Relationship between low mood and challenging behaviour in people with profound and severe intellectual disability

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Abstract

Background: We investigated the relationship between low mood and challenging behaviour in people in the severe and profound range of intellectual disability, whilst controlling for the presence of potentially confounding variables such as diagnosis of autism, physical and sensory problems and ill health.

Method: The key workers of 52 people with severe and profound intellectual disability completed measures of depression, communication, challenging behaviour and provided information on relevant demographic and health variables.

Results: Using the Mood, Interest and Pleasure Questionnaire for classification of mood, a significant difference was found between a “low mood” and “normothymic” group in the reported occurrence of challenging behaviour. This difference remained even when confounding variables such as the presence of autism, health and sensory difficulties were controlled. The frequency and severity of challenging behaviour was predicted by measures indicating the presence of low mood.

Conclusion: People with severe and profound show clear and measurable signs of low mood, and in this relatively small sample of institutionalized individuals, low mood was associated with challenging behaviour.
**Introduction**

In the past, diagnostic overshadowing (Reiss, Levitan, & Szysko, 1982) was a major obstacle for people with intellectual disabilities exhibiting symptoms of a mental illness. While much progress has been made in the area, a tendency remains for mental health practitioners to see presenting challenging behaviours as resulting from the intellectual disability itself rather than being symptomatic of mental illness (Holland & Koot, 1998; Hudson & Chan, 2002).

With regard to depression, it has been posited that adults with mild and moderate intellectual disability display the full range of “classical” symptoms of depression as described in the DSM and ICD classification systems (Marston, Perry & Roy, 1997; Meins, 1995; Sturmey, 1995). In contrast, the identification of depression in people with severe and profound intellectual disabilities (SPID) has proven challenging due to the presence of severe communication difficulties, behavioural difficulties associated with specific disorders and a higher prevalence of physical disabilities.

Research has indicated that some of the classical symptoms of depression (e.g. appetite disturbance, changes in sleep patterns) are presented by adults with SPID (Marston, Perry & Roy, 1997) although they may also represent general distress rather than a specific disorder (Charlot, Doucette & Mezzacappa, 1993). Meins (1995) theorized that people with SPID may also exhibit atypical symptoms of depression. There is little agreement about what constitutes “atypical” and descriptions of atypical symptoms have included the full range of challenging behaviours, with aggression, irritability and self-injurious behaviour being the most commonly cited (Davis, Judd & Herman, 1997; Meins, 1995). Fraser and Nolan (1994) also reported that people with SPID were more likely to present symptoms of depression as regressed or disturbed
behaviour, deterioration in body functioning and a reduced level of adaptive functioning. Reiss and Rojahn (1993) conducted a cross sectional study of 528 adults, adolescents and children with ID using The Reiss Screen. They concluded that there was an association between depression and aggression, with 40% of adults, adolescents and children with both ID and depression exhibiting aggression. However, other studies cautioned against viewing challenging behaviour as symptoms of depression.

Tsiouris et al. (2003) utilised the Clinical Behaviour Checklist for Persons with Intellectual Disability (CBCPID; Marston, 1997) to evaluate the utility of an expanded assessment of psychiatric symptoms and challenging behaviour. They concluded that there was no evidence to suggest that challenging behaviours were depressive equivalents in the ID population. However, a number of significant methodological factors may have impacted on their results. Tsiouris, Mann, Patti and Sturmey (2004) acknowledged the CBCPID to be a broad screening measure for psychopathology, not a specific assessment instrument for depression. They also noted that generally, CBCPID items had low sensitivity and specificity in people with severe and profound ID.

In terms of the instruments specifically used to assess depression, McBrien’s (2003) review concluded that agreement about the most appropriate method of diagnosis for people with SPID remained elusive. Furthermore, a recent study by Myrbakk, Even, von Tetzchner and Stephen (2008), which examined the concordance between four of the most commonly used assessment instruments for psychiatric disorders in people with mild to moderate intellectual disability (Reiss Screen, Mini Psychiatric Assessment Schedule for Adults with Developmental Disability, Diagnostic Assessment for the Severely Handicapped–II and the Assessment of Dual
Diagnosis), found that concordance of the overall psychopathology scores on the four checklists was high, but agreement on the diagnosis of specific psychiatric disorders was limited. Therefore, disorders such as depression may be difficult to identify reliably.

