Xenomelia and Obsessive-Compulsive Disorder: Similarities and Differences

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Abstract: Theoretical background: Xenomelia, also known as Body Integrity Identity Disorder (BIID), is a mental disorder that is characterized by a strong desire to lose one or more limbs, or a functional area of the body. There is still no consensus, where the boundaries of the definition should be set and how BIID can be classified. The scientific community is currently debating whether Xenomelia could be a sub-type of obsessive-compulsive disorders (OCD). Objective: The primary goal of this research was to improve the knowledge about similarities and differences between Xenomelia and obsessive-compulsive disorder. Method: Using the HZI-K (Hamburg Compulsive Inventory, short form), a questionnaire for collecting non-specific compulsive behavior, as well as the BIID screening for severity and intensity of this disorder, the compulsiveness of 33 Xenomelia affected participants was captured with an online survey and evaluated. The evaluation was based on the standard values of the HZI-K. Results: The test results of the 33 Xenomelia affected participants differ from the norms of the calibration sample of the HZI-K on the scales A (repetition controlling, as well as obsessive thoughts after controlling compulsions), D (counting-constrains, compulsions concerning touch, and speech), E (obsessive thoughts) and F (compulsive images to hurt oneself or others). Conclusion: It can be assumed that BIID sufferers have compulsive tendencies in terms of control, action and thought constraints.

Keywords: Body Integrity Identity Disorder, BIID, Apotemnophilia, Amputee Identity Disorder, Xenomelia, OCD, Obsessive-Compulsive Disorder

1. Introduction

Although or just because Xenomelia (also known as BIID short for Body Integrity Identity Disorder) is an unusual phenomenon, scientific discourses about characteristics and classification exist since 1977 [21]. Prevalence about the disorder can only be estimated, Horn [15] indicates that approximately 1-3% of the “clinical population” is affected. Müller [22] and Bayne & Levy [1] estimate the total number of those affected to “thousands worldwide”.

So far Xenomelia is known as a mental disorder that is characterized by a strong need to lose one or more limbs, or a functional area of the body (e.g. vision, hearing). Until today there is still no consensus, where the boundaries of the definition should be set and how it should be classified [see e.g.: 2, 4, 5, 6, 7, 8, 10, 13, 16, 17, 18, 20, 21, 26, 27, 28]. But those affected rely on current research for more clearance and a better understanding of their own disorder and for a chance for therapy and acceptance within the classification systems.

The scientific community is currently debating whether Xenomelia could be a sub-type of obsessive-compulsive disorder (OCD).

In particular S. Müller [22] pointed out repeatedly that Xenomelia has a propinquity to obsessive compulsive disorder: "Among physicians and psychologists exists a controversial discussion whether the amputation desire results from a neurotic disorder, obsessive-compulsive disorder, an identity disorder or a neurological body dismorphic disorder prevails..."..."Just like patients with body dismorphic disorder BIID-patients suffer from uncontrollable, compulsive thoughts about their outer appearance. [...] Distinctive for this disorder are intellectual compulsive concerns but also practical concerns about the bothersome body part. This disorder is correlated with obsessive compulsive disorder; [...].” [22].

The great differences concerning possible classifications (like paraphilia, identity disorder, body dismorphic disorder,
neurological- or obsessive-compulsive disorder) emphasises the need for further research to finally come to an unambiguous definition and thus to be able to derive a therapy from these basics.

By regarding the characteristics of Xenomelia and obsessive-compulsive disorders it seems possible that Xenomelia can be a type of obsessive compulsive disorders. The criteria to classify an obsessive compulsive disorder fit several of the symptoms described from Xenomelia affected people.

Characteristic for both phenomena are imposed thoughts, imaginations or impulses which were not brought up on purpose but neither can be suppressed. Regarding Xenomelia these can be thoughts about amputation, the wish for a disability or in some cases the wish to be blind. The content of these thoughts, imaginations or impulses can be regarded as pointless or ineffectual. Those who are affected are aware of the uselessness of their own thoughts, imaginations or impulses; they feel bothered by those and suffer from psychological strain.

