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Self-reported versus informant-reported depressive symptoms in adults with mild intellectual disability

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Abstract

Background—Virtually nothing is known about potential differences in the types of depression symptoms reported by adults with mild intellectual disability (ID) on self-reported questionnaires as compared with the types of symptoms reported by caregivers on informant questionnaires. Moreover, little is known about how the presentation of depression among adults with mild ID varies based on socio-demographic characteristics.

Methods—We compared findings from two self-reported questionnaires, the Self-Reported Depression Questionnaire (SRDQ) and the Glasgow Depression Scale for People with a Learning Disability (GDS), to that of an informant questionnaire of depressive symptoms, the Glasgow Depression Scale – Caregiver Supplement (CGDS), in 80 adults with mild ID. We also examined the association between age, sex, IQ and the presence of a co-occurring psychiatric disorder and frequency of affective, cognitive and somatic depressive symptoms in our sample of adults with mild ID.

Results—Adults with mild ID self-reported a higher frequency of affective and cognitive depressive symptoms than staff reported on the informant measure. Staff reported a higher frequency of somatic symptoms than adults with mild ID on one of the self-reported questionnaires (GDS) and a similar frequency on the other self-reported questionnaire (SRDQ). Important differences were found in the types of depressive symptoms based on their IQ, age and presence of a co-occurring psychiatric disorder.

Conclusion—Informant questionnaires offer valuable information, but assessment should include self-reported questionnaires as these questionnaires add unique information about internalised experiences (affective and cognitive symptoms) of adults with mild ID that may not be apparent to caregivers. Health care providers should be made aware of the important differences in the presentation of depressive based on their IQ, age and presence of a co-occurring psychiatric disorder.

Keywords

depression; developmental disability; intellectual disability; mental health; self-report measures

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Introduction

Based on a prevalence estimate of 1.6%, there are nearly 5 million individuals with intellectual disability (ID) living in the USA. The large majority (85%) of these individuals have mild ID (American Psychiatric Association 2000). Individuals with ID are at an increased risk for developing mental health problems; studies indicate that more than onethird of adults with ID met criteria for a psychiatric disorder (Bhaumik et al. 2008). Depression is one of the most frequently occurring psychiatric disorders in adults with ID, with some studies suggesting comparable rates to that of the general population (van Schrojenstein Lantman-de Valk et al. 1997) and other studies suggesting that adults with ID are four to six times more likely to experience a depressive disorder in their lifetime than are adults without ID (Richards et al. 2001; Collishaw et al. 2004). Yet, health providers often fail to screen for depression in adults with ID and thus depression often goes undetected (Poindexter 2006). In part, screening efforts for depression may be low because of the paucity of research on self-reported and informant questionnaires in adults with ID. Currently, only a handful of studies have examined the validity and reliability of depressive measures in an ID population and no published studies have examined differences in the types of symptoms reported by adults with mild ID on self-reported questionnaires as compared with the types of symptoms reported by caregivers on informant questionnaires.

Depression is largely defined by internal subjective experiences (i.e. thoughts and feelings), and is typically assessed through self-reported questionnaires in adults without ID. The use of self-reported questionnaires among adults with ID can be challenging, as it requires that individuals understand the question, attend to multiple response alternatives, and respond in an unbiased manner (e.g. not influenced by response option order or demand characteristics). Despite these challenges, there has been a proliferation of self-reported questionnaires in the field of ID (see Hartley & MacLean 2006 for review). These studies indicate that when instruments and training procedures are designed to ensure comprehension and include appropriate response formats, adults with mild ID are able to reliably use self-reported questionnaires with Likert-type scales of up to five response options (Finlay & Lyons 2001; Hartley & MacLean 2006). A handful of studies have now demonstrated adequate levels of reliability and validity in self-reported questionnaires of depression symptoms in adults with mild ID (Reynolds & Baker 1988; Cuthill *et al.* 2003; McBrien 2003; Esbensen *et al.* 2005).

Diagnostic decisions should utilise as many sources of information as possible (Cooper & Collacott 1996). Thus, in addition to self-reported questionnaires, it is beneficial to obtain reports of depressive symptoms by caregivers. However, virtually no research has examined potential differences in the types of depressive symptoms reported by adults with mild ID as compared with their caregivers. Research on the general population indicates that informant reports of depressive symptomology often differ from self-reports. In general, studies suggest that informants report a lower frequency and/or severity of affective and cognitive depressive symptoms than does the individual themselves (e.g. Epstein *et al.* 1989; Burke *et al.* 1998). There is a particularly large discrepancy in the frequency and/or severity of self-reported versus informant-reported affective and cognitive depressive symptoms in individuals with deficits in cognitive functioning due to medical illnesses (Allen *et al.* 2002),

perhaps because of difficulties communicating internalised symptoms to caregivers and/or the failure of caregivers to recognise behavioural manifestations of these internalised symptoms. McBrien (2003) similarly hypothesised that adults with ID may have difficulty describing their cognitive and affective symptoms to caregivers and caregivers may have difficulty deciphering these symptoms from observable behaviours. In contrast, Lunsky *et al.* (2002) proposed that caregivers may be most aware of the somatic symptoms of depressed adults with ID, which are more easily observed (e.g. sleeping longer and eating more). The primary aim of the present study is to identify differences in the types of depressive symptoms (affective, cognitive and somatic) reported by adults with mild ID as compared with their caregivers.

