



## A multimedia program for caregivers of pediatric patients with chronic kidney disease in Guatemala

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### ABSTRACT

**Objectives:** A multimedia medication training program for parents and legal guardians of children with chronic kidney disease (CKD) aimed to improve comprehension CKD and general information about medications used in pediatric patients attending The Foundation for Children with Kidney Disease (FUNDANIER, Guatemala City).

**Methods:** A quasi-experimental study was carried out to measure the impact of the educational intervention on medication knowledge, at FUNDANIER from September to October 2019. Means and standard deviations was used to described test results. A Wilcoxon test was performed, to compare scores of pre and post-tests. Odds Ratio (OR) was used to determine if there was an improvement in the knowledge score before and after the intervention.

**Results:** There was significant improvement in knowledge scores knowledge before and after the intervention (27/35 versus 33/35,  $P < 0.005$ ). Mestizo participants had higher odds of improvement before and after the intervention (OR 7, CI: 0.6–78). Parent-guardians with prior education, and who spoke Spanish had higher odds of improved knowledge scores (OR 3.2, CI: 0.3–35; OR 1.1 CI: 0.1–14 respectively).

**Conclusion:** Caregivers who participated in the educational workshop improved and retained information related to CKD comprehension and medications used. This study provides a model for educational modules that can be used, tested, and applied in other chronic disease settings in low to middle income countries.

**Practice implications:** A culturally relevant multimedia CKD educational platform was effective in improving medication knowledge among parent/guardians of children with CKD in a low literacy setting.

### Introduction

Chronic kidney disease (CKD) results in irreversible loss of renal function and has significant economic, social and psychological impacts on patients and their families (Hill et al., 2016; Levin et al., 2017). In Latin America, the prevalence of patients who require kidney replacement therapy, including hemodialysis, peritoneal dialysis or renal transplant, is 661 patients per 1 million inhabitants (Ministry of Health, and Guatemala, D. of E, 2020; Rosa-Diez et al., 2016). In Guatemala, incidence of pediatric CKD requiring kidney replacement therapy is 4.6 per million children (Cerón et al., 2014). Principal challenges of CKD

treatment include accessibility, availability and affordability of medications in addition to the disparity in access to health services resulting in delayed diagnosis, and treatment (Levin et al., 2017; Tummalapalli et al., 2020).

Patient education activities that aim to improve knowledge and understanding of both the disease and importance of medication use have shown to improve self-care knowledge and self-care behavior in CKD (Park & Kim, 2022). Thus, most educational programs aim to teach patients about their illness and different support systems available to empower decision making processes (Bonner et al., 2014). Successful programs for patients with chronic conditions such as asthma, diabetes,

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and heart failure motivate and sustain self-care practices to improve self-management in the long term (Lozano & Houtrow, 2018; Miller, 2016). There is however, little evidence in the medical literature demonstrating the use of effective educational tools in children with CKD.

Educational programs for children, adolescents, and young adults are complex and take into consideration family structures around patient care and varying levels of patient participation (Lozano & Houtrow, 2018). Most programs aim to improve patient engagement to influence self-care and may be conducted in group sessions or as one-on-one support systems, led by physicians or lay persons (Camp-Spivey et al., 2022). Modern and effective techniques used to educate children with chronic diseases combine didactic approaches including multimedia resources, reading materials and interactive activities to help patients understand their health problems and to influence patient's attitudes with regards to their self-care (Camp-Spivey et al., 2022). Programs tailored for children incorporate caregivers in educational activities to influence belief systems and attitudes about disease states and medication use helping to understand the role of medication in disease management (Niemitz et al., 2019). Most patient education resources are designed and implemented among high literacy populations and provide materials in the English language (Lozano & Houtrow, 2018).

