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# A Follow-Up of Adolescents with Obsessive–Compulsive Disorder

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Twenty-six patients seen at a regional adolescent psychiatry unit between 1974 and 1979 with a discharge diagnosis of obsessive–compulsive disorder were followed up after an average of ten years. Of 24 subjects traced, outcome information was obtained from 20. At the point of follow-up, ten patients remained psychiatrically ill, six having persisting obsessive–compulsive symptoms. Poor outcome was associated with a family history of psychiatric illness and lack of response to therapy at initial contact. All patients who were asymptomatic at discharge had remained well.

Follow-up studies of patients presenting with obsessive–compulsive disorder (OCD) have described the long-term persistence of disabling symptoms in many cases (Black, 1974). Goodwin *et al* (1969), in a review of these studies in adults, summarised the data in terms of treatment status. Of those who received out-patient treatment, 60–80% were asymptomatic or improved one to five years later, whereas of those admitted to hospital only 33% were improved at follow-up. They suggest that between 5% and 10% of patients follow a chronic course often marked by progressive decline. Good outcome was associated with mild symptoms, short duration, and good pre-morbid personality, including the absence of childhood disturbance. Rasmussen & Tsuang (1984) reviewed nine recent studies of the outcome of behavioural treatment of adults with OCD. The proportion asymptomatic in follow-up periods of less than two years ranged between 50% and 67%.

Several studies have noted the onset in adolescence or childhood of symptoms persisting into adulthood in a significant proportion of patients (e.g. Pollitt, 1957; Kringlen, 1965) with consequent pessimism about the long-term outlook in cases of early onset. Berman (1942), following up six OCD patients among 3050 childhood admissions, found two to be schizophrenic, one still to be suffering with severe OCD symptoms, and three to be free of symptoms. Warren (1965) reported the outcome for 15 OCD patients among 187 patients admitted to an adolescent unit. At least six years after admission, five remained seriously handicapped with OCD symptoms, four somewhat handicapped, four symptomatic under stress, and only two completely well. In a retrospective 1.5–14-year follow-up study of 17 children with OCD, Hollingsworth *et al* (1980) traced ten, who were between 12 and 30 years of age. Of these patients, seven continued to have symptoms of OCD and two of the remaining three had been treated for other psychiatric conditions.

There is limited information available about prognosis in terms of psychosocial adjustment in adulthood for adolescents presenting with OCD. Mawson *et al* (1982) found that decrements in social functioning in adult patients were related to the severity of symptoms and showed improvement when symptoms were treated. Probst *et al* (1979) examined the social adjustment of 25 patients whose OCD symptoms began in childhood and concluded that social integration and severity of symptoms are closely associated. Hollingsworth *et al* (1980) found that school performance and employment record were unremarkable at follow-up, but that all patients reported problems in maintaining close personal relationships.

These data, taken overall, suggest a very gloomy outlook. However, the studies involve small numbers of patients, often with wide age ranges and follow-up periods, and with a selective bias towards those requiring in-patient management. Lack of data on outcome criteria and in particular on the reliability and validity of assessments makes confident statements on likely outcome difficult. Furthermore, with the development of behavioural methods in treating the disorder within the last 15 years and the demonstration of their efficacy in adolescents (Bolton *et al*, 1983) it is possible that outcome has changed. This study sought to address these considerations within the limitations of a retrospective design.

## Method

All patients referred to the Highfield Regional Family and Adolescent Unit, Oxford, during the period 1974–79 and receiving a discharge diagnosis of OCD (ICD–9 coding 300.3; World Health Organization, 1978) were identified ($n = 30$) (1974 was the first year for which complete unit records of diagnosis were made and 1979 the last year in which all subjects had reached their third decade at the point of follow-up). The unit records and the computer records of the Oxford Data Linkage Project, Unit of Clinical

Epidemiology, Oxford, were cross-checked over a four-year period and reliability confirmed by a 100% agreement. The clinical notes of all those identified were examined, and those patients who met criteria set out by Judd (1965) for a well defined constellation of OCD symptoms without other major psychiatric disorder and severe enough to interfere with general functioning were included in the study ($n = 26$).