The secondary aim of the present study is to understand how the presentation of depression varies based on socio-demographic characteristics. Within the general population, there are important differences in the presentation of depression by age and sex. Older adults endorse a higher frequency and/or severity of somatic depressive symptoms and a lower frequency and/or severity of cognitive depressive symptoms than younger adults (Drayer et al. 2005; Balsis & Cully 2008; Hegeman et al. 2012) and women report higher frequency and/or severity of somatic depressive symptoms than men (Silverstein 2002; Wenzel et al. 2005). Whether age and sex are similarly related to differences in depressive symptoms in adults with mild ID has yet to be examined. Among adults with mild ID, IQ may also be related to differences in the presentation of depressive symptoms. Adults with higher IOs may be more aware of their feelings and thoughts and better able to communicate these feelings and thoughts to caregivers than are adults with lower IQs (Tsiouris et al. 2011). As a result, adults with mild ID who have higher IQs may endorse and be reported by caregivers to have a higher frequency of cognitive and affective depressive symptoms. Moreover, adults with mild ID who have a comorbid psychiatric disorder (e.g. anxiety disorder or personality disorder) may be more likely to report a higher frequency of depressive symptoms as compared with adults who do not have a comorbid psychiatric disorder, as co-occurring conditions can exacerbate symptoms of depression (Bakken et al. 2010; Tsiouris et al. 2011). Individuals with ID frequently have multiple psychiatric disorders (Levfer et al. 2006; Cooper et al. 2007) and thus understanding the impact of co-occurring psychiatric disorders on the presentation of depression is critical for healthcare providers.

In the present study, we compared findings from two self-reported questionnaires, the Self-Reported Depression Questionnaire (SRDQ; Reynolds & Baker 1988) and the Glasgow Depression Scale for people with a Learning Disability (GDS; Cuthill *et al.* 2003), to that of an informant questionnaire of depressive symptoms, the Glasgow Depression Scale – Caregiver Supplement (CGDS; Cuthill *et al.* 2003), in 80 adults with mild ID. Staff from the adult with mild ID's disability service provider who had contact at least twice a week with the adult and who had known the adult for at least 6 months served as the informant. Of the 80 adults with mild ID, 30 adults had a current diagnosis of a depressive disorder from an independent health care provider, which was verified by research staff. Depressive symptoms were categorised into three domains: Cognitive, Affective and Somatic. We hypothesised that the two self-reported questionnaires would be highly correlated, whereas there would only be a modest correlation between both self-reported questionnaires and the

informant questionnaire. We hypothesised that adults with mild ID would report a higher frequency of cognitive and affective depressive symptoms than would be endorsed by staff on the informant questionnaire. In contrast, staff were expected to endorse a similar frequency of somatic depressive symptoms as the adults with mild ID.

We also examined the association between age, sex, IQ and the presence of a co-occurring psychiatric disorder and the frequency of affective, cognitive and somatic depressive symptoms in our sample of adults with mild ID. We expected age to be positively related to the frequency of somatic depressive symptoms and negatively related to the frequency of cognitive depressive symptoms, based on evidence from the general population. We also expected women with mild ID to report a higher frequency of somatic depressive symptoms than men based on evidence from the general population. We hypothesised that IQ would be positively correlated with the frequency of cognitive and affective depressive symptoms. Finally, we expected that the presence of a co-occurring psychiatric disorder would exacerbate symptoms of depression and thus be related to a higher frequency of depressive symptoms.

Methods

Participants

Eighty-four adults with mild ID (IQ M = 62.78, SD = 9.22, and concomitant impairments in adaptive behaviour) were recruited from 11 disability service providers in the Rocky Mountain region of the USA between 2007 and 2009. Four adults with mild ID were not able to pass the pre-test procedure outlined below and were excluded from the study. Table 1 displays socio-demographic information on the remaining 80 adults with mild ID. Nearly equal numbers of men (n = 38) and women (n = 42) participated in the study. The majority of adults with mild ID were Caucasian, non-Hispanic and had an average age of 38.87 years (SD = 13.09). The large majority of adults with mild ID (n = 74, 92.50%) had an unknown aetiology for ID, while four (5.00%) participants had Down syndrome, one (1.25%) participant had Prader–Willi syndrome and one (1.25%) participant had Williams syndrome. This sample was recruited as part of a larger study on depression in adults with mild ID, and thus special efforts were made to include adults with a diagnosis of depression. As a result, 30 adults with mild ID had a diagnosis of a depressive disorder (i.e. major depressive disorder, dysthymia, bipolar disorder or depression - not otherwise specified) that was determined by an independent health care provider. These participants were also separately deemed to currently meet criteria for a depressive disorder (and to currently be demonstrating significant depressive symptoms) by project staff using the Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation (DC-LD; Royal College of Psychiatrists 2001) criteria. The majority of these participants (n = 27, 90.00%) were prescribed medication to manage their depression. The remaining 50 participants did not have a diagnosis of depression in their medical record and did not currently meet criteria for a depressive disorder based on the DC-LD interview by project staff. Of these 50 participants, 17 (34.0%) had a non-depressive psychiatric disorder diagnosis by their disability service provider. Fifteen (30%) participants in the nondepressed group were taking anti-psychotic medications for purposes other than a depressive

disorder and six (7.50%) participants were taking anticonvulsants for the purpose of controlling epilepsy. The prevalence of depressive disorders and other psychiatric disorders in this sample is consistent with large population-based studies of adults with mild ID (Borthwick-Duffy 1994; White *et al.* 2005).

A staff person from the adult with mild ID's disability service provider was recruited to complete an informant questionnaire of depressive symptoms. Table 1 also displays socio-demographic information on staff. Staff reported working with the adult with mild ID for an average of 3.74 years (ranged: 0.50–8.00 years) and had contact with the adult with mild ID at least twice a week. The average age of the staff was 27.89 years (SD = 6.78).

Measures

Socio-demographic characteristics—Staff reported on the age and sex of the adult with mild ID. The Kaufman Brief Intelligence Test, 2nd Edition (KBIT-2) (Kaufman & Kaufman 2004), a test of verbal and non-verbal cognitive abilities, was individually administered to adults with mild ID. The Composite IQ has satisfactory internal consistency (0.86–0.96), test–retest reliability (0.88–0.92) and concurrent validity (Kaufman & Kaufman 2004), and was used in the present study. To assess the adult with mild ID's adaptive behaviour, staff completed the Adaptive Behaviour Assessment System-2nd Edition (ABAS-II) (Harrison & Oakland 2006). The General Adaptive Composite (GAC) score, which has satisfactory internal consistency (0.97–0.99), test–retest reliability (0.86–0.99) and concurrent validity (Harrison & Oakland 2006), was used to verify the presence of ID.

