

AN ETHNOGERIATRIC PERSPECTIVE ON HEALTH LITERACY AND MEDICATION USE IN EMERGENCY PREPAREDNESS

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Tackling the Tough Topics in Ethnogeriatrics
June 7, 2012 – WEBINAR SERIES

"Fall Risk and Prevention in Older Adults"

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Faculty Disclosure Statement:

As part of our commercial guidelines, we are required to disclose if faculty have any affiliations or financial arrangements with any corporate organization relating to this presentation. Dr's McBride, Gant, and Stemley have indicated they have no conflicts of interest to disclose to the learners, relative to this topic.

Dr's McBride, Gant, and Stemley will inform you if they discuss anything off-label or currently under scientific research.

Melen R. McBride, PhD, RN, FGSA

- Melen R. McBride**, Associate Director Emeriti and Ethnogeriatric Clinical Nurse Specialist at Stanford Geriatric Education Center (SGEC), School of Medicine, Stanford University, has over two decades of experience in ethnogeriatrics, including use of advance educational internet technology (distance learning, webinars, web-based training) and designed the Cohort Historical Analysis Tool (CHAT) currently in use for graduate students in psychology and nursing programs. She provides leadership (since 2001) to infuse ethnogeriatric content into interprofessional emergency preparedness training of health professionals through the Geriatric Emergency Preparedness Response (GEPR) Collaborative composed of six HRSA funded GECs, one of which is SGEC, via webinars, online modules, and other teaching/ dissemination strategies; co-coordinates the 160-hours Faculty Development Program in Ethnogeriatrics (FDPE); and assists with implementation and evaluation of other SGEC educational programs. She is widely published and is active in numerous professional groups and the aging network: the Gerontological Society of America, Association for Gerontology in Higher Education, American Society on Aging, American Public Health Association, Gerontology Section, and the National Association of Geriatric Education Centers in which she is a member of the Board of Directors. She is one of the key leaders in the creation on an active Interest Group on Disaster Preparedness in the American Geriatrics Society. She received an MSN/PhD in Clinical Nursing, Gerontology from the University of Michigan, MEd from Loyola University; was a post-doctoral, Robert Wood Johnson Clinical Scholar at UCSF, scholar-in-residence at Stanford University; and a legislative intern for the US Senate Committee on Aging, chaired by Senator John Heinz of Philadelphia.

Edward Stemley, Pharm.D., M.S.

Dr. Edward Stemley is a Clinical Associate Professor in the Division of Clinical & Administrative Sciences and currently serving as Vice Chair of the Division. His responsibilities include administrative oversight of the Professional Experience Program, Drug Information Center, and Continuing Education.

Dr. Stemley received a Doctor of Pharmacy degree from Xavier University College of Pharmacy prior to earning a Master of Science degree at The Ohio State University. Dr. Stemley also completed a Pharmacy Practice Residency with an emphasis in Health-System Administration from The Ohio State University Medical Center.

Prior to joining the faculty at Xavier, Dr. Stemley served as Chief Pharmacy Officer at the Harris County Hospital District in Houston, Texas, where he was primarily responsible for providing pharmacy service to a health-system consisting of two acute care hospitals, fourteen ambulatory clinics and a geriatric/physical rehabilitation hospital. The clinical and distributive operations provided teaching sites for the University of Houston and Texas Southern University Colleges of Pharmacy. Most recently, Dr. Stemley held the position of Director, ASHP Section of Pharmacy Practice Managers where he served approximately 8000 health-system pharmacy managers of the 30,000 member organization.

Kisha O'Neal Gant, B.S., Pharm. D.

Dr. Gant completed her Bachelor of Science degrees in biology and mathematics at the University of New Orleans. She received her Doctor of Pharmacy degree from Xavier University of Louisiana, where she also completed a Community Pharmacy residency.

Prior to entering pharmacy school, Dr. Gant was a middle and high school mathematics teacher in Hampton, Virginia.

Dr. Gant will teach in Pharmacy Skills Lab II, Introduction to Pharmacy, and Pharmacy Practice. Her clinical site is at the Daughters of Charity Health Center located on Carrollton Avenue.

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2012 SGEC Webinar Series Part II Tackling the Tough Topics in Ethnogeriatrics

June 07, 2012

**National Association of Geriatric Education Centers Initiative
Geriatric Emergency Preparedness, Response (GEPR) Collaborative**

- **2001 – 02:** National Association of Geriatric Education Center (NAGEC) surveyed GECs; presented position statement to HRSA on need for geriatric emergency preparedness training
- **2003 – now:** HRSA funded 6 GECs (*CA, KY, MO, NY, OH, TX*), initially called the Bioterrorism Emergency Preparedness in Aging (BTEPA), developed multidisciplinary training for health professional; continues its work today as the GEPR Collaborative ~ **Consortium of NYGEC, Ohio Valley Appalachia Regional GEC, University of Kentucky, Saint Louis University Gateway GEC of MO & ILL, Stanford GEC, Stanford University, Texas Consortium GEC, University of New England, Maine GEC, and Mather Lifeways.**

National Association of Geriatric Education Centers Initiative Geriatric Emergency Preparedness, Response (GEPR) Collaborative

- **2010-2015:** GEPR committed to offer multidisciplinary preparedness programs through GECs' HRSA funded educational activities.
- **2010-2015:** Webinars Series on Emergency Preparedness
Ohio Valley Appalachia Regional GEC, University of Kentucky, Stanford GEC, and the University of New England, Maine GEC offer various topics in geriatric preparedness through the SGEC webinar series programs.

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6/6/2012
C 2011

Learning Objectives

- Increase awareness of the importance of health literacy in emergency preparedness related to medication access.
- Discuss disasters that restrict access to resources and impact the health and safety of diverse ethnic elders.
- Identify health conditions and risks to older persons that must be prevented or managed in a disaster.
- Describe self-care therapeutic guidelines on medication use for ethnic elders before, during, and recovery from the aftermath of disasters.

Keywords: preparedness in ethnogeriatrics , medication for emergency preparedness

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Health Literacy (HL)



Health literacy ~ capacity to obtain, process, and understand basic health information and services needed to make health decisions.

90 million people in the U.S. can not understand and use information shared by health care providers

47 million people speak a non-English language at home

Hanrahan, 2010; Maas, 2010; IOM, 2004



Functional Health Literacy (FHL)

Broad range of skills/competencies necessary to seek out, understand, evaluate, and use health information/concepts to:

- ~ make informed choices,
- ~ reduce health risks
- ~ reduce inequities in health
- ~ increase quality of life

Zarcadoolas, Pleasant , & Greer, 2006

Areas of Functional Health Literacy (FHL)

○ *Fundamental domains*

Reading
Writing
Speaking
Numeracy



○ *Scientific*

- Civic
- Cultural

Zarcadoolas, Pleasant, & Greer, 2006



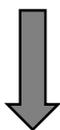
Health Literacy and Prescription Warning Labels (PWLs)

- Descriptive study (N=251): all primary care patients
 - had better understanding of single-step warning labels than multiple-step instructions.
 - had difficulty with multistep instructions
- Patients (33%) with low literacy (<6th grade reading level)
 - had difficulty understanding PWLs.
 - were 3.4 times less likely to interpret correctly PWLs

Davis, T., Wolf, M., Bass, P., Middlebrooks, M., Kennen, E., et., al (2006).

Functional Health Literacy (FHL) and Written Instructions

- English Longitudinal Study of Ageing (N=7857) adults, age 52+ from second wave (2004-05) of cohorts
- Completed four item test of FHL to assess understanding of written instructions for taking an aspirin tablet.



FHL score: associated with increasing age, low SES, less education, depressive symptoms, physical limitations, chronic diseases (CVD, diabetes, stroke, asthma), smoking, physical inactivity, alcohol intake; **not ethnicity** (*white vs non-white*)

Bostock & Steptoe, 2012

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Functional Health Literacy: Scientific Domain

- estimate: 5-15 % U.S. population is considered to be science literate
- at least 63% of American adults do not know viruses and bacteria are different
- what people think when they hear "*trial*"
response - *involves a judge; what the Lord places upon us, trial and error*
- 2009, only 40% of American adults understood the risk sufficiently to plan to have their children immunized against H1N1

Zarcadoolas, Pleasant , & Greer, 2006,

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Health Literacy and Alzheimer's Disease (AD) Knowledge

- Survey : evaluate knowledge of (AD) in ethnic older adults (N=193)
Caucasian (50%), Hispanic/Latino (19%), African American (16%), Asian (16%),
- Caucasian had more AD knowledge than African American, Asian, and Latino
- Level of education accounted for difference between African American and Hispanic Latino
- Years of speaking English accounted for knowledge of Asian Americans

Ayalon & Arean, 2004

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Risk Factors for Limited Health Literacy

Age

Low income

Education

Minority ethnic group

Recent immigrants

Born in U.S. - English is second language (ESL) or limited English proficiency (LEP)



Hikoyeda & Limaye, 2011

Experience of People from Racially and Ethnically Diverse Cultures and LEP Persons in Emergencies

- Historically, emergency preparedness activities have lacked sufficient focus on these individuals. As a result, they often:
 - Do not receive important information about emergencies.
 - Fail to receive needed services, including medical assistance.
 - Experience poorer outcomes.
- Many reports on “lessons learned” after Hurricane Katrina noted the importance of including “special needs populations” in planning, response, and recovery efforts for those efforts to be successful.

Hanrahan, 2010.

Health Literacy Link to Emergency Preparedness



✓ Preparedness information & resources

✓ Health maintenance

nutrition
hydration
medication

✓ Medical care continuum
evacuation
sheltering-in
recovery



Low Literacy Behaviors: Medication Indicators

- ❖ Inability to name medications, purpose, or dosage
- ❖ Report taking medications without change in symptoms/conditions
- ❖ Identify pills by color/appearance not label
- ❖ **Inability to calculate amount/dose needed for 30-day supply**

Hikoyeda & Limaye, 2011

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Low Literacy Behavior Cues: Personal Preparedness Indicators

- Makes excuses in response to written information – *I forgot my glasses. I'll read it when I get home. Can you read it for me?*
- Response: *Let me take this home and discuss it with my children.*
- Eyes wander over a form; may look confused.

Hikoyeda & Limaye, 2011

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Low Health Literacy Outcomes

- Use less screening/preventive services
- Seeks care at late stages of disease
- Are more likely to be hospitalized
- Have poorer understanding of treatment and their own health
- **Adhere less to medical regimens**
- Have increased health care costs
- **Increased mortality; die earlier**

Bostock & Steptoe, 2012; Sudore, Yaffe, Satterfield, Harris, Mehta, et al, 2006;
Schwartzberg, Van Geest, & Wang, 2004

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Limited Literacy and Mortality

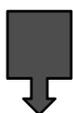
- Prospective study (N=2512); mean age - 75.6 years, 48% - male, 38% - black, and 24% - limited literacy; median follow-up time - 4.2 years.
- ❖ **Limited literacy** - higher risk of death vs. adequate literacy (19.7% vs 10.6%)
- ❖ **Limited literacy** remained independently **associated with mortality** after adjusting for demographics, SES, co-morbidities, self-rated health status, health-related behaviors, health care access, and psychosocial status.

Sudore, Yaffe, Satterfield, Harris, Mehta, et. al., 2006

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Functional Health Literacy (FHL) and Written Instructions

- English Longitudinal Study of Ageing (N=7857) adults, age 52+ from second wave (2004-05) of cohorts
- Completed four item test of FHL to assess understanding of written instructions for taking an aspirin tablet.



FHL score (12.5%) likely to die in 5yrs

Bostock & Steptoe, 2012

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Access to Prescription Drugs in Disaster Preparedness

- Pre-Disaster Preparation
- Mass Dispensing of Medication and Supply
 - home delivery
 - sites for mass prophylaxis
- Public Resources



Cities Readiness Initiative (CRI)
Strategic National Stockpile (SNS)

Access to Prescription Drugs in Disaster Preparedness

- <http://publichealth.lacounty.gov/eprp/cityinit.htm> *
- <http://publichealth.lacounty.gov/eprp/masspro.htm> *
- <http://publichealth.lacounty.gov/eprp/sns.htm> +
- <http://www.echominnesota.org/library/operation-medicine-delivery> *
- <http://www.echominnesota.org/library/mass-dispensing-medicine> *
- www.rand.org – Nelson, C., Parker, A., Shelton, S., Chan, E, & Fillemer, F. (2010). Analysis of the Cities Readiness Initiative: Report Prepared for CDC, Rand Corporation, CA.

* = CRI; + = SNS

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Participants' Contact with Persons of Limited Health Literacy

- Estimate the number of older adults you interact with each week who may have functional health literacy issues associated with medications.
 - a. more than 10
 - b. less than 10
 - c. less than 5
 - d. none

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Contact Information

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<http://sgec.stanford.edu/events.html>

http://sgec.stanford.edu/resources/emergency_preparedness.html

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- FOR MORE RESOURCES, PLEASE GO TO THE HANDOUT ON "OTHER RESOURCES"

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California Department of Public Health: Home & CDPH Programs Food, Drug, Radiation Safety <http://bepreparedcalifornia.ca.gov/Pages/Home.aspx>

<http://bepreparedcalifornia.ca.gov/CDPHPrograms/PublicHealthPrograms/Pages/Food+Drug+and+Radiation+Safety.aspx>

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Stanford Geriatric Education Center website

http://sgec.stanford.edu/resources/emergency_preparedness.html

http://sgec.stanford.edu/resources/addl_resources.html



U.S. Department of Health and Human Services
Office of the Assistant Secretary for Preparedness and Response



Resources for Serving Persons with Limited English Proficiency

Individuals who do not speak English as their primary language and who have a limited ability to read, speak, write, or understand English are considered limited English proficient, or “LEP.” Entities that receive Federal financial assistance must take reasonable steps to provide persons with limited English proficiency meaningful access to the programs, services, and information that they provide.

Legal authority is found in Title VI of the Civil Rights Act of 1964, which prohibits discrimination based on national origin. In addition, Executive Order 13166, “Improving Access to Services for Persons with Limited English Proficiency,” requires Federal agencies to examine the services they provide, identify any need for services to LEP persons, and develop and implement a system to provide those services so persons with limited English proficiency can have meaningful access to them. Many Federal and other resources are available for emergency managers for translation and interpretation services:

- The U.S. General Services Administration (GSA) provides a list of contractors that provide interpretation and translation services. There are also services for persons who are deaf or hard of hearing and persons who are blind or have low vision. The list can be accessed at <http://www.gsa.gov/portal/category/21158>.
- The National Language Service Corps (NLSC) is a Congressionally-authorized civilian corps of volunteers with certified expertise in languages important to the well-being of the United States. It is currently a pilot project with over 1,000 charter members. Information can be found at <http://www.nlscorps.org>.
- LEP.gov, the website of the Federal Interagency Working Group on Limited English Proficiency, has a list of interpretation and translation services, including regional and state-based organizations. Information can be found at http://www.lep.gov/interp_translation/trans_interpret.html.
- CDC’s SNAPS database lists the top five languages spoken in any given locality. This information can be useful as a starting point for determining language assistance that may be needed, and can be accessed at <http://www.bt.cdc.gov/snaps/>.
- The Office of Minority Health’s *Think Cultural Health* initiative provides resources that would be pertinent to emergency managers and the provision of language access services. *The Health Care Language Services Implementation Guide*, as well as the *Cultural Competency Curriculum for Disaster Preparedness and Crisis Response*, provides valuable tools for the implementation of language access services as well as skill-building for working with interpreters and translation organizations. Both of these resources can be accessed at <https://www.thinkculturalhealth.hhs.gov/> and through <http://www.diversitypreparedness.org/>.
- The Refugee Health Information Network (RHIN), sponsored by the National Institutes of Health and its National Library of Medicine, is a national collaborative partnership that has created a database of quality multilingual, public health resources for those providing care to resettled refugees and asylees. Resources include health education materials in various languages and formats (brochures, fact sheets, videos), provider tools (including information on refugee populations and cultures), and links to related Web sites. This resource can be accessed at <http://rhin.org/Default.aspx>.
- The National Health Law Program’s “Language Services Resource Guide” provides information on language services, including a list of national and state interpreter and translator services. It can be accessed at <http://www.healthlaw.org/images/stories/issues/ResourceGuideFinal.pdf>.
- The Migration Policy Institute’s Language Portal provides access to hundreds of state and local agency documents used to provide services to Limited English Proficient clients. It can be searched by state, language, and service delivery type and is found at http://www.migrationinformation.org/integration/language_portal/search.cfm.
- Local groups, such as community-based cultural organizations, may offer translation services. Local colleges and universities with foreign language programs may also be a resource. In addition, Medical Reserve Corps units may have interpreters as part of their community-based teams.



CDC's Division of Strategic National Stockpile Emergency MedKit Evaluation Study Summary

Background, Key Results, and Next Steps
(as of November 15, 2007)

Background

The overarching aim of the emergency MedKit evaluation study was to evaluate a strategy that addresses the timeliness of distributing antibiotics to the general public as an effective measure against a release of anthrax. Five modalities are proposed for bolstering the nation's capacity to respond to large-scale events by providing the necessary countermeasures to the population in a timely manner:

- 1. Classical Points of Dispensing (or PODs) for medicines or vaccines.** This is the primary means local governments currently use. The federal government delivers material to local authorities that, in turn, are delivered to affected people. This mechanism has been used by many communities over many years, albeit not on the scope or at the tempo that a major bioterrorism event would require.
- 2. Direct residential delivery of antibiotics by postal carriers.** With this approach, postal workers would deliver medicine directly to residences. Discussions are ongoing with the U.S. Postal Service to explore the advantages and limitations of this approach.
- 3. Pre-deployed community-based caches of pharmaceuticals for emergency use.** Locally stored caches of pharmaceuticals could be at the front lines of an emergency very quickly. They would be prepositioned in selected institutions with healthcare infrastructure, e.g., hospitals.
- 4. Pre-event dispensing of pharmaceuticals as equipment to first responders.** Providing first responders with potentially needed medicines in advance can better equip them to respond to biological or chemical emergencies.
- 5. Pre-event placement of pharmaceuticals in individual households for use only as directed by public health authorities.** Families in the United States would be supplied a medical kit with critical prescription pharmaceuticals needed during an emergency.

While one or more of these modalities could be used simultaneously, the combination of strategies should be tailored to fit a community's need. One strategy under consideration is the provision of medicines to individual households prior to any direct bioterrorism threat for use only as directed in a declared public health emergency. An evaluation study was designed to provide evidence about the feasibility of placing a cache of antibiotics in individual households.

In January 2006, the Missouri Department of Health and Senior Services agreed to partner with the Centers for Disease Control and Prevention (CDC) to conduct the evaluation. The specific aims of the emergency MedKits evaluation study were to:

- assess the ability of households to maintain MedKits in the home as directed and reserve for emergency use
- explore attitudes, perceptions, and other social factors that may influence participant behavior regarding storage and proper use of the MedKit
- provide information about the acceptability of the household MedKit prototype

In collaboration with the Food and Drug Administration (FDA), the CDC designed an antibiotic MedKit prototype. The prototype consisted of a four-fold cardboard blister pack with a five-day supply of medicine. The blister pack was stored in a sealed bag that was transparent on one side and included instructions for use in an open pouch on the outside.

To meet all federal and state regulatory requirements, the MedKit prototype has been evaluated as an investigational new drug (IND). The study protocol was reviewed and approved by three Institutional Review Boards and the U.S. Office of Management and Budget. A local physician was contracted to serve as the medically qualified professional for clinical oversight. Each enrolled household received monetary incentives.

Design: The design was prospective over a period of eight months. A baseline interview was conducted in-person and each household member was medically screened. Informed consent was required for each member. At the time of enrollment, households were randomly assigned to a two-, four- or eight-month time interval for a follow-up interview and to return their kit.

Setting: The St. Louis metro area, also a Cities Readiness Initiative (CRI) participant, was the pilot test site. Most of the enrolled households were in St. Louis City, St. Louis County and St. Charles County.

Participants: The study population consisted of three cohorts: clients and some employees of a community health clinic; corporations (n =10) such as Sigma and ATT; and first responders, including the FBI.

Key Results

Each household was represented by one household member who was selected to be the custodian of the MedKit and survey responder. The unit of analysis is the household. There were 174 households lost to follow-up; data are complete for 4,076 households (12,040 persons).

Ability of households to maintain MedKits in the home as directed and reserve for emergency use:

- 97% (3,946 out of 4,076) of all study respondents returned the household MedKits upon completion of the study. There was no statistical significant difference between cohorts.
 - Clinic: 1,351 households (94%)
 - Corporate: 1,077 households (98%)
 - Responders: 1,535 households (99%)
- 130 (3%) households did not return their MedKits; 125 of these households (96%) could not locate their MedKit and five (4%) simply refused to return them.
- Four households (3%) reported having used their MedKits. All four were in the clinic cohort.
 - 1 household: elderly woman used during a declared emergency for storm
 - 2 households: member in household had “sore throat”
 - 1 household: refused to state why pills were taken
- Among the MedKits returned, all but 34 of the MedKit bags were intact (more than 99% with no pills missing).
- Curiosity about the contents was the most frequently mentioned reason (55%) given for opening the MedKit bag.
- Majority of the households (28 out of 34) that opened the bag were from the clinic cohort.

