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Investigation of the Effectiveness of Tele-Information or Parents of Children Diagnosed with Adolescent Idiopathic Scoliosis

Elif Yağmur ÖZGER [1*], Tuğba ÇİVİ KARAASLAN [2], Turgut AKGÜL [3], Yaşar Samet GÖKÇEOĞLU [4]

[1] Department of Physiotherapy and Rehabilitation, Faculty of Health Sciences, Istanbul University-Cerrahpaşa, elifyagmur.ozger@ogr.iuc.edu.tr

[2] Department of Physiotherapy and Rehabilitation, Faculty of Health Sciences, Istanbul University-Cerrahpaşa, tugba.civi@iuc.edu.tr

[3] Department of Orthopedics and Traumatology, Istanbul Faculty of Medicine, Istanbul University turgut.akgul@istanbul.edu.tr

[4] Department of Orthopedics and Traumatology, Health Sciences University, Şanlıurfa Mehmet Akif İnan Training and Research Hospital sametgokceoglu@gmail.com

ABSTRACT

The aim of this study was to investigate the effectiveness of tele-information provided to parents of children diagnosed with Adolescent Idiopathic Scoliosis (AIS). Parents of children diagnosed with AIS between the ages of 10-18 were included in this cross-sectional prospective study. A 6-week tele-information program was applied to the parents via brochures and videos about scoliosis and treatment approaches and the use of virtual reality in rehabilitation. Before and after the tele-information, the parents were evaluated with the Evaluation Form for Parents Receiving Education on Scoliosis**.** At the end of the six weeks, the parents were also evaluated with the Satisfaction Questionnaire. The tele-information program was applied to 20 parents, 12 of whom were mothers and 8 fathers. The mean total survey scores of the mothers and fathers before and after the tele-information program were 71±21.10 to 78.50±18.70 and 70.30 ± 20.90 to 78 ±17.60, respectively ($p < 0.001$). When looking at the satisfaction of the parents with the application, 15 parents reported that they were very satisfied with the tele-information program, and 17 parents reported that they would recommend tele-information to others**.** As a result of the study, it is seen that parents of children diagnosed with AIS do not have sufficient information about the disease. The findings indicate that the six-week tele-information program effectively improved parents' knowledge and awareness regarding scoliosis and its management, demonstrating that structured and accessible education can play an important role in supporting families of children with AIS.

Keywords: Health education, scoliosis, virtual reality, telerehabilitation

* Corresponding Author e-mail: elifyagmur.ozger@ogr.iuc.edu.tr

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Adolesan İdyopatik Skolyoz Tanılı Çocukların Ebeveynlerine Yönelik Yapılan Tele-Bilgilendirmenin Etkinliğinin İncelenmesi

ÖZ

Çalışmada, Adolesan İdyopatik Skolyoz (AİS) tanılı çocukların ebeveynlerine yönelik yapılan tele-bilgilendirmenin etkinliğinin incelenmesi amaçlanmıştır. Kesitsel prospektif çalışmaya 10-18 yaş aralığında, AİS tanılı çocuğa sahip ebeveynler dahil edildi. Ebeveynlere skolyoz ve tedavi yaklaşımları, sanal gerçekliğin rehabilitasyon alanındaki kullanımı hakkında broşür ve videolar yoluyla 6 haftalık tele-bilgilendirme programı uygulandı. Tele-bilgilendirme öncesinde ve sonrasında ebeveynler Skolyoza Yönelik Eğitim Alan Ebeveynler için Bilgi Değerlendirme Formu ile değerlendirildi. Altı haftanın sonunda ebeveynler Memnuniyet Anketi ile de değerlendirildi. Tele-bilgilendirme programı 12'si anne 8'i baba olmak üzere 20 ebeveyne uygulandı. Tele

bilgilendirme programı öncesi ve sonrası anne ve babaların toplam anket skorlarının sırasıyla 71 ± 21.10'dan 78.50±18.70'e ve 70.30±20.90'dan 78±17.60'a yükseldiği görüldü (p <0,001). Ebeveynlerin yapılan uygulamadan memnuniyetlerine bakıldığında 15 ebeveyn tele-bilgilendirme programından çok memnun kaldığını, 17 ebeveyn tele-bilgilendirmeyi başkalarına önereceğini bildirdi. Çalışmanın sonucunda AİS tanılı çocuğa sahip ebeveynlerin hastalık hakkında yeterli bilgiye sahip olmadığı görülmektedir. Bulgular, altı haftalık tele-bilgilendirme programının ebeveynlerin skolyoz ve yönetimine ilişkin bilgi ve farkındalık düzeylerini etkili bir şekilde artırdığını göstermektedir. Bu durum, yapılandırılmış ve erişilebilir eğitimin, AİS tanılı çocukların ailelerini desteklemede önemli bir rol oynayabileceğini ortaya koymaktadır.

