The 'place' of data

Abstract: Health disparities research has been at the forefront for many researchers, organizations, and funding agencies. Collecting, interpreting, and disseminating data on particular disparate populations are at the core of this research process, data which have been interpreted to be meaningful to the benefit of and use by communities. The purpose of this paper is to explore the question, "How is data used?" with an appreciation for indigenous beliefs and community based research. An analogy, from the perspective of "place," will be used to illustrate how data is used through various levels of commitment or belonging one has to a particular place. Recommendations on the collection, interpretation and dissemination of data from this perspective conclude this paper. *Key Words:* Pacific Islanders, health services research, action research, cultural competency, health disparities

Mary Frances Mailelauli'i Oneha[*]

Introduction

The National Institutes of Health (NIH) *Strategic Plan for Health Disparities Research* explains that scientific research has contributed to improvements in health care for most Americans[1]. However, the plan also notes these gains in research have not benefited all populations equally. This report notes that striking disparities are experienced by African Americans, Hispanics, Native Americans, Alaska Natives, Asian Americans, and Pacific Islanders, including shorter life expectancy and higher rates of cardiovascular disease, cancer, infant mortality, birth defects, asthma, diabetes, stroke, sexually transmitted diseases, and mental illness[1]. Many others concur with this assessment[2-6]. The National Institutes of Health believe these disparities are "the result of the complex interaction among biological factors, the environment, and specific health behaviors"[1] .

Several recommendations to reduce or eliminate health disparities are offered by NIH[1], including supporting and conducting research that seeks new knowledge about disease and disability leading to innovative diagnoses, treatments, and preventive strategies. Louie[6] makes recommendations that consider the type and topic of research to be conducted, support for researchers representing disparate populations, and exploring models that collaborate with community based organizations representative of the disparate population being studied. Flaskerud et al.[4] recommend research that requires a "greater emphasis on community-focused models and intervention studies in which tangible socioeconomic and health resources (e.g. child care, transportation, health insurance, payment to participants, language, and literacy-specific education) are provided to determine their effects on health disparities." Research that can be interpreted meaningfully to the benefit of and use by communities is vitally important.

In an effort to address health disparities from a women's health perspective, the Region IX Office of Women's Health, Kapi'olani Medical Center for Women and Children, the Hawai'i Primary Care Association, and the Department of Health Maternal and Child Health Branch hosted a conference in December, 2003. This conference, "Developing a Women's Health Agenda for Hawai'i: Identifying Data Needs," was intended to identify the gaps, needs, and strengths of the current data system, discuss the use of data in communities, and identify policy issues that could assist in moving a women's health agenda forward in the State of Hawai'i. This author was asked to respond to the questions, "What does a women's health agenda look like from a community health center?" and "How do we use the data?" The first step in responding to these questions was to identify the reasons women were seen at the Wai'anae Coast Comprehensive Health Center (WCCHC). The top women's health diagnoses based on the number of users included asthma, hypertension, obesity, diabetes, depression, high risk pregnancy, anxiety, cardiovascular disease, and so on. But what do these diagnoses and their associated rates mean to the women in the community?

Therefore, the next step was to identify what women perceive to be their own health agenda.

A few women employed at the Wai'anae Coast Comprehensive Health Center, and residing in the surrounding communities from Ewa Beach to Wai'anae, were asked randomly what they and/or their mothers, sisters, friends, or clients, would like to see on a women's health agenda. These were some of their responses:
· How to survive on your own;
· Making sense of health information;
· Having choices;
· Opportunities to seek positive role models within the community;

*Director of Case Management/Utilization, Waianae Coast Comprehensive Health Center. Contact Mary Frances Mailelauli'i Oneha, Director of Case Management/Utilization, Wai'anae Coast Comprehensive Health Center, 86-260 Farrington Hwy, Wai'anae, Hawai'i, 96792. Tel: (808) 696-1586. Fax: (808) 696-0679. Email: moneha@wcchc.com

- Having the ability to resolve problems;
- Knowing how to keep the family together;
- Sustaining the values of where you come from;
- How to help women transition through relationships;
- Setting yourself up to succeed;
- Knowing how to build a network of "girlfriends"; and
- Ensuring that environmental resources are available for the next generation, and so on.