Attitudes, perceptions, and other social factors that may influence participant behavior regarding storage and proper use of the MedKit.

- At the time of the follow-up interview, more than 75% (n = 3,086) reported that having the emergency MedKit in their homes increased their awareness of the need to prepare for a public health emergency, including a terrorist attack.
- Overall, 75% (n = 3,059) of all respondents reported that they feel “not too prepared” or “not at all prepared” for such an attack.
- The majority of study participants (94% or more in each cohort) reported that based on their experience with the study, they would like to have a MedKit in their home.
- The majority of respondents in all three cohorts (83% to 86%) would pay for a MedKit.
- The average price that households would pay per person was \$23.

Next Steps

An overwhelming majority of study participants appropriately followed instructions regarding storage and reserving the emergency MedKit for use until directed by public officials. A similarly large proportion of study participants reported that they would like to have emergency MedKits in their homes and would be willing to purchase these MedKits, but the MedKit prototype has not yet received approval by the FDA.

The FDA requires additional testing on the MedKit prototype, which is currently under development in the Department of Health and Human Services’ Biomedical Advanced Research and Development Authority (BARDA). Along with the findings from the home MedKit evaluation, the FDA will use the information from the additional studies to facilitate a New Drug Application (NDA) for the MedKit prototype.

The additional studies will provide information about:

- the overall comprehension of the MedKit product labeling and instructions among various literacy levels in the general population
- participants’ understanding of correct use of medications through laboratory simulation
- palatability of Doxycycline and Ciprofloxacin when mixed with several food substances that are common to most households
- participants’ ability to understand and implement home preparation instructions for administering to children in the household

Assuming industry interest and regulatory requirements are met, the overall optimistic timeframe for approval of the MedKit prototype is at least three years (2010).

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Self-Management Support for Ethnocultural Minority Older Adults

An Annotated Bibliography

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Glossary of Acronyms

- ARVL** Age-related vision loss
- ASHC** Arthritis Self-Help Course
- BGM** Blood glucose monitoring
- BME** Black and minority ethnic groups (U.K.)
- BP** Blood pressure
- CALD** Culturally and linguistically diverse communities
- CCM** Chronic Care Model
- CCSM** Chronic condition self-management
- CDK** Chronic disease knowledge
- CDSM** Chronic disease self-management
- CDSMP** Chronic Disease Self-Management Program
- CHAP** Centre for Healthy Aging at Providence Health Care
- CHD** Coronary heart disease
- CNS** Clinical nurse specialist
- DSME** Diabetes self-management education
- EMOA** Ethnocultural minority older adults
- ECCM** Expanded Chronic Care Model
- EPP** Expert Patients Programme (U.K.)
- HBP** High blood pressure
- ISC** Indian subcontinent
- GNP** Geriatric nurse practitioner
- NHS** National Health Service (U.K.)
- OA** Osteoarthritis
- RCT** Randomized control trial
- RDA** Recommended Dietary Allowances
- SMS** (Chronic disease) self-management support
- VSM** Vision Self-Management Programme
- W/E** White Europeans
- WHO** World Health Organization

Executive Summary

Objectives & Basic Search Parameters

The purpose of this annotated bibliography is to identify literature pertaining to chronic disease self-management support (SMS) for ethnocultural minority older adults (EMOA). SMS is a key component of the Chronic Care Model (CCM)¹ – a widely adopted multi-pronged strategy directed at preventing and managing the increasing incidence of chronic disease worldwide – that aims to improve an individual’s ability to manage their symptoms, treatments, and the physical/social consequences of chronic disease through psychological and behavioural modifications.² The Chronic Disease Self-Management Program (CDSMP) is one example of this model that has been widely adopted internationally and forms a major component of BC’s Expanded Chronic Care Model (ECCM).

This review includes literature from Canada and countries with similar immigrant populations and/or health service delivery systems (principally the United Kingdom and Australia). Only articles published after 1990 were considered. Very few articles specific to SMS for EMOA exist within these parameters. The review was thus expanded to include data from the United States on African-American and Hispanic populations. Key examples of articles pertaining to SMS for marginalized or disadvantaged populations (i.e. ethnic minority and older populations) are also included, but presentation of this more peripheral literature is not intended to be exhaustive.

Reviewed Literature

Literature included in this annotated bibliography is organized under five main headings:

Self-management support for marginalized or disadvantaged populations

Though not specific to EMOA, research on SMS for marginalized populations often touches on age, ethnicity or other factors affecting SMS for EMOA (i.e. socioeconomic status or focus on health inequities). In addition to providing us with information relevant to the chronic disease experiences of EMOA, this research also gives an idea of the scope and type of focus within the SMS literature on disadvantaged populations.

Self-management support among older populations

Older populations have been identified by some as requiring unique approaches to implementation if SMS is to be effective.

Self-management support for ethnocultural minority groups

The literature on SMS for ethnocultural minority groups coming out of the US focuses on African-Americans and Hispanics - their largest minority groups. Some work has been done in England on SMS with South Asian communities. In Canada, little attention has been paid to investigating SMS for ethnocultural minority groups.

Self-management support for ethnocultural minority older adults

These articles represent the extent of the literature on SMS for EMOA within Canada and countries with similar immigrant populations and health service delivery systems. So as to expand this limited body of literature, additional research on African-American and Hispanic populations from the US has been included.

Health literacy and self-management support

The scope of the health literacy literature now extends beyond a focus on the individual's ability to understand and communicate information, to include a focus on the health provider and system as being responsible for ensuring patient access to information, and the health benefits such access confers. Ethnocultural minority groups have greater difficulty with SMS because many programs are not culturally sensitive/relevant and assume health literacy. Self-management interventions need to be targeted to ethnocultural minorities of all literacy levels. The evidence on health literacy for EMOA is very limited.

Complementary and Alternative Medicine (CAM) and self-management support

CAM is a common form of therapy among older adults, especially for the purposes of treating chronic health conditions. Most of the available literature on CAM use for chronic disease SMS among ethnic minority populations is focused on arthritis. Use of CAM varies by ethnic group and in some follows predictable patterns, e.g. Chinese immigrants in Calgary regularly blend allopathic with traditional Chinese medicine. The scant literature on CAM and SMS among EMOA suggests that CAM use for chronic disease self-management depends on the availability and suitability of allopathic medicine.

Self-management support and capacity building/community development

Few articles consider of EMOA, SMS, and capacity building/community development. The adoption of a broader view of health that includes the social determinants directs the reader to consider an expanded range of potential supports at the community level. In order to address these determinants, and hence be able access and benefit from available SMS, groups who are disadvantaged benefit from capacity-building approaches. .

What We Found

Literature on SMS for EMOA is sparse and varied. Two evaluations of the CDSMP for older African-Americans indicate some improvements in health behaviours and health status, slight or no improvement in self-efficacy, and no change in health service utilization.

Evaluations of U.K. and Australian programs, similar to the CDSMP in that they are based on a model developed by Lorig and her colleagues, revealed that they predominately appeal to "white middle-class people with long-term conditions who already viewed themselves as effective self-managers"; males, indigenous people, people of non-English speaking background and those with multiple responsibilities were less likely to participate in these courses.

Viable alternative models of SMS for EMOA are not reported in the literature. The chronic disease SMS literature specific to this population primarily examines the more informal self-care practices of these populations. Available evidence indicates that a collaborative model of SMS with partnership between local community service networks, primary care, and health authorities is most effective for marginalized groups. Chronic care services should be embedded within existing community structures to ensure ongoing participation and relevance. SMS models for EMOA must also consider barriers to health service access faced by these populations. Cultural competency within SMS service delivery must extend beyond translation of program materials into an understanding of the cultural context of the chronic disease experience.

Individual self-management needs to be situated within a collective understanding of empowerment. Conventional SMS models focus primarily on individual autonomy and personal responsibility but neglect to address systemic barriers to access experienced by marginalized communities. Instead of reinforcing the status quo, SMS for ethnocultural minority older adults should build on community strengths and bolster capacity to meaningfully engage in self-management.

Introduction

Objectives and search parameters

The purpose of this annotated bibliography is to identify literature pertaining to chronic disease self-management support (SMS) for ethnocultural minority older adults (EMOA). SMS is a key component of the Chronic Care Model (CCM)¹ – a widely adopted multi-pronged strategy directed at preventing and managing the increasing incidence of chronic disease worldwide – that aims to improve an individual’s ability to manage their symptoms, treatments, and the physical/social consequences of chronic disease through psychological and behavioural modifications.² The Chronic Disease Self-Management Program (CDSMP) is one example of this model that is a major component of BC’s Expanded Chronic Care Model (ECCM).^{3, 4}

Efforts were taken to include sources on EMOA from the substantial body of literature on SMS, and to include articles on SMS from the body of literature on EMOA. The latter was achieved through searching an existing database on the health of EMOA currently being conducted through the Centre for Healthy Aging at Providence Health Care (CHAP). This CIHR-funded scoping review is an exhaustive record of research and “grey” literature on the health and health needs, impact of health service interventions on health status, health-related behaviours, and quality of life of EMOA.

Data here was included from Canada and countries with similar immigrant populations and/or health service delivery systems (principally the United Kingdom and Australia). Only articles published after 1990 were considered. The limited nature of this more focused search made it necessary to also include data from the United States on African-American and Hispanic populations, groups with different compositions that interact with a different health system than those of similar ethnocultural background in Canada.

Very few articles exist specific to SMS for EMOA within the parameters described. As such, articles are included here that focus on or include meaningful discussion of SMS for marginalized or disadvantaged populations (i.e. ethnic minority and older populations). This review is not an exhaustive presentation of this literature; rather, key examples are included to give the reader a sense of the type and scope of information that exists.

General SMS literature; prevalence/incidence of chronic disease among EMOA; chronic disease prevention and screening initiatives; and specific research on SMS for indigenous populations, are not included in this review.

Self-management support and related terms

The distinctions between “self-help,” “self-management” and “self-care” are debated and sometimes used interchangeably, although recent efforts have been made to approach a consensus on these terms.

The WHO defines self-care as, “the activities individuals, families, and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health.”⁵ Kennedy et al ⁶ expands on this definition of self-care as the actions individuals “take to lead a healthy lifestyle; to meet their social, emotional and psy-

chological needs; to care for their long-term condition; and to prevent further illness or accidents.”

Self-management is generally agreed upon as extending beyond an individualized approach to include “a more integrated and comprehensive combination of individual self-care together with the negotiation with health services necessary for chronic disease management.”⁷ Self-management support is often conceptualized as a paradigm of chronic disease management that encompasses “a patient-centred collaborative approach to care to promote patient activation, education and empowerment.”⁵ Following this definition, the BC Ministry of Health Services understands SMS as a “two-way” process of communication that encourages patient-provider interaction.¹⁹ Patients are supported by health care staff to increase their skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support.

Articles included in this review focus on the CDSMP, SMS, self-care interventions, self-help, health literacy, coping and lifestyle practices relating to chronic disease.

Literature Review

A. Self-management support for marginalized or disadvantaged populations

Though not specific to EMOA, research on SMS for marginalized populations often touches on age, ethnicity or other factors affecting SMS for EMOA (i.e. socioeconomic status or focus on health inequities). In addition to providing us with information relevant to the chronic disease experiences of EMOA, this research also gives an idea of the scope and type of focus within the SMS literature on disadvantaged populations.

a) Chronic care policy & health inequities:

The following paper and reports describe efforts within the implementation of the Chronic Care Model (CCM) in Australia and the ECCM in Canada to account for variables affecting health inequities in chronic disease self-management.

1. Barr, V. J., Robinson, S., Marin-Link, B., Underhill, L., Dotts, A., Ravensdale, D., et al. (2003). The expanded Chronic Care Model: an integration of concepts and strategies from population health promotion and the Chronic Care Model. *Hospital Quarterly*, 7(1), 73-82.

Given the increasing incidence of chronic diseases across the world, the search for more effective strategies to prevent and manage them is essential. The use of the Chronic Care Model (CCM) has assisted healthcare teams to demonstrate effective, relevant solutions to this growing challenge. However, the current CCM is geared to clinically oriented systems, and is difficult to use for prevention and health promotion practitioners. To better integrate aspects of prevention and health promotion into the CCM, an enhanced version called the Expanded Chronic Care Model is introduced. This new model includes elements of the population health promotion field so that broadly based prevention efforts, recognition of the social determinants of health, and enhanced community participation can also be part of the work of health system teams as they work with chronic disease issues.

2. BC Ministry of Health. (2007). *Primary Health Care Charter: a collaborative approach*. Victoria: Ministry of Health, Government of British Columbia.

The Primary Health Care Charter (the Charter) sets the direction, targets and outcomes to support the creation of a strong, sustainable, accessible and effective primary health care system in B.C. Primary health care provides first contact access for each new need, long-term comprehensive care that is patient-centred, and coordination when care must be sought elsewhere.

There is great potential in primary health care to improve the health of the population and contribute to the sustainability of the health care system. To reach that potential, all partners for a healthy population must work together. To support such collaboration, this provincial charter for primary health care was co-developed with many partners to capture the activity, experimentation and successes of the last five years, and to set strategic direction to move forward.

The following article highlights CCM service delivery implications for specific ethnic groups:

3. Dennis, S. M., Zwar, N., Griffiths, R., Roland, M., Hasan, I., Davies, G. P., et al. (2008). Chronic disease management in primary care: from evidence to policy. *Medical Journal of Australia*, 188(8), 53.

Objectives: To review the effectiveness of chronic disease management interventions for physical health problems in the primary care setting, and to identify policy options for implementing successful interventions in Australian primary care. **Methods:** We conducted a systematic review with qualitative data synthesis, using the Chronic Care Model as a framework for analysis between January 1990 and February 2006. Interventions were classified according to which elements were addressed: community resources, health care organisation, self-management support, delivery system design, decision support and/or clinical information systems. Our major findings were discussed with policymakers and key stakeholders in relation to current and emerging health policy in Australia. **Results:** The interventions most likely to be effective in the context of Australian primary care were engaging primary care in self-management support through education and training for general practitioners and practice nurses, and including self-management support in care plans linked to multidisciplinary team support. The current Practice Incentives Payment and Service Incentives Payment programs could be improved and simplified to encourage guideline-based chronic disease management, integrating incentives so that individual patients are not managed as if they had a series of separate chronic diseases. The use of chronic disease registers should be extended across a range of chronic illnesses and used to facilitate audit for quality improvement. Training should focus on clear roles and responsibilities of the team members. **Conclusion:** The Chronic Care Model provides a useful framework for understanding the impact of chronic disease management interventions and highlights the gaps in evidence.

Consultation with stakeholders and policymakers is valuable in shaping policy options to support the implementation of the National Chronic Disease Strategy in primary care.

b) Effectiveness of self-management support for marginalized and disadvantaged populations:

The following papers outline the effectiveness of SMS for vulnerable populations such as socioeconomically-disadvantaged groups, indigenous groups, rural/remote populations, and low-educated groups. The scope of inquiry ranges from reviews of SMS for vulnerable populations to research on health systems access, current programming gaps and appropriate and effective interventions for these populations. Ethnicity is included but not the exclusive focus of these groupings. Conclusions drawn from these studies and reviews indicate that while SMS (notably the CDSMP) are somewhat effective within the general (typically middle-class) population, chronic disease health disparities remain for marginalized populations. Implications for service delivery are discussed.

A 2009 review of Alberta's experience with chronic disease management (through implementing the ECCM) notes that marginalized communities are most in need of self-management services but do not present for care:

4. Delon, S., MacKinnon, B., & Alberta Health CDM Advisory Committee. (2009). Alberta's Systems Approach to Chronic Disease Management and Prevention Utilizing the Expanded Chronic Care Model. *Healthcare Quarterly*, 13(Spring), 98-104.

Alberta's integrated approach to chronic disease management programming embraces client-centred care, supports self-management and facilitates care across the continuum. This paper presents strategies implemented through collaboration with primary care to improve care of individuals with chronic conditions, evaluation evidence supporting success and lessons learned from the Alberta perspective.

5. Eakin, E. G., Bull, S. S., Glasgow, R. E., & Mason, M. (2002). Reaching those most in need: a review of diabetes self-management interventions in disadvantaged populations. *Diabetes/Metabolism Research & Reviews*, 18, 26-35.

There has been increased recognition of the importance of developing diabetes self-management education (DSME) interventions that are effective with under-served and minority populations. Despite several recent studies in this area, there is to our knowledge no systematic review or synthesis of what has been learned from this research. An electronic literature search identified five formative evaluations and ten controlled DSME intervention trials focused on under-served (low-income, minority or aged) populations. The RE-AIM (Reach, Efficacy, Adoption, Implementation, Maintenance) evaluation framework was used to evaluate the controlled studies on the dimensions of reach, efficacy, adoption, implementation, and maintenance. Fifty percent of the studies identified reported on the percentage of patients who participated, and the percentages were highly variable. The methodological quality of the articles was generally good and the short-term results were encouraging, especially on behavioral outcomes. Data on adoption (representativeness of settings and clinicians who participate) and implementation were almost never reported. Studies of modalities in addition to group meetings are needed to increase the reach of DSME with under-served populations. The

promising formative evaluation work that has been conducted needs to be extended for more systematic study of the process of intervention implementation and adaptation with special populations. Studies that explicitly address the community context and that address multiple issues related to public health impact of DSME interventions are recommended to enhance long-term results.

6. Foster, M., Kendall, E., Dickson, P., Chaboyer, W., Hunter, B., & Gee, T. (2003). Participation and chronic disease self-management: Are we risking inequitable resource allocation? *Australian Journal of Primary Health*, 9(2/3), 132-140.

The Ottawa Charter for Health Promotion supported the empowerment of individuals to participate in their health care and have control over their health. For older adults with chronic conditions, the Chronic Disease Self-Management Program has been widely adopted as an adjunct to existing healthcare options. A growing body of literature has supported the positive impact of self-management programs on outcomes for people with a range of chronic conditions. However, evidence also suggests that participation in these programs is biased. This paper draws on pilot data to describe the profile of those people who inquire, enroll, attend, and complete CDSM courses in Queensland, Australia. As expected, there was evidence that males, Indigenous people, people of non-English speaking background, and those with multiple responsibilities were less likely to participate. Most importantly, participation was affected by a self-selection bias associated with health status. Those who were either unwell or well at the time of the course were unlikely to attend, minimising the preventative value of the CDSM program. Further, CDSM evaluation studies are likely to be inherently flawed and the distribution of health resources can become inequitable.

7. Gibbs, L., & Reidpath, D. What about the men? General differences in utilisation of arthritis self-management services. (2005). *Australian Journal of Primary Health*, 11(1), 63-71.

As self-management programs for chronic illness increasingly become the domain of primary health care providers, it is important to consider gender inequities in access to these services and gender differences in patterns of use to inform the development and delivery of services. This study explores gender differences in levels and patterns of access to arthritis self-management services by analyzing data collected from the Telephone Information Service of Arthritis Victoria. Contingency tables were analyzed and odds-ratios calculated to confirm gender differences in levels and patterns of service utilisation. Men were found to be significantly under-represented as users of the service, even after taking into account gender differences in prevalence of arthritis in the population. Women were more likely than men to contact the service on their own behalf. Men were more likely to have a family member or friend contact the service for them. Women showed more interest in learning about their condition while men focused more on symptom management. These gender differences in rates and patterns of service use indicate that service providers of self-management services for conditions such as arthritis need to take into account the interaction between gender and service utilisation.

8. Glazier, R. H., Bajcar, J., Kennie, N. R., & Willson, K. (2006). A systematic review of interventions to improve diabetes care in socially disadvantaged populations. *Diabetes Care*, 29(7), 1675.

Objective: To identify and synthesize evidence about the effectiveness of patient, provider, and health system interventions to improve diabetes care among socially disadvantaged populations. Research design and methods: Studies that were included targeted interventions toward socially disadvantaged adults with type 1 or type 2 diabetes; were conducted in industrialized countries; were measured outcomes of self-management, provider management, or clinical outcomes; and were randomized controlled trials, controlled trials, or before-and-after studies with a contemporaneous control group. Seven databases were searched for articles published in any language between January 1986 and December 2004. Twenty-six intervention features were identified and analyzed in terms of their association with successful or unsuccessful interventions. Results: Eleven of 17 studies that met inclusion criteria had positive results. Features that appeared to have the most consistent positive effects included cultural tailoring of the intervention, community educators or lay people leading the intervention, one-on-one interventions with individualized assessment and reassessment, incorporating treatment algorithms, focusing on behavior-related tasks, providing feedback, and high-intensity interventions (>10 contact times) delivered over a long duration (≥6 months). Interventions that were consistently associated with the largest negative outcomes included those that used mainly didactic teaching or that focused only on diabetes knowledge. Conclusions: This systematic review provides evidence for the effectiveness of interventions to improve diabetes care among socially disadvantaged populations and identifies key intervention features that may predict success. These types of interventions would require additional resources for needs assessment, leader training, community and family outreach, and follow-up.

