Journal of Pediatric Nursing 71 (2023) 104–110

Contents lists available at ScienceDirect

Journal of Pediatric Nursing

journal homepage: www.pediatricnursing.org

# The self-management and transition manual "*ALL YOU NEED IS LOVE*" for adolescents with chronic kidney disease

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ARTICLE INFO

*Article history:*
Received 8 June 2022
Revised 11 October 2022
Accepted 12 October 2022

*Keywords:*
Chronic kidney disease
Adolescents
Patient education
Health care transition preparation
Self-management

ABSTRACT

*Purpose:* To examine the effects of "*ALL YOU NEED IS LOVE*", a novel six-week, self-directed patient education manual designed to improve chronic kidney disease knowledge/self-management, health care transition readiness, self-advocacy, and mindfulness skills among adolescents with chronic kidney disease.
*Design and methods:* We enrolled 49 adolescents aged 11–17 years (mean age 14.7 ± 1.9; 53.1% males) from a university hospital kidney center who had CKD stages 3 and greater, who were randomly assigned into the "*ALL YOU NEED IS LOVE*" patient education *only* group ($n = 31$) or the "*ALL YOU NEED IS LOVE*" patient education *plus* mindfulness training group ($n = 18$). Participants completed Qualtrics surveys at baseline, post-intervention, and three-month follow-up. The survey included measures of outcome variables (i.e., self-management/transition readiness, patient self-advocacy, and mindfulness), and an additional demographic questionnaire was included in the baseline survey. Multilevel model analyses were used to examine the effects of group and time on the outcome variables.
*Results:* Multilevel model analyses showed an overall significant time effect across all outcome variables in both groups. However, the group effects were not statistically significant across the outcome variables.
*Conclusions:* Both interventions significantly increased participants' self-management/HCT readiness, self-advocacy, and mindfulness over time. Mindfulness training may not bring additional benefits to the "*ALL YOU NEED IS LOVE*" education manual.
*Practice implications:* Pediatric nurses and clinicians may utilize the self-directed "*ALL YOU NEED IS LOVE*" manual to increase self-management/transition readiness, self-advocacy, and mindfulness among adolescents with chronic kidney disease.


## Introduction

Around 111 per million children and adolescents in the United States have end-stage kidney disease (ESKD; United States Renal Data System [USRDS], 2020). Despite the relevantly low prevalence, chronic kidney disease (CKD) and ESKD pose a major health burden to youth who are diagnosed (Bowe et al., 2018). The hospitalization rate is 12 times higher, and the healthcare expenditures are 7.6 times greater for youth with CKD/ESKD, compared to children and adolescents without this condition (USRDS, 2018). CKD is managed by following strict medication and dietary regimens, monitoring blood pressure, and completing specific daily care tasks, especially in those with ESKD (Ferris, Cuttance, et al., 2015).

Treatment adherence is critical to slow progression and prevent complications (Ferris et al., 2017). For adolescents with CKD/ESKD, treatment adherence plays a central role in successful health care transition (HCT) from pediatric care to adult-focused care (Nicholas et al., 2018). Yet, the intricate treatment regimen and the additional stress associated with HCT from pediatric care to adult-focused care bring unique challenges to many adolescents/young adults with CKD/ESKD, including those with kidney transplants (Ferris, Cuttance, et al., 2015). Poor treatment adherence is observed in 35–61% of adolescents and

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https://doi.org/10.1016/j.pedn.2022.10.006

young adults with CKD/ESKD (Pruette et al., 2019), and nonadherence is the main predictor of graft loss or death after pediatric renal transplantation (Gajardo et al., 2021). In addition, treatment nonadherence increases the risk of complications, such as anemia and malnutrition (Ferris et al., 2017).

HCT readiness entails the acquisition of knowledge and skills needed for health self-management and successful transfer to adult-focused care (Blum et al., 1993). HCT is characterized by willingness to make decisions, negotiate with providers, take control over self-care, and act to promote own health (Ferris, Cuttance, et al., 2015). However, many adolescents with CKD/ESKD feel unprepared to manage the disease on their own (Nicholas et al., 2018), which can result in elevated anxiety and depression (Rutishauser et al., 2014) and poor treatment adherence (Ferris & Mahan, 2009), compromising patient outcomes (Fegran et al., 2014). Successful HCT preparation should include high quality, valid and developmentally appropriate tools, to better prepare adolescent/young adult patients for this process and improve patient outcomes.

