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"Contents May Vary": A Pilot Study of Treatment Histories of OCD Patients

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Abstract. Definitions of treatment failure and the labelling of patients as non-responsive typically require treatments to have been offered and failed. For pharmacological treatments, treatment quality is relatively easy to define; this is much more difficult with psychological treatments. This study examined patient recollections of previous therapy for obsessive compulsive disorder (OCD). A Treatment History Questionnaire was administered to a sample of 57 apparently treatment refractory OCD patients from a specialist national OCD treatment unit and a national charity for OCD sufferers. On average, respondents reported an $8\frac{1}{2}$ year wait between the obsessional symptoms interfering significantly with their lives and being diagnosed. Forty-three percent recalled having received either cognitive behaviour therapy (CBT) or behaviour therapy as the first treatment; 31% of the group did not know what type of therapy they had received. The components of therapy that respondents recalled were analysed and contrasted with minimal therapy criteria. These criteria appear not to have been met in most patients who understood that they had received "CBT". The implications of this study for assessment of treatment integrity and the classification of patients as "treatment resistant" are discussed.

Keywords: Obsessive compulsive disorder, cognitive behaviour therapy, treatment history, therapy, resistant.

Introduction

Psychological treatments for obsessive-compulsive disorder (OCD) have improved steadily since Meyer (1966) first described a therapy that included helping patients to confront their fears whilst refraining from ritualizing. The understanding of psychological factors in OCD has improved much further since that time (Rachman, 1976; Salkovskis, 1985), as has the effectiveness of treatment. In the United Kingdom the 2005 National Institute for Clinical Excellence (the independent organization responsible for providing national guidance on health issues) guidelines recommend cognitive-behavioural therapy (CBT) as the treatment of choice for OCD (NICE, 2005). However, many obsessional patients still fail to make or maintain substantial improvements following therapy. Many patients are not offered cognitive behavioural treatment and a substantial proportion that are refuse or discontinue therapy prematurely; and in treatment trials, of those who complete treatment, 25% fail to respond

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or maintain treatment gains (Foa and Kozak, 1996). Rasmussen and Eisen (1997) note that 20–30% of patients treated in treatment trials remain refractory.

Findings concerning factors involved when patients do not accept or benefit from treatment have been influential in the development of cognitive behavioural therapies (Foa, 1979). Rachman (1983) helpfully distinguishes between "technical treatment failures" (when a treatment is not adequately delivered, and the patient fails to improve) and "serious treatment failures" (where the chosen technique is applied adequately, but results in minimal progress). Clearly, the solutions to these two types of treatment failure are quite different. However, we do not know what proportion of "treatment refractory" patients typically fall into each category.

The implications of not responding to treatment can be profound. OCD is one of the main reasons given in psychiatry for resorting to neurosurgical procedures, despite the significant concerns surrounding this approach (Bejerot, 2003). Neurosurgical intervention for psychiatric problems has been prohibited in some countries, and the data relating to such interventions are far from conclusive (Jenike, 2000). Ill effects range from epilepsy through to strokes and death. Nevertheless, psychosurgical interventions continue to be regarded as a serious option for OCD sufferers who fail to respond to several treatments.

There have been few serious attempts to analyse the basis of "treatment resistance". Clinicians and researchers typically attribute treatment failure to factors such as poor patient motivation, secondary gain, personality disorder and so forth, making it difficult for them to obtain further psychological treatment. Such patients tend instead to be treated with polypharmaceutical mixes. Drug combinations are prescribed despite their potentially unpleasant side effects, despite the fact that between 40–60% of patients treated with serotonin reuptake inhibitors (SRIs) remain symptomatic or show no improvement, and despite the fact that no drug combination approaches to treatment resistant OCD have been firmly established (Goodman, Ward, Kablinger and Murphy, 2000).