These responses appear to indicate a disparity between what health professionals and community members see as important women's health issues. On the other hand, these responses are also helpful in identifying alternative strategies to reducing or eliminating health disparities that focus on relationships, values, and choices. The diversity in our lives and cultural experiences, our geographic locations, and the various demands put upon us to succeed as scholars, researchers, professionals, and administrators prompted the realization that there may indeed be a gap in understanding what the disparities are and how data is interpreted to be meaningful and beneficial to communities.

The place of data

The purpose of this paper is to explore the question, "How is data used?" with an appreciation for indigenous beliefs and community-based research. The term "used" is interpreted to mean how data is put into action or practice, and what its purpose or function is. An analogy, from the perspective of "place," will be utilized to illustrate how data is used through various levels of commitment or belonging one has to a particular place. Recommendations regarding the collection, interpretation and dissemination of data from this perspective conclude this paper. This publication presents an opportunity to examine this topic particularly when the health status of Native Hawaiians is one of the poorest in the nation and Native Hawaiians experience one of the highest overall cancer incidence and mortality rates in the nation[5].

> ... this paper is to explore the question, "How is data used?" with an appreciation for indigenous beliefs and community based research. ... "used" is interpreted to mean how data is put into action or practice, and what its purpose or function is.

The place of data begins with first understanding the concept of "place." From a Native American perspective, West[7] indicates that "place is that element of our lives and culture, past and present, that links us to our most primal beginning points." Places have history, they have names, and as such we can call them into existence[8]. For most indigenous peoples, land is a parent – Mother Earth. It is alive, breathing, and reacting. Indigenous peoples are of the land because they were conceived of it [9-11]. According to Luomala[12], many Hawaiians did not distinguish between nature and man, between the environment and one's own body, between living and nonliving. All constituted an interconnected totality.

> "Each object that possessed psychic, utilitarian, or aesthetic significance in daily life – each plant, animal, and feature of the earth, sea, sky, or underworld – was a person, not a thing. ...every existent being had a name, personality, soul, vital principle, power, feelings, and needs, just as did human beings. Because each element in the universe that was significant in daily life was in intimate, psychic rapport with every other, persons might deliberately or involuntarily strengthen or weaken that relationship to harm or benefit themselves, others, and nature."

Therefore, the success of a place could not be separated from the success of its community, its natural settings and surroundings. Likewise, it would be understandable to believe the health of a community also cannot be separated from the success of its place. The natural and human economies are interdependent; they support each other and, therefore, they also have the potential to destroy each other. Oneha[13] described five principles, derived from an ethnographic research study, which reveal how Hawaiians in a particular community understand the relationship between health and place.

Walter[14] introduced the concept of "topistics" derived from the Greek word "topos" to mean, "a holistic mode of inquiry designed to make the identity, character, and experience of a place intelligible." Place is described as having no feelings apart from what is experienced there by humans, a place is a location of experiences[14]. What people do, think and feel in a specific location shapes a reality unique to a place. Walter[14] describes the inseparable notion Australian Aborigines have with feeling and thinking about places. Their world is an example of "perfect topistic unity" –a unity that seems to be disintegrating in the modern world due to rationalized perspectives of urban planners and economics.

These perspectives on "place" are helpful in understanding how to bridge the gap between Western and indigenous models of practice and research. This is an understanding that can lead to how health information or data is retrieved (collected), interpreted and disseminated to the benefit of indigenous communities. Understanding how a place is experienced is critical and analogous to how data is used or put into practice.

An analogy to place

It may be that it is just the physical appearance, the landscape of a place that is important to us, or it may be an awareness of the persistence of place through time, or the fact that *here* is where we know and are known, or where the most significant experiences of our lives have occurred. But if we are really rooted in a place and attached to it, if this place is authentically our *home*, then all of these facets are profoundly significant and inseparable[15].

