Assessing the Quality of the Systems of Care for Children with Congenital Zika Virus Infection and Other Neurodevelopmental Disabilities in the United States Pacific Island Territories

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Abstract

Congenital Zika virus (ZIKV) infection can cause lifelong medical and developmental conditions and management needs. There is limited information on the strengths and weaknesses of the systems of care for addressing ZIKV and other neurodevelopmental disabilities (NRD) in the United States (US) Affiliated Pacific Island Territories. Therefore, the purpose of the study was to assess the quality of the chronic illness systems of care for children with congenital ZIKV and other NRD in the US Pacific Island Territories. A cross-sectional study was conducted among health professionals from American Samoa, Guam, and Commonwealth of the Northern Mariana Islands. Participants completed an adapted version of the Assessment of Chronic Illness Care 3.5 (ACIC), which is based on the Chronic Care Model. The median Total Program Score was calculated, which ranged from limited support (0–2), basic support (3–5), reasonably good support (6–8), to fully developed support for care (9–11). Among the 17 health professionals who completed the survey, 47% were Guamanian/Chamorro, 24% were Samoan, 12% were Filipino, and 6% were Other Pacific Islanders. The median (25th percentile, 75th percentile [interquartile range]) Total Program Score was 5 (3, 6 [3]), indicating basic support for ZIKV and other NRD care for children. As more is learned about the full spectrum of clinical findings related to ZIKV, it is critical to continue to build an interdisciplinary maternal and child health workforce with the capacity and preparation to adequately address the special needs of children with ZIKV and other NRD.

Keywords

congenital Zika virus infection, neurodevelopmental disabilities, US Pacific Island Territories, chronic care model, interdisciplinary

Abbreviations

ACIC = Assessment of Chronic Illness Care
CCM = Chronic Care Model
CNMI = Commonwealth of Northern Mariana Islands
ECHO = Extension for Community Healthcare Outcomes
IQR = interquartile range
NRD = neurodevelopmental disabilities
ZIKV = Zika virus

Introduction

During pregnancy, Zika virus (ZIKV) infection can cause birth defects, as a pregnant woman can transmit the virus to her fetus.[1] Congenital ZIKV infection is associated with adverse birth outcomes in children, such as microcephaly and other neurodevelopmental disabilities.[1] Mosquito-borne and sexual transmission puts many women at high risk for ZIKV, especially in low- and middle-income areas.[2] In 2016, during an outbreak in American Samoa, there was an incidence of confirmed ZIKV of 0.92 per 1,000 persons.[3] The first case of microcephaly associated with non-endemic congenital ZIKV in Hawai‘i was reported in 2016, prompting proactive ZIKV surveillance measures.[4] As the number of mosquitos increases with the rising temperatures, there is a possibility for increased spread of ZIKV infection.[5,6]

Children with congenital ZIKV and other neurodevelopmental disabilities (NRD) need chronic illness care due to associated lifelong medical and developmental conditions and management needs. Understanding the care for NRD can help inform health care workers on the necessary care for managing ZIKV. American Samoa previously had a higher risk of ZIKV than other United States (US) Pacific Island Territories. Although no cases of ZIKV have been reported in Guam and the Commonwealth of the Mariana Islands (CNMI), their similar sub-tropical climate puts them at risk for ZIKV infection, increasing the need of being prepared for ZIKV management. Assessing the systems of chronic illness care for NRD in addition to ZIKV in the Pacific Island Territories can help to build the capacity of maternal and child health professionals to care for children with ZIKV and other NRD.

American Samoa, Guam, and CNMI are rural, which promotes social isolation among Pacific Islanders; resources may be at distant locations, which may affect access to care. Transportation may also be difficult, especially outside of urban areas. Often, visits to obtain health care require long bus or boat rides.[7] Population sizes in some areas are small, and many of the regions have low per capita gross national product, resulting in a low proportion of people with wage-based jobs. Most health care services, however, are provided by the government, and complex cases frequently require the need to seek treatment off-island.[7] These factors may create significant challenges and barriers for children and their families to receive services.

