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





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Out of pocket expenses in obsessive compulsive disorder

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ABSTRACT

Background: Despite anecdotal evidence that the out of pocket costs of OCD can be substantial in some cases, there is no evidence on how many people they affect, or the magnitude of these costs.

Aims: This paper explores the type and quantity of out of pocket expenses reported by a large sample of adults with OCD.

Methods: Data on out of pocket expenses were collected from participants taking part in the OCTET multi-centre randomised controlled trial. Participants were aged 18+, meeting DSM-IV criteria for OCD, and scoring 16+ on the Yale Brown Obsessive Compulsive Scale. Individual-level resource use data including a description and estimated cost of out of pocket expenses were measured using an adapted version of the Adult Service Use Schedule (AD-SUS); a questionnaire used to collect data on resource use.

Results: Forty-five percent (208/465) reported out of pocket expenses due to their OCD. The mean cost of out of pocket expenses was £19.19 per week (SD £27.56 SD), range £0.06–£224.00.

Conclusions: Future economic evaluations involving participants with OCD should include out of pocket expenses, but careful consideration of alternative approaches to the collection and costing of this data is needed.

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Introduction

The World Health Organisation's International Classification of Diseases version 10 describes the central feature of obsessive compulsive disorder (OCD) as recurrent obsessional thoughts or compulsive acts (World Health Organization, 1993). It is the fourth most common mental disorder and the lifetime prevalence of OCD is estimated to be 2–3% (Robins et al., 1984). OCD causes significant distress to people experiencing it but can also lead to significant disability through disruption of other aspects of life including education, occupation, social and personal activities (NCCMH, 2006).



The economic consequences of OCD are also severe. The economic burden of OCD was estimated at \$8.4 million dollars in 1990 in the United States (DuPont et al., 1995). This constituted direct and indirect costs and accounted for almost 6% of the total cost of all mental health disorders in the United States. A recent policy document from the Money and Mental Health Policy Institute stated that people with OCD are almost six times as likely to be in problem debt as those without mental health problems (Holkar,


2019). The implications of this are that these additional costs may be another source of distress, and their effects will be exacerbated in those from more deprived communities where poverty is already an issue.

Despite anecdotal evidence that the out of pocket costs of OCD can be substantial in some cases, there is no evidence on what these costs are, how many people they affect, or the magnitude of these costs. We may be understating the burden on this group of vulnerable people by ignoring the additional costs incurred which may be unique to their diagnosis. Reports in clinical practice of people spending in excess of £50 per week on cleaning materials are not uncommon. In extreme cases, reports of having special cleaning equipment installed or even moving to a new house. This paper explores the type and quantity of out of pocket expenses reported by a large sample of adults with OCD taking part in a randomised controlled trial.

Materials and methods

Data were taken from the Obsessive Compulsive Treatment Efficacy Trial (OCTET). Full details can be found elsewhere

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 Supplemental data for this article can be accessed [here](#).

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(Gellatly et al., 2014; Lovell et al., 2017; Lovell et al., 2017) but brief details are provided below.

Design and population

OCTET was a pragmatic multi-centre three-arm randomised controlled trial with an integrated economic evaluation. Potential participants were identified through primary and secondary care waiting lists by administrative and clinical staff as well as through self-referral. Recruitment took place across 15 sites in England between February 2011 and May 2014. Face-to-face recruitment appointments followed initial telephone screening. Inclusion criteria were: being aged 18 or over; being able to read English; currently waiting to access therapist-led cognitive behavioural therapy; meeting DSM-IV criteria for OCD; and scoring 16+ on the Yale Brown Obsessive Compulsive Scale self-report (indicating a moderate severity of OCD; Goodman et al., 1989; Steketee et al., 1996). Exclusion criteria were: receiving psychological therapy for OCD; meeting DSM-IV criteria for alcohol or substance dependence; and/or experiencing severe and distressing psychotic symptoms. Patients were randomised to receive either guided self-help prior to therapist-led cognitive behavioural therapy, computerised cognitive behavioural therapy prior to therapist-led cognitive behavioural therapy, or a waiting list for therapist-led cognitive behavioural therapy only.

Informed written consent was obtained for each person before entry into the study. Ethical approval was provided by the National Research Ethics Service Committee North West – Lancaster (11/NW/0276).

Resource-use data

Individual-level resource use data were measured using an adapted version of the Adult Service Use Schedule (AD-SUS). The AD-SUS is a questionnaire used to collect data on service use and has been used in a range of adult mental health populations (Barrett et al., 2006; Bower et al., 2000; Byford et al., 2003). In this study, the AD-SUS was adapted to include out of pocket expenses because clinical members of the research team were concerned that behaviours that are common in people with OCD, such as excessive cleaning, may be associated with additional financial burden on the person with OCD and/or their family. Only data collected at baseline is described here because the interventions are likely to have an influence on resource use reported during the follow-up. Participants were specifically asked “Can you think of any extra costs which occur because of your condition? Are there any items you spend money on because of your OCD that you would not have spent so much on if you did not have OCD?” Examples were then provided including cleaning materials, hand cream, locks, redecorating, collecting objects, petrol, hot water, replacing food and so on. Participants were required to provide a description and an estimated extra cost per week.

