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Using the Health Belief Model to evaluate Samoan caregiver perceptions for rheumatic heart disease follow-up care

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Background: The application of health promotion and education theories to better understand clinical efforts in relations to rheumatic heart disease has been recognized by world experts in the clinical field. To help understand the behavior of caregivers of children in Samoa diagnosed with definite RHD, the Health Belief Model (HBM) offers a framework of constructs to assist in gathering and analyzing information obtained from caregivers.

Objective: The objective of this study is to apply the HBM to assess possible barriers to follow-up care compliance among a convenience sample of caregivers of children in Samoa whose child has been diagnosed with definite RHD.

Methods: This was a cross-sectional study. Using the HBM, a questionnaire was developed to compare caregiver knowledge and perceptions regarding their child's RHD diagnosis with the number of follow-up visits reported in a 12-month period.

Results: The Samoan National Health Service personnel arranged for 67 caregivers to participate. Using an unpaired Mann-Whitney-Wilcoxon test, we detected an association between caregiver understanding of treatment location ($p = <.01$), and disease severity ($p = <.01$) with the number of follow-up visits in a 12-month period.

Conclusion: We demonstrated an association between follow-up visits and caregiver perceptions with their belief that their child is actually sick. This showed a significant association with the action of caregivers of children with RHD in Samoa to seek appropriate follow-up treatments. This validates the need to include caregiver education in RHD health promotion program development.

Keywords: Health Belief Model; rheumatic heart disease; follow-up care

Background

The application of health promotion and education theories to better understand clinical efforts in relations to rheumatic heart disease (RHD) has been recognized by world experts in the clinical field (Carapetis and Zuhike 2011; Zuhkle and Engel 2013). The conditions of acute rheumatic fever (ARF), and its sequela RHD, have been identified as significant health concerns in developing countries (Faller and Allen 2009; Carapetis et al. 2013; Kumar and Tandon 2013; Lawrence et al. 2013). RHD is the consequence of a streptococcal pharyngitis bacterial infection, commonly known as strep throat. Left untreated, a streptococcal infection can progress to ARF, and eventually RHD, which in

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children between the ages of 5–15 years primarily causes valvular heart disease and can lead to symptoms of congestive heart failure and possible death. Proper antibiotics, most commonly benzathine penicillin, administered in a timely manner for an acute streptococcal pharyngeal infection can completely eliminate the immune response that can lead to ARF and RHD. Once a child develops ARF or RHD, they are at a substantially higher risk for recurring episodes of strep infections and bouts of ARF. Thus, once a child is diagnosed with RHD, regular prophylactic antibiotics, every 3–4 weeks for a minimum of 5 years, and for some life-long therapy is required. This is a defense against recurrent strep infections and bouts of ARF which can prevent progression of RHD (Remenyi et al. 2013). RHD is both preventable and treatable, if children seek and receive proper medical therapy. Medical professionals and researchers understand the relationship between streptococcal pharyngitis and RHD, but it is not commonly understood among general populations, including the country of Samoa (Zuhkle and Engel 2013). In an earlier study, we demonstrated a relatively low comprehension base among parents in Samoa regarding elements associated with RHD, including the need for proper medical care and the contagion factor (Allen et al. 2011). The significant resources dedicated in countries afflicted with RHD demonstrates a need to educate the general population regarding RHD (Remenyi et al. 2013; Zuhkle and Engel 2013).

Identification of children who would benefit from prophylactic antibiotic therapy can be done by clinical presentation or through echocardiographic screening (Kane et al. 2013). If caregivers were unaware of the potential morbidity and possible mortality associated with a sore throat or RHD, it would reason that they would be less motivated to seek timely and appropriate medical attention (Kane et al. 2013). These details highlight the need for awareness programs to utilize and involve at-risk populations in their personal healthcare (Coyne 2008; Joines and de Chesnay 2008; Davoe-Blanes and La Parra 2012; Ramsey, Watkins, and Engel 2013; Zuhkle and Engel 2013).

