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Evaluation of a telenovela designed to improve knowledge and behavioral intentions among Hispanic patients with end-stage renal disease in Southern California

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Abstract

Objective—Culturally relevant education is needed to improve rates of successful kidney transplantation among Hispanic patients with end-stage renal disease (ESRD). This study examined whether patients' knowledge about kidney disease, post-operative care, and proactive health practices improved after watching a telenovela series about ESRD.

Design—334 ESRD patients and 94 family members/caregivers were assigned to watch a telenovela ("Fixing Paco," a bilingual health education film) or receive standard of care at a transplant center or at a dialysis clinic. Outcomes for pre-transplant patients assigned to standard of care at dialysis centers or at a transplant center were compared to pre-transplant patients in the treatment condition (standard of care + telenovela).

Results—Knowledge and behavioral intention scores at baseline across conditions and locations were similar, suggesting that assignment resulted in comparable groups at baseline. Using linear regression, this study found statistically significant improvements in knowledge scores among the telenovela group as compared to the standard of care groups. The telenovela group also had greater improvements in behavioral intention scores compared to the standard of care groups. Family members assigned to the telenovela group had significant improvements in knowledge scores as compared to the standard of care groups.

Conclusion—Being well informed about ESRD and adopting proactive health behaviors are important mechanisms in improving transplantation outcomes. These findings suggest that knowledge about kidney disease, post-operative care, and proactive health practices could be improved by viewing a telenovela. Implications, limitations, and directions for future research are discussed.

Keywords

Hispanic; End-Stage Renal Disease; Telenovela; Kidney Transplant; Entertainment Education; Health education intervention

1. Introduction

In the United States (U.S.) during 2008, over 500,000 people received treatment for end-stage renal disease (ESRD) (NIDKK 2008; NIH 2010). ESRD occurs when approximately 90% of kidney function has been permanently and irreversibly lost requiring patients to endure kidney dialysis up to three times per week or undergo kidney transplantation. In the U.S., rates of ESRD, and its antecedents, type 2 diabetes and hypertension, are rising more rapidly among Hispanics than among Non-Hispanic whites with disparities in treatment and transplantation outcomes a critical concern (Peralta et al. 2006; Rosella et al. 2012). The risk for type 2 diabetes is 66% higher among Hispanics compared to Non-Hispanic whites (CDC, 2011) and once diagnosed, they are far more likely to have the condition progress to ESRD than other groups (CDC, 2011; Peralta et al., 2006). In Southern California there is a growing Hispanic population at risk for type 2 diabetes. Hispanics currently comprise the majority of ESRD patients undergoing dialysis with many of these patients reporting low literacy rates, limited English language skills, low socioeconomic status, and lack of critical information about care options (Bernabe and Rios 2004; Martinez et al. 2012).

Although recent studies have found that less time on dialysis improves transplant outcomes, patient knowledge and understanding of the eligibility for, the process of transitioning to, and the benefits of, transplantation as a treatment option pose significant challenges to optimal care (Meier-Kriesche et al. 2000; Finkelstein et al., 2008). The Centers for Medicare and Medicaid Services (CMS) mandates that all dialysis patients be informed about treatment options, especially transplantation. However, best practices for disseminating information regarding self-care and eligibility for transplantation have yet to be established. Currently there is tremendous variability in information delivery, which can include verbal communication by a health care provider or social worker, pamphlets, or short informational videos. Receiving and comprehending this information is critical as patients who recall communicating about transplantation with a health care provider are 3 times more likely to be put on a transplantation list compared to patients who do not recall this communication (Salter et al., 2014). Salter and colleagues (2014) also found considerable discordance between physician and patient reports of having been informed about the eligibility and benefits of transplantation and that it was the patient report, not the clinician report, which increased the likelihood of being wait-listed. Moreover, it is often necessary to repeat the discussion several times and it is imperative that the patient understands the transplant process thoroughly. Improving information delivery may be even more critical for patient populations who would benefit from culturally framed messages that are compatible with their day-to-day experience and world-view, particularly if there are language barriers that impede comprehension of messages intended for an English speaking audience. Following recommendations for public health interventions, this study created and evaluated a unique, locally developed, and culturally tailored telenovela series for Hispanic, end stage renal

disease patients residing in southern California (Los Angeles County Department of Public Health, 2009).