Although "treatment refractoriness" or "resistance" is almost always precisely defined in terms of pharmacological interventions, the extent or quality of psychological treatment is more difficult to define. Matthews, MacVicar, Christmas, Butler and Eljamel (2006) outline the treatment patients should have received before being eligible for neurosurgical intervention. They acknowledge that useful tools for measuring treatment resistant OCD do not exist, but argue that patients with treatment resistant OCD should have had at least 20 hours of intensive, therapist guided exposure with response prevention, as the core element of CBT with an accredited cognitive behavioural therapist. This definition goes some way towards attempting to define adequate psychological treatment, but is still open to debate. Until an agreement on what constitutes adequate treatment for OCD is reached, there is a real risk of treatment refractoriness being regarded as a characteristic of patients rather than a characteristic of treatment.

Some may regard this omission as reflecting the fact that quality control is relatively easy in pharmacological treatment. The writing of a prescription, checking dosage against recommendations and either counting pills on repeat appointments or testing blood samples present no special difficulties. The same cannot be said for CBT, which is a highly skilled activity relying on careful formulation and devising and implementing idiosyncratic interventions. This means that the quality of treatment is likely to vary widely according to the theoretical orientation, skill and motivation of the therapist. It seems likely that some patients will receive treatment that is appropriate whilst others may be offered treatment that deviates significantly from the optimal, or may even be detrimental.

The other issue that suggests an urgent need for attention to quality control in psychological therapies concerns "rebadging". As CBT is increasingly identified as the evidence based treatment of choice for a range of psychiatric problems (for example in the NICE clinical guidelines that are intended to be actively disseminated to service users), patients actively seek such treatments on the understandable grounds that they would like to receive CBT rather than an alternative for which evidence is not presently available. One reaction to such requests may be for some clinicians to assert that what they do is "really" CBT, or similarly, that they "incorporate CBT". This is an area that should be researched further – although Deacon and Abramowitz (2004, p. 438) note that even within CBT, inconsistencies in how "cognitive and behavioural treatments are labelled by their developers and proponents constitute another barrier to determine their relative efficacy". Many service users will not be in a position to make the discrimination between CBT and other approaches, let alone discriminate between cognitive and behavioural approaches, and may accept what the professional says to them in this respect. We presently know very little about the match between what patients are told they are receiving and what they are actually being offered. In the longer term, the introduction of quality assurance measures is likely to be the best way to address this issue. However, measurement instruments tend to be generic e.g. the Cognitive Therapy Scale (J. Young and A.T. Beck, unpublished) and the Cognitive Therapy Scale Revised (Blackburn et al., 2001). Until more specialist measurements become more widespread, investigations of quality control have to be retrospective, and therefore subject to the problems such studies usually entail. We are currently working to adapt measures of the integrity of CBT to specialist applications, such as OCD and Panic Disorder.

The main aim of the present investigation is to examine the treatment experiences of a sample of people with a diagnosis of OCD, all of whom had previously been offered at least one course of psychological treatment. Specifically, the aims were to (i) determine the pattern of onset and course of their OCD; (ii) to determine what therapy the respondents reported having received; (iii) to evaluate how this compared with the most basic requirements for CBT for OCD. The results are considered with reference to Rachman's (1983) concept of technical versus serious treatment failures; possible implications for the labelling of obsessional patients as treatment resistant are also considered.

Method

Participants

Participants were 57 volunteers, who were recruited from a specialist OCD treatment unit ($n = 27$) and a national charity for OCD sufferers ($n = 30$). All patients who attended the treatment unit and were diagnosed with OCD were requested to participate in the research. The participants drawn from the charity were recruited at the organization's annual conference.

The ratio of male to female respondents was 25:32. All the respondents had received, and failed to make or sustain significant gains from at least one previous set of therapy. All the participants (including the specialist unit group) were requested to only comment on therapy they had already completed, rather than any therapy they may still have been receiving. The ages of the respondents ranged from 19 to 66 years, with a mean age of 38.35 ($SD = 11.4$). The level of education of respondents was high, with nearly 44% of respondents being educated to degree or diploma level.