Anahtar Kelimeler: Sağlık eğitimi, skolyoz, sanal gerçeklik, telerehabilitasyon.

1 Introduction

Scoliosis is a three-dimensional deformity of the trunk characterized by lateral deviation of the spine above 10° in the frontal plane, same-directional rotation of the spine in the transverse plane accompanying the lateral deviation, and abnormal kyphosis, lordosis, or hyperlordosis in the sagittal plane (Otman AS, 2015). Adolescent Idiopathic Scoliosis (AIS) is a progressive condition that typically develops during adolescence, requiring consistent adherence to treatment protocols such as bracing and therapeutic exercises. Family attitudes play a crucial role in adolescents' acceptance of the condition and adherence to treatment. Because AIS demands strict compliance with bracing and exercise regimens, which can be challenging, parental support and guidance are essential for successful disease management (Huang et al., 2022).

A recent study conducted in our country assessing scoliosis awareness among parents (N≈400) reported that 83% of parents had never heard the word "scoliosis" before (Sürücü, 2019). Studies have also documented the benefits of mindfulness-based interventions on chronic pain, anxiety, emotional disorders, and stress management, highlighting the importance of providing education to adolescents and their families regarding scoliosis (Lee et al., 2017; Yip et al., 2018). In this context, remote healthcare models offered by modern technology may constitute a significant alternative to address parents' lack of knowledge and facilitate access to education.

Telerehabilitation, defined as the delivery of rehabilitation services via communication technologies, has shown positive outcomes in orthopedic, neurological, and pulmonary conditions (Pastora-Bernal et al., 2017; Van de Pol et al., 2015). Despite its widespread application in various patient populations, there is limited research on the effectiveness of telerehabilitation for scoliosis management, particularly in parental education.

This study, which is the first of its kind, aims to raise scoliosis awareness and contribute to scoliosis rehabilitation by integrating a virtual reality-based exercise program and interactive educational sessions for parents.

2 Methodology

2.1. Study Type

This study was designed as a prospective, cross-sectional investigation.

2.2. Study Group

The study included 20 children diagnosed with AIS and their parents who were followed up at the Istanbul University, Istanbul Faculty of Medicine, Department of Orthopedics and Traumatology, between 01.09.2023 and 01.06.2024 and subsequently referred to the Istanbul University-Cerrahpaşa Department of Physiotherapy. The sample size was calculated using the G*Power 3.1.9.4 software (Universitat Düsseldorf). With 95% power and an effect size of 0.77, the required number of participants was determined to be 20. To account for potential dropouts, an additional 10% was recruited (Oğuz, 2021) **resulting** in a total of 22 participants. Data analysis was completed with 20 participants.

2.3. Research Instruments and Processes

Parents were educated about spinal anatomy and curvatures, scoliosis definition, diagnostic and treatment approaches, spinal rotation, range of motion, balance and endurance assessments, use of virtual reality in rehabilitation, daily activity modifications, and exercise recommendations. Educational materials included brochures and 3-minute instructional videos. Educational materials included brochures and instructional videos, each lasting 3 minutes. Within the scope of virtual reality use in rehabilitation, the Kinect Xbox 360 system, which provides visual and auditory biofeedback by detecting individuals joint movements, was introduced to the parents. Exercises performed using the Kinect system by a volunteer with AIS were video-recorded. This allowed parents to observe the process and introduce the basic principles of virtual reality-based rehabilitation. The system was set up, and the parents were informed about how to use the device and its areas of application. To demonstrate the use of Kinect, a screen and Kinect sensor were placed in a room free from external distractions. A volunteer participant was positioned standing at a distance of 1.5–2 meters from the screen. An avatar of the participant was created through the system, and the Kinect Adventures Xbox 360 game was selected. During gameplay, the researcher provided guidance to the participant. The games involved upper extremity movements and lower extremity activities such as trunk lateral flexion, extension, and flexion, as well as running, briefly standing on one foot, and jumping. Informational brochures were sent to the participants weekly via the mobile messaging application WhatsApp. Program was delivered to all parents simultaneously over six weeks. Throughout this period, parents maintained interaction with the physiotherapist via the designated messaging application. Prior to the intervention, participants completed the Personal Information Form and the Evaluation Form For Parents Receiving Education on Scoliosis. After six weeks, the Parents Satisfaction Survey and the same Information Evaluation Form were re-administered for comparison.