Dialysis is not a cure or long-term treatment for ESRD with patients at high risk for serious physical complications, psychological stress, and economic hardship. Compared to dialysis, transplantation has been described as a superior treatment that can increase the likelihood of optimal outcomes for patients. Unfortunately, in areas like Southern California, median wait times for transplantation have climbed to approximately 4 years (Organ Procurement and Transplantation Network [OPTN] 2014a; United States Renal Data System [USRDS] 2011), and roughly 4,000 individuals have been awaiting kidney transplant for over 5 years (OPTN, 2014b). Imparting information is crucial as helping patients to become more proactive in caring for their health during this critical wait time can reduce feelings of powerlessness and frustration, prevent the decline in health, and build life-long skills in active self-care. Approximately one third of patients do not understand the necessary steps and are unprepared for the responsibilities that are essential for continued good health and survival of the transplanted organ (NIT 2009). The most commonly cited barriers to adequate understanding of health care needs and disease management are poverty, limited education, low reading levels, and limited English language skills (Andrus and Roth 2002; Dubowitz et al. 2011). Research has suggested that minority patients are less likely to have a comprehensive understanding of their disease or health management, have less awareness of treatment options, and report more restricted access to essential services than their Non-Hispanic white counterparts (Powe; 2008). Moreover, Hispanics and other minorities have traditionally been skeptical of biomedical and translational research, underscoring the need for further studies that investigate the efficacy of culturally sensitive interventions among vulnerable populations and patients (Ulrich et al. 2013; Mullins, Abdulhalim, and Lavallee 2012).

Entertainment-education, providing important health behavior and health care information in an entertaining narrative or story format (print, radio, television, etc.), is a method of delivering health education material to broad audiences including populations that have limited access to traditional health behavior and health care information or experience language barriers that impede comprehension (Singhal & Rogers, 2002; Unger et al., 2012; Wilkin et al, 2007). The use of versatile, alternative messaging modalities to promote behavior change or adherence may be particularly effective with audiences with lower literacy levels, who are not likely to consume complex, written material. Over the last decade there has been a proliferation of entertainment-education: media based approaches that deliver health information and promote behavior change. Entertainment-education interventions are grounded in social learning theory, which posits that individual behaviors are developed and influenced through the observation of others. The effectiveness of entertainment-education interventions is likely due to the use of familiar positive and negative role models embedded in social contexts similar to those of the viewer (Bandura, 1976). Evaluations of entertainment-education interventions have yielded promising results across socio-demographic groups, ethnicities, and genders, suggesting that utilizing culturally tailored messaging, relevant and understandable characters, and contextual narratives that reflect the concerns and beliefs of specific audiences are an effective means of transmitting important health information (Davis et al., 2004; Vaughn et al., 2000).

Telenovelas may be a particularly favorable form of communication among Hispanic audiences as they are a popular medium perceived to reflect and shape the experiences of Hispanics (de la Luz Casas Perez, 2005). Telenovela based interventions have been used successfully to reduce alcohol use among teenage girls, improve use of cancer screening services, increase understanding of HIV risk, and enhance workplace safety (Lalonde et al., 1997; Sanchez et al., 2013; Wilkin et al., 2007).

In an effort to address the barriers to care and improve health education in central Los Angeles where 57% of residents are Hispanic, 24% of residents live below the federal poverty level, and 33% of residents report difficulty in accessing medical care this study evaluated the effectiveness of an educational video, or telenovela, titled “Fixing Paco.” Unlike printed materials and traditional health education videos, the novela-style video is accessible to low literacy levels, informative and entertaining for the entire family, and can be tailored to the social norms and values of specific cultures. We hypothesized that patients who viewed the telenovela would have greater improvements in knowledge and intentions to adopt proactive healthcare behaviors than patients receiving the standard health education in dialysis clinics or a transplant center. We also hypothesized that patients’ caregivers who viewed “Fixing Paco” would have greater improvement in knowledge scores than patients’ caregivers who did not.

