

# Evaluation Of The Knowledge And Attitudes About Hypospadias Of The Parents Of Children Diagnosed With Hypospadias: A Qualitative Study

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## Abstract

**Purpose:** The purpose of the study to determine the knowledge and attitudes of the parents of children diagnosed with hypospadias.

**Methods:** This descriptive study conducted on the families of children diagnosed with hypospadias and discharged from a pediatric surgery clinic in a state hospital in Istanbul between April 2018 and December 2018. Data collected with parent information form, type recorder, semi-structured interview. Content analysis was used to evaluate the qualitative data. Research results are reported according to the COREQ Checklist.

**Results:** After analyzing the interviews of the participants, eight themes have been created: "Inaccuracy of information about hypospadias", "The fact that the information is not clear and understandable by the family", "Anxiety about the surgery and the prognosis of the disease in the pre-operative period", "Fears about the process and after the surgery", "Positive emotions after surgery", "Negative emotions after surgery", "Supporting post-operative care", "Importance of cosmetic appearance",

**Conclusion:** It was found that the parents did not have enough information about hypospadias and the postoperative process adversely affected the attitudes of the parents towards the disease.

**Keywords:** Attitude; children; parents; hypospadias.

## Özet

**Giriş:** Hipospadias 300 doğumda bir görülen konjetinal doğum anomalisidir. Toplumda görülme sıklığının fazla olması nedeniyle bu hastalığa sahip olan ailelerin bilgi ve tutumlarının bilinmesi önem taşımaktadır.

**Amaç:** Araştırma hipospadiaslı çocuğu olan ailelerin bilgi ve tutumlarının incelenmesi amacıyla yapılmıştır.

**Yöntem:** Tanımlayıcı olan araştırma Nisan 2018-Aralık 2018 tarihleri arasında İstanbul'da bir eğitim araştırma hastanesinin çocuk cerrahisi kliniğinden taburcu olmuş 31 hipospadiaslı çocuğun ebeveyni ile yapılmıştır. Veri toplama aracı olarak; Ebeveyni Tanıtıcı Bilgi Formu, Ses Kayıt Cihazı, Yarı Yapılandırılmış Görüşme Formu kullanılmıştır. Niteliksel verileri değerlendirmek için içerik analizi yapılmıştır. Araştırma sonuçları COREQ Checklist'e göre raporlanmıştır.

**Bulgular:** Katılımcıların görüşmeleri çözümlenmiş ve sekiz adet tema oluşturulmuştur: "Hipospadias Hakkında Doğru Bilgiye Sahip Olmama", "Yapılan Bilgilendirmenin Aile Tarafından Açık ve Anlaşılır Bulunmaması", "Ameliyat Öncesi Dönemde Ameliyat ve Hastalığın Prognozuna İlişkin Anksiyete", "Ameliyat Süreci ve Sonrasına İlişkin Korkular", "Ameliyat Sonrası Olumlu Duygular", "Ameliyat Sonrası Olumsuz Duygular", "Ameliyat Sonrası Bakımın Desteklenmesi", "Kozmetik Görünümün Önemi".

**Sonuç:** Ebeveynlerin hipospadiasla ilgili yeterli bilgiye sahip olmadıkları, ameliyat sonrası sürecin ebeveynlerin hastalığa karşı olan tutumlarını olumsuz etkilediği saptanmıştır.

**Anahtar Kelimeler:** Aile; çocuk; hipospadias; tutum.

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**Received:** 10 March 2023

**Accepted:** 16 September 2023

## Introduction

Hypospadias is a congenital birth anomaly that is seen in approximately one in 300 births and is characterized by the urethral meatus being located proximal instead of ventral to the penis. (1). Although the etiology of hypospadias anomaly is not known exactly, it is thought to be affected by many factors such as environmental, genetic and endocrine causes (2,3). The only treatment method for hypospadias, which is easily diagnosed in the routine examination of the neonate (4), is surgery. (5).

Nursing care gains importance in hypospadias anomaly due to both the psychological status of the child and the parents and the variability of the surgical procedure. Hypospadias care includes pre and post-operative care (6). The nurse, who will carry out the care in a holistic manner during the operation, should ensure that the child and parents are informed about the pre and post-operative procedures and its complications. (7).