9. Health Council of Canada. (2010). *Helping Patients Help Themselves: Are Canadians with Chronic Conditions Getting the Support They Need to Manage Their Health?* Bulletin No. 2. Toronto: <http://www.healthcouncilofcanada.ca>.

Many Canadians with chronic conditions such as diabetes and heart disease say they don't regularly receive some types of support recommended to help them better manage their health. This is the main finding of the Health Council of Canada in a survey of Canadians about their primary health care. The Health Council's analysis focused on Canadians with chronic conditions.

Helping patients manage chronic disease is an increasingly important part of primary health care in Canada. Chronic conditions are on the rise due to unhealthy lifestyles and the aging of our population. Along with prevention, one of the best ways to reduce the impact of chronic disease on people's lives and on their need for expensive health care services is through a partnership of patients, their family doctor, and other professionals. However, the survey suggests disturbing gaps in the delivery of what's known as self-management support, which is intended to give patients the knowledge and skills to manage their health problems between visits. This support includes such things as asking patients about their goals in caring for their chronic conditions and referring them to community services that might help them reach those goals.

Although patients with three or more chronic conditions are more likely to receive self-management support, compared to those with just one chronic condition, this good news is dampened by the low levels of support that patients reported overall.

This bulletin takes a closer look at these data, which are based on the responses of more than 5,000 adults with chronic conditions to the 2008 Canadian Survey of Experiences with Primary Health Care, a collaborative project by Statistics Canada, the Canadian Institute for Health Information, and the Health Council of Canada (see “About the survey”). We then look at the thinking behind self-management support, and at the changing role of primary health care for people with chronic conditions.

The following review from Australia points out that recruitment of patients from diverse backgrounds has been limited within the UK’s Expert Patients Programme (EPP):

10. Jordan, J. E., & Osborne, R. H. (2007). Chronic disease self-management education programs: challenges ahead. *Medical Journal of Australia*, 186(2), 84.

Chronic disease self-management education programs aim to empower patients through providing information and teaching skills and techniques to improve self-care and doctor-patient interaction, with the ultimate goal of improving quality of life. The recent 2006–07 federal budget allocated an unprecedented \$515 million over 5 years for activation of patient self-management activities, commencing this financial year. Previous attempts in other countries to incorporate self-management education activities into the health care sector have faced setbacks because of inadequate integration into primary care. Engagement of health care professionals and their endorsement of self-management activities is critical to success.

The following article examines the extent to which EPP adequately accounts for patient variability (such as individual socioeconomic circumstances):

11. Kennedy, A., Rogers, A., & Bower, P. (2007). Support for self care for patients with chronic disease. *British Medical Journal*, 335(7627), 968.

Effectively managing long term conditions and the burden they place on patients, professionals, and services is a major focus of current health policy. Support for self care is increasingly viewed as a core component of the management of long term conditions. However, despite the enthusiastic promotion of self care, randomised controlled trials often show modest benefits. We examine why current initiatives fail to deliver and suggest what needs to be done.

12. McDonald, J., Harris, E., Kurti, L., Furler, J., Apollini, L., & Tudball, J. (2004). *Action on Health Inequalities: Early Intervention and Chronic Condition Self-Management*. Sydney: Health Inequalities Research Collaboration, Primary Health Care Network.

This report has been developed by the Health Inequalities Research Collaboration (HIRC) Primary Health Care (PHC) Network. The report aims to review the evidence on the effectiveness of chronic condition self-management programs, with a special emphasis on arthritis, asthma and diabetes; and suggest a range of policy options to improve the health of disadvantaged communities and reduce health disparities. The consistently low health status and unequal burden of chronic disease experienced by a

number of population sub-groups has meant that the focus of this report is on: indigenous Australians; those who experience socio economic disadvantage; rural and remote populations; and culturally and linguistically diverse communities (CALD).

The report also considers early intervention for the three conditions, but to a much lesser extent. This is due in part to the amount of literature to be reviewed on chronic condition self-management (CCSM), which meant that CCSM ended up being the major focus of the project and also because the initial search strategy yielded few articles in relation to early intervention.

In the following discussion of chronic care management in eight countries, England is mentioned as having no national interventions or frameworks for SMS within ethnic minority groups, who by extension may not be able to access these programs as readily:

13. Nolte, E., Knai, C., & McKee, M. (2008). *Managing chronic conditions: Experience in eight countries, No. 15*. Copenhagen, Denmark: European Observatory on Health Systems and Policies.

One of the greatest challenges facing health systems in the 21st century is the need to develop effective approaches to address the growing burden of chronic disease. Chronic diseases are complex and require a long-term, multifaceted response that coordinates inputs from a wide range of health professionals, essential medicines and - where appropriate - monitoring equipment, all of which is optimally embedded within a system that promotes patient empowerment.

With many health systems still largely built around an acute, episodic model of care, health professionals, policy-makers and patient organizations struggle to respond in ways that meet the needs of people with complex chronic health problems.

This book examines the health system response to the rising burden of chronic disease in eight countries: Denmark, England, France, Germany, the Netherlands, Sweden, Australia and Canada. It provides a detailed assessment of the current situation, a description of the policy framework and future scenarios, as well as evaluation and lessons learned.

It shows that many different strategies are being implemented, with different models of care at varying degrees of development, and with differing comprehensiveness. Perhaps not surprisingly, the approaches adopted often reflect the characteristics of each health system, each with its own governance mechanisms and relationships between, and responsibilities of, different stakeholders. Nonetheless, there are many lessons for those seeking to develop effective responses to this common challenge.

14. Nolte, E., & McKee, M. (2008). *Caring for people with chronic conditions*. England: Open University Press.

New recognition of the multiplicity of influences on health, the variability in vulnerability and resilience of different individuals and population groups to threats to illness, and the emerging crisis of harm from iatrogenic causes is calling into question the adequacy of health systems to deal in conventional ways with illness burdens of people and populations. It may even call into question the adequacy of conventional ways of classifying illness. The current focus on chronic care management is one approach to

dealing with this rapidly changing challenge of describing and understanding 'disease' in the 21st century. Whether it is the appropriate one remains to be seen.

A disease oriented approach to global health will almost certainly worsen global inequities, because socially disadvantaged people have greater burdens of diseases of all types. Eliminating or controlling diseases one by one is not likely to materially reduce the chances of another in vulnerable populations. It may also be unconscionable when the most serious shortfalls in achieving the Millennium Development Goals are in maternal and child health. Good primary care, which focuses on ALL health conditions with a comprehensive array of services, may be a much better approach to achieve equity in health as well as overall improvement in health.

15. Rogers, A., Gately, C., Kennedy, A., & Sanders, C. (2009). Are some more equal than others? Social comparison in self-management skills training for long-term conditions. *Chronic Illness, 5(December)*, 305-317.

Background: Social comparisons influence self-evaluation and social and psychological adjustment to illness but are under-explored in relation to self-skills training group situations.

Methods: A longitudinal qualitative study embedded within an RCT of a national programme of lay led selfcare support in England (Department of Health, 2001). In-depth interviews were undertaken with a purposeful maximum variation sample of recruits. Data were analysed thematically. Three key themes emerged highlighting (1) the experience of group participation and interaction, (2) the process and (3) function of social comparison.

Results: Data highlight the salience of social comparison as an underlying feature of the group dynamics of self-care skills training. The nature, dimensions and scope of social comparisons extend beyond the cognitive states and dimensions traditionally forming the focus of social-psychological approaches to social comparison to include wider dimensions including entitlement to resources. The results confirm the tendency to make positive comparisons that result in beneficial self-evaluations. However, positive comparisons allow respondents to present themselves as socially and morally worthy, which may act to mask the identification of appropriate need and inequalities.

Conclusion: Social comparisons function both as an accurate representation of internal cognitive states but also constitutes identity work involving competing values and moral requirements. We show that even those who report significant needs will sometimes portray themselves in a way that suggests positive social comparisons, which fit with a rationed and morally prescriptive and acceptable view of entitlement to NHS services. Such insights suggest that social comparisons in initiatives such as the EPP may be beneficial for some but exacerbate rather than alleviate health inequalities in long-term condition management for others.

16. Rogers, A., Kennedy, A., Bower, P., Gardner, C., Gately, C., Lee, V., et al. (2008). The United Kingdom Expert Patients Programme: results and implications from a national evaluation. *The Medical Journal of Australia*, 189(10 Suppl), S21-S24.

The Expert Patients Programme (EPP) is a central element of chronic disease management policy in the United Kingdom. It aims to deliver self-care support by developing peoples' self-care skills, confidence and motivation to take more effective control over their long-term conditions. A large, national randomised controlled trial found that the EPP's lay-led skills training was effective in improving self-efficacy and energy levels among patients with long-term conditions, and was likely to be cost-effective. Key questions remain as to whether existing outcome measures capture the core outcomes that are important to patients with long-term conditions. The development and evaluation of self-care support initiatives should take into account the extent to which self-care support initiatives can be integrated into peoples' everyday lives, and the degree of fit with patients' existing adaptations and strategies. Rather than being concentrated on a single course, central resources for self-management support should be directed at a variety of systems and interventions that are able to meet the wide range of needs of patients with chronic conditions.

Note: The following article is also relevant to section E. a. Interventions for low health literacy in self-management support (p. 36).

17. Sarkar, U., Piette, J. D., Gonzales, R., Lessler, D., Chew, L. D., Reilly, B., et al. (2008). Preferences for self-management support: Findings from a survey of diabetes patients in safety-net health systems. *Patient Education and Counseling*, 70(1), 102-110.

Objective: We sought to identify interest in different modes of self-management support among diabetes patients cared for in public hospitals, and to assess whether demographic or disease-specific factors were associated with patient preferences. We explored the possible role of a perceived communication need in influencing interest in self-management support.

Methods: Telephone survey of a random sample of 796 English and Spanish-speaking diabetes patients (response rate 47%) recruited from four urban US public hospital systems. In multivariate models, we measured the association of race/ethnicity, primary language, self-reported health literacy, self-efficacy, and diabetes-related factors on patients' interest in three self-management support strategies (telephone support, group medical visits, and Internet-based support). We explored the extent to which patients believed that better communication with providers would improve their diabetes control, and whether this perception altered the relationship between patient factors and self-management support acceptance.

Results: Sixty-nine percent of respondents reported interest in telephone support, 55% in group medical visits, and 42% in Internet. Compared to Non-Hispanic Whites, Spanish-speaking Hispanics were more interested in telephone support (OR 3.45, 95% CI 1.97–6.05) and group medical visits (OR 2.45, 95% CI 1.49–4.02), but less interested in Internet self-management support (OR 0.56, 95% CI 0.33–0.93). African-Americans were more interested than Whites in all three self-management support strategies. Patients with limited self-reported health literacy were more likely to be interested in

telephone support than those not reporting literacy deficits. Forty percent reported that their diabetes would be better controlled if they communicated better with their health care provider. This perceived communication benefit was independently associated with interest in self-management support ($p < 0.001$), but its inclusion in models did not alter the strengths of the main associations between patient characteristics and self-management support preferences.

Conclusion: Many diabetes patients in safety-net settings report an interest in receiving self-management support, but preferences for modes of delivery of self-management support vary by race/ethnicity, language proficiency, and self-reported health literacy. **Practice implications:** Public health systems should consider offering a range of self-management support services to meet the needs of their diverse patient populations. More broad dissemination and implementation of self-management support may help address the unmet need for better provider communication among diabetes patients in these settings.

18. Wilson, P. M. (2008). The UK Expert Patients Program: Lessons learned and implications for cancer survivors' self-care support programs. *Journal of Cancer Survivorship*, 2(1), 45-52.

Globally, the enablement of self-care is increasingly being recognised as an essential component of chronic disease management. Within the UK a key self-care policy initiative is the Expert Patients Program. Developed from the Chronic Disease Self-Management Program, this is a 6 week self-management education program for people with different chronic diseases, facilitated by lay volunteers. As an example of a major public health initiative designed to enhance self-management in long-term conditions, this paper draws on evaluations of the EPP and CDSMP and analyzes the implications for the development of similar programs for cancer survivors. There are a number of evaluations of the CDSMP which suggest significant improvement in participants' chronic disease management self-efficacy and some evidence of healthcare utilization reduction. However, whilst the national evaluation of the EPP demonstrated similar improvements in self-efficacy and health status, there was no significant effect on healthcare utilization. Trials of such programs need to be treated with some caution as participants are often not typical of the general population, and as a complex intervention effectiveness is inherently difficult to assess. Qualitative evaluations revealed that the EPP's strength was derived mainly through peer support and learning. Nevertheless, a number of contextual problems were identified including recruitment, clinicians' lack of engagement with the program and inflexible course materials. Lay-led self-care support programs such as the EPP have a significantly positive effect on self-efficacy which could be of benefit to cancer survivors. However, a number of lessons should be learned from the EPP when developing similar initiatives for cancer survivors.

c) Community development and marginalized populations:

The following is an example of community-based approaches to preventing and managing chronic disease within marginalized populations. These articles are not readily identified using the language of CDSM and SMS more typical in the health services literature.

19. Larson, C., Schlundt, D., Patel, K., Goldzweig, I., Hargreaves, M. (2009). Community Participation in Health Initiatives for Marginalized Populations. *Journal of Ambulatory Care Management*, 32(4), 264-270.

Community-based participatory methods have emerged as a response to conventional approaches that have historically failed to make notable improvement in health status or reduce chronic disease among marginalized populations. The social-ecological model provides a framework to develop and implement strategies directed to affecting multiple levels (societal, community, organizational, and individual) of influence on health status. A systems approach can facilitate the identification of the complex interrelationships of factors at all levels that contribute to health disparities by making use of the unique knowledge, expertise, and resources of community partners. Community engagement in the planning, implementation, and evaluation of health initiatives builds community capacity to create sustainable changes at all levels to achieve and maintain optimal health for those who bear the greatest burden of disease.

B. Self-management support among older populations

Older populations have been identified by some as requiring unique consideration of how to implement effective SMS. Gender differences within older populations are described in one of the papers below.

20. Clark, N. M., Becker, M. H., Janz, N. K., Lorig, K., Rakowski, W., & Anderson, L. (1991). Self-management of chronic disease by older adults: a review and questions for research. *Journal of Aging and Health*, 3(1), 3.

This article summarizes the literature describing the at-home management of and psychosocial coping with five chronic diseases (heart disease, asthma, chronic obstructive pulmonary disease, arthritis, and diabetes) by the general population of adults. It also reviews the literature describing self-management of these chronic diseases by older adults. Conclusions drawn subsequent to the review are (a) that there are strong commonalities in the essential nature of tasks that exist across disease entities, (b) that the context for self-management of disease by the ill elderly is likely to differ somewhat from the context for other age groups. Questions for future research are posed.

21. Clark, N. M., Janz, N. K., Becker, M. H., Schork, M. A., Wheeler, J., Liang, J., et al. (1992). Impact of self-management education on the functional health status of older adults with heart disease. *The Gerontologist*, 32(4), 438.

This paper presents findings from the evaluation of a self-management education program based on self-regulation principles. Older men and women (N = 324) were randomly assigned to program and control groups. Outcomes were measured using the Sickness Impact Profile. Twelve months following baseline data collection, psychosocial functioning of program participants was significantly better than that of controls. Different program effects were noted when results were analyzed by participant gender.

22. Glasgow, R. E., Toobert, D. J., Hampson, S. E., & Brown, J. E. (1992). Improving self-care among older patients with Type II diabetes: The "Sixty Something..." study. *Patient Education and Counseling*, 19(1), 61-74.

A 10-session, self-management training program was designed specifically for persons over 60 years of age having Type II diabetes. It targeted social learning variables, especially problem-solving skills and self-efficacy, found to be related to diabetes self care in earlier correlational research. One hundred two adults were randomized to immediate or delayed intervention conditions. At posttest, subjects in the immediate intervention condition showed significantly greater reductions in caloric intake and percent of calories from fat than control subjects. The intervention also produced greater weight reductions and increases in the frequency of glucose testing than did the control condition. Improvements among immediate intervention subjects were generally maintained at a 6-month follow-up. Intervention results from subjects receiving delayed intervention closely replicated those for immediate intervention subjects. We conclude that a relatively short-term program can improve self-management skills of older diabetic adults, and that there is an important need for such interventions.

23. Huang, T. T., Li, Y. T., & Wang, C. H. (2009). Individualized programme to promote self-care among older adults with asthma: randomized controlled trial. *Journal of Advanced Nursing*, 65(2), 348-358.

Aim: This paper is a report of a trial to examine the effectiveness of individualized self-care education programmes in older adults with moderate-to-severe asthma. **Background:** Asthma is a common chronic disease in adults and a major cause of frequent work absences, emergency room visits, and hospitalization. The results of studies of self-care education programmes have been largely supportive and suggest that they have positive outcomes for people with asthma. However, for older people with asthma, the effectiveness of computer-aided, self-learning video programmes has been controversial. **Methods:** Older adult patients with asthma ($N = 148$) were randomly assigned to one of three groups: usual care, individualized education, or individualized education with peak flow monitoring, and followed for 6 months. Data were collected from January to December 2006. The variables studied included demographic data, asthma self-care competence, asthma self-efficacy, and asthma self-care behaviour. **Findings:** Patients in both individualized education groups reported higher asthma self-care competence scores ($F = 334.06$ and 481.37 , $P < 0.001$) and asthma self-care and self-efficacy scores ($F = 104.08$ and 68.42 , $P < 0.001$) than patients in the usual care group. In addition, patients who received individualized education with peak flow monitoring had statistically significantly higher asthma self-care behaviour and self-efficacy scores ($P < 0.001$) and asthma control indicators ($P = 0.025$) than the education alone group. No differences were found among the three groups in unscheduled health service usage. **Conclusion:** Our results suggest that individualized education helps older people with asthma to enhance their self-care behaviours, manage their disease, and increase their quality of life.

24. Jonker, A. A. G. C., Comijs, H. C., Knipscheer, K. C. P. M., & Deeg, D. J. H. (2009). Promotion of self-management in vulnerable older people: a narrative literature review of outcomes of the Chronic Disease Self-Management Program (CDSMP). *European Journal of Ageing*, 6(4), 303-314.

With ageing, older people can become frail, and this has been shown to be associated with a decrease in well-being. Observational studies provide evidence of a positive effect of coping resources on well-being. The question is: can coping resources be improved in vulnerable older people? The Chronic Disease Self-Management Program (CDSMP) is a target group-specific intervention which aims to promote the self-management of older people who are confronted with deteriorating health. The aim of this study was to review intervention studies focusing on the CDSMP and to draw conclusions on the benefits of the program. A systematic search was conducted in PubMed and PsychINFO to identify randomized controlled trials (RCTs) focusing on the CDSMP. Nine RCTs focusing on relatively young older adults, 75% of whom with an average age between 49 and 65 years, were included. We found that the CDSMP was consistently beneficial for Health behaviour, especially with regard to the variables of exercise and self-care. For Health status, the majority of studies only showed improvement in the domain of health distress. Most of the studies that investigated Self-efficacy showed convincing improvement in self-efficacy, cognitive symptom management and mental stress management. In Health care utilization, there was no significant decrease. On the whole, the studies showed that CDSMP led to an increase in physical exercise, a decrease in health distress, an improvement in self-care, and it had a beneficial effect on self-efficacy.

25. Leveille, S. G., Wagner, E. H., Davis, C., Grothaus, L., Wallace, J., LoGerfo, M., et al. (1998). Preventing disability and managing chronic illness in frail older adults: a randomized trial of a community-based partnership with primary care. *Journal of the American Geriatrics Society*, 46, 1191-1198.

Background: Effective new strategies that complement primary care are needed to reduce disability risks and improve self-management of chronic illness in frail older people living in the community. Objective: To evaluate the impact of a 1-year, senior center-based chronic illness self-management and disability prevention program on health, functioning, and healthcare utilization in frail older adults. Design: A randomized controlled trial. Setting: A large senior center located in a northeast Seattle suburb. The trial was conducted in collaboration with primary care providers of two large managed care organizations. Participants: A total of 201 chronically ill older adults seniors aged 70 and older recruited through medical practices. Intervention: A targeted, multi-component disability prevention and disease self-management program led by a geriatric nurse practitioner (GNP). Measurements: Self-reported Physical function, physical performance tests, health care utilization, and health behaviors. Results: Each of 101 intervention participants met with the GNP from 1 to 8 times (median = 3) during the study year. The intervention group showed less decline in function, as measured by disability days and lower scores on the Health Assessment Questionnaire. Other measures of function, including the SF-36 and a battery of physical performance tests, did not change with the intervention. The number of hospitalized participants increased by 69% among the controls and decreased by 38% in the intervention group (P = .083). The total

number of inpatient hospital days during the study year was significantly less in the intervention group compared with controls (total days = 33 vs. 116, $P = .049$). The intervention led to significantly higher levels of physical activity and senior center participation and significant reductions in the use of psychoactive medications. Conclusions: This project provides evidence that a community-based collaboration with primary care providers can improve function and reduce inpatient utilization in chronically ill older adults. Linking organized medical care with complementary community-based interventions may be a promising direction for research and practice.

26. Packer, T. L., Girdler, S., Boldy, D. P., Dhaliwal, S. S., & Crowley, M. (2009). Vision self-management for older adults: A pilot study. *Disability & Rehabilitation, 31*(16), 1353-1361.