Interventions to improve disease knowledge/self-management have been successful in adolescents with chronic conditions (Huang et al., 2014; Mackie et al., 2018; Schmidt et al., 2018), but none specifically targeted CKD/ESKD. In addition, these interventions either take months to complete or require trained professionals for delivery; potentially adding more stress to adolescents/families and healthcare providers. Empirical research on CKD/ESKD patient education interventions has been limited to the adult population. For example, the National Kidney Foundation (NKF) Kidney Early Evaluation Program, a community-based education program for adults with pre-ESKD, resulted in higher rates of ESKD preparation and survival (Tamura et al., 2014). The Medicare Kidney Disease Education program, aiming to educate adults with severe CKD on disease management, complication prevention, and renal replacement treatment options, has been shown to delay CKD progression (Enworom & Tabi, 2015). In contrast, fewer interventions are available for pediatric patients with CKD. The National Kidney Foundation (2020) offers a series of online videos on disease knowledge and self-management for youth with CKD. Additionally, the American Association of Kidney Patients (2020) and Davita Kidney Care (2020) provide disease knowledge and management information for parents and caregivers of children with CKD/ESKD. However, none of the pediatric-focused, self-administered interventions have been validated by empirical studies, thus their effectiveness remains unknown. Moreover, these programs fail to address the HCT process and the associated emotional stress (Nicholas et al., 2018; Rutishauser et al., 2014). Due to these concerns, it is necessary to develop a brief and effective self-administered intervention to meet the specific needs of adolescents with CKD, that include the acquisition of disease-specific knowledge, self-management/self-advocacy skills and coping with the psychological stress associated with the HCT process.

Furthermore, we also hypothesized that, integrating mindfulness practices into a CKD-specific intervention may bring additional benefits to adolescent patients by reducing psychological distress and further increasing HCT readiness. Mindfulness is characterized by maintaining the present-moment awareness and adopting an attitude of acceptance toward the experience (Creswell, 2017). A recent literature review concluded that mindfulness-based interventions have been overall effective to reduce stress, anxiety, and depression while increasing medication adherence among adolescents with chronic health conditions (Semple & Burke, 2019).

The study examines the efficacy of *"ALL YOU NEED IS LOVE" (which stands for **A**dherence and **L**ongitudinal **L**ife skills for **Yo**uth, **U**nder a **N**urturing **E**ducational **E**nvironment on **D**isease **I**ntelligent **S**elf-management: **L**asting **O**utcomes, **V**isionary **E**mpowerment)* manual, an age-appropriate and literacy-congruent tool developed with pediatric patients and middle/high school educators' input to teach disease self-management concepts and HCT readiness. The Spanish-version of the *"ALL YOU NEED IS LOVE"* manual has been examined by Brito-Suárez et al. (2021) among low-income young adults in Mexico, which significantly increased patients' CKD disease knowledge, self-management skills, and health-related quality of life post-intervention. In this study, we further investigated the benefits of adding mindfulness training. We hypothesized that: (a) the *"ALL YOU NEED IS LOVE"* manual will increase HCT readiness, self-advocacy, and mindfulness among adolescents with CKD/ESKD; and (b) adding mindfulness training will further enhance patients' ability to utilize skills taught by the *"ALL YOU NEED IS LOVE"* manual.

## Methods

### *Participants*

The present study was approved by the Institutional Review Board (IRB) at the University of North Carolina at Chapel Hill. Participants ages 11–17 years with CKD stage ≥3 (including dialysis or transplant) were recruited from the University of North Carolina Kidney Center, and were randomly assigned to either the *"ALL YOU NEED IS LOVE"* manual for HCT education *only* group or the *"ALL YOU NEED IS LOVE"* HCT education *plus* mindfulness training group by four research team members (MN, JR, KJ, BP). The group number for each participant was randomly generated by computer at the time of recruitment.

Estimation of sample size was based on the guideline of Hox and McNeish (2020), that a minimum of 15 participants are needed for a longitudinal study using multilevel modeling to test a fixed effect (in this study, group and time effects). Considering the between-group design used in this study, we expanded our target sample size to 50 participants.

### *Procedure*

During the clinic visit, consents and assents were acquired and baseline surveys were collected. Depending on the intervention group, participants were then provided with and oriented to the self-directed intervention materials. For the *"ALL YOU NEED IS LOVE" only* group, participants were sent home with the self-directed *"ALL YOU NEED IS LOVE"* manual containing activities structured in six modules to be completed in six weeks. The *"ALL YOU NEED IS LOVE" plus* mindfulness group was asked to complete the HCT-related activities, plus mindfulness training exercises recorded on an MP3 platform. All participants received biweekly phone calls from a study team member, asking them about progress and ensuring they completed their activities as scheduled. Intervention surveys were deployed via Qualtrics at weeks 3 and 6 of the study. Participants completed the post-intervention assessments at the end of the intervention, and three months later to assess retention.

