

## RELIEVING THE BURDEN OF FAMILY MEMBERS OF PATIENTS WITH OBSESSIVE-COMPULSIVE DISORDER<sup>1</sup>

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### Abstract

**Objective:** Obsessive-compulsive disorder (OCD) burdens family members. Certain responses of family members to OCD augment their burden, namely accommodation and antagonism. Family interventions are successful in reducing severity of OCD but surprisingly, the impact of family interventions on the burden of family members has received little attention.

**Method:** 16 family members of patients with OCD were treated – together with the patient - with our brief CBT family intervention focusing on accommodation, antagonism and normalizing the family relationship. Family burden, accommodation and antagonism were measured before and after the family intervention with: Involvement Evaluation Questionnaire, Impact on Relatives Scale, EuroQol five dimensional questionnaire (EQ-5D), Family Accommodation Scale – Self Report and the Perceived Criticism Measure.

**Results:** The burden of family members of patients with OCD was considerable and comparable to the burden of family members of patients with schizophrenia. Family burden was diminished after the brief dyadic family intervention and correlated to a decrease in accommodation.

**Conclusions:** Our brief dyadic family intervention is promising in relieving the burden of family members of patients with OCD.

**Key words:** obsessive-compulsive disorder (OCD), burden family members, family intervention, involvement evaluation questionnaire, impact on relatives scale, EuroQol five dimensional questionnaire (EQ-5D), family accommodation scale – self report and the perceived criticism measure

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**Declaration of interest:** none

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### 1. Introduction

Obsessive-compulsive disorder is an invalidating disorder with a great impact on the life of patients. Patients experience a poor quality of life (QoL) and limitations with working, household activities, social relations and well-being (Eisen et al. 2006). In addition, OCD burdens people close to the patient as well. Caring for a patient with OCD puts a moderate to severe level of burden on family members (Steketee 1997, Laidlaw et al. 1999). OCD disrupts family relations, home management, leisure activities and social life (Stengler-Wenzke et al. 2006, Laidlaw et al. 1999, Gururaj et al. 2008, Cooper 1996). Family members experience distress, anxiety, depression, frustration, anger, guilt and embarrassment as a consequence of the OCD (Albert et al. 2010, Amir et al. 2000, Stengler-Wenzke et al. 2004, Torres et al. 2012). Compared to the general population, family members of persons with OCD have a reduced

QoL (Albert et al. 2007, Grover and Dutt 2011, Cicek et al. 2013, Stengler-Wenzke et al. 2006).

Family members are insecure how to deal with OCD (Shafraan et al. 1995). They frequently react to the obsessions and compulsions of their relatives by behaviour that is termed ‘accommodation’ and ‘antagonism’. By accommodation is meant the adaptive behaviour of family members to OCD in order to relieve the burden for the patient (Stengler-Wenzke et al. 2004) for instance by participating in performing rituals, giving reassurance to the patient or changing routines because of the demands resulting from obsessions or compulsions. Antagonism means that family members oppose to the OCD, criticize the OCD, or have a rejecting attitude towards the patient. Antagonism is related to the belief that patients are in control of their symptoms (Renshaw et al. 2017). The more family members accommodate, the higher the chance they antagonize the OCD as well (Calvocoressi et al. 1995). In most families with

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a person with OCD one or both these responses occur; accommodation is present in 90% of the families and antagonism is present in 40% of the families (Chambless and Steketee 1999, Calvocoressi 1999).

Both family responses to OCD are related to anxiety and depression in relatives, family burden and a reduced quality of life in family members (Amir et al. 2000, Cherian et al. 2014). In addition, accommodation is associated with poor family functioning and antagonism is associated with family conflict (Calvocoressi et al. 1995, Hibbs et al. 1993). In other words, the burden of family members augments as a consequence of their response to OCD. This stresses the importance of helping family members dealing with OCD, to relieve their burden.

In line with this, it has often been advised to help family members dealing with OCD. Family interventions have been developed to learn family members stopping with accommodation and in some cases also with stopping with antagonism (Gomes et al. 2016, Thompson-Hollands et al. 2015, Abramowitz et al. 2013). With these family interventions, positive results have been found for patients: the severity of OCD is reduced and functioning is improved (Thompson-Hollands et al. 2014). Surprisingly, the impact of family interventions on the burden of family members has received much less attention.

