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# Stigma in Obsessive Compulsive Disorder

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Additional information is available at the end of the chapter

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## Abstract

Stigmatizing attitudes and behaviors of the society can be associated with avoidance of treatment-seeking behaviors and reduced quality of life for the individual with mental illness. Among these problems, individuals with mental impairment are exposed to unfair behavior in the criminal justice system, restrictions on social facilities, and most importantly, reduced their roles in their life and community participation. Although researches have gone far to understand the impact of the disease, it has only recently begun to explain stigma in mental illness. Much yet needs to be done to fully understand the breadth and scope of prejudice against people with mental illness. Therefore, this chapter presents the stigmatization and its historical development and types and stigma in mental health and obsessive-compulsive disorders to provide a brief overview of issues in the area. Moreover, this chapter presents the occupational therapy interventions in stigma both in adults and children with obsessive compulsive disorder.

**Keywords:** community participation, mental disorders, obsessive compulsive disorder, stigma, society

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## 1. Introduction

Individuals with mental impairment are struggling not only with the problems caused by their illnesses but also with the stigmatizing attitudes and behaviors of the society; even for this reason, stigmatization is often referred to as “second disease” [1]. When the stigmatizing attitude of the society is accepted and internalized as it is by the stigmatized individual, the problems in the individual’s life are increasing exponentially [2]. Among these problems, individuals with mental impairment are exposed to unfair behavior in the criminal justice system [3], restrictions on social facilities [4–7], and most importantly, avoidance of treatment seeking behaviors and reduced

quality of life [8–10]. In addition, it is suggested that the stigmatization not only affects the lives of the members of the family and their immediate surroundings but also the quality of life [11, 12]. One of the psychiatric disorders that are exposed to such stigmatizing attitudes and behaviors is obsessive compulsive disorder (OCD) although the stigmatization effect on the individuals who have received the diagnosis of schizophrenic disorder in the first and most recent years is discussed. OCD is a chronic mental disorder that negatively affects the quality of life and social, academic, and occupational functioning of individuals and families with this disorder [13]. Obsessions and compulsions experienced by an individual with OCD diagnosis, especially the distress experienced by them, cause the individual to be more isolated from the society. Moreover, it is stated that the quality of life is affected at a similar level to the diagnosis of schizophrenic disorder in OCD diagnosis [14]. In this chapter, it was aimed to explain the effect of the stigmatization in OCD.

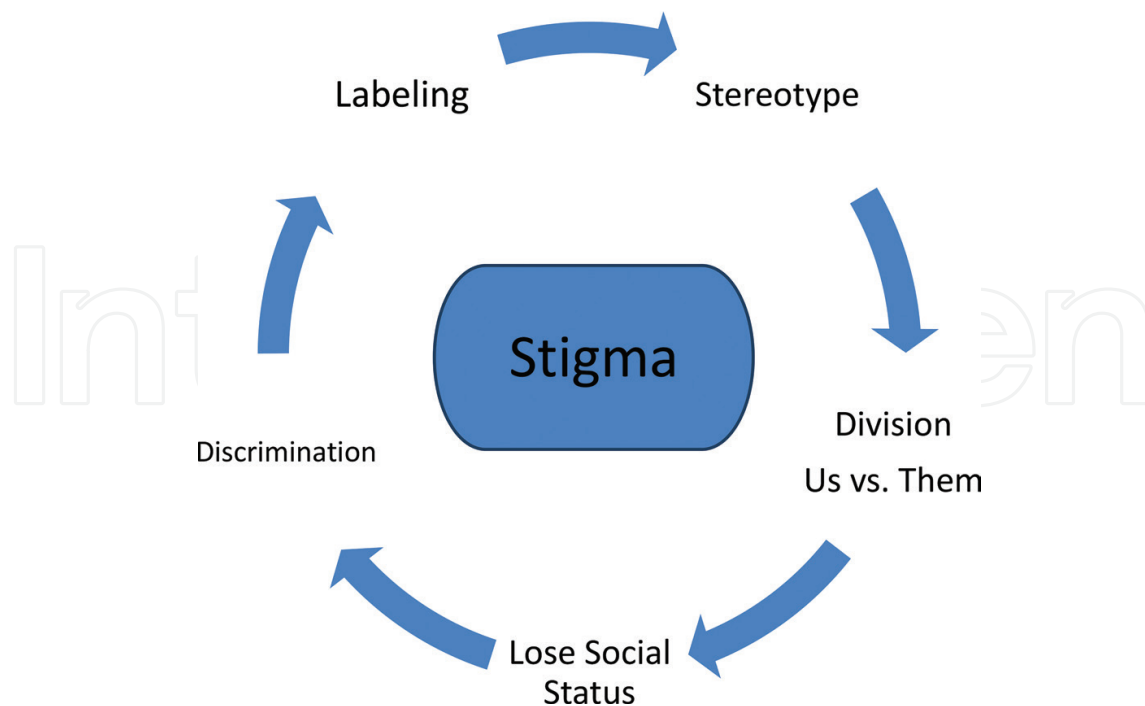
The problems brought by individual and familial problems with a psychiatric diagnosis already have a very negative effect. In addition, individuals with mental disorders are exclusively excluded from society because of the reactions they are likely to exhibit and possibly display, as well as other people's feelings, thoughts, and behaviors, with causal attributions, as seen in people with certain characteristics; rather than seeking treatment, they can choose to hide their problems at home and live a relatively isolated life. This, in turn, reduces the likelihood that many people with a diagnosis of being diagnosed have the potential to get treatment and solve their problems; this situation leads to many types of loss in terms of individual and society. For this reason, reducing the stigmatizing attitudes and behaviors in the society is at least as important as the treatment. In recent years, it appears that the number and nature of initiatives undertaken to reduce the stigmatization of mental disorders has increased significantly [15].

## 2. What is stigma?

Stigma is defined as a characteristic or disorder that separates the individual from “normal” people in society and marks them as “unacceptable.” Stigma is defined by the World Health Organization [WHO] as “a sign of embarrassment, embarrassment, or rejection that has been excluded from rejection, discrimination and participation in different areas of the society.” [16]. The stigmatization process involves the identification of the separating state and then the step of disqualification of the individual [17]. The purpose of the stamp is to separate and exclude the individual from society [18]. Stigma means “scar, trail, sign,” but today, it is mostly used as “black spot.” The stamp is considered a symptom of a situation that is to be embarrassed for a person or a group or an unusual, unacceptable sign [18]. Stigmatizing is the individual's mental or physical disability, his race, drug addiction, or any illness that is considered bad by the society. The individual is stained, flawed, and reduced to the eye of others. This causes the stigmatized individuals to fear the society and isolate itself from society [19] (**Figure 1**).

