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# **PROJECT FINAL REPORT**

**Grant Agreement number:** 223105

**Project acronym:** MentDis\_ICF65+

**Project title:** Prevalence, 1-year incidence and symptom severity of mental disorders in the elderly: Relationship to impairment, functioning (ICF) and service utilisation

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#### **4.1.1 Executive summary of the MentDis\_ICF65+ project**

The 1<sup>st</sup> work stage of our project was the identification, adaptation and translation of instruments. A literature search was conducted, and diagnostic self- and clinician-rated instruments were matched with the ICF dimensions and assessed according to their quality criteria. After the final selection of the MentDis\_ICF65+ assessment battery was completed, the chosen CIDI interview was adjusted within a complex, multi-level adaptation process based on knowledge derived from geronto-psychiatric expert focus groups and scientific evidence about the cognitive abilities and challenges of older people with regard to the clinical diagnostic process. The CIDI65+ was subsequently translated into the required languages: Italian, Spanish, French, Hebrew.

Following the instrument adaptation a multi-method pretesting phase was conducted to qualitatively evaluate the adapted CIDI65+. The pretesting was completed over a 10-week period, with eighteen interviews undertaken in London and Hamburg to pretest the English and German CIDI65+ versions. The sample included healthy elderly and elderly with current or lifetime mental illnesses. The results of the pretesting enabled to improve the instrument with regard to its duration, comprehensibility, acceptability and technical aspects.

The 2<sup>nd</sup> work stage- pilot study- included the psychometric assessment of the newly adapted CIDI65+ in the different language versions. The instrument was administered twice, two to 63 days apart, by two different trained clinical interviewers. Participants were 55 subjects aged 60-79 years, sampled from community and treatment facilities. The CIDI65+ found to be a reliable instrument for diagnosing somatoform, mood, anxiety and obsessive-compulsive disorders as well as for assessing distress, impairment and time-related information. The test-reliability was partly substantially higher than in the standard CIDI, which may indicate that the changes introduced for the elderly might be an effective approach.

In the 3<sup>rd</sup> work stage- cross-sectional study- lifetime, one year and current prevalence rates, age and gender and interaction effects of mental disorders in older people were assessed. An age-stratified, random sample of N = 3142 older men and women (above 65 years) living in selected catchment community areas of the six different European and European associated countries (Germany, Italy, Spain, Switzerland, England and Israel) was assessed with the CIDI65+. In sum, we found higher prevalence rates for most of the mental disorders in the elderly (e.g. affective, anxiety disorders) in comparison to other epidemiological studies. At the same time we found an underutilisation of mental health services in older people.

In the 4<sup>th</sup> work stage- the longitudinal study- the sample of N = 2368 community-based elderly recruited in the cross-sectional phase was reassessed with the CIDI65+ to examine the 1-year incidence of mental disorders in older people. The incidence rate for any mental disorder was 6.8% in our sample. The highest rate was found for any simple phobia with 3.0%, followed by bipolar II disorder and major depressive syndrome with 2.0% each. Lower incidence rates were found for agoraphobia, panic disorder and somatoform pain disorder. No incident cases were found for substance-related disorders, social phobia, PTSD, bipolar I disorder, major depression and abridged somatization.

To summarize, mental disorders in the elderly are highly prevalent in community-living elderly in European and associated countries and new incidences of mental disorders occur in old age. At the same time mental health services are underutilized in older people. These

findings emphasise the need to implement special mental health care services for the elderly across Europe. Furthermore, educational campaigns are needed to raise the public awareness about mental health problems in an ageing society, lower stigmatisation and increase access to health services.

#### 4.1.2 Summary description of project context and objectives

The society's relevance of old age is increasing, mainly due to a higher life expectancy and a decrease in fertility. On the basis of probabilistic population prognosis of the European Union the percentage of older people is expected to increase by approximately 60% by the year 2050 (for the former 15 member states). The fact that the percentage of people above 65 years will increase during the following decades is of great importance. As frequency of diseases, need for care and service utilisation are age-dependent, the demographic shift has significant consequences for the European health care system. With an increasing share of older people the need for professional care can be expected to increase. The demand of services will not only depend on the number of elderly persons, but also on their health. Therefore, mental health of older people increasingly becomes a focus of interest. Specifically aging can bear considerable consequences for mental health, since it comprises numerous stress factors (e.g. social isolation, reduced functional capacity, somatic comorbidity). Conservative estimates of the World Health Organisation (WHO) show that at least 50% of the EU population fall ill with one or more mental disorders in the past year, if lifetime risk is considered. Furthermore, depression is the main reason for suicide amongst the elderly and in over 90% of all countries suicide rate is highest amongst the older age group (above 75 years). Besides, health costs of older people with a comorbid mental disorder, as for example affective disorder, can be 50% higher than of older people without comorbid affective disorder. An examination of the model of the International Classification of Functioning, Disability and Health (ICF; World Health Organisation, 2001) clearly shows that not only the diagnosis is of high relevance, but also the additional factors and components that impact the quality of life of the persons concerned. Thus, member states of the European Union are urged to take on measures reducing mental disorders among older people unable to actively participate within their community due to their illness. For this reason the EU has funded projects, developing social support networks for the promotion of physical activity and community participation. However, no reliable data is available regarding the number of people above 65 years suffering from clinically significant mental illness in Europe, how they are looked after or whether they are involved in community living. Moreover, only scarce empirical cross-national investigations are available concerning the level of activities and participation in people aged 65 years and older. Except for a few cross-national cross-sectional studies for some disorders with extremely variable results, little is known about the prevalence of most mental disorders and the size and burden of mental disorders in the elderly remains unclear. This has been attributed to a number of methodological factors such as lack of appropriate diagnostic instruments for the elderly and extremely variable study designs and methods. In addition and largely as a result of the lack of firm cross-sectional evidence, patterns of incidence and of the natural course and prognosis of mental and physical disorders in people above 65 years are lacking nationally and cross-nationally in the EU, with only a few notable exceptions. Rates on the relationship of mental and physical disorders to impairment, disability and social functioning as well as health care utilisation are largely lacking. There are no cross-national studies investigating the interaction of mental disorders and the utilisation of treatment under specific consideration of the severity and the impairment of activities and participation based on the ICF-categories of older people in different European countries and associated states. The "Health" Programme within the 7<sup>th</sup> EU framework has emphasised the mental health of older people. The "Health outcome measures and population ageing" topic points out that as a core prerequisite there is a pronounced need for development of reliable and valid ICD