2.3.1. Personal Information Form

After consent is obtained the parents were informed about the tele-information program, the sociodemographic details (e.g., gender, age, education level, employment status, and occupation) of the parents who agreed to participate in the study were independently questioned in an appropriate environment.

2.3.2. Evaluation Form for Parents Receiving Education on Scoliosis

Before starting the tele-information program, the 10-question Information Evaluation Form for Parents Receiving Education on Scoliosis was applied to the parents. This form consists of information provided in brochures prepared by the researchers in line with the relevant (Janicki et al., 2007; Berdishevsky et al.,2016). Each item is scored out of 10, with a maximum total of 100 points.. At the end of the 6th week, the Evaluation Form for Parents was applied to the parents again, and the results were compared.

2.3.3. Parents Satisfaction Survey

To assess parents' satisfaction with the tele-information program, the Satisfaction Survey was completed by parents via online platforms. Parents' satisfaction with the tele-information program was questioned by the researcher using the Global Rating of Change (GRC) Scale using the following scores: -2 (not satisfied at all), -1 (not satisfied), 0 (undecided), 1 (satisfied), 2 (very satisfied) (Norman et al., 1997).

2.4. Inclusion Criteria

Parents of children aged 10 to 18 who were diagnosed with scoliosis with a Cobb angle below 20°, and whose children were physically able to exercise, were included in the study.

2.5. Exclusion Criteria

Parents of children with a history of trauma or medical conditions affecting mobility and parents who are illiterate in Turkish were not included in the study.

2.6. Statistical Analysis

SPSS version 28.0. program was used for statistical analysis and evaluation of the data. Kolmogorov-Smirnov test was applied for the distribution of the data.The Independent Sample T-Test was used for comparing normally distributed data, and Mann-Whitney U Test was used for comparing non-normally distributed data. The results were expressed as percentages. A p- value of less than 0.05 was considered statistically significant for the Information Evaluation Form score for Parents Receiving Education on Scoliosis applied before and after tele-information (Hayran O, 2012).

2.7. Ethical Approval

Before starting the study, written permissions were obtained from the administrations of the universities to be included in the study sample to the parents of children with inclusion criteria. Written approval was obtained from the author's Istanbul University-Cerrahpasa Non-Interventional Ethics Committee (Date: 07.12.2022, Approval no: 74555795-050.01.04-626201). The study was conducted in accordance with the Declaration of Helsinki.

3 Results

A total of 20 adolescents with a mean age of 13.20±3.60 years, were included in the study. Regarding gender distribution, 12 were female and 8 were male. Among the participating parents, 12 (60.0%) were mothers and 8 (40.0%) were fathers, with a mean age of 37.40 ±4.50 years. In terms of educational background, 7 participants (35.0%) had completed high school, while 6 (30.0%) had obtained higher education degrees. Employment status revealed that 14 parents (70.0%) were actively employed, whereas 6 (30.0%) were not working. Regarding occupational distribution, 7 participants (35.0%) were employed in the private sector, and 6 (30.0%) were self-employed (Table 1).

Table 1: *Comparison of sociodemographic data.*

Participant	**n**=20, n **(%)**
- Mother	12 (60)
- Father	8 (40)
Age (years)	37.4±4.5 (between 31–42) years
Educational status	
- Elementary education	3 (15)
- Secondary education	4 (20)
- High school	7 (35)
- Higher education	6 (30)
Job status	
- Employed	14 (70)
- Unemployed	6 (30)
Profession	
- Officer	3 (15)
- Private sector	7 (35)
- Self-employed	6 (30)
- Housewife	4 (20)

n: Count, **%:** Column percentage.