Self-Report Depression Questionnaire (SRDQ; Reynolds & Baker 1988)—The SRDQ is a 32-item self-report measure of depressive symptoms developed for adults with mild ID (Reynolds & Baker 1988). Sample items include '*I feel sad*' and '*I am no good*'. Item responses are *almost never* (0), *sometimes* (1) and *most of the time* (3), reflecting the frequency with which the symptom was experienced during the last 2 weeks. For the last item on the SRDQ, the individual had to select one of three faces that expressed how he or she felt during the last 2 weeks [i.e. '*Happy*' (0), '*Neutral*' (1) or '*Sad*' (2)]. Previous studies using the SRDQ have reported high internal consistency (0.90), test–retest reliability (r = 0.63) and criterion validity with the Hamilton Depression Rating Scale (r = 0.65; Reynolds & Baker 1988). Furthermore, Esbensen *et al.* (2005) found that the SRDQ had good to excellent reliability in a sample of 192 adults with mild ID. By comparing adults with mild ID with and without depression, the measure was also shown to have high convergent, discriminant and predictive validity (Esbensen *et al.* 2005).

Glasgow Depression Scale for people with a learning disability (GDS; Cuthill

et al. 2003)—The GDS is a 20-item self-report instrument based on the DC-LD diagnostic criteria that was developed to assess depression in adults with mild ID. Sample items include '*Have you felt that life was not worth living*' and '*Have you felt as if everything is your fault*?' Item responses are *never/no* (0), *sometimes* (1) and *always/a lot* (2), reflecting the frequency with which the symptom was experienced during the last 2 weeks. Cuthill *et al.* (2003) reported that the GDS had a test–retest reliability of 0.97 and internal reliability of

0.90 in a sample of 38 adults with ID. The GDS was also shown to be strongly correlated with the Beck Depression Inventory – II (r = 0.88) in this same sample.

Glasgow Depression Scale – Caregiver Supplement (CGDS; Cuthill et al. 2003)

—The CGDS is an informant measure of depressive symptoms intended to be used in conjunction with the GDS. The CGDS is a 16-item measure administered to either family members or professionals caring for people with ID. Sample items include '*Has X appeared depressed*?' and '*Has X cried*?' Item responses are *not at all* (0), *sometimes* (1) and *extremely* (2), reflecting the frequency with which the symptom was experienced during the last 2 weeks. The CGDS was found to have an internal reliability of 0.88 and inter-rater reliability of 0.98 in a sample of 38 adults with ID (Cuthill *et al.* 2003).

Domains of depressive symptoms—Based on statistical and conceptual findings from previous studies in using the general population (Mackinger & Svaldi 2004; Hoen *et al.* 2010; Quilty *et al.* 2010; Roest *et al.* 2011), a sorting technique was applied to categorise items on the SRDQ, GDS and CGDS into the domains of Affective, Cognitive and Somatic symptoms (see Table 2). For example, the item '*I feel sad*' on the SRDQ, the item '*In the last week, have you felt sad?*' on the GDS and the item '*In the last week, hax A appeared depressed?*' were all categorised into the Affective symptom domain. Items relating to changes in appetite, sleep patterns and energy levels were placed in the Somatic symptom domain. The Cognitive symptom domain contained items related to thoughts of worthlessness, loneliness and withdrawal. As is true of most informant measures, the CGDS is focused on observable behaviours (e.g. '*Has X been more physically or verbally aggressive than usual?*' or '*Has X asked you for reassurance?*') that are considered to be behavioural manifestations of affective, Cognitive and Somatic depressive symptoms. Thus, CGDS items were sorted into the Affective, Cognitive and Somatic domains based on the underlying symptom that is purported to be driving the behaviour.

Procedure

Following receipt of informed consent and assent, adults with mild ID and staff were told the nature, purpose and requirements of the study. A pretest procedure was used to determine whether each adult with mild ID could reliably use a three-point Likert-type scale response option. In the first stage, adults with mild ID were asked to designate size– order relationships among a set of clear containers with varying amounts of water. During the second stage, adults with mild ID were asked to relate the correct container to a written scale of size (no, some, a lot). During the third stage, adults with mild ID were asked to determine where their favourite and least favourite food item fall on a written scale of preference (no, some, a lot). This pretest procedure has been shown to result in low rates of response bias on measures of interest (Hartley & MacLean 2005, 2006). Staff independently completed the CGDS.

Data analysis plan

We first evaluated the psychometric properties of the SRDQ, GDS and CGDS by examining the internal reliability of each measure using Cronbach's alpha and the associations between the total scores of measures using correlations. In order to evaluate convergent validity, we

ran t-tests to compare the total score and symptom domain scores on each measure for the 30 adults with mild ID who had a current depressive disorder (depressed group) versus the 50 adults with mild ID without a depressive disorder (non-depressed group). Next, using the entire sample of 80 adults with mild ID, we examined potential differences in the frequency of Affective, Cognitive and Somatic symptoms on the SRDO, GDS and CGDS by computing a ratio frequency score (domain total/highest possible domain total). This ratio frequency score allowed us to control for differences in the number of items included in each domain within and across measures. We then conducted one-way repeated measure analyses of variance (ANOVAS) to compare the Affective, Cognitive and Somatic ratio frequency scores across the three measures. Relevant socio-demographic variables (i.e. those significantly related to the domain scores) were controlled for in the repeated measure ANOVAS. Follow-up Bonferroni-corrected paired sample *t*-tests were used to determine which measures differed. Finally, using the entire sample of 80 adults with mild ID, multiple linear regressions were conducted to determine the association between socio-demographic characteristics and the domain (Affective, Cognitive and Somatic) ratio frequency scores on each measure. Given that the large majority of our sample was Caucasian, non-Hispanic, we did not make specific hypotheses about the association between ethnicity/race and depressive symptoms. However, ethnicity/race was controlled for in our multiple regression models.