In a study by Grunes (Grunes et al. 2001) the effectiveness of a group therapy for family members of patients with OCD plus individual cognitive behaviour therapy (CBT) for the patient was compared to a control condition existing of individual CBT only; each condition consisted of 14 patient - family member dyads. In the group therapy condition, family members received an 8-week group therapy providing psycho-education, guidance in being a co-therapist, support and coping skills. Subsequently, treatment was individualized: family members learned either reducing accommodation, disentangle from conflict, or how they could contribute to the treatment of the patient, depending on the nature of their response to OCD. Family members in the family group had a greater reduction of depressive and anxiety symptoms than family members in the control condition, who did not participate in the family group. In another study, couples consisting of a patient with OCD and their partner received 16 sessions consisting of psycho-education, partner-assisted exposure, reducing accommodation, and general couple therapy on stressors unrelated to OCD. Partners showed improvements in depressive symptoms after the couple-based treatment, however, this did not maintain at 6-month and 12-month follow-up (Belus et al. 2014).

We have developed a brief dyadic family intervention focusing on accommodation, antagonism and normalizing the relationship between patient and family member. With this intervention we expected to reduce the OCD of the patient as well as to relieve the burden for their family members. The intervention has been tested in a pilot study (Remmerswaal et al. 2016). The brief dyadic family intervention was effective in decreasing severity of OCD of patients and also in decreasing accommodation in family members. However, antagonism did not change after the intervention, apparently because stopping with antagonism generated much anxiety.

The aim of this study is to examine whether the brief dyadic family intervention improves the burden and quality of life of family members of patients with OCD. In addition, we compared the level of burden and quality of life of family members of patients with OCD with relatives of patients with schizophrenia, using data from the literature.

## 2. Materials and methods

### 2.1. Subjects

Sixteen couples, consisting of a patient with OCD and the family member most involved in caring for the patient, were included. The study was conducted at the academic outpatient department for anxiety disorders at GGZ inGeest, Amsterdam, the Netherlands. All participants provided written informed consent.

Inclusion criteria for participating in the study were: 1. OCD of the patient of at least moderate severity (Yale Brown Obsessive Compulsive Scale (Y-BOCS)  $\geq 16$ ; Goodman et al. 1989a, Goodman et al. 1989b); 2. accommodation of the family member of at least moderate severity (Family Accommodation Scale on the family member (FAS)  $\geq 13$ ; Calvocoressi et al. 1999) and/or antagonism of significant degree (Perceived Criticism Measure on the patient (PCM)  $\geq 4$ ; Hooley and Teasdale 1989). Psychotropic medication was allowed but should be kept constant during treatment.

### 2.2. Treatment

Our brief dyadic family intervention consisted of five sessions of 90 minutes, planned every other week. Each session consisted of three parts: 1. decreasing antagonistic responses of the family members and decreasing patients pleading for accommodation by learning effective communication about OCD; 2. response prevention of accommodation by family members; 3. planning pleasurable, joint activities free from OCD. The protocol was added to regular cognitive behaviour therapy of the patient and offered to a couple consisting of a patient with OCD and a family member (Remmerswaal et al. 2016).

### 2.3. Measures

The Involvement Evaluation Questionnaire (IEQ; van Wijngaarden et al. 2000) was used to measure the burden of family members. This instrument is developed for relatives of patients with schizophrenia. We used the scales of the IEQ applicable to relatives of patients with OCD, which were three subscales: 1) tension: strained interpersonal atmosphere between patient and relatives; 2) worrying, for instance about the patient's health and future; 3) urging: activation and motivation of the patient, for instance stimulating the patient to take care of himself. The IEQ is tested on patients with schizophrenia, the validity and reliability of the IEQ are satisfactory (van Wijngaarden et al. 2000).

The Impact on Relatives Scale (IORS) was used to measure the impact of the OCD symptoms of the patient on the family member. The IORS is an OCD-specific measurement of family burden that was constructed for the NOCDA study (Schuurmans et al. 2012) and is based on items of the Y-BOCS, (Goodman et al. 1989a, Goodman et al. 1989b) adapted to relatives. The IORS consists of five items: How much of your time is occupied with reassuring the person with respect to his obsessive thoughts?, How much of your time do you spend helping the person with performing compulsive behaviours?, How much does the OCD of the person interfere with your functioning?, How much of an effort do you make to resist the OCD symptoms of the person? How much have you helped the person gaining control over his OCD symptoms?.

The self-rated EuroQol five dimensional questionnaire (EQ-5D) was used to assess quality of

life. This instrument was proven suitable and reliable in the general population and is applicable in patient samples (EuroQol Group 1990). The EQ-5D contains 5 dimensions: mobility, self-care, daily activities, pain/discomfort and depression/anxiety. Each dimension is rated at three levels: no problems, some problems and major problems. The health states are converted into an index score - the EQ-5D - reflecting the generic overall QoL that can be used to compare QoL in various conditions. The EQ-5D has a value between 1 (best possible health) and 0 (worst possible health).

The Family Accommodation Scale – Self Report version (FAS-SR; Calvocoressi et al. 1999) was used to measure family accommodation. The reliability and validity of the FAS are good. The FAS has two subscales (accommodation, consequences of not accommodating) and a total score.

