



How are OCD patients and their families coping with the COVID-19 pandemic? A qualitative study

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Abstract

Patients with obsessive-compulsive disorder (OCD) are likely to be affected by the COVID-19 crisis since fear of contamination is highly prevalent in this illness and disease reminders are omnipresent during this crisis. The current study aimed to investigate the impact of the pandemic and the lockdown on the mental health, well-being and coping abilities of OCD patients and their families in order to increase our understanding of the underlying mechanisms of the disorder. Twenty-two patients and 13 family members were interviewed one-to-one about their experiences and challenges caused by the pandemic and home-confinement directives. Verbatim transcripts of the interviews were analyzed using inductive thematic analysis. Five overarching themes were identified: (1) changing point of reference: confusion and legitimization of OCD behavior, (2) coping strategies were challenged: too much or too little exposure to obsessional concerns, (3) distress but also relief in some areas, (4) developing a new equilibrium within the family, (5) changes in accessibility and nature of therapy: perils and merits of online treatment. These findings make clear the importance of the accessibility of mental health services during this pandemic through direct patient contacts or in a remote format. In therapy therapists should focus on challenging the changing point of reference, providing practical advice on coping, stimulating to engage in exposure and encouraging patients to seek social support. Furthermore, it is important to involve family members in therapy to support and coach them to be validating, supportive and encouraging, without accommodating to the OCD behaviour.

Keywords Obsessive-compulsive disorder · Family accommodation · COVID-19 · Lockdown · Thematic analysis

Introduction

People with pre-existing mental health disorders are at increased risk for adverse psychosocial outcomes, namely increasing levels of anxiety and depression, caused by the COVID-19 pandemic (Assari & Habibzadeh, 2020; Pfefferbaum & North, 2020). Among them, especially patients with obsessive-compulsive disorder (OCD) are likely to be affected by the pandemic since fear of contamination and washing compulsions are highly prevalent (up to 50%) and core features of the illness (Stein et al., 2019). During the

H1N1 swine flu pandemic in 2009 (Page et al., 2011) and during the HIV-AIDS crisis in 1980s (Rapoport, 1989) contamination fears and washing rituals of OCD were found to worsen. The primary reason for an increase in symptoms is said to be the increased presence of disease reminders (Rubin et al., 2009). During the present pandemic there are constant reminders to wash our hands “properly”, there is an overload of information in the media about the pandemic, and people are preoccupied with concerns about their own health and that of their loved ones. This steady flow of external (media, posters, advertisements) and internal (thoughts about loved ones, a sudden cough) cues may re-activate or increase contamination obsessions and/or washing rituals because of the tendency of OCD patients to respond to danger and uncertainty (Darvishi et al., 2020; Wheaton et al., 2021). The isolation, loneliness, and potential entrapment in adverse circumstances (e.g., domestic abuse, poor housing) resulting from the lockdown, physical distancing, and self-isolation could have a negative impact on mood and wellbeing, which may further increase symptoms (Amerio et al., 2020; Bradbury-Jones & Isham, 2020; Fiorillo & Gorwood, 2020; Zheng et al., 2020).

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Furthermore, the occurrence of depressive symptoms can also result from trait markers (unique sensory processing patterns), which have been reported as crucial factors in determining e.g. hopelessness (Serafini et al., 2017). Living with family could be either protective, due to the emotional support (Brooks et al., 2020) but it could also worsen symptoms due to an increase in family accommodation (FA) and/or expressed emotion (Cao et al., 2020). Family accommodation, shown in nearly 90% of family members, refers to the adjustments that family members make to avoid or reduce distress related to the disorder ranging from performing the person's compulsive rituals for them, to providing reassurance and modifying daily routines. These adjustments provide the patient with temporary relief (Calvocoressi et al., 1995; Renshaw et al., 2005; Shimshoni et al., 2019). It is very distressing for the patient when family members refuse to accommodate by resisting making adjustments, interfering with the patient's compulsions, or overtly opposing the rituals (Garcia et al., 2010; Van Noppen et al., 1997).

Although one recent study among children and adolescents with OCD reported no general increase in symptom severity (Schwartz-Lifshitz et al., 2021), other recent studies found a worsening in OCD symptoms during the quarantine and especially in case of pre-existing contamination fears (Davide et al., 2020; Knowles & Olatunji, 2021; Matsunaga, Mukai, & Yamanishi, 2020) and across all OCD dimensions (Khosravani et al., 2021). However, until now, the reasons as to why OCD symptoms tend to increase during the COVID pandemic, are little/poorly investigated. Therefore, the current study aimed to qualitatively investigate the impact of the COVID-19 pandemic and the lockdown on the mental health, well-being and coping abilities of OCD patients and their families in order to increase our understanding of the underlying mechanisms of the disorder. We expected that the COVID crisis, in a sense an "experiment in nature" would have a major impact on many OCD patients due to the ongoing presence of disease and hand hygienic reminders, the overload of (social)media information and their tendency to respond to danger and uncertainty. Furthermore, we presumed that the negative consequences of the lockdown (loneliness, isolation, ...) would also account for an increase of OCD symptoms as this might impact mood and wellbeing and decrease the accessibility of mental health services in patients with more significant needs. Finally, we also believed that the increase of OCD would have an impact on their live-in family members (e.g. more tension, concern, ...) resulting in more family accommodation. In order to gain an in-depth understanding of the way patients and family members deal with these changing and challenging circumstances we employed a qualitative methodology as this could lead towards a new conceptual understanding of the underlying mechanism of OCD and FA. The specific methodology employed was thematic analysis, a dynamic research method that can be

