A Center for Self-Management of Chronic Illnesses in Diverse Groups

Jillian Inouye PhD, APRN; Mary G. Boland DrPH, RN, FAAN; Claudio R. Nigg PhD; Kathleen Sullivan PhD, RN; Anne Leake PhD, APRN-Rx; Debra Mark PhD, RN; and Cheryl L. Albright PhD

Abstract

Prevention and successful treatment of chronic disease require a scientific understanding of the impacts and interactions of ethnicity, culture, and illness on self-management interventions. This article presents one approach to developing effective methods to address the needs of ethnic minorities living with chronic illnesses. Described is the University of Hawai'i Center for 'Ohana Self-Management of Chronic Illnesses (COSMCI) located in the School of Nursing & Dental Hygiene and funded by the National Institute of Nursing Research (Award Number P20NR010671). The interdisciplinary center focuses on family and community self-management interventions in ethnically diverse populations with chronic illnesses. Areas discussed are: 1) the operational structure for creating an environment conducive to interdisciplinary 'ohana self-management chronic illness research in ethnically diverse populations; and 2) the development of sustainable interdisciplinary, biobehavioral research capacity. The COSMCI uses a social cognitive theory framework to guide the application of established self-management interventions to Asian and Pacific Island populations (API) through three conceptually linked research projects on HIV infection, type 2 diabetes, and chronic obstructive pulmonary disease. COSMI addresses the feasibility of sharing of lessons learned among the approaches taken. The interdisciplinary nature of COSMCI increases the potential success of the intervention efforts.

Introduction

Data indicates that Asian and Pacific Islanders (API) are at increased risk of chronic illness. As theoretical understanding of self-management increases and standard interventions emerge, there is a need to ensure that such interventions are both effective and culturally competent across populations and, when necessary, to modify them. Few studies currently exist on self-management strategies specifically focusing on API ethnic subgroups. The Center for 'Ohana Self-Management of Chronic Illnesses (COSMCI) is one of three Exploratory Centers on Self-Management funded by the National Institute of Nursing Research (NINR). The interdisciplinary Centers provide the venue for such research via their ability to provide access to research interventions for ethnic minorities with chronic illnesses. This article describes the University of Hawai'i (UH) Center's effort to develop effective intervention strategies that address the chronic health needs of ethnic minorities.

The UH responded to NINR's request for proposals to develop exploratory centers focusing on self-management in chronic illness. The requirement for applicants to have at least one RO1 (Established Investigator) type funding in the area of self-management was met by the School of Nursing and Dental Hygiene's (SONDH) active NINR funded project studying self-management in persons with type 2 diabetes (T2D). The UH submitted an application to establish COSMCI and received funding for 5 years. The unique contribution of the Center is the focus on interdisciplinary research and translation provided by the core co-investigators and co-leaders of the participating units: nursing, psychology, public health, and medicine.

Hawai'i's Population and Chronic Illness

The 2008 Hawai'i Health Survey (N = 16,895) ranked self-reported chronic conditions from highest to lowest prevalence in this order: high blood cholesterol, hypertension, asthma, arthritis, and diabetes.[1] Native Hawaiians had the highest vulnerability for chronic conditions and were significantly higher than all other ethnic groups in prevalence of obesity, asthma, and diabetes. Based on CDCs 2008 Behavioral Risk Factor Surveillance System data, a low percentage of Native Hawaiians were diagnosed with coronary heart disease (3.1%) and diabetes (8.2%) whereas a high percentage of Hawai'i's population engaged in regular exercise (80.4%) and identified themselves as non-smokers (84.6%).[2] Despite these health indicators, Asian and Pacific Islanders (API), comprising the majority of Hawai'i's population (51%), were more at risk for developing and dying from cancer, heart disease, and diabetes than the general US population. A recent sample of adult members of a health plan in Hawai'i (n=119,563) found Asians were more likely to rate their health as poor compared to Caucasians, Samoans, and Native Hawaiians.[3] The latter group also had the highest rates of obesity.

Significance of the Center

COSMCI provides the venue for research via the ability, experience and success in recruiting and retention of ethnic minority subjects in research protocols. Figure 1 presents prevalent chronic conditions by ethnicity. These patterns point to important differences among the API subgroups and exemplify the importance of determining which chronic illness health disparities impact which ethnic populations.