Results

Psychometric properties of the depression measures

The SRDQ (Cronbach's $\alpha = 0.89$), GDS (Cronbach's $\alpha = 0.83$) and CGDS (Cronbach's $\alpha = 0.85$) all had high internal consistency. As shown in Table 3, the SRDQ total score was strongly correlated with the GDS total score, but was not significantly correlated with the CGDS total score. The GDS total score was significantly correlated with the CGDS total score. There were also moderate to strong positive significant correlation between the Affective, Cognitive and Somatic domain scores on the SRDQ and GDS. However, the Affective, Cognitive and Somatic domain scores on the SRDQ and CGDS were not significantly correlated. There was a significant positive correlation between the Affective domain scores on the GDS and CGDS. There was not a significant correlation between the Cognitive and Somatic domain scores on the GDS and CGDS.

There were no significant differences between the depressed and non-depressed groups on age, sex, IQ or presence of a co-occurring psychiatric disorder. Thus, socio-demographic characteristics were not controlled for in analyses comparing the SRDQ, GDS or CGDS total scores in the depressed versus non-depressed groups. As shown in Table 4, the SRDQ, GDS and CGDS total scores all significantly differentiated the depressed and non-depressed groups. The one exception to this finding was that the GDS Somatic domain score did not significantly differentiate the depressed and non-depressed groups.

Symptom domains in self-reported versus informant questionnaire

In order to identify and then control for socio-demographic variables significantly related to depressive symptoms, correlations were conducted between the SRDQ, GDS and CGDS

total scores and Affective, Cognitive and Somatic domain scores and socio-demographic characteristics (age, sex, IQ, presence of a co-occurring psychiatric disorder). There was a significant negative correlation between age and the GDS Somatic domain score (r = -0.33, P < 0.01). In contrast, there was a significant positive correlation between age and the CGDS Cognitive domain score (r = 0.35, P < 0.01). There was a significant negative correlation between IQ and the SRDQ Affective domain score (r = -0.27, P = 0.01), and GDS total score (r = -0.24, P = 0.02). There was a significant positive correlation between the presence of a co-occurring psychiatric disorder and GDS Somatic domain score (r = 0.23, P = 0.02). Sex was not significantly correlated with the total or domain scores on the SRDQ, GDS or CGDS.

To identify potential differences in the Affective, Cognitive and Somatic domain ratio frequency scores on the SRDQ, GDS and CGDS, we conducted one-way repeated measure ANOVAS, controlling for relevant socio-demographic variables, and follow-up Bonferroni– corrected paired sample *t*-tests. Table 5 presents the means and standard deviations for the Affective, Cognitive and Somatic domain ratio frequency scores on each of the three measures. A one-way repeated measure ANOVA indicated that the ratio frequency of Affective symptoms significantly differed among the SRDQ, GDS and CGDS ($F_{2,76} = 39.12$, P < 0.001, $\eta^2 = 0.38$).

Bonferroni-corrected paired-samples *t*-tests revealed that the frequency of Affective symptoms on the SRDQ was significantly higher than the frequency of Affective symptoms on the CGDS (t(78) = 8.03, P < 0.001). The frequency of Affective symptoms on the GDS was also significantly higher than the frequency of Affective symptoms on the CGDS (t(79) = -5.61, P < 0.001). The frequency of Affective symptoms on the SRDQ was also significantly higher the frequency of Affective symptoms on the GDS (t(78) = -6.34, P < 0.001.)

A one-way repeated measure ANOVA indicated that the ratio frequency of Cognitive symptoms significantly differed among the SRDQ, GDS and CGDS ($F_{2,76} = 7.98$, P = 0.001, $\eta^2 = 0.17$). Bonferroni-corrected paired-samples *t*-tests revealed that the frequency of Cognitive symptoms on the SRDQ (t(78) = -3.98, P < 0.001) and the GDS (t(78) = 2.91, P = 0.005) were significantly higher than the frequency of cognitive symptoms on the CGDS. There was not a significant difference in the frequency of Cognitive symptoms on the SRDQ and GDS.

A one-way repeated measure ANOVA indicated that the ratio frequency of Somatic symptoms significantly differed among the SRDQ, GDS and CGDS ($F_{2,78} = 29.89$, P < 0.001, $\eta^2 = 0.46$). Bonferroni-corrected paired-samples *t*-tests revealed that the frequency of Somatic symptoms on the CGDS was significantly higher than the frequency of Somatic symptoms on the GDS (t(78) = -2.61, P = 0.010). There was not a significant difference in the frequency of Somatic symptoms on the SRDQ was significantly higher than the frequency of Somatic symptoms on the SRDQ was significantly higher than the frequency of somatic symptoms on the GDS (t(78) = -2.61, P = 0.010). There was not a significant difference in the frequency of Somatic symptoms on the CGDS and SRDQ. The frequency of Somatic symptoms on the GDS (t(78) = 6.34, P < 0.001.)

Socio-demographic characteristics

Multiple linear regressions were conducted in which socio-demographic characteristics were the independent variables and the symptom domain scores were the dependent variables. Table 6 presents the regression findings. There was a significant negative effect of age on the frequency of Cognitive and Somatic symptoms on the SRDQ and GDS and a significant positive effect of age on the frequency of Cognitive symptoms on the CGDS. There was a significant negative effect of IQ on the frequency of Affective symptoms on the SRDQ and GDS. There was a significant positive effect of the presence of a co-occurring condition on Somatic symptoms on the GDS. There was not a significant effect of sex on any of the Total or domain scores.