In 1976, Edward Relph[15] identified the variety of ways place is experienced in his book, *Place and Placelessness*. The essence of his work relates that diverse and distinct places are manifestations of a deep involvement with those places by the people who live in them, and, for many, a profound attachment to place is as essential and significant as a close relationship with other people. Relph[15] shares modes of experiences that pertain to "insideness" and "outsideness." "To be inside a place is to belong to it and to identify with it, and the more profoundly inside you are the stronger is this identity with the place."

Insideness as a mode of experience

The first mode of insideness is *behavioral insideness*, being physically present in a place, seeing it with physically defined boundaries. This experience tells us we are somewhere; sight tells us where we are. The visual patterns created in a particular area describe the experiences one has with identifying with a place. This mode of experience characterizes the uses of data based solely on the visual patterns created in a particular community, based on observation.

Visual patterns may include such attributes as the:
a) Color, texture, climate, or scale of the landscape;
b) Color, number, size, age, distribution of its people;
c) Sequence of patterns observed when entering and exiting a community; and
d) Socio-economic patterns observed by the type of housing, transportation, schools, stores, or health care available.

These patterns for the indigenous peoples of Hawai'i may include observed characteristics: low-income, poor, rural, Native Hawaiian, ocean, mountains, Hawaiian homelands, Pacific Islanders, sacred sites, etc. These are characteristics that identify a place based solely on what is visible or observed, and the relationship of these characteristics to each other is rarely observed. Handy and Pukui[16] describe the meaning of "relationships" for Hawaiians. It is beyond the interpersonal or social and includes those subjective relationships or experiences with all of nature in its totality and all of its parts understood and sensed as personal[16]. Consequently, from a Hawaiian perspective, it is difficult to reduce an experience to what is observed, separate from the total experience with all of nature. The researcher experiencing this mode of insideness may be present in a community solely to collect data or use data that is completely based on observations as characterized above. This mode of experience presents a limited sense of how data is used through activities of collection and interpretation. In some instances, these characteristics alone make communities "ripe" for research or data collection.

> **The first mode of insideness is *behavioral insideness*, being physically present in a place, seeing it with physically defined boundaries. This experience tells us we are somewhere; sight tells us where we are.**

The second mode of insideness is *empathetic insideness.* This is emotional participation and involvement with a place. This mode of experience demands a willingness to be open to the meaningfulness of a place – to know it, to feel it, and to respect its symbols. This goes beyond sight to understanding and appreciation. This experience, Relph[15] indicates, is most possible for people who have some awareness of environment and are not constricted by rigid thought patterns.

This mode of experience indicates an interest or desire to discuss an issue, variable, set of data, or data collection method with a particular place or community. It reveals a degree of commitment to spending some time in a community in order to:
a) Understand the history of a community;
b) Understand the context of the data;
c) Know how the community functions and sustains itself; and
d) Know what is important to a community and the contributions that can be made to the benefit of a community.

These are capabilities a researcher may strive to attain before, during, and after a research project, capabilities that require establishing relationships to attain knowledge, and time commitments to immerse oneself in the community context. There is a self-conscious purpose on the part of the researcher to engage in new experiences about a place and self-reflect on what those experiences are contributing personally and professionally.

Existential insideness is "complete and unselfconscious commitment to a place[15]". This mode of experience is characterized by belonging to a place–knowing implicitly that this place is where you belong, a deep and complete identity with a place. Most people experience this when they are at home, in their own community, when they know the place and the people and are accepted there.

At its best, this mode of *insideness* is having a deep and long-term commitment to the population of interest in the area of collecting and disseminating data. This includes being in it for the long haul:

a) From data collection to intervention development and evaluation;
b) Ensuring sustainability of a significant outcome; and
c) Participating in the process to set public policy, as appropriate.

This mode of *insideness* implicitly means that the implications of data and its dissemination to a community, ethnic or racial group, or organization are critically understood.