Attitude literally means "the way taken, the manner". (8). According to another definition, attitude is defined as "a relatively stable organization of beliefs, feelings, and tendencies towards something or someone, the object of attitude". (9). Attitudes are individual and cannot be observed. Observing attitudes is only possible if it is reflected in behaviour. It is difficult to change because they emerge as a result of experience. If the attitude that develops in the face of thoughts and objects is positive, positive behaviours emerge. Even if a negative attitude is developed, behaviours such as adopting, rejecting, and distancing can be seen. (10). As in hypospadias, the parents who experience stress due to the necessity of a surgical intervention may develop ignorance and negative attitudes towards the procedures performed in the hospital. For this reason, family-centred care should be applied in the care of the child, and the child and the family should be considered as a whole (11). Knowing the attitudes that may occur against any event or disease increases the quality of care by ensuring that the nursing care is effective. (12).

Based on this information, the study was planned to determine the knowledge and attitudes of the families of children diagnosed with hypospadias.

### Research Questions

1. Is the knowledge of the families of children with hypospadias sufficient about the disease?
2. Does the postoperative period affect the attitudes of families about the disease?

The research, which was planned in the phenomenology design, which is one of the qualitative research methods, was carried out in the paediatric surgery service of a

training and research hospital in Istanbul between April 2018 and December 2018.

### Participants

The population of the study consisted of the parents of children with hypospadias who had undergone surgery in the paediatric surgery service of a training and research hospital. Purposive sampling method was used in the research. Parents who met the criteria for the children of the families to have had hypospadias surgery and to voluntarily participate in the study were included in the study. Participants who did not complete the focus group interview were excluded from the study. The sample did not calculate. The study was concluded when the data were satisfactory. The study was concluded with 31 parents.

### Data Collection Tools

**Parent introductory information form:** The form consists of 6 closed-ended questions containing sociodemographic characteristics of parents (age, education level) prepared by the researcher by the literature.

**Semi-structured interview form:** The form consists of 6 semi-structured interview questions prepared by the researcher in line with the literature:

1. Did you know about what hypospadias was before the diagnosis? Please explain.
  2. Were you sufficiently informed about the hypospadias surgery before the operation? Please explain.
  3. What were your preoperative concerns? Please explain.
  4. How did you feel on the day of the surgery? Please explain.
  5. How did you feel after the surgery? Please explain.
  6. How did you feel when you returned home after the surgery? Please explain.
- 6.1. Are you satisfied with the postoperative appearance and voiding function? Please explain.

### Data Collection

Data collection was carried out in the presence of a moderator (researcher KT) and a reporter by means of a mini group interview consisting of 4-6 people. A pilot study was conducted with a group of 5 people in terms of the intelligibility of the questions. Since the participants stated that the questions were understandable, no correction was needed. The study was concluded when the data were satisfied with a total of 31 parents. Verbal permission was obtained from the parents for the interview and a common time frame was determined. The interviews were conducted in the form of face-to-face focus group discussions. Name badges were distributed to the parents participating in the study.

Before starting the interview, it was stated the purpose of the study, a voice recorder would be used during the interview, and that the information and ideas received would not be shared with anyone and would remain confidential. Written consent of the parents was obtained with the "Information Consent Form". First of all, demographic information of the parents was collected with the "Parent Introductory Information Form". During the interview, the parents' feelings, thoughts, attitudes and opinions about the research topic were obtained through semi-structured interview questions. The information was recorded on the voice recorder. The duration of the interviews was between 45 and 60 minutes. The interviews were concluded when the participants started to have similar feelings, thoughts and opinions, that is, when they reached satisfaction.

### Data Analysis

In the analysis phase, all the answers, reactions, moments of silence, etc. of the participants were recorded by making use of the observation notes and it was translated into writing in a short time after the interview in order to avoid data loss. In the first stage of the analysis of the data, firstly, meaning extraction (1st level coding) was made from these data in line with the purpose of the research. In the second stage, the data were classified (2nd level coding). In the third stage, themes were created in line with the classified data (3rd level coding) (13). In terms of reliability, the data were analysed by another expert besides the researcher.