### 2.1. Historical development of stigma

Stigma was originally used by the Ancient Greeks and symbolizes the physical signs that one has unusual and negative qualities in social or moral status. These signs are made by



**Figure 1.** Problematic stigma cycle.

excavating the body or by tattooing, and evidence that a person carrying such a sign is a slave, a person who must be kept away like a criminal or a traitor. With the spread of Christianity, the term stigma is added. This ironic version refers to signs believed to have manifested itself in the form of bud-like sores on the skin, believed to be the physical signs of God's mercy, as it is in the prophet Jesus, and thus believed to be sacred. The first person to take this issue in scientific terms is Goffman [20]. Goffman describes three distinct types of content that are quite different in content: (a) differences in personality (mental disorders, homosexuality, alcoholism, addiction, imprisonment, depersonalization, etc.), (b) various physical deformations (weak wills, extreme passions, perverted and rigid beliefs and immorality, stay, unemployment, suicide attempts) and (c) ethnological stamps (race, nation and religion). Stigmatization is defined as the perception of the individual as imperfect or obtrusive rather than normal; the stigmatized individual is less valued and these people are almost not perceived as human [20]. Stigmatizing is not a new phenomenon, but the traces are based on a rather old history. Many diseases arising from the existence of mankind have been perceived as catastrophic in the society and have caused the sufferers to suffer persecution. The plague that emerged in the 1300s was regarded as a punishment sent by God to sinful people, and people with plague were declared criminals. Individuals caught up in syphilis, which is quite common in Europe during the 15th century, have been cursed for centuries. Although such specimens now seem very out of date and old, similar misconceptions and beliefs still exist today. AIDS, previously known as homosexual disease, has been considered a divine punishment given to sinful people by God [21]. As a result, stigmatization has a history as old as human history, and many diseases have been subjected to stigmatization; it continues to stay.

## 2.2. Types of stigma

There are several categories of stigmatization in our society, and beyond any description, stigmatization has been decisive for negative experiences at both macro and micro level. The three main types of Stigma include social stamping, self-stamping, and professional stamping (**Figure 2**). Social stigmatization is the most common.

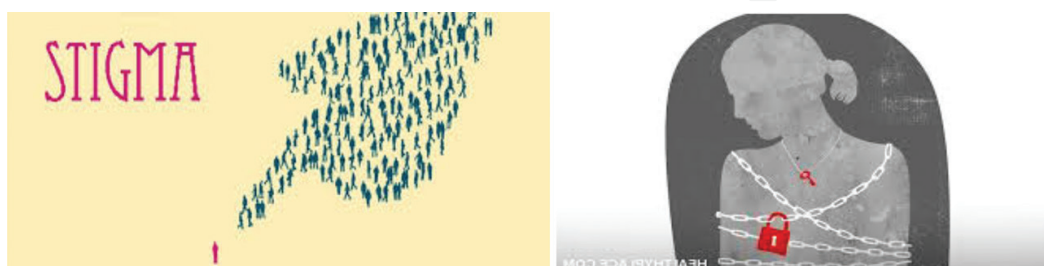
### 2.2.1. Social stigma

According to Merriam Webster, social stigmatization indicates that (or dissatisfaction with) a person or group that is perceived by the other members of a society and serving to distinguish them is socially unapproved. Social theorists view such a stigma as particularly effective. A social group of the past is dependent on social information structures learned by most members [22–24]. In American society, there is a distinction between physical illness and mental illness and is based on the misperception that mental illness is a result of having a weak character or making a heretical choice [25, 26]. Social stigma against mental illness rests on this misperception [27]. This differentiation, which affects consumers, stakeholders, and providers, contributes to division and allows social stigmatization against mental illness, resulting in discrimination in diagnosis, treatment, and social perception. As a result of this social paradigm, people with symptoms are less likely to accept mental illness and receive appropriate mental health care [25–27].

Individuals are generally determined by their behavior, and unfortunately, behavioral problems associated with mental disorders result in poor self-esteem, limited participation, and reduced treatment. In addition, mental health results in avoidance of participation in services [22]. One of the difficulties of social stigmatization is that people who think that others perceive themselves differently perceive themselves differently. It is likely that the self may be stigmatized [23]. Considering that stigma is a social structure, culture significantly influences stigmatization. Culture expresses common behaviors, beliefs, values orientations, and symbols that affect a group of people's own norms and practices. These sociocultural norms and practices also define the meaning, practice, and expression of the stigmatization in different populations [28, 29].

### 2.2.2. Self-stigmatization

According to the literature, self-stigma is associated with perceived stigma. Persons suffering from mental illness will become self-imposed when they acknowledge that the people are



**Figure 2.** Social and self-stigma.

prejudiced and discriminate against them because of their mental illness or illness. It tends to stigmatize itself, create feelings of shame, and lead to worse treatment and consequence [23, 30]. If a person who suffers from depression does not feel that it is worth being treated, the people with mental illness are less likely to have proven service and treatment requirements. A research has shown that negative stereotypes, such as danger or inadequacy, are often associated with mental illness and harm people living with the illness [23]. Therefore, this can be a possible reason behind the self-stigmatization.

### *2.2.3. Professional stigma*

Professional stigmatization refers to the fact that health care workers cause stigmatization of individual with mental disease and strengthen them. Healthcare workers do not want to be perceived as stigmatizing individual with mental illness suffering from mental illness. And for this reason, they can easily reject stigmatizing behaviors and beliefs. For this reason, it is important for professionals to become more aware of how the stigma can be predicted while working with individual with mental illnesses. Professional stigmatization may develop in a manner similar to the development of social stigmatization in the general population. Because a professional does not recognize the lack of appropriate treatment of a disabled client, he may be deprived of his rights and the individual with mental disease may become more vulnerable. This may lead them to terminate the treatment or to be treated elsewhere. Finally, professional stigmatization directed at the individual with mental disease or provider's own illness creates an obstacle to the health of the individual by preventing appropriate treatment. It may also affect the acceptance of disorders by the healthcare worker's own impersonal beliefs [24].