Unfortunately, interest and funding for RHD research and development has decreased in recent years due to reported decrease of the disease in developed countries. This declining interest and awareness impeded efforts to affect the prevention and treatment of this ‘neglected disease’, which remains the most common form of cardiovascular disease affecting young adults and children under the age of 25 years (Remenyi et al. 2013). Underdeveloped countries with limited resources, such as Samoa, continue to bear the burden of this preventable disease (Remenyi et al. 2013). Indigenous populations can help themselves in the effort when appropriate knowledge and resources are available (Engel and Love 2013). Considering the young age of those predominantly afflicted by RHD, caregiver compliance to RHD follow-up treatment protocols for children in their care who have been diagnosed with RHD could create improvement in disease prevention.

The Health Belief Model (HBM), and associated constructs, have been well documented in regards to health education program development and application, including caregivers (Cleland and van Ginneken 1988; Pokhrel and Sauerborn 2004; Brewer and Fazekas 2007; Gh et al. 2007; Mann et al. 2009; Reiter et al. 2009; Smith et al. 2011). The HBM offers a framework of constructs to test the knowledge, and draw suppositions of possible behavior, of caregivers through the lens of individual perception regarding disease susceptibility and seriousness relative to potential benefits, barriers, threats, and the ability to affect the outcome of the child’s condition (Mann et al. 2009). A study conducted by Smith and associates operationalized the HBM to evaluate the association between parents’ beliefs about vaccines and their decision to seek treatment.

The results offered medical providers pertinent information to better understand vaccine safety concerns and why some parents delayed or refused vaccines for their children (Smith et al. 2011).

The objective of the current study was to employ health promotion and education tools to assist clinical professionals to better understand perceptions of caregivers by applying the HBM to assess possible barriers to follow-up care compliance among of children in Samoa who have been identified positive for RHD. We studied determinants of behavior relative to knowledge and perceptions that are associated with adherence to treatment protocols after RHD diagnosis. Participants were from a cohort of caregivers of children in Samoa that have previously been diagnosed with RHD and should have been receiving follow-up care.

Methods

Research team

The study was a collaborative effort with the Samoan Ministry of Health (MOH), the Samoan National Health Services (NHS), and Rheumatic Rescue (RR). Rheumatic Rescue is a non-profit organization presently focusing work in the country of Samoa. The RR program is a joint effort between Utah Valley University (UVU) and Brigham Young University (BYU). The RR program operates under the direction of the Samoan MOH and NHS. The three components of RR include RHD health promotion, echocardiogram screening to detect RHD, and genetic testing of individuals identified with definite RHD. The program involves investigators and data collection from faculty at both BYU and UVU. As such, approval was obtained from both the BYU and UVU institutional review boards. The Samoan MOH, through a five-year agreement signed in 2013, recognized and approved this study and the RR program. The result of this agreement has been the creation of a multidisciplinary and international collaboration to address RHD. This partnership leverages the skills of health educators, medical clinicians, and genetic researchers toward altering the trajectory of RHD in Samoa, while simultaneously contributing to the broader effort of respected researchers and programs throughout the world.

Study design

This was a cross-sectional study of caregivers of children in Samoa between the age of 5–17 years and were previously identified as having definite RHD during echocardiographic screening as defined by the World Heart Federation guidelines (Remenyi et al. 2012). The screenings were performed by certified echocardiogram technicians who were part of the RR team. Other than having a child diagnosed with definite RHD, inclusion criteria specified that the caregiver be 20 years of age or older, was contacted by the NHS to participate, and indicated a willingness to participate.

The RR team conducts an annual educational and echocardiography-screening program at primary schools in Samoa, which are designated by the NHS, to detect children with RHD. The schools are located on the two main islands, Upolu and Savaii. Echocardiographic screening was performed in either 2012 or 2013. Children identified with definite RHD were referred to local physicians responsible for follow up care. Duration of antibiotic therapy, route of delivery, choice of antibiotic (generally benzathine penicillin unless there is a known allergy), location of therapy, and clinical

follow-up was determined by the Samoan NHS and the Samoan Rheumatic Committee. Generally, every 3–4 weeks children should receive monthly benzathine penicillin injections by trained nurses at a local clinic or hospital for a minimum of 5 years. Follow-up visits were documented by self-reporting the number of visits over a 12-month time period, June 2013 to June 2014, in which 12 follow up treatments should have occurred. This study was conducted in June 2014 at district hospitals and clinics in Samoa. Caregivers of children who presented for a routine echocardiographic follow up were invited to answer the questionnaire in a verbal question-and-answer fashion with an NHS staff member. The interview lasted approximately eight minutes.