Purpose: The aim of this study was to pilot test the vision self-management programme (VSM) a newly developed, 8-week self-management intervention. The programme is a structured, repeatable and theoretically derived programme for older adults with age-related vision loss (ARVL). **Method:** A pre-and post-test design was used, and involved 12 older adults with ARVL. The activity card sort, a measure of participation in life situations, was the primary outcome measure. Secondary outcome measures examining general health and vision specific domains were also used. **Results:** Participants reported a statistically significant increase in participation in life situations immediately following the VSM programme. However, whilst an increase in such participation was still present at 12-week follow-up, this was no longer statistically significant. In addition, the participants demonstrated statistically significant gains in both general health and vision specific domains. Although these findings are exploratory they suggest that the VSM may have both short and longer term benefits for older adults living with ARVL. **Conclusions:** Overall findings indicate that the participation in the self-management programme resulted in improved participation and health outcomes and support the need for further study using more rigorous designs.

27. Reeves, D., Kennedy, A., Fullwood, C., Bower, P., Gardner, C., Gately, C., et al. (2008). Predicting who will benefit from an Expert Patients Programme self-management course. *The British Journal of General Practice, 58*(548), 198.

Background: In England, the Expert Patients Programme, a lay-led chronic disease self-management course, was developed to improve self-care support and skills. The course is designed for anyone with a self-defined long-term condition, and attracts a heterogeneous group of patients. A randomised controlled trial has demonstrated effectiveness in improving subjective health. However, it is not known whether particular patient characteristics predict the impact of the course. **Aim:** To determine whether baseline characteristics predict clinical outcomes from attendance at a chronic disease self-management course; and to assess whether identification of such characteristics assists in targeting the course to individuals most likely to benefit. **Design of study:** A post-hoc subgroup analysis of data from a randomised controlled trial to explore predictors of three trial outcomes: self-efficacy, energy, and health-related quality of life. **Setting:** Participants with self-defined long-term conditions ($n = 629$) were recruited from community settings in all 28 strategic health authorities in England. **Method:** Multiple regression was used to examine interactions between baseline variables and trial

outcomes. Results: The predictors demonstrating significant interactions were: age and general health, and baseline values for self-efficacy, energy levels, and health-related quality of life. Conclusion: Participants with lower self-efficacy and health-related quality of life at baseline demonstrated more positive health outcomes. The Expert Patients Programme may have a protective effect on health-related quality of life for patients with poor health and low confidence. *Younger people benefited substantially more than older people.* Results suggest that positive outcomes associated with the course will be demonstrated with a wide variety of patients, although it may be worthwhile encouraging attendance of younger patients, those lacking confidence, and those coping poorly with their condition.

C. Self-management support for ethnocultural minority groups

The literature on SMS for ethnocultural minority groups coming out of the US focuses on African-Americans and Hispanics- their largest minority groups. Some work has been done in England on SMS with South Asian communities. In Canada, little attention has been paid to investigating SMS for ethnocultural minority groups. These studies are not specific to older adults, but to ethnocultural groups irrespective of age.

a) Multiple ethnic group studies:

28. Dyck, I. (1995). Putting chronic illness 'in place'. Women immigrants' accounts of their health care. *Geoforum*, 26(3), 247-260.

This paper discusses the ways in which first generation Canadian women of Vancouver's Chinese and South Asian communities manage their chronic illness. The study reported was concerned with the women's experiences of health care encounters in hospitals and clinics, and their subsequent incorporation or modification of biomedical knowledge as they managed the day-to-day consequences of their illness. The paper presents a critique of culturalist explanations of personal health care practices, through an ethnographic account of the women's institutional and occupational emplacement and their racialized experience of place. In the study women's accounts of their illness and its management indicated a search for the alleviation of symptoms that involved a plurality of illness management strategies. The women's health care practices were mediated by local social networks and a distribution of non-medical resources rooted in the process of 'place', in addition to specific barriers to the use of biomedical techniques. The study suggests that inquiry into problems of health care for minority population groups needs to go beyond a narrow focus on biomedical services, and analysis must be wary of attributing primacy to untheorized concepts of culture, ethnicity or 'race' in explanation.

29. Ford, S., Mai, F., Manson, A., Rukin, N., & Dunne, F. (2000). Diabetes knowledge -- are patients getting the message? *International Journal of Clinical Practice*, 54(8), 535-536.

Diabetes knowledge in a multi-ethnic population was assessed in 161 insulin treated diabetic patients using a 21-point multiple choice questionnaire translated into the appropriate languages. Our data showed a significant difference in diabetes knowledge

related to ethnicity, being less in Asians and Afro-Caribbeans groups compared to Caucasians. In all groups there was a negative correlation with age, with older adults achieving lower scores. Gender and duration of disease did not appear to influence knowledge scores. This information has implications for the way in which we deliver our diabetes educational programme to ethnic minority groups and the elderly.

30. Garvin, C.C., Cheadle, A., Chrisman, N., Chen, R., Brunson, E. (2004). A Community-Based Approach to Diabetes Control in Multiple Cultural Groups. *Ethnicity & Disease*, 14, 83-92.

Diabetes mellitus is one of the most common, serious, and costly chronic diseases, and is a leading cause of death in the United States. Communities of color bear a disproportionate burden of diabetes risk, prevalence, complications, and mortality. REACH 2010 Seattle and King County provides socio-ecological interventions to reduce diabetes disparities among African-American, Cambodian, Chinese, Filipino, Korean, Latino/Hispanic, Vietnamese and soon Samoan groups.

This paper reports evaluation results of REACH classes and support groups. Results from participant pre- and post-surveys demonstrated increases in self-reported physical activity and healthier eating, and increased self-efficacy in managing diabetes. Qualitative focus group results revealed participants' enthusiasm for classes tailored to their ethnic groups, and for intervention impact on management of their diabetes. Qualitative results confirmed survey endings that group participation resulted in significant changes in diet and physical activity. The results underscore the need for more widespread adoption of culturally competent diabetes education and support programs.

31. Moudgil, H., & Honeybourne, D. (1998). Differences in asthma management between white European and Indian subcontinent ethnic groups living in socioeconomically deprived areas in the Birmingham (UK) conurbation. *British Medical Journal*, 53(6), 490.

Background: Hospital admission rates for asthma have been higher for Asian (Indian subcontinent, ISC) ethnic minority groups in the UK than for white Europeans (W/E). As this may in part be due to differences in the uptake or delivery of preventative health care strategies, the extent to which targeted education and treatment programmes reach these groups needs to be determined. Methods: Six hundred and eighty nine asthmatic subjects (345 W/E, 344 ISC) of mean (SD) age 34.5 (15) years (range 11–59) and mean forced expiratory volume in one second (FEV₁) 80% predicted from districts of high ethnicity and socioeconomic deprivation within inner city Birmingham were reviewed in the appropriate dialect (English, Punjabi, Hindi, Urdu) in a community based study. Results: Data adjusted for age and analysed separately for men (M) and women (F) showed no significant differences in the numbers reporting previous asthma education, assessment of delivery techniques, or being taught about medications, but there were significant differences for advice on trigger factors (M: 52% vs 42%; F: 56% vs 42%), recognition of symptoms (M: 51% vs 43%; F: 53% vs 33%), and ownership of peak flow meters (M: 35% vs 22%; F: 36% vs 24%) for W/E and ISC groups, respectively. Anti-inflammatory asthma medications were highly prescribed, but self reported drug compliance (M: 73% vs 62%), understanding medications (F: 59% vs 39%), and self management (F: 23% vs 12%) varied significantly. Asthma follow up in the community was low for both groups with more of the ISC subjects also being followed up by hospital. Conclusions: The

management of both ethnic groups has centred on drug prescription, delivery techniques and compliance, but has been deficient, particularly in the ISC group, in developing understanding of the disease and self management.

32. Swerissen, H., Belfrage, J., Weeks, A., Jordan, L., Walker, C., Furler, J., et al. (2006). A randomised control trial of a self-management program for people with a chronic illness from Vietnamese, Chinese, Italian and Greek backgrounds. *Patient Education and Counseling*, 64(1-3), 360-368.

Objective: This study investigated the effectiveness of the Chronic Disease Self-management Program (CDSMP) when delivered to for people from Vietnamese, Chinese, Italian and Greek backgrounds living in Victoria, Australia. Method: The CDSMP was administered to 320 people with chronic illness(es) in selected low income areas in the State of Victoria, Australia. At 6 months, they were compared with randomised wait-list control subjects ($n = 154$) using analyses of covariance. Results: Participants in the intervention group had significantly better outcomes on energy, exercise, symptom management, self-efficacy, general health, pain, fatigue and health distress. There were no significant effects for health services utilisation. Interactions across language groups were observed with the Vietnamese and Chinese speaking participants gaining greater benefit. Conclusion: Self-management programs can be successfully implemented with culturally and linguistically diverse populations in Australia. Further research is needed to evaluate long-term outcomes; explore effects on service utilisation; and to determine whether the benefits obtained from participating in a self-management program can be maintained. Practice implications: Self-management programs should be considered for people from culturally and linguistically diverse backgrounds. Care also needs to be taken in designing recruitment strategies to minimize withdrawal rates and to ensure harder to reach people are given encouragement to participate.

33. Zgibor, J. C., & Simmons, D. (2002). Barriers to blood glucose monitoring in a multiethnic community. *Diabetes Care*, 25(10), 1772.

Objective: We studied a multiethnic community to determine factors associated with blood glucose monitoring (BGM) and to determine the independent association between barriers to diabetes care and BGM. Research design and methods: A total of 323 participants (35.6% European, 32.2% Maori, and 32.2% Pacific Islander) from the South Auckland Diabetes Project (free of major complications by self-report) completed a qualitative survey to determine barriers to diabetes care. Five barriers to diabetes care categories were generated including internal psychological (self efficacy/health beliefs), external psychological (psychosocial environment), internal physical (comorbidities/side effects of treatment), external physical (finance/access to care), and educational (knowledge of diabetes/services) barriers. Results: Characteristics associated with BGM greater than or equal to twice weekly were female sex, $HbA_{1c} > 8\%$, higher diabetes knowledge scores, and insulin use. Multivariate analyses demonstrated that those reporting external physical barriers (OR 0.47, 95% CI 0.26–0.84), external psychological barriers (0.55, 0.30–1.0), and internal psychological barriers (0.56, 0.32–1.0) were less likely to perform BGM independent of ethnicity, insulin use, age, sex, diabetes knowledge, and glycemic control. Further multivariate analyses demonstrated that those reporting external physical barriers, particularly related to personal finance, were less

likely to perform BGM. Conclusions: These data demonstrate that patient-reported barriers to diabetes care are associated with BGM, particularly in relation to financial, psychosocial, and self-efficacy issues. Understanding these barriers and overcoming them within the context of the patient's ethnic environment may lead to increased participation in self-care.

b) Chinese populations:

A limited number of studies examine SMS among Chinese populations, both immigrant and residents of Mainland China and Hong Kong. Evaluations of Hong Kong and Shanghai residents demonstrate the general effectiveness of the CDSMP within these populations, although program deficiencies are described.

34. Dongbo, F., Ding, Y., McGowan, P., & Fu, H. (2006). Qualitative evaluation of Chronic Disease Self Management Program (CDSMP) in Shanghai. *Patient Education and Counseling*, 61(3), 389-396.

Objectives: To explore the impact of Chronic Disease Self-Management Program (CDSMP) on participants' perception of their behavior, health status and quality of life and how the program achieve its benefits, and to collect suggestions for future improvement and dissemination. Methods: Qualitative data were obtained from 57 participants attending all sessions of the CDSMP course using semi-structured interviews and analyzed using content analysis. Results: The interviewees perceived that CDSMP improved their knowledge, self-management skills, positive health behavior, increased self-confidence, health status and quality of life. Behavior change and self-efficacy were the two main transmitters of the effectiveness of CDSMP in Shanghai. The identified deficiencies focused on language, size and style of helpbook and the lack of Chinese relaxing exercises. Conclusions: CDSMP was perceived to be effective to participants mainly through behavior change and self-efficacy development, though it had a few deficiencies to be modified. Practice Implications: CDSMP in Shanghai needs further work and research on the content and delivery modification for future improvement and dissemination.

35. Dongbo, F., Hua, F., McGowan, P., Yi-e, S., Lizhen, Z., Huiqin, Y., et al. (2003). Implementation and quantitative evaluation of chronic disease self-management programme in Shanghai, China: randomized controlled trial. *Bulletin of the World Health Organization*, 81, 174-182.

Objective: To evaluate the effectiveness of the Shanghai Chronic Disease Self-Management Program (CDSMP). Methods: A randomized controlled trial with six-month follow-up compared patients who received treatment with those who did not receive treatment (waiting-list controls) in five urban communities in Shanghai, China. Participants in the treatment group received education from a lay-led CDSMP course and one copy of a help book immediately; those in the control group received the same education and book six months later. Findings: In total, 954 volunteer patients with a medical record that confirmed a diagnosis of hypertension, heart disease, chronic lung disease, arthritis, stroke, or diabetes who lived in communities were assigned randomly to

treatment ($n = 526$) and control ($n = 428$) groups. Overall, 430 (81.7%) and 349 (81.5%) patients in the treatment and control groups completed the six-month study. Patients who received treatment had significant improvements in weekly minutes of aerobic exercise, practice of cognitive symptom management, self-efficacy to manage own symptoms, and self-efficacy to manage own disease in general compared with controls. They also had significant improvements in eight indices of health status and, on average, fewer hospitalizations. Conclusion: When implemented in Shanghai, the CDSMP was acceptable culturally to Chinese patients. The programme improved participants' health behaviour, self-efficacy, and health status and reduced the number of hospitalizations six months after the course. The locally based delivery model was integrated into the routine of community government organizations and community health services. Chinese lay leaders taught the CDSMP courses as successfully as professionals.

36. Siu, A. M. H., Chan, C. C. H., Poon, P. K. K., Chui, D. Y. Y., & Chan, S. C. C. (2007). Evaluation of the chronic disease self-management program in a Chinese population. *Patient Education and Counseling*, 65(1), 42-50.

Objective: This study evaluated the 6-week Chronic Disease Self-Management Program (CDSMP) in Hong Kong. Methods: A total of 148 subjects with chronic illness were recruited. Subjects were matched on duration of illness and gender, and then randomly allocated to experimental and comparison groups. The experimental group participated in the CDSMP, while the comparison group joined a Tai-Chi interest class in a mass-activity format. Subjects completed evaluation questionnaires before beginning their program and 1 week following the program. Results: Analysis of covariance showed that the CDSMP participants demonstrated significantly higher self-efficacy in managing their illness, used more cognitive methods to manage pain and symptoms, and felt more energetic than the subjects in the comparison group. The CDSMP participants also demonstrated changes in their profile of coping strategies, having a tendency to adopt the cognitive methods of diverting attention, reinterpreting pain, ignoring sensations, and making positive self-statements. Conclusion: The short-term evaluation results showed that the CDSMP primarily increased the self-efficacy, exercise behavior, and application of cognitive coping strategies of the participants. Practice Implication: The effect of the CDSMP in a Chinese population is similar to that found in studies in Western cultures, and the CDSMP could be applied effectively in a Chinese population.

37. Zhang, J., & Verhoef, M. J. (2002). Illness management strategies among Chinese immigrants living with arthritis. *Social Science & Medicine*, 55(10), 1795-1802.

The purpose of this qualitative study was to explore arthritis management strategies among Chinese immigrants in Calgary, Canada, and to assess factors, that impact on these strategies. Purposive sampling was used to select 19 Chinese immigrants living with arthritis. Data were collected by means of in-depth interviews. The interview data were analyzed according to the following steps: (1) transcribing interview materials, (2) developing codes, categories and themes, (3) theoretical coding, and (4) laying out the theoretical framework. The results of this study describe factors that impacted on illness management strategies. These include arthritic symptoms, beliefs about arthritis, beliefs about Western medicine based on treatment experience, beliefs about Chinese medicine, perceived barriers to using Chinese or Western medicine and social support. The

emerging process of illness management shows that immigrants usually started using self-care remedies, followed by consulting Western physicians, consulting Chinese healers, and then returning to Western medicine. The results illustrate that disease management strategies among Chinese immigrants are impacted by disease, personal and cultural factors. These factors suggest helpful directions to providing culturally sensitive care, which can lead to greater satisfaction and well being for Chinese immigrants with arthritis.

c) South Asian (Bangladeshi) populations:

The following two papers from the UK examine the effectiveness of SMS for Bangladeshi populations. A review demonstrates the paucity of research on SMS for this population, and an evaluation of the CDSMP reveals moderate and conditional benefits for Bangladeshis in the UK.

38. Alam, R., Singleton, L., & Sturt, J. (2008). Strategies and effectiveness of diabetes self-management education interventions for Bangladeshis. *Diversity in Health and Social Care*, 5(4), 269-279.

The study aimed to review the evidence regarding the effectiveness of diabetes health-education strategies used for Bangladeshi populations, who are among the most susceptible of the UK communities for developing diabetes, and unfortunately receive inequitable care. Reducing health inequalities and improving health education for patients living with chronic conditions is central to national policy, and the *National Service Framework for Diabetes* has set nationwide standards for diabetes health education. The development of effective structured patient-education programmes is an important public health challenge, and more so for hard-to-reach black and minority ethnic (BME) groups. Such programmes rely on the evidence base, and this review sets out to investigate the effectiveness of health-education strategies used for a vulnerable and particularly high-risk group.

The literature was searched using the following databases from inception to August 2008: AMED, CAB Abs, CINAHL, EMBASE, Ovid MEDLINE(R), PsycINFO, DARE, Cochrane, NIH and the NHS ethnicity and health library. Two reviewers independently assessed studies for inclusion in the review against the following inclusion criteria: a health-education intervention of any setting and type with the aim of providing diabetes-related health education to Bangladeshis. Data were extracted on the participants, interventions, delivery methods, comparison groups and outcome measures. The search strategy revealed four interventions. The authors of the only randomised controlled trial explain that a community lay-led intervention in providing diabetes education was successful, but the benefits were restricted due to a lack of uptake and attendance. Three others have qualitatively described the beneficial effects of link workers/health advocates within the communities, but have not systematically reported outcome measures.

The small number of studies retrieved, and the heterogeneity between the studies, make it difficult to make recommendations on particular strategies that are most beneficial to this

group. There is an urgent need for further quantitative and qualitative research, including formative, process and outcome evaluations, in order to ascertain the most effective education models for specific minority groups, especially for those who are disadvantaged and more susceptible to disease progression.

39. Griffiths, C., Motlib, J., Azad, A., Ramsay, J., Eldridge, S., Feder, G., et al. (2005). Randomised controlled trial of a lay-led self-management programme for Bangladeshi patients with chronic disease. *The British Journal of General Practice*, 55(520), 831.

Background: Reducing the impact of chronic disease in minority ethnic groups is an important public health challenge. Lay-led education may overcome cultural and language barriers that limit the effectiveness of professionally-led programmes. We report the first randomised trial of a lay-led self-management programme — the Chronic Disease Self-Management Programme (CDSMP) (Expert Patient Programme) — in a south Asian group. **Aim:** To determine the effectiveness of a culturally-adapted lay-led self-management programme for Bangladeshi adults with chronic disease. **Design of study:** Randomised controlled trial. **Setting:** Tower Hamlets, east London. **Method:** We recruited Bangladeshi adults with diabetes, cardiovascular disease, respiratory disease or arthritis from general practices and randomised them to the CDSMP or waiting-list control. Self-efficacy (primary outcome), self-management behaviour, communication with clinician, depression scores, and healthcare use were assessed by blinded interviewer-administered questionnaires in Sylheti before randomisation and 4 months later. **Results:** Of the 1363 people invited, 476 (34%) agreed to take part and 92% (439/476) of participants were followed up. The programme improved self-efficacy (difference: 0.67, 95% confidence interval [CI] = 0.08 to 1.25) and self-management behaviour (0.53; 95% CI = 0.01 to 1.06). In the 51% (121/238) of intervention participants attending three or more of the 6-weekly education sessions the programme led to greater improvements in self-efficacy (1.47; 95% CI = 0.50 to 1.82) and self-management behaviour (1.16; 95% CI = 0.50 to 1.82), and reduced HADS depression scores (0.64; 95% CI = 0.07 to 1.22). Communication and healthcare use were not significantly different between groups. The programme cost £123 (€181) per participant. **Conclusion:** A culturally-adapted CDSMP improves self-efficacy and self-care behaviour in Bangladeshi patients with chronic disease. Effects on health status were marginal. Benefits were limited by moderate uptake and attendance.

d) Hispanic/Spanish-speakers (US):

Evaluations of the Spanish-language CDSMP by Lorig and colleagues are positive. Other studies describe culturally-relevant chronic disease intervention strategies for these populations. Based on the amount of available research, diabetes SMS appears to be a key issue for Hispanic populations in the US.

40. Anderson, R. M., Goddard, C. E., Garcia, R., Guzman, J. R., & Vazquez, F. (1998). Using focus groups to identify diabetes care and education issues for Latinos with diabetes. *The Diabetes Educator*, 24(5), 618-625.