## **3. Stigma in mental health**

### **3.1. Wrong beliefs in mental illness**

Common misconceptions about mental disorders can be described as follows:

1. mental disorders, heart disease, and cancer are not real disease;
2. people who need psychiatric care should be locked away at institutions;
3. a person with a mental disorder will never be normal;
4. those with mental disorders are dangerous;
5. individuals and young people with mental disorders do not suffer;
6. those with mental disorders can work at low job levels because they are not suitable for really important or responsible positions; and
7. people with mental disorders will become ill due to their crimes [31].



### 3.2. Reasons for stigmatization for mental illness

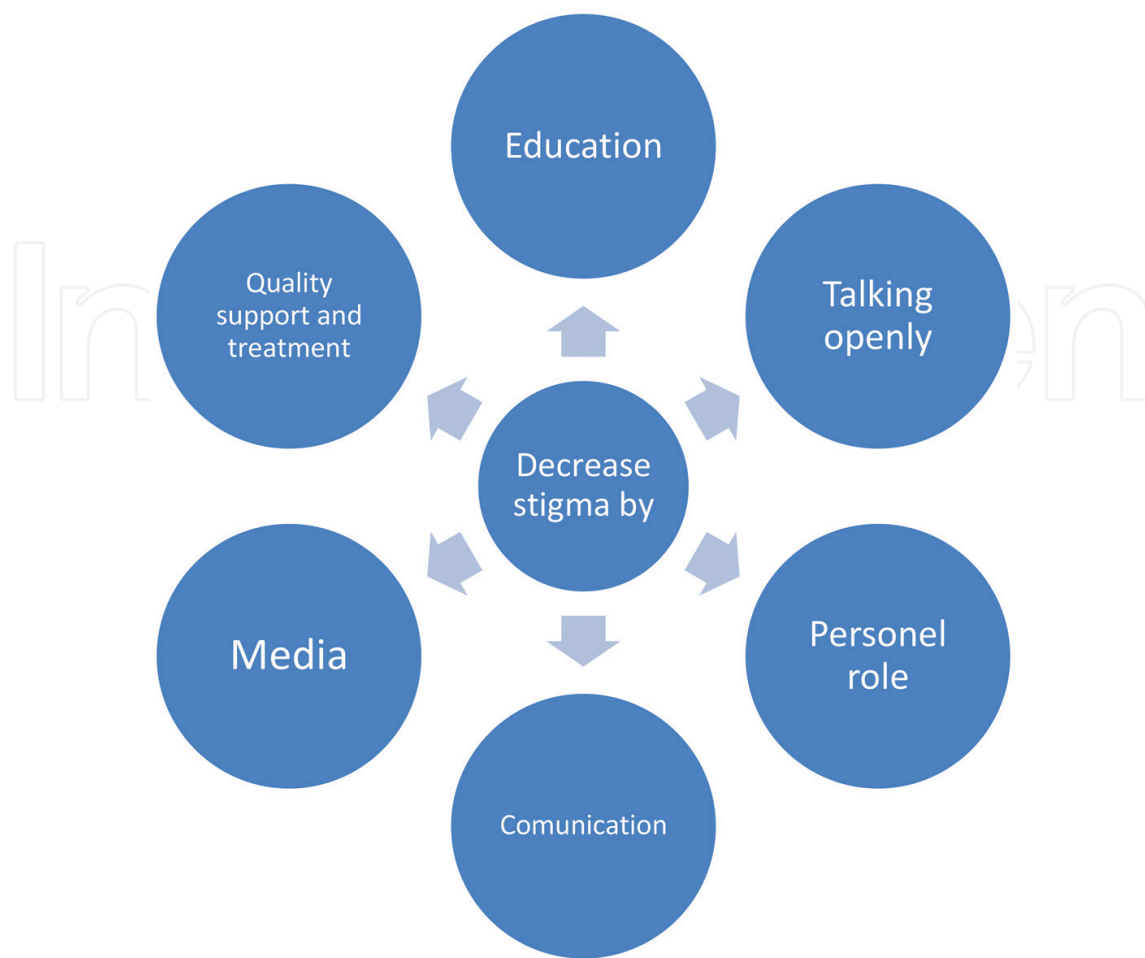
The causes of stigmatization for mental illness can be individual, social, and political. Especially, it is stated that the fear factor against the individual with mental illness is the biggest factor causing the stigmatization. These individuals with mental disease are considered dangerous by society; their balance completely corrupted, when they do not know what they are going to do; they damage their environment; and they have communication problems. Another cause and one of the most important reasons is that the mental illness is not perceived as a disease. Consequently, age, gender, education, occupation, marital status, social class, culture, religious beliefs, knowledge of disease, contact with mental illness, mental illness label, type of psychopathology, characteristics of individual with mental disease, and mass media are factors affecting mental illness stigmatization [32] (**Figure 3**).

### 3.3. Negative consequences of stigma in mental disorders

Stigma has negative consequences for the individual in society. The stigma applied to individuals with mental disorders causes new difficulties in the individual's treatment process. Some of the symptoms of mental illness such as reluctance, lack of motivation, low motivation, and loss of self-confidence lead individuals to withdraw to their own world. While individuals try to cope with the symptoms of illness, they also have to cope with the discriminatory behavior of being stigmatized by the society. Individuals who tend to withdraw from society because of their mental illness that tends to withdraw more out of society when exposed to stigma [1].

Stigma, in mental disorders, negatively affect their confidence in themselves, their participation in the treatment, their working lives, their use of social opportunities, their ability to defend their rights in criminal justice systems, and their participation in daily life activities [33]. Concern for exposure to stigmatization leads individuals and families with mental disorders to be hesitant about treatment. This causes them not to start treatment or to leave it at the start of treatment. Failure to provide regular treatment affects the individual with mental disease recovery process badly [8]. Stigma affects many areas in the daily life of individuals. One of these is a working life. For example, employers are reluctant to recruit because they see it as aggressive, dangerous, frightening, and unreliable. At the same time, they can use insulting words in business life and question their business performance. These thoughts and behaviors prevent individuals with mental disorders from participating in the working life. Moving away from working life leads to new problems such as not being able to be in society. This situation is causing their confidence to be shaken [34].