Perceptions and behaviors of the caregivers were considered in this study as they bear the responsibility to assure the child receives proper medical care post diagnosis. In the country of Samoa the term ‘caregiver’ has a relatively broad meaning, which frequently extends beyond the parents to include siblings, aunts and uncles, and/or grandparents. While the HBM has not been applied directly to those with RHD, it has been used to assess parent beliefs relative to their child’s health, and it was determined that the HBM was an effective means to determine the underlying architecture of parental health-related beliefs relative to the well-being of their child (Highland, KB 2011). Using the HBM, a questionnaire was developed to compare caregiver knowledge and perceptions regarding their child’s RHD diagnosis with the number of follow-up visits reported in a 12-month time period from June 2013 to May 2014. (Table 1)

Items on the questionnaire were designed to test knowledge, not personal opinion, as well as individual limitations, such as access to transportation, that may influence perceived barriers. Questions were not listed in groups according to the HBM constructs, but rather arbitrarily distributed throughout the questionnaire. Response options were limited to ‘yes’, ‘no’, ‘I don’t know. The questionnaire consisted of 16 questions informed by the HBM. These included questions testing caregiver perceptions regarding their child relative to RHD diagnosis and treatment, the severity of disease, susceptibility of development of serious RHD. The questions also explored possible barriers and benefits to seeking the required follow-up care. In addition basic consent, demographics, and the number of clinical follow-up treatments for the 12 months designated, for a total of 30 questions.

As the distribution of follow-up visits deviated significantly from a normal distribution (Sapiro–Wilk test; $p < 0.01$), we used appropriate non-parametric statistics for each test. For each of the 16 questions of interest from the health promotion perspective, we grouped subjects into two subsets, those who responded ‘Yes’, and those who answered either ‘No’ or ‘I don’t know.’ For each question, we performed an independent 2-sample Mann–Whitney–Wilcoxon test using R statistical software, version 3.1.1. For this analysis, alpha was set to $p \leq 0.05$.

Table 1. Health Belief Model design for RHD follow-up assessment.

Construct	Application to Samoan Caregivers
Perceived susceptibility	Caregiver belief concerning the chance of their child getting RHD
Perceived severity	Caregiver belief concerning the seriousness of RHD for their child
Perceived benefits	Caregiver belief in the efficacy of advised follow-up care to reduce the health risk for their child
Perceived barriers	Caregiver belief concerning the physical and psychological burden of RHD
Self-efficacy	Caregiver confidence in their ability to help their child

To measure association of caregiver age on number of follow-up visits, respondents were grouped in intervals of ten years from 20–29 years, 30–39 years, 40–49 years, 50–59 years, and ≥ 60 years. To assess possible association of caregiver education on number of follow-up visits, we grouped respondents by highest education level obtained: Primary school (up to age 11 years), secondary school (up to age 16 years), and college. Caregivers were grouped into one of four classifications: parent; grandparent; extended family, which included siblings aunts, and uncles; and other. We tested for significance of associations using the Kruskal-Wallis test, which is the non-parametric equivalent to the one-way ANOVA, using R version 3.1.1.

Results

Out of the possible number of potential participants, caregivers of 67 children previously diagnosed by the RR team with definite RHD responded to the notification sent by NHS staff for a follow-up consultation and accompanied their child for the follow up echocardiogram. All caregivers consented to participate in the study. Three were eliminated due to incomplete information, giving a convenience sample of 64 participants who either answered all or most of the questions. Parents comprised 77% of the participants, 23% were either grandparents or extended family members, 69% were between the ages of 30–50, and 80% lived on the island of Savaii and 48% had received at least 9 years of formal education (Table 2).

We failed to detect significant association between age and number of follow-up visits ($\chi^2 = 3.26$, $p = 0.51$) or between education level and number of follow up visits ($\chi^2 = 0.25$, $p = 0.97$). Using an unpaired Mann-Whitney-Wilcoxon test, we detected an association between aspects of health knowledge and perception and follow-up (Table 3).

