Problem behaviours and symptom dimensions of psychiatric disorders in adults with intellectual disabilities: an exploratory and confirmatory factor analysis.

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Abstract

Background

The limited evidence on the relationship between problem behaviours and symptoms of psychiatric disorders experienced by adults with intellectual disabilities leads to conflict about diagnostic criteria and confused treatment. This study examined the relationship between problem behaviours and other psychopathology, and compared the predictive validity of dimensional and categorical models experienced by adults with intellectual disabilities.

Methods

Exploratory and confirmatory factor analyses appropriate for non-continuous data were used to derive, and validate, symptom dimensions using two clinical datasets (n=457; n=274). Categorical diagnoses were derived using DC-LD. Severity and 5-year longitudinal outcome was measured using a battery of instruments.

Results

Five factors/dimensions were identified and confirmed. Problem behaviours were included in an emotion dysregulation-problem behaviour dimension that was distinct from the depressive, anxiety, organic and psychosis dimensions. The dimensional model had better predictive validity than categorical diagnosis.

Conclusions

International classification systems should not include problem behaviours as behavioural equivalents in diagnostic criteria for depression or other psychiatric disorders. Investigating the relevance of emotional regulation to psychopathology may provide an important pathway for development of improved interventions.

What this paper adds

There is uncertainty whether new onset problem behaviours or a change in longstanding problem behaviours should be considered as symptoms of depression or other types of psychiatric disorders in adults with intellectual disabilities. The validity of previous studies was limited by the use of pre-defined, categorical diagnoses or unreliable statistical methods. This study used robust statistical modelling to examine problem behaviours within a dimensional model of symptoms. We found that problem behaviours were included in an emotional dysregulation dimension and not in the dimension that included symptoms that are typical of depression. The dimensional model of symptoms had greater predictive validity than categorical diagnoses of psychiatric disorders. Our findings suggest that problem behaviours are a final common pathway for emotional distress in adults with intellectual disabilities so clinicians should not use a change in problem behaviours as a diagnostic criterion for depression, or other psychiatric disorders.

1.0 Introduction

The presentation of psychiatric disorders in adults with intellectual disabilities can differ from that seen in the general population. Therefore, specific classification systems have been developed to diagnose psychiatric disorders experienced by adults with intellectual disabilities. Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities (DC-LD; Royal College of Psychiatrists, 2001) is based on ICD-10 (World Health Organisation, 1993) and DSM-IV-TR (American Psychiatric Association, 2000). The Diagnostic Manual-Intellectual Disability (DM-ID; Fletcher et al., 2007) is developed from DSM-IV-TR (American Psychiatric Association, 2000). There is minimal evidence to inform diagnostic criteria for psychiatric disorders in adults with intellectual disabilities so both classification systems were based on the consensus opinion of experts.

Adults with intellectual disabilities experience increased rates of psychiatric disorders, with a point prevalence of 35-41% (Cooper et al., 2007) depending on the method of diagnosis. Generic classification systems used to diagnose psychiatric disorders, such as ICD-10 and DSM-IV-TR, rely on individuals' verbal communication skills to describe the symptoms they are experiencing. Many adults with intellectual disabilities find it difficult to communicate whether they are experiencing the symptoms of psychiatric disorders included in standard classification systems. Therefore, DC-LD (Royal College of Psychiatrists, 2001) and DM-ID (Fletcher et al., 2007) both propose that problem behaviours experienced by adults with intellectual disabilities may be equivalent to the symptoms of psychiatric disorders listed in standard diagnostic classification systems.

The term ‘problem behaviour’ is used here to describe any behaviour that is of a frequency, severity or chronicity to require clinical assessment and either has a negative impact on an individual’s quality of life or the quality of life of other people, or presents a significant risk to the health and safety of the individual or other people (Royal College of Psychiatrists, 2001). Problem behaviours are the most common type of psychopathology experienced by adults with intellectual disabilities (Cooper et al., 2007). As well as having a negative impact on quality of life, problem behaviours are often associated with significant costs to families and services (Totsika & Hastings, 2009). The onset of problem behaviours is often in early childhood (Emerson & Einfeld, 2010), persisting into adulthood for some individuals. Adults with intellectual disabilities present to clinical services with new onset problem behaviours or a change in frequency and severity of longstanding problem behaviours (Emerson et al., 2001). If an adult with intellectual disabilities presents with symptoms of psychiatric disorder and new onset of, or a change in, problem behaviours it is not clear whether the problem behaviours should be considered equivalent to symptoms of a psychiatric disorder.

Much of the research to understand whether problem behaviours should be considered as equivalents of other symptoms of psychiatric disorders has focussed on depressive symptoms. It has been suggested that problem behaviours are behavioural equivalents of depressive symptoms in adults with intellectual disabilities and should be included in diagnostic criteria (Smiley & Cooper, 2003). However, findings have been equivocal on whether problem behaviours should (Charlot et al.,1993; Felce et al., 2009; Hurley, 2008; Kishore et al., 2005; Marston et al., 1997; Moss et al., 2000) or should not (Holden & Gitlesen, 2003; Sturmey et al., 2010; Tsiouris et al., 2003; Tsiouris et al., 2011) be considered as depressive equivalents. This creates uncertainty that is reflected in

the classification systems, for example problem behaviours are included as symptoms of depression in the DC-LD (Royal College of Psychiatrists, 2001) but not in the DM-ID (Fletcher et al., 2007).

The majority of studies that have considered problem behaviours as equivalents of symptoms of psychiatric disorders have used a methodology that predefined groups of participants based on whether they met diagnostic criteria for depression that do not include problem behaviours (Charlot et al., 1993; Felce et al., 2009; Holden & Gitlesen, 2003; Hurley, 2008; Kishore et al., 2005; Marston et al., 1997; Moss et al., 2000; Tsiouris et al., 2011). This methodology has limited validity (Ross & Oliver, 2002) because the comparison groups are predefined using diagnostic criteria for depression that do not include problem behaviours. Also, very few of these studies controlled for between-group differences in potential confounding variables (Felce et al., 2009) such as level of intellectual disabilities, gender, autism (McClintock et al., 2003) and Down syndrome (Tyrer et al., 2006).