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Measures

We devised the OCD Treatment History Questionnaire to study participant recollections of the different therapies they had received for their OCD. The items in the questionnaire were devised by two experienced clinical psychologists who specialize in the treatment of OCD, and were then modified based on patient feedback, and the feedback of other therapists who also specialize in the treatment of OCD. The five sections of this questionnaire examined: (a) participant demographics (name, age, gender, education, employment status); (b) course of the problem and treatment (age at which problem started, at which it started to interfere significantly, and at which help was sought, when it was offered and by whom); (c) previous therapy (what the sessions were focused on, what was spoken about, what was helpful and not helpful about treatment); (d) the profession to which the therapist belonged, the type of therapy done, and the length of the therapy sessions; and (e) what was done in the therapy sessions. In this section respondents were also asked to comment on whether specific things took place in the therapy sessions e.g. "Did you or your therapist spend most of the sessions talking about your childhood?" and "Did you or your therapist deliberately expose yourself to frightening thoughts or things in your therapist's office?" (see Table 1 for a full list of these items). Respondents were also asked to rate how much specific improvement in OCD was made, as well as general improvement, on two 0–100 scales, where 0 represented "absolutely no improvement" and 100 represented "total improvement". Where the improvement made was for less than 6 months, they were given a list of possible reasons for this and asked which of these applied; they were also asked which aspects of therapy, if any, they had found to be unhelpful. The present study presents only the results of the first set of therapy that the respondents reported having received.

Procedure

The participants were each given a copy of the questionnaire, and asked to complete and return it at their earliest convenience. The respondents, drawn from Obsessive Action, the national charity, were provided with stamped self-addressed envelopes in which to return the questionnaires. Clinicians at the treatment centre collected the questionnaires from these respondents by hand at the session following the one at which the questionnaire had been dispensed. The data were analysed using SPSS.

Treatment of data

With regard to what the respondents recalled having done during the first set of therapy sessions, a small amount of missing data meant that the sample varied from 53 to 56 respondents, with the median being 55. The results in Table 1 are therefore presented as percentages.

Data are mostly presented in the form of descriptive information. Where it had been planned to compare respondents who had received different treatments, chi squared analysis was conducted using "type of therapy" as a category. Respondents were grouped into one of two groups: those who reported having received behaviour therapy or cognitive behaviour therapy, and those who reported having received any type of therapy other than behaviour or cognitive behaviour therapy.

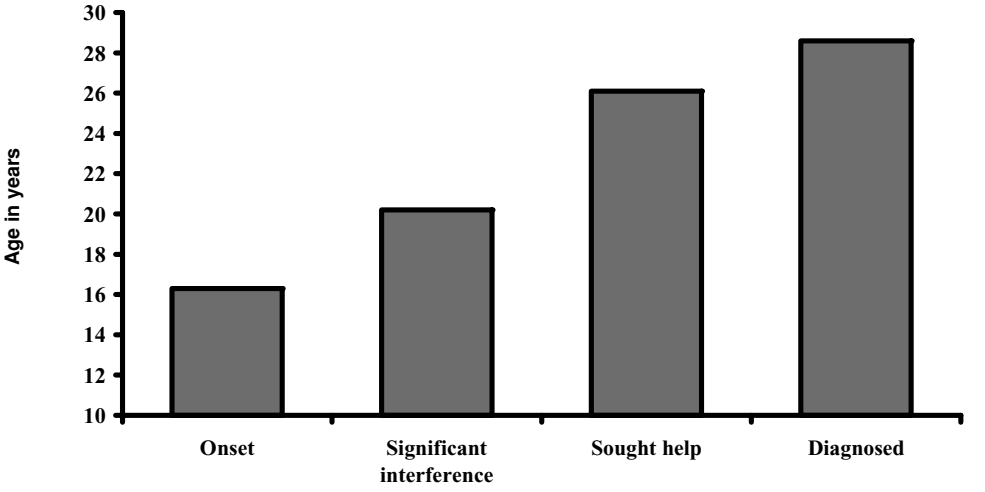

Figure 1. Time course of symptom onset and diagnosis

The behaviour therapy/cognitive behaviour therapy group was broken down further into those respondents who reported having met minimum criteria for adequate behaviour or cognitive behaviour therapy, and those who did not.