Although interdisciplinary chronic illness care is crucial, access to certain health professionals is often restricted in low resource areas. There is limited knowledge of how these systems of chronic illness care are serving individuals with ZIKV and other NRD. The purpose of this study was to evaluate the quality of the chronic illness systems of care for children with congenital ZIKV and other NRD in the US Pacific Island Territories. Children with

congenital ZIKV and other NRD need chronic illness care due to associated lifelong medical and developmental conditions and management needs. The Chronic Care Model (CCM), which has been used to assess the systems of chronic illness care, was used as the framework for this study. The CCM measures strengths and weaknesses in the delivery of chronic illness care and consists of 3 core areas: (1) Organization of the health care system, (2) Community linkages, and (3) Practice level. The Practice level core area is further broken down into 4 subcomponents: Self-management support, Decision support, Delivery system design, and Clinical information systems. In this model, high-quality care is comprised of 6 elements: Organization of health care system, Community linkages, Self-management support, Decision support, Delivery system design, and Clinical information systems.[8,9] To the best of our knowledge, the CCM has not been used previously to address congenital ZIKV virus infection and has not been used with health professionals from the US Pacific Island Territories. However, the model has been shown to be effective in improving chronic illness, such as Type 2 diabetes care in a rural setting in the United States.[10] Maternal and child health professionals can potentially use this information to communicate, coordinate, and improve services for children with congenital ZIKV and other NRD.

Methods

Study Design

A cross-sectional study was conducted among maternal and child health professionals from the US Affiliated Pacific Island Territories. Institutional Review Board approval was obtained from a children's hospital in Southern California.

Participants and Setting

Maternal and child health professionals, such as pediatricians, nurses, child psychologists, and audiologists, were eligible to participate if they were over the age of 18 years and currently working in American Samoa, Guam, or the CNMI. A convenience sample of health professionals working in the fields of chronic illness care from local hospitals, public health departments, and university centers for excellence in developmental disabilities received an electronic survey link via email. A snowball approach was used for additional recruitment, as some participants forwarded the link to other health professionals who were eligible to participate based on their current positions in the field of maternal and child health.

Variables

Demographics. The demographic characteristics of age, gender, race/ethnicity, education, health discipline, and location were collected.

Chronic illness care related to ZIKV and NRD. The Assessment of Chronic Illness Care (ACIC) survey is a tool to measure quality improvement efforts and is based on the CCM constructs.[8] The ACIC has demonstrated effectiveness in measuring the care for chronic conditions and has demonstrated reliability and validity in a Southeast Asian population.[7,9,11] An adapted version of the ACIC 3.5 was used, as each component was modified to specifically ask about the study outcome: the quality of chronic illness care related to congenital ZIKV and other NRD. To adapt the ACIC, the following phrase was added at the end of each item or component: "Zika or other NRD Chronic Illness Care."[12] The ACIC corresponds to the 3 core areas of the CCM by measuring a total of 6 scores: 1) Organization of the health care system, (2) Community linkages, (3) Self-management support, (4) Decision support, (5) Delivery system design, and (6) Clinical information systems. Each ACIC subscale and Total Program Score can be measured on a scale of 0 (not implemented) to 11 (most implemented) on statements about the respective section. The scoring was interpreted and assigned the following categories: (1) 0–2: limited support for chronic illness care; (2) 3–5: basic support for chronic illness care; (3) 6–8: reasonably good support for chronic illness care; and (4) 9–11: fully developed chronic illness care.

Statistical Analyses

Descriptive statistics were used to describe the population demographics. Total scores for each ACIC subscale were created, and the median, 25th, 75th percentile interquartile range [IQR] program scores were calculated based on the number of components in each subscale. The same process was used to calculate the median Total Program Score, along with the 25th, 75th percentile interquartile range [IQR]. A Kruskal-Wallis test was conducted to examine whether there were differences between locations. IBM SPSS Statistics, Version 17.0 was used for all analyses.

Results

The survey was distributed to 29 maternal and child health professionals, in which 17 responded, resulting in a response rate of 59% (Table 1). The majority of participants ranged in age from 30–49 years and all were female. Overall, 47 % of participants were Guamanian or Chamorro, 24% Samoan, 12% Filipino, and 6% Other Pacific Islander. In terms of current location in the US Pacific Island Territories, 41% of participants were from American Samoa, 41% were from Guam, and 18% were from the CNMI.