The patients were traced via general practitioners and family practitioner committees. Those found were invited by letter to take part in a semistructured interview with one or both of the authors. During this, information was obtained about aspects of the patients' psychiatric history and current functioning. Inquiry was made about the patients' perceptions of their illness and its management during adolescence, and the nature and severity of OCD symptoms at discharge from the unit and subsequently. Patients were asked about the nature and severity of other psychiatric symptoms arising during the follow-up period, and about contact with and treatment received from primary care and psychiatric services in this time. There were also questions about psychosocial adjustment in terms of educational achievement, marital, family and employment status, and satisfaction with social and sexual life. As a means of corroborating the interview data, subjects were asked to complete standardised measures of mood and behaviour: the Beck Depression Inventory (BDI; Beck *et al*, 1961), the Maudsley Obsessive-Compulsive Inventory (MOCI; Hodgson & Rachman, 1977), the Speilberger State/Trait Anxiety Inventory (STAI; Speilberger *et al*, 1970), and the Social Adjustment Schedule (Corney & Clare, 1985), administered on the same occasion.

## Results

### Initial contact

The mean age of the sample ($n = 26$, 14 boys, 12 girls) on first assessment at the unit was 15.25 years (range 12.5-18.4 years). The mean age of onset of symptoms was 12 years (range 8-17 years). Sixteen patients had received previous psychiatric treatment for OCD and seven for other problems. The average delay between onset and assessment for those for whom Highfield was their first referral for this problem was 2.1 years (range 6 months to 4 years), whereas for those who had received previous treatment the mean was 3.0 years (range 6 months to 7.5 years). Four patients had chronic or recurrent physical illness, and a further three had minor developmental difficulties. Ten patients had a history of psychiatric disorder in first-degree relatives, and in four this was OCD.

At initial presentation three patients had obsessional symptoms only, all with ruminations. Compulsive symptoms were divided into categories of cleaning and checking rituals following Bolton *et al* (1983) in order to facilitate comparison with other studies (e.g. Apter *et al*, 1984). The term 'checking' is used in a broad sense to include various 'safe-making' rituals including ordering and organising. Of the 23 patients with compulsive symptoms, nine had washing or cleaning rituals only, six checking rituals only, and eight had both cleaning and checking rituals.

Resistance to symptoms was recorded as absent for eight patients, although in a majority no assessment was noted. Temper outbursts associated with symptoms were described for 15 patients. In 11 cases OCD symptoms interfered with school attendance. Social isolation from peers was described by 22 patients; in 20 this problem pre-dated the onset of OCD symptoms. In 12 cases there was evidence of one or both parents being actively involved in the adolescent's ritualistic behaviour. In a further four cases parents gave frequent and repeated reassurance about obsessional thoughts.

The mean duration of contact with patients from referral was 1.4 years (range 0.1-5.7 years). Four patients were not engaged in treatment, and six patients were treated on an out-patient basis. Sixteen patients were admitted for a mean duration of 4.3 months (range 1-15 months).

Of those admitted, three showed sufficient improvement in symptoms (complete remission in one case) with the change in milieu alone, obviating the need for any specific treatment intervention. Behavioural response prevention programmes combined with family work were the management strategy of choice throughout the study period. Fourteen patients were treated in this way, three as out-patients. Overall five of these patients showed complete remission of symptoms at discharge, seven showed significant improvement, and two little or no change in symptom pattern or severity.

Five patients were engaged in other intervention programmes. One, treated as an out-patient with individual psychodynamic psychotherapy, showed complete remission of symptoms. Two patients (one in-patient and one out-patient) took part in family therapy without a behavioural programme, but there was no significant change in OCD symptoms in either. One in-patient was treated sequentially with antidepressants, major tranquillisers and ECT. Another out-patient was involved in a programme designed to improve socialisation and interactional skills. Both showed a deterioration in OCD symptoms during their contact with the unit.