The results of the Evaluation Form For Parents Receiving Education on Scoliosis performed before and after tele-informing parents were statistically significant (p <0.001). While the average score of the mothers who filled out the form before the tele-information program was 71±21.10 (20-100), the questionnaire evaluation score was found to be 78.50±18.70 (20-100) at the end of 6 weeks. While the average score of the fathers before tele-information was 70.30±20.90 (20-100), it was found to be 78 ± 17.60 at the end of 6 weeks. No statistically significant difference was found between mothers and fathers in post-intervention scores (p =0.30). The comparison of the results of the information evaluation form for Parents who Received Scoliosis Education applied to the participants before and after the tele-information was shown in Table 2.

Table 2: *Survey results before and after the information.*

Survey Form	**The person who fills mother (n=12)**		Test value
	Before the information Mean ± SD	After the information Mean± SD	**P***
Scoliosis Information Assessment Form	71.10±21.10 (20 – 100)	78.50 ±18.70 (20 – 100)	**p <0.001**
Survey Form	**The person who fills father (n=8)**		Test value
	Before the information Mean ± SD	After the information Mean ± SD	**P***
Scoliosis Information Assessment Form	70.30±20.90 (20 – 100)	78 ±17.60 (20 – 100)	**p <0.001**

SD: Standart deviation. *** Independent Sample T-Test**

It was reported that 50% (n =10) of the participants were satisfied with the tele-information program, while 25% (n =5) were undecided. Additionally, 75% (n =15) expressed satisfaction with the inclusion of virtual reality rehabilitation content, and 20% (n =4) remained undecided. Furthermore, 80% (n =16) stated they would recommend the tele-information program to other families, whereas 15% (n = 3) were undecided. Seventy-five percent (n =15) agreed that a virtual reality-based rehabilitation program should be used in scoliosis treatment, and 25% (n = 5) were unsure. Moreover, 70% (n =14) indicated a desire

for such a program to be implemented for their own children, while 20% (n = 4) were undecided. Finally, 75% (n =15) reported that they would recommend virtual reality-based rehabilitation to other families, while 15% (n =3) remained undecided. The detailed satisfaction levels of participants are presented in Table 3.

Table 3: *Satisfaction levels of the participants with the tele-information program.*

Parents Satisfaction Survey – The Scale of Global Change (GRC)	n=20	n (%)
Are you satisfied that the information is made in the form of tele-information?	I'm very pleased I'm satisfied I'm ambivalent I'm not satisfied I'm not satisfied at all	3 (15) 10 (50) 5 (25) 2 (10) 0
Are you satisfied that the tele-information program is aimed at scoliosis and virtual reality rehabilitation?	I'm satisfied I'm ambivalent I'm not satisfied	15 (75) 4 (20) 1 (5)
Would you recommend tele-informing to other families?	Yes I'm ambivalent No	16 (80) 3 (15) 1 (5)
What are your thoughts on the use of virtual reality-based rehabilitation applications in individuals with scoliosis?	It should definitely be used Should be used I'm ambivalent Should not be used It should definitely not be used	0 15 (75) 5 (25) 0 0
Would you like to apply a virtual reality-based rehabilitation program to your child?	Yes I'm ambivalent No	14 (70) 4 (20) 2 (10)
Would you like to apply a virtual reality-based rehabilitation program to your child?	Yes I'm ambivalent No	15 (75) 3 (15) 2 (10)

4 Discussion

This study which examined the effectiveness of a tele-information program for parents of children with Adolescent Idiopathic Scoliosis (AIS), findings indicated that parents initially had limited knowledge about AIS. However, the tele-information intervention significantly enhanced their awareness of the condition. Previous research has shown that parents most commonly seek information regarding the causes, progression, diagnosis, and treatment options for AIS (Wellburn et al., 2019). Therefore, it is essential for parents to access accurate, evidence-based resources, such as expert-reviewed guides or reputable online platforms (Surgeons, 2024). In line with these findings, our study demonstrated a significant increase in the parents' knowledge scores after the tele-information program, with mothers' scores increasing from 71±21.10 to 78.50 ±18.70 and fathers' scores from 70.30 ±20.90 to 78 ±17.60 ($p < 0.001$), supporting the effectiveness of remote education in improving parental awareness.

