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Hawaiian Healthcare: An Ecological Approach to the Stressors of Pediatric Illness on the Ohana

Petkus J*

Institute for Health and Behaviour, Integrative Research Unit on Social and Individual Development (INSIDE), University of Luxembourg, Esch-sur-Alzette, Grand Duchy of Luxembourg

Abstract

Despite an increased awareness of the Hawaiian islands troubling health data, less attention has been paid to how these health issues interact with numerous ohana (family) ecological domains to impact stress levels. The scope of this review is to fill such a gap by exploring the impact of pediatric illness on the Hawaiian ohana from an ecological framework. More specifically addressed will be the impact of the interaction with pediatric illness and stress in relation to: socio-economic status, geographic constraints, education level, and cultural issues. Intervention strategies are presented through a preventative lens approach, and utilize a community-based participatory format.

Demographics

Past statistics indicate Native Hawaiians to have among the lowest life expectancy and worst health indicators of the major ethnic groups in the state. Native Hawaiians comprise around 20% of the state's population, their ancestors lived in the Hawaiian islands prior to Western contact in 1778 [1-4]. More recent data indicates infant mortality to rate to be at 9.6%, more than double that for all Asian-American/Pacific Islander groups totaling 4.8%. By comparison to non-Hispanic whites, the 2002 infant mortality rate for Native Hawaiians was 1.7 times greater. One potential influential factor for these numbers is that Native Hawaiian mothers have been found twice as likely not to begin prenatal care until the third trimester of pregnancy what is more, Native Hawaiians/Pacific Islanders have little access to cancer prevention and control programs, and exhibit a higher rate of smoking, alcohol consumption, and obesity in comparison to other ethnic groups [5].

2010 U.S. census bureau estimates roughly 1,225,195 Native Hawaiians/Pacific Islanders to reside in the United States, representing 0.4% of the population. From this number, 3,40,766 Native Hawaiians or Pacific Islanders reside in Hawaii. Ethnic variation is widely distributed in Hawaii ranging from the islands of Micronesia, Polynesia, and Melanesia. The Asian population is also significantly growing, representing more than 50% of the Hawaiian population [6].

Recent years have brought thousands of Micronesians to Hawaii for social, financial and medical reasons. One reason for the influx of migration of Micronesians is the Compacts of Free Association (COFA), which allows citizens of Freely Associated States (FAS) to travel freely without visas in the United States [7]. Numerous barriers to healthcare have been cited to this population such as: language, limited ability to navigate the American health care system, pronounced cultural differences in communication styles, and differences in expectations between patients and providers [7,8].

Review of the Literature

Social problem

While ethnic variation is vast amongst the marginalized populations in Hawaii, there are commonalities these groups face. Particularly in pediatric life threatening illness, ohana's (families) in the Hawaiian Islands share stressors such as low socio economic status, geographic constraints, low education level and cultural issues. These stress factors intersect to create a correlate of the health discrepancy and persist in many domains on the ohana as the illness progresses.

Moreover, the ohana stress factors are in existence prior to a child's birth. In utero, and following the birth, the stress factors are impacting the developing body and may be contributing factors to the illness [9,10]. Once a pediatric illness diagnosis is made, these same factors remain and negatively contribute to the healthy functionality of the ohana as well as physical health of all members.

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*Correspondence:

Justin Petkus, Institute for Health and Behaviour, Integrative Research Unit on Social and Individual Development (INSIDE), University of Luxembourg, Esch-sur-Alzette, Grand Duchy of Luxembourg.