usefully applied to improve understanding of a phenomenon of interest, inform theory development and strengthen clinical practice (Silverstein et al., 2006).

Methods

Recruitment and Selection

Participants were recruited through the Centre for OCD of the Ghent University Hospital (UZ Gent) located in Dutch speaking part of Belgium. Inclusion criteria were: (a) diagnosis of OCD, (b) age of patients between 18 and 65 years old, (c) speaking Dutch fluently. Exclusion criteria were: (a) current substance abuse and (b) psychotic symptoms. In addition, Dutch speaking family members, aged 18–65 years old, who were living in the same household as the patients were asked to participate in the study. Only 22.7% of the patients were living alone.

Demographics of Participants

In total, 22 patients and 13 family members participated in the study (See Table 1). The mean age of the OCD patients was 32.9 years ($SD = 10.97$, range 21–62) and they had a mean symptom duration of 18.0 yrs. ($SD = 11.03$, range 3–47). Of the 22 OCD patients, 8 (36.3%) have contamination fears and washing compulsions, 3 (13.6%) magical thoughts and repetitive behavior, 3 (13.6%) persisting doubting and checking, 2 (9.1%) sexual intrusive thoughts and repetitive "undoing" thoughts, 2 (9.1%) harming thoughts and checking, 2 (9.1%) symmetry and ordering or arranging and 2 (9.1%) fear of forgetting things and checking as their main symptom cluster. Live-in family members (6 mothers, 4 male and 3 female partners) of thirteen patients (5 male and 8 female) participated as well. The mean age of the family members was 46.2 years ($SD = 13.04$, range 25–63). They were all Caucasian, living in the Flemish part of Belgium.

Procedure

All participants were interviewed one-to-one using teletechniques by the third author, who is a female clinical psychologist and cognitive behavioral therapist experienced in treating OCD. All interviews took place in April 2020, with the exception of 2 interviews (in the beginning of May 2020). On average the duration of the interviews was approximately 20 min. The semi-structured interview schedule was developed by two clinicians experienced in OCD and qualitative research. A preliminary version of the semi-structured interview was piloted with one OCD patient who is also a peer support worker with OCD and reviewed by one of the auditors, the second author, who is a qualitative research expert.

Table 1 Description of Patients and Family Members Characteristics

Variable Name	Group	N (%) Patient	N (%) Family member
Gender	Female	13 (59.1)	9 (69.2)
	Male	9 (40.9)	4 (30.8)
Educational attainment	Secondary school	13 (59.1)	5 (38.5)
	Bachelor's degree	1 (4.5)	5 (38.5)
	Master's degree	8 (36.8)	3 (23.1)
Employment status	Employed	5 (22.7)	11 (84.6)
	Unemployed (health related)	8 (36.4)	0 (0)
	Unemployed	3 (13.6)	0 (0)
	Retired	1 (4.5)	1 (7.7)
	Student	3 (13.6)	0 (0)
	Other	2 (9.1)	1 (1.7)
Marital status	Single	10 (45.5)	2 (15.4)
	Relationship not living together	2 (9.1)	3 (23.1)
	Practically or common-law living together	4 (18.2)	0 (0)
	Married	5 (22.7)	8 (61.5)
	Widowed	0 (0)	0 (0)
	Separated	1 (4.5)	0 (0)
Living condition	Living together	17 (77.3)	13 (100)
	Living alone	5 (22.7)	0 (0)
Children	Children	6 (27.3)	
	No children	16 (72.7)	
Mental health treatment	Current treatment	21 (95.5)	
	- GP	5 (23.8)	
	- Psychologist	17 (81)	
	- Psychiatrist	18 (85.7)	
	- Other	2 (9.5)	
	No current treatment	1 (4.5)	
Type of treatment (past or present)	Medication	22 (100)	
	Psychotherapy	20 (90.9)	
	- Cognitive Behavioral Therapy	19 (95)	
	- System Therapy	3 (15)	
	- Psychodynamic Therapy	2 (10)	
	- Other	4 (20)	
	Neuromodulation (TMS, DBS, ECT)	12 (54.5)	

Based on their feedback, the final version was modified. The interview focused on the experiences of patients and family members during the COVID-19 pandemic and home-confinement directives. More specifically, the challenges, the influence of (social) media and accessibility of mental health services were questioned. Verbatim transcripts of these interviews served as the raw data for this study.