The purpose of this study was to identify diabetes care and education issues for Latinos with diabetes. Four focus groups of Latinos with diabetes were held in the Detroit area; these sessions were audiotaped. An expert panel of bilingual health professionals from the United States and Mexico reviewed the audiotapes and identified and prioritized 47 issues using a modified Delphi technique. The highest priority issue identified by a wide margin was the difficulty many Latina women with diabetes have with self-care because of other family responsibilities. Universal diabetes care issues have a specific cultural expression which, when identified, can be incorporated into diabetes care and education programs for a particular cultural group. Focus groups are a useful means for identifying and illuminating such issues.

41. Brown, S. A., Blozis, S. A., Kouzekanani, K., Garcia, A. A., Winchell, M., & Hanis, C. L. (2005). Dosage effects of diabetes self-management education for Mexican Americans. *Diabetes Care*, 28(3), 527.

Objective: The objective of this study was to compare two diabetes self-management interventions designed for Mexican Americans: “extended” (24 h of education, 28 h of support groups) and “compressed” (16 h of education, 6 h of support groups). Both interventions were culturally competent regarding language, diet, social emphasis, family participation, and incorporating cultural beliefs. Research design and methods: We recruited 216 persons between 35 and 70 years of age diagnosed with type 2 diabetes ≥ 1 year. Intervention groups of eight participants and eight support persons were randomly assigned to the compressed or extended conditions. The interventions differed in total number of contact hours over the yearlong intervention period, with the major difference being the number of support group sessions held. The same information provided in the educational sessions of the extended intervention was compressed into fewer sessions, thus providing more information during each group meeting. Results: The interventions were not statistically different in reducing HbA_{1c}; however, both were effective. A “dosage effect” of attendance was detected with the largest HbA_{1c} reductions achieved by those who attended more of the extended intervention. For individuals who attended $\geq 50\%$ of the intervention, baseline to 12-month HbA_{1c} change was -0.6 percentage points for the compressed group and -1.7 percentage points for the extended group. Conclusions: Both culturally competent diabetes self-management education interventions were effective in promoting improved metabolic control and diabetes knowledge. A dosage effect was evident; attending more sessions resulted in greater improvements in metabolic control.

42. Brown, S. A., Garcia, A. A., Kouzekanani, K., & Hanis, C. L. (2002). Culturally competent diabetes self-management education for Mexican Americans. *Diabetes Care*, 25(2), 259.

Objective: To determine the effects of a culturally competent diabetes self-management intervention in Mexican Americans with type 2 diabetes. Research design and methods: A prospective, randomized, repeated measures study was conducted on the Texas-Mexico border in Starr County. A total of 256 randomly selected individuals with type 2 diabetes

between 35 and 70 years of age, diagnosed with type 2 diabetes after 35 years of age, and accompanied by a family member or friend were included. The intervention consisted of 52 contact hours over 12 months and was provided by bilingual Mexican American nurses, dietitians, and community workers. The intervention involved 3 months of weekly instructional sessions on nutrition, self-monitoring of blood glucose, exercise, and other self-care topics and 6 months of biweekly support group sessions to promote behavior changes. The approach was culturally competent in terms of language, diet, social emphasis, family participation, and incorporation of cultural health beliefs. Outcomes included indicators of metabolic control (HbA_{1c} and fasting blood glucose), diabetes knowledge, and diabetes-related health beliefs. Results: Experimental groups showed significantly lower levels of HbA_{1c} and fasting blood glucose at 6 and 12 months and higher diabetes knowledge scores. At 6 months, the mean HbA_{1c} of the experimental subjects was 1.4% below the mean of the control group; however, the mean level of the experimental subjects was still high (>10%). Conclusions: This study confirms the effectiveness of culturally competent diabetes self-management education on improving health outcomes of Mexican Americans, particularly for those individuals with HbA_{1c} levels >10%.

43. Brown, S. A., & Hanis, C. L. (1995). A community-based, culturally sensitive education and group-support intervention for Mexican Americans with NIDDM: a pilot study of efficacy. *The Diabetes Educator*, 21(3), 203-210.

The purpose of this study was to determine the feasibility of providing a diabetes patient education and group-support intervention that was directed by a Mexican-American clinical nurse specialist (CNS), dietitian, and community worker; consistent with national standards; and designed for the Mexican-American culture. In a rural Texas-Mexico border community, subjects with diabetes were randomly selected to participate in the intervention, and a family member of each subject participated as a support person. The intervention involved 8 weeks of educational sessions with instruction on nutrition, blood glucose self-monitoring, exercise, and other diabetes self-management topics, and provided group support. Group discussion was facilitated using a series of Spanish-language videotapes that had been developed and previously tested in the target Mexican-American community. Results suggested statistically significant improvements in diabetes knowledge, fasting blood sugar levels, and glycosylated hemoglobin levels. The study documented the feasibility and potential benefits of the intervention.

44. Lorig, K. R., Ritter, P. L., & González, V. M. (2003). Hispanic chronic disease self-management: a randomized community-based outcome trial. *Nursing Research*, 52(6), 361.

Background: In light of health disparities and the growing prevalence of chronic disease, there is a need for community-based interventions that improve health behaviors and health status. These interventions should be based on existing theory. Objective: This study aimed to evaluate the health and utilization outcomes of a 6-week community-based program for Spanish speakers with heart disease, lung disease, or type 2 diabetes. Method: The treatment participants in this study ($n = 327$) took a 6-week peer-led program. At 4 months, they were compared with randomized wait-list control subjects ($n = 224$) using analyses of covariance. The outcomes for all the treatment participants were

assessed at 1 year, as compared with baseline scores ($n = 271$) using t -tests. Results: At 4 months, the participants, as compared with usual-care control subjects, demonstrated improved health status, health behavior, and self-efficacy, as well as fewer emergency room visits ($p < .05$). At 1 year, the improvements were maintained and remained significantly different from baseline condition. Conclusions: This community-based program has the potential to improve the lives of Hispanics with chronic illness while reducing emergency room use.

45. Lorig, K. R., Ritter, P. L., & Jacquez, A. (2005). Outcomes of border health Spanish/English chronic disease self-management programs. *The Diabetes Educator*, 31(3), 401.

Purpose: The purpose of this study was to evaluate the community-based Chronic Disease Self-management Program (CDSMP) and the Spanish-language version (Tomando Control de Su Salud) programs as delivered in settings along the Texas/New Mexico/Mexico border. The programs had proven effective in randomized trials, and the authors wished to determine if they would be as effective when administered by others to different populations. **Methods:** The El Paso Diabetes Association administered the CDSMP and Tomando to 445 persons with chronic illness (two thirds with diabetes) in Texas, New Mexico, and Mexico. Four-month and 1-year outcomes were compared to baseline using t tests of change scores. Regression models were used to test whether baseline demographics and self-efficacy were associated with positive outcomes of the programs. **Results:** Participants showed improvements in health behaviors, health status, and self-efficacy at both 4 month and 1 year. Baseline self-efficacy and 4-month change in self-efficacy were significantly associated with improved 1-year outcomes. **Conclusions:** The CDSMP and Tomando are effective when used in settings other than that of the original study for populations other than those for which they were initially developed.

46. Mauldon, M., Melkus, G. D. E., & Cagganello, M. (2006). Tomando Control: a culturally appropriate diabetes education program for Spanish-speaking individuals with type 2 diabetes mellitus--evaluation of a pilot project. *The Diabetes Educator*, 32(5), 751.

Purpose: The purpose of this study was to pilot test the feasibility, acceptability, and efficacy of a culturally appropriate and culturally relevant Spanish-language cognitive-behavioral diabetes self-care educational intervention for Hispanic Americans with type 2 diabetes mellitus. **Methods:** The study site was an urban community health center in the Northeast, at which 16 Latino patients with type 2 diabetes mellitus were recruited. This was a 1-group pretest-posttest pilot study, during which qualitative and quantitative data were collected on demographic, physiologic (HbA1c, body mass index, lipids), psychosocial (diabetes-related distress and health beliefs), knowledge, and language-based acculturation variables at baseline, 3 months, and 6 months. Data were collected using questionnaires, laboratory data, and chart review. The intervention was culturally appropriate in terms of language, social emphasis, nutritional guidance, and acknowledgment of cultural health beliefs. Descriptive and inferential statistical analysis was used to evaluate response variables of glycemic control, lipid levels, and psychosocial and knowledge outcomes. The intervention acceptability process was evaluated by attendance and attrition.

Results: This pilot study demonstrated excellent acceptance for and feasibility of this intervention. Most study participants (9 women, 7 men) were middle-aged married individuals who had had diabetes mellitus for an average of 8 years; English was a second language for all of them. Most were overweight and had suboptimal glycemic control and lipid profiles and moderate levels of knowledge at the outset of the study. Most had received a one-on-one diabetes educational session prior to the intervention. Over the 6 months of the study, most of both men and women showed an increase in knowledge scores, improvement in lipid profiles, and reduction in HbA1c levels. Men demonstrated a temporary increase in emotional distress much greater than that reported by women during the first 3 months of the study.

Conclusions: The findings suggest that a culturally relevant type 2 diabetes mellitus educational program, particularly one that addresses different learning needs and styles of men and women, can have a positive impact on Hispanic Americans with diabetes. Implications for practice include awareness of gender-based differences in response to self-management education, the importance of providing realistic samples of meals prepared in a manner consistent with American Diabetes Association principles, and the rationale for offering a brief and focused refresher course 6 to 9 months following this type of intervention.

47. Rosal, M. C., Olendzki, B., Reed, G. W., Ockene, I., Gumieniak, O., & Scavron, J. (2005). Diabetes self-management among low-income Spanish-speaking patients: a pilot study. *Annals of Behavioral Medicine*, 29(3), 225-235.

Background: The prevalence of type 2 diabetes and diabetes related morbidity and mortality is higher among low-income Hispanics when compared to that of Whites. However, little is known about how to effectively promote self-management in this population. Purpose: The objectives were first to determine the feasibility of conducting a randomized clinical trial of an innovative self-management intervention to improve metabolic control in low-income Spanish-speaking individuals with type 2 diabetes and second to obtain preliminary data of possible intervention effects. Methods: Participants for this pilot study were recruited from a community health center, an elder program, and a community-wide database developed by the community health center, in collaboration with other agencies serving the community, by surveying households in the entire community. Participants were randomly assigned to an intervention (n = 15) or a control (n = 10) condition. Assessments were conducted at baseline and at 3 months and 6 months post randomization. The intervention consisted of 10 group sessions that targeted diabetes knowledge, attitudes, and self-management skills through culturally specific and literacy sensitive strategies. The intervention used a cognitive behavioral theoretical framework.

Results: Recruitment rates at the community health center, elder program, and community registry were 48%, 69%, and 8%, respectively. Completion rates for baseline, 3-month, and 6-month assessments were 100%, 92%, and 92%, respectively. Each intervention participant attended an average of 7.8 out of 10 sessions, and as a group the participants showed high adherence to intervention activities (93% turned in daily logs, and 80% self-monitored glucose levels at least daily). There was an overall Group × Time interaction (p = .02) indicating group differences in glycosylated hemoglobin over

time. The estimated glycosylated hemoglobin decrease at 3 months for the intervention group was -0.8% (95% confidence intervals = -1.1% , -0.5%) compared with the change in the control group ($p = .02$). At 6 months, the decrease in the intervention group remained significant, -0.85% (95% confidence intervals = -1.2 , -0.5), and the decrease was still significantly different from that of the controls ($p = .005$). There was a trend toward increased physical activity in the intervention group as compared to that of the control group ($p = .11$) and some evidence (nonsignificant) of an increase in blood glucose self-monitoring in the intervention participants but not the control participants. Adjusting for baseline depressive scores, we observed a significant difference in depressive symptoms between intervention participants and control participants at the 3-month assessment ($p = .02$).

Conclusions: Low-income Spanish-speaking Hispanics are receptive to participate in diabetes-related research. This study shows that the pilot-tested diabetes self-management program is promising and warrants the conduct of a randomized clinical trial.

48. Thompson, J. R., Horton, C., & Flores, C. (2007). Advancing Diabetes Self-Management in the Mexican American Population. *The Diabetes Educator, 33*, 159S.

Purpose: The purpose of this study was to pilot test the effectiveness of health promoters trained in the transtheoretical model of change to provide diabetes management education and support to Mexican Americans in a primary care setting. Methods: The study site was an urban community health center in Oakland, California. This study reports on 142 patients who were enrolled for at least 1 year in the program. Community health workers acted as extenders of the medical staff to facilitate behavior change, using patient-centered counseling. This was a 1-group pretest/posttest pilot study. Descriptive statistics and the paired-sample t test were used to compare the change in clinical outcome measures from baseline to 6 months and 1 year. Statistically significant changes were correlated with frequency of community health worker contact. Results: The paired-sample t test showed significant reduction in glycosylated hemoglobin (HbA1c) from baseline to 1 year ($P < .004$). Reductions were also seen in low-density lipoprotein cholesterol and blood pressure, but they were not statistically significant. When stratified by gender, women showed a greater reduction in HbA1c than men at 1 year. Patients with a higher frequency of community health worker contact showed a greater decline in HbA1c level. Conclusions: The pilot study demonstrates that community health workers, as an integral part of the health care team, are effective agents in providing self-management support to persons with diabetes.

49. Vincent, D., Pasvogel, A., & Barrera, L. (2007). A feasibility study of a culturally tailored diabetes intervention for Mexican Americans. *Biological Research for Nursing, 9*(2), 130.

Latinos, the fastest growing minority group in the United States, are among the hardest hit by diabetes. Among Latinos, Mexican Americans have the highest rate (23.9%) of diabetes. Good self-management can improve glycemic control and decrease diabetes complications but can be challenging to achieve. The purpose of this study was to test the feasibility and examine the effects of a culturally tailored intervention for Mexican Americans with type 2 diabetes on outcomes of self-management. The study used a pretest/posttest control group design with 10 participants in each group ($N = 17$).

Feasibility and acceptability of the tailored diabetes self-management program was assessed by examining ease of recruitment and retention rates. The behavioral outcomes of self-efficacy, diabetes knowledge and self-care measures, and the biologic outcomes of weight, body mass index, HbA1C, and blood glucose were used to examine intervention effectiveness. Successful recruitment of participants came from personal referrals from providers or the *promotora*. Retention rates were 100% for the intervention group and 80% for the control group. Findings suggest that the intervention had a positive clinical and statistical effect on diabetes knowledge, weight, and body mass index. Improvements were also noted in self-efficacy scores, blood glucose, and HbA1C, but these changes did not reach statistical significance. A culturally tailored diabetes self-management program may result in improved outcomes for Mexican Americans with type 2 diabetes.

50. Whittemore, R. (2007). Culturally competent interventions for Hispanic adults with type 2 diabetes: A systematic review. *Journal of Transcultural Nursing, 18*(2), 157.

Culturally competent interventions have been developed to improve outcomes for Hispanic adults with type 2 diabetes. The purpose of this systematic review is to synthesize the research on culturally competent interventions for this vulnerable population. A systematic approach was used to locate empirical reports (n = 11). Interventions were multifaceted with the majority demonstrating significant improvements in clinical outcomes, behavioral outcomes, and diabetes-related knowledge. Culturally competent interventions have the potential to improve outcomes in Hispanic adults with type 2 diabetes. However, improvements were modest and attrition was moderate to high in many studies. Addressing linguistic and cultural barriers to care are important beginnings to improving health outcomes for Hispanic adults with type 2 diabetes.

e) African-American populations (US):

51. Anderson, R. M., Funnell, M. M., Arnold, M. S., Barr, P. A., Edwards, G. J., & Fitzgerald, J. T. (2000). Assessing the cultural relevance of an education program for urban African Americans with diabetes. *The Diabetes Educator, 26*(2), 280.

Purpose: This study was conducted to assess the cultural relevance of an education program for urban African Americans with diabetes. **Methods:** A set of 12 videotape vignettes were developed for use in diabetes education for urban African Americans with diabetes. Focus groups and questionnaires were used to determine if patients and diabetes educators would find the materials stimulating, culturally appropriate, and useful. **Results:** The videotape and discussion guide were perceived as valuable by both healthcare professionals and patients. **Conclusions:** This education program could be a valuable resource for diabetes educators who want to provide culturally sensitive and relevant diabetes education for urban African Americans with diabetes.

52. Goepfing, J., Armstrong, B., Schwartz, T., Ensley, D., & Brady, T. J. (2007). Self-management education for persons with arthritis: managing comorbidity and eliminating health disparities. *Arthritis & Rheumatism*, 57(6), 1081-1088.

Objective: To compare short-term and long-term effectiveness of the Arthritis Self-Help Course (ASHC) and the Chronic Disease Self-Management Program (CDSMP) for persons with arthritis concerning health care use, health-related quality of life, health behaviors, and arthritis self-efficacy. Methods: Forty-eight workshops were randomized to the ASHC (n = 26) or CDSMP (n = 22). A total of 416 individuals, including 365 African Americans, participated. The mean age for each group was 64 years, mean years of education was 11.7, mean number of chronic conditions was 4, and 75-80% of participants in each group were female. Multivariate statistical tests were used to assess effectiveness within and between programs for all workshop participants and African Americans. Results: At 4 months all ASHC participants including African Americans, had significant improvements ($P < 0.05$) in self-efficacy, stretching and strengthening exercises, aerobic exercises, and general health. All CDSMP participants had statistically significant improvements in self-efficacy, disability, pain, and general health. African American CDSMP participants showed statistically significant improvements in general health. Trends toward improvement ($P = 0.051-0.100$) were shown in 5 variables among African American CDSMP participants and in 4 variables among all CDSMP participants. Statistically significant differences between the 2 programs at 4 months were seen in pain and disability in both groups. The CDSMP produced stronger results. Significant results at 1 year within and between programs were minimal for both groups. Conclusion: When populations with arthritis and multiple comorbid conditions are targeted, the CDSMP may be most cost effective.

D. Self-management support for ethnocultural minority older adults

The following articles represent the extent of the literature on SMS for EMOA within the parameters of the scoping review database (described in the introduction). So as to expand this limited body of literature, additional research on African-American and Hispanic populations has been included.

a) CDSMP adaptations for ethnocultural minority older adults:

53. Gitlin, L., Chernett, N. L., Harris, L. F., Palmer, D., Hopkins, P., & Dennis, M. P. (2008). Harvest Health: Translation of the Chronic Disease Self-Management Program for Older African Americans in a Senior Setting. *Gerontologist*, 48(5), 698-705.

Purpose: We describe the translation of K. R. Lorig and colleagues' Chronic Disease Self-Management Program (CDSMP) for delivery in a senior center and evaluate pre-post benefits for African American participants. Design and Methods: Modifications to the CDSMP included a name change; an additional introductory session; and course augmentations involving culturally relevant foods, stress reduction techniques, and communicating with racially/ethnically diverse physicians. We recruited participants from senior center members, area churches, and word of mouth. We conducted baseline and 4-month post-interviews. Results: A total of 569 African American elders attended an

introductory session, with 519 (91%) enrolling in the 6-session program. Of the 519, 444 (86%) completed 4 sessions and 414 (79%) completed pre–post interviews. We found small but statistically significant improvements for exercise ($p = .001$), use of cognitive management strategies ($p = .001$), energy/fatigue ($p = .001$), self-efficacy ($p = .001$), health distress ($p = .001$), and illness intrusiveness in different life domains (probabilities from .001–.021). We found no changes for health utilization. Outcomes did not differ by gender, number of sessions attended, number and type of chronic conditions, facilitator, leader, or recruitment site. Implications: The CDSMP can be translated for delivery by trained senior center personnel to African American elders. Participant benefits compare favorably to original trial outcomes. The translated program is replicable and may help to address health disparities.

54. Rose, M. A., Arenson, C., Harrod, P., Salkey, R., Santana, A., & Diamond, J. (2008). Evaluation of the Chronic Disease Self-Management Program with low-income, urban, African American older adults. *Journal of Community Health Nursing, 25*(4), 193-202.

A 1-group pretest-posttest design to assess for changes in outcomes at 10 weeks and 6 months was the method used to evaluate the standardized 6-session Chronic Disease Self Management Program (CDSMP) with low income, urban African American older adults. Participants included 153 older adults (primarily African American) with 1 or more chronic health conditions. Classes were provided in the community at senior citizen centers, senior housing, and churches. Significant improvements were noted in selected areas at 10 weeks and 6 months after the program completion. The CDSMP was feasible and well-received with the older adults who participated in the study.

b) Alternative self-management support for ethnocultural minority older adults:

55. Agurs-Collins, T. D., Kumanyika, S. K., Ten Have, T. R., & Adams-Campbell, L. L. (1997). A randomized controlled trial of weight reduction and exercise for diabetes management in older African-American subjects. *Diabetes Care, 20*(10), 1503.