Stigma also prevents individual with mental disorders from using as much as they can from social facilities. As well as experiencing problems in having a satisfactory job, there is also a problem with the right to live in a home on safe and appropriate conditions. In a study by Willis and colleagues, individuals with long-term mental illnesses have experienced inadequate support, living in inadequate housing conditions and showing their lives on the streets [35]. Stigma also has negative consequences within the criminal justice system. According to a study by Lamp and Weinberger [36], it has been shown that 6–15% of individuals in prison in the country have



**Figure 3.** How to decrease stigma in society.

severe mental disorders. In a study by Watson, Corrigan, and Ottati [37] investigating the stigmatizing attitude of police officers, it has been shown that an individual with mental impairment is perceived as more dangerous. At the same time, it was revealed that the information given during the query was not reliable. While being in the criminal proceedings is difficult enough even for individuals without mental disorders, this process is more difficult for individuals and families with mental disorders and negatively affects the healing process. The stigma negatively affects the quality of life's the parents, spouses, siblings, caregivers, and people in close proximity to individuals with mental disorders. In a study by Phelan et al. [38], it was shown that families of people with mental disorders tend to conceal mental impairment from other people. Due to mental disorders in their families, they are exposed to social distance-setting behavior by the society. In summary, studies show that stigma is an obstacle for individuals with mental disorders to become active in daily life, participate in working life, and be in society.

### 3.4. Approaches for reducing stigma in mental diseases

1. Educational approaches to the dangers challenge false stereotypes about mental illness and change them to real knowledge. The training strategies included public service



announcements, books, flyers, films, videos, Web pages, podcasts, virtual reality, and other audiovisual support [39].

2. A second strategy for reducing stigmatization is interpersonal communication with the members of the stigmatized group. People with mental illness have the potential to reduce the prejudice levels of the general population who meet and interact with people [40].
3. Social activism or protest is the third type of stigmatization change we have examined. Protest strategies emphasize the injustices of various stigma criminals for stigmatization and discrimination: "There is protest anecdotal evidence, such as embarrassing us all to continue the idea that people with mental illness cannot look after them, are big children." Proposes that the protest can reduce harmful media representatives [41]. Psychiatry and medicine as a whole profession should develop effective methods against stigmatization of a group of mentally ill people and provide basic human rights. The relationship of psychiatry and the media, and especially the media, to psychiatry should be highly fair and professional, based on facts, not on sensation. Adequate and fair media coverage can significantly reduce the stigmatization of individual with mental disease. This can facilitate the functioning of the family and society. Therefore, changing attitudes will help people on medical care become more human and abandon negative attitudes that prevent us from becoming better and fairer [42].

#### 4. Obsessive compulsive disorders

In OCD, we witness obsession and compulsive rituals, usually both of them. Obsessions are repetitive and ongoing thoughts impulses or beliefs which are not as simple as worries of daily life, and individual tries to ignore them through coping mechanisms as they affect daily life and cause great anxiety. People with OCD realize that all of these thoughts only exist in their minds. Permanent impulses such as unwanted thoughts or beliefs that might hurt others, getting worked up over a turned on light or an open door, and suspicions over sexual impulses can be given as examples of obsession [38, 43].

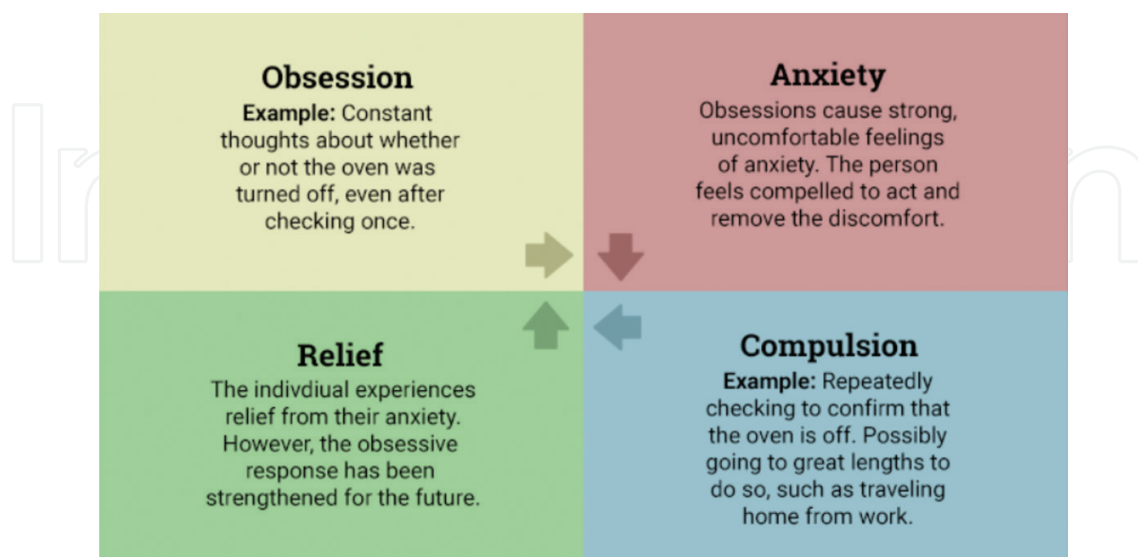
Compulsions are repetitive behaviors and mental acts, as in washing hands consecutively, repeatedly checking the task at hand, praying, and counting. For the person to have rigid rules like counting to ten is a determining factor for the behavioral aspect. Individual would feel under pressure and "compulsed" to do. Compulsions have no relation with reality; their purpose is to decrease the stress and prevent bad things from happening in the person's eye [44].

OCD leads to major difficulties in daily functioning and causes significant personality problems and mental problems when not treated. It is not surprising that the quality of life is affected by the problems encountered in functions and the nature of OCD. The social functions affecting quality of life in OCD are affected rather poorly than other mental

diseases. Problems associated with intensive obsessions and compulsions affect social functions. Symptoms cause the individual to spend time with his or her family or work life. For this reason, the possibilities of positive social interaction and functional experience are reduced [45]. Anxiety may accompany obsessions and compulsions. Individuals feel themselves anxious and nervous. For this reason, the physical and social environment has an important effect on the emotional state of the individual. Both the environmental parameters and the symptoms affect each other. The anxiety that may arise from symptoms of the individual can be controlled by physical environment facilities and positive social support.

