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The relationship between levels of mood, interest and pleasure and “challenging behaviour” in adults with severe and profound intellectual disabilities.

by

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Running head: Mood, interest and pleasure and challenging behaviour

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ABSTRACT

Research on affective disorders in adults with an intellectual disability suggests that in individuals with severe and profound intellectual disabilities depression may not present a “classic picture”, but may include challenging behaviours, referred to as “atypical symptoms” such as self-injury, aggression and irritability. The aim of this study was to explore whether there is an association between constructs relating closely to the core symptoms of depression and challenging behaviours in adults with severe and profound intellectual disabilities. Mood and levels of interest and pleasure were measured in 53 adults with severe or profound intellectual disability using the Mood, Interest and Pleasure Questionnaire (MIPQ). Two groups of adults were identified based on MIPQ scores: a “low mood group” (lowest scoring 12) and a comparison group (highest scoring 12). The groups were clearly differentiated on the MIPQ ($p < .0001$) but were comparable on age, gender and medication use. The Challenging Behaviour Interview (CBI) showed no difference between the two groups in self-injury, aggression or disrupting the environment. A secondary analysis revealed that participants who showed challenging behaviour scored significantly lower on the MIPQ than those who did not show challenging behaviour. Possible reasons for these results and considerations for future studies are discussed.

INTRODUCTION

Mental health problems in adults with intellectual disabilities have received considerable attention since the 1980s (Sturmey & Sevin, 1993). The majority of research has concentrated on the presentation of affective disorders, especially in relation to depression (e.g. Charlot, Doucette & Mezzacappa, 1993; Davis, Judd & Herrmann, 1997; Marston, Perry & Roy, 1997; Meins, 1995). It is suggested that adults with mild and moderate intellectual disabilities display the full range of “classic symptoms” of depression described in standard diagnostic classification systems, e.g. DSM-IV (American Psychiatric Association, 1994) (see Marston *et al.*, 1997; Meins, 1995; Pawlarczyk & Beckwith, 1987; Sovner & Desnoyers Hurley, 1983 and Sturmey, 1995).

There has been less research interest in the presentation of depression in adults with severe and profound intellectual disabilities. This issue presents significant challenges, because a number of “classic symptoms” rely on self-report. The ability to self-report is either limited or absent in people with more severe intellectual disabilities. Indeed, Meins (1995) concluded that the following DSM-III-R (American Psychiatric Association, 1987) criteria were only partially accessible in people with severe intellectual disabilities: feelings of worthlessness, inappropriate guilt; suicide ideation, attempts and decreased concentration, indecisiveness.

There is an emerging argument that in adults with a greater degree of intellectual disability, the presentation of depression may not conform to the usual diagnostic criteria. Whilst it is acknowledged that some “classic symptoms” of depression are presented by adults with severe and profound intellectual disabilities (e.g. Charlot *et al.*, 1993; Marston *et al.*, 1997), it is suggested that there may also be “atypical symptoms”. “Atypical symptoms” are also referred to as “depressive equivalents” (Sovner, DesNoyers Hurley & La Brie, 1982) or “behavioural depressive equivalents” (Marston *et al.*, 1997).

Descriptions of “atypical symptoms” have included the full range of challenging behaviours, although aggression, self-injurious behaviour and “irritability” are the most commonly cited. Accounts of aggression and self-injurious behaviour as indicators of affective disorders are proposed by Charlot *et al.*, (1993), Lowry & Sovner (1992), Meins (1995) and Sovner &

DesNoyers Hurley (1983). Descriptions of irritability can be found in Charlot *et al.* (1993), Davis *et al.* (1997) and Meins (1995). On occasion, definitions of “atypical symptoms” are restricted to “increase or onset of maladaptive behaviours” and/or “decrease of adaptive behaviours” (e.g. Meins, 1995; Sovner & Lowry, 1990).

There appears to be widespread agreement regarding the validity of the concept of “atypical symptoms”. The validity of such assertions is said to be stronger when a time link is identified between the onset of depressive symptoms and the “atypical symptoms” (e.g. Meins, 1995). However, the conclusion that depression causes “atypical symptoms” rarely considers the possible influence of a third variable. One exception is the suggestion that when an individual experiences a particular symptom of depression, events in the environment can become aversive (Lowry, 1994). For example, a person experiencing loss of interest might self-injure, if prompted to engage in an activity. Moreover, significant methodological limitations are apparent in studies identifying “atypical symptoms”. These are outlined in detail elsewhere (see Ross and Oliver, under review, a). In brief, there are three main problems. First, statements about the presentation of depressive symptoms in people with severe and profound intellectual disabilities are based on very small numbers of participants with this degree of disability. Second, constructs under investigation, such as “irritability”, are often poorly and inconsistently defined (Lowry, 1994). Third, the majority of studies identifying “atypical symptoms” rely on a tautological rationale, whereby modified diagnostic criteria that include “atypical symptoms” are used to diagnose individuals with depression who are subsequently employed in studies which aim to explore how depression manifests itself in this client group.