For the purposes of this pilot study, those allocated to the "minimal criteria for CBT met" group, the therapy received by each respondent would have to meet the following criteria: (a) 6 or more sessions; (b) 40 minutes or more per session; (c) exposure (self /guided) must have taken place at some point during the course of the sessions; (d) homework must have been given during the sessions; (e) the main emphasis of the sessions must have been on the obsessional problem; (f) the main focus of the sessions must not have been on childhood; (g) the therapist was not silent for most of sessions.

Results

Time course of the problem

Respondents reported an average age of 16.3 years ($SD = 9.8$) for the start of obsessional symptoms; at 20.23 ($SD = 9.9$) the obsessional problem started to interfere significantly with their lives; on average, participants would only seek help nearly 6 years later, aged 26.05 ($SD = 10.2$), and be correctly diagnosed more than two years later, aged 28.57 ($SD = 10.0$) (see Figure 1).

Treatment type and provider

Many of the participants in this pilot study reported receiving a number of therapies during the course of the illness. Forty-three percent of the sample reported having received either behaviour or cognitive behaviour therapy as the first treatment they received (see below); more worryingly, 31% of respondents were not sure what type of therapy they had received the first

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time. Thirteen percent of the sample reported having first received supportive therapy; 6% psychodynamic therapy, and 7% "other".

What was recalled about the content of the therapy sessions?

Table 1 presents the results of this analysis, divided into those who understood that they had received CBT/BT and those who had had some other type of treatment. Results indicate that the participants' recollections of treatments generally matched what might be expected given the therapy types. For example, none of those who believed that treatment had been CBT/BT had "spent most of the time in the sessions looking at problems other than the obsessional problems (for example, relationship problems)", compared with 43% of the others. More of those who reported having had CBT/BT reported having had some type of exposure. When asked 'Did you receive homework exercises to do between the sessions?', 78% of respondents who received CBT/BT recalled being assigned homework to complete compared with only 39% who received non CBT/BT. Some type of thought stopping was also more likely to have been part of CBT/BT. "My therapist seemed to imply that the origins of my problem lie in my childhood, and the past should be explored in order to understand the present better" was more characteristic of other therapies than CBT/BT. However, note that the difference was not great, with this item endorsed by 23% of those in CBT/BT as opposed to 52% in the "other therapy" group. Other notable deviations included "The therapist was silent for most of the sessions and allowed me to talk freely about whatever was on my mind at the time"; whilst 55% is not surprising in the other therapy group, the figure of 26% for CBT/BT is very surprising.

Adequate cognitive behaviour therapy/behaviour therapy

It was found that only 40% ($n = 23$) of the entire sample *reported* having received BT or CBT. Of these, 60% ($n = 14$) had not met the defined minimal criteria for adequate CBT, with a significant proportion of the "non-adequate" CBT group not being allocated any exposure, nor homework, spending most of the sessions talking freely, or spending most of the sessions talking about their childhoods. The majority of the entire respondent group reported that they had not made, or failed to maintain, significant progress following the sessions.

Recollection of extent of general vs. specific improvement

A 2×2 mixed model analysis of variance was carried out, with treatment (CBT vs. Other) as grouping variable, and rating of specific vs. general improvement as the within subject variable. A main effect was found for treatment type ($F_{[1,51]} = 5.33$, $p < .05$) and for type of rating ($F_{[1,51]} = 11.39$, $p < .0025$). These effects were modified by an interaction ($F_{[1,51]} = 10.75$, $p < .0025$). Post hoc t-tests indicated that this effect was accounted for by a difference between groups in terms of specific improvement $t_{(37.2)} = 3.0$, $p < .01$ but not in terms of general ratings of improvement ($t_{(51)} = 1.2$, $p > .2$). These results are shown in Figure 2.