E-mail: justin.petkus@ext.uni.lu

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Socio-economic status

In 2010, 16% of Native Hawaiian/Pacific Islander ohana's were living in poverty in comparison to 9.9% of non-Hispanic Whites. In terms of income, the median Native Hawaiian/Pacific Islander ohana median income was \$58,083 whereas the non-Hispanic white families earned \$67,892 [6]. Equally troubling, 60.9% of Native Hawaiian/Pacific Islanders by contrast to 75.1% of non-Hispanic Whites had private health insurance in 2010. For public insurance the numbers were similar at 28.1% for Native Hawaiians/Pacific Islanders to that of 28.0% for non-Hispanic Whites. Uninsured numbers showed more discrepancy being 17.4% for Native Hawaiians/Pacific Islanders in comparison to 10.9% of non-Hispanic Whites [5].

Illustrated in a 2009 study, we can see how socio-economic status intersects with health outcomes. The study explored the effects of ethnicity and socioeconomic status on body composition within the multiethnic Hawaiian population. Body Mass Index (BMI) and Waist Circumference (WC) with respondent's answers regarding their educational attainment, income, age, cultural identity, ethnic ancestry, and health. Results suggested that rather than genetic propensity for the high rate of Pacific Islander obesity, socio-economic status and lifestyle choices may be of more influence. By contrast, Asian American populations were found to be less influenced by poor socio-economic factors relating to obesity as they often held higher educational attainment [11]. The importance of this study is that it indicates a discrepancy in factors that lead to healthy living amongst groups. The discrepancies then interact to perpetrate stress.

Geographic and transportation constraints

Living in Hawaii means to live on the most isolated population center on earth. The islands are 2,390 miles from California; 3,850 miles from Japan; 4,900 miles from China; and 5,280 miles from the Philippines [12]. For this reason, the availability of an advanced variety of treatment options for severe pediatric illness can be limited. ohana's may be required to seek care on the mainland leaving higher financial obligation and an added stressor. For pediatric oncology patients living on islands other than Oahu, their treatment may require numerous flights between the islands to receive chemotherapy. In Micronesia, cancer rates continue to rise with an infrastructure unable to provide effective treatment to serve the population [13]. As a result, Micronesians are forced to seek healthcare outside of the Pacific islands. Hawaii often bears this burden as one of the top providers for cancer treatment to Micronesians, and in 2001 the U.S. General Accounting Office estimated this cost to be \$86 million from 1996-2000 [7].

Even if ohana's do not need to travel between islands for care, transportation can still pose stressful. In a 2009 Needs Assessment for Micronesian Healthcare in Hawaii from the University of Hawaii at Manoa, the authors identify such stressors. One being that while Micronesian ohana's are often composed of numerous extended members, they likely own only one vehicle. While buses are available, routes may not be easily accessible or affordable [14]. Language barriers also may deter these populations from riding the bus.

Through the assessment, the authors discovered that The Queens Medical Center has one van available free of cost to patients for transport to and from the hospital, yet it fills quickly.

Kalihi-Palama Health Clinic assists patients in rides with the Handivan, however the two-dollar round trip cost is not reasonable for some ohana's. At the time of the assessment, the clinic had been

successful sending outreach staff to patient homes [14]. While resources can be provided by Social Workers, many times the arrangements are dependent on the ohana's insurance provider.

Educational attainment

For Native Hawaiians/Pacific Islanders, those with high schools diplomas or higher is relatively high at 87%, compared to 91% for non-hispanic whites. Larger discrepancies exist in bachelor degree attainment being 11% for Native Hawaiians/Pacific Islanders, and 20% for non-hispanic whites. In similar fashion, 3.5% of Native Hawaiian/Pacific Islanders to that of 11.7% of non-hispanic whites obtain a graduate degree [5].

As non-hispanic whites often have higher educational attainment than Native Hawaiians/Pacific Islanders, they are likely to serve in more affluent careers such as medicine or education. This poses serious issues for native people because it creates a hierarchical system where they are continuously relying on the whites. In education for example, Hawaiian culture is being taught by a western culture bias with heavy reliance on printed text while traditional Hawaiian culture values oral traditions and interpersonal relationships [15]. In a pediatric setting, caregivers receive medical care and advice from predominately white physicians with a higher educational level. Such a dichotomy can create stress for the ohana, as they may perceive a feeling of inferiority and insincerity in the unfamiliar prestige of a hospital.

