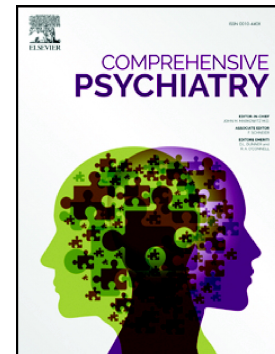


Journal Pre-proof

How to manage obsessive-compulsive disorder (OCD) under COVID-19: A clinician's guide from the International College of Obsessive Compulsive Spectrum Disorders (ICOCS) and the Obsessive-Compulsive Research Network (OCRN) of the European College of Neuropsychopharmacology



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How to Manage Obsessive-Compulsive Disorder (OCD) Under COVID-19: A Clinician's Guide from the International College of Obsessive Compulsive Spectrum Disorders (ICOCS) and the Obsessive-Compulsive Research Network (OCRN) of the European College of Neuropsychopharmacology.

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Journal Pre-proof

The rapid advance of the coronavirus COVID-19 pandemic has significantly increased mortality but also has demonstrated considerable potential to negatively impact mental health, including in the young^{1,2}. From a public mental health perspective, guidelines for responding to mass trauma and disaster emphasize the importance of focusing on resilience. In the immediate and ongoing response, consensus guidelines emphasize the importance of interventions that maintain calm, build community, and sustain hope^{3,4}.

That said, it is important to provide appropriate attention to specific psychiatric conditions that may be initiated or exacerbated by disaster. Perhaps no group of individuals with mental illness is as directly affected by the worsening outbreak of COVID-19 as people living with obsessive-compulsive disorder (OCD). Paradoxically, they are ‘experts by experience’ in attempting to avert dangers through enacting compulsive behaviours. Chiefly, the spike in anxiety about the virus is fuelling existing obsessive fears of contamination in some people with OCD and further triggering harmful compulsive actions. For these people, coronavirus can become all they think about⁵. Indeed, some patients with contamination-related OCD are expressing doubts about the rationality of the therapies they have been pursuing. Several patients have told their clinicians they were “right all along”, as now everybody looks like them. For others, COVID-19 is likely to cast a long shadow, as people of all ages with OCD are known to be particularly inflexible at ‘unlearning’ danger responses when they become obsolete^{6,7} and thereby conditioned to prolonged virus-induced distress and anxiety.

In response to the emerging crisis and growing calls from patients and clinicians for guidance⁵, a working group of clinical experts from the International College of Obsessive Compulsive Spectrum Disorders (ICOCS) and the Obsessive-Compulsive Research Network of the European College of Neuropsychopharmacology (OCRN) have produced this consensus statement with the aim of delivering pragmatic guidance at the earliest opportunity to clinicians for managing this complex challenge.

The advice is largely based on empirical evidence, including the clinical experience gained from working in specialised OCD treatment-services before and during the pandemic. Our group of international experts includes a balanced representation of genders, including clinicians treating child, adolescent and adult patients, with additional contributions from individuals with lived experience of the disorder and early career scientists. Once agreement was reached on the key issues to be covered, in a series of online discussions, an initial draft was prepared and circulated iteratively among the authors and edits were sequentially incorporated. The final report covers the key issues judged by our group of experts to be of most relevance for clinicians for the treatment of OCD under COVID-19 conditions. Although preliminary, based on the ‘precautionary principle’ it was considered a priority to release guidance at the earliest opportunity, on the understanding that it may be updated as new information arises.