Two studies used exploratory factor analysis (EFA) to examine whether problem behaviours and depressive symptoms were extracted within the same symptom dimension (Sturmey et al., 2010; Tsiouris et al., 2003). Neither study found this result and concluded that problem behaviours were not depressive equivalents. Although this statistical modelling approach using factor analysis improves on the tautological problems in the studies using a two group, depression/non-depression method (Charlot et al., 1993; Felce et al., 2009; Holden & Gitlesen, 2003; Hurley, 2008; Kishore et al., 2005; Marston et al., 1997; Moss et al., 2000; Tsiouris et al., 2011) both studies used Pearson correlations for the initial matrix, and principal components analysis, which are unsuited to the analysis of categorical data (Norris & Lecavalier, 2010) and have shown to produce unstable solutions in

Monte Carlo simulation studies (Snook & Gorusch, 1989). Other limitations of these studies were the small sample size (n=92) in one of the studies (Tsiouris et al., 2003) and neither study validated the EFA findings, for example using confirmatory factor analysis (CFA).

We have argued above that there have been important methodological limitations in previous studies examining whether problem behaviours should be considered as equivalents of symptoms of psychiatric disorders. Therefore, one objective of this study was to use robust statistical modelling to examine the relationship between problem behaviours and symptoms of psychiatric disorders experienced by adults with intellectual disabilities. Our second objective was to test whether the model of psychopathology developed was relevant to clinical practice. To achieve these objectives, the study aims were (1) to develop a dimensional model of psychopathology using EFA, (2) to validate the dimensional model using CFA and (3) to examine the relevance of the dimensional model of psychopathology to clinical practice by comparing the predictive validity of the dimensional model against the predictive validity of categorical diagnoses used in clinical practice.

2.0 Methods

2.1 Samples

Data from two separate samples were used to derive and validate the model of symptom dimensions. One sample comprised all referrals to the clinical service of the Glasgow University Centre for Excellence in Developmental Disabilities (UCEDD) between 2001 and 2010 (n=457). The second sample included all referrals to North Northamptonshire's specialist intellectual disabilities psychiatric service during 1994-1999 (n=274). Individuals were referred to these services

because they had symptoms suggestive of psychiatric disorders and/ or behavioural or functional changes requiring further psychiatric assessment.

Following approval by the relevant local ethics committees, written informed consent was provided for all participants in accordance with ethical regulations at the time of data collection. Where an individual was assessed as having capacity to make an informed decision about participation in research, they were invited to choose whether they would like to participate, and if willing were invited to sign a consent form. In circumstances where an individual does not have capacity, the Adults with Incapacity (Scotland) Act allows provision for consent to be given by the individual's nearest relative, or welfare guardian.

2.2 Measures

2.2.1 Psychopathology

The *Psychiatric Present State-Learning Disabilities* examination (PPS-LD; Cooper, 1997) was used to assess symptoms of psychiatric disorders. PPS-LD was developed specifically for use with adults with intellectual disabilities, based upon the *Schedules for Clinical Assessment in Neuropsychiatry*, adapting language to be developmentally appropriate, and adding symptoms that commonly present in this population. PPS-LD includes a broad range of 64 symptoms, including problem behaviours, which are scored positively, as a binary score, if present in the past four weeks and associated with significant impairment. The PPS-LD emphasises that items should only be scored positively where there has been a change in an individual's presentation and functioning. Where a participant is unable, due to cognitive or communication abilities, to self-report symptoms, many items can be rated positively if informants have observed specific changes in the individual's behaviour, e.g. loss of appetite. However, if a participant does not

have verbal communication it is impossible to rate some items e.g. psychotic symptoms; so there are 10 items that should only be rated if the individual can speak in sentences (Table 1). PPS-LD also includes examination items which were not included in our analyses.

**********Insert table 1 about here **********

DC-LD consensus diagnoses (Cooper et al., 2007) were derived, providing a categorical model of psychopathology. There were small numbers of participants within diagnostic sub-categories, so individual diagnoses were collapsed into the five diagnostic groupings in DC-LD axis III (B1 = dementia, B3 = schizophrenia; B4 = affective disorders, B5 = neurotic and stress related disorders, D1 = problem behaviours).

2.2.2 Outcome measures

Outcomes were measured for a sub-sample of the Glasgow sample at baseline at the same time as the PPS-LD to measure severity of illness (n=150), and repeated again after a period of five years to assess longitudinal outcome (n=40). The following battery of instruments was used:

The *Health of the Nation Outcome Scales for People with Learning Disabilities* (HoNOS-LD) was developed to measure the outcome of psychiatric disorders, taking into account the specific needs of individuals with intellectual disabilities (Roy et al., 2002). HoNOS-LD has 22 items (e.g. self-injurious behaviour, mood disturbance, activities of daily living at home) with a specific descriptor for each rating on the five-point scale (0 = no problem, 1 = mild problem, 2 = moderate problem, 3 = severe problem, 4 = very severe problem). The scores for each of the

22 items are added together to give a total (HoNOS-LD total, range = 0-88). The HoNOS-LD has been shown to have adequate reliability and validity for use as a measure of outcome (Roy et al., 2002).

The *Camberwell Assessment of Need for Adults with Developmental and Intellectual Disabilities* (CANDID; Xenitidis et al., 2000) was developed to measure need in adults with intellectual disabilities and psychiatric disorders. CANDID has been shown to be a reliable and valid measure of met, and unmet health needs in adults with intellectual disabilities (Hall et al., 2006; Strydom et al., 2005; Xenitidis et al., 2000) and shown to be sensitive to change over time (Hall et al., 2006). The research version of the CANDID (CANDID-R) was used and ratings for each domain were combined to give two summary variables for use in the analysis: total number of unmet needs and total number of met needs.

The *Global Assessment of Functioning* (GAF; American Psychiatric Association, 2000) was used as a global measure of functioning. A significant measurement error has been shown with the use of the standard method to score the GAF for participants with intellectual disabilities (Hurley, 2001; Shedlack et al., 2005). In this study the GAF was rated using an adapted methodology (Hurley, 2008) similar to the scoring system for persons with physical disabilities. The impact on functioning of impairments due to intellectual disabilities was excluded and the rating was based solely on symptoms and level of functioning where there had been a clear change in functioning related to the onset of symptoms in the PPS-LD.

The *Vineland Adaptive Behaviour Scales* Survey Form (Sparrow et al., 1984) was used as a measure of the current level of adaptive functioning. The instrument is

completed with a carer, or other informant, and used to assess ability level in keeping with ICD-DCR criteria (World Health Organisation, 1993).

