



Self-Management Measurement and Prediction of Clinical Outcomes in Pediatric Transplant

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Objective To further refine a measure of self-management, the Responsibility and Familiarity with Illness Survey (REFILS), and to determine if this score predicts medication adherence and, thus, fewer instances of allograft rejection among pediatric liver transplant recipients.

Study design Participants were 400 liver transplant recipients and their parents recruited for the Medication Adherence in Children Who Had a Liver Transplant study, from 5 US pediatric transplant centers. The REFILS was administered to participants (ages 9-17 years) and their parents at enrollment (n = 213 completed dyads). The REFILS scores, and a discrepancy score calculated between patient and parent report of the patient's self-management, were used to predict Medication Level Variability Index (MLVI), a measure of medication adherence (higher MLVI = more variability in medication levels) and central pathologist-diagnosed rejection over a 2-year follow-up.

Results When patients reported greater self-management, their adherence was lower (higher MLVI, $r = 0.26$, $P < .01$). Discrepancies between patient and parent report (patients endorsing higher levels than parents) were associated with lower adherence ($r = 0.20$, $P < .01$). Greater patient-reported self-management and higher discrepancy scores also predicted rejection.

Conclusions We found that when patients endorse more responsibility for their care, clinical outcomes are worse, indicating that indiscriminate promotion of self-management by adolescents may not be advisable. A discrepancy between patient and parent perception of self-management emerged as a novel strategy to gauge the degree of risk involved in transitioning care responsibilities to the child. (*J Pediatr* 2018;193:128-33).

Findings suggest that patients struggle during the “transition” to the adult healthcare system. Increased rates of nonadherence have been observed during transition, and the period has been shown to be associated with poorer clinical outcomes and increased mortality.^{1,2} It is, therefore, important to be able to assess self-management during transition.

It is largely unknown whether self-management skills are associated with clinical outcomes like medication adherence, although the tacit assumption is that they are. If some adolescents are not ready for transition, prematurely forcing self-management might lead to poorer, not better, outcomes. This seems to resonate with the state of affairs for pediatric self-management; there are many different approaches being implemented for its evaluation but a lack of data on how self-management translates into clinical outcomes.³

There are different approaches to the measurement of self-management acquisition. One is measuring allocation of responsibility, or how healthcare management tasks are divided between patients and their parents.⁴⁻⁸ Previous work in pediatric transplant has suggested that greater self-management, as measured by allocation of responsibility, is associated with poorer medication adherence among adolescent/young adult liver transplant recipients.^{4,9} A second approach is to calculate a numeric score or “level” of patient healthcare management skills.¹⁰⁻¹² This level can be monitored over time to determine if self-management acquisition is increasing.

As patients transition from pediatrics, perhaps the most salient concern is medical instability related to nonadherence and faulty self-management acquisition. We have previously reported preliminary reliability and validity information for a checklist of skills, called the Responsibility and Familiarity with Illness Survey (REFILS).¹¹ We have used this tool to track self-management when patients transition from

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AMBS	Adolescent Medication Barriers Scale
MALT	Medication Adherence in Children Who Had a Liver Transplant
MLVI	Medication Level Variability Index
PMBS	Parent Medication Barriers Scale
REFILS	Responsibility and Familiarity with Illness Survey

pediatric to adult clinics.¹³ However, development of this measure, like others, has been limited by single-center data collection, a less than adequate sample size for demonstrating psychometric properties,¹⁴ and a lack of robust correlation with medical outcomes.

This multisite, prospective cohort study aimed to further develop the REFILS through multisite collection, analysis of technical adequacy, and correlating it with medical outcomes. We furthermore evaluated whether REFILS scores are associated with nonadherence to medications as well as with allograft rejection in pediatric liver transplant recipients. Two different approaches to scoring the measure were employed: a cumulative score and a “discrepancy” score, calculating the degree to which patients report greater self-management than concurrent parent report of their self-management.