The guidance to clinicians is as follows:

1. Take a compassionate calming approach. Use telemedicine including telephone or video calls. Be aware that the pandemic is affecting countries with different cultural environments and different available resources to deal with it. For example, in regions of Latin América and in Africa lack of water and access to the Internet, and poverty levels greater than 50 % make it hard to stay in at home, since there is no monetary support from the government to aid survival

2. Careful history taking. Confirm the diagnosis of OCD, paying particular attention to other obsessive-compulsive related disorders (OCDs) including hypochondriasis (recently endorsed as an OCD in the World Health Organisation (WHO) ICD-11)⁸, as these disorders are likely to be most affected by COVID-19. Clarify the extent to which the current symptoms represent a rational or exaggerated reaction to recent highly stressful events, or a worsening of obsessive-compulsive symptomatology. Establish the level of insight into the irrationality or excessiveness of the symptoms, and the presence or absence of tics, as these may influence the care plan. Note that many OCD patients may not experience exacerbation of their OCD. On the other hand, patients who have experienced contamination symptoms in the past may find that they re-experience contamination fears and cleaning or washing compulsions under the conditions of the pandemic. It is also important not to assume that every patient with contamination fears related to germs and illness will necessarily be excessively concerned about COVID-19. The focus of concerns in those with OCD is often idiosyncratic, and some individuals, for example, may have greater fears of a sexually transmitted disease or an antibiotic resistant infection. Many will, however, have significant exacerbation of contamination or illness concerns, or comorbid conditions that have worsened with stress (such as anxiety disorder, depression or bipolar disorder, or even post-traumatic stress disorder (as reported after the SARS epidemic) that may need to be managed separately in order to prevent decline in level of functioning. Indeed, OCD comorbidity can become particularly problematic, especially if patients have, or have previously shown, cleaning or washing symptoms. Where OCD and related disorder is not the principal diagnosis for clinical attention, please refer to other guidelines. In particular, note WHO ICD-11 guidelines regarding mental health and psychosocial considerations during the COVID-19 outbreak⁸.

3. Assess suicidal risk. Even though OCD has not been considered a disorder with high risk for suicide, recent studies have shown that some patients, particularly those with severe obsessions, comorbid depression, bipolar disorder, impulse control disorders, substance use disorders, personality and eating disorders may be at increased risk⁹. Additional COVID-related factors found anecdotally to potentially increase suicidal risk include a recent increase in OCD severity, experiencing a family member found positive for COVID-19 or finding the effects of quarantine or isolation distressing. For all patients with OCD, but particularly in such cases, consider actively evaluating the suicide ideation and risk through specific questions and instruments (e.g., the Columbia Suicide Severity Rating Scale¹⁰ or similar) and hospitalize the patient if needed.

4. Provide psychoeducation with balanced information about the known risks and impact of COVID-19 on physical and mental health. This includes the difficulties managing uncertainty associated with the virus, which almost everyone is experiencing right now but that might be particularly challenging for some people with OCD, hypochondriasis or anxiety. Highlight the need for physical distancing (staying home except for essential tasks like grocery shopping), with special precautions for the elderly. Patients need to understand that this health crisis may well persist for some time, and they need to manage their stress levels over time (e.g., by putting into play long-term routines of mindfulness techniques, exercise and structure).

5. Enquire about Internet usage and news consumption; some patients are spending hours a day watching television and online media sources, which may be significantly exacerbating their OCD and anxiety. Offer a balanced approach (e.g., individuals should not spend more than an hour a day [1/2 hour in the morning and a half-hour at night] to stay informed about the pandemic, to minimize the triggering of symptoms). Suggest

trusted sources to avoid myths, rumors and misinformation. You may wish to refer the patient to the relevant health education websites of the WHO (https://www.who.int/health-topics/coronavirus#tab=tab_1), the Centers for Disease Control and Prevention (CDC) (<https://www.cdc.gov/coronavirus/2019-ncov/infection-control/hcp-hand-sanitizer.html>), or the Center for Health Security, Johns Hopkins University (<http://www.centerforhealthsecurity.org/resources/COVID-19/index.html>). Handwashing videos may be helpful to guide patients about what is appropriate and discourage unnecessary excess. For example, the National Health Service (<https://www.nhs.uk/video/pages/how-to-wash-hands.aspx>) and CDC videos (<https://www.youtube.com/watch?v=3EoAyQu3LI8>) recommend handwashing for 20 seconds; thus, anything beyond this is likely to be compulsive and excessive.