Overall, the median (25th percentile, 75th percentile [IQR]) Total Program Score on the adapted ACIC was 5 (3, 6 [3]), indicating that there was basic support for ZIKV and NRD care in American Samoa, Guam, and the CNMI (Table 2). The

Table 1. Demographic of Survey Participants (N=17)		
Characteristics	**n**	**Percent (%)**
Age Group (years)		
18–29	3	18
30–49	12	71
50–64	2	12
Sex		
Female	17	100
Race/Ethnicity		
Guamanian or Chamorro	8	47
Samoan	4	24
Filipino	2	12
Korean	1	6
White	1	6
Other Pacific Islander	1	6
Education		
College/university degree	7	41
Graduate degree or above	10	59
Discipline		
Child Development	1	6
Communication	1	6
Developmental Disabilities	1	6
Occupational Therapy	1	6
Pediatrics/Medicine	1	6
Physical Therapy	2	12
Public Administration	2	12
Public Health	3	18
Social Work	3	18
Special Education	2	12
Location		
American Samoa	7	41
Guam	7	41
Commonwealth of the Northern Mariana Islands	3	18

All the survey participants were female and most identified as Pacific Islander. Since the sample size was <200, decimal points were not used, and rounding was used for 0.5 and above. As a result, some percentages are over 100%.

ACIC subscale scores also indicated that there was primarily basic support for ZIKV and NRD care. Subscale scores suggested that there was reasonably good support for Community linkages, with 6 (4, 8 [4]), and Self-management support, with 6 (2, 8 [6]); however, there was basic support for Organization of health care system, Decision support, Delivery system design, and Clinical information systems, which were 5 (5, 9 [4]), 5 (2, 7 [5]), 5 (3, 6 [3]), and 5 (2, 7 [5]) respectively. Results from the Kruskal-Wallis test indicated that there were no statistically significant differences in the median Total Program Score by location, $X^2(2) = 0.13$, $P = .94$.

Table 2. Adapted ACIC Subscale Scores and Total Program Score		
Component (N=15)	**Median**	**25th, 75th percentile [IQR]**
Organization of health care system	5	5, 9 [4]
Community linkages	6	4, 8[4]
Practice level		
Self-management support	6	2, 8 [6]
Decision support	5	2, 7 [5]
Delivery system design	5	3, 6 [3]
Clinical information systems	5	2, 7 [5]
Total Program Score	**5**	**3, 6 [3]**

The median Total Program Score of 5, indicated basic support for chronic illness care. Since the sample size was <200, decimal points were not used, and rounding was used for 0.5 and above.

Discussion

This study is the first known to assess which systems of chronic illness care need improvement in the US Affiliated Pacific Island Territories related to the management of children with ZIKV and other NRD. Although some studies have used the ACIC, no other studies found in literature searches used an adapted version to measure the quality of chronic illness systems of care for children with congenital ZIKV and other neurodevelopmental disabilities.[9-11,13-16] There are unique challenges to pediatric chronic care, such as having fewer resources for high-quality, evidence-based clinical practices, and the complex interaction that chronic illness has on child development.[13] Using the CCM may help assess and redesign systems for pediatric chronic illness care, especially for ZIKV and other NRD in low resource areas promoting movement beyond a basic level of support. Suggestions to improve each CCM component are described below.

Organization of Health Care Systems

American Samoa, Guam, and the CNMI continue to have capacity building as one of their main priorities to prepare for a possible ZIKV outbreak. Strengthening the organization of health care systems is critical. Given the low level of support for organization of health care, a possible intervention might include involving leaders across practice sites to better plan quality improvement efforts.[14] CCM resources that have been successful in smaller health care settings could be shared with larger health care organizations to build the capacity of health care systems when treating complex cases, which may include ZIKV and other NRD. Research demonstrated that implementing components of the CCM improved prevention and strengthened services provided for chronic conditions in rural areas.[15] When planning health strategies, partnerships between administration, finance, and information systems may be necessary to facilitate system-wide changes.[16]