2. Methods

“Fixing Paco” is a video that presents transplant information in the format of a telenovela, in which a fictional story unfolds over several episodes ranging from 4 to 14 minutes in length (total viewing time: 1 hour and 31 minutes) – created for Hispanic patients facing ESRD and their families. “Fixing Paco” is a ten episode series that follows a father of four and owner of a handyman business as his health begins to decline due to kidney failure. Filmed in English and Spanish and starring bilingual actors, “Fixing Paco,” cuts through language barriers and delivers a message of hope as Paco Fuentes contends with the trials and tribulations of kidney failure, learns the information and practices essential to surviving ESRD and ultimately undergoes transplantation. The story was developed by a team of Hispanic cultural experts and medical professionals and was designed to resonate with Hispanic cultural values that are salient in Southern California, home to a largely Mexican American and Central American Hispanic population. Once the study period ended, all patients and family members assigned to the control conditions were provided a copy of “Fixing Paco.”

2.1 Study participants

ESRD patients were recruited from 14 Los Angeles county dialysis clinics and the Kidney Pancreas Transplant Center at USC University Hospital between 2012 and 2013. Eligible patients (age 18 or older, English- or Spanish-speaking, currently on dialysis, no medical conditions precluding a transplant) were identified and recruited at the transplant center and dialysis clinics. Data collection was conducted in compliance with the protocol approved by the Institutional Review Board of the University. A research assistant telephoned each potential participant, described the study, obtained consent and asked each participant to

refer a family member who might be interested in participating; these family members were also telephoned and consented.

2.2 Study design

Patients were assigned to one of two groups: (1) standard of care at a dialysis clinic (peer-education sessions) or Kidney Pancreas Transplant Center (patient information video) during intake at a transplant center or (2) standard of care plus “Fixing Paco.” Initially, patients scheduled for their first appointments at dialysis clinics or Kidney Pancreas Transplant Center on Tuesday, Thursday or Saturday were assigned to the control group whereas patients who had a Monday, Wednesday or Friday appointment were assigned to the telenovela group. Six months later the assignment method was changed at all locations so that patients with appointments on Tuesday, Thursday or Saturday were assigned to the telenovela group while Monday, Wednesday, or Friday patients were assigned to the control condition. This assignment procedure was established to create comparable groups at baseline without overburdening the administrative staff at both dialysis clinics and Kidney Pancreas Transplant Center.

Standard of care patient information at the transplant center consists of a 10-minute video introducing and defining the roles of health care professionals that the patient will encounter, a description of dialysis procedures, and transplantation eligibility information in English and Spanish. Standard of care at dialysis clinics consists of meetings with a social worker who describes dialysis procedures and explains transplantation eligibility and procedures. Some patients also participate in a peer education program. In this study, we selected only those patients who were enrolled in the peer education program, so that we could assess the effect of the telenovela over and above the effects of the most intensive education typically available in a dialysis clinic. We refer to this combined social worker / peer education as standard of care, even though some patients receive even lower levels of education if they decide not to enroll in the peer education program.

All participants completed a pretest questionnaire assessing their knowledge about transplantation, organ donation, pre- and post-operative care, proactive healthcare, and intentions to investigate their eligibility for transplantation and, if eligible, to pursue transplantation. After completing the pretest patients received standard of care or standard of care plus “Fixing Paco” and completed a posttest questionnaire assessing the same topics. Family members were assigned to the same experimental condition as their relative and completed similar surveys (with slight wording modifications such as replacing “you” with “your family member”).

2.3 Measures

Gender was coded as 0 = male and 1 = female. *Location* was a dichotomous variable coded as 0 = dialysis center and 1= UTC (University Transplant Center). *Study condition* was coded as 0 = standard of care (control condition) and 1= telenovela (treatment condition).

Knowledge—A scale measuring knowledge of ESRD and transplantation was created for this study with 25 items assessing important information regarding transplantation, self-care,

compliance and proactive behaviors that were addressed in the telenovela and provided to patients in their standard of care education sessions. Sample questions included: “After a transplant, do I ever need dialysis again?” “Is transplantation a cure for End-Stage Renal Disease?” “Being compliant means:” All items were summed to calculate a total knowledge score.

Behavioral intentions—Proactive behavioral intentions were assessed with 7 items asking patients if they believed that they would initiate proactive health behaviors in the next month. Sample questions included: “In the next month...” “do you intend to talk with your doctor about getting a kidney transplant?”, “do you think you will schedule a medical evaluation to find out if you are a candidate for a kidney transplant?” and “do you think you will put yourself on a transplant list?” Response options were “yes” = 1, “no” = 0, and “I don’t know” = 0. Responses were summed to calculate a composite behavioral intention score (Cronbach’s alpha = .81).