Other data

Key socio-demographic data were collected at baseline using a proforma including details on gender, age, ethnicity, length of time experienced OCD and current anti-depressant use. The Yale Brown Obsessive Compulsive Scale (Y-BOCS) self-report measure was used to assess severity of OCD (Goodman et al., 1989) for the purposes of trial eligibility.

Following a scoping review of the literature it was identified that there were varying levels of agreement regarding the defining of dimensions relating to OCD. Given that the Y-BOCS was used in this study, the focus of the review was on studies that generated dimensions using the Y-BOCS or Dimensional Yale-Brown Obsessive-Compulsive Scale (D-YBOCS). Attention was also focused upon other reviews that had been conducted (e.g. Starcevic & Brakoulias, 2008; McKay et al., 2004; Ball et al., 1996; Bloch et al., 2008; Mataix-Cols et al., 2005) and findings from recent research (Knopp-Hoffer et al., 2016; Knopp et al., 2013). Based on this literature, a decision was made to separate somatic from sexual/religious/aggressive obsessions. Furthermore due to the recent change in guidance about the management of hoarding (American Psychiatric Association, 2013), hoarding was treated as a distinct sub-type. The following dimensions were therefore identified:

Dimension 1 – Contamination obsessions/washing and cleaning compulsions

Dimension 2 – Symmetry obsessions with ordering and arranging compulsions

Dimension 3 – Somatic obsessions with checking compulsions

Dimension 4 – Sexual, aggressive and religious obsessions

Dimension 5 – Hoarding

Dimension 6 – Miscellaneous

Due to the heterogeneous nature of OCD, people experience multiple symptoms and presentations and can, therefore, fall under more than one dimension of OCD (Stewart, 2016). Further details of these dimensions are included in the [Supplementary Appendix](#).

Analyses

Data were analysed using Stata (version 15) [StataCorp, 2017]. Results are primarily descriptive. Sample characteristics and costs were examined using means and standard deviations or percentages as appropriate. Differences between groups were tested using chi-squared analyses. Additionally, we conducted multiple regression analyses exploring associations between costs and key baseline clinical and demographic factors: age, gender, ethnicity (binary White British/Other); duration of OCD, YBOCS score, Patient Health Questionnaire 9 (PHQ-9) score, Generalized Anxiety Disorder 7-item (GAD-7) score, CORE Outcome Measure (CORE-OM) score, current anti-depressant use (binary yes/no), OCD dimensions (described above; binary yes/no), comorbid anxiety or depression (as derived from

the CIS-R; binary yes/no), and comorbid depression (as derived from the CIS-R; binary yes/no). Nonparametric bootstrap regressions (10,000 repetitions) were used to account for the non-normal distribution commonly found in economic data (Thompson & Barber, 2000).

Results

Sample

A total of 473 participants were recruited at baseline, of which 465 (98%) provided data on out of pocket expenses. Sixty-one percent ($n=282$) of participants were female. Ninety-two percent were White British ($n=425$) while 8% ($n=39$) were of another ethnic origin. The mean age of the sample was 36 years old (SD 12.37 years, range 18–78 years old). The mean number of years with OCD was 14 years (SD 12.20 years, range 1–62 years). Fifty-one percent ($n=239$) of the sample were taking anti-depressants at the time of the interview. The mean score on the Y-BOCS self-report measure was 24.24 (4.93 SD) with a range from 16 to 40. Forty-five percent ($n=209$) of participants had a Y-BOCS score between 16 and 23 indicating moderate OCD symptoms, 47% ($n=218$) of participants had a score between 24 and 31 indicating severe OCD symptoms, and 8% ($n=38$) had a score of 32 or above indicating very severe OCD symptoms [Maust et al., 2012]. The most common OCD dimension was somatic obsessions with checking compulsions which 93% of participants ($n=432$) met criteria for. This was followed by sexual, aggressive and religious obsessions which 86% ($n=401$) met criteria for, miscellaneous (85%, $n=396$), symmetry obsessions with ordering and arranging compulsions (83%, $n=387$), contamination obsessions/washing & cleaning compulsions (71%, $n=330$) and finally the hoarding dimension (34%, $n=158$).