Both language and culture have been shown to impact self-care and the ability to learn new information about disease states and disease management (Miller, 2016). To achieve the highest impact, self-care resources should be designed within the context of the clinic and patient culture (Beagley, 2011). Even when locally designed and implemented, it is unclear if educational tools used among the CKD population are effective at improving outcomes, results that are likely an artifact of variance in the population's educational level; programs tend to have a greater impact on low literacy populations in comparison to higher literacy counterparts within clinics (Campbell et al., 2022). Some authors recommend screening patients to recruit "high risk" participants for educational programs, meaning those with more severe disease states and/or lowest literacy rates (Camp-Spivey et al., 2022). There are gaps in the literature, specifically in research conducted outside the United States of America. Guatemala provides a unique context in which self-management can be explored in caregivers of CKD patients outside the U.S. The Foundation for Children with Kidney Disease (FUNDANIER, Guatemala City) is a clinic based at one of the largest tertiary hospitals in Guatemala. The clinic staff is composed of physicians, pharmacists, nurses, nutritionists and psychologists who work together to effectively improve CKD outcomes for children in Guatemala by providing care that focuses on the patient and their family's needs (Lou-Meda, 2015). The clinic serves a diverse group of Spanish speaking patients from Guatemala City, but also from rural parts of the country where Mayan-ethnic groups reside. FUNDANIER's major objective is to provide the highest quality care to Guatemalan patients in the public health care system, and the activities deployed include education, patient service and research. This project, carried out by FUNDANIER clinical staff, aimed to design an educational program about chronic kidney disease in children for low literacy caregivers and evaluate educational program effectiveness on knowledge.

**Methodology**

We conducted a quasi-experimental study to measure the impact of the educational intervention on the comprehension of basic medication knowledge.

*Development of a multimedia educational program*

A multimedia medication training program was developed for Spanish speaking parents and legal guardians of children with CKD attending FUNDANIER. The main educational themes of the program were developed based on a prior study directed toward children with chronic disease (asthma and diabetes) among populations with low

literacy (Wilson et al., 2010). The objectives were defined by the multidisciplinary team at FUNDANIER, and the content was organized in two different modules: Module 1) the basics of CKD; Module 2) General information about medications used in CKD patients at FUNDANIER. Each module was developed and delivered using videos, interactive activities, and illustrative materials [Table 1, supplemental files]. Study leaders collaborated with a graphic designer to create printed material, interactive activities, and narrated video. The same icons and graphics were used in each modality to improve retention of the information presented.

A panel made up of health professionals from the FUNDANIER team was invited to validate the program. They reviewed the proposed content of the multimedia program, methodology and material, and then provided feed-back and responded to a questionnaire consisting of 15 questions, each with 5-item Likert scale response category (very good (5) to very bad (1)). The questionnaire was based on an adaptation of a previous study evaluating an educational tool in children (Wilson et al., 2010). Responses were summarized and described. Statistical analysis was carried out to determine the degree of agreement between the professionals toward the instrument using the Kendall's W (Kendall's coefficient of concordance).

In addition to the panel, educational tools were piloted to assess adequacy by a panel of 15 parents (or legal guardians) of patients from the hemodialysis program at FUNDANIER. The complete multimedia medication training program was presented to participants of the activities and, who then gave comments to improve comprehension of

**Table 1**  
Module 1 content, the basics of CKD. Specific content of each module and activities can be found as supplementary material.

Theme	Module	Content	Objectives
Kidney	1	1. Basic structure	1. Understand the basic structure of the kidneys.
		2. Function	2. Understand the most important/basic function of the kidneys
CKD*	1	1. What is it?	1. Learn about generalities of CKD
		2. Consequences of CKD	2. Learn about consequences of CKD: High blood pressure, problems related to bone structure, anemia, hyperphosphatemia, zinc deficiency
		3. Kidney replacement therapies offered at FUNDANIER	3. Describe KRT**: Hemodialysis, peritoneal dialysis, kidney transplant
Medications for CKD	2	1. Medication names	1. Learn the names of the most important medications used at FUNDANIER and how to identify them
		2. Goal of medication use	2. Understand the purpose of therapy associated with each medication with respect to CKD treatment
		3. How to take medication	3. Learn about dosing intervals and times how medications should be taken
		4. What to expect when taking medication	4. Understand the most relevant clinical results of medications used for CKD at FUNDANIER

\* Chronic Kidney Disease.

\*\* Kidney Replacement Therapy.

language and images used.