OBJECTIVE: To evaluate a weight loss and exercise program designed to improve diabetes management in older African-Americans. **RESEARCH DESIGN AND METHODS:** Overweight African-Americans ($n = 64$) ages 55-79 years with NIDDM were randomized to either an intervention (12 weekly group sessions, 1 individual session, and 6 biweekly group sessions) or usual care (1 individual session, and 6 biweekly group sessions) or usual care (1 class and 2 informational mailings). Clinical and behavioral variables were assessed at 0, 3, and 6 months of treatment. **RESULTS:** Significant net differences in the intervention versus usual care were observed for weight (-2.0 kg, $P = 0.006$), physical activity, and dietary intake of fat, saturated fat, cholesterol, and nutrition knowledge at 3 months (all $P < 0.05$) and for weight at 6 months (-2.4 kg; $P = 0.006$) and mean HbA1c values at 3 and 6 months (respectively, -1.6 and -2.4%, both $P < 0.01$). After the adjustment for changes in weight and activity, the intervention participants were approximately twice as likely to have a one unit decrease in HbA1c value as those in usual care. Blood pressure increase in usual care participants resulted in net differences (intervention minus control) at 3 and 6 months of -3.3 ($P = 0.09$) and -

4.0 (P = 0.05) mmHg diastolic, respectively, and -8.4 (P = 0.06) and -5.9 (P > 0.10) mmHg systolic, respectively. Blood lipid profiles improved more in intervention than usual care participants, but not significantly. CONCLUSIONS: The intervention program was effective in improving glycemic and blood pressure control. The decrease in HbA1c values was generally independent of the relatively modest changes in dietary intake, weight, and activity and may reflect indirect program effects on other aspects of self-care.

56. Cortes, T., Lee, A., Boal, J., Mion, L., & Butler, A. (2004). Using focus groups to identify asthma care and education issues for elderly urban-dwelling minority individuals. *Applied Nursing Research, 17*(3), 207-212.

Investigated an educational program emphasizing asthma care and self-management skills for older, urban-dwelling, minority adults. Focus groups were used to identify cultural barriers to asthma care and self-management that could be addressed in the development of self-management programs. For 2 of the focus groups, 5 older adults with asthma aged 65 and older and 7 unlicensed caretakers of older adults with asthma were recruited from 2 East Harlem community centers in New York. The health care professional focus group consisted of 7 physicians and 3 nurse practitioners. Four questions were asked regarding asthma management, impact of asthma, barriers to getting asthma treated, and educational needs regarding asthma care. Discussions were audiotaped, transcribed, and reviewed by independent raters to determine major themes and concerns. Three common themes occurred, including the negative affect of asthma on quality of life, the prohibitive costs of medications, and nonadherence to the medication regimen. All 3 groups also alluded to difficulties in accessing primary care physicians and the poor quality of the physician-patient relationship. The results provide beginning insights regarding similarities and differences of the understandings of the health-education needs of older adults with asthma among health care professionals, unlicensed caregivers, and the older adults themselves.

57. Elshaw, E. B., Young, E. A., Saunders, M. J., McGurn, W. C., & Lopez, L. C. (1994). Utilizing a 24-hour dietary recall and culturally specific diabetes education in Mexican Americans with diabetes. *The Diabetes Educator, 20*(3), 228-235.

Two objectives were established for this study: 1) to assess the impact of a culturally specific, intensive diabetes education program on dietary patterns, and 2) to assess nutrient consumption relative to the Recommended Dietary Allowances. The study population consisted of elderly Mexican Americans with diabetes living in Harlingen and Brownsville, Texas. The experimental group (n = 78) participated in an intense, 2-hour nutrition education session, while the control group (n = 74) did not. The education session was conducted for groups of eight subjects via videotapes and interactive discussion. All groups experienced significant weight loss except the women in the experimental group. After the education program, however, the experimental women had increased the percentage of calories consumed daily from carbohydrate. Mean calcium consumption was substantially less than the RDA in all groups, and inadequate amounts of ascorbic acid and vitamin A often were consumed. Intensive, frequent, long-term follow-up appears essential for more sustained results.

58. Kim, M. T., Han, H. R., Park, H. J., Ho, L., & Kim, K. B. (2006). Constructing and testing a self-help intervention program for high blood pressure control in Korean American seniors -- pilot study. *Journal of Cardiovascular Nursing, 21*(2), 77-84.

Although significant progress has been made in the reduction of overall cardiovascular risk factors in the United States during the last decade, controlling high blood pressure (HBP) remains a difficult task for many individuals. In particular, socially disadvantaged groups, such as new immigrants, and ethnic minority groups, such as Korean Americans, continue to struggle with this chronic disease and suffer unnecessary complications. We conducted a quasi-experimental study to test the efficacy of a self-help intervention program for HBP control in first-generation Korean American seniors with HBP. The intervention consisted of 3 concurrently administered components: (1) structured behavioral education on HBP management, (2) home blood pressure (BP) monitoring, and (3) monthly support groups facilitated by a bilingual nurse. Of the 49 Korean American seniors (> or =60 years old) who agreed to participate, 31 received the intervention and completed the follow-up interviews at 6 months. Final analysis of BP outcomes using repeated measures and post-intervention data suggested that the self-help intervention was effective in significantly improving the proportion of individuals who achieved BP control (<140/90 mm Hg) and in lowering both systolic and diastolic BP in the sample. Specifically, the BP control rate, which was 29% at baseline, increased at 6 months to 69%. Likewise, the mean systolic and diastolic BP values of 142.7 and 87.1 mm Hg at baseline decreased to 129.3 and 75.3 mm Hg, respectively, after 6 months of follow-up. This improvement of the HBP control rate in the sample highlights the clinical efficacy of the self-help intervention for this traditionally underserved immigrant group.

59. Newman, A. M. (2001). Self-help care in older African Americans with arthritis. *Geriatric Nursing, 22*(3), 135-138.

Arthritis is the third most common health problem among African Americans and the leading cause of activity limitations. Some of the obstacles facing people who are experiencing health care problems fall disproportionately on older racial and ethnic minority populations. Receiving care, which is perceived as racially and ethnically relevant, is an important factor in overcoming these obstacles. The Arthritis Self-Help Course (ASHC) was successfully used with 150 impoverished African-American elders living in public housing to bolster their confidence in managing their arthritis symptoms.

c) Cultural competency in self-management support:

60. Huang, L. (2007). *Chinese culture versus Western medicine: health implications for San Francisco elder Chinese immigrants with heart failure* UMI Dissertation Services, ProQuest Information and Learning, Ann Arbor, MI.

The purpose of this ethnographic study was to explore cultural beliefs of elder Chinese immigrants toward Western medication regimens as few studies were conducted in this area. Hypertension among elder Chinese immigrants is a growing problem in San Francisco with its leading complication of heart failure. This study was designed to reveal any cultural variables that may promote or interfere with medication adherence in the

elder immigrants in San Francisco. Six participants with a history of heart failure were recruited from a clinic in San Francisco. Cultural views were obtained based on data from observation and interviews and grouped into specific categories by software NUDIST with analysis under the guidance of Johnson's behavioral system model and social epidemiological concepts. This study explored inter and intracultural factors that might enable or hinder Western medication adherence behavior. The study found Western medication adherence in elder Chinese immigrants with heart failure can be affected by traditional Chinese and adapted beliefs from U.S. migration toward acute and chronic disease management. This study lends itself to social change by documenting the problems of inadequate communication between Western and Chinese practitioners and emphasizing the critical importance of integration through understanding and utilization of traditional as well as adapted Chinese cultural values. Biases of the study included the convenience and small sample size. As a further step toward social change, the study suggested the importance of future research on Western medication adherence in different geographically located subcultural group of elder Chinese immigrants with heart failure.

61. Owens, A., & Randhawa, G. (2004). 'It's different from my culture; they're very different': providing community-based, 'culturally competent' palliative care for South Asian people in the UK. *Health & Social Care in the Community*, 12(5), 414-421.

This article investigates the challenges faced by those trying to develop 'culturally competent' palliative care for South Asian cancer patients in Luton, UK. It discusses the findings of a phenomenological study of service providers' attitudes to and experiences of caring for South Asian patients. Ten semi-structured in-depth interviews were carried out with a range of staff who work in home and community-based palliative care settings, including nurses, community liaison personnel and representatives of non-statutory organisations. The authors begin by considering how these service providers construct ideas of cultural difference and how these relate to philosophies of palliative care. They then examine attempts to deal with cultural diversity in everyday practice, focusing in particular on the social context of care in the home. The paper considers the ways in which staff attempt to incorporate the cultural needs of patients, family, kin and community. Rather than criticising current working practices, the authors highlight the complexity of delivering culturally competent services from the perspective of those working directly with patients. In doing so, they contribute to ongoing debates about the development of anti-discriminatory practice in health and social care.

d) Chronic disease self-care, coping and lifestyle practices among ethnocultural minority older adults:

62. Berman, R. L. H., & Iris, M. A. (1998). Approaches to self-care in late life. *Qualitative Health Research*, 8(2), 224-236.

Explored the concept of taking care of oneself by examining how older adults articulated their beliefs regarding health and recounted the nature of their self-care behaviors. A total of 50 adults aged 55-91 from various socioeconomic and racial backgrounds living in the Chicago, Illinois area completed in-depth ethnographic interviews. Three approaches to

taking care of oneself were identified during the interviews, including "do and think for your self," "what can I do, others take care of me," and "I don't pay attention to myself." Although one approach dominated the narratives of most individuals, participants referred to more than one way to take care of themselves. The findings suggest that the social setting within which self-care occurs influences the approaches taken, and that self-care beliefs are formed within multiple cultural contexts, including beliefs and practices of ethnic, alternative, or biomedical worldviews. It is concluded that professional in the field of self-care promotion cannot expect all older adults to subscribe equally or easily to the dominant cultural beliefs and values of the current biomedical model, which is to "take charge" of one's care. (MM) (AgeLine Database, copyright 1998 AARP, all rights reserved)

The following article is not specific to chronic disease, but weighs the pros and cons of mainstreaming versus targeted approaches to the provision of home support for ethnocultural minority older adults :

63. Bowes, A. (2006). [Mainstreaming Equality: Implications of the Provision of Support at Home for Majority and Minority Ethnic Older People](#). *Social Policy & Administration*, 40(7), 739-757.

This paper explores the potential impact and practical difficulties of mainstreaming equalities in support at home for minority and majority ethnic older people, drawing on two linked empirical research projects. Social care providers have long faced difficulties in catering for diversity of need. Recently, diversity within minority ethnic groups has increased, and there is now a statutory duty to promote equality. Research findings illustrate the complexity of exclusionary processes, with particular reference to the example of health care. There is a gap between the high-level commitment to mainstreaming equality and people's lived experiences. Autonomy and choice are central to community care legislation, policy and practice guidance, but in reality, the research shows that choices are limited for both minority and majority older people. More user-focused approaches and grassroots involvement may offer ways forward, despite some limitations of current models. In conclusion, the potentiality of a broad mainstreaming equality perspective is highlighted, but challenges include a need for a more grounded approach, better engagement with user groups and a need to focus on understanding issues of implementation.

64. Burnette, D., Mui, A. C., & Zodikoff, B. D. (2004). [Gender, self-care and functional status among older persons with coronary heart disease: a national perspective](#). *Women and Health*, 39(1), 65-84.

Examined the association of self-care and functional status of older men and women with coronary heart disease (CHD), in light of the rising risk and burden of cardiovascular disease in late life and the shift from men to women at age 65. Data were obtained from the National Survey of Self-Care and Aging on 3,485 adults aged 65 and older, including 360 men (mean age 78.34) and 237 women (mean age 79.25) with CHD and 1,439 men (mean age 78.35) and 1,449 women (mean age 77.94) without CHD. Three types of self-care (behavior changes, environmental adaptations, and medical equipment use) were examined, and functional status was measured as difficulty with basic, mobility, and

instrumental activities of daily living. It was found that, regardless of gender, persons with CHD had more functional impairment and used more self-care than those without the disease. Women were more impaired and engaged in more self-care than men. Equipment use was associated with higher functioning for men and women. Behavioral changes were significant only for men, as were advanced age, non-white ethnicity, more depressive symptoms, and low physical activity for women. The results suggest that education, intervention, and supportive care for older adults with CHD should consider the role of specific types of self-care in disease management and prevention of decline as well as gender differences in use of various self-care strategies.

65. Choi, Y. (2002). *Representation of and coping with osteoarthritis among older Koreans in the United States* UMI Dissertation Services, ProQuest Information and Learning, Ann Arbor, MI.

Osteoarthritis (OA) is the most prevalent chronic disease affecting older people and a major cause of disability and utilization of healthcare resources. Coping and self-management behaviors may have a decisive impact on the physical, psychological, and social outcomes of experience with OA. The purpose of this study was to describe the process and pattern of OA representation, coping, and its impacts among older Koreans in the United States. This study employed an exploratory descriptive design. Data were collected using a semi-structured interview method. Participants of the study were 18 older Koreans living in southern California. The findings of the study indicated that representation, coping, and coping appraisal were interconnected concepts in the management of OA. Participants' representation was categorized into symptoms, name, cause and cure of their illness, and concerns for the future. Coping with OA included seeking healthcare providers, using folk remedies, exercising, controlling the mind, praying, comparing to others, accepting destiny, and developing their own healing methods. Participants evaluated the process and outcome of coping and reset their treatment goals. OA affects older Koreans' daily living, financial status, family relationships, social activities, and perceptions of life. Older Koreans were very familiar with OA even before they experienced any initial symptoms. They believed that OA was an incurable, painful illness that caused difficulties in their daily lives and tremendous financial burdens. They were concerned about becoming a burden on their families in the future. They tried most treatments suggested by friends and families and finally adopted or developed their own healing methods. They accepted OA as their destiny, and they were living with it. They were still happy because they were loved and cared for by their family, friends, church, and God. The major significance of the study is its contribution to understanding health behavior among older Koreans in the United States. It is important to provide nursing care in a manner that respects the individuality of each client who has unique life experiences and cultural backgrounds.

66. Coulton, C. J., Milligan, S., Chow, J., & Haug, M. (1990). Ethnicity, self-care, and use of medical care among the elderly with joint symptoms. *Arthritis & Rheumatism*, 3(1), 19-28.

Elderly individuals with self-reported joint symptoms representing three ethnic groups (i.e., blacks [n = 105], Hispanics[n = 100], and whites of Eastern European origin [n = 112] answered questions about their use of self-care and medical care for these

symptoms. Ethnic groups differed in both self-care practices and their use of medical care for joint symptoms. Multiple regression analyses demonstrated that arthritis-specific and general health status were better predictors than ethnicity of the tendency to rely on self-care and medical care. There was no evidence that self-care served as a substitute for medical care.

67. Gallant, M.P., Spitze, G., Grove, J. G. (2010). *Chronic Illness Self-Care and the Family Lives of Older Adults: A Synthetic Review across Four Ethnic Groups. Journal of Cross-Cultural Gerontology, 25(1), 21-43.*

The purpose of this paper is to integrate the literature on family and social ties among older ethnic minority men and women with the literature on chronic illness self-care among elders in these groups, in order to increase understanding of social influences on self-care behavior, raise questions for future research, and inform culturally appropriate interventions to maximize the health-promoting potential of social relationships. The paper presents demographic and chronic illness prevalence information, and then summarizes literature about patterns of chronic illness self-care behaviors for older African-Americans, Latinos, Asian-Americans, and American Indians in the U.S. For each group, the sociological literature about residential, cultural, and socioeconomic patterns, family lives, and other social ties is then reviewed, and the self-care literature that has accounted for these patterns is discussed. Finally, six themes are outlined and related questions are identified to further illuminate the social context of older adults' chronic illness self-care.

68. Luo, R. (2002). *Development and testing a chronic disease health beliefs and lifestyle practices questionnaire for older Chinese Americans UMI Dissertation Services, ProQuest Information and Learning, Ann Arbor, MI.*

A survey health questionnaire was translated into Chinese and tested to assess chronic disease knowledge (CDK), health beliefs, and lifestyle practices among 97 Chinese Americans, 55 and older. Hypotheses on age, gender, acculturation, socioeconomic status, health status, and health behaviors were tested. Pearson's correlations revealed that education, past occupation, getting by in the U.S. were positively related to CDK partially. Gender, health status (summary), and health behaviors (summary) were not related to CDK. Total family income, age, length of stay, communication, health insurance coverage, and barriers were inversely related to CDK partially. Further MANOVA tests also confirmed that age group differences on CDK. In the future, further analysis of these complex patterns will be conducted because they are outside the scope of this exploratory study. (Author Abstract, used by permission) (AgeLine Database, copyright 2004 AARP, all rights reserved)

69. Macaden, L., & Clarke, C. L. (2006). *Risk perception among older South Asian people in the UK with type 2 diabetes. International Journal of Older People Nursing, 1(3), 177-181.*

Examined the experiences of South Asian people with diabetes in England in relation to sociocultural and dietary practices, religion, and aging influences on the perception and understanding of risks. Data were collected through focus groups with ethnic health development workers, interviews with 7 health professionals, and interviews with 20

older adults with diabetes. It was found that a number of issues influence the perception of risk among South Asian older people with diabetes: beliefs about its cause, perceived severity and its visibility, food and its social function, religion and beliefs about external control over their life span, and diabetes management. People weighed up the risks in making decisions about issues such as dietary management and the emphasis placed on diabetes as a pathology. The results suggest that good risk communication will maintain the current trend of improving patient's choice and self-management in health care, and that there is a need for this to be sensitive to the particular issues faced by South Asians with diabetes in the United Kingdom.

70. Wang, J., & Matthews, J. T. (article in press). Chronic Disease Self-Management: Views Among Older Adults of Chinese Descent. *Geriatric Nursing*.

To understand how Chinese culture influences chronic disease self-management, we conducted focus groups with older adults of Chinese descent. Specifically, we explored their perceptions and self-management practices regarding treatment adherence, lifestyle decisions, and patient-provider communication within the context of their culture.

71. Yee, B. W. K. (1997). Stroke, lung cancer, and diabetes health beliefs and lifestyle practices of Vietnamese elders: implications for geriatric rehabilitation. *Topics in Geriatric Rehabilitation*, 13(2), 1-12.

Investigated health beliefs and practices of older Vietnamese adults in the United States related to stroke, lung cancer, and diabetes. Twenty-eight participants aged 50-79 (mean age 62) were interviewed in their homes. Participants clearly identified major risk factors that contribute to increasing stroke risk. Participants varied in their ability to identify risks for lung cancer and diabetes. Most of the participants had healthy lifestyles. Areas recommended for health promotion among Southeast Asian older adults include prevention and cessation of smoking, tuberculosis and hepatitis screening, exercise, nutrition, and stress management. Some traditional medical and diet beliefs may need to be modified. Linguistic and cultural barriers to communication may be reduced by utilizing the natural support systems within families and communities.

e) Self-management support by ethnocultural group:

The following is a listing of the previous references on SMS for EMOA arranged by ethnocultural group:

Chinese: 60, 68, 70

South Asian: 61, 69

African-American: 53, 54, 55, 59

Hispanic: 57

Korean: 58, 65

Vietnamese: 71

Multiple ethnic group studies: 56, 62, 63, 64, 66, 67

E. Health literacy and self-management support:

The Canadian Expert Panel on Health Literacy (established in 2006) defines health literacy as:

The ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course.²⁰

Significantly, this definition moves beyond the notion of literacy, which highlights an individual's ability to understand and communicate information,²⁰ to include a focus on the health provider and system as being responsible for ensuring patient access to information, and the health benefits such access confers. Within this definition ensuring patient access means a consideration of how access is mediated by a constellation of social, economic, political and cultural factors.

The Panel further defined their vision of a health literate Canada:

All people in Canada have the capacity, opportunities and support they need to obtain and use health information effectively, to act as informed partners in caring for themselves, their families and communities, and to manage interactions in a variety of settings that affect health and well-being.²⁰

The following articles represent a sample of the literature on health literacy that focuses specifically on issues around self-management support. References on children/youth and health literacy are not included.

a) Interventions for low health literacy in self-management support

Little research exists in Canada to date on health literacy interventions to improve self-management support for systemically disadvantaged groups. Results included here indicate that literacy is an important factor in effective patient self-management, and that health literacy interventions may produce mild benefits for patients with low literacy.

See additional health literacy-related reference #17 (p. 10) under section A. b) Effectiveness of self-management support for marginalized and disadvantaged populations.

72. Cavanaugh, K., Wallston, K. A., Gebretsadik, T., Shintani, A., Huizinga, M. M., Davis, D., et al. (2009). Addressing Literacy and Numeracy to Improve Diabetes Care. *Diabetes Care*, 32(12), 2149.

Objective: Diabetic patients with lower literacy or numeracy skills are at greater risk for poor diabetes outcomes. This study evaluated the impact of providing literacy- and numeracy-sensitive diabetes care within an enhanced diabetes care program on A1C and other diabetes outcomes.

Research Design and Methods: In two randomized controlled trials, we enrolled 198 adult diabetic patients with most recent A1C $\geq 7.0\%$, referred for participation in an enhanced diabetes care program. For 3 months, control patients received care from existing enhanced diabetes care programs, whereas intervention patients received

enhanced programs that also addressed literacy and numeracy at each institution. Intervention providers received health communication training and used the interactive Diabetes Literacy and Numeracy Education Toolkit with patients. A1C was measured at 3 and 6 months follow-up. Secondary outcomes included self-efficacy, self-management behaviors, and treatment satisfaction.