Analysis

The data were analyzed using inductive thematic analysis. The analysis was performed by three different researchers (first, second, and last authors), the second and last author served as auditors which enhanced the validity of the study. The first author is a female senior psychiatrist, researcher and cognitive behavioral therapist experienced in treating OCD. The second author is a female clinical psychologist and family therapist, who is familiar with OCD and an experienced qualitative

researcher. The last author is a male senior psychiatrist and family therapist, who has a good understanding of OCD and is an experienced qualitative researcher.

The analysis procedure was conducted across different steps and the texts of the patients and family members were analyzed separately. In order to enhance the trustworthiness of the research process, the researchers try to set aside their own beliefs, thoughts and preconceived notions (i.e. "bracketing") about the phenomenon under investigation (Smith, 2008). First all interviews with patients and family members were transcribed verbatim by the first author. Second the first and last author wrote down their first reflections, associations and preliminary interpretations for coding after reading the transcripts several times. Codes were given to all features highlighted on initial readings. Third, coded data were compared, collated and grouped together in meaningful clusters into separate lists by the first author. Coded data and their interrelationships were carefully considered in order to

generate overarching themes. Themes were compared and further broken down in order to capture different nuances of meaning or combined according to their commonalities. The differentiating and merging of themes allowed the development of an analytic hierarchy in which overarching themes and sub-themes were identified and described close to the verbatim data, leading to the development of a table. The process of analysis involved a recursive movement back and forth between transcription, extract and theme in order to ensure that the identified structure of themes continued to be grounded in the original transcripts. Fourth, the validity of the themes was established via two methods. First, the first author listed the themes on a separate sheet and discussed the accuracy of the themes with the two auditors (second and last author). Different opinions were resolved via discussion. Following that, the first author wrote an exhaustive report based on the different themes and subthemes in which all the relevant quotes were included. Second, this report was analyzed and reviewed three times by the two auditors in order to refine the extracted themes. In this way a more integrated set of master themes was developed.

Results

Five themes were derived from the analysis: (1) Changing point of reference: confusion and legitimization of OCD behavior, (2) Coping strategies were challenged: too much or too little exposure to obsessional concerns, (3) Distress but also relief in some areas, (4) Developing a new equilibrium within the family, (5) Changes in accessibility and nature of therapy: perils and merits of online treatment. The corresponding quotes from the participants' interviews for each theme can be found in Table 2.

Changing Point of Reference: Confusion and Legitimization of OCD Behavior

The government-imposed safety measures to contain the COVID pandemic prescribed several hygienic behaviours, such as the thorough and frequent washing of hands and social distancing, which were experienced by the patients as quite similar to specific compulsions to prevent contamination or dirt. Although these washing behaviors previously had been identified as pathological, they were now suddenly the new normal, emphasized in health care guidelines and generally enacted by the public. Consequently, the boundary between normative and pathological behavior was experienced as very difficult to discern and patients' OCD behavior seemed to be justified, as "OCD behavior became the new normal" or was facilitated by these forceful recommendations. The new rules were regarded as a legitimization of the OCD behaviors. Since the normative point of reference was lost, the OCD patients

reported difficulty understanding what behavior was allowed in the new context. They also found it difficult to establish the extent to which their behavior was consistent with that of healthy people. Before the pandemic, this comparison helped them to realize where their behaviour was excessive and what needed to change. Moreover, since the patients have fewer encounters with other people, they have fewer opportunities for 'fact checks', which also makes it difficult for them to apply what they have learned in therapy.

In essence, the new hygienic rules are often very similar to the compulsions that have been unlearned in treatment.

Furthermore, the lockdown measures including the ban on visiting each other's homes, facilitated OCD related avoidance behaviors such as not inviting people home due to the patient's contamination fears.

Coping Strategies Are Challenged: Too Much or Too Little Exposure to Obsessional Concerns

OCD symptoms are often experienced by patients as something forced upon them or something that they don't choose. The main goal of treatment is to help them to re-experience more freedom of choice, especially when it comes to whether or not to respond to certain intrusions and/ or obsessions. However, the COVID-19 pandemic and lockdown measures make this struggle more difficult for the patients by too much or too few opportunities for exposure to the obsessional concern, i.e. some OCD patients reported to be flooded with different kinds of triggers increasing their intrusions and compulsions whereas others experienced very few opportunities for experimenting with therapeutically prescribed exposure.