Stigma is a social force associated with people with many different health situations, feature, and social structures. Moreover, literature review shows that mental problems, sexuality, race, and STDs can also be regarded as related subjects [46]. Symptoms are not the only reason for the problems that people with psychiatric illnesses face in life. When problems these individuals live through are taken into account, stigma can be called a “second illness” [47, 48]. Individuals with psychiatric problems experience discriminatory behaviors and emotional acts in different forms. These labeling acts and situations create barriers against life opportunities for individuals. People who go through with stigmas might internalize these prejudices, in which case they start to believe that these beliefs are completely true and that creates some more barriers for them [49].

Stigma affects the people with OCD, and individuals might find themselves feeling under the weather or feel fear due to mental problem diagnosis, which can later affect the attitude toward the treatment and their motivation [47]. We see stigma as one of the many barriers we encounter on OCD treatment. Individuals with OCD go through a fear of stigma which can be described as a behavior to avoid the necessary help due to fear of a psychiatric diagnosis [50, 51] (**Figure 4**).



**Figure 4.** Obsessions and compulsions are related to anxiety and beliefs.

In society, general attitude toward people with mental issues is basically seen as “keeping away,” “observation,” and lastly isolation. Much of the mentioned compulsive rituals might seem unusual to the people unaware of the process individual with OCD go through. Society labels these individuals as people with strange behavior or people who act madly. The fact that labeling has started indicates that process goes to social stigma. If the person’s actions are found weird but can be tolerated, they are labeled as nervous people. Stigmatized people should be evaluated according to underlying reasons behind their illnesses and their belief in themselves. Rejection of a stigmatized person depends on etiology of the illness and its interpretation [52]. CD has great significance in lives of people with OCD and their families. As the people experience increasing obsessive and compulsive thoughts, they become socially isolated, and by time, their illness gets worse and they might need to be taken care of [53, 54]. Illnesses that are treated by psychiatrists are generally regarded as mental illnesses. This term traditionally used to describe serious mental problems, and it stigmatizes people with this problem via society and themselves. Many individuals with OCD refrain from receiving necessary support because of the risk of being stigmatized. They would often look for somatic explanations such as it being a dermatological problem in order to ignore the mental problem that they have [52]. Self-stigma is a term used in the case where the individual internalizes the negative approach he/she receives. Therefore, a person with OCB who internalizes the societal prejudices would feel a flaw in themselves and therefore would expect to be rejected by the society [1, 2]. Livingston and Boyd [46] show that self-stigma affects—very strongly and negatively—the psychosocial status such as empowerment and self-esteem as much as it affects individual’s psychiatric status.

Before obsessive and compulsive behaviors develop, individuals experience great trauma and intense stressful processes. Individuals’ responsibilities and the value they give to events determine the significance and importance of this process. Their fear of stigma causes to hide their experiences. This situation hampers help requests, including educators and health professionals. Symptoms of OCD cause time and energy loss in the individual’s life. This situation negatively affects the performance of the individuals in the activity areas that require social participation in particular. As a result, individuals isolate themselves from others [55]. Individuals with OCD often hide bullying and shame [56, 57]. They try to keep their obsessions and compulsions against future hurdles and that do not go to places that generate stress and anxiety. The presence of OCD can increase the risk of substance abuse and suicidal thoughts [58]. Attitudes and behaviors of peers are important for OCD children. As a result of negative attitudes and behaviors of peers, the possibility of exclusion of OCD children is very high. A study shows that 25% of participants are being excluded by their peers. Examples of behaviors such as kicking, hitting, rumor spreading, and social isolation are examples of peer attitudes [59].

## 5. Stigma in obsessive compulsive disorder

As describe above, OCD, one of mental disorders, is also adversely affected by stigma. Due to the effects of OCD, both self-attitudes and others attitudes are negatively affected stigma that

can cause problems in self-esteem, seeking treatment, benefiting from social opportunities, criminal justice system, and problems in family and friends' relations. Families of individuals with OCD and close friends live difficult situations due to stigma. Self-stigma and the social stigma have a negative impact on their participation in daily life activities, their functionalities, their occupational lives, their productivity, and their social lives [33].

In individuals with OCD, emotions such as shame, guilt, and fear emerge during the first appearance of the disease. The first reaction is usually a tendency to reject. Individuals try to cope with the symptoms alone. They start to live with disease by trying to hide their symptoms. It is usually later that they perceive this as a disease. For this reason, it can be shown that they have no previous knowledge about the disease. The lack of insight causes them not seeking treatment, not getting help, and not doing research. They acknowledge that there is a trouble when it comes to coping with the symptoms, but the search for treatment with emotional factors such as shame, guilt, and fear is delayed again. OCD, like other mental disorders, is a psychiatric disorder that needs to be diagnosed and treated early. OCD diagnosis is usually delayed for such reasons. Individuals with OCD are resistant to interviewing health personnel and postpone treatment seeking. Treatment with the cause of hesitation in seeking treatment begins at a later stage of the disease. The delay in the onset of treatment affects the treatment process negatively in OCD, just as it is in other diseases. As well as having problems in seeking treatment with the cause of stigma, after the treatment starts, the treatment can also have problems with regular participation, continuity, and concluding the treatment. At the beginning of the treatment, the rate of cessation treatment in individuals is very high. Stigma slows down the process and causes them to have negative emotions. The treatment phase can be long-lasting, sometimes challenging and painful. While this process is difficult enough to cope with, the stigma makes this process even harder. **The self-perception can be changed and his belief that he is a successful cure is shaken.** The negative effect of stigmatization on patience and perseverance prevents the steady maintenance of treatment. These affect the prognosis of the disease negatively [3, 8].

Individuals with OCD experience feelings of shame, guilt, fear, and anxiety when they are diagnosed with the disease and prefer to **fight alone in the treatment process**. Fear of exposure to stigmatization prevents individuals from giving information about their illness to their relatives. In general, individuals tend to keep it confidential from the family and those close to them. This situation causes environmental support to fail. As with all other illnesses, it is important that environmental support is available to deal with the disease during the treatment process [60]. Concerns about accusations and exclusion by those who are close to the family in **relation to other people** cause problems and distances away from others [1, 61]. The tendency to keep the disease secret is caused by the inability to receive support from family members or close associates, and the prognosis of the disease is adversely affected. This is why getting help is important.