(International Classification of Diseases World Health Organisation, 1992) oriented assessment instruments in order to gain prognosis data on the physical and mental state, quality of life and well-being of older people in Europe. The EU initiative serves as an ideal platform to bring together European experts in this field in order to draw on their individual expertise while providing collaborative access to material and data. Based on the current state of the literature it can be stated that so far no empirical data exist, that are based on a detailed and methodological sufficiently sound assessment of the level of severity of mental disorders in older people in different countries in Europe and associated states. Thus further research is needed.

The aim of the present study is to (1) develop, respectively to adapt existing, instruments, for use in the elderly and to establish their reliability, (2) to examine within a standardized assessment the prevalence and 1-year incidence of core mental disorders in adults older than 65 years in different European countries and associated states, and thereby also allowing to describe the natural course and to investigate their prognosis over a 1-year period. In line with this, point-, 1-year and lifetime-prevalence of mental disorders in older adults will be examined in a longitudinal design covering initially a period of one year. A further objective of the present proposal is to assess the demand for specialist treatment of mental disorders with particular emphasis on the severity of disorders in different European countries and associated states. Within this context utilisation of specialist treatment in different countries will also be assessed. A further central objective is the investigation of people above 65 years with regards to their involvement in family and society (activities and participation) across different European countries and associated states. Thereby the interaction between impairment in activities and participation and the utilisation and non-utilisation, respectively, of specialist treatment in older people will be investigated. Gender aspects play an important role in mental disorders in the elderly. For example many empirical studies showed that women had a higher prevalence of affective disorder than men. Therefore gender aspects and differences between women and men in the elderly should be considered in each of the research questions.

In order to realize to previous mentioned objectives the first phase of the present investigation will focus on the identification, the translation process and on the adaptation of the identified instruments for the assessment of the diagnoses (mental and physical), the symptoms severity, quality of life, activities and participation and factors of the utilisation of health services in the elderly in different European countries and associated states. Because the existing interviews have found to be of limited value for the elderly, and because of the existing knowledge and methodological work about how to optimize the use of such structured interview for diagnosing mental disorders in the elderly, the first step is to adapt a well-established structured interview for the assessment of mental disorders according to ICD-10 and DSM-IV, the Composite International Diagnostic Interview for adults (Wittchen, 1994) to the problem situation and the specific situation of older people. Alongside self-rating instruments (e.g. the Brief Symptom Inventory, BSI or the Hospital Anxiety and Depression Scale, HADS), the expert-rating instrument Health of the Nation Outcome Scales- 65+ (HoNOS-65+; Burns et al., 1999) will be employed in order to differentially assess severity. Moreover, additional instruments will be devoted to the adaption of the age-gender specific assessment tools (e.g. WHODAS-II, World Health Organisation, 2000) for older people. If the instruments are not available in the specific language of the countries, the instruments will be translated into the respective language on the basis of the WHO recommendations (translation, back-translation, cognitive debriefing). Within the framework of a pilot test,

translated and adapted instruments will be investigated regarding their psychometric properties. Therefore a one-point measurement with a quasi-experimental design in convenience sample of patients over 65 years stratified by mental disorders (depression, somatoform, substance, level of cognitive impairment) in every country will be conducted. The sample will consist of patients with a severe mental disorder and with a very severe mental illness. Analyses on the feasibility, reliability and validity of the translated/adapted instruments will be realized.

Moreover, in a standardized assessment of the “cross-sectional study for elderly in different European countries and associated states” the prevalence of core mental disorders in adults older than 65 years will be examined. The design of this study component is cross-sectional, using age-stratified, random samples of community respondents in each site/country. For the identification of prevalence rates of mental and physical disorders, determination of level of severity, quality of life, impairment of activities and participation and utilisation of health services the interview set will, alongside a general part on the investigation of sociodemographic aspects, comprise a specific part with a variety of instruments. All participants of the cross-sectional study will be asked for repeated participation after one year.

In the “longitudinal-study on the identification of predictors of the course and outcome of older people with mental disorders”, factors contributing to the incidence and course of the mental disorders in the elderly in different European countries and associated states will be studied one year after the cross-sectional study. The recruited sample will be reassessed in order to examine the incidence of new disorders as well as the incidence of new episodes (for episodic disorders) and to describe the 1-year natural course. This also allows to make statements on the prognosis of mental disorders and the progression respectively improvement with regard to impairment of activities and participation.