Obsessive thoughts can be classified in different kinds such as:
- aggressive obsessive thoughts;
- obsessive thoughts concerning contamination;
- obsessive thoughts with sexual contents;
- obsessive thoughts concerning collecting and storing objects (hording);
- obsessive thoughts with religious themes or contents which produce (remorse);
- obsessive thoughts focussing on symmetry or accuracy;
- obsessive thoughts concerning the own body.

Thoughts which are typical for Xenomelia would fit into the categories aggressive obsessive thoughts, (like fantasies about cutting off / amputating or getting rid of an unwanted body part in some way), obsessive thoughts concerning the own body, but also into the category obsessive thoughts with sexual contents.

One third of those affected feels sexual arousal from the imagination of amputees or being amputated oneself. Even though sexual components can be symptoms of Xenomelia, differential disorders, like paraphilia need to be excluded first.

Further criteria for the diagnosis of obsessive compulsive disorder are obsessive impulses that are defined as behavioural forces (impellents) with aggressive and/or sexual character, rejected or condemned (judged as forbidden) but penetrating into awareness. Mutually in both disorders those affected often show visible behaviours or compulsive acts fitting this definition. The criteria compulsion and pretending describes stereotype acts or rituals which are used purposely to reduce discomfort or fear evoked (aroused) by obsessive thoughts / images or impulses and can be found as a symptom of both disorders, even though (their contents) differ between the disorders. Xenomelia affected usually pretend to be handicapped by using a wheelchair or by tying one leg up onto their body.

The compulsion or pretending is not inherently enjoyable. Tying a healthy leg up -- as Xenomelia affected often do as a form of pretending -- arouses pain after a certain time. Stirm et al. [28] could also verify the so called rebound effect (which is a typical result of obsessive compulsive symptoms) for pretending. Overall the affected patients of both disorders suffer and cannot find their way out of the disorder. In the course of time obsessive behaviours and rituals, used to prevent an alleged damage, get out of hand, require a lot of time and determine the whole daily routine, which impedes the accomplishment of everyday life immensely.

Both disorders have in common that they arise in early childhood or adolescence, their progress is chronically but the intensity of the symptoms varies. Actually the only difference between both disorders is the need for an amputation, which is yet not known as a content of obsessive compulsive disorders. Thus, the goal of this study is an initial approach whether Xenomelia can be explained as a sub-type of obsessive compulsive disorder.

The most common kinds of obsessive compulsive disorders are obsessions of controlling, repeating, counting, collecting, hording, tidying, sorting, cleaning and washing. They are named after the main obsessional content wherefore Xenomelia could be regarded as an amputation obsession.

2. Methods

2.1. Data Collection

All participants were informed about the intentions, requirements and ethical guidelines of this study. The subjects were given the opportunity to ask questions or voice concerns. All participants received a document for informed consent. The study was carried out in accordance to the ethical standards as defined in the Declaration of Helsinki. According to the participant’s data all acquirements of the screening instruments especially those of the HZI-K were fulfilled.

The data were collected over a period of 40 days in summer 2014. In order to simplify the process for the participants all questionnaires were made available online. The online version of the questionnaire was available in a German and an English variation, created with the help of “Google Formulare”. This allowed a computerized data collection.

In addition, ten participants with a secured obsessive-compulsive disorder filled out paper and pencil versions, which were transferred into digital data. All data were evaluated with the help of SPSS and EXCEL.

2.2. Sample Description

The total sample of this study (n=76) consists of three groups:
- Participants with obsessive compulsive disorder (10);
- BIID/Xenomelia affected participants (33);
- a control group with no psychological diagnosis or symptoms (33).

Investigation of the socio-demographic data showed that the sample consisted of 45 (60%) men and 31 (40%) women. The average age was 42.1 years with a range from 16 to 77 years. 93% of the participants were German, 4 % came from
Switzerland, but also a minority of 1% each came from Austria, South Africa and the USA. According to their professions all participants belonged to an equal middle social class. Within the recruitment the control group was obtained according to the sociodemographic characteristics of the Xenomelia affected or obsessive-compulsive diagnosed patients.