2.3 Data Analysis

Tetrachoric correlations were calculated for the parallel analysis using Psych package for R version 2.15 (R Core Team, 2013). Mplus v7.0 (Muthen & Muthen, 2012) was used for all other factor analyses. SPSS version 19.0 (IBM Corp, 2010) was used for the statistical modelling to compare the dimensional and categorical models of psychopathology.

To examine the external validity (Brewer, 2000) and generalisability of the dimensional model to different study populations, the Glasgow sample was used as a training dataset for the EFA and the North Northamptonshire sample as a validation dataset for the CFA.

2.3.1 Exploratory factor analyses

The first aim of the study was to develop a dimensional model of psychopathology using EFA. Reliability of a factor solution can be affected by the inclusion of items that score positively infrequently (low variance; Everitt, 1975). Twenty-six PPS-LD symptoms were rated positively in less than 5% of cases so were not included in the analyses (table 1). This left 38 symptoms for inclusion in the statistical modelling (table 1).

Glorfeld's adaptation of Horn's parallel analysis is the optimal method for estimating the number of factors to retain (Costello & Osborne, 2005) and works well for binary data (Glorfeld, 1995). The likely number of factors (*k*) was indicated by the number of factors with eigenvalues >95th percentile of the simulated null

distribution of eigenvalues, and was visualised using a scree plot. Models were compared for k – 1, k, and k + 1 factors, and model fit gauged using accepted cut-offs for four fit indices: relative χ^2 <2:1 (Tabachnik & Fidell, 2001); comparative fit index (CFI) ≥0.95 (Hu & Bentler, 1999); Tucker Lewis index (TLI) ≥0.95 (Hu & Bentler, 1999); root mean square of approximation (RMSEA) ≤0.06 (Hu & Bentler, 1999), with <0.03 representing excellent fit (Hooper et al., 2008).

In keeping with guidelines, common factor analysis was used for EFA (Costello & Osborne, 2005). Since individual data items were binary, factor analysis was based on tetrachoric correlations rather than standard Pearson correlations (Mislevy, 1986) and loadings estimated by factor analysis of tetrachoric correlation matrices. Factor loadings were estimated using the method of mean and variance adjusted weighted least squares (WLSMV), reported as more accurate for binary data than the more widely used maximum likelihood (Beauducel & Herzberg, 2006). Oblique rotation (*oblimin)* of the initial factor solution was used to allow examination of correlations between symptom dimensions (Costello & Osborne, 2005). For Pearson´s correlations, the minimum item loading often accepted as significant is usually 0.32, since this translates to the factor accounting for 10% of the variance of the item (Tabachnik & Fidell, 2001). To account for the considerably higher sampling error in tetrachoric correlations among binary responses we examined the loading structure for each EFA carried out on 1000 bootstrap samples of the data. A guide to the overall stability of the model was provided by the number of bootstrap samples aligned to the EFA.

2.3.2 Confirmatory factor analysis

To meet the second study aim of testing the validity of the model derived from the EFA, a CFA used WLSMV structural equation modelling and compared the same

four fit indices and cut-offs used for the EFA. Initially, three candidate models were derived by applying three different criteria for selecting robust symptoms to models fitted on the training data set: symptoms were selected if the EFA loading ≥0.32 in 80% (CFA model 1) and 90% (CFA model 2) of bootstrap samples; CFA model 3 included symptoms with loadings significant at the 1% level, i.e. where the loading > (2.58 × SE), where SE is the bootstrap standard error for the loading estimate output by Mplus. Model 1 gave the best it to the validation data set. It was therefore judged to be the most robust of the three candidate models and is reported below.

2.3.3 Predictive validity of dimensional and categorical models of psychopathology

The third aim of the study was to compare the predictive validity of dimensional model of psychopathology and categorical diagnoses used in clinical practice. To achieve this aim, factor/dimensional scores were calculated for the final dimensional model and their relationship with severity of psychiatric disorders and longitudinal outcome examined. The factor score is a composite measure representing the degree to which an individual scores positively on the items with high loadings onto a dimension and has been used in previous studies comparing dimensional models of psychopathology and categorical diagnosis (Dikeos et al., 2006; Prisciandaro and Roberts, 2009; van Os et al., 1996; van Os et al., 1999a; van Os et al., 1999b). Three linear regression analyses were run for each outcome measure, with the score on the outcome measure being the dependent variable. This was done with baseline data, to measure severity of psychiatric disorders (Brittain et al., 2013), and repeated using the 5-year follow-up data to measure longitudinal clinical outcome. The three statistical models included categorical diagnosis (statistical model 1); dimensional scores (statistical model 2); a full

model categorical diagnosis and factor/dimensional scores (statistical model 3). All three models included socio-clinical variables found to be associated with severity and outcome in a feasibility study (age, gender, level of intellectual disabilities, living circumstances, visual impairment, hearing impairment and incontinence; Melville, 2010). Since statistical models 1 and 2 were nested within statistical model 3, they were compared to the full model using the -2 log likelihood score and likelihood ratio test. A p-value less than 0.05 from the likelihood ratio test indicates a statistically significant difference between the full and nested model.

3.0 Results

Demographic and clinical information on the two samples is provided in table 2. There were no statistically significant differences in the demographic characteristics of the two samples in Table 2. The mean age of the Glasgow (mean= 42.3 years, SD 14.4) and North Northamptonshire (mean= 34.7 years, SD 13.0) samples were different ($t= -7.3$, $p < .000$).

**********Insert table 2 about here **********

3.1 Exploratory factor analysis- study aim 1

The break point in the scree plot suggested that between three and five factors could be extracted (Figure 1) and the respective fit indices from the EFA were compared (Table 3).

**********Insert figure 1 about here **********

**********Insert table 3 about here **********

Based on fit indices below accepted cut-offs, the three factor model was rejected at this stage, and the four factor (Table 4) and five factor (Table 5) models were taken forward to CFA, using the validation dataset.

