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Experiences of Individuals Suffering from Obsessive Compulsive Disorder: A Qualitative Study

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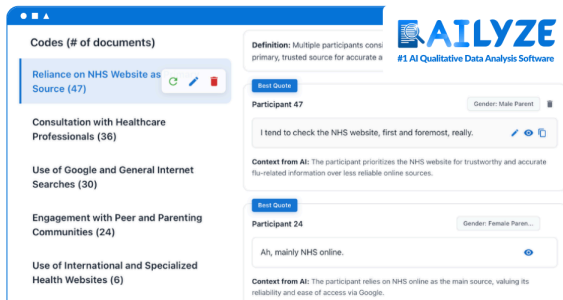
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Abstract

This study was aimed at giving voice to the experiences of four people suffering from obsessive compulsive disorder (OCD). Five in-depth interviews were conducted on each individual constructing themselves in the light of their own experiences. A “case study approach” was chosen as the suitable method to go in depth into the information and “thematic content analysis” was used as the method of analysis. The life stories of these individuals were reconstructed in terms of themes, and recurring themes were further explored and elucidated and linked with literature. This study helps in reaching the depths of life experiences of individuals suffering from obsessive compulsive disorder and how it affects their life in the domains of family, interpersonal relationships, occupation and self- concept. The main themes identified were that of “Connection vs. Disconnection,” “Feeling of Guilt,” and “Authenticity” as particularly important areas for clinical practice and future research.

Keywords

Obsessive Compulsive Disorder, Case Study, Qualitative Research, Thematic Analysis

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Experiences of Individuals Suffering from Obsessive Compulsive Disorder: A Qualitative Study

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This study was aimed at giving voice to the experiences of four people suffering from obsessive compulsive disorder (OCD). Five in-depth interviews were conducted on each individual constructing themselves in the light of their own experiences. A “case study approach” was chosen as the suitable method to go in depth into the information and “thematic content analysis” was used as the method of analysis. The life stories of these individuals were reconstructed in terms of themes, and recurring themes were further explored and elucidated and linked with literature. This study helps in reaching the depths of life experiences of individuals suffering from obsessive compulsive disorder and how it affects their life in the domains of family, interpersonal relationships, occupation and self- concept. The main themes identified were that of “Connection vs. Disconnection,” “Feeling of Guilt,” and “Authenticity” as particularly important areas for clinical practice and future research. Keywords: Obsessive Compulsive Disorder, Case Study, Qualitative Research, Thematic Analysis.

The main purpose of this research was to participate in depth with four individuals who have been suffering from Obsessive Compulsive Disorder. The study aimed to indulge in a participative inquiry into the life of these individuals in an attempt to look at their story, and their meaning about their illness. It was an attempt to give voice to these individuals to develop a deeper understanding so that therapeutic intervention is more individual specific and effective.

These individuals engaged with the researcher and explored various aspects of their life (occupation, interpersonal relationship, self- concept) so that they are able to reflect back on their lives and take appropriate measures to lead a meaningful existence.

Statement of the Problem

Obsessive Compulsive Disorder (OCD) is a severe and debilitating anxiety disorder with a lifetime prevalence of 0.6% in Indian population (Khanna et. al., 1993). It is twice as prevalent as schizophrenia and bipolar disorder, and the fourth most common psychiatric disorder (Karno et al., 1988; Rasmussen & Eisen, 1990).

There have been very few studies to examine the extent to which the presence of persistent obsessions and compulsions impact on the quality of life (QOL) of persons with OCD. A review of literature in this area highlighted the profound personal, social, and financial costs associated with anxiety disorders, but there was a striking dearth of studies conducted on patients with OCD (Mendlowicz & Stein, 2000).

A review study done by Srivastava and Bhatia (2008) revealed OCD patient are less likely to find employment, have lower average income, poor academic performance and

higher dependence on social security. In an Indian study by Gururaj et al. (2008) OCD patients were compared with patients with Schizophrenia in terms of family burden, quality of life and disability. Results indicated that patients with OCD were comparable with patients with schizophrenia and were associated with significant disability, poor quality of life and higher family burden.

In another study done by Stengler-Wenzke and colleagues (2007) the differential impact of obsessions and compulsions on quality of life (QOL) of patients with OCD was examined. 75 (32 male, 43 female) patients recruited from Department of Psychiatry, University of Leipzig. They were given Yale Brown obsessive compulsive scale, Beck Depression Inventory and WHOQOL-BREF. It was seen that compulsions had an impact on patients' QOL domain of "physical, psychological and environmental well-being" while obsessions did not have impact on QOL ratings. Comorbidity of depression was another predictor of poor QOL in OCD.

Subramaniam and colleagues (2013) in a recent review article emphasize that suffering from OCD substantially impairs QOL across all domains compared to normative subjects. Patients with OCD scored better on QOL domains than patient with Major Depressive Disorders (MDD) but did not show much difference or scored worse than suffering from Schizophrenia. They have found a major gap in QOL research in OCD patients due to lack of suitable instruments measuring QOL. They have also highlighted the need for a multidimensional reliable and valid instrument for measuring QOL and a need for longitudinal studies to understand the temporal relationships.

There is a dearth of qualitative studies in understanding the impact of Obsessive Compulsive Disorder on the quality of life of individuals suffering from this disorder. There have been very few attempts to look into the subjective aspect of the illness. Moreover, in the Indian scenario an exploration in this area is still at its nascent stage.

Purpose

This study intended to better understand significant issues that arise when a person develops this OCD, in order to prepare individual, their families and the psychotherapist to work with this population. The researcher specifically investigated the experiences of individual's suffering from Obsessive Compulsive Disorder and the impact of this illness on their life, and how they subjectively look at their illness in a hope of learning how to best improve clinical approaches to meeting the needs of this population.

The results of this study will contribute to a developing insight regarding more humanistic approaches for therapists working with individual's suffering from Obsessive Compulsive Disorder that includes critical consideration of the ways in which they are pathologized. The researcher would take a neutral stance where the experience of the individual is the priority in looking at his illness rather than dictating mechanical ways to overcome the symptoms. The research would be more of a self -discovery rather than a one sided attempt to cure just the symptoms.