This preliminary study attempts to overcome these methodological limitations. It is beyond the scope of this study to explore the full range of “classic symptoms” of depression. Clark, Reed & Sturmey (1991) suggest that since there is, as yet, no standard classification system to diagnose depression in people with an intellectual disability, a logical initial step would be to investigate how one construct, such as sadness, might relate to a number of “difficult” behaviours. Hence, this study aims to explore the relationship between constructs which correspond closely to the two core symptoms of major depression and challenging behaviour in adults with severe and profound intellectual disabilities. The core symptoms of major depression are low mood and

reduced levels of interest and pleasure (DSM-IV, American Psychiatric Association, 1994); the constructs under investigation in this study are mood levels and levels of interest and pleasure. Whereas symptoms of depression are characterised by change in an individual's behaviour, as exemplified by the description "reduced levels of interest and pleasure", the constructs identified for this study do not incorporate the concept of behaviour change. Despite this difference in emphasis, given the literature outlining a possible association between depression and challenging behaviours, it seems reasonable to hypothesise that a similar association may exist between constructs akin to the core symptoms of depression and challenging behaviours.

This study aims to compare two groups from a sample of 53 people who were part of a larger study (Ross and Oliver, under review, b). Groups are defined on the basis of scores on the Mood Interest and Pleasure Questionnaire (MIPQ), an informant based measure of two aspects of affect for people with severe and profound intellectual disability. One group will consist of the 12 lowest scorers on the MIPQ, indicating low levels of mood, interest and pleasure (referred to henceforth as the "low mood" group). The comparison group will consist of the 12 highest scorers on the MIPQ. The two groups will be compared by administering an interview measure of challenging behaviour, the Challenging Behaviour Interview (CBI, Oliver, Smith, Hodge, Dagnan & Stenfert-Kroese, under review), to examine whether the groups differ in terms of presence and severity of challenging behaviour.

METHOD

Participants

As part of a larger study questionnaire data were obtained in relation to 53 individuals with severe and profound intellectual disabilities (Ross and Oliver, under review, b). Participants were randomly selected from a community sample and were not necessarily in contact with services. Participants were included in they were rated "partly verbal" or "non-verbal" on the Wessex Scales (Kushlick, Blunden & Cox, 1973). Informants of 24 participants of the original sample were subsequently interviewed.

Informants. All 24 informants had known a participant for at least six months. Fifteen (62.5%) were keyworkers, 7 (29.1%) were managers, 1 (4.2%) was a support worker and 1 (4.2%) was a parent.

People with an intellectual disability. The mean age of the total sample was 39.96 years (SD= 10.88), 15 (62.5%) were males, 7 (29.2%) experienced seizures and 4 (16.7%) had been diagnosed as autistic. From data collected using the Wessex Scales (Kushlick *et al.*, 1973), 12 (50%) were non-verbal, 12 (50%) were partly verbal, 24 (100%) were not literate and 13 (54.2%) were fully mobile. Formal categorisation of level of intellectual disability was not available. No participants were receiving anti-depressant medication.

Measures

The Mood, Interest & Pleasure Questionnaire (MIPQ). The 25 item MIPQ was devised as part of a larger study (Ross & Oliver, under review, b). It is designed for use in relation to people with severe and profound intellectual disabilities and requires informants to rate aspects of participants' behaviours that are correlated with affect on 5 point Likert scales. The Mood subscale has 12 items and the Interest & Pleasure subscale 13 items. Inter-rater and test-retest reliability for the full scale are 0.76 and 0.87 respectively. Inter-rater reliability for the Mood subscale is 0.69 and 0.76 for the Interest & Pleasure subscale. Test-retest reliability for the Mood subscale is 0.90 and 0.84 for the Interest & Pleasure subscale. Internal consistency was found to be excellent: 0.94 for the total scale, 0.89 for the Mood subscale and 0.90 for the Interest & Pleasure subscale. Low scores denote low mood and interest and pleasure levels. The maximum possible score is 100.