Too Much Exposure to Obsessional Concerns

The fear of contamination, the increased demands of hand washing, and the media information constantly presented the patients with an overload of anxiety-related triggers, increasing their OCD symptoms. Furthermore, the fear of being responsible for suffering or death of others, which is one of the driving forces behind OCD, was also enhanced by the risk of contaminating others. The frequent reporting of Covid-19 deaths also triggered specific obsessions concerning the death of a relative often resulting in an increase of compulsions. The live-in family members also noticed the increase of OCD symptoms of the patients, e.g. that their affected family member is scared that an infection enters the house or that their family member is responsible for the contamination of others.

Too Little Exposure and Anticipation of Future Exposure

The pandemic restrictions disrupting the professional, social and daily life are creating a new social reality beyond the control of the patients, with fewer opportunities for

Table 2 The quotes from participants' interviews grouped by the different reported themes**Theme 1: Changing point of reference: confusion and legitimization of OCD behavior.**

The thing is that I wash my hands much more often these days, and now it's like just right when you do that, because you have to, you have to (Female patient, 62, fear of contamination)

It's like you have fewer social reference or something, yeah, normality seems to fade away, so uhm, OCD seems to get more space, gets free rein. Instead of when you meet people then unconsciously each time you have some kind of fact check, you know many people don't have OCD so then you can see, yeah you know, now your point of reference is lost (Male patient, 37, ordering and arranging)

Oh, the corona virus can be on it, you know, and then you should wait two or three days to take up and read your book from the library and all that, you know, I have the impression it gets more of a grip on me that way, so it's like I have to do exactly these things now I needed to unlearn in the past. (Female patient, 62, fear of contamination)

These days no one would even propose to come by my place, so uhm, very weird yeah, I have the feeling that the government almost facilitates my OCD and tells me 'you can't do this and you have to do that'. (Female patient, 36, fear of contamination)

Theme 2: Coping strategies are challenged: too much or too little exposure to obsessional concerns**2.1 Too much exposure to obsessional concerns**

[It] has had a huge impact on my fear of contamination, which was very limited before, and now it returned and it's much more intense (Female patient, 38, fear of contamination)

But I do feel scared, let's say when I come to the consultation or something, I wear a lot of layers, being scared like 'I don't want to get infected' (Male patient, 44, fear of contamination)

Did people go out? Did I count correctly? Then the thoughts like 'there are too many people inside, they all are going to be infected, that's my fault, how many people will die?' Uhm, can I control it, I can't control whether people will die, so that makes it worse. (Male patient, 43, persisting doubting)

Just like, because it's often about death and uhm, I'm not good at that, and it makes the compulsions increase (Female patient, 26, magical thoughts)

Mostly with regard to hygiene, being clean, uhm, masks, yeah, being scared that an infection enters the house or the family. (Male partner of patient with fear of contamination, 38)

The fear that there would be a contamination, that she would uhm, would come into contact with somebody who is infected, and that she would pass it on to me, so it's especially not about, about her becoming ill, but the fact that she would pass it on to people around her. (Mother of patient with magical thoughts, 53)

2.2 Too little exposure and anticipation of future exposure

I always say, my job and seeing my friends, that's part of my exposure, you know, it was my exposure actually (Male patient, 21, sexual intrusive thoughts)

So at the moment, I think it's pretty ok, my OCD is under control. But I don't see it clearly, because I also, yeah, I don't come out so it's a different safer situation for me. (Male patient, 25, persisting doubting)

I'm afraid that the OCD will be worse when I meet certain people again (Male patient, 21, sexual intrusive thoughts)

While I'm also thinking that when this is all over, I will start thinking 'oh no, no viruses in the house', so I'll have to pay more attention to that again. (Female patient, 62, fear of contamination)

2.3 Too little distraction/ reallocation of attention

So in general the quarantine isn't helpful, it keeps the obsessive thoughts going on and on. I lack distraction, so I spend more time dwelling and lingering on a particular thought. (Female patient, 31, fear of contamination)

Obsessive thoughts come up at moments when you're most lonely, you don't have anything to do, then they come up. (Male patient, 28, sexual intrusive thoughts)

The OCD increases, because she's at home more often (...). Uhm, she can engage in compulsive rituals whenever she wants, like yeah, more than ever I guess (laughs). Also, yes, she can't, she can't go anywhere except for going for a walk or riding her bike. (Male partner of patient with contamination fears, 38)

2.4 Too much avoidance

Now I'm at home almost all of the time, so for myself, you know, I do wash my hands very often and when I have to wash things, again, yeah doing the laundry used to be a huge problem three years ago, because I needed to wash everything separately in my washing machine or I needed to wash the inside of the washing machine before it could run again, or wash things twice, those are things I see coming back now. (Female patient, 31, fear of contamination) (active avoidance)

Because I still lock myself up in my safe cocoon, being at home, at home and outside, but actually I don't dare to go on the street at all, I don't dare to go through the front door, I stay in my own environment. (Female patient, 50, fear of contamination) (passive avoidance)

So before corona popped up in the news, I think starting from the middle of February, beginning of February I started to have fears about it, when other people weren't concerned with it yet. Already at that moment I didn't go outside anymore and people told me not to exaggerate, it's, it's in China.