Researcher's Position

The researcher considers her role to be that of a theorist, researcher and a therapist. These positions allow her to consider multiple implications of the study. She draws from theories that guide psychotherapy and qualitative research. With respect to her theorist/ researcher/ practitioner role she believes that how therapists understand the experience of illness, more as a social or personal issues faced by the individual greatly impact how she works with them in a therapeutic context.

Often in the mental health profession symptoms are dealt with objectively leading to a neglect of the subjective distress faced by the individuals and the experience of living with the illness. There is lack of awareness among caregivers and practitioners about the personal relevance of these symptoms. The values and beliefs of the researcher will impact her role as a research- practitioner. Hence, having an increased awareness of her conceptual frameworks will allow her to understand the personal implication of the illness and it's symptom in the individuals' life.

In her role as the researcher and interviewer, adequate measures were taken to remain open, ethical, authentic, and curious in all communication and writing with the study participants.

Research Questions

Research questions were constructed by considering pre-existing literature, what is missing from the literature, circumstances that surfaced for individuals with OCD the researcher met at the outpatient unit, her research interests, and what she had experienced while being involved in therapeutic intervention with people suffering from OCD. The four primary areas that guided questions included: (1) family-of-origin and significant relationships; (2) impact on occupation (3) self-concept (4) goals for future. There were two questions that guided the inquiry and the first was: What is the lived experience of individual's suffering from OCD and those in relationships with them? Specifically, the research questions that explored this were:

- How did this living with OCD influence their relationships?
- What metaphors capture these people's experiences?
- How does their illness effect their occupation?
- How does OCD impact on their self -concept?
- And finally, living with OCD how do these individual's conceive of making their life meaningful?

Methods and Approaches

Qualitative research methodology challenges the idea of a fixed and natural reality and instead values competing realities (Denzin & Lincoln, 1994). It also allows for research participants to describe their experiences from their own perspectives (Patton, 2002). Following such a methodology then, this study explores and seeks to understand a phenomenon that is rarely studies. Hence, the researcher selected qualitative inquiry, specifically phenomenology, which is most likely to capture the rich experiences of individuals with OCD.

Phenomenological research seeks to describe how participants live through their experiences and then create meaning from those experiences (van Manen, 1990) including – how they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others (Patton, 2002). This study situates the participants as experts and the researcher's main role is to work with them to interpret and understand their words. Her goal is to understand participants' experiences of OCD.

Participant Recruitment

Purposive sampling was used, it allowed the researcher to develop a sample guide by contacting participants who had experiences that were related to the phenomenon of interest

(Daly, 2007). The participants' stories in this study help to create a narrative about how people deal with their illness namely OCD personally and in their relationships, their profession and self- concept. Snowball sampling was also used, it's an approach where the researcher asks well-suited people who else they might recommend the researcher speak with. Snowball and purposive sampling are often used together to gain access to people with unique experiences (Daly, 2007). The participants were three males and one female patient suffering from O.C.D. Participants ranged in age from 18 to 25 years of age. The patients were selected from the outpatient unit of the hospital, wherein the researcher contacted the individuals on the basis of their availability, the researcher spoke with each participant on the phone and face to face to discuss the study in further detail.

Participant Selection

Initial selection criteria for this study included: (a) patient diagnosed with OCD as per ICD 10 criterion; (b) between the age of 18-25; and (c) able to meet for a face-to-face interview. Participants were asked for their consent before taking the interview and audiotaping it. Their real names were not used, pseudonyms were used to protect their privacy. Participants were assured of confidentiality. Participants were informed that there were no tangible benefits for participation in the study and that they could withdraw from the study at any point of time. All participants were informed regarding availability of the investigator if they wished to contact her for further clarification.

Data Collection

Interviews took place in Ranchi city in the Ranchi Institute of Neuro-Psychiatry. Participants were called in the hospital and interview was taken in a peaceful environment where the chances of distractions were minimal. Interviews were conducted mainly in Hindi and English. All interviews were audio recorded.

Qualitative research methodology was used to conduct the research. Participants who had given consent were interviewed.

The interviews were taken individually; individual interviews were preferred because participants could have found it difficult to discuss hardships as they relate to the other family members present in the interview. Painful experiences that would otherwise be discussed may be held back in conversation in order to protect the emotions of the other person.

An interview guide was used by the researcher by first administering Sack's sentence completion test and then further exploring the different areas and the conflicts being portrayed in details. These included the participants' experience of illness in relation to his family, relation with significant others, difficulty in professional relations and impact on the individual's self-concept. Open ended questions were incorporated which were developed as a basis of the study.

Interviewees were granted opportunities to reveal how they experienced family events throughout the interview, which helped researcher develop a framework that accurately described their perceptions. Direct quotes contributed to the study as a source of raw data (Patton, 2002). While each interview conversation was guided by a number of questions, the researcher followed up with additional questions to gain in-depth information. The interviews were transcribed into text documents.

Data Analysis

Thematic analysis entails coding and identifying patterns, themes and sub themes as they emerge from the data (Braun & Clarke, 2006), which is the method the researcher used to analyze this data. Braun and Clarke outline six phases to conducting thematic analysis which include (1) familiarizing oneself with the data, (2) generating initial codes or ideas about what is interesting in the data, (3) searching for themes by sorting codes, (4) reviewing themes for coherent patterns and validity in relation to the entire data set, (5) defining and naming themes, and (6) producing the report by writing up sufficient evidence that tells the overall story of the data. For this study, themes reflect detailed experiences and meanings described by the participants.

Results

Various themes which arise out of significant experiences of the participants living with Obsessive Compulsive Disorder:

Participant 1: Ahmed Ansari

Ahmed was in his mid twenties, averagely built, belonging to low socio economic status from rural back ground of West Midnapur, West Bengal, India.

Brief History of Illness

Ahmed's was apparently asymptomatic till the age of 14 years when he was studying in the 8th standard. Ahmed wanted to apply in a different school since all his friends were going to the other school, but since his parents had taken the obligation of his teachers to get their land back from some goons, they decided to pay back their gratitude by letting Ahmed stay in the same school. Since Ahmed was a good student his results would boost up the image of the school. Moreover, the girl Ahmed used to love also joined some other school. Gradually it became difficult for Ahmed to deal with his loss, he started indulging in compulsive acts like washing his hands a number of times. He would count before eating or drinking. Ahmed also started getting obsessive thoughts about following symmetry. He would try to finish from the same place he had started. If he had taken particular path while going somewhere he would try to take the same path back. Even in studies he would follow symmetry. He would turn the pages in a fixed number of times in a particular way. He would try to say things in the end of the conversation with which he had begun initially. His symptoms gradually increased. This also started hampering his studies and his relations with his family members and friends. Ahmed would stubbornly refuse to change his behaviour. He would follow his own whims and fancies and would get irritated if somebody tried to stop him from following his rituals. He also refused treatment and was extremely resistant to psychotherapeutic treatment. He would refuse to follow anything being asked from him and would stubbornly say that nothing could make him better and all these efforts were just a waste of time.