The records were listened to by a second expert who is an expert in pediatric nursing and has scientific studies on qualitative research method, and they were translated into writing independently of the researcher, and the themes were finalized by comparing them with the codes created by the researcher. In the analysis of sociodemographic characteristics, number, percentage, mean and standard deviation were used according to the normal distribution characteristics of the data. Research results are reported according to the COREQ Checklist.

### Ethical Considerations

Ethical approval was obtained from the Ethics Committee of Marmara University Health Sciences Institute with the approval number 78 dated 05.03.2018. Written and verbal consent was obtained from all participants. Research and publication ethics were complied with in the article.

### Results

Sociodemographic characteristics of the parents participating in the study are shown in Table 1.

**TABLE 1: Sociodemographic characteristics of parents**

| Characteristic                              | n         | %          |
|---|-----------|------------|
| <b>Education</b>                            |           |            |
| Literate                                    | 1         | 3.23       |
| Primary school                              | 4         | 12.90      |
| Secondary school                            | 9         | 29.03      |
| High school                                 | 10        | 32.25      |
| Associate degree                            | 2         | 6.46       |
| Bachelor's degree                           | 4         | 12.90      |
| Master degree                               | 1         | 3.23       |
| <b>Number of children whom parents have</b> |           |            |
| 1   | 12        | 38.70      |
| 2   | 10        | 32.25      |
| 3   | 7         | 22.59      |
| 4   | 2         | 6.46       |
| <b>TOTAL</b>                                | <b>31</b> | <b>100</b> |

As a result of the focus interviews held during the research process eight themes namely "Inaccuracy of information about hypospadias", "The fact that the information is not clear and understandable by the family", "Anxiety about the surgery and the prognosis of the disease in the pre-operative period", "Fears about the process and after the surgery", "Positive emotions after surgery", "Negative emotions after surgery", "Supporting post-operative care", "Importance of cosmetic appearance", were created and related results were presented.

#### Theme 1 Inaccuracy of information about hypospadias

When the parents participating in the research were asked the question "Did you know about hypospadias?", the majority of them stated that they heard the disease from the internet source, from the people around them, from their relatives.

#### Theme 2 The fact that the information is not clear and understandable by the family

When the question of the adequacy of the information given to the parents was asked, they stated that they were not informed or that the information provided was not sufficiently understood.

#### Theme 3 Anxiety about the surgery and the prognosis of the disease in the pre-operative period

When the parents participating in the study were asked about their preoperative concerns, they expressed many concerns about the surgery and the prognosis of the disease. Some of these are: sexual problems, inability to

have a child, the psychological state of the child, the fear of being able to get out of the surgery.

#### **Theme 4 Fears about the process and after the surgery**

When parents were asked how they felt about the surgery on the day of the surgery, most of them stated that they were sad, stressed, fearful that the surgery might repeat, restless, distressed and nervous.

#### **Theme 5 Positive emotions after surgery**

When parents were asked how they felt after the surgery, most of them expressed positive emotions such as relief, gratitude and happiness.

#### **Theme 6 Negative emotions after surgery**

When parents were asked how they felt after the surgery, some of them stated that they cried, panicked and felt uncomfortable seeing their children with medical devices like foley catheter.

#### **Theme 7 Supporting post-operative care**

When parents were asked about what they experienced and felt on returning home, they stated that they had difficulty in providing post-operative care, the development of complications made care difficult, they had a bad period and they could not get support from physicians for home care.

#### **Theme 8 Importance of cosmetic appearance**

When parents were asked whether they were satisfied with the post-operative appearance, some stated that they were satisfied, while others stated that they were not.

## **Discussion**

The discussion section was written under the theme titles obtained from the research results.

#### **Theme 1 Inaccuracy of information about hypospadias**

In a study evaluating the experiences of hypospadias surgery, it was concluded that only 28% of hypospadias was noticed by the family. (14). On the other hand, Özgör ve ark. found that the diagnosis was made mostly by the doctor and traditional circumciser (15). It was determined that parents generally searched for information about hypospadias from the internet, heard from their friends or learned during the doctor's examination when they went to the hospital to be circumcised. This suggests that families do not have enough information about hypospadias.

Illness perception and health beliefs are affected by the society and culture in which the person lives (16). Knowing hypospadias as the circumcision of the prophet in our society may cause delays in the diagnosis of the disease. These studies are similar to the findings of the research.