Discussion

We examined similarities and differences in the types of depressive symptoms (affective, cognitive and somatic) endorsed in self-reported questionnaires by adults with mild ID versus informant questionnaires completed by staff from the adult's disability service provider. We found that that the SRDQ, GDS and CGDS all had good inter-item reliability and convergent validity with the other measures. Furthermore, the two self-reported questionnaires, the SRDQ and GDS, and the informant questionnaire, the CGDS, were all able to significantly differentiate the depressed from the non-depressed group. The affective and cognitive, and somatic symptom scores on the SRDQ, GDS and CGDS also discriminated the depressed from the non-depressed groups, with the exception that there was not a significant difference between the depressed and non-depressed groups in somatic symptoms on the GDS. These findings add to the small number of studies (Reynolds & Baker 1988; Cuthill *et al.* 2003; Esbensen *et al.* 2005; Ailey 2009; Hermans & Evenhuis 2010) examining the properties of these measures and support the reliability and validity of these measures in an independently collected sample of adults with mild ID.

In support of our hypothesis, we found that adults with mild ID self-reported a higher frequency of affective and cognitive depressive symptoms than staff reported on the informant questionnaire. This finding is consistent with previous studies on adults with cognitive deficits due to medical illnesses (Allen *et al.* 2002) and suggests that adults with mild ID may have difficulty describing their thoughts and feelings to staff and/or it may be difficult for staff to recognise behavioural manifestations of these internalised experiences (e.g. acting aggressive or asking for reassurance). Thus, affective and cognitive depressive symptoms may be best captured through self-reported questionnaires. Also in line with our hypothesis, staff reported a higher frequency of somatic symptoms than adults with mild ID on one of the self-reported questionnaires (GDS) and a similar frequency on the other self-reported questionnaire (SRDQ). Somatic depressive symptoms are more observable and recognisable as depressive symptoms and thus caregivers may be more aware of somatic depressive symptoms than affective and cognitive depressive symptoms. Somatic depressive symptoms may thus be a critical indicator of depression in adults with mild ID in informant questionnaires.

The secondary aim of the present study was to evaluate the association between depressive symptoms and socio-demographic characteristics in adults with mild ID. As hypothesised,

there was a positive relation between age and frequency of somatic depressive symptoms on the informant questionnaire after controlling for all other socio-demographic characteristics. Thus, older adults with mild ID were reported by staff to exhibit a higher frequency of somatic depressive symptoms than younger adults with mild ID, which is in line with findings from the general population (Balsis & Cully 2008). Unexpectedly, there was a negative relation between age and frequency of somatic depressive symptoms on the two self-reported questionnaires; younger adults with mild ID reported higher frequency of somatic depressive symptoms than did older adults with mild ID. The mechanism driving these contradictory findings is not clear. Perhaps, older adults with mild ID consider somatic symptoms to be normative changes due to ageing or other health problems and do not signify these symptoms as 'problematic'. However, among younger adults with mild ID, a new somatic symptom may be attributed to depression as opposed to an ageing or a health condition and seen as non-normative and as 'problematic'.

In support of our hypothesis, there was a negative association between age and the frequency of cognitive depressive symptoms on the two self-reported questionnaires. Research on the general population has similarly found that older adults endorse a lower frequency and/or severity of cognitive depressive symptoms than younger adults (Balsis & Cully 2008). As hypothesised, adults with mild ID who had a co-occurring psychiatric disorder reported having a higher frequency of somatic depressive symptoms on the GDS than did adults with mild ID who did not have a co-occurring psychiatric disorder in our models. This finding supports previous studies indicating that the presence of co-occurring psychiatric disorders can exacerbate symptoms of depression in adults with mild ID (Bakken et al. 2010; Tsiouris et al. 2011). Unexpectedly, there was a significant negative effect of IQ on the frequency of affective depressive symptoms on the two self-reported questionnaires when all other socio-demographic characteristics were controlled for in models. This is in opposition to our hypothesis that adults with higher IQs would be more aware of their emotions. Further research is needed to understand the mechanisms driving this finding. It may be that adults with lower IQs utilise a different threshold for judging the severity of their negative affect than adults with higher IQs. Unlike in the general population, where women report higher frequencies of somatic symptoms than men (Silverstein 2002; Wenzel et al. 2005), there was not a significant association between sex and depressive symptoms in our sample.

There are several limitations to this study. Although all adults with mild ID in the depressed group were deemed to currently meet diagnostic criteria for a depressive disorder and were currently demonstrating significant depressive symptoms, the majority had been prescribed antidepressant medication, which may have influenced self-reported as well as informant-reported depressive symptoms. Side-effects from the medication may have also influenced endorsement of somatic symptoms. Future research may benefit from investigating depressive symptoms endorsed by depressed adults with mild ID before they begin treatments. Future research should also use semi-structured clinical interviews of depressive symptoms with both the adult with mild ID and staff to elucidate the mechanisms driving discrepancies in the type of depressive symptoms reported on self-reported questionnaires

and informant questionnaires, as well as differences based on socio-demographic characteristics.

Overall, the present findings support the assertion that informant questionnaires offer valuable information in the assessment of depression in adults with mild ID. But, that assessment should also include self-reported questionnaires as these questionnaires add unique information about internalised experiences (affective and cognitive symptoms) of adults with mild ID that may not be apparent to caregivers. Health care providers should be aware that there appear to be important differences in the types of depressive symptoms that are reported by adults with mild ID as compared with their staff. Moreover, there are important differences in the types of depressive symptoms reported by adults with mild ID and their staff based on their IQ, age and presence of a co-occurring psychiatric disorder.