Emerging Themes

Connection vs. Disconnection. This theme describes the participant's sense of connection and disconnection with his family and friends.

From an early age Ahmed felt a strong sense of disconnection from his parents. Regarding his mother he said:

“I am close to my mom...I say a lot of things... but don't tell her everything...how can I tell everything...everything can only be told to a good friend...close friends...but don't have anybody like that...”

He could not share much with his siblings either. As he grew older he had few meaningful relationships, but whenever he tried to grow the connection in his relationships, his efforts were thwarted in between. He recalled:

“The youngest brother... he is not able to understand...he behaves differently... he would call me mad... if I say that lock is not closed properly repetitively he would also say the same...he would tease me...he understands me less... he teases me...but I understand he is young and doesn't understand me... the other brother understands he doesn't say anything...he understands me...”

His few close friends moved to different schools when he needed them the most, even the girl for whom he had feelings which went unexpressed left him and went away.

Feeling Different from Others vs. Feeling Similar to Others. This theme describes Ahmed's feeling of alienation from other individuals.

Ahmed due to his illness started feeling himself to be separate from others. He realised that his actions and his behaviour were different from other students around him. Once during the interview he said:

“I don't feel like other normal people... I have these strange thoughts. While going to college I have to travel by the same path I had taken earlier. This leads me to end up wasting a lot of time and energy. If I were like other normal people I could just do anything and travel easily.”

Due to this feeling he gradually became isolated from his other classmates. He would feel similar to them in all the other aspects except thinking, his thoughts were different from other people and this is something which had always made him alienate himself from others.

Conditional Love or Acceptance. Gaining love and acceptance involved conditions for Ahmed. Whenever he wanted care or concern, when he needed other people to understand him, he realised he would have to fulfil their expectations. When he was unable to do so, he had to face hardships and heart breaks. Moreover, the illness gradually made him feel helpless to fulfil the expectations of other significant people around him, which further led to a sense of isolation since he realised that all his efforts were not leading him anywhere.

The Loss of an Authentic Sense of Self. Ahmed's symptoms; his living an inauthentic life helped him cope with his sense of loss. It provided him a secure domain from which nobody would try to force him out. He created a world around him through his symptoms where nobody would be able to make him do things against his wishes. His stubbornness to change his ways was a way to express his bottled up rage. It was an expression to his inner disquiet. As Ahmed himself said:

“What can be the reason behind my illness? Don't u get it was because of lack of love... because I used to think of that girl... and to complete that emptiness... lack of good friends... this happened... to fulfil that loneliness to fill that pain... absence of the good friends... because of that pressure... I got

this illness...I feel I can go back to my past life by this...like it has started I want it to remain the same...so that nothing can change... everything remain as it was... so I try like that”

Doubting Himself vs. Believing Himself. Ahmed suffered from intense self doubt, for everything he did he needed approval of other people. This tendency manifested itself in the form of obsessive symptoms, where he had to repeat something again and again to be fully sure.

Feeling Powerless vs. Feeling Powerful. As Ahmed tended to deny and doubt his authentic self, he often felt powerless in his relationships. In addition he also felt powerless to change things in his life. Although Ahmed has feeling of powerlessness in numerous of his relationships, there has also been times when he has experienced power. Ahmed has ambition to become a lyricist one day, and he makes active attempts like sending his lyrics to music companies. He feels that this is one area where he can achieve something and he actively indulges in trying to hone his skills in this.

Participant 2: Shantanu

Shantanu was an 18 years old student preparing for his intermediate exams. He belonged to low socio economic status. His father was a farmer and mother was a home maker.

Brief History of Present Illness

According to Shantanu his illness started when he was in the 7th standard. He had been a good student all throughout his childhood, but when he reached puberty his mind gradually diverted to sexual thoughts. He started thinking about sex most of the times, which hampered his academic performance. He started masturbating once or twice in a day initially but gradually increased it to 4 times a day. Even during study hours he would ponder about sex and would have images related to it. Moreover, he was close to a girl in the village and would fantasize about having his sexual experience with her. Most of his days were preoccupied by thinking about means to have sexual contact with her. He was close to the girl's brother and would at times stay at night in their home. There too he would try to coerce the girl into having sexual contact with him. But all his moves were unsuccessful since the girl refused to be physical with him. Due to this Shantanu became further frustrated, gradually his performance in studies started declining. In the class when the teacher would teach, he would day dream and imagine about sex. His absentmindedness led to a lot of embarrassment since he was unable to answer questions in the class and students started making fun of him.

All these experiences started making him feel that he was doing something very wrong. He started feeling that his excessive preoccupation with sexual thoughts was not right, but when he tried to come out of it he felt helpless. The more he would try the more the images would haunt him. He also started feeling that his masturbatory practices were wrong. He would feel guilty and since he did not have much knowledge about sex, he started thinking that nobody else indulged in it and what he was doing was unacceptable and wrong.

When Shantanu came to the 8th standard he went to his grandparents place in the city to study, he thought the change of environment would do him good. But there too the same thoughts chased him. He was unable to perform satisfactorily. His dismal performance further led his relatives to talk negatively about him. He gradually started keeping aloof and depressed. He would not mix with others because of the fear that he would not be able to

participate meaningfully. He started living separately when he reached 11th standard. But his further exacerbated his problems and most of the days he was preoccupied with his thoughts.

In the year 2007 finally he decided to seek treatment for his problems. He initially showed to a private psychiatrist where he did not disclose about his sexual problems and just complained about feeling low and inability to concentrate. The treatment did not help him much. Then he started showing to a government hospital, but again hesitated to open up and the treatment did not improve his condition much. Finally after much hesitation he disclosed his problems to a psychologist who helped him get the proper treatment and explained him the symptoms of Obsessive Compulsive Disorder.