Therefore, at discharge seven of the 26 patients referred were recorded as being completely without symptoms, nine as showing significant symptomatic improvement, four as being little changed with treatment, two as having deteriorated symptomatically, and four as refusing treatment.

### Follow-up

Of the 26 identified patients, 24 were traced. Of these, four declined to take part. A further six patients declined to complete questionnaires, but were willing to provide information about their health and circumstances. Outcome information is, therefore, available on 20 patients. There were no significant differences in age, gender, symptom pattern, compliance with treatment or presence of symptoms at discharge between those interviewed and the rest of the sample.

The mean age at follow-up was 25.1 years (range 20.1-28.5 years). This represented a mean of 9.8 years (range 6.5-12.0 years) since first presentation to the unit.

Table I
*Mood rating scores at follow-up*

| | *Total* | | | *With OCD symptoms* | | | *Without OCD symptoms* | | |
|---|---|---|---|---|---|---|---|---|---|
| | | *(n = 14)* | | | *(n = 6)* | | | *(n = 8)* | |
| | *Mean* | *Range* | *s.d.* | *Mean* | *Range* | *s.d.* | *Mean* | *Range* | *s.d.* |
| BDI | 11.7 | 0–29 | 8.4 | 17.8 | 12–29 | 5.88 | 7.12 | 0–18 | 6.29 * |
| MOCI | 8.3 | 0–21 | 6.3 | 14.0 | 10–21 | 3.70 | 4.0 | 0–11 | 3.39 ** |
| STAI state | 43.6 | 23–77 | 16.5 | 51.3 | 40–77 | 12.63 | 37.9 | 23–67 | 15.68 NS |
| STAI trait | 48.6 | 21–73 | 21.7 | 55.3 | 40–73 | 9.83 | 43.5 | 21–67 | 14.59 NS |

Mann–Whitney $U$ test *$U=5$, two-tailed, $P<0.05$.
**$U=3.5$, two-tailed, $P<0.05$.

### *Psychiatric symptoms*

Ten patients had psychiatric disorder at follow-up. Six had OCD, all with compulsive rituals, their symptoms being severe enough to interfere with daily functioning, and four of these were receiving treatment. Two patients had subsequently been diagnosed as suffering from schizophrenia, both of whom were in the in-patient care of psychiatric rehabilitation services. Two patients were receiving outpatient treatment for depressive disorder without predominant OCD symptoms.

Since discharge from adolescent psychiatric services, a further four subjects had received treatment for psychiatric disorder, but at the time of interview were free of symptoms and discharged from treatment. One patient had received further successful behavioural treatment for OCD from a clinical psychologist, two had consulted their general practitioners about symptoms of anxiety and depression, and one obtained counselling about adjustment difficulties to acknowledged homosexuality.

Table I shows the scores on questionnaire ratings of mood and behaviour for the symptomatic and non-symptomatic patients at follow-up. The group with persisting symptoms scored as significantly more depressed on the BDI. Interview data regarding OCD symptoms were corroborated by significant differences between the group's scores on the MOCI. The scores of the non-symptomatic group are very similar to norms published by Dent & Salkovskis (1986) for this age group. There was no gender or age difference between groups.

### *Social variables*

Table II presents characteristics on a range of variables associated with social adjustment in such a way as to allow some comparison between psychiatrically symptomatic and asymptomatic groups.

## Comparison of variables at initial contact and at follow-up

The inter-relationship of variables at initial assessment and follow-up was examined. Age of onset, time between onset and assessment, age at assessment, gender, OCD symptom pattern, presence of temper outbursts, familial involvement with symptoms and peer relationship difficulties before and after onset did not discriminate the symptomatic and asymptomatic groups at follow-up. A history of psychiatric disorder in first-degree relatives was associated with treatment for psychiatric disorder following discharge from adolescent services ($\chi^2=11.37$, d.f. 4, $P<0.025$), although not with short-term outcome or symptom status at follow-up.