It is assumed that there is currently a deficit in the health care of older people with mental and physical disorders in Europe. For the first time, it will be possible to deliver national and cross-national results on a broad representative basis using a secured methodological basis, which will form the foundation for interventions on manifold levels. These levels include the level of the treating doctor or the treating primary care institution, the nursing service, the inpatient health care and rehabilitation. This refers to the general physical health care as well as to specialised offers for people with mental disorders. Results will help to change health care in direct contact with people, and beyond this, they offer starting points for structural changes initiated in the level of health politics. Results should also be relevant for various non-professional support groups (as for example self-help groups). Finally, they do not only refer to the patient, but also to the social network of support by affiliated, friends and relatives. By considering different countries with various health systems and different cultures of dealing with mental and physical illnesses in the elderly it will also be possible to design model interventions for an individually optimal approach. At the same time the design allows for necessary country-specific adjustments.

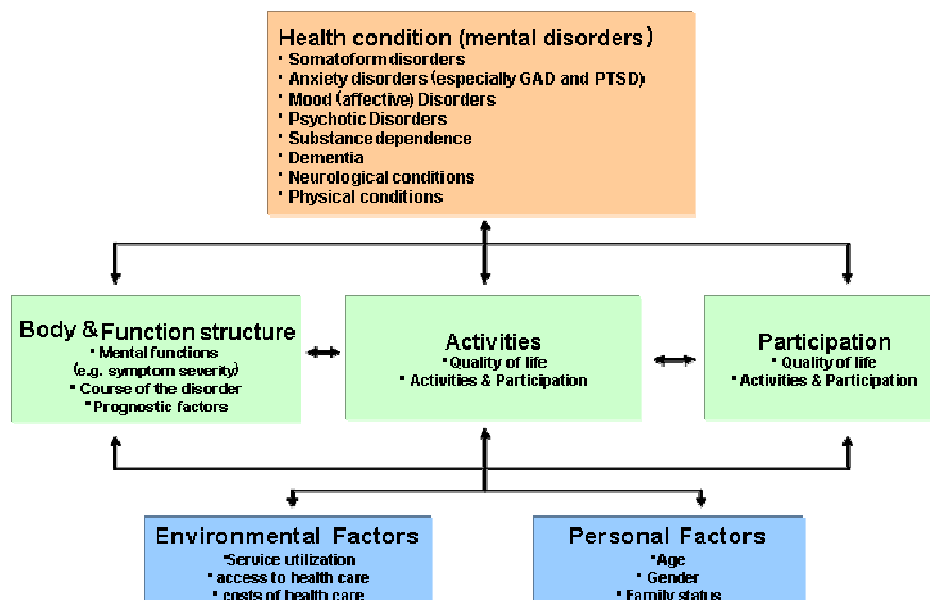
### 4.1.3 Main results of the MentDis\_ICF+ project

#### 4.1.3.1 Adaptation of instruments for elderly people with mental disorders

##### 4.1.3.1.1 Identification of instruments

At the first project-meeting in December 2008 the consortium decided to carefully check each of the instruments proposed in Annex 1 before starting to translate and adapt them. This included an in-depth review of relevant literature followed by an elaborate multi-level analysis of considered instruments. This analysis comprehended examination of the quality criteria (including psychometric properties) as well as language availability and prior application in an elderly sample. Moreover all beneficiaries were asked to look for further relevant instruments or domains to be covered in the MentDis\_ICF65+ assessment battery. To discuss the results of these efforts within the consortium an extraordinary meeting was scheduled in March 2009. Steps prior to this meeting and the meeting itself turned out to be essential for the project, providing a profound and science-based pool of widely applied, well standardised instruments for subsequent data collection in an elderly community sample.

To structure the process of identification of instruments the International Classification of Functioning, Disability and Health (ICF; World Health Organisation, 2001) was chosen as a reference frame. Domains to be covered in the assessment battery can be allocated to the ICF model as follows: the superior health condition will be displayed by the **diagnosis of mental and physical disorders**, body and function structure will be covered by assessment of **severity of mental and physical disorders**, the domain activities and participation is naturally represented by instruments covering **activities and participation**, as well as **quality of life and well-being**. Furthermore environmental as well as personal factors are covered assessing **service utilization** of participants as well as **sociodemographic characteristics** (see figure 1).



**Figure 1:** International Classification of Functioning, Disability and Health (ICF; World Health Organisation, 2001)

Moreover for the evaluation of instruments, quality criteria- including psychometric assessment- based on the recommendations by Terwee et al. (2007) were deployed. In



addition to these criteria it was considered whether an instrument had been applied in the elderly in previous empirical studies as well as language availability.

The following table 1 lists the final core set and additional instrument selected for the use in the MentDis study:

**Table 1:** Final core and additional instruments of the MentDis\_ICF65+ study

Instrument	CIDI65+ section	Content	Duration (M, SD)
Adapted version of the Composite International Diagnostic Interview for the elderly (CIDI65+)	A	sociodemography	19.60 (16.28)
	B	screening for nicotine abuse	5.86 (6.08)
	C	somatic, somatoform	11.45 (25.72)
WHOQoL-BREF		quality of life	
WHODAS II		activities and participation	
Adapted version of the Composite International Diagnostic Interview for the elderly (CIDI65+)	D	anxiety disorders	12.12 (42.58)
	E	depressive disorders	12.99 (36.24)
	F	bipolar disorders	2.67 (2.98)
	G	psychotic symptoms	2.50 (3.10)
	I	alcohol use disorders	4.23 (3.62)
	K	obsessive compulsive disorders	1.12 (1.77)
	L	screening for drugs and medication abuse	2.14 (1.85)
	N	posttraumatic stress disorder, adjustment disorders	8.06 (43.36)
	M	cognitive impairment (MMSE)	4.77 (6.04)
	Q	service utilisation	3.37 (15.73)
Health of the Nation Outcome Scales 65+ (HoNOS-65+)	X	interview observation	8.64 (50.58)
		symptom severity	
		personality assessment	
10-item version of the Big Five Inventory (BFI-10)		personality assessment	
Shalev's Coping Efficacy Scale (CES)		coping efficacy	
Total			106.85 (58.68)