Emerging Themes

Connection vs. Disconnection. The theme of connection and disconnection arose strongly in Shantanu's story. This seems to be prominent in relation to others in life, but also in relation to himself. About his relation with his father Shantanu said:

“My relation is good...but I cannot tell him anything... I only talk about business... nothing light... only serious issues...”

He recalled that he felt disconnected from others. It seemed that his illness made him feel this disconnection more. He said:

“Even in a group... when other people are talking... I would just sit aside and listen... most of the time I would become lost in my own world...I feared participating since none of them seem to listen to me...I would feel so lost... they would not tell me things they knew...I would feel myself so small and inferior”

Feeling Different from Others vs. Feeling Similar to Others. This theme resonated more in lieu of his relation with his peers. He often felt himself different from the larger peer group. He would feel alone even when he was amidst his friends. He said:

“I feel my friends...if I do some things with them... studying... I feel my confident is low... their confidence is high...if somebody ask them something... they would reply incorrectly but still they would reply.... but when somebody ask me I would not reply thinking that my answer would be wrong... the confidently say that there incorrect answers are right... so I feel myself confidence has gone down... I used to feel earlier that I was better than most people... but most of the time I don't feel so... “

Moreover, his obsessive sexual thoughts would make him be preoccupied most of the time and not able to participate meaningfully with his friends. Even when he would interact with his friends he would get these intrusive thoughts revolving around sexual themes, which would at times make him speak something unacceptable and embarrassing.

Trust vs. Distrust. This theme seemed to link with the sense of ambivalence that Shantanu had about his relationships. It seemed as though Shanatanu found it difficult to trust others, as the messages he received from them were often contradictory and confusing. However, it also seems that he himself would give them contradictory indications by preferring to stay aloof, and being critical towards others, and yet looking for connections.

Conditional Love or Acceptance. Shantanu felt accepted and loved only when he could accommodate his parents' needs and demands placed on him. He realised that if he is unable to perform as per their expectation they would not love him. Even in his peer group Shantanu would feel accepted when he would act according to the whims and fancies of the large peer group. His deviant activities, preoccupation with sexual thoughts made him separate from them

Feeling Powerless vs. Feeling Powerful. He seemed to feel completely helpless in dealing with his situation. He felt that because of illness he had not been able to fulfil his responsibilities towards his family. Even when Shantanu was thinking about his future he felt powerless. He felt that he would not be able to do much because of his illness. He said:

“When I am ok...I feel I will return to my old normal self...but when it becomes too disturbing I have feeling that I am not even 1% ok... and would never be able to get well”

Feeling of Guilt. One significant theme permeating all the other themes has been the theme of guilt. Shantanu felt himself responsible for his illness, he had tremendous amount of guilt that because of his own fault he had started thinking about sinful thoughts which had ruined his life. At one place he also mentioned that since he was overconfident in childhood about his capabilities and did not think that studying was big deal for him these thoughts had started bothering him. He felt himself responsible for letting these thoughts come to his mind and indulging in sinful acts like masturbation which he thought other people don't engage in like he did. He said:

“I think I am myself responsible for my own illness...I think now...if I would have worked hard earlier...I was dependent on medicines earlier...that I would be okay...would see for 1-2 months...I feel if at that time I would have worked hard to improve my condition...I think I could have been much better...I am not well yet is because of my own fault...and my illness...starting is also because of my own actions...I started thinking sinful things and then acted in wrong ways...”

Participant 3: Prakash

Prakash was an 18 year old male, student, preparing for his intermediate exams. Prakash belonged to a low socio economic status family, where his father was a shopkeeper and his mother a housewife. Prakash had one elder sister and one younger sister.

Brief History of Illness

Prakash's illness started when he was 17 years old. One day after suffering from nightfall he started feeling that his bed sheet was contaminated. He would wash his clothes, hands and bed sheets numerous times. He would have intrusive thoughts about dirt and would feel that things around him are dirty and contaminated with his sperms. He started feeling that if he touched anything without bathing he would sin. After coming from the lavatory he would have feelings that his hands were smeared with shit and that everything was unclean so he would spend a lot of time cleaning his bathroom and clothes. He would bath for 1 hour and wash his hands 20 to 25 times in a day unless and until he was satisfied that he was clean. If he had to go out somewhere to buy something he would feel dirty and contaminated after coming back and would have to wash his hands and bath before resuming his studies. After

taking bath he would prefer sitting on his bed to study. When his thoughts bothered him excessively he would prefer sleeping as he said sleeping would reduce his anxiety.

Gradually due to his preoccupation with his illness his relation with other family members as well as academic performance started getting hampered. He would avoid other people because he started thinking that they would not understand his illness. His concept about his own self too gradually started changing, his relation with his friends was fraught with uncertainty and he started becoming unsure of his own capabilities.

In this research endeavour Prakash finds a voice to convey his insecurities about himself and his life. It helps him find a way to come to terms with his illness as he expresses himself. It gives him space to make his subjective feelings clear to other people. As he is a very shy person this research endeavour helps him open up about his illness.

Emerging Themes

Connection vs. Disconnection. This theme was again quite prominent in Prakash's life. His relation with his family members, friends, career, and self-concept everything seemed to revolve around this one theme. His greatest sense of disconnection was with his own self. He said about his father:

"I have never been able to share much with him; he owns a small shop and keeps busy with it the whole day. Since childhood I don't remember a single day when we would really talk heart to heart. He has always been busy. When my illness started, he said that it was all in the mind and I should try to get out of it on my own. He has not really taken much interest in how I feel or how I am coping. He fends for the family and that seems to be more than enough for him."

Prakash said he failed to understand what has led to this illness. This illness made him feel helpless. Whatever he tried to do he was unable to control his intrusive thoughts. They kept on haunting him and he felt he was unable to perform to his maximum capabilities

Feeling Different from Others vs. Feeling Similar to Others. Somewhere he did feel connected to others, his sense of confusion was apparent. This theme was in connection with his own self, his feeling of changing with time. Where earlier he considered himself similar and capable of taking care of his own life, now he had the feeling that things were going out of his hand. He said:

"They expect a lot from me... they take me as good student...but when I am unable to fulfil their expectation I feel guilty...it's like I really want to, but I become helpless."