6. If OCD symptoms are the main problem:

I. Review medication status as a priority: Based on the risks associated with exposure and response prevention (ERP) in the pandemic (see below), and uncertainty as to which of the two evidence-based treatments, pharmacotherapy or cognitive behaviour therapy (CBT), represents the most efficacious first line treatment modality¹¹, pharmacotherapy should be the first option for adults and children with OCD with contamination, washing or cleaning symptoms during the COVID-19 pandemic. Consider A) type of medication; most patients should receive an SSRI, or if not responsive, another SSRI and as a third choice clomipramine (for which an ECG may be required in certain patient groups); B) dosage; if the patient is on a suboptimal dose, consider increasing it, paying attention to any contraindications; C) SSRI-resistance; consider low dose of adjunctive antipsychotic (aripiprazole, risperidone, quetiapine, olanzapine), especially if a tic is present; D) adherence; ensure the patient is able to obtain an adequate supply and is taking the treatment regularly. In cases where adherence is problematic, especially if insight is poor or there are executive dysfunction deficits, it may be necessary to provide additional support either from clinical support staff or the family to ensure adherence. The use of Medi Pill Organisers (dosette boxes) and tools such as medisafe (free application that aids patients to remember to take medications and sends reports to the psychiatrists) can be helpful to monitor adherence; E) manage sleep disturbance when present, as healthy sleep contributes to immune function and enhances anxiety management.

II. Review and risk assess the CBT plan: Considerations include whether it is feasible in the pandemic situation, and specifically whether it fits with government safety guidance. In many countries, psychotherapy services are being dramatically cut back as staff are redeployed to cover emergency care. Consider that it can be difficult to disentangle OCD-related cleaning and checking compulsions from rational COVID-19-related safety behaviours and to devise ERP strategies that are coherent and robust. Moreover, as COVID-19 is highly contagious, and patients can easily be confused by exposure exercises, particularly during the early stages of therapy or when practising exposure on their own at home, the risk of patients becoming seriously infected with the coronavirus could be increased. This risk becomes even more true for children whose knowledge base and judgment is not yet matured.

We therefore recommend significantly tailoring CBT to take into account the CDC guidance (e.g., hand washing for 20 seconds with soap and water rather than ceasing hand washing completely). However for OCD patients with contamination fears and cleaning or washing compulsions, active and in vivo CBT with exposure and response prevention (ERP) will need to be sensibly adapted and may need to be paused. This specifically relates

to active, in vivo exposure aimed at tackling contamination. Instead we suggest using therapist time to support patients and trying to prevent them from deteriorating, e.g. by encouraging them to restrain their compulsions as far as possible, rather than directed at actively treating contamination fears and concentrating on techniques such as behavioural activation and activity scheduling which can assist in preventing deterioration and help with depressive symptoms¹². Indeed, activity scheduling can be particularly useful as a form of CBT at this time. Obsessions often expand to fill a vacuum of time and keeping busy is particularly important as a means of staying well. Patients can be asked to fill out an activity schedule diary in advance, making sure that they have a balance between activities which may give them a feeling of mastery as well as those for pleasure (see below)

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For clinicians working in specialist centres, other less evidence-based forms of CBT not involving ERP, such as imaginal exposure or danger ideation reduction therapy, could potentially be offered for patients with contamination – related OCD, even when their concern is COVID. This should be considered on a case-by-case basis and only done if the patient has good insight, is willing, and is stable enough to do so. It would need to be made clear that the efficacy of this form of treatment is not as well established and it should not be viewed as a substitute for in vivo ERP when post pandemic restrictions are lifted.