References

- Ailey SH. The sensitivity and specificity of depression screening tools among adults with intellectual disabilities. Journal of Mental Health Research in Intellectual Disabilities. 2009; 2:45–64.
- Allen RS, Haley WE, Small BJ, McMillan SC. Pain reports by older hospice cancer patients and family caregivers: the role of cognitive functioning. The Gerontologist. 2002; 42:507–514. [PubMed: 12145378]
- American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 4th edn. Washington, DC: Author; 2000. text revision.
- Bakken TL, Helverschou SB, Eilertsen DE, Heggelund T, Myrbakk E, Martinsen H. Psychiatric disorders in adolescents and adults with autism and intellectual disability: a representative study in one county in Norway. Research in Developmental Disabilities. 2010; 31:1669–1677. [PubMed: 20493660]
- Balsis S, Cully JA. Comparing depression diagnostic symptoms across younger and older adults. Aging and Mental Health. 2008; 12:800–806. [PubMed: 19023732]
- Bhaumik S, Tyrer FC, McGrother C, Ganghadaran SK. Psychiatric service use and psychiatric disorders in adults with intellectual disability. Journal of Intellectual Disability Research. 2008; 52:986–995. [PubMed: 19017168]
- Borthwick-Duffy SA. Epidemiology and prevalence of psychopathology in people with mental retardation. Journal of Consulting and Clinical Psychology. 1994; 62:17–27. [PubMed: 8034819]
- Burke WJ, Roccaforte WH, Wengel SP, McArthur-Miller D, Folks DG, Potter JF. Disagreement in the reporting of depressive symptoms between patients with dementia of the Alzheimer type and their collateral sources. The American Journal of Geriatric Psychiatry. 1998; 6:308–319. [PubMed: 9793579]
- Collishaw S, Maughan B, Pickles A. Affective problems in adults with mild learning disability: the roles of social disadvantage and ill health. The British Journal of Psychiatry. 2004; 185:350–351. [PubMed: 15458996]
- Cooper SA, Collacott RA. Depressive episodes in adults with intellectual disabilities. Irish Journal of Psychological Medicine. 1996; 13:105–113.
- Cooper SA, Smiley E, Morrison J, Williamson A, Allan L. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. British Journal of Psychiatry. 2007; 190:27–35. [PubMed: 17197653]
- Cuthill FM, Espie CA, Cooper SA. Development and psychometric properties of the Glasgow Depression Scale for people with a Learning Disability. British Journal of Psychiatry. 2003; 182:347–353. [PubMed: 12668412]
- Drayer RA, Mulsant BH, Lenze EJ, Rollman BL, Dew MA, Kelleher K, et al. Somatic symptoms of depression in elderly patients with medical comorbidities. International Journal of Geriatric Psychiatry. 2005; 20:973–982. [PubMed: 16163749]

- Epstein AM, Hall JA, Tognetti J, Son LH, Conant L. Using proxies to evaluate quality of life: can they provide valid information about patients' health status and satisfaction with medical care? Medical Care. 1989; 27:S91–S98. [PubMed: 2921889]
- Esbensen AJ, Seltzer MM, Greenberg JS, Benson BA. Psychometric evaluation of a self-report measure of depression for individuals with mental retardation. American Journal on Mental Retardation. 2005; 110:469–481. [PubMed: 16212449]
- Finlay WML, Lyons E. Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. Psychological Assessment. 2001; 13:319–335. [PubMed: 11556269]
- Harrison, P.; Oakland, R. Adaptive Behavior Assessment System-Second Edition (ABAS-II). San Antonio, TX: Harcourt Assessment; 2006.
- Hartley SL, MacLean WE Jr. Perceptions of stress and coping strategies among adults with mild mental retardation: insight into psychological distress. American Journal on Mental Retardation. 2005; 110:285–297. [PubMed: 15941365]
- Hartley SL, MacLean WE Jr. A review of the reliability and validity of Likert-type scales for people with intellectual disability. Journal of Intellectual Disability Research. 2006; 50:813–827. [PubMed: 16999781]
- Hegeman JM, Kok RM, van der Mast RC, Giltay EJ. Phenomenology of depression in older compared with younger adults: meta-analysis. The British Journal of Psychiatry. 2012; 200:275–281. [PubMed: 22474233]
- Hermans H, Evenhuis HM. Characteristics of instruments screening for depression in adults with intellectual disabilities: systematic review. Research in Developmental Disabilities. 2010; 31:1109–1120. [PubMed: 20547035]
- Hoen PW, Conradi HJ, Denollet J, Martens EJ, de Jonge P. Interview-based ratings of somatic and cognitive symptoms of depression and their impact on cardiovascular prognosis. Psychotherapy and Psychosomatics. 2010; 79:319–320. [PubMed: 20689349]
- Kaufman, AS.; Kaufman, NL. KBIT-2: Kaufman Brief Intelligence Test. 2nd edn. Shoreview, MN: American Guidance Service; 2004.
- Leyfer OT, Woodruff-Borden J, Klein-Tasman BP, Fricke JS, Mervis CB. Prevalence of psychiatric disorder in 4 to 16-year-olds with Williams syndrome. American Journal of Medical Genetics Part B. 2006; 141B:615–622.
- Lunsky Y, Emery C, Benson BA. Staff and self-reports of health behaviours, somatic complaints, and medications among adults with mild intellectual disability. Journal of Intellectual and Developmental Disability. 2002; 27:125–135.
- McBrien JA. Assessment and diagnosis of depression in people with intellectual disability. Journal of Intellectual Disability Research. 2003; 47:1–13. [PubMed: 12558690]
- Mackinger HF, Svaldi JJ. Autobiographical memory predicts cognitive but not somatic change in sleep apnea patients vulnerable for affective disorder. Journal of Affective Disorders. 2004; 81:17–22. [PubMed: 15183595]
- Poindexter, AR. Diagnosis of depression in people with developmental disabilities: progress and problems. In: Glidden, LM., editor. International Review of Research in Mental Retardation. San Diego, CA: Elsevier; 2006. p. 261-281.
- Quilty LC, Zhang KA, Bagby RM. The latent symptom structure of the Beck Depression Inventory-II in outpatients with major depression. Psychological Assessment. 2010; 22:603–608. [PubMed: 20822272]
- Reynolds WM, Baker JA. Assessment of depression in persons with mental retardation. American Journal on Mental Retardation. 1988; 93:93–103. [PubMed: 3415843]
- Richards M, Maughan B, Hardy R, Hall I, Strydom A, Wadsworth M. Long-term affective disorder in people with mild learning disability. The British Journal of Psychiatry. 2001; 179:523–527. [PubMed: 11731356]
- Roest AM, Thombs BD, Grace SL, Stewart DE, Abbey SE, de Jonge P. Somatic/affective symptoms, but not cognitive/affective symptoms, of depression after acute coronary syndrome are associated with 12-month all-cause mortality. Journal of Affective Disorders. 2011; 131:158–163. [PubMed: 21159385]

