steunverlener) bedanken.

In de eerste plaats wil ik alle cliënten die hebben deelgenomen aan het GOUD onderzoek bedanken: zonder jullie was dit hele onderzoek er niet geweest! Ik wil jullie bedanken voor jullie enthousiasme en inzet tijdens de testdagen en jullie openhartigheid tijdens de persoonlijke gesprekken over depressie en angst. Ook dank aan de wettelijk vertegenwoordigers voor het verlenen van toestemming tot deelname. Uiteraard wil ik ook de vele begeleiders die de cliënten hebben begeleid tijdens de testdagen, talloze vragenlijsten hebben ingevuld en aanvullende vragen hebben beantwoord, bedanken voor hun inzet en flexibiliteit. Jullie zijn niet alleen voor de zorg, maar ook voor onderzoek onmisbaar!

Ook onmisbaar bij de vorming van dit proefschrift was mijn promotor Prof. Dr. Heleen Evenhuis. Heleen, bedankt voor alle dingen die ik in de afgelopen jaren van je heb mogen leren, voor het zorgvuldig bekijken van alle artikelen en presentaties, voor het 'er boven hangen' als ik er nog middenin zat en voor je aanstekelijke enthousiasme voor praktijkgericht onderzoek.

Een onderzoek met deze omvang was nieuw voor de drie betrokken zorgorganisaties (Amarant, Abrona en Ipse de Bruggen), maar heeft desondanks op veel interesse, betrokkenheid en inzet van allerlei medewerkers kunnen rekenen. Hartelijk dank aan Anneke, Jos, Lyanne, Tineke, Ilse, Annelies, Ireen, Matty, Inge M., Loes, Tessa, Marieke, Janneke, Merle, Angela, Astrid, Mariëlle, Marian, Kim, Annemarieke, Lilian, Nelleke, Esther, Simone en Inge N., voor het meedenken over de instrumentenkeuze, afnemen van de vragenlijsten over depressie en angst en/of afnemen van de diagnostische psychiatrische interviews. Ook grote dank aan alle gedragsdeskundigen voor het opzoeken en verstrekken van dossiergegevens. Voor de organisatie en uitvoering van de metingen bij Amarant wil ik alle testafnemers (de fysiotherapeuten, bewegingsagogen, doktersassistente, logopedisten, ergotherapeut, diëtiste) hartelijk danken voor hun inzet, creativiteit en flexibiliteit. Daarnaast wil ik Rian, Bianca, Lenneke, Elly, Anita, Jan, Natascha, Hedy, Els en Sandra bedanken voor de ondersteuning bij de organisatie van de metingen binnen de drie organisaties, ik wil Inge, Marion, Sunny, Raissa, Ineke, Yvette en Marian bedanken voor hun hulp bij het invoeren van de grote hoeveelheid data en ik wil Ilse, Augusta en

Bianca bedanken voor het schrijven van de leuke artikelen over het onderzoek en het meedenken rondom de communicatiemogelijkheden en –valkuilen. Ook dank aan de leden van de begeleidingscommissie van het consortium en de beleidscommissie ouderen voor het voorzien van probleempunten, hun aanhoudende interesse in het verloop van het onderzoek en hun enthousiasme om de resultaten te implementeren. Ook wil ik de ethische commissies en cliëntenraden van de betrokken organisaties bedanken voor het beoordelen van dit onderzoek op het praktische nut voor de zorg en de baten voor de cliënt.

Natuurlijk ook dank aan de bestuurders (Ronald Helder van Amarant, Nico Peelen en later Jan Duenk van Abrona en Jan Fidder van Ipse de Bruggen) dat zij kozen om bij te dragen aan het vergroten van de kennis over de groeiende groep ouderen en hun organisaties hebben verbonden aan dit onderzoek. Ook grote dank aan de directeuren zorg (Frank Brouwers, Margriet Euverman, Ditte van Vliet, Marcel Schellart en Ankie Lubbers) voor hun daadkracht in het nemen van beslissingen zonder daarbij de voorwaarden voor goede zorg én goed onderzoek uit het oog te verliezen. En tot slot ook veel dank aan de interne coördinatoren (Erwin van den Hout, Ineke Bootsman, Anemone Linthorst en haar voorgangers Arjen Louisse en Stephan Cramer) voor jullie adviezen en ondersteuning bij het regelen van praktische zaken rondom het onderzoek. Dankzij jullie is het een praktisch uitvoerbaar onderzoek geworden.