**********Insert tables 4 and 5 about here **********

3.2 Confirmatory factor analysis- study aim 2

The five factor model had superior model fit indices ($\chi 2/df=1.27$, CFI=0.981, TLI=0.979, RMSEA=0.032) compared to the CFA using the four factor model ($\chi 2/df=1.7$, CFI=0.953, TLI=0.948, RMSEA=0.049). Comparing the four factor and five-factor models from the CFA (Table 6), factor 1 was interpreted as a *depressive* dimension, factor 2 as an *anxiety* dimension, and factor 3 as an *organic* dimension (reduced cognitive and behavioural functioning). Interpretation of factor 4 was unclear in the four-factor model. However, this was resolved in the five-factor model by the separation of items into an *emotion dysregulation-problem behaviour* (ED-PB) dimension (factor 4), that is commonly encountered in clinical practice, and a *psychosis* dimension (factor 5). The four clinicians involved in the study all independently interpreted the results in this way, such that consensus discussion was not required. Therefore, based on superior fit indices and improved clinical interpretation the five-factor model was selected as the preferred model. This was the model then used in the regression analyses.

**********insert table 6 about here**********

3.3 Predictive validity of dimensional and categorical models of psychopathology- study aim 3

The results in Table 7 address the third aim of the study by comparing the relationship of the dimensional and categorical models to severity of psychiatric disorders and five year longitudinal clinical outcome. Although the R^2 was always higher in the full model, the likelihood ratio tests (Table 7) indicated that removing the categorical diagnosis (model 2) did not change the fit of the model for any of the measures of severity or longitudinal clinical outcome. However, removing the symptom dimensions significantly reduced the fit of the model for three of the measures of baseline severity (HONOS-LD, CANDID-unmet and GAF) and two of the measures of longitudinal outcome (HoNOS-LD and GAF). Therefore, since a simpler model is preferable, based on parsimony symptom dimensions appear to have a stronger relationship to outcome than categorical diagnosis.

********** insert table 7 about here**********

4.0 Discussion

We believe our study is the first to develop and validate a dimensional model of psychopathology experienced by adults with intellectual disabilities using robust statistical methods (Melville et al., 2016). This is also the first study to compare the predictive validity of dimensional and categorical models of psychopathology in this population. Since problem behaviours were included in the ED-PB dimension and not the depressive dimension, our findings suggest that problem behaviours should not be considered as depressive equivalents. This has important treatment implications, and should also inform the development of improved psychiatric

classifications for this population. Symptom dimensions had excellent discriminant and face validity, and the clinical relevance of the dimensional model is strongly supported by the finding that the dimensional model had better predictive validity when compared against categorical diagnoses used in clinical practice. Our findings also highlight the importance of emotional regulation in relation to problem behaviours, which might provide a pathway to development of new, improved interventions.

4.1 Strengths and limitations

A statistical modelling approach to derive dimensional models of symptoms of psychiatric disorders has greater validity to examine whether problem behaviours are depressive equivalents than a two group, depression/non-depression methodology. Our statistical methods improved on the exploratory factor analysis used in the two previous studies that developed dimensional models (Sturmey et al., 2010; Tsiouris et al., 2003). We also believe that our study improves on previous methodologies by the use of two populations to develop and then validate an *a priori* model of symptom dimensions.

A strength of this study was that we collected data on a broader range of psychopathology compared to previous studies. We used a robust method of assessing psychopathology that emphasised the importance of clarifying that the presentation was distinct from the long standing problem behaviours that are commonly experienced in clinical practice and that there was a change from the previous level of functioning of the individuals with intellectual disabilities. The relatively large sample size suggests that the rates of psychopathology were likely to be similar to psychopathology presenting to clinicians working in intellectual disabilities services elsewhere. However, the low frequency of positive ratings for

many PPS-LD symptoms reduced the number of symptoms that could be included in the analysis. Although this improved the stability of the model it may have reduced the number of dimensions that could be extracted.

The majority of studies that have considered problem behaviours as depressive equivalents compared rates of problem behaviours in groups of participants with, and without a categorical diagnosis of depression. Previous authors have commented on the small, biased samples (Thakker et al., 2012) in these studies and the tautological challenges inherent in involving participants already diagnosed with depression in studies to understand the different presentation of depression in adults with intellectual disabilities (Ross & Oliver, 2002).

Around a third of the two samples were unable to provide ratings on the 10 PPS-LD items that require an individual to communicate in sentences (table 1) which effectively introduces missing data. Seven of these 10 items are psychotic symptoms. This explains why the psychosis dimension has fewer symptoms than the other four dimensions, which all meet the recommended minimum for stability of five items in a dimension (Costello & Osborne, 2005). Missing data has been shown to affect stability in statistical modeling (Muthen & Muthen, 2002). A commonly used solution to this issue is to increase the sample sizes to increase the power of the study. Previous studies have increased power by combining two or more samples, for the EFA and CFA. However, this would not have allowed the examination of external validity of the model that was possible in this study, and which we consider to be a strength of the study.

Although a relatively large sample was used in the analysis examining the relationship between the models of psychopathology and severity of psychiatric

disorder, the loss to follow up of participants between measurement of outcomes at baseline and five years was a limitation. Therefore, future studies with larger samples are needed to replicate the finding that the dimensional model of psychopathology is a better predictor of prognosis than categorical diagnoses.

4.2 The relevance of dimensional models of psychopathology to clinical practice

The third aim of the study was to consider the relevance of the dimensional model to clinical practice. This is the first intellectual disabilities study to compare the validity of an empirically derived dimensional model and a categorical model of psychopathology. Improved validity of the dimensional model compared to categorical diagnoses is in keeping with evidence from non-intellectual disabilities (Brittain et al., 2013; Dikeos et al., 2006; Markon, 2010; Prisciandaro & Roberts, 2009; van Os et al., 1996; van Os et al., 1999a; van Os et al., 1999b). The weak relationship between categorical diagnoses and clinical outcomes is recognised as an important limitation to the clinical utility of categorical diagnoses. However, categorical diagnoses make a useful contribution to communication with service users and between health professionals (Kendell & Jablensky, 2003), so dimensional models are best considered as complementary, rather than an alternative, to categorical diagnoses (Kotov et al., 2011). Using dimensional models alongside categorical diagnoses may provide more accurate information on prognosis, and facilitate clinical decision making about management. There is also some evidence that dimensional models of psychopathology lead to improved phenotypes for use in research investigating gene-environment contributions to psychiatric disorders (Kendler et al., 2011) and neuroimaging studies (Bebko et al., 2014). National Institute of Mental Health (NIMH) have recently proposed the

use of Research Domain Criteria (RDoC), incorporating dimensional models of psychopathology within a matrix of complicated, biological and behavioural, domains and constructs (Insel, 2014).