All documents regarding the selection process of the instruments can be accessed in the login area of the [www.mentdiselderly.eu](http://www.mentdiselderly.eu) webpage in the folder “instruments”.

### ***Adaptation process of the CIDI65+***

The Dresden work group (Hans-Ulrich Wittchen, Frank Jacobi, Jens Siegert, Rea Recknagel) started to modify the existing elderly modules according to the study needs in Month 1-2, modifying consistently all relevant sections, taking into account comments and suggestions of all centres. In month 3 and 4 sub threshold modules were developed with diagnostic algorithmic cross-walks to ICD-10 and DSM-VTR. Subsequently in month 4 and 5 we explored for each language area the language translation process and CAPI programming. 9 weeks were spent for the Hebrew version compatibility checks (resolved). In month 5 and 6 a feasibility trial in 26 elderly was run with acceptable administration duration. Subsequent to the 2 days CIDI65+ training session in Hamburg in December 2009, the language versions were produced step by step and by language area. As part of the increasing knowledge about the technical details hundreds of requests for changes were received, requiring up to now three complete revisions of the CIDI interview. This feedback made it impossible to proceed with the finalization of the language versions. As a result, in March 2010 development of a new, considerably different version of the CIDI65+, in German and English, largely incompatible with the original was completed. This version was then pre-tested in Hamburg and London, revealing close to 150, partly significant further modifications. This process resulted in a delay of the finalization of the instrument. We then assembled and modified the last revisions in German and English and started testing the newly revised version of the computerised CIDI65+ in June. Subsequently after debugging, the language translation process and programming was completed.

### ***Expert focus groups***

Another step to support the adaptation of the CIDI65+ comprised conducting an expert focus group workshop on “symptom differences and characteristics of the elderly using the example of depression” with clinically well- experienced, geriatric psychiatrists at the University Medical Centre in Hamburg. In preparation for this expert focus group a comprehensive literature review was also carried out. Due to time limitations, it was decided to focus on depression, the most prevalent mental disorders in the elderly. The workshop consisted of 1) brainstorming on differences and characteristics of depression in the elderly and 2) a discussion on differences and characteristics of depression based on the literature research. For the first part experts explored specific characteristics of depression in old age based on their profound clinical experience. In the second part experts were presented ICD-10 (WHO, 1992) criteria of depression with their corresponding CIDI items and findings of the literature research to make specific suggestions on the adaptation needs for the elderly.

At our 3<sup>rd</sup> ordinary project meeting in Ferrara in March 2010, we conducted a further expert focus group workshop with all MentDis partners to review the CIDI65+. At this time all partners had participated in the CIDI65+ training conducted by Hans-Ulrich Wittchen in Hamburg in December 2009 and were thoroughly familiarized with the instrument. At the workshop the CIDI interview and respondent booklet were reviewed on item level with regard to feasibility, clarity and comprehensiveness and specific recommendations were made for improving, shortening and streamlining the CIDI65+.

Due to the comprehensiveness and richness of feedback derived from the 2 expert focus groups on improving the CIDI65+ and time constraints the study group decided to proceed in the translation process and pre-testing the instruments with patients (see section 2.2). A summary of the findings from the 2 focus groups can be accessed from the login area of our webpage [www.mentdiselderly.eu](http://www.mentdiselderly.eu) in the folder “adaptation”.

### **Translation process of the identified instruments into languages of the involved countries**

The English paper and pencil version of the CIDI65+ and other self- & clinician-rated instruments included in the assessment battery have been translated into required languages of all project partners: Italian, French, Spanish and Hebrew. The German version was provided by the Dresden partner. Each project partner undertook the translation of the English version into their respective language. In order to simplify the translation process partners build on existing language versions of the CIDI65+ and used these as a basis for the translation of the newly adapted CIDI65+.

All documents regarding the translation process of the instruments can be accessed in the login area of the [www.mentdiselderly.eu](http://www.mentdiselderly.eu) webpage in the folder “translation”.

#### **4.1.3.1.2 Pretest results**

##### ***Background***

Pretesting is an indispensable part of structured interview development because it detects problems in advance (Presser et al, 2004). We used pretesting to evaluate the acceptability of the MentDis\_ICF65+ to interviewees and its usability for interviewers, so that the CIDI (version 2.0) could be improved, prior to its psychometric evaluation (4.1.3.2) and use in the prevalence survey (4.1.3.3).

##### ***Method***

The pretesting was completed over a 10-week period. Eighteen interviews were undertaken in London and Hamburg to pretest the English and German language versions of the adapted CIDI.