The internet is a widely used tool for supporting families in AIS management. However, current research indicates that the quality of online information about AIS and its treatment options is frequently inaccurate or misleading (Wellburn et al., 2013). Studies have shown a ninefold increase in the number

of parents of children with AIS seeking health information online (Hesse et al., 2005). As much of this content is not evidence-based, it may result in misinformation, leading families to acquire incomplete or incorrect knowledge, which can adversely impact the rehabilitation process (Lysenko et al., 2016). Our results underscore the potential value and acceptability of structured tele-information programs: 50% of participants reported satisfaction with the program, and 80% indicated they would recommend it to other families. These findings suggest that guided online interventions may help counter misinformation and support more informed decision-making among parents.

Existing literature on parental awareness of scoliosis remains limited. Most studies have focused on the information needs of AIS patients and their families, particularly concerning surgical interventions (Bull & Grogan, 2010) . In one study, Van Schaik et al. administered mailed questionnaires to 83 patients with idiopathic scoliosis and 23 of their family members to assess their knowledge. The findings revealed a lack of adequate understanding of the condition among participants (Van Schaik et al., 2007). In our study, we found that before the tele-information program, parents' baseline knowledge was at a moderate level, emphasizing the need for structured educational interventions to address gaps in understanding, regardless of prior educational background or employment status.

It has been demonstrated that parents experience increased levels of anxiety when their children are diagnosed with scoliosis and particularly during surgical treatment (Hines et al., 2015). Such anxiety may be alleviated through innovative communication methods (Kwan et al., 2016). Parents of children with AIS tend to exhibit higher rates of anxiety and depression compared to parents of children without the condition. These levels are especially elevated in mothers and in parents of children with spinal curves greater than 50 degrees (Wang et al., 2019). As such, parental responses to scoliosis and its treatment can influence children's engagement in care (LaMontagne et al., 2001). Our findings reinforce this perspective, as the inclusion of virtual reality-based rehabilitation content was well-received by 75% of participants, and 70% expressed a desire to implement such programs for their own children, indicating that informative and immersive interventions may help reduce parental anxiety and promote active engagement in care.

A systematic review of 18 studies exploring the informational and psychological needs of parents of children with AIS revealed common concerns, including uncertainty about disease progression, variability in treatment approaches, and the perceived severity of surgical procedures (Motyer et al., 2021). In a study evaluating the reliability of trunk asymmetry detection using a smartphone app, parents were trained via educational videos to use an inclinometer. The results demonstrated that parents could reliably and validly measure trunk asymmetry, enabling non-professionals to detect spinal deformities up to a reference angle of 6°, thereby supporting early and appropriate medical intervention (Beauséjour et al., 2022). In this context, our study found high parental satisfaction with the content of the virtual tele-information program, suggesting that well-designed educational tools would be a supportive approach to helping parents better understand and participate in their child's treatment.

In a cross-sectional study designed to educate parents of adolescents with idiopathic scoliosis, two identical sets of 14 cases (eight with scoliosis and six without) were presented to 100 parents. Based on visual assessment, parents were asked to determine whether each case warranted medical referral. After receiving training on scoliosis recognition, parents re-evaluated the second set of cases. The intervention increased their ability to identify scoliosis from 68.8% to 74.0%, without raising the false positive referral rate (26.8% before training, 25.2% after) (de Groot et al., 2022). In parallel, our study shows that both mothers and fathers benefited equally from tele-information, and no significant difference was observed among parents after the intervention ($p = 0.30$), indicating that the program was effective across genders.

A prospective study evaluating the use of SMS to reduce parental anxiety during surgery in individuals with AIS included the parents (both mothers and fathers) of 50 AIS patients scheduled for surgery. While anxiety levels remained high in parents who did not receive SMS messages during the perioperative period, a significant reduction in anxiety was observed in parents who received SMS messages starting six hours before surgery and continuing until one day after the operation. These findings indicate that regular communication with parents is effective in reducing anxiety levels (Kwan et al., 2016). Our findings extend this evidence to tele-education programs, showing that 75% of parents would recommend virtual reality-based rehabilitation and tele-information to other families, suggesting that ongoing digital communication may help support parental confidence and engagement.