Ross and Oliver (2002) highlighted significant methodological limitations of some of the earlier studies focused on the diagnosis of depression. These included the use of ambiguously termed items, items not assessable in people within the severe and profound range, and the use of a tautological methodology (i.e. people with a prior diagnosis of depression are engaged in studies, which aim to explore how depression is manifested in people with ID). The majority of these studies also had a relatively small number of people within the severe and profound range. To overcome the limitations of existing assessment tools, Ross and Oliver (2002) developed the Mood, Interest and Pleasure Questionnaire (MIPQ), which specifically assesses low mood and interest/pleasure (two main constructs of depression) in people within the severe and profound range using behavioural correlates of mood (e.g. smiling, laughing, crying). A preliminary study (Ross & Oliver, 2003) yielded robust inter-rater, test-retest and scale score reliability values and good concurrent validity. Ross and Oliver (2002) used the MIPQ to investigate the relationship between low mood, interest and pleasure and challenging behaviour and reported statistically significant lower levels of affect in those displaying challenging behaviours. They noted, however, that a large proportion of their participants had a diagnosis of autism and questioned whether this was a confounding factor, since the presentation of depression in people with autism may be different from that in non-specific intellectual disability syndromes.

The aim of the current study was to extend the work of Ross and Oliver (2003) and investigate the relationship between mood and challenging behaviour using the
MIPQ, whilst controlling for the potential confound of a diagnosis of autism spectrum disorder (ASD).

**Method**

**Participants**

The managers of two residential services for people with an intellectual disability were provided with a list of participant criteria required for inclusion in the study and asked to identify potentially suitable participants for the study. These criteria were:

- Aged 18 or over.
- Not taking anti-depressant medication.
- No sensory disability.
- Registered on the National Intellectual Disability Database (NIDD) in Ireland as having a severe or profound degree of intellectual disability, based on psychological assessment.

A sample size calculation was conducted based on the number of individuals with severe and profound ID in Ireland that were accessing residential services. According to the National Intellectual Disability Database in 2006, 4369 individuals with moderate, severe and profound ID were registered as living in residential services for people with ID. It was estimated from the database that those with Severe and Profound ID alone would approximate 3000. Using a power calculator with 3000 as the population available at 90% confidence, it was calculated that a sample size of 67 was required.

There were 102 residents registered as having a severe and profound ID within the services we surveyed. Following a review of the participant characteristics by the
first author and the service managers, 52 residents were identified as meeting the further criteria for inclusion in the study.

There were 39 males and 13 females, who ranged in age from 18 to 55 years ($M = 29.9$ years; $SD = 7.61$). The diagnosis (or absence) of autism, based on previous psychological assessment using DSM criteria, was obtained from the national database (29 had a diagnosis, 23 did not). The informants were the key workers of the participants and they provided demographic and background information and completed the relevant clinical questionnaires. In addition to details about current mood and current challenging behaviour, we obtained information about communication skills ($n = 51$; 98% reported to have extremely limited communication), mental health difficulties ($n = 13$; 25% had a diagnosed mental health difficulty other than depression), physical health difficulties ($n = 28$; 54% had physical difficulties such as immobility and cerebral palsy) and use of prescribed medication ($n = 38$; 73% were prescribed benzodiazepines, anti-psychotic and anti-epileptic medications). See Table 1 for demographic information.