He found that he was different from all his other friends who could perform normally, but Prakash saw that he was unable to do that. His feeling different from others mainly arose from the fact that he could feel the change from what he was earlier, he felt he was just like other people, but now because of the illness he had changed and this change was difficult to assimilate.

Feeling Powerless vs. Feeling Powerful. He was at an age where his entire world revolved around making his career. His sense of feeling powerful and powerless arose out in this context. His focus was on career and when he saw that his illness was having a significant impact on his ability to perform he started feeling vulnerable. He said:

“I don’t feel inferior to others; I know if I want I can do as well as them, but this illness...it bounds me...however much I try I feel unable to achieve to my fullest potential...I know I can do well... but...it’s extremely difficult.”

Feeling of Guilt. Another significant theme which arose out from Prakash’s narration was feeling of guilt. He too like Shantanu had feeling of guilt about his condition. His illness started with nightfall which he said he would get due to sexual imagery, he felt guilty of indulging in such thoughts. Though the sexual images were not intrusive, he kept regretting that if only he did not indulge in it at that time when his studies should have been his priority. He felt guilty of not being able to perform to his parents and teachers expectation. He said:

“I feel bad... guilty of not being able to do what other people want me to do...I don’t know how to cope with this guilt... I want to be an engineer in the future... then do an M.B.A and establish my own business... but if the state of affairs are like this then I don’t know how far I would be able to achieve... if only I did not get this illness... I know many people have many hopes from me... I just wish I could make them happy.”

He at times felt that he could control his behaviour but was unable to do so. His guilt feelings were also about his change in behaviour. Where earlier he was calm and composed now he would get easily irritated and lash out at people for small reasons.

Participant 4: Julie

Julie was the 2nd of eight brothers and sisters, she had lots of responsibilities in life, but she found it difficult to fulfill her duties due to her illness. Julie’s illness started from a very young age. She was just 13 when her illness started, initially she would have repetitive thoughts that bugs were crawling on her back. She would also feel that the bugs are crawling inside her hand. She then started having thoughts that whatever she is reading in school or pronouncing is not right, she had to check the same thing again and again to be reassured that she was not reading or pronouncing it the wrong way. She also had the feeling that whatever she is saying is getting imprinted in her head, she would have repetitive imagery of the words she would say. Her problems would further increase when she had to work at house. She would find it difficult to complete her chores due to her problems. Julie has been a very bright student in school, she would perform better than other students but gradually due to her illness her performance started deteriorating and after giving the 10th standard exams her situation became worse. She found it increasingly difficult to concentrate on her studies and had to finally quit it completely.

For Julie living with her illness included getting scolding and abuses from her parents for not working, they took her illness as making excuses to shun her duties. Moreover, Julie being a bright student always found it difficult to accept that all her friends were performing much better than her while she had to stop her studies in between.

This research endeavour is an attempt to help Julie find her answers; it is a means to let Julie express her anger, her frustration and her helplessness about not being able to understand her relatives and others about her illness.

Emerging Themes

Connection vs. Disconnection. Julie has always felt disconnected from people around her, from her parents to her siblings; she felt that she was unable to connect to most of

the people around her. Moreover, belonging to a conservative Muslim family where there are numerous relatives she felt her emotional needs had been neglected most of the time. She said: *“My dad still understood me... he would love me and take care of me...he also took me to different doctors... but he has so many tensions... even he would get short tempered at times and would beat me if I would ask for something... I don't know whom to depend on...”*

Her sense of disconnection also remained towards her siblings who all were younger than her and did not understand her. She took them more as a burden than somebody with whom she could confide about her problems. Moreover, even at school she had not felt connected with her friends. Her sense of disconnection also existed in understanding her own self. At times she felt she understood her problems and could come out of it. But at the same time she felt helpless of controlling her problems.

Feeling Different from Others vs. Feeling Similar to Others. Julie also had a feeling of being separate from a young age. Since her illness started from a young age she felt she was not like other students. With her siblings too she felt different; she felt she had always been the rebellious kind. But she felt her demands were never met, her parents were bogged down with the responsibilities of such a big family. Moreover, her conservative background never gave her an opportunity to be herself, she had to follow the norms of the society, there were stringent code of conduct and she felt her illness made it worse to conform to these norms. She would feel herself disconnected and different from others. She said:

“Things started getting imprinted in my head... I don't think anybody else has this... I don't understand why this is happening to me...and how this stated....my mind just started getting disturbed...maybe it's because of early childhood experiences or I don't know... I have been asking everybody but don't get an answer.”

Conditional Love or Acceptance. Julie felt from a young age that to get love and acceptance she would have to fulfil the expectation of her parents, when she was unable to do so she would get scolding and beating. Her mother never liked her since she felt she was making excuses to escape from the responsibilities. She said:

“I don't know where to take out my frustrations...I would scold my younger sister...I just can't escape from this situation... my parents never gave me the love I had desired for... they were more fond of my elder brother who is working now...he has fulfilled their expectation...which I have not been able to do...”

For getting love she realised that she would have to just go along the wishes of her caregivers. Julie realised from a young age that if she has to be loved she has to go by the rules of her caregivers. Whenever she would rebel or demand for something, all she got was beating.

The Loss of an Authentic Sense of Self. Feeling authentic comes when an individual is able to accept himself/herself what they are. When they know their strengths and weaknesses and can live with their vulnerabilities. For Julie the idea of accepting her weak portion becomes difficult. She blamed others for her illness; she was unable to accept her illness as a part of herself. She looked for remedies outside herself and felt that whatever she would try wouldn't help her because her symptoms were beyond her control. Julie found it difficult and tedious to introspect. Her living her illness made her live an inauthentic life, where she would not have to take responsibilities for her behaviour. Her illness was a way to

help her cope with her problems. But in this process all she got was a deep sense of dissatisfaction with her life.

Doubting Herself vs. Believing Herself. Julie has always been in two minds about things. She did not know what to believe in; whatever she did was fraught with doubts, all her actions made her doubt whether she was doing the right thing. Whenever she would read something or pronounce something she would doubt having done the right thing. She would have images of words she had spoken to others to make sure she said the right thing. When the researcher was asking about her future too Julie had her doubts, she was unsure whether she would be able to fulfil her dreams. She had big dreams, she hoped to fulfil them through her boyfriend, but was not sure whether after knowing about her illness he would accept her. She said regarding her boy friend

“I have not told him about my illness...I don’t know how he would react...I hope to have a happy life with him...I just wish I would become better before he returns back...but I don’t know...I just hope Allah tala will make everything alright.”