Table III illustrates the relationship between short-term symptomatic outcome at discharge and symptomatic outcome at long-term follow-up. The patients who were free from symptoms at follow-up included all those whose symptoms had completely remitted during earlier contact. None of these patients had received further psychiatric help or run a relapsing course. Two patients who were not engaged in treatment at initial contact spontaneously remitted in late adolescence and had remained free from

Table II
*Social variables at long-term follow-up*

| | *No. of all respondents* | *No. of symptomatic respondents* | *No. of asymptomatic respondents* |
|---|---|---|---|
| Living with parents | 6 | 4 | 2 |
| Reporting social isolation from peers | 11 | 8 | 3 |
| Unmarried | 17 | 9 | 8 |
| Reporting sexually active relationships | 5 | 0 | 5 |
| In work | 11 | 5 | 6 |
| Entered further education | 6 | 1 | 5 |

TABLE III
*Relationship of short- and long-term outcome (*n *= 26)*

| *Short-term outcome* | *Long-term outcome*<br>*Non-symptomatic* | *Symptomatic* | *Refused* | *Not traced* |
|---|---|---|---|---|
| Complete remission of symptoms ($n=7$) | 7 | 0 | 0 | 0 |
| Symptomatic improvement ($n=9$) | 1 | 4 | 3 | 1 |
| Little, or no change ($n=4$) | 0 | 4 | 0 | 0 |
| Worse ($n=2$) | 0 | 2 | 0 | 0 |
| Not known ($n=4$) | 2 | 0 | 1 | 1 |
| Total | 10 | 10 | 4 | 2 |

symptoms without psychiatric intervention. In contrast, of the six patients who had not improved with initial treatment all remained psychiatrically ill, and had been in psychiatric care more or less continuously from discharge. Both patients subsequently diagnosed schizophrenic were in this group, neither receiving response prevention treatment. It is interesting in retrospect that both were suspected of having auditory hallucinations at some point in their illness and that both were noted at initial contact to have prominent affective symptoms in conjunction with their compulsions.

Of the patients who had shown symptomatic improvement but not remission at discharge, only one of those taking part had become free of symptoms. Three had persisting OCD symptoms with relapse occurring in the teenage years and following a chronic course despite treatment.

Few associations between variables recorded at initial contact and the follow-up indicators of social adjustment emerge. The maintenance or otherwise of good peer relationships in adolescence before and after onset of OCD symptoms is, however, significantly associated with reported satisfaction with peer relationships at interview in adulthood ($\chi^2=6.97$, d.f. 2, $P<0.05$).

## Discussion

Although the highest incidence of first onset of OCD symptoms is between 10 and 15 years (Black, 1974) prospective long-term outcome studies of the condition in this age group have not been forthcoming. This may be due to a relatively low prevalence, the frequent delay in presentation, and the difficulty of enlisting the co-operation of a considerable proportion of patients at this age. Prospective treatment studies have been of relatively small numbers of teenagers selected either by referral to national centres (Bolton *et al*, 1983; Apter, 1984) or by response to advertisement (Flament *et al*, 1985). Long-term outcome information is however essential in order to aid prognosis, assess treatment effectiveness, plan services, and highlight areas for further research. A study with retrospective design, despite all the well known shortcomings, can provide useful information. This study represents some improvement over earlier follow-up studies of OCD presenting in adolescence (e.g. Warren, 1965; Hollingsworth *et al*, 1980) by virtue of reporting a larger series of consecutive referrals in a relatively less selected population. The longer and more uniform duration of follow-up into adulthood together with the validation of interview data with questionnaire ratings of mood and behaviour are also advantages. However, the lack of complete follow-up data, particularly questionnaire responses, means that the results must be interpreted with caution.

