Diagnosis and Treatment of Depression in Adults with Intellectual Disability through Direct Support Worker, General Practitioner and Psychiatry Collaboration

Researchers:

Dr. Jennifer Torr Dr. Teresa Iacono Ms. Jennifer Galea Dr. Jean Graham Dr. Mary Burbidge Professor Bruce Tonge Associate Professor Stewart Einfeld

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Progress Report:

Prevalence rates of depression in intellectual disability have been reported as between 1.3% and 3.7% (Deb et al., 2001). These figures have been argued to be underestimates because of problems with diagnosing depression in people who, characteristically, have communication problems (Davis et al., 1997). At CDDHV, a clinical audit indicated that of 100 consecutive patients with intellectual disability seen by CDDHV clinicians, 40 were prescribed antidepressant medication because of either diagnosed or suspected depression. In addition, pilot data from a survey of 598 adults with intellectual disability indicated that over 50% had some degree of depressive symptomatology that limited their activity, participation, and independence, as reported by carers.

A major problem with the use of current assessment tools is that they rely on self report, hence cannot be used with people with severe communication impairment. Other tools have been developed that rely on reports of carers about changes in observable symptoms (e.g., weight loss, lack of interest in activities, or onset of behaviour problems). These tools have been designed, however, for use by psychiatrists or other mental health practitioners with experience in intellectual disability. The issue of concern is ensuring that people with intellectual disability who may be at risk of depression or other mental health problems are able to access mental health services, but this is dependent on GPs' ability to recognise symptoms that could signal the need for a mental health referral. GPs rarely, however, have the skills or experience in intellectual disability to recognise changes in the individual that are indicative of a need for referral. In addition, they often have difficulty obtaining the information required from carers, who may not know the person with intellectual disability well enough to comment on observable changes. This project was designed to provide a means of assisting GPs in conducting an initial screening for depression and related disorders in adults with severe intellectual disability.

The main aim of the project was to develop two depression checklists, one for use by carers (support workers) and the other by general practitioners. Both checklists were developed from the literature and clinical experience of Dr. Jennifer Torr, CDDHV Consultant Psychiatrist. The carer checklist was designed to ensure that carers provided relevant information to the person with intellectual disability's GP. The GP checklist was designed to alert the GP to potential symptoms, in terms of recent observable changes, of depression and related disorders. Hence, it had an additional educational objective. Here we report on the results of the carer checklist in terms of its internal consistency, construct validity and concurrent validity.

Method

Participants

We recruited adults with intellectual disabilities through government and nongovernment disability services in Melbourne and some rural communities. Forty-nine participants with intellectual disability (31 males and 18 females) aged 18 to 61 years (mean = 34 years). They were reported to have moderate to severe levels of intellectual disability. For 84% of participants, help for mental health problems had been sought prior to participation in the study.

Carer Checklist

This checklist was developed by Dr. Jenny Torr. It comprised an initial symptom of suicidal thoughts, talking or actions, and 54 other symptoms organised according to the following 12 sections: depressed mood, depressed thinking, irritability, and loss of interest in or enjoyment of usual activities, anxiety, social interaction and communication, general functioning, other behaviours, appetite / weight, sleep and mood variation. The written instruction to carers was that they put a tick in a box next to each symptom for which they had observed onset, increase or change.

Procedures

Following receipt of informed consent, participants' support workers were sent a package, which included the carer checklist. Also included in the package was the Developmental Behaviour Checklist – Adults (DBC-A) (Mohr et al., 2005), a published test of psychopathology in adults with intellectual disability. The checklists were completed by a key support worker who knew the individual well.

Results

Because of the dichotomous nature of the item data of the checklist, internal consistency was determined using KRS-20. An overall score of 0.90 was obtained. Deletion of individual items did not result in increases in the overall score for either checklist; hence all items were retained.

All section totals were included in a factor analysis because they met the criteria of (a) linearity, as indicated by high intercorrelations; (b) factorability, as indicated by Bartlett's test of sphericity (p < .001); and (c) sampling adequacy, as indicated by the Kaiser-Meyer-Olkin (KMO) statistic, with anti-image correlations above 0.57 for all subsections, with most having scores above 0.74. The analysis, with loadings of 0.30 suppressed, yielded a 4 factor solution, which accounted for 69% of the variance.

Subsections with moderate to high loadings onto component 1 were depressed mood (0.80), depressed thinking (0.62), loss of interest (0.71), social interaction and communication (0.84), appetite and weight loss (0.68), and general functioning (0.53). This component was interpreted to be depression. Sections with high loadings onto component 2 were anxiety (0.82) and mood variation (0.70); this component was interpreted to be anxiety. Sections that loaded highly onto component 3 were loss of interest (0.77) and other behaviours (0.74); finally, the only section to load onto component 4 was sleep (0.81).

Spearman rho correlations were conducted between subsections of the carer checklist and subscales of the DBC-A. The highest correlation was between depressed mood on the carer checklist and the DBC-A depressive subscale ($\rho = 0.70$; p<.01). Moderate and significant correlations were also obtained between the DBC-A Depressive subscale and the checklist subsections of depressive thinking, loss of interest, communication, general functioning, appetite/ weight, and sleep. Small to moderate significant correlations were also found between other subscales of the DBC-A and subsections of the carer checklist, demonstrating other overlaps in the constructs or aspects of psychopathology being tapped by the two screening tools.

Implications

The results for the carer checklist indicated that it did tap depression in adults with intellectual disability using indicators that could be observed by carers, as opposed to relying on self report. Although the carer checklist did have a high correlation with the depressive subscale of the published screening tool, the DBC-A, it should be noted that it was not designed as a way of screening for depression perse. Instead, it is meant to provide the information that would be required by a GP or other professional in deciding if a referral for a mental health assessment is warranted. Hence, it provides carers with a systematic strategy of knowing what information is of relevance to a primary health care or mental health professional, and of recording the information. We envision it will be most useful for GPs if carers take a completed checklist when accompanying an adult with intellectual disability to a consult. In this way, GPs can overcome the difficulties they experience in obtaining the information they need in order to determine the appropriateness of a referral.

Further work is needed on the carer checklist, in particular, determining its inter-rater reliability. To this end, we have included a modified version (based on the results of the factor analysis) in a larger study of depression in adults with intellectual disability, which is also being funded by beyondblue. In this study, two carers will complete checklists for one adult.

At this time, we are completing analysis on the GP checklists, and on comparing information obtained through these sources and the DBC-A with psychiatric diagnosis made on the basis of a comprehensive assessment. The modified version of the carer checklist can be downloaded from http://www.cddh.monash.org/.

References

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