Table 2. Summary of cohort by age, education, and island of residence.

Age group of caregiver: count	Caregiver category: count	Caregiver education level: count	Island: count
No response: 1			
20–29 years: 5	Parent: 0 Grandparent: 0 Ext. Family: 5 No response: 0	Primary: 0 Secondary: 1 College: 4 No response: 1	Upolu: 2 Savaii: 3 No response: 0
30–39 years: 21	Parent: 18 Grandparent: 0 Ext. Family: 3 No response: 0	Primary: 0 Secondary: 7 College: 14 No response: 0	Upolu: 5 Savaii: 16 No response: 0
40–49 years: 23	Parent: 22 Grandparent: 0 Ext. Family: 1 No response: 0	Primary: 4 Secondary: 9 College: 10 No response: 0	Upolu: 4 Savaii: 19 No response: 0
50–59: 11	Parent: 7 Grandparent: 3 Ext. Family: 1 No response: 0	Primary: 3 Secondary: 5 College: 2 No response: 1	Upolu: 3 Savaii: 8 No response: 0
60 years+: 3	Parent: 2 Grandparent: 1 Ext. Family: 0 No response: 0	Primary: 2 Secondary: 0 College: 1 No response: 0	Upolu: 0 Savaii: 3 No response: 0

Table 3. Response to HBM- directed questions and association with follow up visits.

Construct question	No/don't		Mean #	Mean #	P-value
	Yes	know	Follow-up Visits (Yes)	follow-up visits (no/don't know)	
<i>Perceived Susceptibility</i> Do you believe your child is sick?	26	38	3.0	1.1	<0.01
<i>Perceived Severity</i> Do you understand your child's diagnosis concerns their heart?	51	13	2.0	1.2	0.19
Are you concerned your child receives follow-up care?	46	13	2.1	1.6	0.67
<i>Perceived Benefit</i> Do you understand that your child can be healthy with medication?	53	9	1.9	1.7	0.83
Do you understand that medication can help avoid future serious health problems?	56	7	2.0	0.6	.10
<i>Perceived Barrier</i> Can you drive a car?	12	52	2.4	1.7	0.23
Are you worried about the cost of follow-up care?	15	49	2.8	1.6	0.02
Is it too far to travel for follow-up care?	31	33	1.8	1.9	0.99
Do you understand the treatments must be monthly?	21	19	3.3	0.3	<0.01
Do you know where to go for follow-up care?	57	7			<0.01
<i>Self-efficacy</i> Do you think you can help your child and their heart health by taking him/ her in for follow-up care?	61	3	1.9	1.0	0.74

Table 4. Breakdown of questionnaire using the Health Belief Model.

HBM constructs/other	Number of questions on questionnaire
Consent to participate	1
Basic Demographics	3
Perceived Severity	3
Perceived Barriers	6
Perceived Benefits	5
Perceived Susceptibility	2
Self-efficacy	2
Clinical	8

Affirmative answers to the following questions demonstrated a possible association to a significant increase in follow-up visits: 'Do you believe that your child is sick?' 'Are you worried about the cost of follow-up care?' 'Do you know where to go for follow-up care?', 'Do you understand the treatments must be monthly?' A subset of the questions is listed in Table 4. Only responses that could be accurately recorded are included in the numbers and analyses, resulting in less than 64 total responses for some questions.

Discussion

Our data demonstrate that knowledge about frequency and location of follow-up treatment, and perception of whether the caregivers believe their child is actually sick, are significantly associated with seeking appropriate follow-up treatments among caregivers of children with RHD in Samoa. When these factors are properly adhered to, it would suggest that knowledge about frequency, locations for care, and a belief in their child's condition would positively influence action to seek follow-up care. We failed to detect a significant association between caregiver age and follow-up care or between caregiver education level and follow-up care. We also failed to detect evidence that the ability to drive and the distance to travel for care has an impact on follow-up care.

