

Research Article

A Prospective Knowledge Assessment of Adolescent Liver Transplant Recipients after Tailored Education Intervention

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Introduction and Purpose. Given the importance of a successful transition to adult care for pediatric transplant recipients, there is a critical need to better understand modifiable factors which may affect that process. This study assessed the knowledge of adolescent liver transplant recipients about their disease and evaluated if a disease-specific educational intervention could increase their knowledge and impact clinical outcome. *Methods.* A four-category measure was created to assess the knowledge regarding diagnosis, surgical history, lab values, and medications in adolescent liver transplant patients. Teens were randomized to receive one-on-one, verbally administered education from a medical provider versus standard care (control). *Results.* Fifty-six liver transplant recipients completed the measure, with 24 completing a posttest. The median age at transplant was 6.9 years and at pre-test was 17.8 years. Thirty-eight percent did not know their original diagnosis at pretest. The average pretest total score was 43%. Teens who received the intervention had an average posttest score of 61% versus 42.4% for controls ($p < 0.05$). Teens who scored $\geq 50\%$ at pretest had 2.0 rejection episodes per patient while those scoring $< 50\%$ had 0.95 rejection episodes per patient ($p = 0.04$). *Conclusions.* Adolescent liver transplant recipients have low baseline knowledge about their condition. Tailored outpatient education is effective at improving knowledge, but this did not translate to improved outcomes. The role of oppositional behaviors, parental supervision, and other high-risk activities on clinical outcomes needs to be determined by further studies. These data suggest that teen liver transplant recipients require more supervision than their level of knowledge implies.

1. Introduction

Approximately 750,000 children with special healthcare needs transfer to adult care annually. With 10-year survival rates now greater than 90%, an increasing number of adolescents or young adults who received a liver transplant as a child will be among them [1, 2]. As a result, there is a need for improved transition from pediatric to adult care and a focus on adherence to treatments in order to ensure the best outcomes following transfer to adult-based care. Nonadherence to recommended transplant care has been shown to be associated with increased complications including hospitalization, rejection, and death [3–6].

Adolescence is a unique developmental phase making the transition in care more challenging, and transition should not occur until adolescents have the necessary skills for functioning effectively in the adult healthcare system [7]. Adolescents experience a transition from concrete to abstract thinking and development of executive function [8] and simultaneously develop reliance on self rather than parents [9]. As patients prepare to make the transition to an adult provider, it is clear that key aspects of transition of care include knowledge of medications, independent responsibility of medications, and adherence [10]. Additionally, the development of self-management skills is crucial in mediating the psychological and social impacts of transplant on a patient's life [11].

Information You Need to Take Care of Your Transplant

Patient Name: _____

You come to see us in the transplant clinic at CHOA because you have had a liver transplant. Describing what a transplant is can be as simple as saying "took a sick liver out and put a new one in." That's it!

It is also important to be able to tell people why you had a liver transplant—such as doctors or other medical providers who may not know your entire history. You had your transplant for:

In addition to being able to discuss what a transplant is and why you had one, knowing about any other surgeries or procedures you have had done is important information to be able to give to a new doctor or clinic. Below are the surgeries or procedures you have had done aside from your transplant:

Important Labs & What They Mean. Knowing these is useful because it helps you understand what we are talking about when we discuss how you are doing or changes that need to be made in your care.