2.3. Inventory Descriptions

The Hamburg Compulsive Inventory (short form; originally named: “Hamburger Zwangsinventar”, [31]), the Body Integrity Identity disorder screening instrument for severity and intensity from M. Fischer [11, 12]. Because none of the existing obsessive-compulsive screening instruments captures the specific typical compulsive behaviour of Xenomelia affected people, it was necessary to develop an own questionnaire named “Questionnaire for detecting non-specific compulsive behavior” (“Fragebogen zur Erfassung unspezifischen zwanghaften Verhaltens; FzEuzV”). The FzEuzV-questionnaire consists of two parts with a total of 9 items: Part A contains five statements, on a unipolar frequency scale (from "strongly disagree" to "strongly agree"). These statements should be ranked according to the extent of consent. The implementation- and evaluation objectivity is thus given by the predetermined response scale. The statements have been derived in accordance with OCP criteria according to ICD-10. Part B, with a total of four items, is based on the "Zwangs-Check", a screening instrument for OCP of the Christopher-Dornier Clinic in Germany [32]. This instrument measures the extent to which those affected suffer under their compulsiveness and experience restrictions or limitations in their daily life within the last month. Also Part B should be assessed on a unipolar frequency scale by the participants according to their degree of agreement. Through clear instructions and predefined answers also part B of the test ensures the implementation- and evaluation objectivity.

The BiID screening instrument for severity and intensity [11, 12] was used in this study to confirm the diagnosis of Xenomelia (BiID) and to classify the severity of the disorder. According to Mrs. Fischer, the screening instrument has a Cronbach's Alpha of .929 and reliability scores higher than 0.7 [11]. Standardized instructions, constant questions and largely predetermined response options secure objectiveness within the execution, analysis and interpretation of the questionnaire. The screening instrument is thus able to detect and to classify Xenomelia in its extent.

The HZI-K (“Hamburger Zwangsinventar”) is a standardized instrument for the diagnosis of obsessive-compulsive disorder; its validity was proven in numerous studies and the test retest reliabilities (2 weeks after the first testing) for each HZI scale lie between r = .78 and r = .96; the retest reliability for the overall test is r = .9.

The HZI-K was used because it differentially depicts obsessive thoughts and behavioural compulsions. The short form of the HZI still consists of six dimensions, which were explored with the 72 most significant items. All items are operationalized and according to the test manual free from personality psychological or neurosis theoretical concepts. The six subscales of the HZI-K depict compulsions of: A) repetition controlling, as well as obsessive thoughts after controlling compulsions B) washing and cleaning, C) sorting, D) counting-constrains, compulsions concerning contact/ touch, and speech; E) obsessive thoughts F) compulsive images to hurt oneself or others. The HZI-K can be used for people age 16 or older. Only patients who have a severe endogenous or neurotic depression, massive compulsive constraints or mania are excluded. Also patients with suicidal tendencies may not fill out this test form. Additional questions within the test battery ensured that these requirements have been made. All scales are independent of symptom duration or patient’s age.

3. Results

The results of the BiID screening instrument for severity and intensity from Fischer were transformed into arithmetic means which were classified in accordance with the standard values developed by Fischer [11, 12]. The sample of this study showed variations from very low up to medium extents of severity of Xenomelia. All Xenomelia-volunteers could therefore be identified as secured BiID diagnosed patients. For the tested sample of n = 76, a Cronbach's alpha of 0.797 was calculated for the HZI-K. Considering the scales separately the values became lower, especially for the scales A (0.612), B (0.505) and C (0.427).

Critical differences were calculated to identify simulation tendencies. In a deviation from d_{crit} by more than 5% between the sums of the raw values of the lowest to the highest difficulty level, simulation tendency seems to be likely. This calculation is only useful as long as the raw values of the second difficulty level are bigger than zero. According to this formula in a few subjects of different samples at different scales simulation trends could be identified.