Cultural differences

Differences in the complexity of the US health system can lead to numerous stress factors for the Micronesian population. 42% of Native Hawaiians/ Pacific Islanders speak a language other than English in the home [5]. Moreover, Micronesians may be unfamiliar with hospital visits, taking medications, completing paperwork, or answering personal questions. In addition, some Micronesians have the misconception that their insurance card will pay for treatment. Many cannot read English and face housing, transportation and urban lifestyle challenges [14]. Some ohana's may attempt to understand English in a pediatric setting with hospital staff in effort to not be viewed as incompetent. Variation in parenting styles may also lead to hospital staff viewing parents as poor caregivers leading to intervention from Child Protective Services and adding stress to the ohana.

Theoretical Framework

Human ecology

Central to the ecological framework is the concept of thinking of ohana as an ecosystem. The idea is that features effecting healthy ohana functioning are best understood through examining the intersection of biological and social influences. By way of bonadaptation or maladaption to these influences, ohana's either survive or falter. White and Klein [16], identify the focus and scope assumptions of the framework as: (1) individuals and groups are both biological and social in nature; (2) humans are dependent on their environment for sustenance (air, water, food, etc.); (3) human beings are social and thus are dependent on other human beings; (4) humans are finite, and their life cycle coupled with their biological needs for sustenance impose time as both a constraint and a resource; (5) human interactions are spatially organized; and (6) human behavior can be understood on several levels, most common in human interaction are population and individual.

There are numerous sets of theoretical propositions that have

been applied to understanding human ecological theory, thus the theory itself follows its own principle of adaptation to time and knowledge. Earlier propositions include the works of Emlen [17] and Hawley [18] for example. Still, Bronfenbrenner is credited most often with best depicting human development within the ecosystem. In his propositions he states, (1) “the individual grows and adapts through interchanges with its immediate ecosystem (the family) and more distant environments such as school” [19]; (2) “the developmental status of the individual is reflected in the ability of the individual to initiate and maintain a new level of adaptive range and to maintain these behaviors in the absence of directions from others” [19]; (3) “when one member of a dyad undergoes developmental change, the other member of the dyad will also likely to undergo change” [19]; and (4) “different settings have different distinctive patterns of roles, activities, and relationships for persons in those settings” [19].

The usage of ecological theory in the healthcare industry is well documented. In one example Stokols [20] applied the theory to community health promotion as a way to expand the then traditional lifestyle modification programs to beyond the emphasis of solely individually focused behavior change, and to incorporate the environmental underpinnings of health and illness. More recently, Scott and Wilson [21] approached their study with an ecological lens with qualitative inquiry to understand the social determinants of health among African Americans living in a Deep South rural community. The determinants were identified at individual, relational, environmental, structural, and super structural levels. Viewing the social determinants of health through multiple ecological levels provided a more wholesome picture for ways to address intervention.

Synthesis of research with theory with the social problem

Due to the diverse populations in the Hawaiian Islands, medical practitioners have a responsibility to understand the numerous ways pediatric illness impacts the environment and individual of these cultural groups and *vice versa*, in order to appropriately heal. Having the knowledge insight and cultural awareness of these stress factors is critical to meet this goal. What is more, the impact of pediatric illness on the health of the ohana continues throughout the lifespan, even if the cure of a specific illness has been met. Preventative measures must be in place to address these ecological issues of the stress impact on development on all beyond hospital discharge.

Assessment

With any pediatric illness, assessment should include an examination of ecological stress factors. Without proper identification of the common stress factors for the ohana within their individual culture, the hospital runs the risk of increasing stress and thus decreasing the ability to heal. In such a case, the hospital contributes to negative health outcomes, which makes the role of the service counterproductive.