The male preponderance reported in some series of children and adolescents with OCD (e.g. Adams, 1973; Hollingworth *et al*, 1980) compared with the uniformly equal sex distribution in series of adult patients, taken together with variations in symptoms, has led to suggestions of a discontinuity between childhood and adult forms of the disorder. This study provides confirmation of the continuity of the condition between adolescence and adulthood. The population presenting in adolescence appears epidemiologically similar to that seen in adult practice. Absent or little resistance to symptoms, temper outbursts sometimes with violence, and the rewarding involvement of family members are confirmed as common features of the condition in this age group. The results of treatment at initial contact as gauged by outcome at discharge, with 27% being symptom free and 61% having gained benefit from treatment, are in line with those reported by Bolton *et al* (1983) for a teenage population treated with behavioural programmes.

The level of psychiatric morbidity at long-term follow-up is high, with 38% of the sample reporting active symptoms of psychiatric illness at the point of follow-up, 23% having active symptoms of OCD. The validity of the finding is confirmed to some extent by the questionnaire results showing significant differences between symptomatic and asymptomatic groups, the latter being within established normative ranges. Rasmussen & Tsuang (1984) reviewed retrospective follow-up studies of adult OCD patients between 1936 and 1983. The percentages showing no change at follow-up after widely varying periods have ranged from 22% to 61%. The percentage of patients with an adverse outcome is thus less in the present study than in previously reported series of cases presenting in adolescence and more in line with studies of adult patients. Although it is necessary to be cautious as follow-up data are incomplete, this raises the possibility that presentation in the adolescent years does not carry *per se* an adverse prognosis. Those who continue to have OCD symptoms into adult life do, however, appear to have a poor prognosis with only one becoming free of symptoms as a result of subsequent treatment. This may be related to chronicity or severity of symptoms rather than age of onset.

Zeitlin (1986) found that among patients who attended both child and adult psychiatry departments of the same hospital, 72% of those with the symptom of obsessions in childhood continued to have the symptom at later presentation. This continuity was less marked for the ten patients given a diagnosis of OCD in childhood, only four of whom had the same diagnosis as adults. In this study six of the ten patients with psychiatric illness at follow-up had OCD. Overall 12 patients had been seen by adult psychiatric services and seven had been diagnosed with OCD.

High rates of celibacy and single status have been reported among OCD patients by a number of authors (e.g. Lo, 1967; Hollingsworth *et al*, 1980). Coryell (1981) reported little difference between matched OCD and depressed patients. The lack of normative information and a suitable comparison group make the data concerning social adjustment at long-term follow-up in this study difficult to interpret. There is, however, clear evidence to support the findings of Probst *et al* (1979) and Mawson *et al* (1982) that decrements in social adjustment are closely related to the presence and severity of symptoms. Nevertheless the association between peer relationships at first contact and subsequent satisfaction with friendships in adult life suggests a continuity in friendship patterns, with many patients remaining socially isolated throughout their lives. The follow-up interviews suggest that this is not confined to patients whose symptoms persist, but that a number of those who reported themselves free of symptoms had significant difficulties in social adjustment. A variety of personality traits have been associated with OCD (Lewis, 1957) and although no assessment of personality was included in this study, it seems likely that the social adjustment difficulties found, in particular social isolation and withdrawal, reflect such variables. It is interesting to speculate whether these patients represent a group at high risk of future symptomatic relapse and whether any preventative intervention is possible.

It is not surprising in view of the design of the study and the relatively small number of patients that few factors predictive of outcome emerged. An early and complete response to treatment and the absence of a family history of psychiatric illness were associated with a favourable long-term outcome. It may be that patients who respond best to treatment also have better outcomes at follow-up due to some, as yet undefined, predisposition possibly relating to personality variables or the precise nature of symptoms, rather than the efficacy of the treatment itself. Nevertheless the findings of this study suggest the importance of work to increase understanding of effective treatment methods for OCD in this age group and of the provision of adolescent psychiatric services with the resources to provide intensive treatment and support to patients and their families.

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