Since the newly developed FzEuzV is not a standardized instrument the degree of internal consistency was checked first. Part A of the questionnaire had a Cronbach's Alpha of 0.898; for part B a Cronbach's Alpha of 0.905 could be calculated. Both parts aligned came to a Cronbach's Alpha of 0.938. These values are within the excellent range and confirm that the items of this scale content the same construct, in this case, compulsiveness or restrictions and strains as results of compulsiveness. The item selectivity with > .68 for the individual items confirms this, thus no item needed to be excluded from the analysis. The questionnaire was evaluated by a numerical assignment of the possible answers presented in form of a Likert-scale. The numbers are rising from 1 up to 5 per item according to the degree of agreement. The critical cut-off value for the diagnosis of OCD for Part A of the test (consisting of 5 items) is ≥ 10 points. The critical cut-off value for the diagnosis of OCD on Part B (consisting of 4 items) is ≥ 8 points. (The cut-off values were set according to those of the
Christopher-Dornier Clinic, [32]).

Figure 1. The above shown figure depicts the results of the participants with obsessive-compulsive disorder (OCD), those with no known psychologically symptoms: control group (C) and Xenomelia affected people (X), achieved in the “questionnaire for nonspecific compulsive behaviour” (FzEuzV). As the figure displays, the OCD sample exceeds the respective cut-off values (marked as red lines). These patients therefore count as conspicuous (concurring to their already secured diagnosis) according to obsessive-compulsive symptoms. Both other groups reveal abnormally high values. However the Xenomelia affected sample does not only exceed the cut-off values but also those of the control group.

As shown in figure 1 the sample of OCD patients (colored purple in figure 1) came to a total average of 19.3 (SD ± 1.1) in Part A and a total average of 13.0 (SD ± 0.9) in Part B. Thus, the total values of these patients in both test parts exceed the respective cut-off values (red lines in figure 1). These patients therefore count as conspicuous (concurring to their already secured diagnosis) according to their known obsessive-compulsive symptoms. The sample of Xenomelia affected persons (drawn blue in the figure 1) reached a total average of 9.9 with a standard deviation of ±1.4 in Part A and a total average of 7.8 with a standard deviation of ±1.2 in part B. A total of 39% of Xenomelia affected achieved levels of ≥10 in Part A and 42% of those affected achieved levels of ≥8 in part B. The control group (colored orange in figure 1) achieved sum averages of 9.3 (SD ±1.2) in Part A and sum averages of 7.2 (SD ±1.0) in Part B. Thus Xenomelia affected do not only have results exceeding the cut-off values (see red lines in the figure) but also those of the control group.

Regarding these results, 39% of the Xenomelia sample fit into the diagnosis criteria of OCD. 42% answered to feel restricted in their daily lives, 86% of this group had compulsive constrains according to Part A of the test. It can be concluded that the restrictions experienced in everyday life result from the symptoms depicted in Part A (namely compulsiveness/ obsessiveness).

For further evaluation such as significance testing the conditions for parametric testing methods were checked first. As serious violations of the normal distribution were found a non-parametric method for the significance testing was chosen.

The Mann-Whitney test for independent samples shows that the central tendencies of OCD patients with a 5% - level differ significantly (p = .000) of the control group. Because the data had ordinal level only ranks could be calculated. The mean rank of the OCD patients was calculated as 34.78 by SPSS and the mean rank of the control group was calculated as 17.88.

The U-test for the sample of Xenomelia-affected and OCD patients showed at a 5% level statistically significant differences of central tendencies between the groups, because here the exceedance probability is p = .000. (Here the mean rank of OCD patients was calculated 34.20, the mean rank of the Xenomelia affected sample was 18.30). However, the results of the Xenomelia affected group did not differ statistically significant at a 5% level with a p-value of .816 from those of the control group (mean rank Xenomelia affected sample: 32.95; mean rank control group: 34.05).

To show the abnormalities of Xenomelia affected in terms of compulsion compared to psychological unsuspicious people their test results taken from the HZI-K were compared with the standard values presented in the HZI-K manual as shown in figure 2. As cut-off value the first and third quartile were chosen. Values that are below the first or above the third quartile are considered as conspicuous.

Figure 2. The table is taken from the HZI-K manual and depicts the percentile norms for psychologically unsuspicious people. The 1st and 3rd quartile are marked with green circles.

As shown in figure 2, the Xenomelia affected group (X) obtained values that are significantly different from the 1st and 3rd quartile of the control group (C) as well as from the Xenomelia affected group (X).