4.3 Clinical implications

We did not find evidence to support the inclusion of problem behaviours as items within diagnostic criteria for depression (Royal College of Psychiatrists, 2001) when experienced by adults with intellectual disabilities. This is an important finding for clinicians, to improve diagnostic accuracy and therefore the development of appropriate intervention plans. It may avoid overdiagnosis of depression and potentially over-prescription of medication. Future revisions of classification systems to diagnose psychiatric disorders experienced by adults with intellectual disabilities should also heed this finding, and consider incorporation of valid dimensional measures to be used alongside categorical diagnoses.

Problem behaviours may represent a “final common pathway” for distress experienced by adults with intellectual disabilities. There is a growing recognition of the relevance of emotion regulation to developmental psychopathology (Gross & Thompson, 2007). Compared to broader emotion regulation research (Aldao et al., 2010; Hill et al., 2006) the study of emotion regulation in individuals with intellectual disabilities is at an early stage (McClure et al., 2009). However, recent studies have begun to investigate the relationship between emotional dysregulation, problem behaviours and psychiatric disorders (Sappok et al., 2014) and our findings further highlight the link between emotional dysregulation and problem behaviours. Importantly, the development of interventions to enhance emotional regulation may increase the armoury of interventional packages to help adults with problem behaviours to learn to manage them. This might also improve

self-confidence as well as opening opportunities for enhanced community participation.

4.4 Future research

Given the significant costs to individuals with intellectual disabilities, families and communities, and the lack of evidence-based management strategies (Campbell et al., 2014) problem behaviours are a priority area for research. This study highlights the need for work to examine the relationship between problem behaviours and other psychopathology, with the aim of improving the assessment, diagnosis and management of psychiatric disorders experienced by adults with intellectual disabilities.

The RDoC may be a useful framework to investigate the relevance of emotional dysregulation to the pathophysiology of psychopathology experienced by individuals with intellectual disabilities. For example, the arousal/ regulatory processes domain within the RDoC framework could offer insights to the link between the ED-PB dimension and relevant physiological systems e.g. autonomic nervous system or behaviour paradigms e.g. motor activity (Casey et al., 2014).

5.0 Acknowledgements

We are very grateful to the participants, family members and paid carers who participated in this study. This research was funded by a grant from the Chief Scientist Office, Scottish Government Health Department (Reference: CZG/2/556).

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Figure 1. Scree plot of eigenvalues from polychoric and polyserial correlations between 38 Psychiatric Present State-Learning Disabilities items for the 457 subjects in the training dataset. The shaded area shows a 95% confidence band for eigenvalues from 50 simulated random (uncorrelated) data sets.

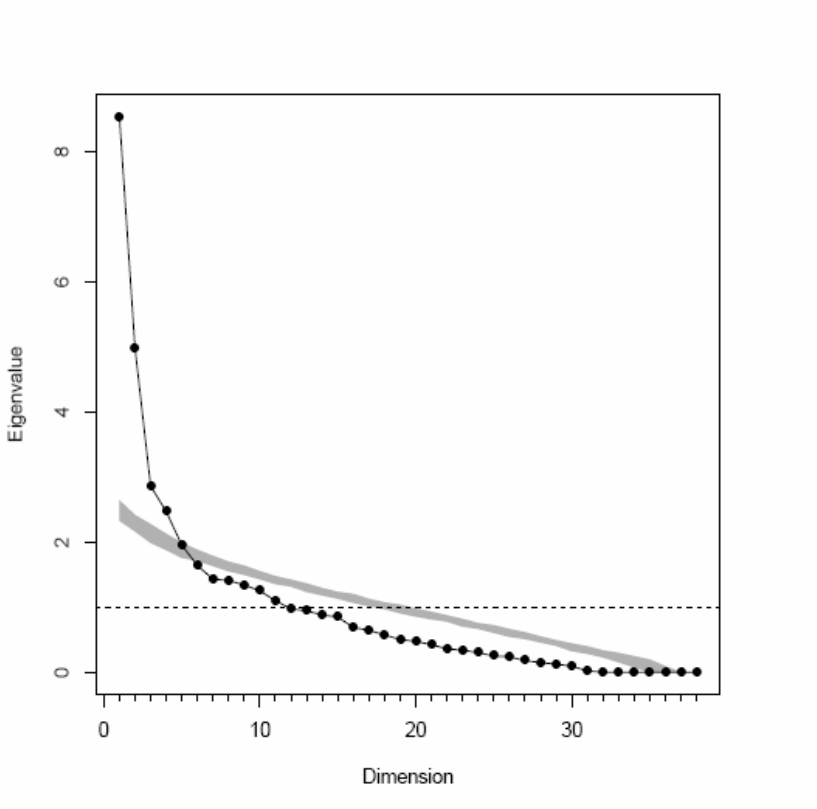

Table 1. Items of psychopathology rated in the Psychiatric Present State- Learning Disabilities (PPS-LD)

	PPS-LD item	Verbal descriptor
1	Worry	Worries or feels apprehensive about everyday events and problems.
2	Generalised anxiety	Trouble with anxious or panicky feeling?
3	Agoraphobia*	Fear in two or more specific situations e.g. going out, crowds, public transport etc
4	Animal phobia	Irrational fear of animals
5	Social anxiety*	Irrational fear of social situations
6	Specific phobia	Irrational fear of specific trigger item
7	Repetitive rituals	Obsessional checking and repeating
8	Excessive orderliness	Obsessional actions associated with need for excessive orderliness
9	Obsessional cleanliness*	Obsessional actions associated with need for excessive cleanliness
10	Intrusive, distressing thoughts†	Intrusive thoughts that individual tries to resist
11	Low mood	Change in mood, lower mood than usual, miserable
12	Increased mood lability	Mood more changeable than usual
13	Irritable mood	More irritable than normal
14	Social withdrawal	More socially withdrawn than usual
15	Anhedonia	Less interest or enjoyment of activities
16	Reduced quantity of speech	Reduced quantity of speech
17	Increased quantity of speech*	Increased quantity of speech
18	Tearfulness	More tearful than usual
19	Reduced self-care skills	Reduced self-care skills
20	Loss of energy	Reduced energy levels compared to normal
21	Increased energy levels*	Increased energy levels compared to normal
22	Reduced cognitive functioning	Getting muddled and confused
23	Forgetting names*	Forgotten the names of people used to know
24	Gets lost in familiar places*	Got lost in places where used to find way around e.g. home, local streets
25	Reduced verbal comprehension	Less able to follow instructions than before
26	Expansive mood*	Claims to be especially good at something or everything
27	Memory problems	Forgotten things that would usually remember
28	Mixing up day and night*	Thinks it is night during the day, or it is daytime at night
29	Change in literary skills*	Loss of literary skills compared to previously
30	Change financial skills*	Loss of financial skills compared to previously
31	Word finding problems*	Get words mixed up or can't remember the names of things
32	Change in personality	Change in personality, coarsening of personality traits
33	Initial insomnia	Problems falling asleep when goes to bed
34	Mid-insomnia	Wakes up during the night and difficult to fall asleep
35	Early morning wakening	Wakes up more than an hour earlier than