Best assessment is provided through an interdisciplinary team to approach the ecological factors from multiple perspectives. In their book *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, The Institute of Medicine explains that interventions to optimize biomedical health care to manage the psychological, behavioral and social aspects of illness and its consequences promotes better health [22]. The purpose of an interdisciplinary team assessment is to provide expert care for each of these domains. Following the assessment, the team creates care plan goals for the patient and ohana to meet needs on medical, social, psychological,

economic, cultural, and spiritual levels. Professionals then carry out their respective discipline target interventions coinciding with the team care plan. This well informed understanding of patient and ohana multi-ecological needs decreases stress and anxiety thus improving the health of all.

Stress impact on health

A child’s ability to cope with stress early in life can have long-term physical and mental consequences. If not properly managed, toxic pediatric stress can disrupt the architecture of the developing brain [23]. This stress disruption later affects adult health by either collective damage throughout time or by the biological implanting of adversities during sensitive developmental periods. In both examples, many years and even decades can pass before the early stress experiences are expressed in the form of adult disease [24].

Clearly the effects of stress are long reaching, not existing in isolation from numerous ecological influences. As such, the ecological factor of stress on the healthcare team is also likely to correlate with the stress of the pediatric patient and ohana. This has proven true in palliative care. Within palliative care, an interdisciplinary team of health providers such as physicians, child life specialists, chaplains and child psychologists combine perspectives to provide ohana-centered end-of-life care [25]. As these professionals work in direct contact with ohana’s throughout the death of children, there is potential to experience emotional distraught. Despite this, other influences such as organizational factors related to management, lack of institutional support, teamwork, heavy work-load, and shortage of staff contributed to more stress than the actual emotional distress of the death itself in one palliative care team model in the Netherlands [26]. The example illustrates the need to examine the ecological impact factors of intervention within specific populations to ensure effective rather than further disruptive outcome.

The impact of stress on long-term survivorship in pediatric illness is gaining increasing attention. Case in point, Peterson and Drotar [27] found many family impact factors of neurodevelopmental late effects in pediatric cancer survivors. The authors suggested that survivors have a range of psychological adjustment issues as they reintegrate into society with attention, memory, information processing and other executive functions. The ohana environment influenced further difficulties, such that parents and other members may perceive a burden for caring for the child post illness [27]. It is apparent then how these issues can cause bidirectional ohana-child stress and further impede the ability to heal, as well as create further health issues for both.

Intervention

Many of the issues surrounding pediatric illness and stress could be reduced by preventative intervention through community-based education to promote healthy living. While it is excellent that pediatric hospitals have adopted care teams such as child life specialists, palliative care, chaplains and psychologists to help reduce the stress of illness/procedures/hospitalization, the problem itself still persists: children getting sick. There is a need for these care teams to utilize their skills to support ohana and children healthy living so that there is no need for them to receive hospital care which adds to their stress and negative health outcomes.

To reduce these stress experiences that are biologically embedded Shonkoff, Boyce and McEwen [24] recommend confronting the origins of mental and physical health disparities early in life as a way to

produce greater effects than attempting to treat these health outcomes later in life after they have done much damage [24]. Doing so in the Hawaiian community requires intervention by way of policy change and program implementation in the ecological domains of socio-economic status, geographic constraints, education level, and cultural issues mentioned earlier as these are where the populations stress factors derive. Further, culturally appropriate change necessitates the use of a community-based participatory approach.

Community-based ecological change

Community-Based Participatory Research (CBPR) emerged in the last decade to develop, implement and disseminate health interventions in marginalized communities where power is shared with the researcher and community partners [28]. Numerous projects in Hawaii have engaged in community-based approaches, outreach, community engagement and networking. Community engagement is a process by which groups that are affiliated by geographic proximity work collaboratively on their special interests [29]. An example of where community engagement was successful occurred under a grant from the Hawaii Community Foundation entitled "Mo' Better Together." Here, church leaders came together in a series of community-based meetings to discuss what they saw as the needs of new Hawaiian migrants. Conversation centered on health being a major concern, but also mentioned was the assistance needed in affordable housing, job training and placement, legal counseling, education, transportation and health insurance. As a result, numerous agencies have collaborated to meet these community-identified priorities [7]. From the example, the value of networking with the community shows a culturally appropriate way to spread the word and make change that the people want for themselves in their ecological domains.