[ TABLE 1 HERE ]

**Measures and Procedures**

Ethical and operational approval for the study was granted by the University Ethics Committee and local service providers. Consent was obtained from the legal guardian of each participant. The Psychiatric Registrar in each service provided information about prescribed medications and history of psychiatric disorders. Demographic information and questionnaire data was obtained from direct caregivers who had known the service user for at least six months.
The informants were asked to complete a number of questionnaires including: Mood, Interest & Pleasure Questionnaire (MIPQ; Ross & Oliver, 2002), an informant-based, 25 item likert scale (0-4). The MIPQ has two subscales (Mood and Interest & Pleasure), based on the two core symptoms of major depression in the DSM-IV (depressed mood and reduced interest and pleasure in activities). The MIPQ is intended as a measure of low mood and has not been evaluated as a measure of elevated mood such as hypomania or bipolar disorder. The MIPQ items were rated on operationally defined, observable behaviours considered to be indicative of mood. This questionnaire was developed for use with adults who have severe/profound learning disability with low scores considered to be indicative of depression and higher scores considered to reflect normothymic mood. Ross and Oliver (2002; 2003) provide evidence attesting to the psychometric soundness of the MIPQ.

The Diagnostic Criteria – Learning Disability (DC-LD; Royal College of Psychiatrists, 2001) Depression Subscale was used as a confirmatory measure of depression. The DC-LD is a dichotomous (yes/no) 15 item measure which assesses for the presence of symptoms of depression. It can be used as a stand alone system for those with severe/profound ID. A person must present with four symptoms on the DC-LD to meet the criteria for depression, two of which must be low mood or irritability and loss of interest/pleasure. Although there are no psychometric properties available for the DC-LD, in its development it demonstrated good face validity against clinical diagnosis.

The Social and Communication Questionnaire (SCQ; Rutter, Bailey & Lord, 1999) is a 40 item dichotomous (yes/no) questionnaire completed by a primary caregiver which measures communication ability. In terms of its psychometric
properties, Rutter et al. reported scale score reliability coefficients of 0.86 and obtained
70% agreement with the Autism Diagnostic Interview – Revised.

The Challenging Behaviour Interview (CBI; Oliver, McClintock, Hall, Smith, Dagnan, & Stenberg-Kroese, 2002), is a two-part carer interview which identifies and assesses the frequency and severity of challenging behaviours. It is scored on a 5 point scale (0-4) with higher scores representing higher frequency and severity of challenging behaviour. The psychometric properties of this measure include high test-retest reliability with a mean Kappa coefficient of 0.86 (range 0.71-0.91) and good inter-rater reliability with a Kappa coefficient of 0.67 (range 0.50-0.80). In addition, good concurrent validity has been demonstrated.

**Results**

We categorised participants as being either “low mood” or “normothymic” based on their MIPQ scores. As there are no established diagnostic cut-off scores for the MIPQ, we used the method described by Ross and Oliver (2002) and used the lowest 15 scores ($M = 21.66$) as indicative of low mood. When compared with the highest possible score of 100, the mean of 21.66 appeared to have face validity in accurately representing low mood, interest and pleasure and was considered to appropriately reflect a “low mood” group. We then compared this group to the 15 highest scores on the MIPQ ($M = 69.73$), which was called the “normothymic” group. Independent samples t-tests were conducted in order to identify whether any significant differences in demographic information was apparent between the two groups being measured and none emerged.

We compared the MIPQ, DC-LD and CBI scores of the low mood and normothymic groups and found that participants in the Low Mood group displayed
significantly higher scores on CBI measures of frequency and severity (see Table 2), with large effect sizes (Cohen’s d).

[ TABLE 2 HERE ]

The ASD (n=29) and non-ASD (n=23) groups were compared across measures of depression and challenging behaviour (See Table 3). Independent samples t-tests were employed to evaluate the difference between the two groups in terms of mood and the frequency and severity of challenging behaviour. Statistically significant results were found between the two groups for low mood, interest and pleasure as measured by the MIPQ and for the frequency of challenging behaviour, with large effect sizes for each comparison. The results did not yield significant differences between groups in terms of the severity of challenging behaviours or for depression as measured by the DC-LD, although in each case the ASD group scored in the direction of more symptoms.

