

Families of OCD Sufferers Seldom Get the Help They Need: Why They Don't and Why They Should

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12-year-old Jill is late for a family gathering and getting more frustrated by the minute. She and her parents have been waiting in the car for half an hour while her brother checks every corner of his room to be certain nothing has been lost. She wonders, "Why does the whole family have to suffer because of him?"

Sam lost his temper this afternoon after his wife asked him the same question for the 25th time. He's the only one who can reassure his wife she is harmless despite her obsessive doubts about being a serial killer. He feels guilty about losing his temper, but is overwhelmed by his wife's constant reassurance-seeking.

Jack and Susan have compassion for their 29-year-old son, but their resentment and anger are growing. "If he's too disabled to help out around the house or to get a job, then why won't he seek help for his OCD?" They try to be understanding, but they know he must feel their discontent.

OCD is a family affair. The toxic tentacles of this disorder extend far beyond its identified victim. Jill, Sam, Jack, and Susan all suffer from OCD. Though none of them has the disorder, their lives and those of many other family members are greatly affected by OCD. In addition to dealing with the disruption OCD creates, family members must contend with their own emotional reactions, which can include guilt, shame, anxiety, frustration, and depression.

Research has documented the plight of those who interact with or care about an OCD sufferer. A majority of family members report some degree of distress adjusting to OCD (Calvacoressi et al., 1999) and for a smaller portion the stress is significant. In one study of individuals who were the primary caregiver for an OCD sufferer, a quarter of those surveyed indicated they were "severely burdened" by the situation and "extremely distressed" at the prospect of continued burden (Laidlaw et al., 1999). If there are benefits that come from the effort involved in accommodating the OCD sufferer's avoidance and compulsions, they may not justify the costs. Although accommodation can temporarily relieve the distress of the OCD sufferer, in the long run it may contribute to unsatisfactory treatment outcomes (Amir et al., 2000).

Given the far-reaching impact of OCD, one might expect to see family members lining up at therapists' offices or busily seeking other resources to help them cope effectively. But such is not the case. The usual focus of family concern is squarely on the OCD sufferer. They may work diligently to find help for the OCD sufferer, but it is the exception when family and friends exert similar effort on their own behalf.

This state of affairs is not too surprising when we examine the number of people with OCD who do not pursue professional help. If many OCD sufferers do not seek help, why would we expect other

members of the family to do so? In fact, some of the obstacles that discourage help-seeking in OCD sufferers are the same as those that dissuade other family members from getting help.

There are a number of practical obstacles that make it difficult for families to get help. Some people are unable to locate a qualified provider or support network in their area, while others have difficulty paying for healthcare even if it is available. If a family member is fortunate enough to have met with a clinician familiar with OCD, the discussion is typically focused on the OCD sufferer. Many otherwise knowledgeable clinicians pay insufficient attention to the rest of the family. Too often, they underestimate the amount of support and direction needed by families who have to deal with OCD and its impact.

Families also have to contend with psychological obstacles. In a prior issue of this newsletter, we discussed how fears about the recovery process and competing incentives lead some OCD sufferers to avoid dealing with their disorder constructively. We called this failure to pursue help “recovery avoidance.” Other family members may grapple with recovery avoidance as well. A husband may avoid therapy because he mistakenly believes the therapist will blame him for his wife’s problems or parents may not want to deal with the anger their son might exhibit if they seek help. An individual’s assessment of the costs (e.g., danger) and benefits (e.g., incentives) of seeking help are influenced by his or her beliefs about therapy, personal control, responsibility, and other issues. Unfortunately, there are several common, but misguided notions that can discourage family members from effectively attending to their own well-being.

For the purposes of this article, we will call these notions “myths.” These myths are fictitious ideas that discourage the families of OCD sufferers from seeking help. There might be dozens of such myths, but in this article we focus on the 6 we have observed most often. Table 1 outlines the 6 myths and the fallacies behind them. If you are stressed by the presence of OCD in your family and have not considered getting help for your self, take a moment to review Table 1. See if any of the myths described have influenced your behavior.

Table 1. Six Family Help-Seeking Myths and the Fallacies Behind Them

THE MYTH	THE FALLACY
<p>1. The only way for my life to improve is if the person with OCD gets better.</p>	<p>This myth recognizes only one way your life can improve and rests your happiness completely on the behavior of another person. It will almost certainly be better for you if he gets better, but his progress is not in your control. What if he chooses not to seek help? What if he seeks help and doesn’t participate adequately in treatment? What if his OCD is not treatable? These possibilities are difficult to accept. But, once you do, you can refocus your efforts on to things you can do to improve the quality of your life, which is still important if he gets better and even more important if he does not.</p>

<p>2. <i>It's selfish to try to help myself.</i></p>	<p>This myth portrays healthy concern about your self as something shameful. The word "selfish" is a put down, not an accurate or useful description of taking care of your self. It implies that concern about your own well-being is inconsiderate, that it is somehow harmful to someone else. On the contrary, taking care of your self usually helps others (see myth #3 for more on this).</p>
<p>3. <i>Getting help for me will jeopardize my efforts to help her.</i></p>	<p>This myth incorrectly suggests that helping yourself will make you less able to help him. In fact, quite the opposite is true. When you are less burdened by frustration, guilt, and other negative emotions, you will actually be more effective in dealing with other people, including her. Can you honestly say that how you interact with her in your current state of mind is always level-headed and constructive?</p>
<p>4. <i>He'll be upset if I seek help.</i></p>	<p>The inaccuracy of this myth is not the prediction that he will get upset. There is a very good chance he will. In fact, you should be fully prepared for this outcome and plan how you will handle his expressions of anger. The problem with this myth is its two underlying assumptions: 1) that you can control whether he gets upset; and 2) that he won't get upset if you don't seek help. You really don't have a choice over whether he gets upset. He has OCD. He will get upset. The choice you have is whether what you do is helpful or unhelpful.</p>
<p>5. <i>I shouldn't have to be the one to change.</i></p>	<p>This myth is based on the laws of a world that doesn't exist, a world in which things are always fair. People usually use the word "should" when they don't want to deal with the real world. "Should" refers to how you feel things ought to be. But it has little to do with the world in which you live, the world about which you must make real decisions.</p>

<p>6. <i>I should be able to cope without help.</i></p>	<p>There is that “should” word again. This myth refers to the make believe world in which you are all-knowing and never need assistance from others. In the real world, reasonable people seek assistance from others who have expertise or access to resources they don’t have. Knowing when to seek help is not a weakness. It is a strength that improves your ability to function. Don’t be the person who never reaches her destination because she won’t ask for directions.</p>
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Left unchallenged, these myths can be quite persuasive. They are not just intellectual concepts. They are deeply held convictions tied to strong emotions. Unfortunately, that is what makes them so powerful. If myths of this nature are as common and influential as we believe they are, then it is easy to understand why so many family members neglect their own needs.

If there is someone in your life who has OCD, we hope this article has helped you sort some things out. Perhaps you have determined that the OCD in your family does not directly affect you. However, if you are one of the many family members whose lives are adversely impacted by this disorder, please consider taking action steps to improve your emotional well-being. If the OCD sufferer is in therapy, ask his or her therapist for consultation or a referral. If not, check with clinicians in your area to see if there is someone who can work with you. See if there is a support group for family members within driving distance. Explore resources on the internet. Attend the annual meeting of the OC Foundation. Do everything you can to free yourself from the negative effects OCD has had on your life. Or, you could wait until the OCD sufferer gets better. It’s your choice.