- Royal College of Psychiatrists. DC–LD [Diagnostic Criteria for Psychiatric Disorders for Use With Adults With Learning Disabilities/Mental Retardation]. London: Gaskell Press; 2001.
- van Schrojenstein Lantman-de Valk HMJ, van den Akker M, Maaskant MA, Haveman MJ, Urlings HFJ, Kessels AGH, et al. Prevalence and incidence of health problems in people with intellectual disability. Journal of Intellectual Disability Research. 1997; 41:42–51. [PubMed: 9089458]
- Silverstein B. Gender differences in the prevalence of somatic versus pure depression: a replication. American Journal of Psychiatry. 2002; 159:1051–1052. [PubMed: 12042198]
- Tsiouris JA, Kim SY, Brown WT, Cohen IL. Association of aggressive behaviours with psychiatric disorders, age, sex and degree of intellectual disability: a large-scale survey. Journal of Intellectual Disability Research. 2011; 55:636–649. [PubMed: 21492292]
- Wenzel A, Steer RA, Beck AT. Are there any gender differences in frequency of self-reported somatic symptoms of depression? Journal of Affective Disorders. 2005; 89:177–181. [PubMed: 16202455]
- White P, Chant D, Edwards N, Townsend C, Waghorn G. The prevalence of intellectual disability and comorbid mental illness in an Australian community sample. Australian and New Zealand Journal of Psychiatry. 2005; 39:395–400. [PubMed: 15860028]

Characteristics of adults with intellectual disability (ID) and staff

Adult with ID	
Age, M (SD)	38.87 (13.09)
Range	21.32-67.23
IQ, M (SD)	62.83 (9.68)
Range	55.21-72.25
Sex, <i>n</i> (%)	
Male	38 (47.50%)
Female	42 (52.50%)
Race/ethnicity, n (%)	
Caucasian, non-Hispanic	69 (86.25%)
African-American	4 (5.00%)
Hispanic	3 (3.75%)
Asian	2 (2.50%)
Unknown	2 (2.50%)
Psychiatric disorder, $n(\%)^*$	
Depressive disorder	30 (37.50%)
Anxiety disorder	8 (10.00%)
Personality disorder	13 (16.25%)
Schizophrenia/psychotic disorder	8 (10.00%)
Substance abuse/dependence	3 (3.75%)
ADHD	5 (6.25%)
Intermittent explosive disorder	3 (3.75%)
Adjustment disorder	1 (1.25%)
Staff	
Age in years, M (SD)	27.89 (6.78)
Range	21.52-66.52
Sex, <i>n</i> (%)	
Male	42 (52.50%)
Female	38 (47.50%)
Years worked with adult with ID, M (SD)	3.74 (2.89)
Range	0.50-8.00

Many adults with mild ID had multiple psychiatric disorders. ADHD, attention-deficit hyperactivity disorder.

Affective, Cognitive and Somatic domain items on the SRDQ, GDS and CGDS

Domain	Symptom	SRDQ item	GDS item	CGDS item
Affective	Нарру	2, 14	20	
	Sad/crying	7, 8, 22	1, 7, 17	1,6
	Anhedonia	20, 27	3, 4	5, 8
	Worried	17	18	
	Mad/aggressive	26	2	2
	Changes in mood			16
Cognitive	People don't like me	4, 9	8, 16	
	Avoidance	6, 10		3
	Appearance		5	4
	Suicidal	11	14	14
	Self-blame	12, 25	15	
	Self-defeat	13		
	Helpless	23	19	
	Concentration	28	9	
	Sorry for myself	29		
	Decision-making		10	
	Anxious thoughts			15
Somatic	Tired	1, 16, 24, 30	6	10, 13
	Sick	3, 18		7
	Appetite	5, 31	12	11
	Insomnia	15, 21	13	12
	Restless	19	11	9

SRDQ, Self-Report Depression Questionnaire; GDS, Glasgow Depression Scale - ID; CGDS, Carer Supplement of the Glasgow Depression Scale.

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		SRDQ				G	GDS			S	CGDS	
Measure		1	2	3	4	5	9	7	8	6	10	11
SRDQ	1. Total	I										
	2. Affective	0.86^{**}	I									
	3. Cognitive	0.92^{**}	0.74^{**}	Ι								
	4. Somatic	0.79^{**}	0.64^{**}	0.59^{**}	I							
GDS	5. Total	0.66**	0.49^{**}	0.64^{**}	0.52^{**}	I						
	6. Affective	0.75**	0.74^{**}	0.70^{**}	0.46^{**}	0.69^{**}	I					
	7. Cognitive	0.78^{**}	0.63^{**}	0.75*	0.63^{**}	0.67**	0.68^{**}	Ι				
	8. Somatic	0.54^{**}	0.29^{**}	0.51^{**}	0.60^{**}	0.57^{**}	0.45**	0.52^{**}	ļ			
CGDS	9. Total	0.20	0.15	0.24	0.08	0.45**	0.27^{*}	0.13	0.03	I		
	10. Affective	0.21	0.19	0.24^*	0.09	0.44^{**}	0.30^{**}	0.17	0.03	0.76^{**}	I	
	11. Cognitive	0.04	0.03	0.13	-0.11	0.21	0.04	0.03	-0.22	0.73^{**}	0.64^{**}	I
	12. Somatic	0.13	0.10	0.08	0.16	0.24^*	0.10	-0.01	-0.06	0.77**	0.58**	0.62^{**}

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SRDQ, Self-Report Depression Questionnaire; GDS, Glasgow Depression Scale - ID; CGDS, Carer Supplement of the Glasgow Depression Scale.