Methodological model: The team developed a multi-method strategy, which involved combining respondent debriefing, interviewer debriefing, behavior analysis and desk-based review (see Tolonen [undated] for an overview of pre-testing methods). Different pretesting methods produce different results with regard to the number and type of problems identified (Presser & Blair, 1994), so the rationale for using a multi-method approach is that the weaknesses of one method will most likely to be offset by the strengths of another (Childs & Goerman, 2010).

Sample: Purposive sampling was used to select both healthy elderly and elderly with current or lifetime mental illnesses, which enabled us to field test as many branches of the CIDI interview as possible.

Data collection: After each interview both respondent and interviewer were debriefed to find out their views on how the interview could be improved. These debriefings were recorded and transcribed for subsequent analysis. The 18 CIDI interviews were recorded and listened to afterwards to identify behaviours that indicated problems with the interview (e.g. where a question had to be repeated several times, or where the respondent refused to answer). These field-based evaluation methods were supplemented by desk-based review, which involved an analyst carefully running through the CIDI and entering various response permutations to test the routing of the instrument and check for other problems.

Data analysis: The qualitative data were indexed using a simple, standardised coding scheme. The London and Hamburg teams analysed their own datasets separately. Separate summary reports about each language version were compiled, showing the completion times for each interview section and detailed feedback on CIDI items and the accompanying Respondent Booklet. Results were compared to identify problems that were present in both versions, as this indicated pan-European issues. The feedback reports were used to inform changes to the CIDI and interviewer training.

## ***Results***

General findings: (1) The interview duration was much longer than the expected 90 minutes; most time was required to fill in the Respondent Booklet and CIDI sections A and C. Even respondents without any mental disorder or cognitive impairment took about two hours to complete, and the majority of respondents became tired after 1.5 – 2 hours. (2) Throughout the CIDI the timeframe changed frequently (lifetime, last 12 months, last four weeks, last 7 days), and it seemed that respondents had difficulties keeping track of the correct timeframe. (3) Respondents found the Respondent Booklet confusing and difficult to read at times because of the inconsistent layout of lists. (4) A number of technical problems were revealed, e.g. empty screen, incorrect ratings and items not corresponding with the Respondent Booklet. Item-level feedback: Detailed feedback was provided about each section of the CIDI, with suggestions offered for how to improve particular items.

## ***Conclusions***

Pretesting the CIDI65+ proved to be an indispensable part of structured interview development because it detected problems prior to the pilot study.

After completing the revision of the CIDI65+ based on the pretesting findings, the instrument was ready for assessment of its psychometric properties in the pilot study.

### **4.1.3.2 Psychometric properties of the CIDI65+**

#### **4.1.3.2.1 Test-Retest results**

##### ***Background***

Standardized diagnostic interviews for use in community survey consistently reveal substantially lower 12-month and lifetime rates of mental disorders in the Elderly as compared to younger age groups. Concerns have been raised that these lower rates might be an artifact of the assessment strategy that might not appropriately take into account age–

related differences in the processing speed and understanding of highly complex symptom questions.

### ***Aims***

We describe rationale and procedures chosen to adapt the DSM-IV-TR version of the Composite International Diagnostic Interview for use in a pan European “Mental Disorders in the Elderly” (*MentDis ICF65+*) project and evaluate the test-retest reliability of a range of mental disorders and measures using different language versions.

### ***Methods***

Based on substantive prior experimental work and a feasibility study in  $n = 298$  subjects (mean age: 74 years), the CIDI symptom questions were shortened, respectively broken down in shorter subsets of questions and combined with section specific sensitization questions. The resulting modified CIDI65+ version was then administered twice, two to 63 days apart, by two different trained clinical interviewers. Participants were 55 subjects aged 60-79 years, sampled from the community and treatment facilities. T-RT reliability for categorical measures was analysed using % agreement, kappa and yules Y statistics, dimensional measures were intraclass-coefficients.

### ***Results***

T-RT reliability was good to excellent for having any mood (0.60), any somatoform (.63), any anxiety (.70), substance (.88) and obsessive-compulsive disorder (1.00). T-RT agreement was also good for single diagnoses as well as core syndromes like sleeping problems and suicidal ideation/acts (range .48-1), except for early awakening (.44). Agreement for depressive disorder was slightly attenuated when the time lapse between test-and retest interview was larger, due to lower reliability of the depression stem questions. Intra-class coefficients for age of onset, recency, quantity and frequency and duration questions as well as dimensional distress and functioning disability measures ranged between .6- .9.

### ***Discussion***

The CIDI65+ was found to be a reliable instrument for diagnosing somatoform, mood, anxiety and obsessive-compulsive disorders as well as for assessing distress, impairment and time-related information. The finding that the test-reliability is actually partly substantially higher than in the standard CIDI provides indirect evidence that the changes introduced for the elderly might be an effective approach, prompting additional research as with regard to the validity.

- 5 Subsequent to the successful completion of the pilot study, the cross-sectional study to assess prevalences of mental disorders in the community-living elderly from different European and European-associated countries, was implemented.

#### **4.1.3.3 Prevalence and symptom severity of mental disorders**

The overall aim of WP3 comprises a population representative investigation on the prevalence of physical and mental disorders in the elderly in different European countries, regarding level of severity of mental disorders, behaviour regarding utilisation, and associated quality of life and impairment of activities and participation. DSM-IV diagnoses were obtained by the age-sensitive CIDI65+.