#### *"ALL YOU NEED IS LOVE" patient education manual group*

The *"ALL YOU NEED IS LOVE"* manual includes HCT readiness and self-management education structured into six weekly modules: (1) the kidneys and their functions, (2) CKD medication management, (3) nutrition, diet, and lifestyle habits with CKD, (4) HCT readiness, self-management (including understanding insurance and transfer to adult-focused providers) (5) CKD-related reproductive issues, and treatment adherence; and (6) interacting in the health care system. Each session was 15 min in length.

#### *"ALL YOU NEED IS LOVE" patient education manual plus mindfulness training group*

In addition to the *"ALL YOU NEED IS LOVE"* manual, participants in this group completed self-directed mindfulness training integrated into the six-module patient education. The additional mindfulness topics include: (a) understanding mindfulness and exploring stress, (b) foundations of mindfulness, (c) developing a mindfulness practice and present moment awareness, (d) cultivating self-care with mindfulness, (e) mindfulness-based coping strategies and forgiveness, and

(f) mindful resilience and working with unpleasant thoughts and events. Due to the extra mindfulness training component, each module was 25 min in length.

### Measures

**Demographic Questionnaire.** Information about the participant's age, gender, race/ethnicity, age at diagnosis of CKD/ESRD, and types of health insurance were gathered.

***"ALL YOU NEED IS LOVE"*-related Surveys.** To document all participants' progress and module completion, for each intervention group, two Qualtrics surveys were deployed at week 3 (covered content from weeks 1–3) and week 6 (covered content from weeks 4–6). These surveys included multiple choice and short answer questions about the manual content, such as "*Which of the following is something that the kidney does?*" or "*In your own words, what is mindfulness?*" as applicable.

**The Self-Management and Transition to Adulthood with Rx = Treatment ($STAR_x$) Questionnaire.** The $STAR_x$ (Ferris, Cohen, et al., 2015; Nazareth et al., 2018) assesses self-reported HCT readiness in adolescents with chronic conditions. The research version of the $STAR_x$ Questionnaire was used in this study. Shorter than the clinical version, the research version consists of 13 items rated on a 5-point Likert scale and has three subscales: disease knowledge (e.g., "*How much do you know about your illness?*"), self-management (e.g., "*How easy or hard is it to take your medicines like you are supposed to?*"), and communication with providers (e.g., "*How often did you work with your doctor to take care of new health problems that came up?*"). The ratings for each item ranged from 1 ("*never*", "*nothing*", *or* "*very hard*") to 5 ("*always*", "*a lot*", *or* "*very easy*"). Higher score indicates greater HCT readiness. The $STAR_x$ Questionnaire demonstrated moderate to good internal consistency, $\alpha = 0.69–0.77$ (Ferris, Cohen, et al., 2015). In this study, the overall internal consistency of the $STAR_x$ measured by Cronbach's alpha was 0.77, and internal consistencies of the subscales were 0.49 for disease knowledge, 0.72 for self-management, and 0.41 for provider communication.

**Patient Self-Advocacy Scale (PSAS).** The PSAS (Brashers et al., 1999) measures self-advocacy among patients with chronic conditions. It consists of 12 items rated on a 5-point Likert scale and has three subscales: illness education (e.g., "*I actively seek out information on my illnesses*"), assertiveness (e.g., "*I am more assertive about my health care needs than most U.S. citizens*"), and mindful nonadherence (e.g., "*Sometimes there are good reasons not to follow the advice of a physician*"). The ratings for each item ranged from 1 ("*strongly agree*") to 5 ("*strongly disagree*"). Lower score indicates higher self-advocacy. The PSAS demonstrated moderate to good internal consistency in an adult sample, $\alpha = 0.64–0.79$ (Brashers et al., 1999). In this study, the overall internal consistency of the PSAS measured by Cronbach's alpha was 0.50, and internal consistencies of the subscales were 0.68 for illness education, 0.22 for assertiveness, and 0.67 for mindful nonadherence.

**Child and Adolescent Mindfulness Measure (CAMM).** The CAMM (Greco et al., 2011) assesses mindfulness in children and adolescents. It is a unidimensional scale, consisting of 10 items rated on a 4-point Likert scale. A sample item is "*I keep myself busy so I don't notice my thoughts or feelings.*" The ratings for each item ranged from 1 ("*never*") to 4 ("*always*"). All items are reversed scored, and a higher score indicates higher mindfulness. In this study, the internal consistency of the CAMM measured by Cronbach's alpha was 0.81, which was comparable to the previously reported Cronbach's alpha of 0.80 (Greco et al., 2011).