In another study targeting parents of individuals with AIS, it was revealed that these parents experienced difficulties in accessing and understanding information during clinical consultations and had specific information needs unique to their situation (Bray et al., 2023). These findings align with a systematic review conducted by Motyer et al., which reported that parents of children diagnosed with AIS found clinical processes stressful and had challenges in obtaining reliable information to participate effectively in decision-making. Our study found that 75% of parents were satisfied with the inclusion of virtual reality content and 80% would recommend the program to others, highlighting that structured tele-information interventions may help meet parents' information needs and may help alleviate the stress associated with AIS management.

This study investigates the effectiveness of a tele-education program designed for parents of children diagnosed with AIS. A review of the existing literature reveals that educational programs for parents of children with AIS generally do not sufficiently address current treatment methods and the use of virtual reality in rehabilitation, nor do they evaluate parental satisfaction. These aspects represent some of the strengths of our study. Furthermore, to reinforce our findings, we assessed the effectiveness of the education using the Knowledge Assessment Form for Parents Receiving Scoliosis Education, which is based on the educational content. However, a limitation of this study is that the number of children and household size were not evaluated. To enhance the generalizability of the study, we recommend increasing the sample size in future research and investigating the long-term effects of the educational programs provided to parents.

5 Conclusions

For patients to actively engage in the decision-making process, their informational needs must be adequately addressed. This study aimed to enhance parental knowledge of AIS and offer a new perspective on the condition and its treatment options. The findings suggest that this goal was successfully achieved. A particularly noteworthy result is that virtual reality-based rehabilitation programs, previously underutilized in AIS management, may become a preferred option among parents.

We believe that this study, as the first to adopt a multidisciplinary approach integrating scoliosis education with tele-rehabilitation, will contribute meaningfully to the literature and underscore the need for further investigation in this area.

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6 Declarations

6.1 Study Limitations

This study investigates the effectiveness of a tele-education program designed for parents of children diagnosed with AIS. A review of the existing literature reveals that educational programs for parents of children with AIS generally do not sufficiently address current treatment methods and the use of virtual reality in rehabilitation, nor do they evaluate parental satisfaction. These aspects represent some of the strengths of our study. Furthermore, to reinforce our findings, we assessed the effectiveness of the education using the Knowledge Assessment Form for Parents Receiving Scoliosis Education, which is based on the educational content. However, a limitation of this study is that the number of children and household size were not evaluated. To enhance the generalizability of the study, we recommend increasing the sample size in future research and investigating the long-term effects of the educational programs provided to parents.

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6.4 Competing Interests

The authors declare no potential conflicts of interest concerning the research, authorship, and/or publication of this article.

6.5 Authors' Contributions

1. Corresponding Author Elif Yağmur ÖZGER: Contribution to the article planning the materials and methods to reach the results, taking responsibility for the experiments, organizing and reporting the data, taking responsibility for the explanation and presentation of the results, taking responsibility for the literature review during the research, taking responsibility for the creation of the entire manuscript or the main part, reworking not only in terms of spelling and grammar but also intellectual content.

2. Author Tuğba ÇİVİ KARAASLAN: Contribution to the article planning the materials and methods to reach the results, taking responsibility for the experiments, taking responsibility for the creation of the entire manuscript or the main part, reworking not only in terms of spelling and grammar but also intellectual content.

3. Author Turgut AKGÜL: Contribution to the article planning the materials and methods to reach the results, taking responsibility for the experiments.

4. Author Yaşar Samet GÖKÇEOĞLU: Contribution to data analysis and comments

7 Human and Animal Related Study

7.1 Ethical Approval

Before starting the study, written permissions were obtained from the administrations of the universities

to be included in the study sample to the parents of children with inclusion criteria. Written approval was obtained from the author's Istanbul University-Cerrahpasa Non-Interventional Ethics Committee (Date: 07.12.2022, Approval no: 74555795-050.01.04-626201). The study was conducted in accordance with the Declaration of Helsinki.

7.2 Informed Consent

Informed consent form was obtained from all participants for the study that they agreed to participate in the study.

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