These findings are consistent with previous studies that have shown the use of the HBM. A study conducted on foot care in diabetic patients demonstrated that increasing patient knowledge of the ability to prevent future complications including foot amputation if treatment is neglected, as well as the long-term commitment to treatment, resulted in better foot care by the patients themselves (Mann et al. 2009). The treatment protocol for RHD is similar in that it is intended to prevent major future complications, and RHD is a medical condition needing long-term care. A study by Reiter et al. effectively used the HBM to assess parent beliefs and perceptions relative to preventive vaccines for cervical cancer. The study concluded that identifying parents' beliefs offers potentially modifiable behavior opportunities that could increase vaccination rates (Reiter et al. 2009).

We did detect a significant decrease in follow-up care when caregivers did not know the location for follow-up treatment. It would be helpful if an effort were made to provide location information verbally and in written form when Samoan medical professionals identify and approve children requiring follow-up care. Additional outreach programs in Samoa among outer villages may also promote compliance with treatment protocols. Other investigators have seen the need for education for RHD. Heart Kids Australia has indicated the need to educate not only health staff, but also patients and families, which would ensure correct diagnoses and management of RHD (Heart Kids, Australia 2015). The government of New Zealand, another neighbor of Samoa, has recognized the need to broaden the scope of current programs to increase community awareness and provide better access clinics for sore throat management (World Heart Federation 2013).

Caregivers' perceptions of the effectiveness of continued treatment to help their child, and of medication effectiveness, also show a significant association with the mean number of follow-up visits, which offers an opportunity to build on positive factors when developing programs to promote caregiver compliance. Understanding follow-up treatments are required on a monthly basis also showed a significant association with number of follow-up visits as recorded by the caregivers. Samoan medical personnel could be educated on the protocol for follow-up treatment and effective ways to disseminate this information, which would allow them to go beyond diagnosis and explain to caregivers what is required of them for follow-up care and the effort necessary to avoid negative long-term consequences. The NHS could include these factors when educating and counseling caregivers. This demonstrates an opportunity for the NHS and the people of Samoa to work together to lessen the burden of RHD and to expect increased compliance to follow-up protocols, as was suggested in the study by White et al. (2010). The cooperative work with the NHS and RR teams should emphasize these factors, as well as continue to canvas caregivers for additional understanding of health

behavior compliance. The current study can assist in the efficient allocation of resources and development of programs in Samoa.

A more directed understanding of caregiver knowledge and perceptions of RHD will develop better communication between medical clinical personnel and RHD patient caregivers. The improved understanding of caregivers can have a direct affect on perceptions of the children themselves. This was demonstrated in a study by Wark et al. (2013), where it was reported that ‘parental perception of ill health, irrespective of actual diagnosis, had the greatest impact on children’ among the markers measured. Labeling a healthy child as diseased could have deleterious implications (Wark et al. 2013).

This study was limited by the following issues with the sample caregiver group: (1) It was a convenience sample of caregivers whom we were able to contact through the assistance of the NHS, creating selection bias directed to those who responded, (2) all participants did not respond to all questions, (3) information was self-reported by caregivers, (4) possible caregiver response bias due to unforeseen factors such as past experience with RHD, and (5) a relatively small sample size. In addition, we have not evaluated possible interactions between questions. Due to the more rural nature of Savaii when compared to Upolu, specifically the capitol city of Apia, contacting caregivers was easier on Savaii, which could explain the difference in participation rates between the islands. The NHS staff suggested other extenuating factors that may have influenced participation to include time away from work, distance to the clinic or hospital, time and cost of travel using public transportation as many of the participants do not own cars, disinterest, and family or other conflicts. More education outreach to these caregivers, along with governmental considerations regarding availability of follow-up care among the district clinics, would help with these issues.

Future studies should compare medical clinical records, where possible, of follow-up visits with caregiver account. The findings from this study may not be generalizable not only because of the convenience sample size and selection bias, but also due to cultural considerations and conditions specific to the country of Samoa.

Conclusion

We were able to demonstrate through operationalizing constructs of the HBM that caregiver knowledge about frequency and location of follow-up treatment, and perception of whether a caregiver believes their child is actually sick, showed a significant association with the action of caregivers of children with RHD in Samoa to seek appropriate follow-up treatments. This validates the need to include caregiver education in RHD health promotion program development.

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Disclosure statement

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