### Statistical analysis

Descriptive statistics were obtained using SPSS 27 to describe the characteristics of the study sample. Mixed (multilevel) models using SAS 9.4 were employed to test the effects of the interventions on participants' HCT readiness, self-advocacy, and mindfulness. To better capture the patterns of temporal change in outcomes, as well as accommodate variations in target assessment timings, time (in weeks) was modeled as a continuous predictor referenced to the commencement of intervention (i.e., assessment week). For each outcome variable, unconditional growth models (Raudenbush & Bryk, 2002; Singer & Willett, 2003) were conducted to partition and quantify variance across individuals and time. Fixed effects estimate the starting point and slope of all participants' average change trajectory, regardless of grouping. Random effects capture the amount an individual's intercept and slope deviate from the average intercept and slope, respectively. Statistically significant random effects were kept in the conditional growth model.

The initial conditional growth model included random intercept and fixed effects including time measured in weeks (week), curvature of change across time (i.e., quadratic effect of time; $week^2$), intervention group, as well as interactions between group and time (group*week) and group and curvature of change across time (group*$week^2$). Additionally, age, age at diagnosis, and interaction between intervention group and age (group*age) were included in the fixed effects as covariates. Insignificant higher-order terms were taken out from the conditional growth model, forming the final conditional growth model.

## Results

### Sample characteristics

We enrolled 53 eligible participants in this study. Data were collected between June 9, 2015, and August 14, 2016. Due to random study ID assignment more participants were assigned to the "*ALL YOU NEED IS LOVE*" patient education *only* group ($n = 33$) than the "*ALL YOU NEED IS LOVE*" *plus* mindfulness training group ($n = 20$). Out of the 53, four were missing baseline data (two from each group) and therefore excluded from the analysis. The final sample included 49 participants (mean age 14.7 ± 1.9; 53.1% males), 31 in the "*ALL YOU NEED IS LOVE*" *only* group and 18 in the "*ALL YOU NEED IS LOVE*" *plus* mindfulness group.

Participant characteristics for each intervention group are presented in Table 1. For most variables, the group differences were not statistically significant at a type I error of 0.05, suggesting that both groups were similar in terms of background characteristics. However, there was a significant group difference in the PSAS assertiveness subscale and a marginal difference in age at diagnosis. The "*ALL YOU NEED IS LOVE*" *only* group scored higher in the PSAS assertiveness subscale and were diagnosed with CKD at a relatively older age.

For the 31 participants in the "*ALL YOU NEED IS LOVE*" *only* group, 80.65% completed the survey at week 3 (i.e., after the completion of sessions 1–3), and 70.97% completed the survey at week 6 (i.e., sessions 4–6). For the 18 participants in the "*ALL YOU NEED IS LOVE*" *plus* mindfulness group, 94.44% completed the survey at week 3 (i.e., sessions 1–3), and 83.33% completed the at week 6 (i.e., sessions 4–6).

### Multilevel modeling results

In the final conditional growth model using $STAR_x$ total score as the outcome variable, only the effect of time was significant, $t(43.6) = 2.77$, $p < .01$. For the disease knowledge subscale, only the effect of time was significant, $t(47.1) = 2.45$, $p < .05$. For the self-management and the provider communication subscales, none of the fixed effects were significant (See Table 2).

For the final conditional growth model using PSAS total score as the outcome variable, none of the fixed effects were significant. On the subscale level, for the illness education subscale, only the effect of time was significant, $t(34.3) = -3.51$, $p < .01$. For the assertiveness subscale, only the effect of time was significant, $t(63.6) = -2.28$, $p < .05$. For the mindful nonadherence subscale, only the effect of time was significant, $t(32.9) = 2.28$, $p < .05$ (See Table 3).

For the final conditional growth model using CAMM total score as the outcome variable, the effects of time [$t(60.3) = 8.68$, $p < .001$]