Results: At 3 months, both intervention and control patients had significant improvements in A1C from baseline (intervention -1.50 [95% CI -1.80 to -1.02]; control -0.80 [-1.10 to -0.30]). In adjusted analysis, there was greater improvement in A1C in the intervention group than in the control group ($P = 0.03$). At 6 months, there were no differences in A1C between intervention and control groups. Self-efficacy improved from baseline for both groups. No significant differences were found for self-management behaviors or satisfaction.

Conclusions: A literacy- and numeracy-focused diabetes care program modestly improved self-efficacy and glycemic control compared with standard enhanced diabetes care, but the difference attenuated after conclusion of the intervention.

73. Kim, S., Love, F., Quistberg, D. A., & Shea, J. A. (2004). Association of health literacy with self-management behavior in patients with diabetes. *Diabetes Care*, 27(12), 2980.

Limited health literacy, common in patients with diabetes, has been associated with worse diabetes outcomes. While patients with limited health literacy have worse diabetes knowledge, knowledge does not necessarily predict outcomes. Because diabetes requires extensive self-care, differences in self-management behaviors may be a key contributor to the disparity in outcomes. In fact, low health literacy has been associated with poor self-care in other chronic illnesses. However, no study has examined the relationship between health literacy and self-management behaviors in patients with diabetes. In addition, studies have not assessed whether diabetes education, which is widely recommended, is effective in improving self-management behaviors in patients with limited health literacy. The objectives of our study were to examine the association of health literacy with self-management behaviors in patients with diabetes and to determine whether diabetes education improves self-management behaviors in patients with limited compared with adequate health literacy. Understanding the relationship between health literacy and self-management behaviors should enhance efforts to improve diabetes outcomes.

74. Paasche-Orlow, M. K., Riekert, K. A., Bilderback, A., Chanmugam, A., Hill, P., Rand, C. S., et al. (2005). Tailored education may reduce health literacy disparities in asthma self-management. *American Journal of Respiratory and Critical Care Medicine*, 172(8), 980.

Rationale: Although inadequate health literacy has been associated with lower asthma medication knowledge and worse metered-dose inhaler (MDI) technique, the relationship between health literacy and the capacity to learn asthma self-management skills is unknown.

Objectives: In this prospective cohort study of adults hospitalized for severe asthma exacerbations at two inner-city hospitals, we examined the relationship between inadequate health literacy and difficulties learning and retaining instructions about discharge medications and appropriate MDI technique.

Methods: At hospital discharge, participants received one-on-one, 30-min, guideline-based, written and oral instruction about their asthma discharge regimen as well as

appropriate MDI technique.

Measurements and Main Results: Seventy-three patients were enrolled. Inadequate health literacy was identified in 16 (22%) participants. Before instruction, inadequate health literacy was associated with lower asthma medication knowledge (5.2/10 vs. 7.2/10, $p < 0.001$) and worse MDI technique (3.2/6 vs. 3.9/6, $p = 0.03$). However, inadequate health literacy was not associated with difficulty learning ($p = 0.33$) or retaining ($p = 0.35$) instructions about the discharge regimen. Similarly, inadequate health literacy was not associated with difficulty learning ($p = 0.26$) or retaining ($p = 0.97$) appropriate MDI technique. Results were similar in multivariable models adjusted for demographic characteristics and asthma severity indicators. **Conclusions:** These findings suggest that inadequate health literacy is a surmountable barrier to learning and remembering key asthma self-management skills.

75. Rothman, R. L., DeWalt, D. A., Malone, R., Bryant, B., Shintani, A., Crigler, B., et al. (2004). Influence of patient literacy on the effectiveness of a primary care-based diabetes disease management program. *Journal of the American Medical Association*, 292(14), 1711.

Context: Low literacy is an important barrier for patients with diabetes, but interventions to address low literacy have not been well examined. **Objective:** To examine the role of literacy on the effectiveness of a comprehensive disease management program for patients with diabetes.

Design, Setting, and Participants: Analysis of the influence of literacy on glycemic control and systolic blood pressure using data from a randomized controlled trial (conducted from February 2001 through April 2003) of a comprehensive diabetes management program. Participants were 217 patients aged 18 years or older with type 2 diabetes and poor glycemic control (glycosylated hemoglobin [HbA_{1c}] levels 8.0%) and presenting to a US academic general internal medicine practice. **Interventions:** All communication to patients was individualized and delivered to enhance comprehension among patients with low literacy. Intervention patients received intensive disease management from a multidisciplinary team. Control patients received an initial management session and continued with usual care. **Main Outcome Measures:** Achievement of goal HbA_{1c} levels and systolic blood pressure at 12-month follow-up for control and intervention patients stratified by literacy status.

Results: Complete 12-month data were available for 193 patients (89%). Among patients with low literacy, intervention patients were more likely than control patients to achieve goal HbA_{1c} levels (7.0%) (42% vs 15%, respectively; adjusted odds ratio [OR], 4.6; 95% confidence interval [CI], 1.3 to 17.2; $P = .02$). Patients with higher literacy had similar odds of achieving goal HbA_{1c} levels regardless of intervention status (24% vs 23%; adjusted OR, 1.0; 95% CI, 0.4 to 2.5; $P = .98$). Improvements in systolic blood pressure were similar by literacy status.

Conclusions: Literacy may be an important factor for predicting who will benefit from an intervention for diabetes management. A diabetes disease management program that addresses literacy may be particularly beneficial for patients with low literacy, and increasing access to such a program could help reduce health disparities.

76. Schillinger, D., Grumbach, K., Piette, J., Wang, F., Osmond, D., Daher, C., et al. (2002). Association of health literacy with diabetes outcomes. *Journal of the American Medical Association*, 288(4), 475.

Context: Health literacy is a measure of patients' ability to read, comprehend, and act on medical instructions. Poor health literacy is common among racial and ethnic minorities, elderly persons, and patients with chronic conditions, particularly in public-sector settings. Little is known about the extent to which health literacy affects clinical health outcomes.

Objectives: To examine the association between health literacy and diabetes outcomes among patients with type 2 diabetes.

Design, Setting, and Participants: Cross-sectional observational study of 408 English- and Spanish-speaking patients who were older than 30 years and had type 2 diabetes identified from the clinical database of 2 primary care clinics of a university-affiliated public hospital in San Francisco, Calif. Participants were enrolled and completed questionnaires between June and December 2000. We assessed patients' health literacy by using the short-form Test of Functional Health Literacy in Adults (s-TOFHLA) in English or Spanish.

Main Outcome Measures: Most recent hemoglobin A_{1c} (HbA_{1c}) level. Patients were classified as having tight glycemic control if their HbA_{1c} was in the lowest quartile and poor control if it was in the highest quartile. We also measured the presence of self-reported diabetes complications.

Results: After adjusting for patients' sociodemographic characteristics, depressive symptoms, social support, treatment regimen, and years with diabetes, for each 1-point decrement in s-TOFHLA score, the HbA_{1c} value increased by 0.02 ($P = .02$). Patients with inadequate health literacy were less likely than patients with adequate health literacy to achieve tight glycemic control (HbA_{1c} 7.2%; adjusted odds ratio [OR], 0.57; 95% confidence interval [CI], 0.32-1.00; $P = .05$) and were more likely to have poor glycemic control (HbA_{1c} 9.5%; adjusted OR, 2.03; 95% CI, 1.11-3.73; $P = .02$) and to report having retinopathy (adjusted OR, 2.33; 95% CI, 1.19-4.57; $P = .01$).

Conclusions: Among primary care patients with type 2 diabetes, inadequate health literacy is independently associated with worse glycemic control and higher rates of retinopathy. Inadequate health literacy may contribute to the disproportionate burden of diabetes-related problems among disadvantaged populations. Efforts should focus on developing and evaluating interventions to improve diabetes outcomes among patients with inadequate health literacy.

77. Schillinger, D. (2001). Improving the quality of chronic disease management for populations with low functional health literacy: a call to action. *Disease Management*, 4(3), 103-109.

Successful disease management is predicated on effective, systematic, interactive communication between a population of patients with the targeted disease and the providers and health system with whom they make contact. Despite a large body of literature exploring the key elements of effective physician-patient communication, little attention has been paid to the communication barriers that impede disease management efforts. Communication barriers can be challenging to those who design and implement

disease management programs. However, the nature of disease management offers tremendous opportunities to positively impact the health of vulnerable populations, the groups who most frequently struggle with communication barriers. The growing recognition of racial, ethnic, and socioeconomic disparities in health outcomes presents an opportunity for those in the quality improvement movement to reduce these disparities. To do so, we must develop a collaborative model of chronic disease care that includes input from a diverse patient population. We must optimize the health messages we share with these patients, and how we share them, to improve the quality of communication, and thus improve outcomes. This paper will (1) review functional health literacy (FHL), which is one measure of a patient's health communication facilities; (2) develop a framework for the association between FHL and the quality of chronic disease care; (3) explore the model of diabetes mellitus; and (4) describe potential health communication interventions to improve the quality of chronic disease management for patients with low FHL.

78. Schnipper, J. L., Roumie, C. L., Cawthon, C., Businger, A., Dalal, A. K., Mugalla, I., et al. (2010). Rationale and Design of the Pharmacist Intervention for Low Literacy in Cardiovascular Disease (PILL-CVD) Study. *Circulation: Cardiovascular Quality and Outcomes*, 3(2), 212.

Background: Medication errors and adverse drug events are common after hospital discharge due to changes in medication regimens, suboptimal discharge instructions, and prolonged time to follow-up. Pharmacist-based interventions may be effective in promoting the safe and effective use of medications, especially among high-risk patients such as those with low health literacy.

Methods and Results: The Pharmacist Intervention for Low Literacy in Cardiovascular Disease (PILL-CVD) study is a randomized controlled trial conducted at 2 academic centers—Vanderbilt University Hospital and Brigham and Women's Hospital. Patients admitted with acute coronary syndrome or acute decompensated heart failure were randomly assigned to usual care or intervention. The intervention consisted of pharmacist-assisted medication reconciliation, inpatient pharmacist counseling, low-literacy adherence aids, and tailored telephone follow-up after discharge. The primary outcome is the occurrence of serious medication errors in the first 30 days after hospital discharge. Secondary outcomes are health care utilization, disease-specific quality of life, and cost-effectiveness. Enrollment was completed September 2009. A total of 862 patients were enrolled, and 430 patients were randomly assigned to receive the intervention. Analyses will determine whether the intervention was effective in reducing serious medication errors, particularly in patients with low health literacy.

Conclusions: The PILL-CVD study was designed to reduce serious medication errors after hospitalization through a pharmacist-based intervention. The intervention, if effective, will inform health care facilities on the use of pharmacist-assisted medication reconciliation, inpatient counseling, low-literacy adherence aids, and patient follow-up after discharge.

79. Wolff, K., Cavanaugh, K., Malone, R., Hawk, V., Gregory, B. P., Davis, D., et al. (2009). The Diabetes Literacy and Numeracy Education Toolkit (DLNET): materials to facilitate

diabetes education and management in patients with low literacy and numeracy skills. *The Diabetes Educator*, 35(2), 233.

Purpose: Diabetes self-management education is an important component of comprehensive diabetes care. Patients with low health literacy and numeracy may have difficulty translating information from traditional diabetes educational programs and materials into effective self-care.

Methods: To address this potential barrier to successful diabetes teaching and counseling, the authors developed the Diabetes Literacy and Numeracy Education Toolkit (DLNET).

Conclusion: The DLNET is composed of 24 interactive modules covering standard diabetes care topics that can be customized to individual patient needs and used by all members of the multidisciplinary diabetes care team. The material's content and formatting aims to improve the ease of use for diabetes patients with low literacy and numeracy by adhering to a lower text reading level, using illustrations for key concepts, and color-coding and other accommodations to guide patients through instructions for self-care. Individual sections of the DLNET may be provided to patients for initial teaching, as well as for reinforcement. Although designed for lower literacy and numeracy skills, the DLNET provides unique materials to facilitate diabetes education for all patients.

b) Health literacy and self-management support among older populations:

80. Baker, D. W., Wolf, M. S., Feinglass, J., Thompson, J. A., Gazmararian, J. A., & Huang, J. (2007). Health literacy and mortality among elderly persons. *Archives of Internal Medicine*, 167(14), 1503.

Background: Individuals with low levels of health literacy have less health knowledge, worse self-management of chronic disease, lower use of preventive services, and worse health in cross-sectional studies. We sought to determine whether low health literacy levels independently predict overall and cause-specific mortality.

Methods: We designed a prospective cohort study of 3260 Medicare managed-care enrollees in 4 US metropolitan areas who were interviewed in 1997 to determine their demographic characteristics, chronic conditions, self-reported physical and mental health, and health behaviors. Participants also completed the shortened version of the Test of Functional Health Literacy in Adults. Main outcome measures included all-cause and cause-specific (cardiovascular, cancer, and other) mortality using data from the National Death Index through 2003.

Results: The crude mortality rates for participants with adequate (n = 2094), marginal (n = 366), and inadequate (n = 800) health literacy were 18.9%, 28.7%, and 39.4%, respectively ($P < .001$). After adjusting for demographics, socioeconomic status, and baseline health, the hazard ratios for all-cause mortality were 1.52 (95% confidence interval, 1.26-1.83) and 1.13 (95% confidence interval, 0.90-1.41) for participants with inadequate and marginal health literacy, respectively, compared with participants with adequate health literacy. In contrast, years of school completed was only weakly associated with mortality in bivariate analyses and was not significant in multivariate models. Participants with inadequate health literacy had higher risk-adjusted rates of cardiovascular death but not of death due to cancer.

Conclusions: Inadequate health literacy, as measured by reading fluency, independently predicts all-cause mortality and cardiovascular death among community-dwelling elderly persons. Reading fluency is a more powerful variable than education for examining the association between socioeconomic status and health.

81. Kaufman, D. R., Pevzner, J., Hilliman, C., Weinstock, R. S., Teresi, J., Shea, S., et al. (2006). Redesigning a telehealth diabetes management program for a digital divide seniors population. *Home Health Care Management & Practice, 18*(3), 223.

Recent advances in health information technologies promise to significantly improve the quality of care and quality of life for individuals who are chronically ill. However, significant challenges exist in targeting Digital Divide populations who are likely to be older, less educated, and novice computer users. This article presents a framework for understanding and reducing barriers for older adults to effectively use health information systems designed for disease management. The research is illustrated in the context of the IDEATel project, a large-scale telemedicine diabetes management and education program. The framework has three interdependent foci: hardware and software systems, tasks supported by the system, and user profiles. These foci are addressed in the context of usability and training studies. The studies document the challenges faced in facilitating patients' access to Web resources supporting disease management. The article discusses system design changes that are intended to increase participants' productive use of system resources.

c) Health literacy and self-management support for ethnocultural minority groups:

Ethnocultural minority groups have greater difficulty with SMS because many programs are not culturally sensitive/relevant and assume health literacy. Self-management interventions need to be targeted to ethnocultural minorities of all literacy levels.

82. Poureslami, I. M., Rootman, I., Balka, E., Devarakonda, R., Hatch, J., & FitzGerald, J. M. (2007). A systematic review of asthma and health literacy: a cultural-ethnic perspective in Canada. *Medscape General Medicine, 9*(3), 40.

Background: Asthma is one of the most common inflammatory lung diseases and its prevalence and incidence have increased in many developed and developing countries. Asthma places a heavy burden on healthcare expenditures and productivity, which in turn diminishes the quality of life of the individuals involved as well as their families. The goal of improving a patient's knowledge about asthma management should include the enhancement of the individual's skills with the hopeful outcome of improving how the individual manages the condition. However, when health professionals prepare a training program, they are faced with the challenging cosmopolitan reality of individuals with different ethnic backgrounds.

Methods: In order to find links between asthma and health literacy in a cultural/ethnicity perspective, we performed a systematic review of all publications on the topic of asthma, health, and literacy among cultural groups from 1980 to 2006 using the Internet and journals: Medline (Ovid), ERIC, EMBASE, PsycINFO, Google, Google Scholar, Sociological Abstracts, and Anthropology Plus. Key words included the following: "asthma," "culture," "ethnicity," "literacy," "health," "health literacy," "health beliefs,"

“adults,” “disease management,” “chronic condition,” “ethnocultural groups,” “minority groups,” and “newcomers/immigrants.”

Results: More than 650 articles were initially identified in our review; 65 met our inclusion criteria. From these, we examined the factors related to asthma and literacy/health literacy with a cultural lens. All of these are categorized and summarized below. We chose what we considered to be the most relevant and important articles/documents in the research literature to date. Because many of the studies were qualitative, a formal meta-analytic review was not undertaken. We found that current asthma management techniques – including patient education – are not culturally sensitive, linguistically sensitive, or relevant, which creates further difficulties for ethnocultural communities and minority groups in many Western countries. In this systematic review, several themes were identified, including: approaches to language limitation and cultural barriers; the recognition of healthcare system bias (in terms of culturally competent care); and relationship-building to facilitate participatory decision-making by both provider and patient. This review provides further understanding and considerations regarding the beliefs and perspectives of care providers and populations in relation to health and illness, literacy and health literacy, and their association with asthma among ethnocultural communities.

Conclusions: There is an urgent need to better define the impact of cultural and ethnic issues in the management of asthma in Canada. Appropriately designed studies should better define the barriers in the optimal delivery of asthma care influenced by these parameters.

83. Rosal, M. C., Goins, K. V., Carbone, E. T., & Cortes, D. E. (2004). Views and preferences of low-literate Hispanics regarding diabetes education: results of formative research. *Health Education & Behavior, 31*(3), 388.

Hispanics are twice as likely as non-Hispanic Whites to have diabetes and are also at higher risk for diabetes-related complications and poorer outcomes. The prevalence of diabetes is inversely related to educational status. Low literacy is common, especially among older Hispanics. Little literature exists on formative research to create diabetes education materials for this audience. Two focus groups assessed views and preferences for diabetes education of low-literate, low-income, non-English-speaking urban Caribbean and Central American Hispanics with diabetes, as well as utility of materials developed specifically for this population, as part of the preliminary work for a pilot study of a diabetes intervention. Implications for practitioners and researchers are discussed.

84. Sarkar, U., Fisher, L., & Schillinger, D. (2006). Is self-efficacy associated with diabetes self-management across race/ethnicity and health literacy? *Diabetes Care, 29*(4), 823.

Objective: Although prior research demonstrated that improving diabetes self-efficacy can improve self-management behavior, little is known about the applicability of this research across race/ethnicity and health literacy levels. We examined the relationship between diabetes self-efficacy and self-management behavior in an urban, diverse, low-income population with a high prevalence of limited health literacy.

Research Design and Methods: We administered an oral questionnaire in Spanish and English to patients with type 2 diabetes at two primary care clinics at a public hospital.

We measured self-efficacy, health literacy, and self-management behaviors using established instruments. We performed multivariate regressions to explore the associations between self-efficacy and self-management, adjusting for clinical and demographic factors. We tested for interactions between self-efficacy, race/ethnicity, and health literacy on self-management.

Results: The study participants were ethnically diverse (18% Asian/Pacific Islander, 25% African American, 42% Latino/a, and 15% white), and 52% had limited health literacy (short version of the Test of Functional Health Literacy in Adults score <23). Diabetes self-efficacy was associated with four of the five self-management domains ($P < 0.01$). After adjustment, with each 10% increase in self-efficacy score, patients were more likely to report optimal diet (0.14 day more per week), exercise (0.09 day more per week), self-monitoring of blood glucose (odds ratio 1.16), and foot care (1.22), but not medication adherence (1.10, $P = 0.40$). The associations between self-efficacy and self-management were consistent across race/ethnicity and health literacy levels.

Conclusions: Self-efficacy was associated with self-management behaviors in this vulnerable population, across both race/ethnicity and health literacy levels. However, the magnitude of the associations suggests that, among diverse populations, further study of the determinants of and barriers to self-management is warranted. Policy efforts should be focused on expanding the reach of self-management interventions to include ethnically diverse populations across the spectrum of health literacy.

85. Shaw, S. J., Huebner, C., Armin, J., Orzech, K., & Vivian, J. (2009). The Role of Culture in Health Literacy and Chronic Disease Screening and Management. *Journal of Immigrant and Minority Health, 11*(6), 460-467.

Cultural and language differences and socioeconomic status interact with and contribute to low health literacy, defined as the inability to understand or act on medical/therapeutic instructions. Health literacy is increasingly recognized as an important factor in patient compliance, cancer screening utilization, and chronic disease outcomes. Commendable efforts have been initiated by the American Medical Association and other organizations to address low health literacy among patients. Less work has been done, however, to place health literacy in the broader context of socioeconomic and cultural differences among patients and providers that hinder communication and compliance. This review examines cultural influences on health literacy, cancer screening and chronic disease outcomes. We argue that cultural beliefs around health and illness contribute to an individual's ability to understand and act on a health care provider's instructions. This paper proposes key aspects of the intersection between health literacy and culturally varying beliefs about health which merit further exploration.

86. Thackeray, R., Merrill, R. M., & Neiger, B. L. (2004). Disparities in diabetes management practice between racial and ethnic groups in the United States. *The Diabetes Educator, 30*(4), 665.