- **AST & ALT** – These are called "liver enzymes" or "transaminases." They can tell you whether the liver is inflamed. We follow them closely because they are usually the first lab to go up if you have rejection, but there are many other things, such as infections, that can cause them to be high. There is also a lot of AST & ALT in the muscle, so sometimes muscle injury or stress can cause them to be elevated. These only tell you about inflammation in the liver and do not tell you how well it is working, but they are still important to monitor.
- **Bilirubin** – this is the lab value that is high when patients have yellow eyes ("icterus") or yellow skin ("jaundice"). There are two types of bilirubin, direct and indirect. Direct is the kind that comes from the liver, and if the liver is not draining bile well—which can be due to problems with the bile ducts or also with cells inside the liver—the direct bilirubin can be high. If the total bilirubin is normal many times we will not check a direct because we know it will also be ok.
- **BUN & creatinine** – these are labs that tell you how well the kidneys are working. When they are high, that means that the kidneys are not working as well as they should be. One reason that can happen is dehydration—which is why we make a big deal out of drinking enough water. Another reason they are important is that some of the medicines we use to take care of your transplant can affect your kidneys, so it is important to make sure we know if this is happening.
- **Albumin** – this is a protein that is made by the liver. The liver may not make a normal amount of it if there is a lot of inflammation in the liver or elsewhere in the body. Albumin may also be low if your nutrition is not good, or if your transplant is very sick and not working well.
- **INR** – this is a lab test that measures how well the blood is clotting. Because the liver makes proteins that help the blood clot, if the liver is not working well, then the INR is high. We may not even check your INR after a while if you are doing well and all of your other transplant-related labs look good.
- **Tacrolimus level** – This is the level of the main drug you take to prevent rejection of your transplant. It makes the immune system a bit weaker than normal so that it will not attack your new liver. The levels are measured in units called nanograms (ng) per milliliter (mL). We follow the levels closely to make sure the level is high enough to protect your transplant but not so high that it will cause problems or dangerous side effects.

Finally, the most important job you have of all is to remember to take your medications! This keeps your liver transplant and the rest of you healthy. The first step towards being able to take all of your medicines is to know what you are supposed to take and when. Using a weekly pillbox is then a good way to keep your medicines organized. You will be given a list of all of your prescriptions with your discharge paperwork at the end of clinic today. Please keep this list and work on memorizing it over the next few months.

FIGURE 2: Teaching sheet was provided to each intervention group participant regarding transplant, medications, and labs.

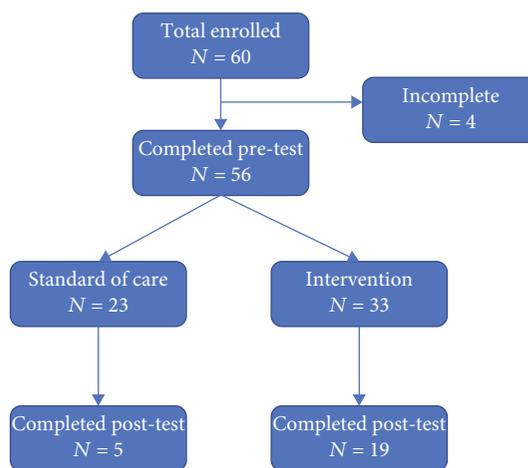


FIGURE 3: Enrollment information flow chart.

The same measure was administered again at a subsequent clinic visit to allow for pre- and posttest analyses. Scores were calculated by giving one point for items 3, 7, and 8 and 2 points for 4, 5, and 6. Items 1 and 2 were not scored. Responses that were turned in blank or incorrect were scored as zero. Data was analyzed using Student's *t*-test, and results were statistically significant with a $p < 0.05$.

Inclusion criteria included adolescents enrolled in the API101 clinic. The primary outcome was a change in disease-specific knowledge between pre- and posttest. Secondary outcome included the association of pretest scores with clinical outcomes. Exclusion criteria included anyone who did not speak English, had severe cognitive delays, or was in the process of being transferred to adult healthcare during the timeframe of the study.

3. Results

At the time of the study, there were 75 patients in the adolescent clinic. A total of 60 patients were initially enrolled, with 56 patients completing the pretest survey with a median age of 17.8 years (± 2 years). Of these, 23 patients were in the standard of care arm and 33 were in the intervention arm. Five patients in the standard of care arm completed a posttest survey and 19 in the intervention arm (Figure 3).

The median age for all participants at transplant was 6.9 ± 6.0 years. Of the 56 participants, 34% (19) were male. The majority of patients in this study had biliary atresia, acute liver failure, autoimmune hepatitis, and Alagille's syndrome that required liver transplant. Fifty-nine percent of patients were white, 34% black, and 3.5% Hispanic, with the remainder being Asian or other. The majority of these patients had Medicaid (37.5%) or private insurance (48%). The median ALT at baseline knowledge questionnaire was 30, the median GGT was 26, and the number of episodes of rejection at baseline was 1.35 rejection episodes per

TABLE 1: Demographic characteristics of participants from the standard of care and intervention groups.