2.4 Analyses

Independent sample t-tests were used to compare pretest scores across conditions and paired t-tests were used to compare pretest and posttest scores across conditions. A difference score (or change score) was calculated for knowledge and behavioral intentions for all participants. Given that several dialysis clinics participated in the current study, patients attending one site may have shared similar characteristics relative to those attending a different site. Appropriate diagnostics demonstrated that intraclass correlation was negligible in this study. For example, the intraclass correlations were .0013 and .0026 for knowledge and behavior intention outcomes respectively. Further diagnostic analyses indicated that the assumptions of ordinary least squares regression were met.

Separate linear regression models assessed whether experimental condition and demographic characteristics were associated with change scores for knowledge and behavioral intentions among patients as well as change scores for knowledge among participants’ family members/caregivers. Interaction terms were calculated for gender* age, gender*location, age*location, age*experimental condition, gender*experimental condition, and experimental condition*location to determine whether or not pretest-posttest knowledge and behavioral intention gains varied by demographic characteristics or standard of care conditions.

3. Results

Five hundred and twenty two patients were initially contacted. Of the 447 who were eligible to participate, 405 provided informed consent and completed the pretest. By December 2013, 334 completed the posttest, and 71 patients were lost to attrition. Retention was 78% at dialysis centers and 83% at the Kidney Pancreas Transplant Center. Among the 99 family members who provided consent 94 also provided pretest and posttest data. Patients were ethnically diverse; the largest group was Hispanic (66%), followed by Non-Hispanic white (11%), Asian Pacific Islander (9%), African American (7%), and “other (4%).” Patients’ ages ranged from 19 to 85. Sixty percent of participants were born outside of the U.S. with

75% reporting that they spoke English or English and another language, with 25% reporting that they spoke only Spanish.

Table 1 describes the demographic characteristics of participants and participants' family members/caregivers by study condition. Comparisons revealed no significant differences in gender, education and ethnicity and no significant differences in knowledge or behavioral intention scores across study conditions at pretest (Table 2). At posttest there were significant differences in knowledge and behavioral intention scores across study conditions with patients viewing "Fixing Paco" reporting greater increases. Table 3 describes the association between demographic variables, study condition and changes in patients' knowledge and behavioral intention scores as well as changes in patients' family members'/caregivers' knowledge scores.

At posttest, there was a significant difference in knowledge scores ($\beta = 4.06$, $p < .001$) among those who viewed "Fixing Paco" as compared to patients who received standard of care at both Kidney Pancreas Transplant Center and dialysis centers. There was an inverse relationship between age in years and changes in knowledge scores ($\beta = -.08$, $p < .05$), a positive association between education and changes in knowledge scores ($\beta = 2.18$, $p < .001$), and an inverse association between pretest scores and change in knowledge scores ($\beta = -.81$, $p < .001$). There was a significant association between location and knowledge scores ($\beta = -1.81$, $p < .01$), and a significant interaction between location and condition ($\beta = 1.17$, $p < .05$) with knowledge change.

There were also significant changes in patient behavioral intention scores across the two conditions. Patients in the video condition had significantly greater change in behavioral intention scores than those assigned to receive standard of care ($\beta = .62$, $p < .05$). There were no significant interactions for behavioral intentions by gender or location. At posttest patients' family members and caregivers assigned to the video condition reported greater knowledge gains than those assigned to the standard of care condition ($\beta = 3.74$, $p < .01$). Among family members those with the lowest pretest scores ($\beta = -.62$, $p < .001$) reported the greatest increases in knowledge at posttest.

4. Discussion

Being well informed about ESRD and adopting proactive health behaviors are important mechanisms in improving transplantation outcomes. The present findings suggest improvements in knowledge and in behavioral intentions can be achieved after watching a telenovela among a diverse group of ESRD patients. After viewing "Fixing Paco" patients and patients' family members showed improvements in their knowledge of ESRD, the transplantation process, and important aspects of self-care. Patients with lower pretest scores demonstrated the greatest improvements across these two domains, suggesting that the most vulnerable groups benefitted most from the telenovela format. This study builds on the work of recent studies employing telenovelas that have reported promising results, although these studies were conducted without the use of pretests and/or comparison groups (Unger, Molina, and Baron 2009; Unger et al., 2012; Valle, Yamada, and Matiella 2006). The use of

a comparison group and family members in this study advances the growing literature that suggests telenovelas may be an effective health education tool for Hispanic patients.