#### **Theme 2 The fact that the information is not clear and understandable by the family**

In the studies in which the literature was accessed, it was found that the information provided was not clear and intelligible because the information period was short, explanations were made using medical terms or the physicians did not inform sufficiently (17-18). Parents who participated in the study stated that the information provided by the physicians was generally insufficient and sometimes they could not get any information at all. Although the families signed the informed consent, they stated that the information was insufficient. These statements are consistent with the research.

#### **Theme 3 Anxiety about the surgery and the prognosis of the disease in the pre-operative period**

Fear of surgery, fear of repeat surgery, small child, fear of complications, etc. These situations cause families to experience fear and anxiety. Due to the importance given to the penis in Turkish society, families may feel high anxiety. In the literature, it is stated that preoperative anxiety is an expected situation and is generally moderate in severity (19-21).

#### **Theme 4 Fears about the process and after the surgery**

In studies on the subject, parents' concerns and fears about anesthesia were found to be quite high (19,21,22). It is thought that parents develop a fear of anesthesia because of their insufficient knowledge about anesthesia and their fear of its side effects. In the study of Karadağ Arlı, it was determined that the surgery creates different emotions in people and they feel different intensities according to the degree of surgery (23). These findings are the emotions that apply to the parents of the child who has undergone surgery. Families feel anxious and fearful when their children undergo surgery.

#### **Theme 5 Positive emotions after surgery**

Karaman Turan mentions that families experience anxiety for reasons such as not being able to help their children, reducing their pain, and invasive procedures (22). In the study of Karaca Çiftçi et al., it was concluded that the anxiety of the parents was high on the day of surgery (21). The same results were obtained in this study. After the surgery, it was determined that the anxiety left its place to the feeling of relaxation.

#### **Theme 6 Negative emotions after surgery**

In studies conducted on day case surgery, the causes of anxiety in parents were found to be inability to wake up after anesthesia and not being able to control pain at home (19). Mutlu and Savaşer concluded that emotional support was provided to parents by informing them about the appearance of their children after the surgery (24). It is thought that informing families about home care will reduce the anxiety of the family. It is thought that

informing families about how their children will look after hypospadias surgery will make them feel comfortable.

### Theme 7 Supporting post-operative care

Studies have shown that the burden of caregiving varies from person to person (24, 25). It has been found that the burden of caregiving changes depending on the patient's illness, daily working process, and the effect on social life. In the study, families stated that they had difficulties in home care. Pfeil et al. stated that nurses take on many roles during the operation process and have important contributions to the success of the operation (preparation for surgery, pain control, wound care, preparation for discharge, etc.) (26). In a study, it was determined that the rate of giving information about home care was 57.1% (27). It is thought that providing information about home care while sending children with hypospadias home will help in the care of the family and increase the speed of recovery.

### Theme 8 Importance of cosmetic appearance

When studies on this subject are examined, penile appearance and voiding function were found to be variable according to prognosis and mean age in cases operated for hypospadias. Appearance is evaluated differently according to individuals, and post-operative satisfaction is stated in general (28-30). The results are consistent with this research.

### Limitations

The research is limited to the parents in the institution where the study was conducted and cannot be generalized to the country.

### Conclusion

In the research, the answer of the question "Is the knowledge of the families of children diagnosed with hypospadias sufficient about the disease?" was "No" and; the answer of the question "Does the post-operative process affect the attitudes of families about the disease?" was "Yes". It was found that the parents did not have enough information about hypospadias and the postoperative process adversely affected the attitudes of the parents towards the disease.

### Implications for Nursing Practice

According to the results, nurses' knowledge of parents' attitudes will increase the quality of care. For this reason, training on attitudes towards nurses should be organized. Primary nursing services related to hypospadias should be planned. Care plans should be established by determining the needs of the child and family, and standards of care should be established to provide quality care. Structured trainings should be organized before the operation in order to inform the families about the disease and the operation process. Educational brochures/mobile

applications should be prepared for families. Parents should be given the opportunity and time to express themselves. In the postoperative period, home visits and follow-ups should be made within the scope of home care services.

### Declarations

**Funding:** Not applicable

**Conflicts of interest:** No conflict of interest between the authors.

**Ethics approval:** Marmara University Institute of Health Sciences Ethics Committee for Non-Interventional Studies (05.03.2018/ 78). Written and verbal consent was obtained from all participants. Research and publication ethics were complied with in the article.