Character	Total N = 56	Standard of care N = 23	Intervention N = 33
Male	19	6	13
Female	37	17	20
Insurance type			
Medicaid	21	9	12
Tricare	2	0	2
Kaiser	3	1	2
Private	27	11	16
None listed	3	2	1
Race			
White	33	14	19
Black	18	7	12
Hispanic	2	1	1
Asian	1	0	1
Declined	1	1	0
Age at baseline knowledge questionnaire (BKQ)	17.8 ± 2.0	17.5 ± 2.0	18.2 ± 1.9
Age of transplant	6.9 ± 6.0	5.8 ± 5.8	7.6 ± 6.2
Median ALT at BKQ	30	28	31
Median GGT at BKQ	26	31	23
Rejection at BKQ	76	32	44

patient overall (Table 1). These patients received the baseline knowledge questionnaire (BKQ) (Figure 1).

Of the 56 adolescents enrolled, 21 (38%) of them did not know their primary diagnosis for which they had received the liver transplant (Figure 4(a)). Less than a quarter of patients had a BKQ medication knowledge score of greater than 50%, and there was no significant difference between genders with respect to medication knowledge (Figure 4(b)).

Interestingly, those with lower pretest scores initially had only 0.95 rejection episodes per person, whereas those who scored higher than 50% on the BKQ had 2.0 rejection episodes per patient ($p < 0.05$). Those who scored lower on their pretest also had a lower average ALT and GGT (Figure 5). Each intervention group participant was then provided a teaching sheet with information regarding their individual transplant, medications, and labs (Figure 2).

When comparing pre- and posttest scores in the intervention and standard of care groups, the intervention group had a significant increase in disease and lab knowledge by 18.6% ($p < 0.05$) (Figure 6(a)). The most significant improvement was seen in the area of medication knowledge (35%), as seen in Figure 6(b) ($p < 0.05$). A large number of patients were able to provide the names and dosages of medications.

Of the 24 patients with posttests completed, 18 of 24 scored greater than 50%. Those with higher scores had ALT 53.4 and GGT 58.5 and 2.05 episodes of rejection per patient, versus average ALT 117, GGT 103, and only 1.33 rejection episodes per patient (Figure 7).

4. Discussion

This study is aimed at assessing the primary diagnosis/indication for transplant and medication regimen knowledge for adolescents who had received a liver transplant and at evaluating the impact of tailored educational intervention and its impact on clinical outcomes. When comparing pre-posttest scores, the intervention group increased their disease knowledge by 18% versus the group receiving standard of care, who increased their overall disease knowledge by only 8%. When looking at medication knowledge alone, the intervention group increased their knowledge by 35%, while the standard of care group demonstrated no change in their medication knowledge, which again indicated the efficacy of this educational intervention. Previous studies demonstrate similar benefit of education in this age group on liver transplant patients in the adult age range [15]; however, no study, to our knowledge, has demonstrated the benefit of educational intervention in adolescent patients on disease knowledge.

Those with higher pretest scores also had higher liver enzyme levels and more rejection episodes. This may be partly explained by the more frequent exposure of sick patients to medical personnel, which might lead to a higher baseline pretest score. If patients were to have higher severity of disease, more complications such as rejection, and resultant frequent admissions to the hospital or increased frequency of clinic visits, it is possible that these patients had a higher knowledge base than those who require fewer medical system interactions. These findings highlight that while knowledge of both medication regimen and underlying