Figure 3. The figure above depicts the results (raw values) of the Hamburg Compulsive Inventory (short form) for each scale (A-F) achieved by the Xenomelia affected sample (X) and the psychologically unsuspicious group (N) (according to the HZI-K manual). The raw values of the 33 Xenomelia affected participants differ from the norms of the calibration sample of the HZI-K on the scales A, D, E and F. Therefore it can be assumed that Xenomelia affected show compulsive tendencies related to control, and counting compulsions as well as thought constrains. Compulsive tendencies in relation to washing – or sorting compulsions can be expelled.

Figure 3 depicts the test results as raw values from the HZI-K. The green circles show the cut-off values taken from the HZI-K manual (compare figure 2). By this standard, 52%
of the results of the Xenomelia affected were conspicuous compared to average values on scale A (controlling compulsions, repetitive controlling compulsions as well as obsessive thoughts after controlling compulsions), 33% on scale E (E: obsessive thoughts) and 27% on scale F (F: compulsive image to hurt/harm oneself or others). 15% of those received values higher than the cut-off values on scale A and E and 27% received higher values on scale F, which can easily be seen in figure 3.

Figure 4 illustrates whether the results of Xenomelia affected people differ from those of the control group or from the group of psychologically unsuspicious people measured by the HZI-K. In addition the figure reveals how much each group differs from the norm/ cut-off values (taken from the HZI-K manual-drawn as green lines).

To verify the general hypothesis that Xenomelia is closely linked to OCD the raw values of the HZI-K were compared to those of the control group to reveal abnormalities referring to compulsiveness. Here the raw values of the control group were used because the HZI-K norm values are only given as percentiles, which are not so exactly as the raw data.

As reasoned before the Mann-Whitney test was used. The following p-values resulted for each scale: Scale A: \( p = .0435 \), Scale B: \( p = .031 \), Scale C: \( p = .0225 \), Scale D: \( p = .0065 \), Scale E: \( p = .414 \), Scale F: \( p = .389 \). Because the values of scale A - D are below the level of significance of \( p < .05 \), it can be assumed that statistically significant differences between the groups exist.

Figure 4 illustrates the results found for scales A – F.

The distribution on scale A of Xenomelia affected is much higher than the one of the norm values of the HZI-K. As scale A of the HZI-K captures control actions, repetitions of control actions and notionally check for an action. The increased values which were found for this scale among Xenomelia affected, provide information about the fact that people affected from Xenomelia have compulsive tendencies.

In contrast to the box-plots in figure 4 in which the mean raw values (and ranges) between Xenomelia affected and psychological unsuspicious people are equal, the results of the Mann-Whitney Test showed statistically significant differences between the central tendencies of scale B (\( p = .031 \) < .05). These differences can be explained by the different values between Xenomelia affected and those of the control group. In this study the control group achieved abnormally low values on scale B (compared to the norm defined in the HZI-K manual) and therefore differs significantly from the Xenomelia affected sample. Therefore a connection between Xenomelia and compulsions in terms of washing and cleaning can be excluded.

Figure 4 also shows that the findings from the U-test for scale C results from the abnormally low values within the Xenomelia affected sample. The values of Xenomelia affected in scale C do not exceed the standard values for psychologically unsuspicious people of the HZI-K. Thus, this figure reveals that in contrast to the result of the U-Test Xenomelia affected people clearly do not show tendencies of compulsiveness on this particular scale (C: sorting compulsions).

Also in scale D (counting- compulsions, compulsions concerning contact and speech) the lower quartile of the distribution of the Xenomelia-affected lies below the distributions of psychologically unsuspicious people of the HZI-K and the one of the control group. Again, figure 4 reveals that the extremely significant outcome from the U-test (\( p = .0065 \) < .05) may result from the differences between the values of Xenomelia-affected and those of the control group, because here again the values of the control group differ from the norm range. Nevertheless, the distribution of the Xenomelia affected, shows even higher values in comparison to the values of psychologically unsuspicious people.