**Table 1**
Descriptive statistics for participants.

| | Patient education only group ($N = 31$) *N (%)* or *M (SD)* | Mindfulness-based patient education Group ($N = 18$) *N (%)* or *M (SD)* | *t-test* or $\chi^2$ | *p* |
|---|---|---|---|---|
| Age (range 11–17 yrs) | 14.7 (2.0) | 14.6 (1.8) | $t(47) = -0.27$ | ≤0.79 |
| Age at Diagnosis | 8.1 (6.0) Range: 0–17 | 5.0 (5.2) Range: 0–15 | $t(44) = -1.72$ | ≤0.09 |
| Gender | | | | |
| Male | 15 (48.4%) | 11 (61.1%) | $\chi^2(1) = 0.74$ | ≤0.39 |
| Race/Ethnicity | | | | |
| Hispanic | 9 (29.0%) | 5 (27.8%) | $\chi^2(3) = 3.92$ | ≤0.27 |
| White | 12 (38.7%) | 5 (27.8%) | | |
| Black | 7 (22.6%) | 8 (44.4%) | | |
| Other | 3 (9.7%) | 0 (0%) | | |
| Insurance | | | | |
| Private | 13(41.9%) | 5 (29.4%) | $\chi^2(3) = 5.55$ | ≤0.14 |
| Public | 13 (41.9%) | 5 (29.4%) | | |
| Private and Public | 0 (0%) | 1 (5.9%) | | |
| Other | 1 (3.2%) | 3 (17.6%) | | |
| Baseline $STAR_X$ | | | | |
| $STAR_X$-Total | 46.28 (8.32) | 45.93 (7.16) | $t(30) = -0.13$ | ≤0.90 |
| $STAR_X$-Disease Knowledge | 15.56 (3.52) | 15.29 (2.13) | $t(30) = -0.25$ | ≤0.80 |
| $STAR_X$-Self-Management | 19.61 (4.41) | 19.29 (4.18) | $t(30) = -0.21$ | ≤0.83 |
| $STAR_X$-Provider Communication | 15.26 (2.79) | 15.64 (3.18) | $t(31) = 0.37$ | ≤0.72 |
| Baseline PSAS | | | | |
| PSAS-Total | 35.00 (4.07) | 33.94 (5.72) | $t(46) = -0.75$ | ≤0.46 |
| PSAS-Illness Education | 9.58 (2.57) | 9.88 (2.87) | $t(46) = 0.37$ | ≤0.71 |
| PSAS-Assertiveness | **11.23 (2.00)** | **9.65 (2.32)** | **$t(46) = -2.48$** | **≤0.02*** |
| PSAS-Mindful Nonadherence | 14.19 (3.20) | 14.41 (3.59) | $t(46) = 0.77$ | ≤0.83 |
| Baseline CAMM | 22.52 (5.29) | 23.00 (5.69) | $t(46) = 0.30$ | ≤0.77 |

* $p < 0.05$ (two-tailed).

and curvature of change across time [$t(61.6) = -4.89$, $p < .001$] were significant (Table 3). The pattern was depicted by Fig. 1, which shows how mindfulness increased by week for a prototypic participant in each group.

For the scales/subscales that showed significant time effects, we calculated the predicted scores of a prototypic participant in each group at baseline (time = 0 week), post-intervention (time = 6 weeks) and three-month follow-up (time = 13 weeks), using their corresponding final conditional growth models presented in Tables 2 and 3. Percentages of change magnitude were then calculated by the following formulas:

1. pre-post change % = (post-intervention score – baseline score) / baseline score * 100
2. pre-follow-up change % = (three-month follow-up score – baseline score) / baseline score * 100

The results were presented in Table 4. It is important to note that these were predicted values estimated from multilevel models, thus, statistical analysis of change scores was not applicable. However, the time effects were significant in the multilevel models, indicating significant changes in these scale/subscale scores across time.

## Discussion

The present study examined the effect of a novel self-directed, low-literacy patient educational manual called the *"ALL YOU NEED IS LOVE,"* targeted specifically at adolescents with CKD/ESKD. In addition, the study tested the added benefits of mindfulness training. Multilevel model analyses results showed that overall, time effect was significant for outcome variables, indicating that both the *"ALL YOU NEED IS LOVE"* patient education *only* intervention and the *"ALL YOU NEED IS LOVE" plus* mindfulness training intervention changed participants' self-management/HCT readiness, self-advocacy, and mindfulness across time. For the $STAR_X$ total scale and its disease knowledge subscale, time effect was significant, suggesting that both interventions significantly increased participants' HCT readiness, especially their CKD/ESKD disease knowledge. The estimated increase in the $STAR_X$ total score was approximately 3% at post-intervention and 7% at three-month follow-up after both interventions.

**Table 2**
Summary of the final conditional growth models for health care transition readiness.

| | $STAR_X$ Questionnaire Total | | $STAR_X$ Disease Knowledge | | $STAR_X$ Self-Management | | $STAR_X$ Provider Communication | |
|---|---|---|---|---|---|---|---|---|
| Fixed effects | Est. | SE | Est. | SE | Est. | SE | Est. | SE |
| Intercept | **42.79*****| **10.69** | **15.46***** | **3.56** | **18.10***** | **5.42** | **10.03*** | **4.10** |
| Age | 0.04 | 0.76 | −0.07 | 0.25 | −0.02 | 0.32 | 0.36 | 0.29 |
| Age at diagnosis | 0.25 | 0.28 | 0.09 | 0.09 | 0.12 | 0.12 | −0.05 | 0.11 |
| Week | **0.24**** | **0.09** | **0.09*** | **0.03** | −0.06 | 0.04 | −0.03 | 0.03 |
| Group | 0.55 | 2.83 | 0.63 | 0.94 | 0.25 | 1.19 | −0.11 | 1.09 |
| Random effects | Est. | SE | Est. | SE | Est. | SE | Est. | SE |
| Intercept ($\tau_{00}$) | **49.28**** | **16.27** | **4.73**** | **1.94** | **7.73**** | **2.91** | **7.36***** | **2.32** |
| Slope ($\tau_{11}$) | – | – | – | – | – | – | – | – |
| Residual ($\sigma_e^2$) | 25.93 | 6.11 | 4.70 | 1.10 | 7.44 | 1.67 | 4.16 | 0.92 |