Table 3. Feedback on Adapted ACIC for Congenital ZIKV Infection and Other Neurodevelopmental Disabilities	
Organization in Health Care Delivery System	"American Samoa "is a resource-limited health care system that other specialty services are not available and rely on off-island referral system once deemed urgent or appropriately needed." "I think more collaboration among agencies need(s) to happen to optimize resources and prevent duplication of services. Also, I think leaders and personnel must be held accountable for their services."
Community Linkages	"…a more active collaboration between agencies is still needed. And perhaps more effort to improve patient/client awareness in terms of what services are available to them." "manpower, funds and sustainability of enforcement of such programs has always been a challenge."
Self-Management Support	There is "very limited opportunity for this on island."
Decision Support	"…access to" [evidence-based practice]"(EBP), opportunities for professional development, and improving service provider accountability."
Delivery System Design	"I think improving the system guidelines to include a more defined roles/responsibilities, expectations, and a regular teaming."

Feedback from health professionals indicated limited resources and a high need to improve the system of care for chronic illness.

Community Linkages

There have been limited opportunities for active coordination between the health system, community agencies, and patients in the US Pacific Island Territories. Hiring staff to coordinate and promote the use of resources may help to build capacity and improve community linkages. The Pacific Islander community has a collectivist culture, which includes family involvement in making decisions about health.[7,17] Pacific Island parents of children with special needs were interviewed in Hawai'i about how they maintained emotional strength; results indicated that they derived strength from family, community, and faith-based support.[18] Self-care and respite, as well as faith-based practices, may offer a "whole family approach" and help relieve the burden families often feel.[19]

Practice Level

Self-management support. Within the practice level, self-management support had the highest amount of support for chronic illness care, suggesting that some families in American Samoa, Guam, and the CNMI may be more open to receiving additional support and services. Early intervention providers working with children with ZIKV and other NRD should provide care that is family-centered and culturally competent.[20] Challenges for Pacific Islander parents of children who are medically fragile include the financial burden, burden of providing care, role conflicts with other responsibilities, and limited parent independence.[18] Counseling is recommended for mothers of children with ZIKV-associated microcephaly to better support families.[21] The Department of Health in American Samoa has a ZIKV roadmap for parents to keep track of the visits and screenings throughout the first 36 months.[22] As knowledge of the clinical findings of ZIKV continues to increase, families can improve self-management of care.

*Decision support***.** In order to characterize and provide the appropriate care for the full spectrum of congenital ZIKV in the US Pacific Island Territories and throughout the United States, providers should follow the recommended evaluation and management procedures established.[23] The Centers for Disease Control and Prevention has provided detailed guidelines and an algorithm for both clinical findings, such as the presence of microcephaly, and testing results of infants with possible ZIKV.[24] These guidelines recommend interdisciplinary care from the start, such as from developmental-behavioral pediatricians, neurologists, and clinical geneticists. Continued monitoring and follow-up are also important as the child grows.[24] Other specialists, such as early intervention providers, occupational therapists, physical therapists, and speech and language pathologists may be needed to help a child with developmental and educational growth beyond infancy.[23] These specialty consultations could be conducted in the hospital setting before discharge or in an outpatient setting. Providing access to interdisciplinary teams and cross-training may help to prevent the need to transfer patients to other off-island facilities for subspecialty care.[24]

Telehealth, which is the provision of health services from a distance using electronic information and communication, could increase access to specialists and may provide the necessary interdisciplinary care.[25] Rehabilitation through telehealth has been shown to increase access to subspecialty services and provide effective care for neurologic cases.[25] Increasing the role of telehealth in low resource areas, such as through the use of the Extension for Community Healthcare Outcomes, better known as ECHO, model,[26] could help to train health care providers and provide access to interdisciplinary care. This may help to build the capacity of health care professionals in American Samoa, Guam, and the CNMI.