Significant research questions pertaining to health disparities require significant contributions and appropriate dissemination to communities. The interpretation of data from a research question has the potential to contribute to the sustainability of a community's livelihood and to reduce or eliminate disparities. Likewise, disseminating data to appropriate stakeholders can make a similar contribution. *Existential insideness* is experienced by researchers who have a purposeful and long-term commitment to the place and people from which the research question is derived, data is put into practice, and associated health behaviors are changed. This mode of *insideness* characterizes the researcher whose body of work may be dedicated to a particular place and people. Individuals whose lives have been connected to a particular place and people from childhood may also experience this unselfconscious commitment to place, as Relph[15] describes:

> "The identity of a place is an expression of the adaptation of assimilation, accommodation, and the socialization of knowledge to each other. For the existential insider this process of balancing assimilation and accommodation is, of course, quite unselfconscious, for there is a gradual and subtle development of an identity with and of his place that begins in childhood and continues throughout life."

These modes of experience are identified by Relph[15] as immediate and direct. Other modes that are less immediate include *vicarious insideness*, experiencing place secondhand as through a novel or movie, whether real or fantasy. The degree to which one becomes deeply involved or is transported to those places is wholly dependent on the artist's skill of description and the person's own imagination. This mode of experience describes the person reading the data, findings, or published articles. The people engaged in this experience could be policy makers, funders, researchers, community members, students, etc. They understand an experience, phenomenon, or people secondhand.

Outsideness as a mode of experience

Existential outsideness is experienced as a profound alienation from place. It is a self-conscious un-involvement, an alienation from people, and a sense of not belonging. Places are not significant and assume a meaningless identity. Unless the context of the data is understood for the benefit of the community from which it was derived, it takes on a meaningless identity.

Communities, particularly indigenous communities, are always challenged with assuring that researchers see data as they are, as a specific ethnic group, and that researchers understand it as the host culture understands it. The passion, and, at times, anger of communities as representatives of a specific culture, ethnicity, age, or community group are there to ensure the success and health of their own lives–the communities in which they live and thrive.

Conclusion

"How should data be used?" Researchers should collect, interpret and disseminate data with complete and unselfconscious commitment to a place. The first steps to consider in beginning this process includes:

1) Ask the people who will be affected the most how they would interpret the data;
2) Understand the long-term implications of data or findings to the operations of an organization or the functioning of a community;
3) Be responsible to whatever the findings may be for the data gathered. For example, it would be irresponsible to go about identifying a problem, only to find that the majority of the population exhibits this problem and there are no resources to address it;
4) Know why the data is needed–ask the right questions;
5) Assure that the working data are accurate and reliable, and;
6) As much as communities are looked to for answers to problems or issues, researchers might look to themselves for the same.

The next steps involve understanding the importance of disaggregating data. Multiple factors impact on the uniqueness of Hawai'i as a research setting. There are multiple and distinct ethnic groups across multiple and distinct islands or communities. Having knowledge of each of these distinct populations allows for more effective tailoring of health services delivery[17]. Accurately collecting and disseminating evidence regarding health disparities requires that racial categories be disaggregated. Researchers must consider identifying the uniqueness of the community in which the research is conducted. It is only through this step that true disparities and the elements which impact on them can be

---

The next steps involve understanding the importance of disaggregating data. Multiple factors impact on the uniqueness of Hawai'i as a research setting.

---

identified and eliminated.

Finally, understanding the context of the place or community in which research is to be conducted, and being vested in this place, is vital. This involvement is more than gaining knowledge on or having exposure to a community's history, patterns, or cultural experiences. To experience *existential insideness* means that a common origin has been shared, that there is an implicit knowledge of knowing you belong. A deep identity to a place has been experienced. "The most fundamental form of insideness is that in which a place is experienced without deliberate and self-conscious reflection yet is full with significances"[15]. Therefore, when data is collected, interpreted, and disseminated to the benefit of the community, researchers truly experience the burden findings may reveal. The data becomes a part of the place and the place becomes a part of the researcher. These are steps consistent with research conducted with indigenous peoples. Various authors have described protocols they have developed to conduct research as a result of "what has not worked" in their community, including Wai'anae[18-21]. The steps proposed in this article further articulate the association between how data is used within the context of place.