*$p < .05$, **$p < .01$, ***$p < .001$ (two-tailed).

**Table 3**
Summary of the final conditional growth models for self-advocacy and mindful non-adherence using the patient self-advocacy scale and the childhood/adolescent mindfulness measure.

| | Patient Self-Advocacy Scale Total | | Patient Self-Advocacy Scale Illness Education | | Patient Self-Advocacy Scale Assertiveness | | Patient Self-Advocacy Scale Mindful Non-adherence | | Child and Adolescent Mindfulness Measure Total | |
|---|---|---|---|---|---|---|---|---|---|---|
| Fixed effects | Est. | SE | Est. | SE | Est. | SE | Est. | SE | Est. | SE |
| Intercept | **36.91**$^{***}$ | **4.57** | **11.83**$^{***}$ | **2.53** | **14.18**$^{***}$ | **2.58** | **12.62**$^{**}$ | **3.62** | **20.58**$^{***}$ | **6.01** |
| Age | −0.11 | 0.31 | −0.11 | 0.17 | −0.18 | 0.17 | 0.08 | 0.25 | 0.21 | 0.41 |
| Age at diagnosis | −0.11 | 0.11 | −0.09 | 0.06 | −0.08 | 0.06 | 0.05 | 0.09 | −0.10 | 0.14 |
| Week | −0.06 | 0.06 | **−0.09**$^{**}$ | **0.03** | **−0.06**$^{*}$ | **0.03** | **0.09**$^{*}$ | **0.04** | **1.19**$^{***}$ | **0.14** |
| Week$^2$ | – | – | – | – | – | – | – | – | **−0.03**$^{***}$ | **0.01** |
| Group | −0.31 | 1.24 | 0.12 | 0.68 | −0.92 | 0.70 | 0.44 | 0.99 | 0.07 | 1.63 |
| Random effects | Est. | SE | Est. | SE | Est. | SE | Est. | SE | Est. | SE |
| Intercept ($\tau_{00}$) | **6.56**$^{*}$ | **3.41** | **6.11**$^{***}$ | **1.75** | **3.00**$^{**}$ | **1.01** | **8.52**$^{***}$ | **2.71** | **19.21**$^{***}$ | **5.49** |
| Slope ($\tau_{11}$) | – | – | **0.01**$^{*}$ | **0.01** | – | – | – | – | – | – |
| Residual ($\sigma_e^2$) | 15.70 | 3.07 | 1.82 | 0.51 | 3.14 | 0.61 | 3.54 | 1.04 | 10.39 | 2.07 |

$^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$ (two-tailed).

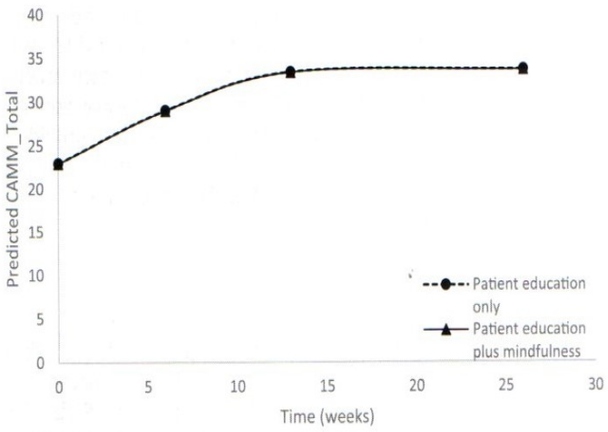


**Fig. 1.** Pattern of change in mindfulness by week for a prototypic participant in each group.

For the PSAS full scale, none of the fixed effects were significant, indicating that neither intervention changed participants' overall self-advocacy. However, when looking at the subscale level, the time effects were significant but in opposite directions. It is possible that the opposite directions of change cancelled out each other, leading to an insignificant interventional effect on overall self-advocacy. At the subscale level, results suggested that both interventions increased participants' self-advocacy in illness education (i.e., actively seek out and acquire disease information; Brashers et al., 1999) and assertiveness (i.e., willing to ask questions of the physician and engage in more decision-making regarding the treatment; Brashers et al., 1999), and decreased participants' mindful non-adherence (i.e., reject the treatment when it fails to meet own expectations; Brashers et al., 1999). In other words, after both interventions, adolescents were more likely to actively seek out disease knowledge, engage in decision-making about their treatment, and adhere to the prescribed treatment. The estimated magnitude of change in these subscale scores was around 3–6% at post-intervention, and around 7–12% at three-month follow-up.