The Challenging Behaviour Interview (CBI, Oliver et al., under review). Part one of the CBI records the occurrence, in the past month, of five operationally defined topographies of challenging behaviour (self-injurious behaviour, physical aggression, verbal aggression, disruption and destruction of property or the environment, inappropriate vocalisations). Part two consists of 14 items rated on Likert scales to generate data about the severity of each identified behaviour. A higher score on part one denotes more topographies of challenging behaviours, higher scores on part two indicate higher degrees of severity for each observed challenging

behaviour. Mean Kappa coefficients across behaviours for part one of the CBI for test-retest and inter-rater agreement have been reported as 0.86 and 0.67 respectively (Oliver *et al.*, under review). Mean test-retest and inter-rater reliability for part two of the CBI are 0.76 and 0.48 respectively. Thus, the reliability of the CBI appears to be good.

The Diagnostic Assessment for the Severely Handicapped-II (DASH-II, Matson, 1995)

The DASH-II is an informant interview measure designed to assess the frequency, duration and severity of symptoms of psychopathology in people with severe or profound learning disabilities. Individual items are rated on dimensions of frequency, duration and severity. Items are scored 0, 1 or 2 on each dimension; higher scores denote higher levels of psychopathology. Data from autism and other pervasive developmental disorders subscale were used in this study.

Medication. Information on the use of carbamazepine, anti-epileptics, anti-psychotics and anti-depressants was collected by interview.

Procedure

Questionnaire packs containing the Wessex Scales, the MIPQ, instructions and pre-paid envelopes were distributed to informants via managers. Scores on the MIPQ were used to identify two groups, 12 participants with the lowest scores (the “low mood group”) and 12 participants with the highest scores (the comparison group). CBI and DASH II data were subsequently collected with participants’ informants between 3-4 months after the questionnaires had been completed.

RESULTS

The “low mood” and comparison groups were compared with regard to gender, age, medication use, and the disability categories of the Wessex Scale (Incontinence, Mobility, Speech, Self-help, Literacy and Sensory). The results revealed no significant differences suggesting the groups were comparable on these variables. The proportion of participants diagnosed with autism was higher in the “low mood” group ($n = 4$; 33.3%) than in the comparison group ($n = 0$) and this difference was significant (Fisher’s exact; $p < .01$). However, the mean score on the autism and other pervasive developmental disorders subscale was not significantly higher for the “low mood

group” ($x = 4.17$; $SD = 2.79$) than the comparison group (Mean = 2.42; $SD = 1.38$) ($U = 42$; n.s.). Finally, as expected, the groups differed significantly on the MIPQ total score (“low mood group” Mean = 41.27; $SD = 5.83$; comparison group Mean = 82.00, $SD = 4.75$; $t(21) = 18.40$; $p < .0001$), the Mood subscale score (“low mood group” Mean = 24.91; $SD = 7.19$; comparison group Mean = 43.10, $SD = 3.42$; $t(21) = 7.85$; $p < .0001$), and the Interest and Pleasure subscale score (“low mood group” Mean = 16.67; $SD = 3.75$; comparison group Mean = 38.92, $SD = 4.29$; $t(22) = 13.50$; $p < .0001$). Thus the groups were clearly differentiated with regard to the MIPQ.

Differences were investigated between scores on the CBI obtained by the “low mood” and comparison groups, to explore the hypothesis that participants in the “low mood” group would exhibit higher levels of challenging behaviour than those in the comparison group. Fisher’s Exact Test was employed where the expected cell frequencies were less than five to investigate differences between the two groups in terms of the occurrence of the categories of challenging behaviour measured by part one of the CBI. Hence, the Fisher’s Exact Test was used for all categories except “self-injurious behaviour”, for which it was possible to use the Chi-Square test. All results were non-significant. There was also no significant difference between the groups on the total occurrence across all topographies of challenging behaviour ($U = 53.00$, $p = .29$), as measured by total scores on part one of the CBI. Mean total occurrence scores for the “low mood” and comparison groups were 1.50 ($SD, 1.00$) and 1.08 ($SD, 1.50$) respectively.

The Mann-Whitney U test was employed to compare scores for the severity of each topography of challenging behaviour and for total severity scores across all categories of challenging behaviour, as measured by part two of the CBI. None of the Mann-Whitney U test calculations was found to be significant, although the severity score for the category of self-injurious behaviour did approach significance ($U = 39.00$, $p = .06$). Finally, there was no significant difference between the two groups in terms of total severity scores ($U = 45.00$, $p = .13$), as measured by total scores on part two of the CBI. Mean total severity scores for the “low mood” and comparison groups were 34.17 ($SD, 27.48$) and 18.92 ($SD, 27.97$) respectively.