Een aantal collega's van Amarant verdienen wat extra aandacht in dit dankwoord. Frank, bedankt voor je rust, nuchterheid en vertrouwen. Mede dankzij jou is in de afgelopen jaren de aandacht voor onderzoek binnen Amarant enorm gegroeid. Erwin, bedankt voor je positieve doch realistische houding, het delen van kennis over processen in de zorg en je zorgzaamheid. Rian, ik wil je bedanken voor je tomeloze inzet, het oplossen van locatie- en planningsproblemen en vooral je gezelligheid, humor en betrokkenheid (bij werk en privé). Ook wil ik de lunchgroep (Jolanda, Annelies, Marlies, Aartje, Nicol, Ina, Ylse, Susanne en iedereen die tijdelijk is aangeschoven) bedanken voor de leuke gesprekken, het lijntje met de praktische zorg en het aanhoren van mijn gemopper en enthousiaste verhalen over het onderzoek.

Ook bij het Erasmus MC zijn er collega's die ik in het bijzonder wil bedanken. Allereerst de 'startgroep' van het GOUD onderzoek: Thessa, Luc en Marieke, jullie zijn ontzettend fijne collega's. Ik vond het heerlijk dat ik alle onderzoeksbeslommeringen met jullie kon bespreken, altijd terecht kon met vragen en ik ook over alle andere, niet onderzoeksgerelateerde zaken tegen jullie aan kon kletsen. Thessa (en ook Radzies) bedankt dat ik regelmatig mocht blijven slapen als Tilburg wat te ver was, ik vind het altijd heel gezellig en hoop dat ik in de toekomst nog regelmatig redenen krijg om bij jullie in Den Haag te

vertoeven. Ook de andere collega's van GVG (Sandra, Sonja, Ellen, Josje, Michael, Fleur, Ymie, Rob), van de Westzeedijk en van 'de overkant' wil ik bedanken voor het meedenken, kritisch kijken en delen van jullie kennis en ervaringen, maar ook zeker voor alle gezelligheid. Ik wil daarnaast de studenten die ik heb mogen begeleiden (Naftha, Femke, Niels, Hanneke, Marieke en Jeanne) bedanken voor hun frisse blik en bijdrage aan dit onderzoek. Femke en Naftha ook bedankt voor jullie bijdrage aan enkele artikelen. Ook wil ik Jannelien Wieland bedanken voor de leuke samenwerking. Ik ben blij dat ik door jou Kristal heb leren kennen en dat we een mooie start hebben kunnen maken met de validering van de GAS-VB. Tot slot wil ik Aartjan Beekman bedanken voor het meedenken over de instrumentenkeuze, inschatten van de mogelijkheden van onze data en zijn bijdrage aan enkele artikelen.

Sabine wil ik bedanken voor het ontwerpen van de omslag en Fien wil ik bedanken voor het poseren.