Studies show that violence and sexual obsessions are not shared in particular and that it is **more difficult to seek help** in this regard. Because of the feeling of embarrassment in these obsessions, it is delaying the search for treatment that cannot be shared with health personnel [61]. In another study, 738 adults were asked about pollution, symmetry, damage, and taboo



obsessions. While symmetry obsessions were defined as OCD, subjects with taboo obsessions were exposed to stigma. Failure to have sufficient knowledge of OCD leads to the exposure of people with certain obsessions to the stigma, such as in this study [62].

Exposure to stigma, prejudiced and degrading attitudes, and discriminatory behavior of the community **negatively affect the self-esteem of individuals**. The stigma applied by the community is internalized by the individual and starts negative attitudes toward themselves. Individuals are self-stigmatizing and are beginning to label themselves. Once individuals begin to stamp themselves, they begin to diminish a sense of self-sufficiency. Later on, they do not have as much as self-confidence, self-esteem, and feeling of accomplishment, self-expression, and self-esteem. Self-esteem begins to be damaged, and the daily life of those who have problems people without self-esteem is negatively affected. Self-stigma influences their sense of success in their lives and their work life, their dissatisfaction, and their learning and development desires in the negative. They prefer to stay behind in business life, starting work, continuing, and finishing. But the problems of self-esteem and self-esteem of individuals are reducing the trust of employers. Self-stigma is also preventing participation in daily life activities. In everyday life, they are starting to refrain from carrying out activities such as communication, shopping, money management, and housekeeping. The problem that people live in self-esteem is causing their independent living skills to be negatively affected. Over time, they are becoming more dependent on their life. At the same time, they are also avoiding social activities that may be associated with other people. Their social activities such as participation in group activities, playing games, and being in contact with other people are being hurt. Self-stigma prevents the individual from making efforts on behalf of the formation of the social environment necessary to participate in social life. It leads to problems in the functionality of individuals [63, 64]. In sum, both the stigma created by other people and the stigma they apply to themselves are affecting negatively the quality of life of the individual with OCD.

Stigma also negatively affects the **relationship of individuals with their parents**. An individual may be exposed to stigma by his or her family. Having inadequate knowledge about OCD or having a false belief due to a mental illness leads the families to exclude them. They tend to reject the disease just like individuals when they first learn it. The families are starting to feel feelings such as shame, fear, anger, and guilt-like individual with OCD. This causes the individual with OCD tend to hide the signs of the disease and to hide themselves from other people. The treatment of the individual with OCD is adversely affected until the family begins to accept the disease. The fact that the parents do not see the symptoms of the disease as illness causes accusations of individuals with OCD [1, 3, 61]. During this period, the individual continues to internalize his self-labeling. The treatment of the individual is badly affected by his/her family's and self-stigma of the individual with OCD stigma thus leads to the lack of family support and the poor prognosis of the treatment.

Stigma affects **the relationship of individuals with OCD to their friends**. Individuals tend to conceal their illness from time to time, even from friends. They try to hide the symptoms of their illness by their anxiety, anger, mockery, exclusion, and stigma exposure by their friends. For this reason, they prefer to stay away from their friends in this period, to be alone. The tendency to go away, the desire to be alone, and the closure causes the individual to be left alone

with this disease. In the course of treatment, environmental support is reduced in this way. At school, at home, at work, and in social life, we spend time with friends almost everywhere. Friends have an important place in everyday life. At school, at home, at work, in cinema, in theater, at the café, in sports, in social activities, etc., getting away from friends who spend time together negatively affects daily life. Exposure to stigma after sharing your illness with friends also affects individual with OCD's life negatively. The lack of knowledge and misunderstandings about OCD causes the symptoms of the illness to be perceived by the individual as deliberate behavior, and the individual's friends may expose them to stigma in this case. It adversely affects the ability of the individual to perform daily life activities, productivity, occupational performance, and leisure activities. This causes the individual's self-esteem to be impaired and the prognosis of the treatment to deteriorate [3, 62]. Persons who are friends with individuals with OCD are also exposed to stigma. People tend to think that they have the same behavior as individuals whose OCD is their friends. The personal characteristics and wrong evaluations attributed to the stamped individual are also attributed to the friends of these individuals. This situation also causes bad influence on friendship relations. The stigmatized individual's friends lead him away from him, leaving him alone and weakening the friendship relationship. The daily lives, productions, social activities, and social support of the stamped individuals are negatively affected on the treatment process [3, 62].

OCD is a psychological disorder that **affects daily life for individuals and their families**. The general attitude of society to this disease is to stay away at first. Individuals with OCD start struggle in their daily lives because of indecisiveness, self-reliance, and disruptive behaviors. As individuals with OCD become more difficult to manage their daily lives, the individual with OCD's families are starting to do it on their behalf. But sometimes families also begin not to deal with the tasks and activities of individual with OCD. For this reason, families feel stressed to take more responsibility for the daily life activities of the OCD individual [1]. Family members of individuals with mental disability are also exposed to stigmatization. Negative personal characteristics directed to the individual with OCD are also mirrored to the relatives of the individual with OCD. Families are shown as defective, guilty, and embarrassed. Recently, studies have been carried out on the stigma that the family is exposed to. Surveys reveal that they are worthless and humiliated because they are family members of the person with a mental disorder. The families exposed to stigma are under the pressure of the society. This increases the stress and anxiety of the family. Stress, anxiety, social stigma, can also cause mental ill effects on the family. Family stigmatization leads to a negative impact on both the relationship between the individual with OCD and the family as well as the relationship with society. They are moving away from society, starting to be alone and living in environmental constraints. Because of family stigma, family members are getting away from school, work, and outside, and their social participation is decreased [1, 65, 66].

The treatment process can be a lengthy and challenging process. It may become a situation that consumes the family and the individual with OCD. In the meantime, the family and the individual with OCD should be supported mentally well. Stigma can prevent with this support from family and individual with OCD. Negative attitudes toward the family influence the individual, giving the right support in the treatment process. Moreover, they are influenced negatively psychologically and socially. The inability of the family members to support



as much as their ability to handle leads to slowing and prolonging the prognosis. At the same time, some of the destructive effects of the disease increase, causing negative attitudes about the process [1, 65, 66]. In summary, stigma on family of person with OCD; adversely affects family, person with OCD and their relationship.