When working on research or evaluation with formerly colonized indigenous peoples throughout the Pacific, it is recommended to use an indigenous people's centered model [30]. The Centers for Disease Control illustrates this by stating, "Simply counting deaths, cases of disease, and other events will not give a complete picture of health disparities... researchers must talk with people in the community to get their personal stories and opinions [31]". These qualitative approaches have led to linkages within the Hawaiian community bringing together many independent groups such as the Nations of Micronesia, Micronesians United and the Micronesian Community Network to share and advocate for their goals through a united voice [7]. The Hawaii Department of Health also recognized the need for a forum where Micronesians could discuss issues of importance to the issues of migrants in Hawaii. As a result of these meetings, ideas and information have been shared amongst participants representing the Public Health Nursing Branch, the Tuberculosis Control Branch, the STD/AIDS Prevention Branch, the Hansen's disease Branch, the Maternal and Child Branch, the Immunization Branch, as well as the Chronic Disease Prevention and Control Branch, and Bilingual Health Services.

External organizations have also been involved such as the University of Hawaii, Hawaii Primary Care Association, the Pacific Islands Primary Care Association, and the Pacific Island Health Officers Association [7].

Cultural interventions

In order to engage communities in preventative health measures, it is necessary to provide services in a culturally and linguistically appropriate manner. For example, The Chronic Disease Management

and Control Branch programs make information including booklets on diabetes available in languages for the diverse Hawaiian population [32]. More of these efforts are needed for prevention of numerous diseases and healthy living. Additionally, because of transportation restraints due to financial and geographic restraints, healthcare providers should provide community based health screenings. Health organizations should partner with community groups to determine the best way health can be delivered to the population where the people do not need to travel far for treatment. Preventative screenings and early education is a way to minimize future health problems and thus reducing financial and travel stressors on both the community members and healthcare provider. As an example, several Hawaiian health projects recognized the importance of religion in the Micronesian society and have delivered immunizations and health screenings at faith based organizations. Additionally, The Public Health Nursing Branch has established a Support Ministry Program within Micronesian churches (both Marshallese and Chuukese) as a way to address health-related concerns. Ministers have been successful in helping ohana's complete documentation for health insurance, financial assistance, Social Security, I-94, and low cost housing through their churches [7].

There is much encouragement from the above. Still, much more is needed to continue to support these efforts. Increased financial funding from state and federal levels is needed to provide resources such as immunizations and screenings. Funding should also be expanded to allow for more community-based participatory research projects as a way to understand up to date needs of the population. Education systems need to be improved to allow for better educational attainment thus leading to increased likelihood for career possibilities. Improving the healthcare of Micronesia is needed with assistance from numerous organizations in the United States and abroad and should be community based. Success in improving the health of children and ohana's in the State of Hawaii and throughout Micronesia, Polynesia, and Melanesia cannot be accomplished without motivated and engaged community members to buy into the change. Ultimately, an increased awareness of health issues and access to resources should permit less stress in all ecological domains, allowing for less pediatric health problems.

Conclusions

This review explored the stressors of pediatric illness on the Hawaiian ohana from an ecological framework. Stress factors included: socio-economic status, geographic constraints, education level, and cultural issues. Past and present research is shared on the issues throughout. Discussion was two-fold. First, awareness of the stress factors during pediatric illness on the ohana is presented. Secondly, intervention strategies focus on preventative measures to address the health stressors. As such, the scope of the writing is more preventative in nature as a way to show the need for early health intervention as a way to decrease the need for future hospitalization for pediatric illness. Thus this work could be expanded to include more support strategies for current ohana's experiencing stress from pediatric illness.

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