Extent to which the person felt their therapist had understood their problem

Most of the items concerning the characteristics of therapy focus on items that are expected to differ. However, there are no a-priori reasons to presume that the different types of therapy would differ in terms of the therapeutic relationship; this was assessed in the crudest form here by asking respondents a yes/no question about whether they felt that their therapist had *failed*

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Table 1. Percentage of respondents who reported particular features as being part of the therapy they were first offered, divided into those who were offered BT/CBT contrasted with those offered other therapies

Did you or your therapist do any of the following in therapy?	% of participants who reported having received behavioural or cognitive behavioural therapy who answered "Yes" to this statement.	% of participants who reported having received therapy other than behavioural or cognitive behavioural therapy who answered "Yes" to this statement.
Draw a diagram explaining the problem, which included links between thoughts, feelings and behaviours	32	3
Draw a diagram showing the patterns I have in relating to people	4	0
Spent most of the sessions talking about my childhood /past experiences	27	68
Deliberately expose your self to frightening thoughts or things in the therapist's office	48	6
Go into situations outside the therapy room where you had to face whatever you were afraid of on your own	43	10
My therapist seemed to imply that the origins of my problem lie in my childhood, and the past should be explored in order to understand the present better	23	52
Looking at links between beliefs, thoughts and feelings	43	20
Explored patterns of relating to people in my life	26	33
Go into situations outside the therapy room where you had to face whatever you were afraid of with your therapist present	22	7
Concentrated on beliefs about obsessions in most sessions	36	17
The therapist was silent for most of the sessions and allowed me to talk freely about whatever was on my mind at the time	26	55
Be given or do set reading on the obsessional problem	17	13
Keep records of your thoughts	41	14
The therapy emphasized changing behaviour rather than working directly on thoughts	57	3
Try to stop your thoughts, for example by getting me to snap an elastic band on my wrist	30	7
Spent most of the time in the sessions looking at problems other than the obsessional problems (for example, relationship problems)	0	43
Do relaxation exercises	35	42
Changing the meaning attached to thoughts	36	13
Give you homework to do between sessions	78	39

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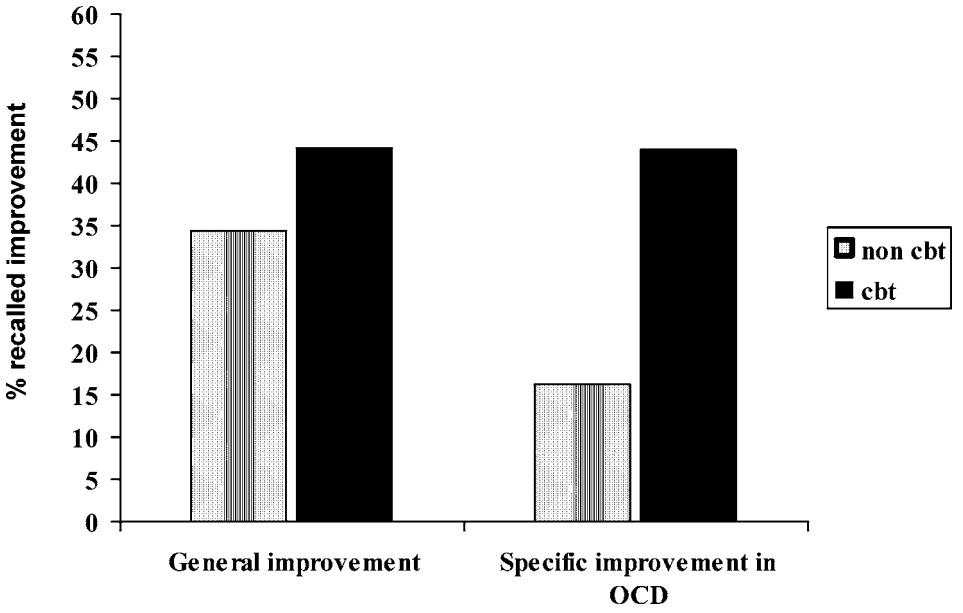

Figure 2. Ratings of general and specific improvement for CBT/BT vs. other treatments

to understand their problem. This was analysed using a 2×2 Chi square test with Pearson correction. For CBT, those understood/not understood were 14:5, and for other therapies combined 8:16; $\chi^2_{[1]} = 6.9, p < .01$.