Uiteraard wil ik ook mijn ouders bedanken, gewoon omdat het fijn is om lieve ouders te hebben, maar ook omdat ze mijn nieuwsgierigheid nooit hebben afgeremd (waardoor ik nu van alles wil onderzoeken). Ook al is het vaak onduidelijk wat voor werk ik doe, toch zijn jullie altijd betrokken en geïnteresseerd. Ook wil ik Jac en Stance bedanken voor hun onverminderde interesse in m'n onderzoek. Regelmatig nam het onderzoek veel tijd en ruimte in beslag, maar Esther, Irene, Sabine, Jannie, Gwendolyn, Angelina, Linda, Floortje, Rob en de psychologiemannen laten me altijd weer inzien dat werk leuk en belangrijk is, maar dat er nog veel meer is in het leven (feestjes, festivals, concerten, wandelen, weekendjes weg, carnaval, films kijken, etc.). Tot slot wil ik mijn eigen 'psychologieman' bedanken. Lieve Roel, dankjewel voor je onvoorwaardelijke steun in de afgelopen jaren. Je maakt me aan het lachen als ik er even klaar mee ben en brengt rust (of is het traagheid) als ik maar doorwervel. Het leven met jou is heerlijk!

Publications

PUBLICATIONS

Evenhuis HM, Hermans H, Hilgenkamp TIM, Bastiaanse LP, Echteld MA. (in press). Frailty and disability in the older population with intellectual disabilities: Results from the Healthy Ageing and Intellectual Disability Study (HA-ID). Journal of the American Geriatric Society.

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Curriculum Vitae

CURRICULUM VITAE

Heidi Hermans werd geboren op 10 juli 1983 in Breda. In 2001 behaalde zij haar VWO diploma aan het Markland college te Oudenbosch. Aansluitend begon zij aan de studie psychologie aan de Universiteit van Tilburg. Naast haar studie bekleedde zij in 2004-2005 een bestuursfunctie binnen de studievereniging voor psychologie. Na een stage in het Catharina ziekenhuis te Eindhoven en een scriptie over de psychosociale gevolgen van bariatrische chirurgie is zij in 2006 afgestudeerd in de richting Klinische gezondheidspsychologie. Vervolgens was zij werkzaam als begeleider op een woongroep bij Amarant. In 2008 is zij bij Amarant (in samenwerking met het Erasmus MC, leerstoel voor verstandelijk gehandicapten) gestart met haar promotieonderzoek. Sinds 1 januari 2012 is zij werkzaam als psycholoog en onderzoeker/beleidsmedewerker bij Amarant.

PhD Portfolio

PhD PORTFOLIO

Summary of PhD training and teaching

Name PhD student:	Heidi Hermans
Erasmus MC Department:	Intellectual Disability Medicine, Department of General Practice
PhD period:	01/01/2008 - 31/12/2011
Promotor(s):	Prof. dr. H.M. Evenhuis
Supervisor:	Prof. dr. H.M. Evenhuis

1. PhD training

	Year	Workload (ECTS)
General courses		
- Didactic Skills	2011	0.7
- BROK ('Basiscursus Regelgeving Klinisch Onderzoek')	2011	1.0
- Biomedical English Writing and Communication	2009	4.0
Specific courses (NIHES Research School)		
- Diagnostic research	2011	0.9
- Regression Analysis	2010	1.9
- Basic principles of Epidemiology	2009	0.7
- Introduction to Data-analysis	2009	1.0
Presentations (national)		
- Congress 'Focus on Research' (oral presentation)	2011	0.6
- Congress NVAVG (oral presentation)	2011	0.6
- VGN Kennismarkt (poster presentation)	2010	0.4
- Symposium NGO (oral presentation)	2009	0.6
International conferences		
- MHID Congress, Manchester (oral presentation)	2011	2.0
- 3rd European congress IASSID, Rome (2 oral presentation)	2010	1.0
- Roundtable SIRGAID IASSID, Prato (oral presentation)	2010	3.0
- Roundtable SIRGAID IASSID, Edinburgh (poster presentation)	2009	2.0
- MHID Congress, Amsterdam (oral presentation)	2009	1.0

2. Teaching

Lecturing

-	Health-care for older people with ID, Amarant (1 lecture)	2011	1.0
-	Intellectual Disability Medicine, Erasmus MC (2 lectures)	2009 - 2011	1.2

Supervising Master's theses

-	2 Master Medical Science student research projects	2008 - 2009	2.9
-	4 Master behavioural therapist student research projects	2009 - 2011	5.8