		usual
36	Increased daytime sleeping	Sleeping more during the day
37	Reversed sleep pattern*	Awake at night and asleep during the day
38	Reduced need for sleep*	Doesn't need as much sleep compared to normal
39	Reduced appetite	Loss of appetite
40	Increased appetite*	Increased appetite
41	Weight loss	Weight loss
42	Increased weight	Increased weight
43	Diurnal mood variation-morning	Feels worst in the morning and better as the day goes on
44	Diurnal mood variation-evening*	Feels best in the morning and worse as the day goes on
45	Less able to concentrate	Less able to concentrate
46	Increased verbal aggression	Increased verbal aggression
47	Reduced verbal aggression*	Reduced verbal aggression
48	Increased physical aggression	Increased physical aggression
49	Reduced physical aggression*	Reduced physical aggression
50	Increased need for reassurance	Increased need for reassurance
51	Self harm/ self-injurious behaviour	Self harm/ self-injurious behaviour
52	Increased somatic complaints	Increased complaints of physical health problems
53	Change in sexual behaviour*	Inappropriate sexual behaviour or significant change in sexual behaviour
52	Loss of interest in sex*	Loss of interest in sex
54	Reckless, irresponsible behaviour*	Reckless, irresponsible behaviour
55	Social disinhibition*	Over familiarity, intrusive social disinhibition
56	Ideas of guilt†	Ideas of guilt
57	Preoccupied with morbid thoughts†	Preoccupied with morbid thoughts or death
58	Reduced self-esteem†	Loss of self-esteem
59	Hopelessness†*	Loss of hope for the future
60	Delusions†	Fixed, unshakeable beliefs
61	Auditory hallucinations†	Hearing noises or voices that can't be explained
62	Visual hallucination†*	Complaining of seeing things which aren't there
63	Schneider's first rank symptoms†*	Schneider's first rank symptoms
64	Impossible, bizarre delusions†*	Impossible, bizarre delusions

† Items only rated if the individual can communicate verbally in sentences

* Items rated positively in less than 5% of cases

Table 2. Participant characteristics of the Glasgow and North Northamptonshire samples.

Variable		Glasgow (N=457)			North Northamptonshire (N=274)		p
		N	%		N	%	
Gender	Female	206	45		134	49	.223
	Male	251	55		140	51	
Level of intellectual disabilities	Mild	82	21		39	15	.531
	Moderate	74	19		54	21	
	Severe	90	23		74	29	
	Profound	137	36		91	35	
Epilepsy	No	312	70		174	64	.187
	Yes, well-controlled	86	19		51	19	
	Yes, poor control	47	11		48	18	
Vision	No visual impairment	353	82		215	88	.700
	Visual impairment	76	18		30	12	
Hearing	No hearing impairment	392	91		239	94	.581
	Hearing impairment	38	9		15	6	
Mobility	No mobility problems	322	74		187	73	.529
	Mobility problems	116	26		69	27	
Urinary incontinence	No urinary incontinence	282	63		165	60	.690
	Urinary incontinence	164	37		109	40	
Bowel incontinence	No bowel incontinence	332	74		202	74	.751
	Bowel incontinence	114	26		72	26	

Table 3. Fit indices for the exploratory factor analysis models with three-five factors. The recommended cut-offs for the four indices are shown in brackets.

No of factors	**χ^{2a} (df[b])**	**χ^2/df** (<2:1)	**CFI[c]** (≥0.95)	**TLI[d]** (≥0.95)	**RMSEA[e]** (≤0.06)
3	896.0 (592)	1.5	0.922	0.908	0.034
4	734.6 (557)	1.3	0.955	0.943	0.026
5	659.7 (523)	1.3	0.965	0.953	0.024

[a] Chi square statistical test

[b] Degrees of freedom

[c] Comparative Fit Index

[d] Tucker Lewis Index

[e] Root Mean Square of Approximation

Table 4. Four-factor model with pairwise deletion on full Glasgow data with bootstrap standard errors- 457 participants & 38 variables (*Oblimin rotation & WLSMV* [a] *extraction*)