### Effectiveness of multimedia educational program

We conducted a quasi-experimental study in order to measure the impact of the educational intervention on medication knowledge, at FUNDANIER from September to October 2019. All Spanish speaking parent-guardians of hemodialysis patients were invited to participate by the clinical psychologist during their weekly hemodialysis session. Patient guardians who affirmed their interest in participating were formally invited to the clinic to participate in the educational intervention the following week. On the day of the intervention, parent guardians were taken to a private room and taken through the informed consent process. Guardians were only excluded if their child/dependent was not part of the hemodialysis program.

Enrolled parent/guardians participated in the one-hour educational activity starting with a pretest, followed by an educational video and interactive activity that covered modules one and two. Clinic staff including the psychologist, nutritionist and pharmacist, who developed the materials were responsible for delivering the course materials. A take-home brochure reinforcing the information of the educational video was given to participants. Before leaving, the participants were asked to respond to a post activity ("Post-test 1") questionnaire. The following week, the questionnaire was administered in person during patient hemodialysis sessions to measure retention of the concepts presented in the educational activity ("Post-test 2"). The questionnaire was verbally administered, and responses were noted in a tablet using google forms.

Tests were developed by the study team based on objectives previously established by multimedia educational programs. The test consisted of seven questions including six multiple choice questions and one true/false question. Multiple choice and true/false questions aimed to establish the ability to recognize the names of medications used at FUNDANIER, including why and how they should be taken. Each question was equally valued at 5 points each, for a total of 35 points for the entire set of questions (Niemitz et al., 2019; T. D'Alonzo, 2011). The questionnaire in English and Spanish can be found as a [supplemental files].

### Data analysis

Descriptive statistics summarize patient demographics and scores. Differences in knowledge before and after the educational intervention were assessed by comparing before and after scores (Wilcoxon test, significance  $p < 0.05$ ). Outcome variables were dichotomized assigning a 1 to participants who demonstrated an improvement between the pretest and first post-test score and odds Ratios were calculated to assess the likelihood of obtaining an improved score after the intervention based on demographic variables (OR, significance  $p < 0.05$ ). Excel (XLSTAT for students) was used to carry out data analysis.

### Ethical considerations

This study protocol was approved by the ethics committee for human subject research at the faculty of Sciences and Humanities, Universidad del Valle de Guatemala, protocol QF-008-

2019–13,408 September 2019. All participants voluntarily signed informed consent before participation. Personal health information and all sensitive data were anonymized and stored in password protected documents.

## Results

### Validation by panel members and patient discussion group, multimedia program

Two pediatric nephrologists, 6 hemodialysis technicians, 1 nutritionist, 1 psychologist and 1 pharmacist participated in the validation of materials for multimedia program. Fifty-six percent of panel members scored the first module and 77% the second module with the highest possible total Likert scale score (75 points). A significant concordance between panel members was detected (Kendall's  $W = 0.2$ ,  $p < 0.05$ ) indicating a high degree of agreement between the panel members in regard to their opinions about the instrument. Specific observations were incorporated to improve module delivery. For example, discussion group leaders were instructed to take pauses between the presentation of each medication class giving participants the opportunity to discuss medications.

### Effectiveness of multimedia program on the knowledge of prescribed medications

A total of 24 guardians (parents, grandparents and other family members) had children who receive hemodialysis and therefore met criteria and accepted to participate in the program. Twenty three people completed the educational intervention and three measures. One participant was lost due to drop out. Among the participants 87% were female, ranging in age from 22 to 72 years. Fifty-seven percent of the participants self-identified as mestizos (European/indigenous), 30% as Indigenous (Mayan) while 13% of respondents chose not to respond to this question. The average educational level of participants was 4th grade (52%) followed by 23% that indicated never having received formal education (illiterate). Ninety-one percent of participants' primary language was Spanish. Ninety-one percent of the participants traveled >1 h to get to FUNDANIER to receive Kidney Replacement Therapy (KRT), of them 87% used public transportation (buses) from outside the city to arrive to the clinic (Table 2).

The test was worth a total of 35 points, the average pretest score was 27, the first post-test score average was 33, and the second post-test score was 32 points (Table 3). There was a significant improvement between the pretest and the first post-test scores (27 vs 33,  $P < 0.005$ ), there was also a significant improvement between the pretest and the

**Table 2**

The total study population included 23 participants, the distribution by demographic characteristic is indicated.