Feeling Powerless vs. Feeling Powerful. Julie felt powerless about her illness, she felt unable to fulfil her desires and goals. In her relationship with her parents, she found it difficult to fulfil their expectations. This seemed to add on to her feeling of powerlessness. Julie said:

“This illness...it has made me be accused of so many things which I have not done. My parents, my siblings, my relatives everybody thinks I am feigning. I just am not able to do what I want to in life. Please tell me why this happened to me...what should I do to come out of it? I feel so helpless...I have been showing to skin doctors... have got many blood tests done...I have even shown to psychiatrists... I have got CT scan and EEG’s done...but nobody is telling me what is exactly wrong?...why do I have this...I wish to do a lot of things...when I see my other friends...they have achieved so many things in life...why am I the only one to get this...”

Discussion

The themes that seemed to re-occur in all the four life stories of the participants were the following:

- Connection vs. Disconnection
- Feeling different from others vs. Feeling similar to others
- Conditional love or acceptance
- Being authentic vs. Being inauthentic
- Trust vs. Distrust
- Feeling powerless vs. Feeling powerful
- Feeling of guilt

The Theme of Connection vs. Disconnection

In several of Ahmed’s and Shantanu’s interactions with others they seem to experience a strong sense of disconnection with their parents as well as their peers. Ahmed describes his relation with his younger brother and says,

“The youngest brother...he is not able to understand...he behaves differently...he would call me mad...if I say that lock is not closed properly repetitively he would also say the same...he would tease me...he understands me less...he teases me...but I understand he is young and doesn't understand me...the other brother understands he doesn't say anything...he understands me...”

For Shantanu too, his illness made him feel a sense of disconnection more intensely. He says:

“Even in a group...when other people are talking...I would just sit aside and listen...most of the time I would become lost in my own world...I feared participating since none of them seem to listen to me...I would feel so lost...they would not tell me things they knew...I would feel myself so small and inferior.”

Even for Julie and Prakash there existed a sense of isolation in their relation with other people. This disconnection became more apparent with the onset of the disorder, which seem to have exacerbated the sense of isolation in these individuals.

Prakash's view about his relationships with his father:

“I have never been able to share much with him; he owns a small shop and keeps busy with it the whole day. Since childhood I don't remember a single day when we would really talk heart to heart. He has always been busy. When my illness started, he said that it was all in the mind and I should try to get out of it on my own. He has not really taken much interest in how I feel or how I am coping. He fends for the family and that seems to be more than enough for him”

Julie also felt that her emotional needs were neglected, as she belonged to a large Muslim family. She says:

“My dad still understood me... he would love me and take care of me...he also took me to different doctors...but he has so many tensions...even he would get short tempered at times and would beat me if I would ask for something...I don't know whom to depend on...”

The findings are further supported by previous researches where in it was found that perceived parent-child interactions have been long linked with anxiety difficulties (Arrindell et al. 1983) and vulnerability to psychopathology closely associated with OCD such as depression (Alloy et al., 2001, 2004), however, research into the specific role of parenting in OCD is scarce and results have been largely equivocal. Ehiobuche (1988) found that students with high scores on an obsessiveness scale reported their parents to be more rejecting, more overprotective, and less emotionally warm compared with students with low obsessiveness scores. In another student sample, Trautmann (1994) reported correlations in the small to moderate range between OC symptoms and parental over-protectiveness and both anxious and avoidant attachment.

According to Guidano and Liotti (1983), ambivalent attachments are characterized as insecure parent-child transactions, where children are uncertain of the degree to which they

are loved, wanted or worthy. Perfectionism and compulsive behaviours emerge as means for securing approval and unifying one's self-perceptions as a worthy and lovable individual.

A study by Doron and Kyrios (2005) proposed that internalized attachment experiences may increase the likelihood of developing a limited number of valued self-domains (e.g., morality, job competence, social acceptability), in which the individual feels incompetent (i.e., sensitive domains). In addition, attachment experiences generalize and influence the development of the individual's perceptions of the world. Doron and Kyrios (2005) suggest that sensitive self structures underlie vulnerability to intrusive thoughts resulting in the triggering of OC related cognitions and anxiety.

Although it is difficult to identify if Julie's and Shantanu's parents had any particular psychological difficulties, one may hypothesize through their description of them that they may have had some degree of emotional difficulties. Pollock et al. (1995) argues that parents with severe psychological or psychiatric difficulties may tend either to overprotect their children or be unable to provide their children with sufficient protection or be emotionally available to them, and therefore be either emotionally absent or alternatively emotionally intrusive towards their children. Such parents may also find it difficult to guide their children in "acquiring adaptive coping strategies" (Pollock et al., 1995, p. 761).

The Theme of Feeling Different from Others vs. Feeling Similar to Others

As Ahmed, Julie and Shantanu from a young age had a sense of being different from others, they used to feel disconnected and therefore question their belonging to their family, their peer, and their relationships with people from the opposite gender and their fellow classmates.

Ahmed said,

"I don't feel like other normal people... I have these strange thoughts. While going to college I have to travel by the same path I had taken earlier. This leads me to end up wasting a lot of time and energy. If I were like other normal people I could just do anything and travel easily."

For Shantanu too this theme resonated when he was describing his relation with his peers. He often felt isolated even when he was amidst his friends. He said:

"I feel my friends...if I do some things with them... studying...I feel my confident is low...their confidence is high...if somebody ask them something...they would reply incorrectly but still they would reply...but when somebody ask me I would not reply thinking that my answer would be wrong...the confidently say that there incorrect answers are right...so I feel myself confidence has gone down...I used to feel earlier that I was better than most people...but most of the time I don't feel so..."

In July's own words,

"Things started getting imprinted in my head...I don't think anybody else has this...I don't understand why this is happening to me...and how this started...my mind just started getting disturbed...maybe it's because of early childhood experiences or I don't know...I have been asking everybody but don't get an answer."

This seems significant as Fiske et al. (1996) noted that people are likely to feel anxious when their subjective experience of belonging to a group and/or their skill to remain as members of a group is threatened. The latter seem particularly important as Ahmed as well as Julie often had the sense that they did not “measure up” to others in terms of their abilities and/or personal characteristics. Fiske et al. (1996) highlighted in order for persons to feel “competent...good and worthy.”