Means, standard deviations and t-test values related to total scores and symptom domain totals on SRDQ, GDS and CGDS for depressed and nondepressed groups

		naces to se					
Measure		Mean	SD	Mean	SD	t	Ρ
SRDQ	Total	63.52	10.65	55.53	10.03	-3.44	0.001^{**}
	Affective	96.6	3.51	7.93	3.36	-2.52	0.01^*
	Cognitive	10.63	5.23	7.43	4.58	-2.83	0.007**
	Somatic	9.90	3.51	7.93	3.36	-2.65	0.01^*
GDS	Total	18.17	7.05	13.05	5.83	-3.60	0.001^{**}
	Affective	7.43	3.40	5.39	2.94	-2.77	0.008^{**}
	Cognitive	6.87	3.04	4.80	3.19	-2.91	0.004^{**}
	Somatic	3.73	1.80	3.09	1.93	-1.72	0.09
CGDS	Total	12.03	6.53	7.04	4.48	-3.93	0.001^{**}
	Affective	3.43	2.43	1.91	1.53	-3.07	0.004^{**}
	Cognitive	2.83	1.73	1.82	1.17	-2.81	0.007**
	Somatic	4.27	2.59	2.67	1.98	-2.82	0.007^{**}

P < 0.01.

SRDQ, Self-Report Depression Questionnaire; GDS, Glasgow Depression Scale; CGDS, Carer Supplement of the Glasgow Depression Scale.

Table 5

Mean and SD of ratio scores for affective, cognitive and somatic symptoms on the SRDQ, GDS and CGDS

	Affective	tive	Cognitive	itive	Somatic	atic
	Mean	SD	Mean	SD	Mean SD	SD
SRDQ	0.49	0.20	0.42	0.23	0.43	0.19
GDS	0.38	0.20	0.36	0.21	0.19	0.28
CGDS	0.23	0.18	0.29	0.18	0.29	0.21

SRDQ. Self-Report Depression Questionnaire; GDS, Glasgow, Depression Scale; CGDS, Caregiver Supplement of the Glasgow, Depression Scale.

Multiple regression results for effect of socio-demographic characteristics on SRDQ, GDS and CGDS scores

Affective Cognitive Somatic Affective Cognitive Cognitive Somatic Affective Cognitive Somatic Affective Cognitive Somatic Affective Cognitive Somatic Somatic Somatic Somatic Somatic Somatic Somatic Cognitive Somatic Somatic <t< th=""><th>Affective Cognitive Somatic Affective Somatic Affective Cognitive Color Color</th><th>psychiatric disorder</th><th></th><th>GDS</th><th></th><th></th><th>CGDS</th><th></th></t<>	Affective Cognitive Somatic Affective Somatic Affective Cognitive Color Color	psychiatric disorder		GDS			CGDS	
$ \begin{array}{llllllllllllllllllllllllllllllllllll$	$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	$\begin{array}{cccc} -0.15 & -0.27^{*} \\ 0.07 & 0.01 \\ -0.18 & -0.11 \\ -0.31^{**} & -0.17 \\ psychiatric disorder & 0.10 & 0.17 \\ 0.12 & 0.11 \\ 2.28^{*} & 2.21^{*} \end{array}$	matic Affective	Cognitive	Somatic	Affective	Cognitive	Somatic
$ \begin{array}{cccccccccccccccccccccccccccccccccccc$		$\begin{array}{cccc} 0.07 & 0.01 \\ -0.18 & -0.11 \\ -0.31^{**} & -0.17 \\ psychiatric disorder & 0.10 & 0.17 \\ 0.12 & 0.11 \\ 2.28^{*} & 2.21^{*} \end{array}$		-0.17	-0.33**	0.07	0.33^{**}	0.02
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	$\begin{array}{cccccccccccccccccccccccccccccccccccc$	$\begin{array}{ccc} -0.18 & -0.11 \\ -0.31^{**} & -0.17 \\ psychiatric disorder & 0.10 & 0.17 \\ 0.12 & 0.11 \\ 2.28^{*} & 2.21^{*} \end{array}$		0.06	-0.06	0.09	-0.04	0.03
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	$\begin{array}{cccccccccccccccccccccccccccccccccccc$	-0.31*** -0.17 psychiatric disorder 0.10 0.17 0.12 0.11 2.28* 2.28* 2.21*		-0.06	-0.12	-0.04	0.05	-0.06
psychiatric disorder 0.10 0.17 0.08 0.14 0.15 $_{0.21}^{*}$ 0.09 0.06 0.06 0.12 0.11 0.05 0.08 0.08 0.19 0.05 0.07 2.28* 2.21* 1.75 1.41 1.44 3.57** 0.92 2.40*	psychiatric disorder 0.10 0.17 0.08 0.14 0.15 0.21^* 0.09 0.06 0.12 0.11 0.05 0.08 0.08 0.19 0.05 0.07 2.28* 2.21* 1.75 1.41 1.44 3.57^{**} 0.92 2.40*	psychiatric disorder 0.10 0.17 0.12 0.11 2.28* 2.21*		-0.19	-0.10	-0.19	-0.08	-0.07
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	0.12 0.11 0.05 0.08 0.08 0.19 0.05 0.07 2.28^* 2.21^* 1.75 1.41 1.44 3.57^{**} 0.92 2.40^*	0.12 $0.112.28^* 2.21^*$		0.15	0.21^{*}	0.09	0.06	0.21
2.28^* 2.21^* 1.75 1.41 1.44 3.57^{**} 0.92 2.40^*	2.28^{*} 2.21^{*} 1.75 1.41 1.44 3.57^{**} 0.92 2.40^{*}	2.28* 2.21*		0.08	0.19	0.05	0.07	0.05
	P < 0.05.			1.44	3.57**	0.92	2.40^{*}	0.74

SRDQ, Self-Report Depression Questionnaire; GDS, Glasgow Depression Scale; CGDS, Carer Supplement of the Glasgow Depression Scale.