In general, these results are consistent with the previous findings that HCT readiness interventions addressing disease knowledge, self-management, and communication with health care providers are effective to improve the HCT readiness of adolescents with chronic conditions (Huang et al., 2014; Mackie et al., 2018; Schmidt et al., 2018). The results also align with the findings from the Mexican study (Brito-Suárez et al., 2021), suggesting that the *"ALL YOU NEED IS LOVE"* manual is effective in improving transition readiness, especially disease knowledge, among adolescents/young adults with CKD.

Moreover, results suggest that the *"ALL YOU NEED IS LOVE"* manual may have additional benefits for increasing adolescents' mindfulness. For the CAMM, the effects of time and curvature of change across time were significant, indicating that participants in both groups gained significant increase in mindfulness, although the rate of increment diminished over time. This suggests that both interventions were effective in enhancing adolescents' mindfulness, but the change was not as significant in the long term.

To our knowledge, this study is the first to discover the additional benefits of patient education intervention on increasing adolescents' mindfulness. In this study, the greatest change occurred in the mindfulness CAMM total score, with both interventions resulting in approximately 26% increase at post-intervention and 45% increase at three-month follow-up. Mindfulness entails the present-moment awareness and an accepting attitude toward the experience (Creswell, 2017). We hypothesize that the current intervention featuring patient education on disease knowledge and self-management may have increased adolescents' self-awareness on their current level of disease knowledge and health behaviors, and increased their acceptance toward the experience with CKD, therefore enhancing their mindfulness. Further investigation is required to examine this hypothesis.

**Table 4**
Predicted scale/subscale scores of a prototypic participant in each group.

| | Patient Education Only Group | | | Patient Education Plus Mindfulness Training Group | | |
|---|---|---|---|---|---|---|
| | Baseline | Post-intervention | Three-month follow-up | Baseline | Post-intervention | Three-month follow-up |
| $STAR_x$ | | | | | | |
| $STAR_x$ Total | 45.12 | 46.56 (+3.19%) | 48.24 (+6.91%) | 45.67 | 47.11 (+3.15%) | 48.79 (+6.83%) |
| $STAR_x$ Disease Knowledge | 15.06 | 15.60 (+3.59%) | 16.23 (+7.77%) | 15.69 | 16.23 (+3.44%) | 16.86 (+7.46%) |
| PSAS | | | | | | |
| PSAS Illness Education | 9.59 | 9.05 (−5.63%) | 8.42 (−12.20%) | 9.71 | 9.17 (−5.56%) | 8.54 (−12.05%) |
| PSAS Assertiveness | 10.98 | 10.62 (−3.28%) | 10.20 (−7.10%) | 10.06 | 9.70 (−3.58%) | 9.28 (−7.75%) |
| PSAS Mindful Nonadherence | 14.14 | 14.68 (+3.82%) | 15.31 (+8.27%) | 14.58 | 15.12 (+3.70%) | 15.75 (+8.02%) |
| CAMM total | 22.96 | 29.02 (+26.39%) | 33.36 (+45.30%) | 22.93 | 28.99 (+26.43%) | 33.33 (+45.36%) |

*Note.* For the PSAS, lower scores indicate higher levels of self-advocacy; for the $STAR_x$ and the CAMM, higher scores indicate higher levels of transition readiness and mindfulness.

On the other hand, while both interventions have increased adolescents' mindfulness, the level of enhancement was limited in the long term. Additionally, the group effect was insignificant for all outcome variables, suggesting that adding mindfulness training may not bring extra benefits in self-management/HCT readiness, self-advocacy, and mindfulness. These results are inconsistent with our hypothesis and the published studies that mindfulness-based interventions are effective to improve the physical and mental health of adolescents with chronic conditions (Abujaradeh et al., 2018; Semple & Burke, 2019). The dosage effect and sample size may explain the limited benefit of the mindfulness training in this study. A study discovered that minimal dosage should be achieved to find benefits of mindfulness interventions (Brake et al., 2016), but the minimal dosage is not determined in the existing literature. Previously examined mindfulness interventions were typically 8–12 weeks in length with a minimum of 30 min per session, guided by trained professionals, and required adolescents to practice mindfulness both inside and outside sessions (Abujaradeh et al., 2018; Creswell, 2017; Semple & Burke, 2019). In contrast, the mindfulness training in our study was six weeks in length, 10 min per session, and self-directed by adolescents, which may weaken its interventional effect. It is necessary to conduct future research to improve the mindfulness training component to enhance the interventional effect on adolescents with CKD to further improve adolescents' physical and mental health (Abujaradeh et al., 2018; Creswell, 2017; Semple & Burke, 2019) and reduce health risk behaviors (Creswell, 2017).