Out of pocket expense items

Of the total sample with data, 45% ($n=208/465$) reported out of pocket expenses due to their OCD. Of those with moderate OCD, only 39% ($n=82/209$) reported out of pocket expenses, compared to 48% ($n=104/218$) of people with severe OCD and 58% ($n=22/38$) of people with very severe OCD ($\chi^2 = 5.9982$, $p = 0.050$). Table 1 shows the percentage and number of people reporting out of pocket expenses

due to OCD by those meet criteria for each of the OCD dimensions and those not. The table shows there are no substantial differences between the dimensions in the percentage of people reporting out of pocket expenses or between those people who meet criteria for each dimension versus those who did not.

Participants reported costs related to purchases of additional amounts of some items which they would use even if they did not have OCD, such as cleaning products, and also costs related to things they would not buy in the absence of OCD, such as books on OCD.

Over half of all out of pocket expenses reported were linked to cleaning related items. These included additional products and resources for cleaning the home and personal cleaning, such as hand wash, toiletries, home cleaning products, hot water, and electricity. Costs relating to food were common, including vitamins and supplements and throwing away food for fear of contamination, as was additional money spent on travelling, for example using taxis because the participant was not able to use the bus or driving to check on things. Other items which were reported less frequently included padlocks, buying things in 3s, being compelled to buy things which are not needed and phone credit.

Costs

Participants found it difficult to estimate the value of out of pocket expense items. Of the 208 people who reported out of pocket expenses, 81% ($n=168$) provided an estimate of the cost of their out of pocket expense items. For those reporting out of pocket costs, the mean cost was £22.17 per week (SD £42.12) with a range from £0.06 to £423.08. Two high cost individual items were reported by two participants as one-off costs rather than weekly costs. If these one-off costs were removed, the mean cost of out of pocket expenses was £19.19 per week (SD £27.56 SD), range £0.06–£224.00 (Table 2).

When split by OCD severity, those with moderate OCD had the lowest mean cost per week at £14.67 (SD £20.78). For those with severe and very severe OCD the mean cost per week was similar at £21.88 (SD £32.79) and £21.48 (SD £15.57) respectively (all reported with the high cost individual items mentioned above removed). The mean cost per week was similar for all dimension groups ranging from £19.09 (SD £28.49) to £21.03 (SD £23.76) and similar

Table 1. Percentage and number of people reporting out of pocket expenses due to OCD by those meet criteria for each of the OCD sub-types and those not meeting criteria.

	Percentage (number) reporting out of pocket expenses for those meeting criteria for sub-type	Percentage (number) reporting out of pocket expenses for those not meeting criteria for sub-type	Chi ² (<i>p</i> value)
Subtype 1 – Contamination obsessions/washing & cleaning compulsions	42.73 ($n=141$)	49.63 ($n=67$)	1.85 (0.17)
Subtype 2 – Symmetry obsessions with ordering and arranging compulsions	45.48 ($n=176$)	41.03 ($n=32$)	0.52 (0.47)
Subtype 3 – Somatic obsessions with checking compulsions	44.21 ($n=191$)	51.52 ($n=17$)	0.66 (0.42)
Subtype 4 – Sexual, aggressive and religious obsessions	44.39 ($n=178$)	46.88 ($n=30$)	0.14 (0.71)
Subtype 5 – Hoarding	48.10 ($n=76$)	43.00 ($n=132$)	1.10 (0.29)
Subtype 6 – Miscellaneous	44.95 ($n=178$)	43.48 ($n=30$)	0.05 (0.82)

Table 2. Mean and standard deviation of out of pocket costs (with outliers removed).

	Number	Mean cost (SD), £
Total sample	166	£19.19 (£27.56)
Cost by severity		
Moderate OCD	61	£14.67 (SD £20.78)
Severe OCD	88	£21.88 (SD £32.79)
Very severe OCD	17	£21.48 (SD £15.57)
Cost by subtype		
Subtype 1 – Contamination obsessions/ washing & cleaning compulsions	110	£19.29 (£30.89)
Subtype 2 – Symmetry obsessions with ordering and arranging compulsions	141	£19.52 (£29.03)
Subtype 3 – Somatic obsessions with checking compulsions	150	£19.26 (£28.48)
Subtype 4 – Sexual, aggressive and religious obsessions	143	£19.70 (£29.19)
Subtype 5 – Hoarding	62	£21.03 (£23.76)
Subtype 6 – Miscellaneous	141	£19.09 (£28.49)

between those people who meet criteria for each dimension versus those who did not.

Multiple regression of the association between cost and key clinical and demographic factors revealed that costs were only associated with GAD-7 score with costs decreasing as GAD-7 scores increased (coefficient: -0.73 , 95% CI -1.36 to -1.10 , p 0.022: Table 3). The association between costs and comorbid depression neared significance with costs higher for people who had comorbid depression (coefficient: 4.09 , 95% CI -0.18 to 8.20 , p 0.051).

Discussion

Almost half of the participants in the OCTET trial reported out of pocket expenses due to their OCD, with the percentage reporting such expenses increasing with the severity of OCD from around 40% for those with moderate OCD to 60% for those with very severe OCD.