	Positive Responses	Factor 1	Factor 2	Factor 3	Factor 4
Anhedonia	133 (29.1%)	0.86 (0.24)	0.06 (0.18)	0.12 (0.22)	0.06 (0.15)
Low mood	160 (35.0%)	0.68 (0.21)	0.33 (0.19)	0.02 (0.18)	0.12 (0.16)
Social withdrawal	177 (38.7%)	0.65 (0.18)	0.12 (0.16)	0.12 (0.17)	0.09 (0.13)
Loss of appetite	98 (21.4%)	0.62 (0.25)	0.21 (0.19)	0.00 (0.19)	-0.10 (0.18)
Weight loss	99 (21.7%)	0.60 (0.23)	0.12 (0.18)	-0.01 (0.19)	-0.04 (0.16)
Excessive orderliness	91 (20.2%)	-0.49 (0.19)	0.23 (0.18)	0.24 (0.18)	0.06 (0.18)
Reduced quantity of speech	87 (19.2%)	0.49 (0.19)	-0.09 (0.12)	0.48 (0.17)	0.10 (0.18)
Loss of energy	166 (36.4%)	0.48 (0.19)	0.10 (0.12)	0.42 (0.14)	0.01 (0.12)
Repetitive rituals	92 (20.2%)	-0.45 (0.20)	0.34 (0.19)	0.30 (0.19)	0.08 (0.21)
Increased daytime sleeping	42 (9.2%)	0.32 (0.18)	-0.06 (0.15)	0.28 (0.14)	0.08 (0.17)
Early morning wakening	39 (8.5%)	0.28 (0.16)	0.26 (0.17)	-0.12 (0.15)	0.12 (0.16)
Worry	208 (46.8%)	0.04 (0.15)	0.77 (0.19)	-0.06 (0.10)	-0.05 (0.19)
Ideas of guilt	43 (15.5%)	0.15 (0.21)	0.76 (0.24)	-0.09 (0.13)	-0.25 (0.28)
Preoccupied with morbid thoughts	38 (13.7%)	0.05 (0.20)	0.76 (0.24)	0.04 (0.13)	0.12 (0.23)
Generalised anxiety	124 (27.7%)	0.05 (0.14)	0.65 (0.17)	-0.09 (0.11)	-0.04 (0.19)
Intrusive, distressing thoughts	28 (9.5%)	-0.23 (0.20)	0.58 (0.22)	0.06 (0.16)	0.19 (0.22)
Loss of self-esteem	57 (20.6%)	0.37 (0.20)	0.58 (0.22)	-0.02 (0.12)	-0.04 (0.18)
Initial insomnia	101 (22.1%)	0.04 (0.14)	0.57 (0.18)	-0.18 (0.12)	0.09 (0.17)
Increased somatic complaints	63 (14.0%)	0.04 (0.17)	0.47 (0.17)	0.22 (0.13)	0.02 (0.19)
Mid-insomnia	87 (19.0%)	0.27 (0.15)	0.42 (0.18)	-0.06 (0.14)	0.13 (0.16)
Tearfulness	163 (35.7%)	0.38 (0.15)	0.40 (0.18)	-0.07 (0.14)	0.24 (0.18)
Increased need for reassurance	158 (35.0%)	0.01 (0.15)	0.35 (0.15)	0.32 (0.12)	0.24 (0.21)
Animal phobia	38 (8.3%)	-0.10 (0.15)	0.20 (0.13)	-0.07 (0.13)	0.18 (0.16)
Memory problems	51 (11.4%)	-0.08 (0.14)	0.04 (0.12)	0.97 (0.25)	-0.12 (0.25)
Reduced verbal comprehension	54 (12.1%)	0.14 (0.15)	-0.19 (0.10)	0.86 (0.22)	-0.09 (0.22)
Reduced cognitive functioning	73 (16.0%)	0.07 (0.14)	0.02 (0.09)	0.85 (0.21)	-0.11 (0.22)
Change in personality	35 (7.7%)	0.45 (0.19)	-0.30 (0.14)	0.59 (0.20)	0.06 (0.20)
Reduced self-care skills	124 (27.6%)	0.46 (0.17)	0.08 (0.12)	0.50 (0.16)	0.19 (0.20)
Less able to concentrate	183 (40.0%)	0.15 (0.15)	0.23 (0.14)	0.33 (0.12)	0.29 (0.22)
Increased verbal aggression	186 (40.7%)	0.06 (0.26)	-0.01 (0.24)	-0.07 (0.19)	0.88 (0.54)
Increased physical aggression	118 (25.8%)	0.06 (0.26)	-0.22 (0.23)	-0.21 (0.19)	0.88 (0.54)
Increased mood lability	163 (35.7%)	0.01 (0.18)	0.14 (0.18)	-0.08 (0.14)	0.58 (0.35)
Irritable mood	189 (41.4%)	0.29 (0.16)	0.23 (0.19)	-0.04 (0.15)	0.55 (0.34)
Auditory hallucinations	49 (17.6%)	-0.27 (0.33)	0.15 (0.25)	0.35 (0.24)	0.55 (0.42)
Delusions	39 (14.0%)	-0.23 (0.31)	0.19 (0.24)	0.49 (0.23)	0.51 (0.40)
Self harm	117 (25.7%)	0.04 (0.17)	0.16 (0.16)	-0.30 (0.15)	0.47 (0.28)
Diurnal variation-worse in the morning	38 (8.3%)	0.20 (0.18)	0.03 (0.17)	0.10 (0.15)	0.38 (0.28)
Specific phobia	41 (9.0%)	-0.03 (0.14)	0.04 (0.13)	-0.11 (0.13)	0.13 (0.16)

[a] Mean and variance adjusted weighted least squares

Table 5. Four-factor model with pairwise deletion on full Glasgow data with bootstrap standard errors- 457 participants & 38 variables (*Oblimin rotation & WLSMV* [a] *extraction*)