As described previously we interviewed a total sample of sample of N = 3,142 older men and women (65-84 years) living in selected catchment community areas of each participating country. The frequency of mental health problems was assessed with regard to 3 different timeframes within the MentDis\_ICF65+ study: past two weeks, past year and lifetime, whereby all current and past year cases are naturally included in the lifetime prevalence numbers. The final analyses were conducted using Stata 12.1. Survey analyses were weighted according to the number of inhabitants and stratified by gender and two age groups: 65-74 and older than 74 years. The adjusted prevalence was estimated as marginal mean from a weighted logistic regression adjusting for age in 5-year-intervals, sex and centre. Differences were tested using odds ratios (OR) and 95% confidence limits. Interaction terms of sex and age were added and kept in the model if significant. The interaction effect was tested using adjusted Wald tests and orthogonal polynomial contrasts in the level values using also Wald tests.

In sum, we found that nearly half of our sample suffered from any mental disorder within their lifetime, nearly one third of our sample experienced psychological symptoms within the last year and nearly a quarter of our sample had any current mental disorder. We showed significant differences between the catchment areas of the included countries. We also found some significant interaction effects between age and gender for any current mental disorder. In comparison to other epidemiological studies we found higher prevalence rates for most of the disorders in the elderly. At the same time, we found that underutilization of mental health services of older people is quite common and interventions are needed to improve an adequate use of services. These findings emphasise the need to implement special mental health care services for the elderly across Europe.

Subsequent to conducting the cross-sectional study, we also implemented a 1-year follow-up longitudinal study to investigate the incidence of mental disorders in community-living elderly.

#### **4.1.3.4 Incidence of mental disorders**

Subsequent to conducting the cross-sectional study, we also implemented a 1-year follow-up longitudinal study to investigate the incidence of mental disorders in community-living elderly.

The sample recruited in the cross-sectional phase of the study has been reassessed one year later in order to examine the incidence of mental disorders. The overall drop-out rate was 24.6% resulting in a follow-up sample of 2368 elderly participants, who were interviewed from 03/2012 to 11/2012.

We discussed different strategies of analysis and decide to report about the *first incidence* of mental disorders within the follow-up period of one year. The numerator of first incidence comprises the individuals who have had an occurrence of the disorder for the first time in their lives and the denominator includes only persons who start the period with no prior history of the disorder.

To summarize, mental disorders in the elderly are not only highly prevalent in community-living elderly in European and associated countries, but new incidences of mental disorders also occur in old age. These findings emphasise the need to implement special mental health care services for the elderly across Europe. Furthermore, educational campaigns are needed to raise the public awareness about mental health problems in an ageing society, lower stigmatisation and increase access to health services.

#### **4.1.4. Potential impact & main dissemination activities**

##### **Geneva**

As for the other study sites, over the last century, Switzerland has witnessed an increase in life expectancy at birth by over 30 years, a threefold increase in the proportion of people aged 65 and older, and an eightfold increase in the percentage of persons aged 80 years and older. Among the social changes we can observe an increasing individualisation of life courses and pluralisation of values and lifestyles, which have brought more degrees of freedom but also an increasing disorientation associated with a higher risk of marginalisation. Results from other previous epidemiological studies show that currently around 10% of the Swiss population commit one or more suicide attempts, ranking above the European average. While this prevalence tends to drop in younger age, it tends to increase in old age, especially in men aged 65+. One possible explanation is the under- and misdiagnosis of mental health disorders in the population of older adults.

In Switzerland, and more precisely in its French-speaking part including Geneva, studies on old age have been the centre of empirical research for several years, and mental health issues have received increasing attention. A large interdisciplinary survey has addressed the progress and equalities of living conditions in the aged population of Switzerland since 1979 ([www.lives-nccr.ch](http://www.lives-nccr.ch)). While the original focus was the dependency in aged individuals, this focus shifted to autonomy and socio-cultural environment in 1994. Interestingly, in 2011, physical and psychological health in old age became the new specific targets. Pushing one step further, the Mentdis65+ICF project addressed the issue of mental health prevalence in old age by means of a cross-cultural comparison, thus allow discussing specific Swiss characteristics within the context of its European neighbours.

The recognition of the specificity of the clinical features of mental disorders in old age, the treatment and care needs of older persons, their needs for protection against stigma and discrimination - even inside the health and social sectors -, have contributed to the development of specialized geriatric psychiatry services in Switzerland. Indeed, Switzerland has a full range of long-term, hospital-based and community based old age mental health services in many parts of the country, contrary to other European countries. All Swiss residents are covered by mandatory health insurance, mostly of the indemnity type, with no limits on mental health care, so that an individual can initiate a consultation with a mental health specialist. Furthermore, the density of suppliers of mental health services in Switzerland is among the highest in the world—for every 10,000 residents in Geneva Canton, there are 6 psychiatrists. Nevertheless, study results of the MentDis65+ICF project on service utilization showed that older adults prefer family doctors (general practitioner) to specialized old age psychiatric services, despite this virtually unrestricted access to mental health services in Switzerland. Consultation rates and their social and cultural determinants need to be better understood, especially in systems in which primary care physicians regulate patients' access to specialized services.

Therefore, the main dissemination activity will focus on the communication of prevalence rates of the mental disorders in old age, as well as their impact on subjective quality of life, to general practitioners and specialized health services. Generalized practitioners are part of the Medical Association of Geneva and their website and newsletter offers the necessary communication means to promulgate results. Older primary care patients are more likely to accept collaborative mental health treatment within primary care than in mental health clinics.



Results suggest that integrated service arrangements improve access to mental health services for older adults who underuse these services.