The Perceived Criticism Measure (PCM) was used to assess perceived criticism (Hooley and Teasdale 1989). The instrument consists of one item: ‘How critical is your partner of you?’ and has a score between 1 and 10. The psychometric properties of the PCM are satisfactory (Chambless and Blake 2009, Hooley and Teasdale 1989). Antagonism was assessed with the PCM on the patient with OCD, which we reported in a previous paper (Remmerswaal et al. 2016).

### Statistical analyses

Results were examined using two-tailed t-tests in the intent to treat (ITT) sample. Missing values at post-test (n=5) were imputed with pre-test scores. Furthermore, the pre-test score of quality of life of family members of patients with OCD was compared to the general Dutch population with one-sample t-tests, using data from Szende et al. (Szende et al. 2014). The subscales of the IEQ (burden) at pre-test were compared to family members of patients with schizophrenia with one-sample t-tests. We used data from Wijngaarden et al.

(van Wijngaarden et al. 2000) to determine the reference values.

Correlations between pre-test scores and difference scores (post-test score minus pre-test score) of accommodation, antagonism and the measurements of family burden were determined with Pearson’s correlation coefficient.

## 3. Results

### 3.1. Sample characteristics

**Table 1** presents the characteristics of family members of patients with OCD. Most family members were partner of the patient (vs parent), well-educated and employed. None of them used psychotropic medication.

**Table 2** presents the comparisons of the burden of family members of patients with OCD with family members of patients with schizophrenia. None of the subscales of the IEQ that we measured differed significantly from family members of patients with schizophrenia.

### 3.2 Change of involvement in OCD of family members after the brief dyadic family intervention

**Table 3** presents the results of the ITT analyses. Compared with the pre-test, urging and the impact of the OCD on the life of family members were significantly ameliorated at post-test. A non-significant trend of improvement of consequences of not accommodating appeared after the family intervention. Quality of life of family members of patients with OCD did not significantly differ from the general Dutch population, which is 0.89 (Szende et al. 2014; (t(15)=1.63; p=0.12).

**Table 1.** Characteristics of family members of patients with OCD, n=16

	Mean (SD) or n (%)
Age	41.6 (10.1)
Gender, female	7 (44%)
Children, yes	9 (56%)
Relation to patient	
Partner	15 (94%)
Parent	1 (6%)
Length partner-relationship with patient <sup>1</sup>	14.3 (13.6)
Use of psychotropic medication	0 (0%)
Education, years	13.1 (2.8)
Employed, yes	13 (81%)

<sup>1</sup> n=15

**Table 2.** Comparison of burden of family members of patients with OCD with family members of patients with schizophrenia with one sample t-tests, ITT sample, n=16

Family burden	Mean (SD) relatives of patients with OCD	Mean (SD) relatives of patients with schizophrenia <sup>1</sup>	t(df)	p
Urging <sup>2</sup>	12.4 (3.8)	14.1 (5.6)	t(15)=-1.84	0.09
Tension <sup>2</sup>	13.9 (4.3)	14.3 (4.3)	t(15)=-0.39	0.70
Worrying <sup>2</sup>	13.5 (4.5)	14.3 (5.8)	t(15)=-0.71	0.49

<sup>1</sup> Data from van Wijngaarden (van Wijngaarden et al. 2000)

<sup>2</sup> Involvement Evaluation Questionnaire



**Table 3.** Involvement of family members in OCD, before and after a brief dyadic family intervention, ITT sample, n=16

	Pre-test	Post-test	t(df) p
Urging <sup>1</sup>	12.38 (3.76)	10.63 (3.42)	t(15)=3.05 0.01*
Tension <sup>1</sup>	13.88 (4.35)	12.88 (3.69)	t(15)=1.55 0.14
Worrying <sup>1</sup>	13.50 (4.50)	12.25 (3.89)	t(15)=1.11 0.29
Impact on relatives <sup>2</sup>	13.81 (3.54)	11.44 (3.56)	t(15)=2.73 0.02*
Quality of Life <sup>3</sup>	0.93 (0.10)	0.92 (0.10)	t(15)=0.27 0.79
FAS-SR <sup>4</sup>			
accommodation	22.56 (8.23)	20.25 (9.27)	t(15)=1.29 0.22
consequences	8.00 (2.85)	6.88 (2.83)	t(15)=2.09 0.05
total	33.31 (10.24)	29.50 (11.99)	t(15)=1.68 0.11
Perceived criticism <sup>5</sup>	5.38 (2.36)	5.75 (2.24)	t(15)=-0.75 0.46

<sup>1</sup> Involvement Evaluation Questionnaire<sup>2</sup> Impact on Relatives Scale<sup>3</sup> EuroQol five dimensional questionnaire (EQ-5D)<sup>4</sup> Family Accommodation Scale – Self Report<sup>5</sup> Perceived Criticism Measure

\* p&lt;0.05

### 3.3 Relation between family burden measurements and family accommodation and antagonism

Family burden measurements were related to accommodation and antagonism at pre-test: FAS SR accommodation, consequences of not accommodating and the total score were significantly correlated with tension (respectively:  $R=0.52$ ,  $p=0.04$ ;  $R=0.71$ ,  $p<0.01$ ;  $R=0.68$ ,  $p<0.01$ ), while antagonism was significantly correlated with impact on relatives ( $R=0.57$ ,  $p=0.02$ ).