The COSMCI addresses the NIH Roadmap, by supporting interdisciplinary research that integrates the biological sciences with the behavioral or social sciences, and the two overarching goals of Healthy People 2010 to increase quality and years of healthy life and eliminate health disparities.[4] In conducting research on appropriate self-management interventions for diverse populations with chronic illnesses, the conceptual model presented in Figure 2 and a collaborative, interdisciplinary approach that typifies Hawai'i's cultural values, guide the Center's efforts.

Methods

Infrastructure Development

Within the SONDH and the Manoa campus, the COSMCI functions as the focal point for self-management research by expanding the breadth and depth of available resources. The infrastructure development to increase the quantity and quality of research projects aimed at improving self-management in diverse populations with chronic illness is supported by the Dean and the Vice-Chancellor for Research and Graduate Education.

COSMCI focuses on increasing understanding of the application of established self-management interventions to API populations. Studies employ comparable measures to create a Center database available for sharing with investigators in self-management research.

The initial projects use social learning theory as the framework to address self-management in HIV infection, T2D, and COPD which are prevalent in Hawai'i. Figure 2 outlines the concepts and methods.

The goals of the COSMCI program mesh well with the vision of the SONDH Research Strategic Plan, to "focus on research that advances the health of diverse populations in our region," and core commitments, "specific research emphasis on family health promotion and disease prevention throughout the life cycle, health disparities/inequities, community health including disaster preparedness, chronic illness, health professions education and healthcare policy." The emphasis of the Center on self-management provides faculty and graduate students interested in health promotion and chronic disease management with access to archived methods and tools. Further, the activities of the Center strengthen existing relationships with the community health centers and schools within UH.

Center Organization and Specific Aims

Activities of the group are implemented through the Administrative Core comprised of the project leaders and funded staff. Within this core are sub-cores for research and evaluation respectively. Figure 3 illustrates the operational structure of COSMCI.

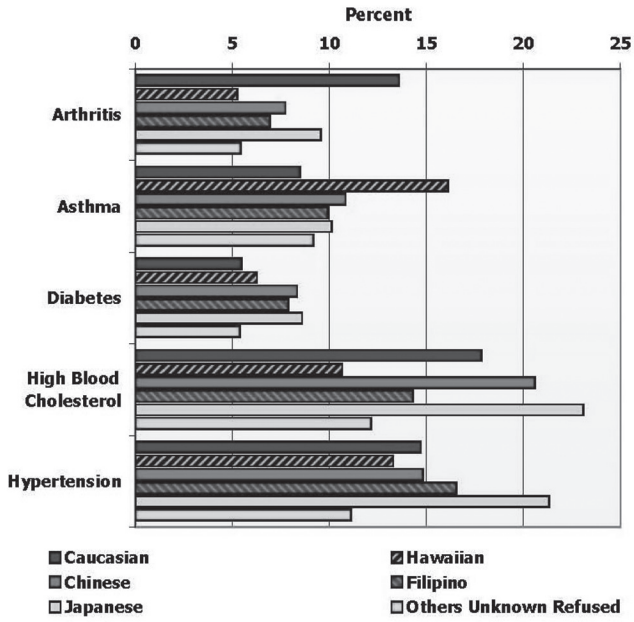

Figure 1. Chronic Health Condition Prevalence by Ethnicity, Hawai'i Health Survey, 2008[1]