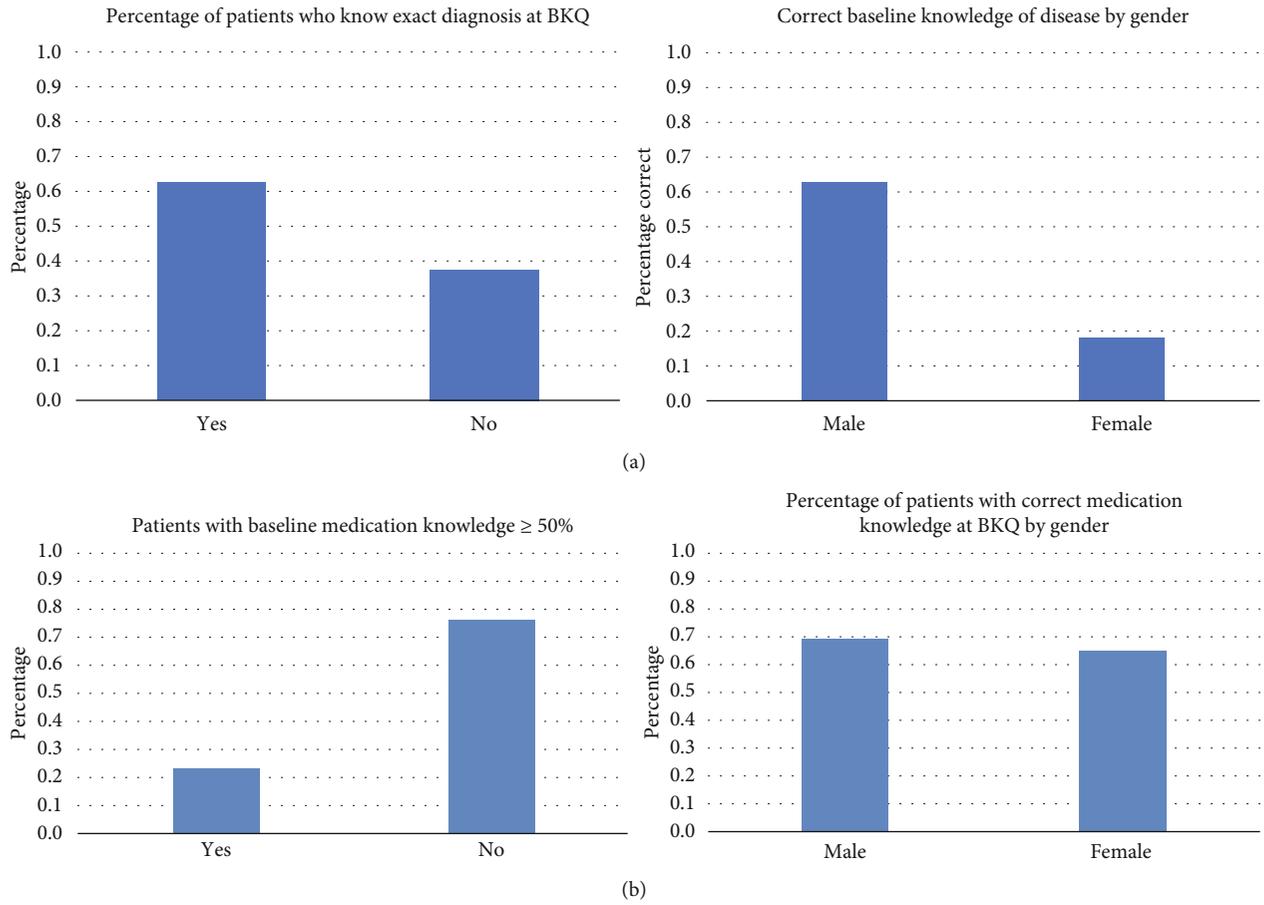


FIGURE 4: (a) Comparison of patients who knew the exact primary diagnosis at baseline knowledge questionnaire (overall vs. by gender). Is the male/female difference in baseline disease knowledge not significant? (b) Percentage of patients who had baseline medication knowledge greater than 50% at baseline knowledge questionnaire overall and percentage correct when comparing males and females.