Ahmed and Julie were critically aware of their difficulty and need to fit in with the norms or dominant voices prescribed by the various contexts in which they functioned. According to Owen (cited in Rapmund, 2000) social constructionist see relationships between people as either conforming to or failing to fit such proposed or idealised way of relating to others. It seems as though the less Shantanu fitted with others, the more he doubted himself the more he longed to fit in. However, the more he tried to fit in, the more he felt he lacked skills and qualities to fit in and more he became anxious increasing the severity of the symptoms.

For Prakash the same thing holds. But for both of them when they do believe in themselves and focussed on the activities they enjoyed and were good at, they found that there were others who believed in them too with whom they had a sense of belonging.

For Prakash, earlier he considered himself similar and capable of taking care of his own life, now he has the feeling that things are going out of his hand. He said:

“They expect a lot from me...they take me as good student...but when I am unable to fulfill their expectation I feel guilty...it’s like I really want to, but I become helpless.”

Social constructionists argue that often people’s personal experiences or accounts of reality do not have a place within dominant belief system (Becvar & Becvar, 2000; Doan, 1997; Rapmund, 2000). It therefore seemed that Ahmed, Shantanu, Julie, and Prakash at times felt that their preferred ways and voices were silenced by more dominant voices of those in contexts in which they needed to function.

The Theme of Conditional Love or Acceptance

Rogers (cited in Meyer et al., 2003) believes that people need unconditional positive regard to be healthy and lead full lives. For Ahmed, Julie, Shantanu and Prakash love and acceptance seemed to be given based on certain conditions. This is similar to Rogers’ (cited Meyer et al., 2003) ideas regarding conditional positive regard. These conditions included that Julie abide by the strict rules of her parents and that she conforms to their wishes, both physically and emotionally.

Julie’s mother never liked her since she felt she was making excuses to escape from the responsibilities. Julie said:

“I don’t know where to take out my frustrations...I would scold my younger sister...I just can’t escape from this situation... my parents never gave me the love I had desired for... they were more fond of my elder brother who is working now...he has fulfilled their expectation...which I have not been able to do...”

For Ahmed, Shantanu and Prakash to gain acceptance meant abiding by the rules as dictated by his parents and fulfilling their expectations. When they failed to conform to their parents’ wishes at the cost of their own wishes, they felt unloved and unaccepted. They often faced

emotional and/or physical punishment. The emotional punishments seemed more prominent, and were often geared at making them feel guilty about their actions.

This seems to link in some way to Freud's ideas about punishment or guilt. In short he argues that an individual unconsciously attempts throughout his or her life to find balance between meeting his or her need, whilst avoiding punishment or guilt. However to find a workable balance seemed difficult for these individuals leading to their obsessive symptoms.

The Theme of Being Authentic vs. Being Inauthentic

In relation to their parents, it seemed as though Ahmed and Julie experienced little or no space to experience their authentic self, as their parents appeared to accept them only when they met their wishes and expectations.

Ahmed: "What can be the reason behind my illness? Don't u get it was because of lack of love...because I used to think of that girl...and to complete that emptiness...lack of good friends...this happened...to fulfill that loneliness to fill that pain...absence of the good friends...because of that pressure...I got this illness...I feel I can go back to my past life by this...like it has started I want it to remain the same...so that nothing can change...everything remain as it was... so I try like that."

For Prakash and Shantanu too expressing their authentic self was difficult, they had to conform to the societal norms to be accepted. Needing approval of others, according to Roger's (cited in Meyer et al., 2003) is a common need of all humans. It is necessary for people to feel approved or accepted as they need that approval in order to accept themselves. For Ahmed, to balance between his own needs as well as societal norms meant leading an inauthentic life with the symptoms taking an upper hand. Where in his way of getting his desires fulfilled was by living an inauthentic life whenever he tried to return back to the time when he was happy and symptom free. For Julie to balance between her unconscious desire to shun responsibilities and escape getting scolding from her mother was manifested in the form of obsessive thoughts whenever she had to work. Similarly for Prakash and Shantanu to overcome their guilt of thinking about unacceptable thoughts cleaning compulsions and reciting mantras formed a part of leading an inauthentic life.

The Theme of Trust and Distrust

This theme was apparent in Shantanu's story where he struggled to trust the connections he had with others. He always had doubts about trusting people which might have aroused since he had difficulty connecting with his parents in childhood. Ruben and Mills (cited in Weems et al., 2002) states that people who experience insecure attachments with their primary caregivers tend to develop "negative cognitive response styles," and struggle to make accurate interpersonal interpretations and often "display interpersonal distrust...of others" conflicting messages Shantanu received in his relationships with his parents seemed to leave him feeling confused about the nature of his connections with his parents.

The Theme of Feeling Powerless vs. Feeling Powerful

As pointed earlier, all the four individuals had to conform to their parents' wishes to feel loved and accepted. Moreover, the illness contributed to their feeling helpless and unable to conform to the societal norms as well as difficulty in gratifying their parents' expectations.

All these individuals found it difficult to live up to their parents' expectation because of their illness due to which their sense of helplessness and powerlessness becomes an apparent theme.

Even when Shantanu was thinking about his future he felt powerless. He felt that he would not be able to do much because of his illness. He said:

"When I am ok...I feel I will return to my old normal self...but when it becomes too disturbing I have feeling that I am not even 1% ok... and would never be able to get well."

Prakash: *"I don't feel inferior to others; I know if I want I can do as well as them, but this illness...it bounds me...however much I try I feel unable to achieve to my fullest potential...I know I can do well... but...it's extremely difficult."*

Julie: *"This illness... it has made me be accused of so many things which I have not done. My parents, my siblings, my relatives everybody thinks I am feigning. I just am not able to do what I want to in life. Please tell me why this happened to me...what should I do to come out of it? I feel so helpless...I have been showing to skin doctors...have got many blood tests done...I have even shown to psychiatrists...I have got CT scan and EEG's done...but nobody is telling me what is exactly wrong?...why do I have this...I wish to do a lot of things...when I see my other friends... they have achieved so many things in life...why am I the only one to get this..."*

Moreover, regarding their future and their ambitions too, the obsessive compulsive symptoms acted as thwarting their progress. All four of them are at a stage when their career takes centre stage in their life, but due to the OC symptoms they have been unable to perform to their fullest, leading to the sense of powerlessness. For Julie and Ahmed they think that if only they could come out the illness they would be able to achieve their dreams of becoming a lyricist for Ahmed and a producer for Julie.