### **5.1. Negative consequences of stigma in children with obsessive compulsive disorder**

Stigma not only affects adults but also youth and children. Since the incidence of OCD is lower in children, there is not much research done on them. Obsessions and compulsions seen in children affect their daily routines, family relationships, friendship relationships, and self-esteem. The self-esteem of children exposed to stigma by their friends is negatively affected. This causes many problems to emerge, in children, as in adults. Reduced self-esteem caused experiencing problems such as having trouble with going to school, not doing homework, not having friendship relationship, closing up, and difficulty to participate in the treatment.

Stigma also negatively affects children's friendship relationship. The play takes an important place in the child's life. Friends are needed to play games. Exposure to stigma among friends is causing them to move away. The game environment of a child who is away from friends is disappearing. Moreover, friendship relationship improves the level of stress of the child and loneliness. The exposure of the child to stigma causes nervous, angry, and anxious behaviors. The family of the child, whose stress level is increasing, is also negatively affected by this situation [67, 68].

The family that is exposed to the child's stigma is also exposed to stigmatization. Family stigma causes family relations to be influenced, family members to be affected by the friendship relationship, and the level of family stress to be increased. The fact that the parents try to cope with these stress factors negatively affect their participation in the long treatment process of the child. Such problems caused by stigma are adversely affecting the treatment process in children, as well as in adults. Because of stigma, diminished supportive mechanisms, increased stress, emotional impact of the child, and problem of participation in the game are problematic in the progress of the treatment process [69].

## **6. Psychosocial interventions for stigma**

In OCD management, medical perspective is dominant in general sense [70, 71]. However, OCD people continue their lives in society beyond medical drug treatment. Stigma is often referred to as secondary disease [48]. For this reason, it is important to have a biopsychosocial approach to OCD. Occupational therapists use the biopsychosocial and holistic approach for clients. In the following sections, individuals with OCD are referred to as *client*. For occupational therapy, it is important that the clients fulfill his roles, participation in occupations, and social participation and existence as an individual [72]. Occupational therapists do individual and/or community-based interventions to combat self-stigma, professional stigma, and social

stigma that individuals are exposed to. Interventions to be conducted to client centered can be classified as promotion self-awareness, coping strategies, and encouragement. Interventions for social and professional stigma can be classified as occupational justice, community-based rehabilitation, education, and support groups.

“Self-stigma interventions can be classified promotion self-awareness, coping strategies and encouragement.”

### 6.1. Promotion self-awareness

In mental illness, individuals may not be aware of self-stigmatization. Because of wrong beliefs or thoughts about themselves, they may have difficulty in performing their roles and participating in their daily activities. For this reason, it is important to increase insight and to create individual awareness in reducing stigmatization. Occupational therapists can use cognitive behavioral therapy, psychoeducation, and also photovoice methods to help clients write and express their thoughts and behaviors who have difficulty in verbally expressing in order to provide individual awareness; thus, contributing to the client's occupational identity and avoiding self-stigmatization.

Cognitive behavioral therapy involves changing individuals' misconceptions with the right thinking. In this regard, it is accepted as a direct and permanent method. CBT, which is used in combination with medical treatment in many mental disorders, is highly effective. CBT, the most commonly used method of treating person with OCD, also has a significant role in reducing self-stigmatization [73, 74]. This method, which is widely used in OCD seen in children, helps to prevent the self-stigma that the individual applies to himself [75, 76]. CBT can be done individually or in groups [77]. Reaching of cognitive behavioral treatment is difficult because of the lack of specialized therapists in the field of reaching. Occupational therapists can specialize in this area to help OCD individuals overcome self-regulation. In addition, CBT is cost effective and accessible via the Internet [78].

One of the most important causes of self-stigmatization is having missing or incorrect information about the disease. Also, diagnosis can lead to labeling in individuals. Psychoeducation is one of the most effective and widely used method as CBT. Even brief information reduces the violence and social distance applied to the individual with OCD. The aim of this psychoeducation is to give information about the individual's illnesses, to reduce the self-labeling, and to raise the inner awareness of the client. In the context of ideal psychoeducation; medical, psychological, and sociological information about the disease should be included, information about treatment and process should be given, strategies for coping should be explained, and practical training should be done. In addition to these contexts, stories of individuals on similar conditions may increase the effectiveness of education. Occupational therapists can provide these trainings in community mental health centers, hospitals, OCD associations, or individuals with OCD who consultate to them [79].

Photovoice methods used for clients are actively involved in reflecting their lives through photography/draw picture and group work. Photovoice methods enable the individual to increase his/her inner awareness and understand the conditions of the disease and the

obstacle [80]. Very few studies have focused on photovoice methods to prevent stigmatization and participatory approaches [81]. Nonetheless, the photovoice methods can be used to understand the paradoxical relationship between social stigma and ethical values. Kawa model developed by Iwama is a photovoice occupational therapy model. This model enables the individual to demonstrate a direct relationship with culture [82]. The client describes the situations in which the individual perceives their own life as difficulty or opportunity in his Kawa drawings. For this reason, in occupational therapy, Kawa River model can be used as an evaluation and intervention in providing stigma awareness. Bavaro has used the Model of Human Occupation [MOHO] to deeply understand the client with OCD. He stated that habits, rituals, environment, and an occupational therapy model can be used for evaluation and intervention of an individual's occupational identity and performance [83]. With the MOHO model, occupational therapist can help to client to reconstruct his own occupational identity and find the source of inner motivation.

Also, Garland noted that in his study, animal-assisted therapy promotes family and individual communication, contributes to participation, and reduces stigmatization of the disease due to this signification and normalization [84]. Occupational therapist can use purposeful occupations such as animal-assisted approaches to increase social participation of the client and to facilitate social relationships.

## 6.2. Coping strategies

Obsessions and compulsions and related maladaptive behaviors are the most common causes for individuals to social and self-stigma. Management of obsessions and compulsions are thought to diminish the problems encountered in social participation. Occupational therapists play a pivotal role in teaching different coping strategies and in providing effective use of these coping strategies in different environments and conditions with motor learning principles. Coping strategies can be classified relaxation techniques, body awareness, time management, and desensitization.

Relaxation techniques, which have 35.9% of the strategies used in OCD individuals, are frequently used in the management of anxiety disorders resulting in obsessions and compulsions [85, 86]. Relaxation techniques have been reported to cause somatic and cognitive components to relapse in obsessive compulsive disorders [87]. However, there is still a need for more study for OCD. Relaxation techniques control the repetitive rituals of individuals in their participation and therefore suggest that they can be protected from stigma. Occupational therapist specializing in body-mind awareness and relaxation techniques is needed. By promoting mind and body integration with the biopsychosocial approach, increase in body awareness is thought to have a positive effect on clients' own thoughts.