Numerous health behavior intervention studies have noted diminished effects of interventions over time; however the ease of dissemination and the opportunity for repeated viewing at low cost to the patient are two clear benefits of an entertainment- education intervention (Carey et al., 2011; Hoffman et al., 2011; Simons-Morton et al., 1996). Patient surveys included questions about their perceptions of the video; over 90% of patients reported that the events in the video were relevant to their everyday lives and that the characters presented in the video were understandable and accessible. These subjective responses confirm that patients perceived the characters and the narrative to be pertinent and that the telenovela maintained the patients' interest for several viewings, a significant factor in health information dissemination and behavior change models. Future research should expand the application and evaluation of telenovelas as an adjunct to standard of care information and behavior change programs across diverse populations who also have limited resources and mobility. In addition, the significant knowledge gains among the family members/caretakers that watched the telenovela may have important implications for patients dependent on family or caregivers for their day-to-day needs while undergoing dialysis and transplantation. Active family member participation in chronic disease care has been shown to improve the care giving experience of family members and be a promising means for reducing rates of subsequent hospitalizations for the chronically ill (Coleman et al. 2004; Maas et al. 2004)

4.1 Limitations

Several limitations should be noted when considering study findings. Findings may only generalize to populations with similar demographic backgrounds in Southern California as access to care and standard of care may vary across cities and states. Because all dialysis patients are eligible for Medicare, and participating dialysis clinics were located throughout the greater Los Angeles area, this study's sample likely represents a cross section of ESRD patients in this region. The knowledge measure was designed specifically for the current study to assess patient retention of information conveyed in the video series "Fixing Paco." The video itself was developed in response to observations – made over several years – of notable knowledge deficits among transplant candidates. A thorough literature review did not yield a transplant patient knowledge scale appropriate for the literacy level of this population; therefore this study developed a measure that assessed crucial knowledge about transplantation and proactive health behaviors conveyed in the telenovela. We did not validate whether or not patients or family members/caregivers watched the entire video series, however the significant improvement in knowledge and behavioral intention scores in the video groups suggests that partial or complete viewing of the series improved knowledge and behavioral scores. If patients watched all episodes they were exposed to a total of 1 hour and 31 minutes of material. We did not confirm how many episodes patients watched and those who were especially drawn to the characters or story line may have had repeated exposure by viewing the episodes several times. If some patients did not watch or pay attention to the entire series, the finding that exposure to the series produced a significant knowledge gain is even more impressive. Due to the burden placed on administrative staff

and peer educators at multiple dialysis clinics and the transplantation center, this study selected the most feasible assignment procedure. The assignment procedure fell short of pure random assignment, but produced two similar groups on observable/measured characteristics. This study did not follow patients or family members after completing the posttest survey and therefore cannot determine if behavioral intentions led to actual behavior change. Longitudinal research is needed to assess whether or not patients can adopt healthcare practices, pursue transplantation, and maintain optimal self-care.

4.2 Implications

Despite these limitations, findings indicated that telenovelas could be an effective method to improve knowledge and behavioral intentions during the waiting period leading up to transplantation. It is reasonable to assume that chronically ill patients are sufficiently well informed about their condition, potentially beneficial life style changes, self-care, and available treatment options. However, previous studies and the baseline knowledge scores for this study sample suggest that patients lacked critical knowledge in these areas and that improved methods of information delivery should be considered (Dagedorf & Cavanaugh, 2014). Telenovelas are a promising format that can increase patient awareness and knowledge retention, as they are available for periodic, repeated viewing.

In light of these findings telenovelas are an intervention strategy that should be integrated into health behavior information delivery services for Hispanic patients. ESRD patients need to understand the scope of their responsibilities toward self-care, learn how and when to seek professional help as well as learn how to access the resources that will ensure their continued wellbeing. These skills are imperative since successful transplantation hinges upon a lifelong commitment from patients to incorporate these skills into their day-to-day routines. Because ESRD patients often depend on caregivers, a well-designed, informative telenovela is an especially favorable medium to enhance communication between patient and caregiver without further straining the resources of individuals and families burdened by a serious illness. Future research should be conducted to explore how telenovelas can be integrated into healthcare delivery systems across the spectrum of chronic disease and whether or not providing health information material to patients that is entertaining, easy to absorb, can be kept at home and shared with friends and family strengthens the commitment to long term care among all members of the patient's support network.