The average cost of reported out of pocket costs was approximately £19 per week or £1,000 per annum, when extremely high one-off costs were excluded. This cost is substantially higher than out of pocket expenses estimated in other disorders such as ulcerative colitis (approximately £1.50 per week; Bassi et al., 2004) and Crohn's disease (approximately £2.50 per week; Bassi et al., 2004) but lower than estimates for autism (£66–£100 per week; Järbrink et al., 2003).

Costs were higher for those with severe or very severe OCD (approximately £21 per week or £1,100 per annum) compared to those with moderate OCD (approximately £15 per week or £780 per annum). These findings highlight the importance of out of pocket expenses in OCD populations and the need to include assessment and valuation of out of pocket expenses in economic evaluations of OCD when taking a societal or patient perspective.

The number of participants reporting out of pocket expenses and the cost of those expenses were similar between participants with different dimensions of OCD. However, as many participants met criteria for multiple dimensions, the groups overlapped substantially, therefore

Table 3. Multiple regression of baseline demographic and clinical factors associated with costs.

Baseline characteristic	Adjusted coefficient	95% CI	p Value
Gender			
Female	–	–	–
Male	-1.13	-5.09 to 2.83	0.576
Ethnicity			
White British	–	–	–
Other	2.88	-2.45 to 8.20	0.289
Age (years)	-0.11	-0.24 to 0.02	0.108
Duration of OCD (years)	0.08	-0.08 to 0.24	0.321
YBOCS score	0.41	-0.11 to 0.93	0.123
PHQ-9 score	0.26	-0.22 to 0.73	0.291
GAD-7 score	-0.73	-1.36 to -0.10	0.022
CORE-OM score	0.42	-0.05 to 0.89	0.081
Anti-depressant medication use			
No	–	–	–
Yes	-0.73	-4.66 to 3.21	0.717
Subtype 1 – Contamination obsessions/ washing & cleaning compulsions			
No	–	–	–
Yes	-1.93	-5.30 to 1.44	0.261
Subtype 2 – Symmetry obsessions with ordering and arranging compulsions			
No	–	–	–
Yes	0.56	-3.02 to 4.14	0.758
Subtype 3 – Somatic obsessions with checking compulsions			
No	–	–	–
Yes	-1.29	-7.92 to 5.33	0.702
Subtype 4 – Sexual, aggressive and religious obsessions			
No	–	–	–
Yes	0.56	-3.31 to 4.44	0.775
Subtype 5 – Hoarding			
No	–	–	–
Yes	3.10	-0.78 to 6.98	0.118
Subtype 6 – Miscellaneous			
No	–	–	–
Yes	-0.83	-6.03 to 4.38	0.755
Comorbid anxiety or depression			
No	–	–	–
Yes	0.77	-6.14 to 7.68	0.827
Comorbid depression			
No	–	–	–
Yes	4.09	-0.18 to 8.20	0.051

making it difficult to detect any differences between the dimensions.

The only baseline demographic or clinical factor which was associated with out of pocket expense costs was GAD-7. Costs decreased as GAD-7 score increased. This finding is contradictory what might be expected, and as this was an exploratory analysis of data collected for another purpose, should be viewed with caution.

This study benefited from a large sample of participants recruited from 15 sites across the UK, including rural and urban areas, and thus provides findings that should be representative of people across the UK accessing treatment for OCD. Further, the demographic and baseline clinical data are similar to other OCD studies in the UK. However, several limitations need to be considered in relation to these findings. Although the number of participants providing information on whether they had spent money on out of pocket expenses was high at 98%, only 81% of those were able to give an estimate of how much the items cost. Although this amount of missing data is not particularly high, it could skew the mean cost of the sample. Further,

participants reported finding it very difficult to estimate their out of pocket costs, particularly those costs where they were required to estimate the cost of items over and above the amount they would otherwise have spent had they not had OCD. Additionally, the costs reported are estimates and could be subject to recall bias. In terms of hoarding, we recognise that the latest version of the DSM has separated hoarding out as a separately category, but as it is a clear dimension within the Y-BOCS, we have kept it included here. Finally, as the participants in this study were recruited from a trial, they may not be representative of all individuals with OCD and may not be generalisable.

Despite these limitations, this is the first examination of out of pockets expenses in people with OCD and as such provides important information to support the design of future economic evaluations involving participants with OCD. Future research should however consider alternative approaches to the collection and costing of this data in order to maximise accuracy.

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





Disclosure statement

MH, DM and SB are co-applicants on UK National Institute of Health Research (NIHR) grants, in addition to the OCTET trial. DM is additionally a board member of UK NIHR Research for Patient Benefit (RfPB) Yorkshire and Humberside Committee. This Board was not involved in any way in the funding of the OCTET trial.

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