### *Practice implications*

Nonadherence has been observed in many adolescent patients with CKD/ESKD and has been shown to result in adverse health outcomes (Ferris et al., 2017; Gajardo et al., 2021). Enhancing treatment adherence and self-management skills in adolescents/young adults with CKD/ESKD are crucial to the promotion of HCT outcomes. In this study we developed a self-directed, age-appropriate, and literacy-congruent patient education manual called *"ALL YOU NEED IS LOVE,"* which includes topics about CKD disease knowledge and management, self-management, treatment adherence, HCT readiness, healthcare system, and self-advocacy. Unlike prior interventions that span over two months (Huang et al., 2014) or complete eight modules within two days led by psychologist and pediatrician (Schmidt et al., 2018), the self-administered *"ALL YOU NEED IS LOVE"* manual is less cumbersome because of its relative brevity, allowing flexibility for adolescents to complete the intervention at their own pace. In addition, compared to other prior interventions (Mackie et al., 2018; Schmidt et al., 2018), using the *"ALL YOU NEED IS LOVE"* manual may be more cost-effective because it does not require extensive training for health professionals to conduct this intervention. Pediatric nurses and other clinicians may use the manual as a convenient patient education tool to hand out to patients during their medical appointment. The *"ALL YOU NEED IS LOVE"* manual is freely available on the following website: https://www.med.unc.edu/transition/current-projects/all-you-need-is-love-adherence-and-longitudinal-life-skills-for-youth-under-a-nurturing-educational-environment-on-disease-intelligent-self-management-lasting-outcomes-visionary-empowerment/.

### *Limitations*

Several limitations may affect the interpretation of findings. First, the study did not include a waitlist control group, which may reduce the internal validity of the study (Christ, 2007). It is possible that other confounding factors such as maturation may partially contribute to the improvement in transition readiness, self-advocacy, and mindfulness among both interventional groups across time. For instance, previous research showed that HCT readiness is positively associated with chronological age (Nazareth et al., 2018), so the participants' readiness may increase naturally during the course of the intervention. However, because our intervention only lasted for six weeks, it is unlikely that maturation alone could lead to a significant increase in the outcome variables. Second, the sample size in this study was small, which may limit the power of the study. Relatedly, given the sample size, we were unable to explore response by CKD stage. Future research should consider adding a control group and increasing sample size to better investigate the interventional effect and minimize the influence of confounding factors. Third, the low internal consistency of the PSAS assertiveness subscale and the $STAR_X$ provider communication and disease knowledge subscales may have affected the results of our study, suggesting the need to further refine these measures. Fourth, the imbalance of the sample size of two groups, as well as the group differences in age at diagnosis and the baseline PSAS assertiveness subscale score may have affected the results of the study as well.

## Conclusion

The six-week self-directed and low-literacy *"ALL YOU NEED IS LOVE"* manual featuring patient education on CKD disease knowledge, self-management, and communication with health care providers was efficacious in improving HCT readiness and self-advocacy among adolescents with CKD. In addition, the intervention alone may increase adolescents' mindfulness and self-awareness. Health care providers may utilize the patient education material described in this study to educate adolescents with CKD and help them better prepare for health self-management and HCT.

## CREDIT Statement

**Yunzhen Huang:** formal analysis, data curation, writing-original draft, writing - review & editing, visualization. **Eniko Rak:** conceptualization, methodology, writing - review & editing, supervision. **Richard A. Faldowski:** methodology, formal analysis, writing - review & editing. **Meaghan Nazareth:** investigation, data curation, writing - review & editing, project administration. **Jessica Ryan:** investigation, data curation, writing - review & editing, project administration. **Karina Javalkar:** conceptualization, writing - review & editing, supervision, project administration. **Brian Pitts:** investigation, writing - review & editing, project administration. **Maria Díaz-González de Ferris:** conceptualization, methodology, resources, writing - review & editing, supervision.

## Declaration of Competing Interest

This study was supported by the Renal Research Institute (RRI) grant.

## Acknowledgments

The authors would like to thank Renal Research Institute for their support on this project. The authors would like to thank the participants for their generous participation in this study. We also would like to thank the members of the University of North Carolina $STAR_X$ Laboratory for their timely contributions and comments.

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