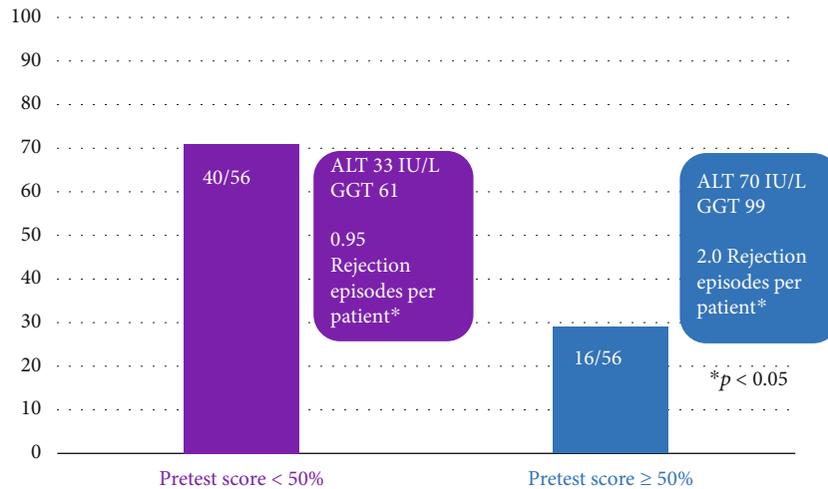
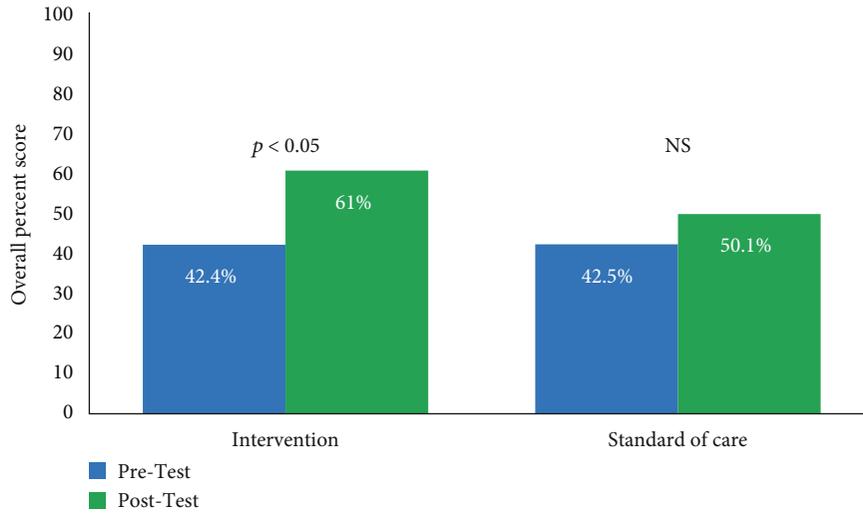
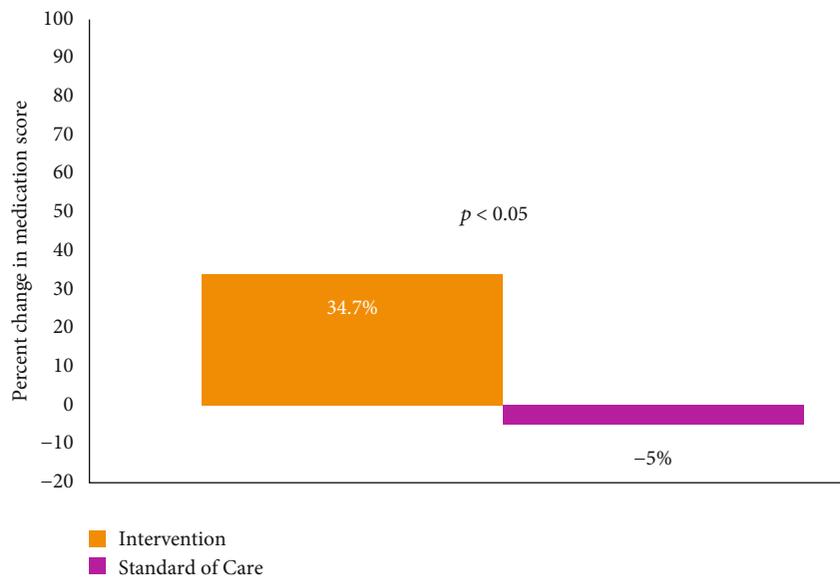


FIGURE 5: Box chart comparing percent pretest score to lab values and rejection episodes per patient at pretest.



(a)



(b)

FIGURE 6: (a) Comparison of pre- and posttest overall score data in the intervention and standard of care groups. (b) Comparison of medication knowledge changes at pre- and posttest in the intervention versus standard of care group.

condition is important to assess readiness and independence with healthcare, tailored education may be necessary to support this endeavor. Tailored education would involve addressing illness-related factors such as time since transplant, age at transplant, adolescent behaviors, family composition, general avoidance of the medical system, and prioritization of social life that could interfere with adherence.

Medication adherence has previously been shown to have a relationship with health literacy [16]. This study indicates that health literacy alone is inadequate to ensure good adherence. Given the fact that nonadherence can lead to poor health outcomes including increased frequency of rejection, morbidity, and mortality [17–19], it is crucial to provide quality education in

the setting of a comprehensive transition program that also includes close monitoring for and addressing of nonadherence to most effectively prevent future rejection episodes.