For those patients whose exposures are not contamination related, many ERP treatment plans could be continued (e.g. addressing urge to check, obsessive thoughts of harm, symmetry/order obsessions), especially those that can be done at home, and as long as they are within CDC recommended precautions such as maintaining physical distancing. Once again it is important to remember that even if the OCD does not focus on contamination fears, the physical distancing can increase symptoms of anxiety and depression. ERP increases distress and can also temporarily increase depression and so the patient's mental state must be monitored carefully.

Keeping people calm and reducing the risk of depression using supportive techniques is an essential element of care. Nevertheless, the clinician should still try to find ways to help the patient foster resilience towards obsessional thinking and compulsive acts. Thus, extreme behaviours should be discouraged along with mental compulsions. Avoidance and accommodation should be assessed carefully to determine whether it is proportional to the current situation and addressed carefully to prevent backsliding.

We suggest therapists should regularly check e.g. by phone or digitally, those OCD patients likely to engage in particularly harmful decontamination rituals or behaviours. The use of video calls with the patients should be recommended, where possible. The added benefit of video calling is that it helps the therapist perform a visual risk evaluation, which is especially valuable for patients living alone, to determine the condition of the patient's hands, presence of food in the fridge or cupboard, etc. One group of patients requiring particularly vigilant care are those who, as a result of doubt or uncertainty about whether food in the house is contaminated, respond by throwing everything away and consequently have little or no food in the house. Identify and discourage high-risk obsessive-compulsive behaviours, such as washing in boiling (very hot) water or bleach, or total fasting. On the contrary, encourage eating and drinking to maintain health.

III. Deep brain stimulation (DBS): For this small group with extremely severe, treatment resistant illness, a moderate increase of psychological distress or OCD symptoms may be expected during the pandemic, but this does not mean that DBS is not working. We recommend delaying the implantation of electrodes in those OCD

patients waiting for DBS until the outbreak is over. In those who have electrodes implanted, a worsening of OCD symptoms may be experienced if the battery stops working. Such patients should be encouraged to check with their treating clinician in case the power has simply been turned off, or if there is a real need for battery replacement. If the latter, a balance between risks and benefits should be evaluated in each case and consideration given to whether the replacement procedure may be delayed to reduce the increased risk of being exposed to COVID-19 in hospital.

IV. Social and occupational care: There is great value in activity scheduling and establishing a daily routine, even if stuck at home. Patients under quarantine or staying at home under national restrictions are at great risk of circadian rhythm disruption. Circadian rhythms disruption could increase anxiety and worsen OCD symptoms while regular circadian rhythms and regular physical activity are relevant in order to reduce anxiety or alarm levels and therefore achieve better control of OCD symptoms. Therefore it is recommended to respect a regular awakening time and bedtime every day and to regularly perform some physical activity in the morning especially in a bright room. Finally it is recommended to avoid late-night dinners so as not to affect sleep quality.

Offer guidance regarding a rational amount of time spent listening to news as a distraction to occupational or preferred activities, provide acknowledgement of fear but also a balanced perspective on risk, address grief and loss of control and recommend hedonic activities especially those that involve children, such as baking, cooking, gardening, inventing a new game or watching a movie.

Help the isolated patient to overcome loneliness and build stability by increasing communication with friends, family members and loved ones, even if at a distance via the multiple online platforms including Facetime; Skype and Zoom. Learning to use these can be a helpful experience in terms of the acquisition and mastery of new skills as well as the pleasure of social contact. In the case of those with a poor social network, telephone helplines such as those run by OCD charities are particularly useful, especially if managed by qualified trained professionals.

Also encourage patients and family members to keep weight under control e.g. by creating new places for sports in the home and including physical activity in their home routine. Exercise can be additionally helpful for some patients coping with the mental effects of the pandemic. Aerobic exercise has in some studies been shown to have positive effects for those with depression, anxiety^{14,15} and OCD¹⁶. Where there is ability to go out for aerobic exercise once a day then a brisk walk or run can be useful. Some excellent videos are available online (e.g. using home-based workout exercises that are freely available on YouTube or other mobile apps), demonstrating aerobic exercises that can be performed in a limited space. Gyms and yoga studios centers are fuelling the drive to stay active by offering online exercise classes, some free of charge, or extending trial periods for at-home workouts.