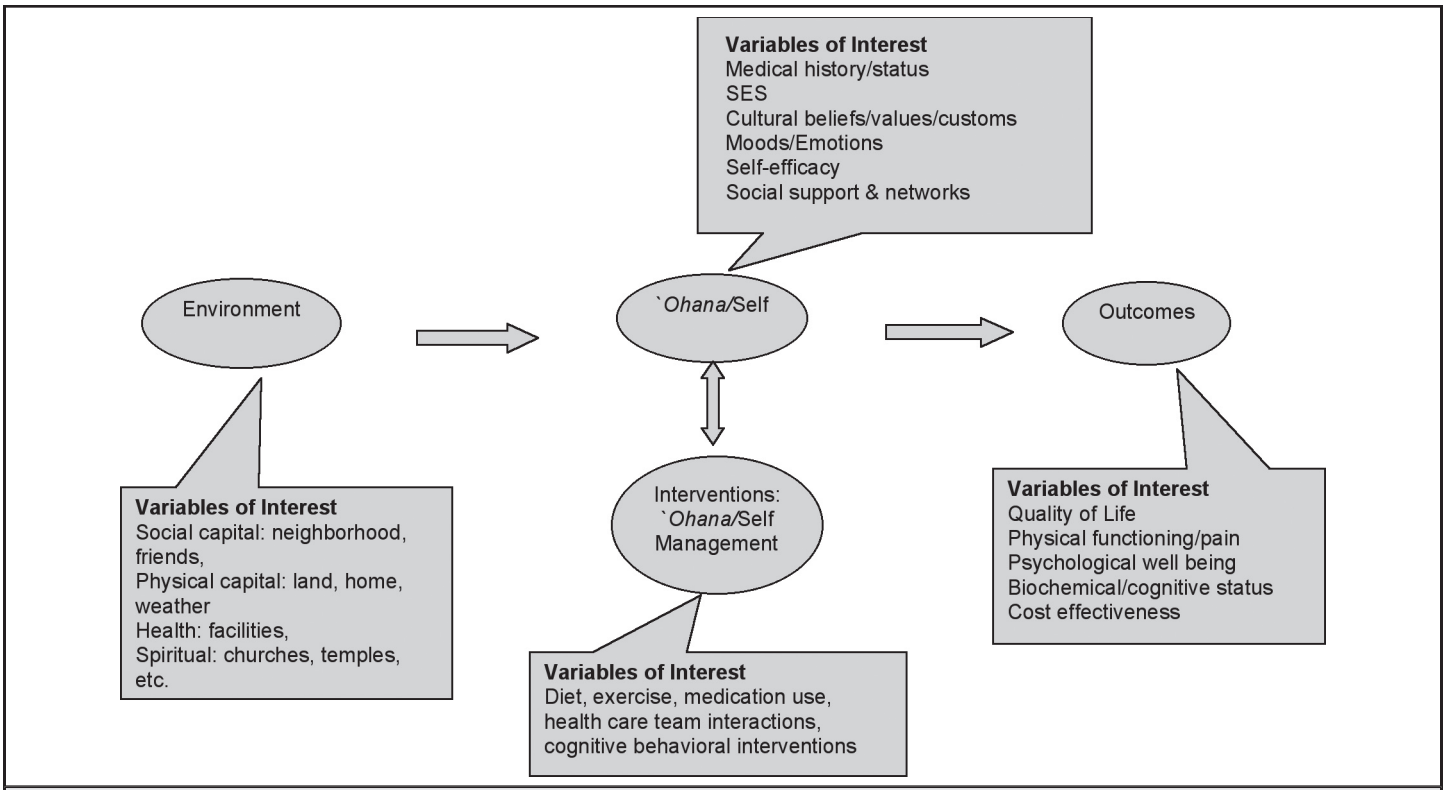

Figure 2. COSMCI Conceptual Framework

External Advisory Committee

The External Advisory Committee (EAC) provides overall guidance to the COSMCI. Committee members were selected based on expertise in self-management research, their role in the community and their strong history of collaboration. The EAC consists of renowned national scientists with expertise and experience relevant to the COSMCI's scientific program and several scientific members of the Hawai'i community involved in self-management research. They include two physicians, a nurse-physiologist, a nurse-certified diabetes educator, and two psychologists. The Committee meets in person annually with conference calls as necessary. The committee: 1) provides guidance and counsel to the Executive Committee; 2)