(Female patient, 31, fear of contamination) (passive avoidance)

[So, it didn't have] a good impact and I decided to keep it at a distance as much as possible, because when I read all those articles, like stupid articles, sometimes I see in the title 'can I still grab a shopping cart?' 'can you touch the door handle?' How contagious is this and how contagious is that? And in the beginning, I read all of that, but it only resulted in an increase of my fear and it didn't help me. So it's better to keep away from the media because it just triggers too many thoughts and acts related to fear of contamination. (Female patient, 31, fear of contamination)

Theme 3: Distress but also relief in some areas

Sometimes I am a little down because you don't, you don't have a perspective anymore, like applying for jobs is completely at a standstill, so yeah, you don't really have the feeling that you get on in life, or that it, everything is at a standstill at the moment. (Female patient, 26, harming thoughts)

A feeling of hopelessness, a feeling like 'this is never gonna be over' and that's very difficult sometimes. Uhm, and it strongly reminds me of an OCD problem, in that I also very often think 'this is never gonna stop' when it comes to OCD, there's no perspective there. (Male patient, 37, ordering and arranging)

People in the media contradict each other, one person says this, the other one says it differently, and that makes him very unsure and he says 'when this is gonna take much longer I'm afraid I might get a relapse', that's something he literally said a couple of days ago. (Mother of patient with sexual intrusive thoughts, 51)

As I'm living on my own, the loneliness is more tangible to me and the situation more concrete (Female patient, 36 fear of contamination)

It's incredibly hard, so like human contact is not possible, both with friends and family, yes loneliness is coming into play (Female patient, 50, fear of contamination)

So also the feeling of being forgotten somehow, yes, because yeah who cares you know, that I'm sitting here, yes kind of (Male patient, 37, ordering and arranging)

The only good thing is that my weeks are less busy (Female patient, 24, ordering and arranging)

In general, the positive effect it has, things are more quiet, somehow it's pleasant and there is less obligation to make uhm, to make progress (Male patient, 37, ordering and arranging)

So for him the pressure is gone too. (Female partner of patient with persisting doubting, 28)

Theme 4: Developing a new equilibrium within the family**4.1. Changing family dynamics**

So luckily, her brother is with her at home, because at other times he is with his girlfriend very often, but now he's home too, and they get along very well and they laugh together and for her that's a plus.

Table 2 (continued)

(Mother of patient with harming thoughts, 62)
 They both really like the game, so once in a while we play it, then they say ‘shall we play again?’ And then that’s one hour we do that together, that’s fun. (Mother of patient with magical thoughts, 54)
 Sometimes it’s hard to be together in the family 24/7, sometimes that results in tensions (Female patient, 26, harming thoughts)

It’s just the family. And that’s good for the connection between us in the family, you know, in the relationship with my son. But sometimes I’m fed up with it, sometimes I want to be more than a Mum and a housewife. (Female patient, 38, fear of contamination)

Because sometimes we’re too close, too close together, and, and yes, one needs some rest or he sits too close to me, repeating the same thing over and over again, or talking about the compulsion, or this or that, then I think ‘oh gosh’. And I’m the kind of person who needs her space, uhm, that’s the way it is. (Female patient, 41, of patient with persisting doubting)

4.2.Changing family coping: from correction to family accommodation
 I make clear to him often like ‘B., try to wash your hands for a shorter period of time, try this, try that’
 (Mother of patient with fear of contamination, 51)
 I tell her not to be on Facebook all the time, where you see everything, I tell her ‘you have to, just leave it like...’ (Male partner of patient with fear of contamination, 63)

Sometimes I tell her ‘stop it, enough’, sometimes, than she’s often angry with me, but afterwards she’s happy and she thanks me. (Male partner of patient with fear of contamination, 38)

G it’s just the OCD, come on: no. (Mother of patient with magical thoughts, 53)
 Because I’m pretty occupied with it, and I think it’s remarkable because that way it’s a lot easier to empathize with him. (Female partner of patient with persisting doubting, 28)

I don’t make a fuss when I notice the umpteenth pair of trousers in the laundry and then I think: ‘ok yes, with corona I understand, even for us it’s you know, for us too it is, you’d get OCD right away so to say’. (Mother of patient with contamination fears, 51)

His sister came to me now and then, asking me ‘how is N. doing?’ ‘would it bother him a lot? Or sometimes she said ‘Mum, try not to uhm, show your own fears... ‘She was worried about me but also about her brother. (Mother of patient with sexual intrusive thought, 51)

So I try to reassure her saying ‘I try my best not to get infected, because I know I’m at risk. (Male partner of patient with contamination fears, 38)