The second focus will be the older adults themselves. We will organize a conference for the 520 Swiss participants to offer feedback on the study results. This will be the occasion to acknowledge and thank them for their participation, and also offer the occasion for an encounter between researchers and participants. Furthermore, Geneva hosts several old age associations (Pro Senectute, Avivo, etc.), which offer a precious interface for communication to a larger public of older adults.

The third target will be Swiss mental health professionals. The MentDis65+ICF members of the Geneva team are working at the University Hospitals of Geneva and the Faculty of Medicine of Geneva University. Since the hospital is affiliated with the university, it provides numerous meetings and classes to provide education and training to future and current health professionals. These spaces can be used to disseminate the results of the study. Indeed, the study results offer the rich opportunity to question, analyse and discuss the suitability of the existing psychiatric and mental health services in Geneva, and thus directly improve the delivered medical care.

More precisely, Dr Alessandra Canuto, psychiatrist in charge of the MentDis65+ ICF project in Geneva, is part of the training program for geriatricians and she is in charge of the team supervision of several nursing homes in Geneva. She further weakly teaches at the Faculty of Medicine of the University of Geneva as part of the graduate and post-graduate medical training in psychiatry. Likewise, Kerstin Weber, psychologist and member of the Geneva team, trains psychology students at the Faculty of psychology. Alessandra Canuto and Kerstin Weber have been working since 1998 in the psychogeriatric division of the University Hospitals in Geneva and can indeed rely on a large network of health professionals to organize conferences for dissemination of study results.

Further, beyond these local conferences and teachings, we plan on presenting the results in national congresses such as the annual congress of the Swiss Society for Psychiatry and Psychotherapy (SSPP).

Regarding to written communications of the results, Dr Canuto is editor for the annual liaison psychiatry issue of the "Revue Médicale Suisse", official journal of the Swiss medical association of the French-speaking part (Société Médicale de la Suisse romande, SMSR) and the Swiss society for internal medicine (Société suisse de médecine interne, SSMI) and could set up an article published in French language for the Swiss health professionals.

Publications of the results of the present study in international peer-reviewed journals by the Geneva team will include a special focus on the relationship between mental disorders and personality traits, and thus be aligned and benefit from previous publication work of the team in this domain (i.e. Weber K. et al. Exploring the impact of personality dimensions in late-life depression: from group comparisons to individual trajectories. *Curr Opin Psychiatry*. 2011 Nov;24(6):478-83.). Indeed, the main line of research of Dr Canuto and her team has previously focused on old age psychiatry and she has published several articles on mental disorders in older adults, specifically with respect to mental health assessment (i.e. Canuto et al. Structured assessment of mental health status in psychogeriatrics: validity of the French HoNOS65+. *Can J Psychiatry*. 2007; 52: 37-45) and community-based psychiatric treatment programs for elderly (i.e. Canuto et al. Longitudinal assessment of psychotherapeutic day hospital treatment for elderly patients with depression. *Int J Geriatr Psychiatry*. 2008; 23: 949-956)



## **Madrid**

The impact on research: We have developed a specific diagnostic tool for the elderly (the CIDI65+) that can be used in subsequent studies in Spain and other Spanish fluent countries. The Spanish part of Mentdis65+ is the first epidemiological study in Spain centred in the older population that has used age adapted strategies and instruments. This will improve the understanding of the development of mental disorders in the elderly in these countries. By the way this is the first epidemiological study that has included a 12-months follow-up.

The impact on society: we have focused attention on a group often excluded from prevalence studies, older people. By therefore, this study has given visibility to this group. We hope that the information provided could assist in the design of services and socio-sanitary politics in Spain.

The impact on services: improving knowledge of the prevalence and development of mental disorders in the elderly, may make changes and improvements in health and social services. In addition, we have evaluated the use of services in this population. This will draw conclusions about the use of the same (barriers to entry, hyper / hypo-utilization of services, adequacy of services for mental disorders and needs presented by this population, etc.).

- National/international congress activities:
  - Beginning of the study published in two of the main national newspapers (ABC, El País).
  - Jornadas Salud Mental y Exclusión Social en Personas Mayores Workshop Mental Health and Social Exclusion in Older People. IMSERSO (National Institute of Social Services). Madrid 5- 7 May 2010. We hope that IMSERSO could be interested in the organization of a Workshop on mental health in age population once we have our results ready for the general audience dissemination.
  - 30 ICP Congress 2012. International Congress of Psychology. Cape Town 22-27 July 2012.
- We have confirmed the publication of the main results of the study in the Completeness University review (not scientific review, but a scientific and academic dissemination publication).
- We plan to hold a press conference in the next months sustained by the Complutense University and Madrid City Council, inviting all associations interested in the health of older people, in order to present the Spanish data from the first phase of MentDis.
- Scientific publications in coordination with the Mentdis65+ team. The first main publication: A special number on Mentdis65+ in the British Journal of Psychiatry: Alcohol use, abuse and dependence in people above 65 years in Europe: results from the Mentdis65+ European project.