Based on the data in this study, it is apparent that tailored educational intervention in a posttransplant adolescent group can be effective in improving patient knowledge. However, it is also evident that knowledge on its own is not sufficient to guarantee good clinical outcomes or to prevent rejection in this case, so condition-specific education should be given in the context of a rigorous multipart transition program. Such a program may be our most effective tool in improving morbidity and mortality in this at-risk population as adolescents work towards transition of care.

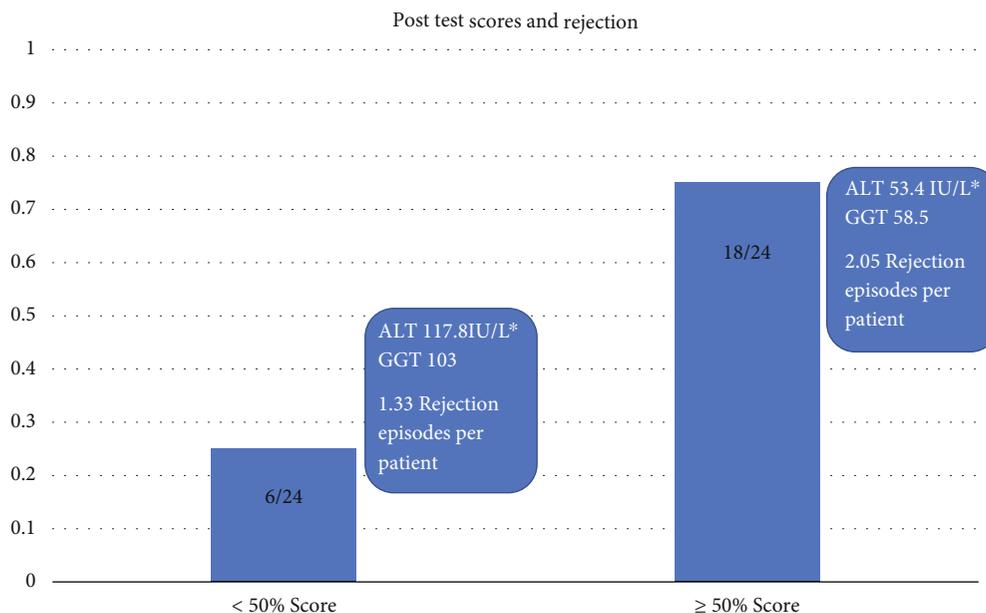


FIGURE 7: Box chart comparing percent overall posttest score to lab values and rejection episodes per patient at posttest.

5. Conclusions

Adolescent liver transplant recipients have low baseline knowledge about their disease. It seems that adolescents with more episodes of rejection and higher lab numbers had higher baseline knowledge. This may be a result of repeated education during increased interactions with the healthcare system that results in a higher BKQ score. The strengths of this study include a simple intervention that is low-burden and highly scalable. Another strength is that this intervention was able to be completed without disrupting clinic flow. Limitations include a low posttest survey sample size in the standard of care arm though it is likely representative of the rest of the group. Importantly, the posttest survey sample in the intervention arm was robust. Finally, this study demonstrates that outpatient education is effective with greatest impact on improving medication knowledge, but education alone did not improve patient outcomes. This may be because medical literacy may not be enough to make positive health changes to increase adherence. Perhaps more extensive personalized counseling that is specific to each patient's lifestyle is necessary to improve healthcare outcomes. Specific barriers such as transportation, ability to get to a pharmacy, lack of family structure or supervision of medications, and deference to parents regarding medical care may be barriers to address during this counseling that would improve healthcare outcomes by increasing medication adherence along with knowledge.

Abbreviations

BKQ: Baseline knowledge questionnaire
 GGT: Gamma glutamyl transferase
 ALT: Alanine aminotransferase.

Data Availability

The data used to support the findings of this study are available from the corresponding author upon request.

Additional Points

Key Messages. (i) Provision of education to adolescent transplant recipients is critical in improving medication knowledge. (ii) Educational interventions can be successfully completed within typical clinic flow.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Supplementary Materials

Authors have included scoring system details for the baseline knowledge questionnaire. (*Supplementary Materials*)

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