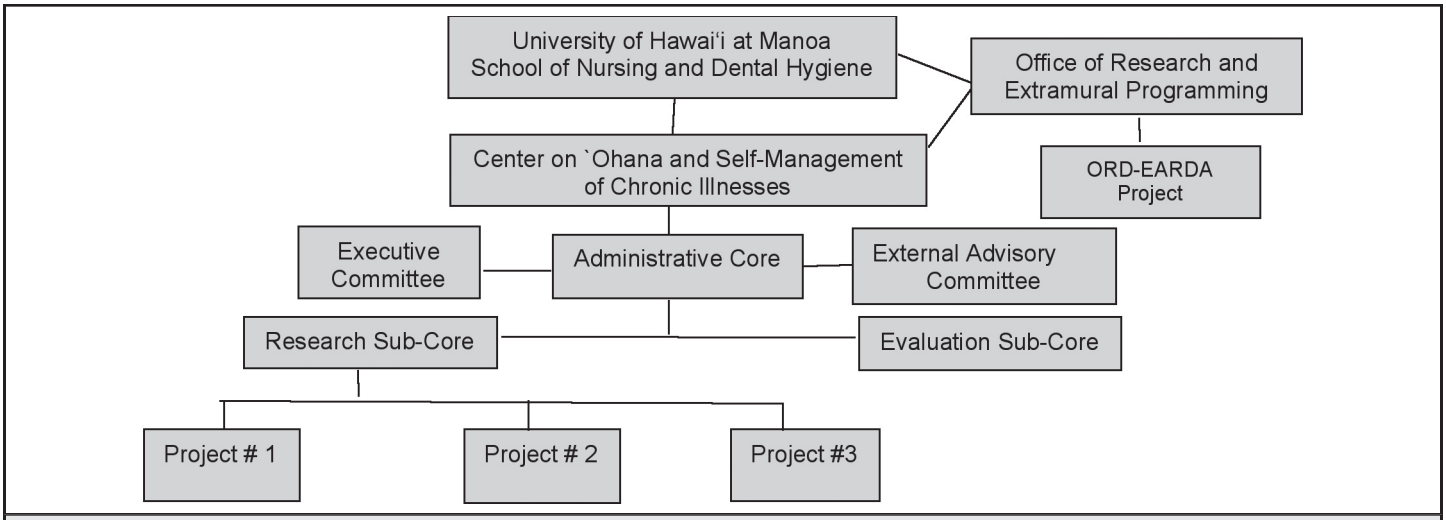

Figure 3. COSMCI Operational Structure

reviews the Center annual report and recommends strategic direction and/or course correction; 3) collaborates with the executive committee to develop an equitable and fair process for project funding; and 4) participates actively in the Center evaluation process.

Executive Committee

The Executive Committee (EC) is responsible for the operations of the COSMCI, including resource allocation, research strategies, evaluation, and dissemination. They maintain oversight of the solicitation, review, and selection of all research projects. Membership includes the Administrative Core/Center Director (PI), the Center Co-Director, sub-core leaders, and SONDH Director of Operations (business official). These key personnel represent nursing, public health, and the Cancer Research Center of Hawai'i, to bring complementary expertise to the Center. Collectively, they have a history of collaborating with each other on grants. Each individual brings skills including NIH program background, management in a large health care system, and administrative access in the university system. The commitment to creating a sustainable center guided the effort to develop the conceptual framework, proposal narrative, budget, and strategy for the administrative core.

Administrative Core

The Administrative Core (AC) develops, coordinates and assures seamless integration of the Center efforts to achieve the mission and specific aims. The AC developed the COSMCI's infrastructure, coordinates activities of the academic and community partners, and assures external evaluation of the Center. The AC experience and expertise in research, education, and grant administration within the University of Hawai'i provides the management of the Center.

The aims of the AC are to: 1) develop and coordinate the Center's long and short-term activities; 2) optimize utilization of shared resources of the Center; 3) promote networking and collaboration with the larger research community; 4) establish and maintain communication with EC, EAC, research projects, and other entities; 5) publicize and disseminate activities and study results by publicizing the Center's activities through the web page, electronic newsletter, and other means; 6) in conjunction with the evaluation core, assist with the evaluation plan; and 7) plan for sustainability of the Center once support is completed, including development of collaborations and seeking NIH and other support.

Research Sub-Core

The goal of this sub-core is to guide the research capacity development within the Center, university, and community partners. The research sub-core facilitates research activity through mentoring and coaching of researchers, refining the conceptual framework for self-management, and management of interdisciplinary research training. The aims of the research sub-core are to: 1) maintain oversight of the solicitation, review, selection, and support of all projects; 2) collaborate with the evaluation sub-core to review the COSMCI's research activities and adherence to the aims and objectives; 3) support research and training activities related to self-management; and 4) serve as the resource center on research related to 'ohana and self-management.