An improvement in accommodation was significantly correlated with an improvement of worrying (FAS SR accommodation:  $R=0.64$ ,  $p=0.01$ ; FAS SR total score:  $R=0.57$ ,  $p=0.02$ ) and an improvement of the impact on relatives (FAS SR accommodation:  $R=0.57$ ,  $p=0.02$ ; FAS SR consequences:  $R=0.78$ ,  $p<0.01$ ; FAS SR total score:  $R=0.66$ ,  $p=0.01$ ). Change in antagonism was not significantly correlated with change in family burden measurements (IEQ and IORS) or QoL, probably because antagonism did not change significantly from pre-test to post-test.

## 4. Discussion

The level of burden of family members of patients with OCD was comparable to the burden of family members of patients with schizophrenia in the areas that we measured, which is considerable. Our result is congruent with previous findings that family burden of patients with OCD, anxiety disorders, depression and schizophrenia is equivalent (Senaratne et al. 2010, Magliano et al. 1996, Angermeyer et al. 2006). This underlines the importance of helping family members how to live with a patient with OCD. It might help patients with OCD as well: previously it was found that the level of experienced family burden and severity of OCD are related (Ramos-Cerqueira et al. 2008), however, another study did not find such a correlation (Gururaj et al. 2008).

Pre-test scores of accommodation and antagonism were significantly correlated to family burden, which is congruent with previous findings that accommodation and antagonism are related to family burden (Amir et al. 2000, Cherian et al. 2014). The burden of family members of patients with OCD was reduced after the brief dyadic family intervention. Not all measurements

of burden changed significantly, probably because we had a small sample, however, our intervention is promising in relieving family burden.

QoL of the family members at pre-test was comparable to the QoL of the general Dutch population, which is not congruent with previous findings showing a reduced QoL in family members of patients with OCD (Albert et al. 2007, Grover and Dutt 2011, Cicek et al. 2013, Stengler-Wenzke et al. 2006). Our sample of family members was well-educated and most of them were employed; possibly, this protects their quality of life against the impact of OCD. This is congruent with a research finding that QoL of family members of patients with schizophrenia was higher when family members were employed and were better educated (Lua 2011). Another explanation might be that our quality of life instrument, EQ-5D, is different from quality of life instruments used in other studies (for example SF-36 and WHOQOL), which include domains like social life, environment and role limitations. QoL of family members in our study was not improved after the family intervention, probably because of a ceiling effect.

Perceived criticism of family members was lower than the perceived criticism of their relatives with OCD, which we have reported in our previous paper (mean (SD) pre-test: 6.8 (1.6); post-test: 6.9 (1.3); Remmerswaal et al. 2016). It has been reported that the concept of perceived criticism reflects a critical interaction as it is related to the amount of critical comments made by the other person, but also to the amount of critical comments made by the person himself, both verbal and nonverbal comments (Gerlsma et al. 2009). Apparently, patients perceive the interaction as more critical than their family members. However, the perceived criticism score of the family members indicates a critical interaction as well. Possibly, interventions on antagonism may be improved by making family members and patients more aware of their verbal and nonverbal critical comments, which contribute to a critical interaction, and by re-appraisal of critical comments by the patient.

**Summary and conclusion:** living with a patient with OCD burdened the life of family members considerably, even in our sample of family members with a QoL comparable to the general population. Family members were worried about the patient, experienced tension in the relationship with the patient and urged the patient for instance to self-care or to employ activities. In addition,

family members accommodated and antagonized the OCD symptoms in a severe degree. A high family burden was significantly correlated with more severe accommodation and antagonism. Family burden was diminished after our brief dyadic family intervention and was correlated to a decrease in accommodation. We presume that family burden diminishes further when family members stop with antagonism. However, family members commonly do not stop with accommodation and antagonism by themselves, because – as they reported in our study - they are afraid it causes quarrels or worsens the mental symptoms (OCD) of the patient. In addition, family members frequently are unsure how to deal with OCD (Shafran et al. 1995). Advice and support during treatment may enable the family to normalize their behaviour and to decrease the burden they experience. Our brief family intervention focusing on accommodation, antagonism and normalizing the family relationship is promising in relieving the burden and the impact of OCD on family members.

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