I’m pretty scared myself, not in general but at my job I am, because there’s an outbreak at work. Uhm rules aren’t followed so strictly. So yeah, for myself I try to uhm, but yeah, I’m not gonna talk a lot about that to her, well yeah now she’s next to me, because I know for her it’s, you know, yeah, I learn to sail right? There’s no other way, it’s the same for everyone. (Mother of patient with magical thoughts, 52)

Well, it’s clear that she’s avoiding the news, she stopped watching because she preferred not to know. She avoided it, so I myself didn’t bring it up explicitly or when I heard someone or someone in my environment uhm. To the contrary in fact, I tried to, even I’m not so scared, but I tried to put things into perspective even more, to make her feel more at ease. (Mother of patient with magical thoughts, 53)

But now, in that situation I’ve taken over, sometimes I stop her. (Male partner of patient with fear of contamination, 38)

I’m, I’m the one who does the groceries, because she doesn’t dare to go out, so yeah, someone needs to go out right? (Male partner of patient with contamination fear, 55)

When F. comes home, it’s mostly like me making him do things, because it then enters our house and yeah that’s the safe space for me so, then he comes in and he knows that when he hasn’t disinfected his hands and he touches the door knob, he should disinfect the handle afterwards, so after he washed his hands and put his clothes in the laundry. (female patient, 31, fear of contamination)

Theme 5: Changes in accessibility and nature of therapy: perils and merits of online treatment
 My daughter has a very difficult time, she can’t turn to anybody and both me and her found it really hard. She felt a bit abandoned I might say. (Mother of patient with magical thoughts, 53)

Somehow, I have the feeling that when it comes to people with mental health problems, these people are put on hold more easily in one way or another. Or that it’s seen as less urgent compared to someone with a physical problem. It’s still, I think it’s often underestimated. (Mother of patient with magical thoughts, 53)

Of course, it’s different to see each other via a screen, uhm, and sometimes that increases the feeling of loneliness I feel, because you, yeah, the contact with the therapist, that is so important. (Female patient, 24, ordering and arranging)

I do think it’s completely different to have a conversation via a webcam compared to face to face, because in face to face contact there’s more emotion, yeah (Female patient, 26, harming thoughts)

Seeing a psychologist is also part of my therapy, it’s about going there, having the conversation, tape recording everything, making notes, than driving to the city to have a coffee and reread everything, then I’m on my own (Male patient, 21, sexual intrusive thoughts)

When it’s the day of your consultation and that’s a possibility, she gains a lot of time. (Mother of patient with magical thoughts, 54)

I think it’s ok, I think it’s very relaxing in a way, because I can talk to her from my own room. (Male patient, 21, fear of contamination)

“therapeutically prescribed” exposure or experimenting with non-pathological behavior and interactions. This lack of opportunities for experimenting with new behavior worried several patients because they realized that exposure is likely to prevent relapse. Some were also afraid that they would experience an exacerbation of OCD symptoms after the lockdown because of an expected intensive exposure to anxiety-evoking triggers.

Too Little Distraction/ Reallocation of Attention

The lockdown measures have afforded fewer opportunities for distraction focusing on social and leisure activities, which are valuable ways of coping with OCD symptoms. In that regard patients report that they spend more time dwelling and lingering on a particular thought or engaging in compulsive rituals and that obsessions emerge more.

Too Much Avoidance

While the lockdown only prohibits non-essential activities outside the home and indoor sports activities, many patients have isolated themselves at home and have chosen not to go outside anymore. As a result, they were unable to expose themselves to all the normal OCD triggers associated with daily life. Avoidance of these triggers is generally considered to be maladaptive since it disallows new learning about the trigger, thereby perpetuating the exaggerated fear response. Avoidance affords relief, which negatively reinforces the avoidance. Some patients reported that they were already isolating themselves before the start of lockdown and hygienic measures because they were already overwhelmed by severe infection fears. Other patients also (passively) avoided (social) media in order to expose themselves as little as possible. However, this avoidance behavior may be considered as a good and protective strategy to decrease OCD symptoms.

Distress but Also Relief in some Areas

The outbreak of COVID-19 and the lockdown measures were imposed without any indication as to when they would be lifted, resulting in a constant state of uncertainty. This was accompanied by the lack of any ability to anticipate and plan, resulting in feelings of anxiety, hopelessness, loss of control, depression, and demotivation of patients and family members. The conflicting information by the government and public health authorities further increased the distress of the patients and their families. The lockdown, social distancing, and self-isolation had a detrimental impact on social life and interactions increasing loneliness in many patients and family members, even feelings of being abandoned.

However, the lockdown also resulted in less social pressure as daily life had fewer social or family activities or obligations. In general, it made the patients (and families) feel more relaxed and at ease.

Developing a New Equilibrium within the Family

Changing Family Dynamics

As the lockdown mainly occurred within the family context, patients and family members were forced to spend more time together. On the one hand, this created more opportunities for them to enjoy activities together as a family, often increasing cohesion and creating a positive atmosphere within the family.