Evaluation Sub-Core

The Center project evaluation uses the evidence collected for the first three center aims. The evaluation sub-core: 1) monitors the quantity of 'ohana and self-management research conducted in the state; 2) monitors and documents the development of sustainable research capacity relevant to 'ohana and self-management of chronic illnesses; and 3) monitors the dissemination and translation of knowledge obtained from project studies. The Center components and project specific studies are monitored through periodic progress reports. These progress reports are based on the components included in the logic model for each center component and for each project specific study. In addition, this sub-core developed and monitors the Center evaluation plan including an ongoing assessment of early outcomes.

Center Research Projects

The three funded research projects utilize the COSMCI theoretical framework but focus on different 'ohana or self-management areas and illness categories. The specific illnesses include HIV infection, T2D, and COPD. Standardized tools are used for each study including the SF-36 and the Self-Efficacy for Managing Chronic Disease (S-EMCD). This approach contributes to the larger COSMCI aims

by increasing the pool of data for multiple chronic illnesses across ethnic groups. This is a unique collaboration, which highlights the communication among the research project directors and the COSMCI to fulfill the larger objectives. Partnering with senior faculty from other disciplines addresses NIH's Roadmap initiative of interdisciplinary and mentored science.

Self-Efficacy and Self-Management of Symptomatic HIV/AIDS A Pilot Study. The objectives of this pilot study are to: 1) deliver to a sample of symptomatic HIV-seropositive clients residing in Hawai'i, a group educational program for chronic disease self-management entitled, Positive Self-Management Program For HIV [PSMP]; 2) test the feasibility and efficacy of the PSMP within an ethnically diverse HIV seropositive population; and 3) measure the effects of the PSMP on a variety of physical, psychological and behavioral indicators.

Kalusagan ay Kayamanan (Health is Wealth)
The three objectives for this project are to: 1) develop an innovative culturally tailored lifestyle intervention for Filipino-Americans to reduce the risk of developing T2D; 2) test the feasibility of this lifestyle intervention which incorporates flexible scheduling of the curriculum on weekends to accommodate working adults; 3) assess the efficacy of this lifestyle intervention by gathering preliminary data to inform a fully powered study.

COPD Self-Management: A Breathing Pattern Retraining Intervention with an Interactive Telecommunication System among People with COPD
The aims of the study are to: 1) explore the feasibility of an interactive telecommunication system to reinforce the self-management intervention; 2) compare a structured pursed-lips breathing self-management intervention for dyspnea reduction, increased physical activity, and improved health-related quality of life (HQOL) to a wait-list control group; 3) examine if self-efficacy predicts changes in dyspnea, physical activity, and HQOL.

Center Synergy
The individual proposals included within COSMCI are logically related on several levels and the represented chronic diseases provide breadth to the research. The interventions are delivered through varying modes with the ultimate outcome of sustainability and dissemination in mind (see Table 1). One project implements a peer/lay led education model where the information is disseminated to the participants through peers or lay leaders; one utilizes a tested model for self-management in a different population; and one project involves technology as the main mode (i.e., web technology) of intervention. Each project includes the general multicultural population from Hawai'i or a specific minority group (e.g., Filipino). Primary care providers play a key role in the recruitment of participants from their patient population for one of the studies. Other studies include community participants with no linkage to their primary care providers. All projects are feasibility studies, and preliminary data collection indicated no clinical issues for health care providers. In the event of any untoward findings, the participants will be referred to their care providers. Other impacts on providers are not anticipated as the cost and time impact on the primary care provider is negligible.

Additionally, all intervention approaches utilize the social cognitive model that facilitates measurement of the same concepts across interventions (e.g., self-efficacy). In terms of outcomes, all projects are addressing feasibility issues allowing lessons learned to be shared among the approaches taken, and all projects will assess their interventions' impact on quality of life.