Time is an important concept in the management of obsessions and compulsions seen in OCD. Participation of daily activities or social activities needs requirements for performance patterns. In occupational therapy, performance patterns define roles, habits, and routines. Beyond these performance patterns, there is also requirement for time management. Occupational therapists conduct an activity analysis to reveal the personal, environmental,

and activity demands that activities require. The division of activities into tasks, followed by these steps, allows the regulation of the rituals of clients with OCD. However, occupational therapists teach OCD individuals time management techniques.

Sensory processing disorders in childhood may lead to excessive ritual behaviors. Children with tactile hypersensitivity were found to have an OC tendency later in life, and oral and tactile hypersensitivity in adults were associated with obsessions and compulsions. Studies of OCD on sensory processing both in childhood and on adult individuals show that desensitization techniques are effective on obsessions and compulsions [88–90]. In occupational therapy, sensory integration therapy and desensitization techniques in children and adults and the environment they live in have an important role in enabling individuals to cope with symptoms, fulfill their roles, and interact with the environment. These methods are thought to reduce stigmatization.

Individuals with OCD are also stigmatizing in their treatment seeking or avoiding treatment seeking because they are stigmatizing [91, 92]. Within this paradox, clients' attainment of treatment and social inclusion are affected [30]. Occupational therapists should encourage individuals to participate in activities and manage health [72]. Encouraging clients with OCD is an important intervention to remove the negative consequences of the stigma.

*For social and professional stigma, occupational therapy interventions can be categorized as providing occupational justice, community-based rehabilitation, education and support groups.*

The concept of occupational justice argues that individuals have activity capacities, needs, and routines in their environments and have the right to use these capacities to maintain their lives and social participation and empowerment social inclusion [93, 94]. Stigma inhibits social inclusion in OCD individuals [47]. In occupational justice framework; occupational balance and occupational deprivation terms have been used. Occupational deprivation refers to the deprivation of the purposeful occupations the clients is doing due to social factors over time; the occupational alienation refers to estrangement, loss control, and sense of isolation due to social or self-conditions, while the clients fulfill their occupations and roles, and the occupational imbalance, in which there is an imbalance between the occupations required by the roles and the time allocated. Occupational deprivation and occupational alienation are inevitable for OCD due to stigma. The stigma in OCD needs to be considered in the context of occupational science.

Community-based psychiatric rehabilitation aims to provide rehabilitation services and sustainable services within the society and culture in which the individual lives. Studies about people with OCD and society can be effective in changing the cultural history of stigmatization. Projects supported by volunteers can also influence the cultural sub-structure of the stigma [95]. Occupational therapists can conduct community-based rehabilitation work and contribute to the social consensus of clients [96]. Community-based rehabilitation practice with an occupational justice conception that will provide social participation and reduce stigma is among the



interventions occupational therapists will have [97]. Community participation, social inclusion, and occupational engagement are highly important occupational therapy interventions for reducing stigma and discrimination [98].

Occupational therapists visit the home where the client lives and make the home assessments. OT can provide OCD management and can make appropriate house arrangements for the client. The family and/or caregiver are informed. For school-aged OCD clients, OTs can visit the school, be informed by interviewing their peers and their teachers and if necessary, make appropriate environmental adjustments to the client. Informing adults and making workplace visits and environmental adaptations for clients with OCD have an important place in interventions that can reduce stigmatization.

Anti-stigma or reducing stigmatization interventions focused on the people with OCD and their families, health professionals, the general public, pupils and teachers, and health professionals. Education about OCD and misbeliefs is the primary aim of most campaigns, followed by the empowerment of people OCD and the prevention of impact of stigmatization [99, 100]. Occupational therapists have an advocacy role to promote social awareness and support the social integration of clients [72]. For OCD, occupational therapists can make these campaigns at a social level, and they can argue with politicians for legal regulations. It is among the responsibilities of occupational therapists to defend the rights of clients and to ensure the participation of clients with OCD in this way.

The media, however, play an important role in determining the attitudes of individuals toward perceptions and stigma and have a growing voice [101]. TV programs and publications have been reported to have positive effects on stigma [102]. A study on media reported that the Monk character, an individual with OCD, reduced stigma against OCD [60]. In the technology world, there are many people who reach through social media and individuals can be encouraged to tell their stories by digital storytelling methods. Thus, stigmatization can be decreased by increasing social awareness [103].

It has been noted that individuals with OCD have avoided treatment seeking because of the stigma they have seen most from their families. More stigma is reported to be applied especially in socio-demographic lower income families [104]. Also, family members living with the patient (such as parents, partners, children and siblings) are involved in daily rituals and undergoing social stigmatization. For this reason, families may encounter inequalities in occupational role performing. It is possible for OCD individuals to have access to treatment and to support their social integration and to provide social inclusion for the OCD individual's family members. The biggest profit from the support groups could have individuals with high levels of self-stigmatization and poor social networks. Such groups might be focused on stigmatization (and thus indirectly on building self-esteem). The biggest profits from the support groups were the high levels of self-stigmatization and poor social networks. Educational activities are of great importance as such groups might be focused on stigmatization (and thus indirectly on building self-esteem), adaptive coping strategies to deal with daily hassles and interpersonal conflicts, and adopting supportive behaviors. These trainings can be made for health professionals for professional stigma, for children and adolescents with OCD [105], or for general public [100].

Taking social support from family and peers is the way to reduce the social stigma that families are going through. In many countries, support groups have been established for OCD individuals and their families. Bringing together individuals who live in similar conditions allows a group to become less isolated from society [106]. Children learn from their peers. Child or adolescent peer groups are also important in the context of the participation of children [80]. Web-based systems can communicate with social media [103] or virtual-based systems can be effective. The direction of occupational therapists to social support groups and peer support groups is the occupational therapy interventions that promote social integration of clients and thus reduce stigma [79, 106].

The best approach to reduce stigma should be a holistic approach and community-based rehabilitation to control clients' symptoms, to protect the clients' occupational identity, to tackle the client and the living environment together, and to raise the awareness of the clients, family, and the community.

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