A secondary analysis was conducted to compare mood interest and pleasure in participants showing challenging behaviour with those who were not. The challenging behaviour group comprised all participants for whom at least one form of challenging behaviour had occurred in the last month ($n = 15$). The total score on the MIPQ was significantly lower in the challenging behaviour group (Mean = 54.40, SD = 20.04) than the comparison group (Mean = 77.75, SD = 15.30) ($t(21) = 2.87, p < .01$). Similarly the score on the mood subscale was lower in the challenging behaviour group (Mean = 30.67, SD = 10.81) than the comparison group (Mean = 41.37, SD = 6.63) ($t(21) = 2.54, p < .05$) and the score on the interest and pleasure subscale was lower in the challenging behaviour group (Mean = 23.73, SD = 11.06) than the comparison group (Mean = 34.56, SD = 10.93) ($t(21) = 2.33, p < .05$). These results indicate that participants showing challenging behaviour were experiencing lower affect than those who were not showing challenging behaviour.

DISCUSSION

This study is a preliminary examination of the association between levels of mood, interest and pleasure and challenging behaviour in adults with severe and profound intellectual disabilities. It can be regarded as a departure from the methodology of previous studies that have investigated links between depression and “atypical symptoms” in people with more severe intellectual disabilities. It is the first study to explore the possibility that internal states (mood levels and levels of interest and pleasure) may be related to levels of behavioural disturbance, irrespective of psychiatric diagnosis. From a methodological perspective, it has the advantage both of focusing exclusively on people with severe and profound intellectual disabilities with limited or no expressive language and of using a community sample (other studies rely heavily on participants already in contact with psychiatric services). Moreover, it has avoided the tautological rationale apparent in most studies of “atypical symptoms” of depression.

The study did not demonstrate any significant difference between the “low mood” and comparison groups in terms of the presence or severity of challenging behaviours. However, it is worth noting that the severity score for self-injurious behaviour was higher for the “low mood” group than for the comparison group and that this result approached significance. This is of interest given the emphasis placed on self-injury in previous reports of atypical presentations of

depression (Charlot *et al.*, 1993; Lowry & Sovner, 1992; Marston *et al.*, 1997; Meins, 1995; Sovner & DesNoyers Hurley, 1983). However, it is entirely possible that any reported association between self-injurious behaviour and depression arises from the phenomenology of autism related to flat affect and social withdrawal being interpreted as depressive symptomatology. In this study the unconfirmed diagnosis of autism was significantly higher in the “low mood” group although scores on the autism and other pervasive developmental disorders subscale did not differ between the groups. Future research into the association between self-injurious behaviour and depressive symptomatology in adults with severe learning disability should control for the presence of autistic spectrum disorders.

There are several potential explanations for the non-significant findings for this phase of the study. First, there may not be higher levels of challenging behaviour when low levels of mood, interest and pleasure prevail if objective measures of affect and behaviour are employed. Second, as there was an unavoidable time delay between the questionnaire and interview phases of the study, behaviour amongst participants in either group could have altered, thus affecting the outcome. A final consideration is that studies which have reported links between depression and “atypical symptoms” have included individuals with a range of depressive symptoms, not just the core symptoms, low mood and reduced levels of interest and pleasure. Hence, the participants in this study might not be sufficiently “low” to exhibit elevated levels of challenging behaviour. Finally it is possible that the groups were too small to detect a difference.

The secondary analysis revealed significantly lower levels of affect in those showing challenging behaviour. This difference was evident despite the small sample size and warrants further examination in larger samples. It is perhaps not surprising that affect should be lower given the nature of challenging behaviour but this has not previously been reported. Taken together with the results of the first analysis, this finding raises the possibility that ‘atypical’ symptoms of depression may in fact be contributory to low mood as opposed to indicative of low mood.

Given the findings of this study and past research, further work is needed to clarify the results. It is possible that behaviours on the autistic spectrum might be a confounding variable when associations are found between low mood and self-injury, stereotypies and/or withdrawn

behaviours (c.f. Ross and Oliver, under review b). Additionally it is possible that low mood arises as a result of challenging behaviour and its inevitable sequelae or that challenging behaviour is indicative of low mood. Finally, it would be beneficial if future studies in this area examined more complex models of causation, i.e. whether the presentation of challenging behaviour and low mood might be mediated by a third variable, such as environmental influences (see Lowry, 1994) and whether low mood might influence operant antecedents to challenging behaviour as is suggested in the setting event literature.

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