Discussion

Consistent with previous findings (Hollander, 1997), it was found that there was a considerable gap between the reported onset of OCD and diagnosis. The first psychological treatment offered appeared nominally appropriate in only 40%. More careful examination strongly suggests that even this low figure represents a substantial overestimate, because participants' recollection of the elements of treatment indicates that it met minimal defining criteria in a scant 40% of those cases. This means, of course, that only 16% of obsessional patients were offered even minimally appropriate treatment at first. Despite this serious problem, there was evidence that those who were offered something badged as CBT recall finding it and their therapist subjectively more helpful than approaches that were described in other terms (or not defined at all).

The findings reported here are based on the recall of a relatively small sample of convenience, drawing from people who clearly had not fully benefited from therapy. The study is retrospective, raising issues about the reliability of the participants' recall. The participant sample was opportunistic, bringing potential bias to the study. Sampling concerns suggest that care needs to taken if we wish to generalize the findings, and the findings need to be replicated in a more systematically defined sample of apparently treatment refractory patients. In addition, treatment has evolved over the past few years, and most of the sample had been

treated some considerable time ago. Focusing on the first treatment (rather than most recent treatment) data may have contributed to poorer recall and a greater likelihood that the present study may have focused on more outdated treatments than the most recent treatments patients had received – this should be examined more closely in future research. However, the criteria set for minimum therapy elements are a better match for treatment as offered 20 years ago rather than current best practice. The treatment adequacy figures would be very substantially lower than the present figure of 16% were current criteria to be applied.

Although the precise figures here are open to question, they undoubtedly identify a major problem for the definition of treatment refractoriness, at least for people referred to specialist and national services and for those involved in OCD charities as sufferers. All patients in this study would be defined as "treatment failures" in terms of the prior treatment they were reporting; however, at least 84% were, in the terms set out by Rachman (1983), "technical failures", meaning that they may have failed to respond because the treatment they had been offered was either fundamentally inadequate or inadequately delivered. Assuming that participants' recall of treatment was a reasonable match to the treatment actually offered, the findings suggest that many clinicians offering treatment for OCD are either inadequately trained or supervised. Some are in the ethically dubious position of offering inappropriate treatments. Apart from better dissemination of treatment, what options might there be to solve these problems? Promoting psychosurgery as a "last resort" treatment to be tried when other treatments have failed would, in our opinion, be seriously inadvisable, given the controversy in this area, the damage which these procedures have the potential to cause, and the fact that patients who are deemed suitable for this intervention by virtue of not having responded to several previous psychological treatments may not have actually received these treatments, as highlighted by the present study. Clearly, discontinuing the common practice of offering first-line treatments that do not have any basis in evidence would be a promising start. Specialist training and supervision in CBT would also be appropriate. Serious exploration of stepped care options would seem appropriate; however, caution is needed; we do not know if computerized CBT or bibliotherapy might undermine the later response to treatment in those not helped. Development of a filter/predictive system would seem to be a particularly promising approach, but requires a major research effort.

We are presently gathering data more systematically from a larger group and comparing this with another anxiety disorder (Panic Disorder). In order to assess the impact of recall on the treatment elements identified, we are also gathering data on the questionnaire in a group of patients where the elements delivered during therapy sessions are well documented to evaluate the extent to which we may be underestimating treatment quality as a result of memory failures.

Overall, the present study suggests that there are a proportion of people suffering from severe and disabling OCD who have not been offered a treatment that stood a real chance of helping them. Even those who have apparently had CBT may in fact have been offered too little too late. This must change.

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