References

1. United States Department of Health and Human Services, National Institutes of Health. Strategic research plan to reduce and ultimately eliminate health disparities. October 2000; 1-47. [http://www.nih.gov/about/hd/strategicplan.pdf]

2. Shin P, Jones K, Rosenbaum S. Reducing racial and ethnic health disparities: Estimating the impact of high health center penetration in low-income communities. George Washington University, Washington DC, September 2003.

3. Alegria M, Perez DJ, Williams S. The role of public policies in reducing mental health status disparities for people of color. *Health Affairs* 2003; 22(5):51-64.

4. Flaskerud JH, Lesser J, Dixon E, Anderson N, Conde F, Kim S, Koniak-Griffin D, Strehlow A, Tullmann D, & Verzemnieks I. Health disparities among vulnerable populations. *Nursing Research* 2002; 51:74-85.

5. Busch J, Easa D, Grandinetti A, Mor J, & Harrigan R. Healthy people in Hawaii?: An overview of ethnic health disparities in Hawaii for the Healthy People 2010 initiative targeted health concerns. *Hawaii Medical Journal* 2003; 62:10-14.

6. Louie KB. White paper on the health status of Asian Americans and Pacific Islanders and recommendations for research. *Nursing Outlook* 2001; 49:173-178.

7. West WR. A Native American view of history and place. *History News* 1997; 52(1):22-24.

8. Archibald RR. The places of stories, the stories of places. *History News*, 1997; 52(1):5-8.

9. Armstrong J. Keepers of the earth. *In* Roszak T, Gomes M, Kanner A (editors) *Ecopychology: Restoring the Earth, Healing the Mind.* Sierra Club Books, San Francisco; 1995:316-324.

10. Barreiro J. Indigenous peoples are the "miner's canary" of the human family. *In* Willers B (editor) *Learning to listen to the land.* Island Press, Washington D.C. 1991:199-201.

11. Kanahele GHS. *Kū Kanaka, Stand Tall: A Search for Hawaiian Values.* University of Hawai'i, Honolulu, Hawai'i, 1986.

12. Luomala K. Polynesian religious foundations of Hawaiian concepts regarding wellness and illness. *In* Sullivan LE (editor), *Healing and restoring, health and medicine in the world's religious traditions.* Macmillan, New York, 1989:287-326.

13. Oneha MFM. Ka mauli o ka 'āina a he mauli känaka: an ethnographic study from a Hawaiian sense of place. *Pacific Health Dialog* 2001; 8(2):299-311.

14. Walter EV. *Placeways: A theory of the human environment.* The University of North Carolina Press, Chapel Hill; 1988.

15. Relph E. *Place and placelessness.* Pion Limited, Brondesbury Park, London; 1976.

16. Handy ESC. & Pukui MK. *The Polynesian family system in Ka-'u, Hawai'i.*: Charles E. Tuttle Company, Rutland VT, 1972.

17. Mays VM, Ponce NA, Washington DL, & Cochran SD. Classification of race and ethnicity: Implications for public health. *Annual Review of Public Health* 2003; 24:83-110.

18. Matsunaga DS, Enos R, Gotay CC, Banner RO, DeCambra H, Hammond OW, Hedlund N, Ilaban EK, Issell BF, & Tsark J. Participatory research in a Native Hawaiian community. *Cancer* 1996; 78(7 Suppl):1582-1586.

19. DeCambra H, Enos R, Matsunaga DS, Hammond OW. Community involvement in minority health research: participatory research in a native Hawaiian community. *Cancer Control Res Rep Public Health* October 1992.

20. Macaulay AC, Delormier T, McComber AM, Cross EJ, Potvin LP, Paradis G, Kirby RL, Saad-Haddad C, & Desrosiers S. Participatory research with native community of Kahnawake creates innovative code of research ethics. *Canadian Journal of Public Health* 1998; 89(2):105-108.

21. American Academy of Pediatrics. Ethical considerations in research with socially identifiable populations. *Pediatrics* 2004; 113(1):148-151.

■