Shantanu and Prakash are more realistic in their approach to life; they plan on utilising their potentials keeping in mind their limitations being imposed by the disorder.

Feeling of Guilt

This theme resonated strongly in the life stories of Shantanu and Prakash. In both the case their obsessions were related to sexual themes. These thoughts were unacceptable in lieu of the societal norms, and hence led to an immense sense of guilt. Moreover, their obsessions did not let them concentrate on their studies which further led to their deteriorating performance academically.

Shantanu: *"I think I am myself responsible for my own illness...I think now...if I would have worked hard earlier...I was dependent on medicines earlier...that I would be okay...would see for 1-2 months...I feel if at that time I would have*

worked hard to improve my condition...I think I could have been much better...I am not well yet is because of my own fault...and my illness...starting is also because of my own actions...I started thinking sinful things and then acted in wrong ways..."

Prakash: *"I feel bad...guilty of not being able to do what other people want me to do...I don't know how to cope with this guilt...I want to be an engineer in the future...then do an M.B.A and establish my own business...but if the state of affairs are like this then I don't know how far I would be able to achieve...if only I did not get this illness...I know many people have many hopes from me...I just wish I could make them happy."*

Sexual themes seem to go against the norms of Indian society, indulging in such thoughts led to a feeling of performing something unacceptable, this leads to immense guilt and feeling of social isolation which is portrayed clearly in Shantanu's life story. He considers his thoughts abominable and had this feeling of indulging in a morally wrong act.

Guilt has been implicated in psychiatric problems ranging from depression (Beck, 1972) to post-traumatic stress disorder (Klass, 1990). Its role in obsessive-compulsive disorder (*OCD*) has been frequently noted, although infrequently studied as a significant factor in its own right. Typically, those studying *OCD* have found positive correlations between questionnaire measures of *guilt* and self-reported symptoms of the disorder (Cameron, 1947; Manchanda, Sethi, & Gupta, 1979; Steketee, Grayson, & Foa, 1987; Steketee, Quay, & White, 1991). Those working with sufferers have also found that obsessive-compulsive clients in therapy report feelings of *guilt* with respect to their symptoms (Rapoport, 1989). *Guilt* has also been implicated in *OCD* since the disorder was initially conceptualized.

Behavioral theorists have suggested that the doubts characterizing the OC sufferer may be attempts to ward off feelings of *guilt* over making incorrect decisions (Rachman & Hodgson, 1980). Rosen (1975) and Salkovskis (1985, 1989) posited that profound fears of responsibility and *guilt* played a substantial role in motivating sufferers to ritualize, in much the same way as anxiety reduction motivated phobic avoidance. Conversely, some have suggested that *guilt* is most prominent in the disorder with respect to the content of obsessional thoughts, which tend to include sexual and aggressive content (Steketee, Quay, & White, 1991; Thyer, 1989).

Limitations of this Study

The researcher acknowledges that her interpretation and practical presentation of the stories were likely to be coloured by her own experiences, perceptions and values. In this regard, the researcher's participation in the interviews is likely to have influenced the way in which the interview was constructed. The researcher also acknowledges that the manner of the writing and eliciting of themes will also be coloured by her own perceptions and beliefs. Other researchers may highlight different themes/ or include other themes. Hence, the outcome of this study cannot be considered the reflection of an absolute truth about individuals with *OCD* or their lives.

Another limitation of the study was that due to the nature and aims of this study, participants were asked to share personal and sensitive information which in itself highlights ethical questions (Terre, Blanche, & Durheim, 1999). However, the researcher remained sensitive to this by using her clinical judgement throughout the interviews, and at all times,

made sure that the respondents were at ease with the degree of intensity or exploration in the interview.

Conclusion

The researcher identified themes present in all the four stories of Ahmed, Shantanu, Prakash and Julie as they emerged through her lens of analysis. Again she acknowledges that another person may choose to highlight different themes or even choose different language with which to describe the themes highlighted here. In some ways these themes link with previous studies about the childhood and/or later experiences of individuals with OCD. Even though the themes highlighted here seemed to link here and there with literature, it seems important that these themes be considered in their unique contexts of each participant's life story. Those who work with individuals with OCD in the future therefore also need to consider the emergence of some of these themes noted here within context of those individual persons with whom they interact, and be open to other themes that may emerge in the life stories of their individual clients. In a sense, the most prominent theme that the researcher felt emerged from this study, and which says something profound about her and her journey, was that of "being authentic," or remaining true to authentic self. Although other theorists have pointed to this or a similar concept and perhaps described it using different language, the researcher felt that the term "authentic self" captures the essence of what all people know themselves to be.

Areas for Focus in Clinical Practice and Future Research

In Clinical Practice

For the researcher, the sense of disconnection and feeling of powerlessness along with a search for authentic self stood out as cardinal points in understanding the phenomenology of the disorder in individual suffering from OCD. Perhaps within the context of clinical practice, clinicians might focus on exploring their clients, firstly those areas and/or those impacts from others. A further exploration could entail exploring with clients their authentic needs and various ways of expressing these within each client's individual context.

This could further extend to assisting parents, in terms of parental guidance, in allowing their children to remain in contact with their authentic beings, whilst still teaching them respect for those socially constructed rules. The researcher also found that if a person's authentic self is threatened and/or even smothered, the person may respond with symptoms which will symbolically resemble the smothering, or "fear of dying responses" true to humans. This physical reaction to fearing loss or even "death" of the authentic being is not perhaps experienced by those who have developed authentic selves that are consistent with the dominant voices of the world, and who therefore do not feel a regular threat to their authentic beings.

Suggestions for Future Research

Future research may include an exploration of effective ways in which people may remain connected with their authentic beings, and therefore not feel that they have to sacrifice their authentic selves, and still remain functioning and/or have a voice within a larger socially constructed reality or norm. This kind of inquiry may also extend to the clinical context that deals with parental guidance. Practical ways in which parents may explore with their children

their authentic needs, whilst still teaching them the socially constructed rules that are aimed at facilitating order and safety in society, may thus be explored in future studies.

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