[ TABLE 3 HERE ]

In order to determine whether a significant difference remained between the low mood and normothymic group on measures of frequency and severity of challenging behaviour when controlling for potentially confounding variables, a MANCOVA was employed. Controlling for the presence of autism spectrum disorders (ASD), communication problems, health related factors and prior history of mental health problems (based on the answers provided by key-workers in the semi-structured interviews), we found a significant difference between the low mood and normothymic
A stepwise linear regression analysis (Table 4) was conducted in order to investigate the extent to which the presence of low mood as indicated by scores on the DC-LD and MIPQ predicted the frequency and severity of challenging behaviour. Regarding frequency of challenging behaviour, in the first step the DC-LD total score was a significant predictor of CBI scores, $F(1, 51) = 7.036, p < .011$, accounting for 11% of the variance. The $F$ value for the second step was statistically significant, $F(1, 51) = 6.481, p < .003$, suggesting that inclusion of the MIPQ in Step 2 accounted for an additional 18% of the variance. Regarding severity of challenging behaviour, in the first step the DC-LD was a significant predictor of scores on the CBI severity scale, $F(1, 51) = 9.902, p = .003$, accounting for 15% of the variance. The $F$ value for the second step was statistically significant, $F(1, 51) = 7.734, p = .01$, suggesting that inclusion of the MIPQ in Step 2 accounted for an additional 21% of the variance in predicting severity scores on the CBI. Thus, both the DC-LD and the MIPQ were statistically significant predictors of both the frequency and severity of challenging behaviour.

[ TABLE 4 HERE ]

Discussion

This study explored the relationship between low mood and the frequency and severity of challenging behaviour in people within the severe and profound level of intellectual disability. Using the MIPQ to classify people as belonging to either a low...
mood or normothymic group, we found that there was a higher frequency and greater severity of challenging behaviour in the low mood group. The findings of this study supported those of previous studies (e.g. Marston et al. 1997; Meins, 1995, Ross & Oliver, 2002), which found a relationship between low mood and challenging behaviour. This relationship still remained after controlling for potential confounds such as diagnosis of autism spectrum disorder, sensory problems, communication problems and the presence of physical and mental health difficulties. Regression analyses showed that scores on the DC-LD and MIPQ each predicted the frequency and severity of challenging behaviour. The MIPQ was a stronger predictor of CBI scores than the DC-LD scale. The results of the study suggest that the presence of challenging behaviour may, in at least some cases, be indicative of underlying mood problems within this sample of people living in institutional residences.

This study attempted to address a problem identified by Ross and Oliver (2002) whereby the presence of autism spectrum disorder may have confounded the diagnosis of depression. Although our ASD group had higher scores on the two depression measures, when the presence of ASD was controlled statistically, a significant difference in challenging behaviour between the low mood and normothymic group was still found. The results suggest that the difference in challenging behaviour in the low mood group compared to the normothymic group is robust, as the difference remains even when the potential confound of ASD is taken into account.

A recent review of the literature on the treatment of challenging behaviour using a variety of serotonergic antidepressants (Janowski & Davis, 2005) reported significant decreases in the ratings of global maladaptive behaviour and aggression, self-injurious behaviour, destruction/disruption and depression after the commencement of antidepressants. The results suggested that anti-depressant
medications, which have less serious side effects than the major tranquilisers, could be useful in the management of challenging behaviour. As well as having an anxiolytic function, it is possible that antidepressants may actually be addressing a mood disorder underlying the challenging behaviour, for at least some participants. It is certainly possible that organic deficits in brain structure, function or dynamism may predispose people with an intellectual disability to a greater risk for mental health problems, including depression. Arguably, the life circumstances of some people with an intellectual disability may also be characterised by more negative experiences (such as frequent loss of attachment figures), which may increase risk for reactive mental health difficulties.

We found a significant difference between the ASD and non-ASD group on the MIPQ and on the frequency of challenging behaviour. We do not yet know if depression presents differently in people with ASD as suggested by Long, Wood and Holmes (2000). Alternative assessment methods may be required to specifically identify depression in people with ASD, based for example on behaviour change indices. A study to explore whether different types of challenging behaviour are presented in those with depression when compared with those with other psychiatric disorders would be useful in order to develop possible behaviour-type indicators to assist with the diagnosis of mental health difficulties in people with more severe levels of intellectual disability. Using knowledge of behavioural phenotypes, it may be possible to diagnose the presence of mood disorders through the identification of behaviour patterns not typically seen in people with intellectual disability generally, or within specific sub-groups of the intellectual disability population. Some work in this area has already been reported (e.g. Clarke, 2003; Kishore, Nazemi & Nazemi, 2005),
but the identification of reliable clusters of behavioural indicators for diagnosing depression remains elusive.