Demographic	Population, N = 23 (%)
Ethnicity	
Indigenous	7 (30.4)
Mestizo	13 (56.5)
No response	3 (13.0)
Level of education	
No formal education	5 (21.7)
3 years elementary school	7 (30.4)
6 years elementary school	5 (21.7)
Middle school	4 (17.4)
High school	1 (4.4)
University	1 (4.4)
Language	
Spanish	21 (91.3)
K'iche'	1 (4.4)
Mam	1 (4.4)
Time to get to clinic	
1/2 h.–1 h.	2 (8.7)
>1 h.–2 h.	10 (43.5)
>2 h.	11 (47.8)
Transportation	
Bus/public transportation	20 (86.9)
Private Car	2 (8.7)
Private Motorcycle	1 (4.4)

**Table 3**

Average values of test scores and differences between pretest and post-tests.

Baseline Measure	Average score	Comparator	Average score	p-value
Pretest	27	Post-test 1	33	0.005
Pretest	27	Post-test -2	32	0.003
Post-test-1	33	Post-test -2	32	0.34

second post-test (27 vs 32,  $P < 0.003$ ). There was no significant difference between the first and second post-test (33 vs. 32,  $P = 0.34$ ) (Table 3). Test scores by demographic characteristics are show in Table 4.

Odds ratios demonstrate that specific populations had higher odds of improving in medication knowledge after participating in the multimedia program. Mestizo participants had higher odds of improvement in the pretest / first post-test score after the intervention (OR 7.0, CI: 0.6–75.7). Female parent-guardians with formal education, and who spoke Spanish had higher odds of improved knowledge scores (OR 1.3, CI: 0.1–17.3; OR 3.2, CI: 0.3–35; OR 1.1 CI: 0.1–14 respectively), Table 5.

## Discussion

This study reports on an educational program using videos, interactive activities, and illustrative materials in Spanish to improve caregiver knowledge of CKD management in children and to assess any changes in knowledge of medications used for CKD that may be appropriate for use in other Latin American countries. Much needed didactic materials for self-management in CKD are provided that can be used in low literacy populations (Campbell et al., 2022).

There was a demonstrated improvement in medication knowledge, that was retained during the study period. Most review articles presenting self-management have mixed results on knowledge outcomes due to differences in intervention strategies and outcomes reported across studies (Campbell et al., 2022; Sheridan et al., 2011; Stenberg et al., 2019). Providing specific support for groups of people with lower levels of education may be a more efficient way to expend resources used for educational activities. Nevertheless, we found that the entire population benefited from the intervention, regardless of educational status. In agreement with existing literature, didactic multimedia activities were shown to be highly effective in promoting immediate participants' knowledge base and the long-term retention of concepts related to healthcare (Sheridan et al., 2011). Icons and images from printed material, in addition to verbal feedback provided through videos and discussion, have effectively supported comprehension of disease processes and medications (Wilson et al., 2010).

**Table 4**

Demographic characteristics and average test scores during study period.

	n = 23	Pre-Test, average score	Post-Test 1, average score	Post-Test 2, average score
<b>Ethnicity</b>				
Indigenous	7	63%	88%	80%
Mestizo	13	86%	98%	98%
No response	3	67%	100%	90%
<b>Level of education</b>				
No education	5	57%	89%	86%
3 years primary school	7	69%	94%	84%
6 years primary school	5	91%	97%	100%
Middle school	4	69%	94%	84%
High school	1	86%	100%	100%
University	1	100%	100%	100%
<b>Language</b>				
Spanish	21	78%	96%	93%
K'iche'	1	43%	86%	86%
Mam	1	71%	86%	71%

**Table 5**

Odds ratios representing the likelihood of improvement in test scores before and after intervention.