Table 1. Summary of Research Projects

Chronic Disease	Modes of Delivery	Population	Common Outcome Measures
T2D	Peer/Lay led	Filipino	SF-36, S-EMCD*
COPD	Computer	Mixed	SF-36, S-EMCD
HIV/AIDS	Peer/Lay led	Mixed	SF-36, S-EMCD

*Self-Efficacy for Managing Chronic Disease 6-Item Scale

Results and Discussion

Successes to date include development of learning opportunities coordinated by COSMCI and offered to interdisciplinary faculty, students, community agencies, and collaborating organizations. Within UH, COSMCI is one of a few funded health sciences research venues where faculty and students in at least four disciplines interact, collaborate, and learn together. The community-focused research may increase patients' participation in their own care. As pilot studies recruited or will recruit primarily from churches, self-help groups, and non-profit organizations, the impact on the workload of primary care physicians are not excessive. To apprise them of their patient's participation, one study has pre- and post-intervention biometric measures written in one of the workbooks so participants can share results with their health care providers.

The learning opportunities for those in academia include journal clubs, training sessions, research colloquia, and symposiums open to all faculties in the university. A writing group facilitates dissemination of activities, which includes input from a Native Hawaiian organization representative. COSMCI efforts led to a diversity supplement to enrich and expand one of the pilot research projects. The greatest impact is the interdisciplinary nature of the projects and core faculties and associates, which have added richness to the center. In concert with these efforts, the Center members submitted a joint research grant on a topic central to self-management (obesity) and are awaiting the funding decision. Thus, the Center is building UH capacity for health sciences research that crosses the boundaries of schools and disciplines.

Plans for the Future
The stakeholders and Center's experience will inform the sustainability of COSMCI. Components of a sustainability plan include, but are not limited to: a) institutional commitment; b) Center membership and maintenance of structures; c) growing the individual faculty research programs started from the P20 projects; d) increasing dissemination; e) diversifying support; and f) progression to a larger funded center of excellence.

The nature of the interdisciplinary efforts has increased the potential for success in these efforts. For example, physicians can refer patients to the projects. Findings will inform the structure and operation of the medical homes of the future including referring patients with chronic illness to community-based self-management programs. If larger studies develop from these pilot investigations, physicians and other health care workers could be involved with recruitment for the community study sites where their practices are located.

Summary

This paper describes the first two years of UH experience in developing an interdisciplinary research center focused on self-management of chronic conditions. This first phase focused on building organizational capacity and establishing community relationships. While each research project addresses a distinct chronic condition, the use of social cognitive theory as the conceptual framework and common data measures supports the self-management focus. Future reports will describe the results of the projects, experience with research capacity building, and sustainability.

Acknowledgments

The Center described was supported by Award Number P20NR010671 from the National Institutes of Nursing Research. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Nursing Research or the National Institutes of Health.

The authors acknowledge Rosa Castro, Chun-I Li, Marla Acosta, and project staff at the University of Hawai'i at Manoa School of Nursing and Dental Hygiene Center for 'Ohana and Self-Management of Chronic Illnesses in Hawai'i (5P20NR010671) and the Office of Research Development Extramural Associates Research Development Award (G11HD054969) for their assistance.

Authors' Affiliations:

- University of Hawai'i at Manoa School of Nursing & Dental Hygiene,Honolulu, HI, 96822 (J.I., M.G.B., K.S., A.L., D.M.)
- Department of Public Health Sciences, John A. Burns School of Medicine, University of Hawai'i at Manoa, Honolulu, HI, 96813 (C.R.N.)
- Cancer Research Center of Hawai'i, Honolulu, HI, 96813 (C.L.A.)

Correspondence to:

Jillian Inouye PhD, APRN
University of Hawai'i at Manoa School of Nursing & Dental Hygiene
2528 McCarthy Mall, Webster Hall 402, Honolulu, HI, 96822
Ph: (808) 956-8522; Fax: (808) 956-3257; Email: jinouye@hawaii.edu

References

1. Hawaii State Department of Health. Hawaii Health Survey. 2008. Available at: http://hawaii.gov/health/statistics/hhs/hhs_08/index.html. Accessed February 8, 2010.
2. U.S. Center for Disease Control and Prevention. Behavioral Risk Factor Surveillance System. 2008. Available at: http://cdc.gov/brfss/index.htm. Accessed February 8, 2010.
3. Juarez, DT, Samoa, RA, Chung, RS, Seto, TB. Disparities in health, obesity and access to care among an insured population of Asian and Pacific Islander Americans in Hawai`i. Hawaii Med J. 2010;69(2)42-46.
4. U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. Healthy People 2010. Available at: http://www.healthypeople.gov. Accessed February 1, 2010.