V. Carer support: Remember that family members and caregivers of patients with OCD are also at increased risk of developing stress related disorders owing to the worsening of patients' symptoms and may need additional support in their own right. Parents of children with OCD are likely to require even more coaching and support than before, especially as relationships may be impacted in unpredictable ways by the fact that parents and children are spending so much time together. Consider that parents are burdened differently under COVID-19, especially single parents who may be heavily burdened or those with little living space, especially if children are

becoming irritable or aggressive (as is often the case for children with OCD if their behaviours are not accommodated).

Parents and children should be encouraged to maintain social contact with their environment via the Internet or phone for distraction and support. Rules for dealing with possible conflicts and tantrums should ideally be established in advance. Parents should not only focus on the problems connected with the current pandemic situation but be encouraged to engage in joyful activities with their child instead. Especially in a quarantine situation it is important to make clear that not all aspects of life are determined by the coronavirus or OCD. Staying hopeful and together seems one of the most important points (especially for parents, acting as role models for their children), and increased family togetherness may be a “silver lining” in the pandemic.

We are aware this guidance marks a change in practice for many clinicians treating OCD. Temporarily modifying or pausing in vivo CBT with ERP for contamination-related OCD, which is an effective form of treatment often preferred by patients in normal times, is a difficult decision to make, but as with any treatment, the benefits and risks need to be balanced up and clear messages that take public health into account need to be given at this time of heightened risk of infection, to avoid confusion. On the other hand, many forms of CBT can be continued with modification for safety as needed. We believe that under COVID-19, stringent efforts should be made to provide effective care for individuals with OCD and that the best available treatments for most patients are likely to include providing evidence-based pharmacotherapy and modifying or pausing CBT in conjunction with enhanced supportive therapies including social and occupational care. Understanding the impact of a pandemic like COVID-19 on the expression of OCD in affected patients, and on the development of new cases of OCD, is likely to provide important insights into the environmental determinants of the disorder. We consequently urge research-active groups to engage in investigating the impact of such changes on health outcomes among their patients, as well as initiatives to explore the expected rise in incidence of OCD once the pandemic is over.

Conflicts of interest and source of funding

NF declares; In the past 3 years I have held research or networking grants from the ECNP, UK NIHR, EU H2020, MRC, University of Hertfordshire. In the past 3 years I have accepted travel and/or hospitality expenses from the BAP, ECNP, RCPsych, CINP, International Forum of Mood and Anxiety Disorders, World Psychiatric Association, Indian Association for Biological Psychiatry. In the past 3 years I have received payment from Taylor and Francis and Elsevier for editorial duties. In the past 3 years, I have accepted a paid speaking engagement in a webinar sponsored by Abbott. Previously, I have accepted paid speaking engagements in various pharmaceutical industry supported symposia and have recruited patients for various pharmaceutical industry-sponsored studies in the field of OCD treatment. I lead an NHS treatment service for OCD. I hold Board membership for various registered charities linked to OCD. I give expert advice on psychopharmacology to the UK MHRA and NICE.

MVA reports being on the Advisory Boards of Allergan, Almatica, Brainsway, Janssen, Lundbeck, Myriad Neuroscience, Otsuka, and Purdue Pharma (Canada); MVA is on the Speaker's Bureau for Allergan, Lundbeck, Otsuka, Pfizer, Purdue Pharma (Canada) and Takeda ; and has received research support from Janssen, Purdue Pharma (Canada), the Canadian Foundation for Innovation and Hamilton Academic Health Sciences Organization (HAHSO).

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Authors' contributions

All authors were involved in drafting the manuscript and agreed to its publication. All authors read and approved their sections of the final version of the manuscript.

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