Methods

Participants were enrolled in the Medication Adherence in Children Who Had a Liver Transplant (MALT) cohort.¹⁵ This multisite prospective trial recruited 400 children or adolescents ages 1-17 years and their families from 5 pediatric liver transplant centers in the US (Cincinnati Children’s Hospital Medical Center; Mattel Children’s Hospital, University of California Los Angeles; Ann and Robert H. Lurie Children’s Hospital of Chicago; Children’s Hospital of Pittsburgh of University of Pittsburgh Medical Center; and Mount Sinai Medical Center, New York) and followed them each for 2 years.

The study was approved by the respective institutional review boards and involved parent/caregiver consent and child assent. At their enrollment visit, parents and patients were asked to complete a brief questionnaire assessing possible predictors of nonadherence (described below) as well as the REFILS, to capture self-management level and to examine its predictive validity. In the event that more than 1 parent attended the enrollment visit, families were asked to choose 1 respondent. In addition, patient medical variables and outcomes were followed for a 2-year period (ending in June 2015). Quarterly chart reviews were conducted during which time all tacrolimus values were obtained to characterize adherence (as described below). Data were sent via a secure web-based interface to a data-coordinating center (The EMMES Corporation, Rockville, Maryland).

The MALT study included a brief psychosocial assessment aimed at measuring self-management and possible predictors of nonadherence. In the present study, for further validation of the REFILS, measures assessing barriers to adherence¹⁶ were included.

Originally, the REFILS consisted of 22-items,^{11,17} drawing on the work of Vessey and Miola, but to decrease participant burden it was shortened to 13 items for this study based on factor analyses; there are companion patient and parent versions. Similar to other questionnaires that investigate responsibility for healthcare in children and adolescents,^{7,8} the REFILS taps into 2 domains: perceived knowledge about the illness and responsibility for medical management. Patients and their

parent are asked to choose from 3 options, “Never,” “Sometimes,” or “Always,” indicating how often the patient engages in the behavior listed, scored on a scale from 1 to 3, respectively. We calculated the total score from 13 items with possible scores ranging from 13 to 36. Higher scores, therefore, indicate greater self-management, and lower scores may indicate that either parents or no one is overseeing the task. The REFILS was administered to dyads when the patient was age 9 years and older (corresponding to just before “young teens” as per Centers for Disease Control definitions).¹⁸ In addition, a “discrepancy” score was calculated; this score is the difference between patient and parent report of the patient’s self-management level. Higher discrepancy scores indicate not only greater disagreement between patients and parents, but also that patients rated their self-management higher than parents.

The Adolescent Medication Barriers Scale (AMBS) and Parent Medication Barriers Scale (PMBS)¹⁶ are scales designed to assess parent/patient perceived barriers to child medication adherence. These companion measures consist of 17 (AMBS) or 16 items (PMBS). Each item is rated on a 5-point Likert-like scale from “strongly disagree” to “strongly agree.” Reliability and validity have been established with Cronbach’s alphas of 0.86 and 0.87, respectively, as well as factor analyses supporting the composition of items.¹⁶

Chart Review

The Medication Level Variability Index (MLVI)¹⁹ is defined as the degree of variation in blood levels of tacrolimus, the primary immunosuppressive medication used to prevent allograft rejection in liver transplant recipients. Measurement of trough blood levels of tacrolimus was standard practice in participating centers and was obtained approximately once every 3 months. The MLVI is calculated as the SD of at least 3 consecutive tacrolimus trough blood levels for each patient. A higher MLVI denotes more fluctuation in levels. MLVI also was treated as a dichotomy (a predefined value greater than 2.5 units was considered to denote clinically significant non-adherence based on previous data). A higher MLVI was a significant predictor of future rejection in MALT¹⁵ and other cohorts.^{19,20}

The primary clinical outcome measure in the MALT study was biopsy-defined rejection, as determined based on 2 independent readings in a central pathology laboratory; if the pathologists disagreed, the case was adjudicated by the senior study pathologist.¹⁵ For each participant, if there was at least 1 biopsy-proven episode of rejection during the study period, it was entered as a positive value (positive rejection). Thus, even if a participant had more than 1 rejection, it was counted as 1 event for the primary analysis (yes/no rejection occurring during the follow-up period, regardless of the number of rejection episodes).

Statistical Analyses

Reliability of the REFILS was examined using the Cronbach alpha to measure internal consistency and Kappa coefficients, and intraclass correlations were used to determine

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