In scale E the distribution of values of Xenomelia affected is identical to the distribution of the control group, thus no significant differences could be found within this scale. Comparing the values, however, with the standard values of psychologically unsuspicious people, Xenomelia affected received higher values. Thus, it can be concluded, that Xenomelia affected show tendencies of obsessive thoughts/ thought constrains.

On scale F the values of Xenomelia affected are higher than those of the other two groups (control group and OCD patients). The U-test showed no significant differences of central tendencies between the values of Xenomelia affected and those of the control group on scale F, since no differences in skewness and between the arithmetic means of the distributions could be found. The distribution of the standard values, presented in the HZI-K for psychologically unsuspicious people, also differ from the values of Xenomelia affected, as figure 4 reveals. According to the HZI-K manual, scale F describes the compulsive constrain to harm oneself or others. The screening instrument for severity and intensity
from Fischer asks for attempts and thoughts concerning self-harm and the wish for an amputation or handicap. The numeric assignment of values from 1 to 6 added up to an average value of 3.3 with a standard deviation of ±2.2 for this item, which proofs that the thought of self-harm truly does exist among Xenomelia affected. On the other hand most of the affected strive for a pain free operation. In addition, it can be assumed that many Xenomelia affected do not regard the injury (resulting from an amputation) as a painful restriction but rather as a satisfaction.

Thus the scale definition „to harm/ injure oneself or others“ can be regarded as unfavourable in this context, nevertheless the results show that Xenomelia affected achieve abnormally high values.

As expected from the theoretical basis, meaningful results were found on the scales A, D, E and F, which differs from the values of the control group and are higher than the norm values, presented in the HZI-K.

As expected these findings verify that Xenomelia affected show compulsive tendencies related to control, and counting compulsions as well as thought constrains. On the other hand, compulsive tendencies in relation to washing – or sorting compulsions can be excluded.

4. Discussion

Overall, the results of this work were able to show statistically significant results in some scales of the HZI-K. The values obtained give reason to believe that Xenomelia affected certainly show tendencies towards compulsiveness. The consideration to classify Xenomelia as an own form of OCD is based on the assumption that Xenomelia-typical thoughts, such as the desire for an amputation or disability can be regarded as thought constrains. It is conceivable that the so-called pretending can be seen as control compulsion, used to break down the tension built up from thoughts ruminating about amputation. So far these are only hypothetical considerations. However, they are emphasized by the fact that tendencies towards control and thought constraints were found in this study. Taking into consideration, that the sample of this study was very small the findings are even more meaningful (as it is known to be difficult for small sample sizes to become significant). Another important fact considering the results is that the control group of this study was not psychologically tested. Therefore the results may be influenced by the fact that not all participants of the control group were free from any kind of psychological symptoms.

Xenomelia-typical patterns of thinking or behavior cannot yet be fully depicted in previous/ existing categories (e.g. sorting-, counting-, cleaning compulsion etc.). Thus, no existing OCD screening instrument is able to depict the whole extent of compulsiveness within Xenomelia. Therefore in future studies an independent screening instrument, such as the FzEuZV, should be used. Only then it can be ensured that Xenomelia-typical symptoms are recognized as compulsive. This requires the standardization of a much larger sample of OCD patients, Xenomelia affected and a control group, which can be classified as clinically normal after careful diagnosis. Another verification of results could be carried out additionally by external assessments or standardized interview processes.

Like most this study was a pure psychological-psychiatric description and survey. As neuroscientific methods are perceived as more objective further studies should include both methods. However, the few available experiments show discordant or no statistically significant results [29]

Nevertheless also studies that find no statistically significant differences [30] between Xenomelia affected and control groups deliver results and new perspectives. Eventually the idea of Xenomelia being e.g. a parietal lobe dysfunction [3, 14, 20] also shows parallels to neurological findings concerning OCD [19, 25].

"As for the desire to amputate a healthy limb or to be paraplegic, it has not yet been proven whether brain differences are preexisting or follow from this atypical behaviour.[31] It is the classical dilemma of nature or nurture: which comes first?“ [24]

If the above established consideration: Xenomelia may be a previously unknown form of OCD, could be proven it is conceivable that in the future with the help of specialized treatment or therapy those affected may not only be freed from suffering, but may lose the desire for amputation or disability.

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