	Positive Responses	Factor 1	Factor 2	Factor 3	Factor 4
Anhedonia	133 (29.1%)	0.86 (0.24)	0.06 (0.18)	0.12 (0.22)	0.06 (0.15)
Low mood	160 (35.0%)	0.68 (0.21)	0.33 (0.19)	0.02 (0.18)	0.12 (0.16)
Social withdrawal	177 (38.7%)	0.65 (0.18)	0.12 (0.16)	0.12 (0.17)	0.09 (0.13)
Loss of appetite	98 (21.4%)	0.62 (0.25)	0.21 (0.19)	0.00 (0.19)	-0.10 (0.18)
Weight loss	99 (21.7%)	0.60 (0.23)	0.12 (0.18)	-0.01 (0.19)	-0.04 (0.16)
Excessive orderliness	91 (20.2%)	-0.49 (0.19)	0.23 (0.18)	0.24 (0.18)	0.06 (0.18)
Reduced quantity of speech	87 (19.2%)	0.49 (0.19)	-0.09 (0.12)	0.48 (0.17)	0.10 (0.18)
Loss of energy	166 (36.4%)	0.48 (0.19)	0.10 (0.12)	0.42 (0.14)	0.01 (0.12)
Repetitive rituals	92 (20.2%)	-0.45 (0.20)	0.34 (0.19)	0.30 (0.19)	0.08 (0.21)
Increased daytime sleeping	42 (9.2%)	0.32 (0.18)	-0.06 (0.15)	0.28 (0.14)	0.08 (0.17)
Early morning wakening	39 (8.5%)	0.28 (0.16)	0.26 (0.17)	-0.12 (0.15)	0.12 (0.16)
Worry	208 (46.8%)	0.04 (0.15)	0.77 (0.19)	-0.06 (0.10)	-0.05 (0.19)
Ideas of guilt	43 (15.5%)	0.15 (0.21)	0.76 (0.24)	-0.09 (0.13)	-0.25 (0.28)
Preoccupied with morbid thoughts	38 (13.7%)	0.05 (0.20)	0.76 (0.24)	0.04 (0.13)	0.12 (0.23)
Generalised anxiety	124 (27.7%)	0.05 (0.14)	0.65 (0.17)	-0.09 (0.11)	-0.04 (0.19)
Intrusive, distressing thoughts	28 (9.5%)	-0.23 (0.20)	0.58 (0.22)	0.06 (0.16)	0.19 (0.22)
Loss of self-esteem	57 (20.6%)	0.37 (0.20)	0.58 (0.22)	-0.02 (0.12)	-0.04 (0.18)
Initial insomnia	101 (22.1%)	0.04 (0.14)	0.57 (0.18)	-0.18 (0.12)	0.09 (0.17)
Increased somatic complaints	63 (14.0%)	0.04 (0.17)	0.47 (0.17)	0.22 (0.13)	0.02 (0.19)
Mid-insomnia	87 (19.0%)	0.27 (0.15)	0.42 (0.18)	-0.06 (0.14)	0.13 (0.16)
Tearfulness	163 (35.7%)	0.38 (0.15)	0.40 (0.18)	-0.07 (0.14)	0.24 (0.18)
Increased need for reassurance	158 (35.0%)	0.01 (0.15)	0.35 (0.15)	0.32 (0.12)	0.24 (0.21)
Animal phobia	38 (8.3%)	-0.10 (0.15)	0.20 (0.13)	-0.07 (0.13)	0.18 (0.16)
Memory problems	51 (11.4%)	-0.08 (0.14)	0.04 (0.12)	0.97 (0.25)	-0.12 (0.25)
Reduced verbal comprehension	54 (12.1%)	0.14 (0.15)	-0.19 (0.10)	0.86 (0.22)	-0.09 (0.22)
Reduced cognitive functioning	73 (16.0%)	0.07 (0.14)	0.02 (0.09)	0.85 (0.21)	-0.11 (0.22)
Change in personality	35 (7.7%)	0.45 (0.19)	-0.30 (0.14)	0.59 (0.20)	0.06 (0.20)
Reduced self-care skills	124 (27.6%)	0.46 (0.17)	0.08 (0.12)	0.50 (0.16)	0.19 (0.20)
Less able to concentrate	183 (40.0%)	0.15 (0.15)	0.23 (0.14)	0.33 (0.12)	0.29 (0.22)
Increased verbal aggression	186 (40.7%)	0.06 (0.26)	-0.01 (0.24)	-0.07 (0.19)	0.88 (0.54)
Increased physical aggression	118 (25.8%)	0.06 (0.26)	-0.22 (0.23)	-0.21 (0.19)	0.88 (0.54)
Increased mood lability	163 (35.7%)	0.01 (0.18)	0.14 (0.18)	-0.08 (0.14)	0.58 (0.35)
Irritable mood	189 (41.4%)	0.29 (0.16)	0.23 (0.19)	-0.04 (0.15)	0.55 (0.34)
Auditory hallucinations	49 (17.6%)	-0.27 (0.33)	0.15 (0.25)	0.35 (0.24)	0.55 (0.42)
Delusions	39 (14.0%)	-0.23 (0.31)	0.19 (0.24)	0.49 (0.23)	0.51 (0.40)
Self harm	117 (25.7%)	0.04 (0.17)	0.16 (0.16)	-0.30 (0.15)	0.47 (0.28)
Diurnal variation-worse in the morning	38 (8.3%)	0.20 (0.18)	0.03 (0.17)	0.10 (0.15)	0.38 (0.28)
Specific phobia	41 (9.0%)	-0.03 (0.14)	0.04 (0.13)	-0.11 (0.13)	0.13 (0.16)

[a] Mean and variance adjusted weighted least squares

Table 6. Confirmatory factor analysis on North Northamptonshire data (n=274) using items selected from five- factor exploratory factor analysis if 80% of resample loadings are greater than 0.32

	Estimate	Standard error	p-value
Depressive			
Anhedonia	0.94	0.03	<0.001
Low mood	0.98	0.02	<0.001
Social withdrawal	0.90	0.03	<0.001
Reduced quantity of speech	0.85	0.04	<0.001
Loss of energy	0.87	0.04	<0.001
Anxiety			
Worry	0.79	0.08	<0.001
Ideas of guilt	0.73	0.11	<0.001
Preoccupied with morbid thoughts	0.63	0.11	<0.001
Generalised anxiety	0.68	0.07	<0.001
Initial insomnia	0.63	0.09	<0.001
Loss of self-esteem	0.63	0.12	<0.001
Intrusive, distressing thoughts	0.69	0.18	<0.001
Increased somatic complaints	0.75	0.08	<0.001
Organic			
Memory problems	0.92	0.04	<0.001
Reduced cognitive functioning	0.94	0.03	<0.001
Reduced verbal comprehension	0.96	0.03	<0.001
Change in personality	0.90	0.06	<0.001
ED-PB			
Increased verbal aggression	0.95	0.04	<0.001
Increased physical aggression	0.85	0.04	<0.001
Increased mood lability	0.76	0.07	<0.001
Irritable mood	0.94	0.05	<0.001
Self harm	0.69	0.08	<0.001
Psychosis			
Auditory hallucinations	0.93	0.12	<0.001
Delusions	0.98	0.13	<0.001

Table 7. Comparing the contribution to clinical outcome measures of nested models with categorical diagnosis and dimensional scores to a full model.

	Adjusted R^2 (-2 Log Likelihood, p[a])					
	Baseline (severity)			**5 year follow up (longitudinal outcome)**		
	Model 1[b]	**Model 2**	**Model 3**	**Model 1**	**Model 2**	**Model 3**
HoNOS-LD	0.13 (31.2, < .000)	0.37 (3.2, .67)	0.39	0.31 (11.2, .048)	0.41 (38.7, .12)	0.43
CANDID-unmet	0.19 (11.2, .047)	0.27 (1.7, .89)	0.28	0.03 (8.01, .156)	0.10 (4.32, .501)	0.12
CANDID-met	0.43 (6.7, 0.24)	0.47 (2.6, .764)	0.47	0.03 (10.14, .072)	0.10 (2.97, .705)	0.12
GAF	0.13 (30.3, <.000)	0.37 (4.26, .513)	0.37	.543 (11.09, .049)	.579 (4.70, .454)	.615

[a] p value from likelihood ratio test to compare each of the nested models to the full model.

[b] Model 1= socio-clinical variables and categorical diagnosis; Model 2= socio-clinical variables and dimensional scores; Model 3= socio-clinical variables, categorical diagnosis and dimensional scores.