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Table 1Demographic characteristics at baseline^a

	Patient f%		Family f%	
Demographic Variables	Control n=170	Treatment (video) n=164	Control n=46	Treatment (video) n=48
<i>Gender^a</i>				
Male	103(61%)	99(61%)	17(37%)	17(35%)
Female	67(39%)	65(40%)	29(64%)	31(65%)
	X ² = .11, p = .90		X ² = .18, p = .67	
<i>Ethnicity^a</i>				
African American	18(11%)	16(10%)	2(4%)	2(4%)
API	11(6%)	15(9%)	3 (7%)	3(6%)
Hispanic	115(68%)	113(69%)	35(76%)	34(70%)
Caucasian	21(12%)	15(9%)	2(4%)	4(8%)
Other	6(4%)	5(3%)	4(9%)	5(10%)
	X ² =1.26, p = .26		X ² =1.13, p= .29	
<i>Education^a</i>				
Never went to school	9(5%)	5(3%)	--	--
Elementary school	44(26%)	40(24%)	11(24%)	13(26%)
Middle/Junior high	9(5%)	7(3%)	3(3%)	2(4%)
Some High school	16(9%)	25(17%)	4(9%)	5(10%)
High school grad/GED	35(21%)	39(25%)	9(22%)	15(31%)
Some college	39(23%)	30(18%)	12(14%)	2(4%)
College grad	18(11%)	16(9%)	7(26%)	12(25%)
Other	--	2(1%)	--	--
	X ² =6.45, p = .38		X ² = 2.16, p = .16	
<i>Age^b</i>				
	54.23(11.82)	53(12.53)	45.54(18.06)	47.43(14.0)
	t=.90, p=.35		t=-.65 p=.54	
Dialysis center ^c	70(55%)	58(45%)	22(45%)	23(48%)
UTC ^c	100(49%)	106(51%)	44(55%)	25(52%)

^aNumbers in cells are frequencies for each characteristic across study condition. Frequencies were compared using chi square tests.^bNumbers in cells are means and corresponding standard deviations. Means were compared using independent sample t tests with equal variances.^cUTC (university transplant center), Numbers in cells reflect the sample size of patients enrolled in each condition by location.

Table 2Knowledge and behavioral intention scores at baseline and post intervention ^a

Variable	Patient		Family	
	Control	Treatment	Control	Treatment
Knowledge (baseline)	19.51(4.92)	19.05(4.48)	22.41(5.50)	22.05(5.76)
Knowledge (post intervention)	24.03(4.63)	29.94(3.54)	22.02(5.76)	28.92(4.36)
Behavioral intentions (baseline)	6.1(1.49)	5.9(1.42)		
Behavioral intentions (post intervention)	6.9(1.72)	11.2(1.69)		

^aNumbers in cells are means and corresponding standard deviations. Independent sample t-test with equal variances were used for comparing pretest scores across conditions while paired t-test with equal variances were used for comparing change in scores at posttest.

Table 3Correlates of changes in knowledge and behavioral intentions ^{a, b}

Predictor	Patient knowledge		Family knowledge		Patient behavioral intentions	
	Beta	s.e.	Beta	s.e.	Beta	s.e.
Gender	.71	.68	1.41	1.43	-.13	.12
Age	-.08**	.02	-.04	.04	-.01	.10
Education	2.12**	.48	.81	.45	.16	.10
Pretest (knowledge)	-.81***	.05	-.62**	.16	--	
Location	-1.81**	.50	1.67	1.78	-.03	.19
Study condition	4.06***	.62	3.75***	1.7	.62*	.14
Location*condition	1.17*	.86	-1.21	1.92	.23	.19

^aNumbers in cells are unstandardized coefficients from linear regression models with corresponding standard errors.

* p < .05,

** p < .01,

*** p < .001

^bstudy condition is coded 0 = standard of care, 1 = standard of care + telenovela