While the study utilised the MIPQ and DC-LD for identification of depression, a recent diagnostic manual, the DM-ID (Fletcher, Loschen, Stavrakaki & First, 2007) provides an alternative method of diagnosing depression, based on an adaptation of the DSM-IV-TR. There is preliminary support for the diagnostic sensitivity and specificity of the DM-ID (Fletcher et al, 2009) and future studies could usefully compare the relative utility of the DM-ID, the DC-LD and the MIPQ.

The study had certain limitations. The participants in the study were recruited solely from large residential institutions and it may be that participants from institutions are more likely to have lower mood and higher levels of challenging behaviour, although other studies with participants who lived in the community also reported a relationship between low mood and challenging behaviour (e.g. Marston et al 1997). Whilst the number of participants was relatively small, it included only people within the severe and profound range, whereas other studies in this area tend to have reported on participants across the range of intellectual disability. Despite the small sample size, we found both statistically and clinically significant differences between groups. It is possible, however, that the study was underpowered to detect smaller differences. Challenging behaviour is not a formal psychiatric diagnosis, although it is the most common reason that people with an intellectual disability are referred to psychiatrists (Moss, 2000). Caution should be taken to not assume that all challenging behaviour is indicative of an underlying mental health difficulty – several decades of high quality research has informed us that challenging behaviour is multifaceted in its origin and functional analysis technologies have highlighted the communicative function of challenging behaviour. Furthermore, it is also possible that
physical health remains a key factor in both low mood and challenging behaviour. Whilst the physical health history of each participant was recorded in both questionnaires and later in the interview, no objective, quantifiable measure of ill health was used. Evenhuis, Henderson and Beange (2001) reported people with intellectual disabilities to be more likely to develop health and medical problems than the general population. Hence, it is particularly important to control for health and physical problems as they could also potentially account for both challenging behaviour and low mood. Future studies should record a detailed medical history in a quantifiable format for the purpose of correlating elevated scores in depression measures, indicators of behaviour disturbance and the potential role of physical ill-health.

A further point of which to be cognisant is that people with ID could have low mood related to discomfort or distress associated with side effects of medications (Valdovinos et al., 2005) and this warrants attention in future studies. Finally, while we found that the relationship between low mood and challenging behaviour still held after controlling for variables such as the presence of a mental health diagnosis, future research such aim to systematically elucidate the potential role of co-morbid psychiatric illness. Since 13% of our sample had a diagnosed mental health difficulty, clearly there is the possibility of diagnostic clouding by the presence of some categories of psychiatric illness with symptom overlap (for example, anxiety and depression) as well as the possibility that co-morbid illness may interact to change the expression of behaviour, distress and the clinical picture of depression itself.

In summary, people with severe and profound intellectual disability show clear and measurable signs of low mood, and in this relatively small sample of institutionalised individuals, low mood was associated with the presence of
challenging behaviour. Future research should aim to elaborate the nature of this relationship, for example, to further explore whether certain behaviour change indices could be used as an aid to the diagnosis of depression and perhaps also as an indicant of change following treatment.

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use with adults with learning disabilities.* London: Royal College of
Psychiatrists.


Table 1: Participant demographic information.

<table>
<thead>
<tr>
<th>Gender</th>
<th>ASD Diagnosis</th>
<th>Previous Mental Health Diagnosis</th>
<th>Physical Health Difficulties</th>
<th>Medication*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Female</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

| N     | 39 13 | 29 23 | 13 39 | 28 24 | 38 14 |
| %     | 75 25 | 55 45 | 25 75 | 53 47 | 73 27 |

* (Anxiolytics, anti-psychotics, or anti-epileptics)
Table 2: Mean scores for the low mood and normothymic groups, based on MIPQ classification.