However, on the other hand, continuously living together also led to more tensions, irritability and conflicts between them.

Changing Family Coping: From Correction to Family Accommodation

Most family members tried to correct OCD behavior (e.g. by limiting it in time) or encouraged their affected relative to restrict their OCD. Correction and/or interfering with OCD behaviors, at the opposite side of a continuum with FA, is thought to be an important factor in patients' exposure, finally resulting in habituation.

However, since family members acknowledged that the COVID pandemic was very stressful for their relative and they themselves experienced fears of contamination, they became more tolerant, empathic and understandable of the OCD behaviors. Moreover, it led many of them to participate in compulsions and adjusting their daily routines to their OCD relative. Different forms of FA, especially reassuring and taking over, were reported by them. Some family members also encourage each other not to burden their affected family member by showing their concerns about the pandemic. Family members also avoided talking about COVID-related topics to not to upset their relative. Alternatively, they facilitated avoidance behavior of the OCD patient by taking over some of their activities. Likewise, FA arises when patients prompt family members to adhere to strict hygienic measures, asking their partner to participate in compulsions or to follow rules the patient imposes in order to prevent "contamination" of the house with the virus.

Changes in Accessibility and Nature of Therapy: Perils and Merits of Online Treatment

The lockdown measures had a great impact on the mental healthcare services as direct patient encounters were greatly curtailed or even completely stopped. Patients and family members felt abandoned by this 'lockdown' of the mental health care services as it gave them the impression that psychiatric problems are not considered important enough to be prioritized. Online treatment sessions were often organized as a way to provide continuous mental health care. Several patients experienced the online treatment sessions as less personal, less supportive, sometimes even increasing their feeling of loneliness, or as a loss of exposure opportunity. However, others and their family members experienced them as very positive saving time and making therapy more comfortable.

Discussion

Our findings are consistent with previous findings that people with pre-existing mental disorders are more prone for relapses and stress during pandemics (Duan & Zhu, 2020) and OCD patients are particularly vulnerable (Davide et al., 2020; Khosravani et al., 2021; Knowles &

Olatunji, 2021; Matsunaga et al., 2020). Only one recent study in children and adolescent showed no increase in OCD symptoms (Schwartz-Lifshitz et al., 2021). Further, our study increases our understanding of the factors underlying this increase of symptoms, as OCD concepts, core beliefs and coping strategies are tackled, and families tend to respond with an increased FA.

When confronted with the new government-imposed hygiene and social distance measures patients engaged more in OCD-driven behaviours (i.e. washing rituals and avoidance), although they also clearly understood that doing so is likely to have long-term counterproductive effects, as many of the patients (90.9%) had received a psychotherapeutic treatment in which this had been outlined extensively. Why then engage in more OCD-driven behaviours? The short answer is that their normative points of reference have changed and they experienced less social correction, resulting in validation of the OCD behaviours. In this regard, it is important to note that there are speculations on the evolutionary origins of OCD (particularly contamination/washing symptoms) as a defense against infection (Polimeni et al., 2005; Rajkumar, 2020) or as a more general defense against threat (Feygin et al., 2006), which may be further enforced by the COVID pandemic. But as only 36.3% of participants in this study had contamination fears as their main symptom cluster, other important mechanisms might underly the increase of OCD – i.e. the facilitation of avoidance by the government, which ‘accommodates’ the OCD and worsens the outcome as shown in FA (Garcia et al., 2010; Van Noppen et al., 1997). This underscores the extent to which all forms of OCD are supported by the same general scaffolding – negative appraisal of the meaning and importance of obsessional concerns, need for certainty that harm has been avoided, negative reinforcement of compulsions and avoidance, concern about being responsible for harm, core beliefs of vulnerability, incompetence that undermine self-trust, etc. (Frost et al., 1997; Steketee et al., 2003). Family members may also be more anxious about contamination and also have lost their points of reference, and therefore are more sympathetic to making accommodations.

In addition, patients have less opportunity to use their normal coping strategies of exposure and distraction and are able to avoid obsession triggers more easily. First, the increased exposure to OCD-related triggers was reported to have a significant impact on patients’ symptom severity as was also found by Davide et al. (2020). As observed elsewhere, the increased prevalence of disease reminders (Rubin et al., 2009) have an impact on patients’ symptoms, and may also effect the core OCD beliefs, i.e. the inflated sense of responsibility (Frost et al., 1997). Second, having learnt the importance of exposure and response prevention in order to withhold relapse, patients reported concerns about having fewer opportunities for exposure and were concerned about future exposure (Foa & Goldstein, 1978; Marks et al., 1975).