## **Ferrara**

1. Press conference with main results, inviting the Policymakers, the Media and the stakeholders (GP's representatives, patients organizations) when the final longitudinal data will be available. This will be the most cost effective way to reach the local population and stakeholders in order to present the main results and to

acknowledge the precious contribution of the participants. The aim is not only to raise visibility to the project itself and on its results, but also to raise awareness about the implications of the results. For example the fact that Quality of life is affected by mental distress may favour the development of specific programs for the elderly (e.g. psychogeriatric services); the use of services may induce to create campaign to increase screening policies for mental distress in the elderly

2. Articles and information to local, regional and national newspapers and magazines having pages / sections dedicated to health and medicine will support dissemination of the data with possible implications in terms of sensitizing of citizens and general population on the topic
3. National Health Websites articles will also favour dissemination of the data with possible implications in terms of sensitizing of citizens and general population on the topic
4. Participation to talk-shows and/or TV programs and /or broadcasts can reach broad segments of the population with the same aims as above
5. Participation to scientific meetings and congresses related to the areas of geriatrics and/or general internal medicine can favour the sensitization of physicians and health professionals to the problem of mental health and quality of life in the elderly
6. Papers in national scientific journals of different specialties (not only psychogeriatrics) favour dissemination of the data and consequently sensitization on the problem with possible impact in the organization of services, creation of networking, collaboration between centres.

### **London**

The London team will produce and disseminate accessible materials for a range of audiences. Since 2010 there has been a page on the Royal College of Psychiatrists' website, which describes the study and provides a link to the main website ([www.mentdiselderly.eu](http://www.mentdiselderly.eu)). A series peer review publications have been written or are in preparation (see Table A2 for details). The London team have led the paper about the pretesting of the CIDI survey interview (due to be submitted to the British Journal of Psychiatry) and is preparing a paper about the prevalence of mental health problems and help seeking behaviour in English adults aged 65-84. These core results will be disseminated to the UK scientific community via the journal article and a presentation at the Royal College of Psychiatrists International Congress in July 2013 (abstract submitted), and to the general public and policy makers via the Royal College's press office and Age Concern, a national charity for older adults which collaborated with us on the study. The London team is also preparing a scientific paper about financial strain and mental health in European older adults, the results of which will also be disseminated by a presentation to the Royal College of Psychiatrists International Congress. A paper on the course of service utilisation by European older adults is being prepared for submission. Combined, these dissemination activities will raise the profile of older adults' mental health and flag up the need for mental health services that are appropriate to their needs.

### **Jerusalem**

The Israel team is joining other centres in the preparation and dissemination of all core papers of the MentDis65+ project. In addition, our publication on the relationship between coping efficacy (Shalev's Coping Efficacy Scale) and mental illness as well as the prevalence

and longitudinal course of PTSD in ages 65-85 in various European countries and Israel are currently being prepared.

### **Dresden**

From the beginning of the project we have widely communicated and distributed our developmental work to work group around the world, for example within the CIDI advisory group (12 members from 7 countries), the participants of the World mental health Group (42 members from 29 countries), to stimulate them to review and comment on early drafts, explore its use and eventually use our new modules for the Elderly. We assume, pending the finalisation and publication of the scientific papers that our approach will impact on future improved epidemiologic studies in elderly populations. We expect that our strategy to adapt the standardized interview questions to the patients/subjects age related cognitive abilities will result on improved (most likely higher) rates of mental disorders.

Major strengths of the new instrument are:

- increased reliability (test-retest and interrater)
- improved validity (indirect evidence)
- improved feasibility and transfer
- greater utility by incorporation of dimensional measures.

### **Hamburg**

To establish the empirical framework for the MentDis study the Hamburg team conducted a meta-analysis of epidemiological mental health studies in the elderly in western countries (Volkert et al., 2012). Another work related to this meta-analysis was published in a national journal in January 2011 (Mehnert, A, Volkert, J, Wlodarczyk, O, Andreas, S (2011) Psychische Komorbidität bei Menschen mit chronischen Erkrankungen im höheren Lebensalter unter besonderer Berücksichtigung von Krebserkrankungen. Psychological comorbidity in elderly patients with cancer Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz, 54 (1), 75-82).

In terms of qualification work a bachelor thesis entitled "Qualitative evaluation of the Composite International Diagnostic Interview (CIDI) adapted for use in the elderly" could be finalized in July 2010 (Author: Olga Wlodarczyk). Moreover two doctoral theses are in preparation, one dealing with "Somatoform spectrum disorders in the elderly: prevalence, manifestations and course of disease" (Author: M.Hausberg) and one about "The relationship of Meaning in life and diagnosis and severity of mental disorders, quality of life and service utilisation in the elderly in different European countries" (Author: J.Volkert). First results from Jana Volkerts dissertation work were presented at the 42nd international meeting of the Society for Psychotherapy Research in June 2011 as well as at the 43<sup>rd</sup> annual meeting of this society in June 2012 (*„Protective effects of meaning in life in traumatized older people?“*). At this conference first results of the HoNOS65+ German version validity study were also presented (*“How to measure symptom severity in patients with mental disorders in the elderly? Psychometric evaluation of the German version of the “Health of the Nation Outcome Scales for the Elderly (HoNOS65+-D)”*).

To report the main results of the MentDis study to the scientific community a symposium on „*Size and burden of mental disorders in the elderly: an European perspective*“ was held at the annual conference of the German Association for Psychiatry and Psychotherapy (DGPPN) in November 2013 in Berlin and another one is scheduled for the 5th of June at the 14th Congress of the International Federation of Psychiatric Epidemiology (IFPE), in Leipzig, Germany.

In terms of scientific papers, the design of the MentDis study has been published in an open access journal (<http://www.biomedcentral.com/1471-244X/13/62>) and the consortium is currently preparing a supplement within the British Journal of Psychiatry, as well as a main paper on the prevalence of mental disorders in the general elderly population in Europe.

Furthermore, all study participants received a letter explaining the findings of our study.

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