<table>
<thead>
<tr>
<th>Measure</th>
<th>Low mood (n=15)</th>
<th>Normothymic (n=15)</th>
<th>t</th>
<th>p</th>
<th>Cohen’s d</th>
</tr>
</thead>
<tbody>
<tr>
<td>MIPQ Mean Total Score</td>
<td>21.66 (SD=1.63)</td>
<td>69.73 (SD=4.33)</td>
<td>-42.1</td>
<td>&lt;0.05</td>
<td>-14.69</td>
</tr>
<tr>
<td>DC-LD Mean Total Score</td>
<td>4.13 (SD=1.76)</td>
<td>0 (SD=0)</td>
<td>9.06</td>
<td>&lt;0.05</td>
<td>3.32</td>
</tr>
<tr>
<td>CBI Score</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Frequency</td>
<td>4.13 (SD=2.7)</td>
<td>1.4 (SD=1.08)</td>
<td>10.16</td>
<td>&lt;.004</td>
<td>1.33</td>
</tr>
<tr>
<td>- Severity</td>
<td>58.6 (SD=27)</td>
<td>17.06 (SD=15)</td>
<td>6.78</td>
<td>&lt;.015</td>
<td>1.90</td>
</tr>
</tbody>
</table>

MIPQ = Mood Interest and Pleasure Questionnaire; DC-LD = Diagnostic Criteria – Learning Disability; CBI = Challenging Behaviour Interview.
Table 3: Summary of comparison of mean scores for the autism spectrum group (ASD) and the non-autism group.

<table>
<thead>
<tr>
<th>Measure</th>
<th>ASD Group (n=29)</th>
<th>Non-ASD Group (n=23)</th>
<th>t</th>
<th>p</th>
<th>Cohen’s d</th>
</tr>
</thead>
<tbody>
<tr>
<td>MIPQ – M (SD)</td>
<td>57.62 (14.75)</td>
<td>40.13 (15.21)</td>
<td>4.18</td>
<td>&lt;0.05</td>
<td>1.17</td>
</tr>
<tr>
<td>DC-LD - M (SD)</td>
<td>2.66 (3.34)</td>
<td>1.61 (2.77)</td>
<td>1.21</td>
<td>0.23</td>
<td>0.34</td>
</tr>
<tr>
<td>CBI Frequency - M (SD)</td>
<td>3.72 (2.59)</td>
<td>2.17 (1.78)</td>
<td>2.44</td>
<td>&lt;0.05</td>
<td>0.70</td>
</tr>
<tr>
<td>CBI Severity - M (SD)</td>
<td>47.97 (39.79)</td>
<td>31.30 (30.04)</td>
<td>1.66</td>
<td>.10</td>
<td>0.47</td>
</tr>
</tbody>
</table>

MIPQ = Mood Interest and Pleasure Questionnaire; DC-LD = Diagnostic Criteria – Learning Disability; CBI = Challenging Behaviour Interview
Table 4: Summary of hierarchical regression analysis for variables predicting the frequency and severity of challenging behaviour.

<table>
<thead>
<tr>
<th></th>
<th>Variable</th>
<th>β</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Frequency of CB</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>STEP 1</td>
<td>DC-LD</td>
<td>.351</td>
<td>2.68*</td>
</tr>
<tr>
<td>STEP 2</td>
<td>DC-LD</td>
<td>.274</td>
<td>-2.09*</td>
</tr>
<tr>
<td></td>
<td>MIPQ</td>
<td>-.303</td>
<td>-2.30*</td>
</tr>
<tr>
<td><strong>Severity of CB</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>STEP 1</td>
<td>DC-LD</td>
<td>.407</td>
<td>-3.15*</td>
</tr>
<tr>
<td>STEP 2</td>
<td>DC-LD</td>
<td>.335</td>
<td>-2.60*</td>
</tr>
<tr>
<td></td>
<td>MIPQ</td>
<td>-.282</td>
<td>-2.19*</td>
</tr>
</tbody>
</table>

Note: (n=52). * = p<.05, Total adjusted R² are .358 and .287, respectively. MIPQ = Mood Interest and Pleasure Questionnaire; DC-LD = Diagnostic Criteria – Learning Disability; CB = Challenging Behaviour.