**Availability of data and material:** Available upon request.

**Authors' contributions:** Concept - ÇÇÖ, KT; Design - ÇÇÖ, KT; Supervision –Data Collection and/or Processing - KT; Analysis and/or Interpretation - ÇÇÖ, KT; Literature Search - ÇÇÖ, KT; Writing Manuscript - ÇÇÖ, KT; Critical Review - ÇÇÖ

**Acknowledgements:** We thank all participants for their participation.

| Table 2: Quotes, codes, subthemes and main themes obtained from parents   |   |  |
|---|---|--|
| Quotes  | Subthemes   | Main themes  |
| <p>"When we took him for normal circumcision, they said that the child should have an operation and that there should not be a normal circumcision, so I learned that." (HG, 30 aged, mother)</p> <p>"I had no knowledge, I only knew the name of the circumcision of the prophet." (SA, 33 aged, mother)</p> <p>"I didn't know about it either, but it happened to a friend of mine, and we got information from him. His child also had this problem. The surgery was troublesome, and it happened 2-3 times. So, we waited for a while, but then we applied. After all, we chose this place because it was a surgery that needed to be done." (AY, 30 aged, father)</p> <p>"I always search online." (AY, 27 aged, mother)</p> <p>"It seems like a good thing at first, but when you start researching, you see that it is not so. So, it breaks you down a bit. So, it's completely destroyed. The name of the circumcision of the prophet attracts people. Oh, you say, my child, the prophet was born circumcised, but the truth of the matter is that it's not like that. (İÇ, 30 aged, father)</p> <p>"I even thought that if the prophet was circumcised, it would be good, but it was problematic. But then we found out what." (ZE, 29 aged, mother)</p> | <ul style="list-style-type: none"> <li>• Inaccuracy of information about the disease</li> <li>• Sources of false information</li> <li>• Inaccuracy of information about hypospadias is a disease</li> <li>• Inaccuracy of information about the importance of hypospadias</li> <li>• Thinking that hypospadias is a good thing</li> </ul> | <p><b>Theme 1</b><br/>Inaccuracy of information about hypospadias</p>  |
| <p>"I did not get very clear information below in the first place. So, while you're inspecting below. To be honest, they did not inform much." (SK, 30 aged, mother)</p> <p>"No notification has been made." (BÖ, 37 aged, mother)</p> <p>"Yes, but what we experienced had nothing to do with it, it was very different from what was told." (EÇ, 29 age, mother)</p>  | <ul style="list-style-type: none"> <li>• Insufficient information of physicians about the disease</li> <li>• The information is not clear and understandable.</li> </ul>  | <p><b>Theme 2</b><br/>The fact that the information is not clear and understandable by the family</p>            |
| <p>"I lived with that fear, the day of the surgery, I thought a lot if something would happen, could it hold up, could it take the body?" (AY, 27 aged, mother)</p> <p>"I wonder how can it remove the anesthesia? She was very small when we had the operation because, as a mother, you think about everything whether she plays or pulls that hose. We were shocked, but not as much as we feared, thank goodness." (SA, 33 aged, mother)</p> <p>"We were worried if there would be sexual problems in the marriage, but they said it had nothing to do with it, I hope not." (SS, 39 aged, mother)</p> <p>"The first thing that comes to my mind is the question of will there be infertility when he grow up?" (ÖG, 28 aged, mother)</p>   | <ul style="list-style-type: none"> <li>• Fear-anxiety related to the operation process</li> <li>• Health in advanced ages</li> <li>• fear-anxiety about problems</li> </ul>   | <p><b>Theme 3</b><br/>Anxiety about the surgery and the prognosis of the disease in the pre-operative period</p> |