Demographic variable and comparator groups	N = 23 n (%)	Odds Ratio	Confidence Interval
<b>Gender</b>			
Feminine	20 (87.0%)	1.3	0.1–17.3
Masculine	3 (13.0%)		
<b>Ethnicity</b>			
Mestizo	10 (43.4%)	7.0	0.6–75.7
Indigenous/not identified	13 (56.5%)		
<b>Education</b>			
Formal education	5 (21.7%)	3.2	0.3–34.6
No formal education	18 (78.3%)		
<b>Maternal language</b>			
Spanish	21 (91.3%)		
Mayan language	2 (8.6%)	1.1	0.1–14.0

We show that caregivers have higher odds of retaining information if they are mestizo, have any history of formal education, and if they speak Spanish. These tendencies are similar to findings in health literacy, where education, ethnicity, and language are attributed to higher levels of health literacy in a population, specifically in Spanish speaking populations (Christy et al., 2021; Guntzville et al., 2017; Hoffman et al., 2017). Here, we did not collect information on health literacy although it would be advisable for future studies in order to understand the long term impact of educational interventions. Advances in self-care, and medication comprehension may be minimal among populations with poor health literacy and should be addressed in the design of multimedia programs (Schrauben et al., 2020).

Multimedia educational design facilitates retention of concepts among participants, as we have shown, and addresses educational and linguistic barriers in clinics where patients have varying levels of literacy (Van der Heide et al., 2014). Design of personalized interventions in collaboration with the ministry of health, that incorporate cultural norms and practices are more likely to ensure participant engagement, as has been shown in Guatemala (Mendoza Montano et al., 2016; Tschida et al., 2021). Using similar methodologies, chronic disease health care workers have effectively developed educational materials for low-literacy Mayan-speaking Adult populations in Guatemala and have successfully adapted US based educational frameworks to improve diabetes indicators and self-care outcomes (Tschida et al., 2021). These types of programs enable patients to participate in decision making processes that improve health and to adhere to medication regimens (Miller, 2016; Stenberg et al., 2019). Herein we provide a similar, culturally relevant multimedia CKD educational platform, adapted for a low literacy population that can be used with parent/guardians of children with CKD. Implementation will enable the clinic to explore effectiveness of the educational platform on CKD outcomes.

## Limitations

There were some limitations to our study in terms of the impact that our educational program may have on patient outcomes. To identify the impact this educational approach has on adherence and clinical care, long term studies should be conducted to measure clinical outcomes and should include larger groups of patients, including a control group. Odds ratios and corresponding wide ranging confidence intervals demonstrate deficiencies in the power of the clinic's population to describe the true odds of improved knowledge of specific demographic groups after the educational intervention. To our knowledge this is the first time in Central America that a pediatric kidney clinic develops a strategy to convey highly complex health care concepts to a low-formal-education

population. Our findings, although limited by the size of the study, show the improvement in knowledge and the retention of this knowledge in this population. We plan to continue using this Multimedia Program strategy in our clinic, and to deploy similar contents for educational interventions with other Kidney Clinic Programs, such as Advanced Kidney Failure, Peritoneal Dialysis and Transplantation.

### Implications to practice

A culturally relevant multimedia CKD educational platform was effective in improving medication knowledge among parent/guardians of children with CKD in a low literacy setting.

### Conclusion

Caregivers, primarily parents, grandparents and family members, who participated in the educational workshop in Guatemala improved and retained information related to CKD comprehension and medications used. This study provides a basic model for educational modules that can be used, tested, and applied in other chronic disease settings in low to middle income countries. More work needs to be done involving larger groups of patients to understand the clinical impacts of these educational interventions.

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pedn.2023.08.016>.

### CRediT authorship contribution statement

**Brooke M. Ramay:** Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing – original draft, Writing – review & editing. **Ana Gabriela Espinoza Sierra:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Data curation, Writing – original draft. **Ana Lucía Enríquez:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Data curation, Writing – original draft. **Celeste Espel:** Conceptualization, Methodology, Validation, Resources, Writing – original draft. **Cristina Zelaya:** Conceptualization, Methodology, Validation, Resources, Writing – original draft. **Angie Lizet Aguilar Gonzalez:** Conceptualization, Methodology, Validation, Resources, Writing – original draft. **Randall Lou-Meda:** Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing – review & editing, Supervision.

### Declaration of Competing Interest

None.

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