Delivery system design. A lack of health care professionals in the US Pacific Island Territories contributes to the limited access to health care services and lack of interdisciplinary care for children with chronic conditions, such as ZIKV and other NRD.[27] There is a need to expand the maternal and child health workforce, especially in program areas such as birth defects, genetic counseling, newborn hearing screening, and early intervention services. The delivery system design could

be improved by increasing provider time and training, and by ensuring follow-up care is provided to better support children. Examples in the clinic setting include optimizing clinic flow, planning sessions, scheduling follow-up sessions, and having maternal and child health professionals perform routine screenings and other preventative tests.[13] In the home setting, care managers could apply subspecialist expertise to address the needs of these children, and community health workers could perform routine assessments and provide health education.[13] These access strategies may help minimize transportation barriers and off-island referrals.[28,29]

Clinical information systems. Geographic barriers, a lack of resources, and a lack of proper training limit the quality of health information systems in the US Pacific Island Territories.[30] Many of the health records are incomplete, unreliable, and with minimal productive analyses to inform clinical practice.[30] Improving patient tracking, follow-up, and feedback collection can strengthen clinical information systems. For example, an option is to create and maintain registries of children with ZIKV and other NRD, which could be simple spreadsheets to fully developed electronic health records. Registries used to monitor screening, manage follow-up visits, and track health outcomes may help to promote consistent communication with families.[13] With appropriate training on data management and usage, health providers can serve as partners in maintaining current and accurate health information systems.[30]

Research on Chronic Illness Care

A research agenda is needed in the US Pacific Island Territories that addresses health inequities and long-term needs. Studies using the US Zika Pregnancy Registry may better inform research priorities, as it is not yet clear which parts of the CCM are the most effective and feasible to implement.[31] Researchers interested in measuring specific delivery processes and systems could use the CCM in conjunction with additional tools, such as the Team Functioning Assessment Tool and other quality improvement instruments.[32,33,34] Studies are needed that examine the benefits of using interdisciplinary teams to provide care. Longitudinal studies are also needed on how team culture and performance impact quality of care and services.[35,36] Further research could explore how collectivist cultural beliefs in the US Pacific Island Territories influence the implementation of the CCM in areas such as health care decision making.[37] Embedding cultural competence into a health care model requires building on the current knowledge of the local population and developing methods that will be accepted.[38] Understanding caregiver attitudes about children with ZIKV and other NRD in the US Pacific Island Territories may help to provide systemic changes to address needs better.[39]

Policy Related to Chronic Illness Care

Policy implications include maintaining best practices, health care coverage, and continuity of care.[19] To protect pregnant women and infants, more prevention strategies such as increased education on ZIKV and minimizing unplanned pregnancies are important.[39,40] Effective vector control is needed to understand the screening and magnitude risk of ZIKV.[20,40] Using the US Zika Pregnancy Registry could also aid in developing clinical guidelines and strategies to build the capacity of health systems to care for affected infants and children throughout their lives, including transition planning to adult care.[20,40]

Limitations

Although the CCM has been used to improve care in many systems, it may not have provided precise identification of areas of need for certain health systems, especially health systems that were under-resourced and had weaker organizational infrastructures.[16,41] While this study utilized a relatively small convenience sample, there was consensus across all sites that there was a basic level of support for ZIKV and other NRD care. As a cross-sectional study, it is unknown how changes in systems of care were monitored over time, and results may not be generalizable to other low resource areas with different health systems and cultures.[42] Given the small sample size, there was limited statistical power to detect potential differences in Total Program Scores between American Samoa, Guam, and the CNMI. However, past research on the health of the populations in these three locations has been limited. This study provides baseline information on which systems of chronic illness care for children with ZIKV and other NRD may need improvement, such as delivery system design and clinical information systems.

Conclusion

Study findings may help raise awareness among health professionals, researchers, and policymakers that additional support is needed to address chronic illness care for children with ZIKV and other NRD. Prioritizing quality indicators in health care systems and team performance measures may help to identify areas for improvement better.[43,35] Interdisciplinary training, primarily through telehealth, may enhance team performance and provide more comprehensive management of complex cases.[44,45] It is critical to continue to build an interdisciplinary maternal and child health workforce with the capacity and preparation to adequately serve children with ZIKV and other NRD who need chronic illness care management in the US Affiliated Pacific Islands.

Conflicts of Interest

None of the authors identify any conflict of interest.

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