| Table 2: Quotes, codes, subthemes and main themes obtained from parents   |   |  |
|---|---|--|
| Quotes  | Subthemes   | Main themes  |
| <p>"Will we go into the second surgery, will it stop?" (İÇ, 30 aged, father)</p> <p>"He was afraid of getting narcosis, in case he couldn't get out of the surgery. Thank goodness he survived." (BÖ, 37 aged, mother)</p> <p>"Mine was already crying until they got out of the way they took Batu. It was very bad, I don't know. There were problems after he came out, we spent 12-13 days in the hospital for the first operation with the foley catheter. Let's say we're worried." (ÖG, 28 aged, mother)</p> <p>"I was very nervous that day too. Ensar was very restless. he was crying and he was nervous because he had been hungry all day. I mean, if they let me go, I would go to the surgery with him. I wanted to stay downstairs all the time, and they even allowed me a little. It was a tense and troublesome process." (ZE, 29 aged, mother)</p> | <ul style="list-style-type: none"> <li>• Fear of repeat surgery</li> <li>• Fear of giving anesthesia</li> </ul> <p>Feeling different emotions on the day of surgery</p> | <p><b>Theme 4</b></p> <p>Fears about the process and after the surgery</p> |
| <p>"I was relieved after surgery. I saw him with my own eyes and he came to me. I don't know, the fear was gone a little bit." (AY, 27 aged, mother)</p> <p>"After the surgery, we felt a lot of relief. But when my son came to bed, he wasn't himself. He was afraid at first. He was not himself. But we relaxed a lot and the child was relieved too." (AY, 30 aged, father)</p> <p>"Either we experienced two emotions together. We were both sad and happy. Of course, we were happy that the doctor said that we were successful and that there will be no second time." (MK, 35 aged, father)</p> <p>"I am very happy that he finished a 2-3 session procedure in one session." (EY, 33 aged, father)</p>   | <ul style="list-style-type: none"> <li>• Post-operative relief</li> <li>• Post-operative happiness</li> </ul>   | <p><b>Theme 5</b></p> <p>Positive emotions after surgery</p>               |
| <p>"I was scared from foley catheter frankly, it sounded like something bad happened to me but then I get used to it as the hours pass of course." (ZE, 29 aged, mother)</p> <p>"A week after he went home, his stitches opened. When I brought it to the control, they said that two more surgeries may be needed. I mean, there are two surgeries at the moment, but I don't know, of course. That's a huge problem." (AY, 27 aged, mother)</p> <p>"It hurts a lot with the foley catheter. He wants it removed. But it has to stay there too, he gets used to it after a while, but we had some difficulties in the process of getting used to it, of course." (İÇ, 30 aged, mother)</p>   | <ul style="list-style-type: none"> <li>• Continuing anxiety after surgery</li> <li>• Unpleasant feelings after surgery</li> </ul>                                       | <p><b>Theme 6</b></p> <p>Negative emotions after surgery</p>               |

| Table 2: Quotes, codes, subthemes and main themes obtained from parents   |   |   |
|---|---|---|
| Quotes  | Subthemes   | Main themes   |
| <p>"We learned something by living and started to act accordingly. This allowed the stitches to hold. We don't seem to have a problem now." (AA, 37 aged, mother)</p> <p>"We slept here for 7-8 days, but it was difficult to take care of her at home. Because the foley catheter was attached and we were drilling 2-3 times a day. We were soaking them in water, they had creams or something. got us so busy. (BG, 34 aged, father)</p> <p>"We were discharged in the first surgery, we went home and the stitches were opened. It was very bad, of course, we took it back again, the seams were still on it, the seams were still on it. Then he said to us that such things could happen, of course we were shocked. While I was waiting for it to get better, it got worse than before." (YB, 28 aged, mother)</p> | <ul style="list-style-type: none"> <li>• Strain in post-operative caregiver role</li> <li>• Lack of knowledge about post-operative care</li> </ul>  | <p><b>Theme 7</b><br/>Supporting post-operative care</p>    |
| <p>"Before the child had surgery, I felt that something was wrong, he was peeing intermittently. I could see he was peeing at his feet. We are happy with the normal look now." (BT, 30 aged, mother)</p> <p>"Since we were not informed, my child urinates intermittently and urinates very often. I am not satisfied. Frankly, I'm not very happy with the way it looks." (DK, 30 aged, mother)</p> <p>"Normal in appearance, normal in function. He said that it hurts for the first 6 months, but now there is no problem, everything is normal." (MK, 35 aged, father)</p>   | <ul style="list-style-type: none"> <li>• Evaluation of penis appearance and voiding function evaluated differently by parents to parents</li> </ul> | <p><b>Theme 8</b><br/>Importance of cosmetic appearance</p> |

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