Another important factor in symptom increase was the loss of opportunities for distraction, resulting in more time to engage in their OCD. This may also contribute to an increase of fear, worry and depressive symptoms (Abramowitz et al., 2003; Najmi et al., 2009). Finally, avoidance prevents new learning about the obsessional concern and prevents exposure and subsequent habituation, which contribute to the persistence of the OCD (Salkovskis et al., 1998).

Patients and family members also mentioned the amount of uncertainty at the start of the lockdown, which caused feelings of loss of control, anxiety, hopelessness and depression. Feelings of loss of control drive fear and uncertainty in all people as the trajectory of the pandemic is constantly changing (Han et al., 2018), but this may even be worse in OCD patients as beliefs of losing control can worsen their OCD (Carr, 1974; McLaren & Crowe, 2003). Conflicting messages in the media foster fear, which further contributed to their lack of any ability to predict and plan, as also seen in the general population (Fiorillo & Gorwood, 2020; Pfefferbaum & North, 2020).

On top of the above challenges, family dynamics have also changed. Positive family processes (i.e. increase of rest and relaxation) are supportive and may have positive outcomes (e.g. more resilience), whereas negative family processes marked by conflict, tension and irritability may result in negative outcomes (e.g. distress) (Günther-Bel et al., 2020). These changes may have an impact on the attitude toward the illness and the affected family member. In this study different forms of FA, especially reassuring and taking over, were reported. Family members reported that they felt greater empathy, understanding, concern, or fear for their family member.

In our sample, 11 of 13 (84.6%) family members accommodated in some way, only 2 partners reported not accommodating. Why some family members are involved in FA and others not remains unclear (Albert et al., 2017).

The above challenges to patients and their relatives highlight the importance of appropriate (psycho)therapy. In addition, evidence suggest that OCD patients currently in treatment cope well during the COVID-19 pandemic (Kuckertz et al., 2020; Schwartz-Lifshitz et al., 2021). However, several patients reported that their therapy shifted to telehealth or was terminated. Most patients experienced the online sessions as less personal or supportive, which increased feelings of loneliness. These findings contradict previous research findings (Berger, 2017) However, younger patients in this study reported more positive experiences. Nonetheless, a shift to e-mental health technologies will require a period of adjustment for both patient and therapist (Rogers et al., 2017).

Finally, some patients experienced a reduction of pressure and expectations since the pace of life slowed due to the pandemic, a “lockdown relief”.

Several factors limit the transferability of our results: the small sample size of the group of family members, the use of teletechniques for the interviews and the restriction to one specialist Flemish OCD clinic, the latter possibly constituting a source of bias in terms of a greater OCD severity, comorbidity, chronicity in comparison with less intensive forms of out-patient treatment in the community. Further, mainly mothers and partners of patients participated in the study and relatives of patients who were living alone were not included. Although the duration of the interviews was rather short, the extract of the in-depth qualitative material was warranted by the high number of interviews, leading eventually to the saturation of the data and by the quality of the interviewer, who was also a senior psychologist, experienced in OCD and total time of all interviews was higher than in another qualitative OCD study (Halldorsson et al., 2016).

Conclusion and Implications

There is a growing amount of research evaluating the mental health of OCD patients during this pandemic, as it is recognized that this group of patients may be more vulnerable. This study indicates that almost all participants reported that the COVID-19 crisis had led to an increase in their OCD symptoms, a diminished ability to use healthy coping strategies and families tended to respond by increased FA. In addition to this, the pandemic has put a strain on patients' social and family life and has resulted in the withdrawal of face-to-face therapy, making many feel less supported. These findings firmly underscore the importance of a continued availability of direct or e-mental health services, particularly for the most vulnerable patients and involvement of family members in treatment even during this pandemic. Furthermore, therapists should also focus in therapy on challenging the changing point of reference, providing practical advice on coping and offering stress management techniques, as well as stimulating opportunities or motivating to engage in exposure and encouraging patients to seek social support albeit remotely. Moreover, as the OC symptoms of the OCD patients tend to increase, it is important to involve family members in therapy to support and coach them to be validating, supportive and encouraging, without accommodating to the OCD behaviour.

Availability of Data and Material The datasets generated or analysed during the current study are not publicly available because individual privacy could be compromised due to the nature of the raw data (interviews).

Code Availability Not applicable.

Authors' Contributions Hannelore Tandt and Gilbert Lemmens designed the study and wrote the protocol. Lemke Leyman conducted all

interviews. The analysis was performed by Hannelore Tandt, Hanna Van Parys and Gilbert Lemmens across different steps as described in the manuscript. Hannelore Tandt conducted literature research and wrote the first manuscript and all authors contributed to and have approved the final manuscript.

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Declarations

Ethics Approval This study was approved by the Ethical Committee of the Ghent University Hospital (UZ Gent, BC-07561).

Consent to Participate Informed consent was obtained from all individual participants included in the study.

Consent for Publication Informed consent was obtained from all individual participants included in the study.

Conflict of Interest The authors declare that they have no conflicts of interest.

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