Purpose: The purpose of this study was to evaluate the association between race/ethnicity and self-management practices of people with diabetes. Methods: Analyses were based on data from the 2001 Behavioral Risk Factor Surveillance System. Contingency tables and multiple logistic regression were used to assess the data. Results: Frequency distributions of selected diabetes management variables significantly varied across levels

of race/ethnicity. These differences persisted after adjusting for current age, age at diagnosis, gender, marital status, income, and education. Analyses revealed that Hispanics, compared with whites, were more likely to take oral agents to control their blood glucose, less likely to monitor their blood glucose daily, and less likely to check their feet for sores or irritation. There was no difference among the racial/ethnic groups use having participated in a diabetes education class. Conclusions: Health literacy and cultural factors, including the influence of family, beliefs about diabetes, and access and utilization of health care, may influence Hispanic diabetes management behaviors. Understanding these influences is essential to the development of programs, policies, and other strategies that are culturally appropriate and relevant.

d) Health literacy and self-management support among ethnocultural minority older adults:

Two articles investigate aspects of SMS among older African Americans.

87. Kripalani, S., Henderson, L. E., Chiu, E. Y., Robertson, R., Kolm, P., & Jacobson, T. A. (2006). Predictors of medication self-management skill in a low-literacy population. *Journal of General Internal Medicine, 21*(8), 852-856.

Background: Patients' ability to manage medications is critical to chronic disease control. Also known as medication management capacity (MMC), it includes the ability to correctly identify medications and describe how they should be taken. Objective: To evaluate the effects of low literacy, medication regimen complexity, and sociodemographic characteristics on MMC. Design: Cross-sectional analysis of enrollment data from participants in a randomized trial. Participants: Patients with coronary heart disease in an inner-city clinic. Measurements: Medication management capacity was measured with the Drug Regimen Unassisted Grading Scale (DRUGS), which scores subjects' ability to identify, open, describe the dose, and describe the timing of their medications. DRUGS overall and component scores were compared by literacy. Mini Mental State Exam score, regimen complexity (number of prescription medications), and sociodemographic characteristics. Results: *Most of the 152 participants were elderly (mean age 65.4 years), women (54.6%), and African American (94.1%).* Approximately half (50.7%) had inadequate literacy skills, and 28.9% had marginal skills. In univariate analysis, MMC was significantly associated with literacy ($P < .001$), and this effect was driven by the ability to identify medications. In multivariable models, patients with inadequate literacy skills had 10 to 18 times the odds of being unable to identify all of their medications, compared with those with adequate literacy skills ($P < .05$). Conclusions: Adults with inadequate literacy skills have less ability to identify their medications. Techniques are needed to better educate low-literacy patients about their medications, as a potential strategy to enhance adherence.

88. Ntiri, D. W., & Stewart, M. (2009). Transformative Learning Intervention: Effect on Functional Health Literacy and Diabetes Knowledge in Older African Americans. *Gerontology & Geriatrics Education, 30*(2), 100-113.

This study evaluated the effect of a transformative learning (TL) intervention on functional health literacy and diabetes knowledge in older African Americans. Twenty participants from senior community centers completed a six-session intervention. The

short-form Test of Functional Health Literacy in Adults (s-TOFHLA), Literacy Assessment for Diabetes (LAD), and Diabetes Knowledge Test (DKT) were used to perform pre- and postmeasurements. Postintervention s-TOFHLA scores and DKT scores were significantly increased ($p < .5$). Participants' verbal responses further affirmed the positive influence of the TL principles.

F. Complementary and Alternative Medicine (CAM) and self-management support

The National Centre for Complementary and Alternative Medicine (National Institutes of Health – UK) defines CAM as, “a group of diverse medical and health care systems, practices, and products that are not generally considered to be part of conventional medicine.” CAM therapies are diverse and are supported by different levels of conventional Western scientific evidence.

Complementary medicine is used alongside conventional or “allopathic” medicine for treatment purposes. Alternative medicine, however, is used in place of allopathic medicine. A particular treatment may fall into either category depending on the means of its usage.

a) CAM & SMS among older adults

Three articles are presented here: one is a general look at CAM therapy use among community-dwelling older adults in the United States, and the other two examine the use of CAM among older adults with arthritis. All three studies determine that CAM is a common form of therapy among older adults, especially for the purposes of treating chronic health conditions.

89. Cheung, C. K., Wyman, J. F., & Halcon, L. L. (2007). Use of complementary and alternative therapies in community-dwelling older adults. *The Journal of Alternative and Complementary Medicine*, 13(9), 997-1006.

Objectives: Although complementary and alternative medicine (CAM) use is becoming increasingly prevalent in the United States, knowledge regarding complementary and alternative therapy use in older adults is limited. The purposes of this study were to (1) assess the prevalence and patterns of CAM use in a probability-based sample of older adults; (2) describe the characteristics of older CAM users; and (3) identify factors associated with complementary and alternative medicine use/nonuse.

Methods: A cross-sectional survey design was used. An age-stratified sample of community-dwelling adults ages ≥ 65 ($N = 1200$) was randomly selected from the Minnesota Driver's License/Identification Tape using names from the Twin Cities seven-county metropolitan area. The mailed questionnaire included items on demographics, health status, health care utilization, CAM modality use, reasons for use, costs, and complementary and alternative therapy use satisfaction. Descriptive statistics, chi-square tests, and regression analysis were performed.

Results: Overall, 62.9% ($N = 445$) of the respondents reported use of one or more complementary and alternative medicine modalities with an average of three modalities ($SD \pm 1.9$, range 1–11). The top five CAM modalities used were nutritional supplements (44.3%), spiritual healing/prayer (29.7%), megavitamins (28.3%), herbal supplements (20.7%), and chiropractic (17.8%). Maintaining health and treating a health condition were the primary reasons for CAM use. The most common conditions treated were arthritis (44.4%) and chronic pain (23.5%). Demographic variables were not significantly

different between CAM users and nonusers. CAM users reported more unhealthy days than nonusers did. Overall satisfaction with CAM use was high (80%). Symptoms of a health problem and desire for personal control over health motivated CAM use. The main barriers to CAM use were lack of reason to use and knowledge about CAM. Only 53% of users disclosed CAM use to their primary care providers.

Conclusions: CAM use is common in older adults, especially those with health problems. The widespread use of oral supplements combined with not disclosing CAM use to primary care providers is a concern.

90. Kaboli, P. J., Doebbeling, B. N., Saag, K. G., & Rosenthal, G. E. (2001). Use of complementary and alternative medicine by older patients with arthritis: a population based study. *Arthritis Care & Research*, 45(4), 398-403.

Objective: To determine the prevalence of complementary and alternative medicine (CAM) use and to identify factors associated with its use in older patients with arthritis. Methods: A population-based telephone survey of 480 elderly patients with arthritis was conducted to determine demographics, comorbidities, health status, arthritis symptoms, and the use of CAM and traditional providers and treatments for arthritis.

Results: CAM provider use was reported by 28% of respondents, and 66% reported using one or more CAM treatments. Factors independently related to CAM provider use ($P < 0.05$) included podiatrist or orthotist use, physician visits for arthritis, and fair or poor self-reported health. For CAM treatments, independent associations were found with physical or occupational therapist use, physician visits for arthritis, chronic obstructive pulmonary disease, and alcohol abstinence. Rural residence, age, income, education, and health insurance type were unrelated to CAM use.

Conclusion: Many older patients with arthritis reported seeing CAM providers, and most used CAM treatments. The use of CAM for arthritis was most common among those with poorer self-assessed health and higher use of traditional health care resources.

91. Ramsey, S. D., Spencer, A. C., Topolski, T. D., Belza, B., & Patrick, D. L. (2001). Use of alternative therapies by older adults with osteoarthritis. *Arthritis Care & Research*, 45(3), 222-227.

Objective: To examine the rates of use and expenditures on alternative therapies by adults with osteoarthritis (OA).

Methods: Adults with OA recruited from the community to participate in a randomized clinical trial recorded alternative and traditional health care use on postcard diaries. General and arthritis-specific quality of life was assessed by questionnaires.

Results: More than 47% of participants reported using at least one type of alternative care during the 20-week intervention period. Among alternative care consumers, the most commonly used treatments were massage therapy (57%), chiropractic services (20.7%), and nonprescribed alternative medications (17.2%). Four percent of subjects reported using only alternative care during the study period. Expenditures for alternative therapy averaged \$1,127 per year, compared with \$1,148 for traditional therapies.

Conclusion: Use of and expenditures for alternative care were high among this cohort of older adults with OA. Clinicians may want to inquire about use of these therapies before recommending treatments for this condition.

b) CAM & SMS among ethnic minority populations

Most of the available literature on CAM use for chronic disease SMS among ethnic minority populations is focused on arthritis. A comparative study of four ethnic groups on CAM use for osteoarthritis found a high overall use of CAM that varied by ethnic group. A Canadian study found that arthritis management strategies among Chinese immigrants in Calgary follow a predictable pattern blending allopathic with traditional Chinese medicine.

92. Herman, C. J., Dente, J. M., Allen, P., & Hunt, W. C. (2006). Peer Reviewed: Ethnic Differences in the Use of Complementary and Alternative Therapies Among Adults With Osteoarthritis. *Preventing Chronic Disease*, 3(3)

Introduction: The use of complementary and alternative medicine (CAM) in the United States has been rising steadily, especially among people with chronic conditions such as osteoarthritis. It has been suggested that ethnicity and acculturation may influence use of CAM. The purpose of this study was to assess the influence of ethnicity and acculturation on patterns of CAM use among Hispanic and non-Hispanic white adults with osteoarthritis.

Methods: We conducted interviews in person, in English or Spanish, using a 255-item survey. We randomly selected participants aged 18 to 84 years from patients at university-based primary care outpatient clinics who had been diagnosed with osteoarthritis during the previous year. Measures included prevalence and types of CAM use, sociodemographic factors, self-reported ethnicity, and degree of acculturation according to language use.

Results: The Hispanic (n = 218) and non-Hispanic white (n = 204) populations showed similar rates of overall current CAM use (65.5% Hispanic vs 67.8% NHW) at time of interview. However, although more Hispanics used oral herbs ($P = .03$) and magnets or copper jewelry ($P = .03$), more non-Hispanic whites used nutritional supplements ($P < .001$). Hispanics speaking primarily English mirrored patterns of CAM use among non-Hispanic whites. These effects persisted after controlling for age, sex, income, education, degree of disability, and disease duration.

Conclusion: In this population, ethnicity was a significant influence on patterns of CAM use but did not affect overall rates of use. Some differences were more pronounced among Spanish-speaking Hispanics, reflecting the incorporation of folk or traditional remedies into their health care practices.

93. Katz, P., & Lee, F. (2007). Racial/ethnic differences in the use of complementary and alternative medicine in patients with arthritis. *JCR: Journal of Clinical Rheumatology*, 13(1), 3.

Objective: To examine use of complementary and alternative medicine (CAM) by individuals with osteoarthritis (OA) from 4 ethnic groups, differences in CAM use among groups, and correlates of CAM use.

Methods: Data were obtained from individuals from 4 ethnic groups (African, Asian, and Hispanic Americans, and Caucasians) participating in trials assessing celecoxib efficacy. A questionnaire assessing CAMs specifically used to help arthritis was administered at screening. Use of 42 specific therapies within 7 categories-alternative medical systems, mind-body interventions, manipulation and body-based methods, energy therapies, and 3

types of biologically based therapies-was queried.

Results: More than 80% of subjects reported that they used some CAM for arthritis in the past month. In contrast, 50% reported the use of prescription medicines, and 52% reported the use of over-the-counter medicines. Dietary practices were the most common type of CAM (71.5%), followed by mind-body interventions (42.4%), topical agents (38.1%), use of supplements or herbs (32.9%), and manipulation and body-based methods (21.4%). African Americans were more likely to report any CAM use than other groups (89.1% versus 83.1% [Asian], 81.1% [Hispanic], 77.7% [Caucasian]). African and Asian Americans more commonly reported the use of mind-body interventions in general, and prayer in particular. African Americans were also most likely to report the use of topical agents. Asian Americans were most likely to report use of alternative medical systems, manipulation methods, and supplements. Caucasians were least likely to report use of dietary practices.

Conclusion: Individuals with OA commonly use CAM. Use of these therapies varies by racial/ethnic group. Some CAMs may be effective for symptom relief, while others may interact with prescription medications, suggesting that routine queries by physicians concerning CAM use would be beneficial.

94. Zhang, J., & Verhoef, M. J. (2002). Illness management strategies among Chinese immigrants living with arthritis. *Social Science & Medicine*, 55(10), 1795-1802.

The purpose of this qualitative study was to explore arthritis management strategies among Chinese immigrants in Calgary, Canada, and to assess factors, that impact on these strategies. Purposive sampling was used to select 19 Chinese immigrants living with arthritis. Data were collected by means of in-depth interviews. The interview data were analyzed according to the following steps: (1) transcribing interview materials, (2) developing codes, categories and themes, (3) theoretical coding, and (4) laying out the theoretical framework. The results of this study describe factors, that impacted on illness management strategies. These include arthritic symptoms, beliefs about arthritis, beliefs about Western medicine based on treatment experience, beliefs about Chinese medicine, perceived barriers to using Chinese or Western medicine and social support. The emerging process of illness management shows that immigrants usually started using self-care remedies, followed by consulting Western physicians, consulting Chinese healers, and then returning to Western medicine. The results illustrate that disease management strategies among Chinese immigrants are impacted by disease, personal and cultural factors. These factors suggest helpful directions to providing culturally sensitive care, which can lead to greater satisfaction and well being for Chinese immigrants with arthritis.

c) CAM and SMS among EMOA

The literature documenting CAM use among EMOA specifically for chronic disease management purposes is limited. The available literature suggests that CAM use for chronic disease self-management depends on the availability and suitability of allopathic medicine.

95. Applewhite, S. L. (1995). Curanderismo: Demystifying the health beliefs and practices of elderly Mexican Americans. *Health and Social Work, 20*(4)

Effective health care intervention with various ethnic groups requires special attention to cultural differences. This is especially true for elderly Mexican Americans, many of whom retain a strong attachment to indigenous values, including those about health care. Culturally specific beliefs and attitudes about folk healing play an essential role in elderly Mexican Americans' approach to their own health and use of health care resources. Despite this fact, little knowledge is available about the role of folk healing in the lives of this population.

96. Arcury, T. A., Bell, R. A., Snively, B. M., Smith, S. L., Skelly, A. H., Wetmore, L. K., et al. (2006). Complementary and alternative medicine use as health self-management: rural older adults with diabetes. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 61*(2), S62.

Objectives: This study describes complementary and alternative medicine (CAM) use among rural older adults with diabetes, delineates the relationship of health self-management predictors to CAM therapy use, and furthers conceptual development of CAM use within a health self-management framework.

Methods: Survey interview data were collected from a random sample of 701 community dwelling African American, Native American, and White elders residing in two rural North Carolina counties. We summarize CAM use for general use and for diabetes care and use multiple logistic modeling to estimate the effects of health self-management predictors on use of CAM therapies.

Results: The majority of respondents used some form of CAM for general purpose, whereas far fewer used CAM for diabetes care. The most widely used CAM categories were food home remedies, other home remedies, and vitamins. The following health self-management predictors were related to the use of different categories of CAM therapies: personal characteristics (ethnicity), health status (number of health conditions), personal resources (education), and financial resources (economic status).

Discussion: CAM is a widely used component of health self-management among rural older adults with diabetes. Research on CAM use will benefit from theory that considers the specific behavior and cognitive characteristics of CAM therapies.

97. Cherniack, E. P., Senzel, R. S., & Pan, C. X. (2001). Correlates of use of alternative medicine by the elderly in an urban population. *The Journal of Alternative & Complementary Medicine, 7*(3), 277-280.

Objective: To investigate the prevalence and predictors of use of complementary and alternative medicine (CAM) by the elderly.

Design: Cross-sectional survey examining patterns of use of complementary therapies in two urban multiethnic populations of older adults.

Setting and Subjects: A convenience sample of 421 older participants were interviewed at two sites: a university geriatrics primary care practice and a veterans medical clinic, both in New York City. Subjects were excluded if they did not speak English or if they were moderately cognitively impaired.

Measurement: Use of CAM within the previous year.

Results: Fifty-eight percent (58%) of all subjects surveyed used some form of CAM, and close to 75% at the university practice alone. Use correlated most strongly with female gender ($p < 0.0001$), greater education ($p = 0.0095$), thyroid disease ($p = 0.0190$) and arthritis ($p = 0.0251$). There was no correlation with income, race, age, or self-perceived health status.

Conclusions: CAM use is highly prevalent in older persons in this study, especially among females and those who are more highly educated.

98. Dickson, G. L., & Kim, J. I. (2003). Reconstructing a meaning of pain: Older Korean American women's experiences with the pain of osteoarthritis. *Qualitative Health Research, 13*(5), 675.

The purpose of this grounded theory study was to gain a deeper understanding of older Korean American women's experiences of chronic osteoarthritic pain. The data included a set of 3 interviews with 7 women over age 60, field notes, observations, memos, and the literature about the chronic pain of osteoarthritis. Through constant comparative analysis and coding typical of grounded theory, a five-stage process emerged inductively from the data. The core variable, Reconstructing a Meaning of Pain, included the concepts of the process in the grounded theory through which the women learned to manage and tolerate the pain. During this process, the women came to perceive their pain as a component of aging rather than as a symptom of disease.

99. Huang, L. (2007). Chinese culture versus Western medicine: Health implications for San Francisco elder Chinese immigrants with heart failure. PhD Dissertation, Walden University.

The purpose of this ethnographic study was to explore cultural beliefs of elder Chinese immigrants toward Western medication regimens as few studies were conducted in this area. Hypertension among elder Chinese immigrants is a growing problem in San Francisco with its leading complication of heart failure. This study was designed to reveal any cultural variables that may promote or interfere with medication adherence in the elder immigrants in San Francisco. Six participants with a history of heart failure were recruited from a clinic in San Francisco. Cultural views were obtained based on data from observation and interviews and grouped into specific categories by software NUDIST with analysis under the guidance of Johnson's behavioral system model and social epidemiological concepts. This study explored inter and intracultural factors that might enable or hinder Western medication adherence behavior. The study found Western medication adherence in elder Chinese immigrants with heart failure can be affected by traditional Chinese and adapted beliefs from U.S. migration toward acute and chronic disease management. This study lends itself to social change by documenting the problems of inadequate communication between Western and Chinese practitioners and emphasizing the critical importance of integration through understanding and utilization of traditional as well as adapted Chinese cultural values. Biases of the study included the convenience and small sample size. As a further step toward social change, the study suggested the importance of future research on Western medication adherence in different geographically located subcultural group of elder Chinese immigrants with heart failure.

100. Loera, J. A., Black, S. A., Markides, K. S., Espino, D. V., & Goodwin, J. S. (2001). The use of herbal medicine by older Mexican Americans. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 56(11), M714.

Background: Little is known about use of herbal medicines by older Mexican Americans. The objective of this study was to determine the characteristics among older Mexican Americans that correlate with use of herbal medicines.

Methods: We administered a cross-sectional regional sample survey, the 1993-1994 Hispanic Established Populations for the Epidemiologic Study of the Elderly of Mexican Americans, by in-home interviews of noninstitutionalized older Mexican Americans age 65 and over living in Texas, New Mexico, Colorado, Arizona, and California.

Results: The use of herbal medicine in the 2 weeks prior to the interview was reported by 9.8% of the sample. Chamomile and mint were the two most commonly used herbs.

Users of herbal medicines were more likely to be women, born in Mexico, over age 75, living alone, and experiencing some financial strain. Having arthritis, urinary incontinence, asthma, and hip fracture were also associated with an elevated use of herbal medicines, whereas heart attacks were not. We found that herbal medicine use was substantially higher among individuals reporting any disability in activities of daily living, poor self-reported health, and depressive symptoms. Herbal medicine use was associated with the use of over-the-counter medications but not with prescription medications. Herbal medicine use was particularly high among respondents who had over 24 physician visits during the year prior to interview.

Conclusions: Herbal medication use is common among older Mexican Americans, particularly among those with chronic medical conditions, those who experience financial strain, and those who are very frequent users of formal health care services.

101. Mikuls, T. R., Mudano, A. S., Pulley, L. V., & Saag, K. G. (2003). The association of race/ethnicity with the receipt of traditional and alternative arthritis-specific health care. *Medical Care*, 41(11), 1233-1239.

Background: The role of race/ethnicity in the receipt of arthritis-specific health care has not been well defined.

Objective: To examine the association of race/ethnicity with the utilization of arthritis health care among community-dwelling older adults.

Research Design: We used a computer-assisted telephone interview.

Subjects: A population-based random sample was drawn from 6 preselected Alabama counties. Eligible respondents had self-reported arthritis and were over 50 years of age; 1424 people responded to the survey.

Measures: Logistic regression was used to examine the association of race/ethnicity with the use of conventional (including use of a rheumatologist, primary care physician, and prescription arthritis medicines) and complementary and alternative medicines (CAM), including the use of chiropractic care, glucosamine and/or chondroitin, and herbals.

Results: Reflecting stratified sampling, respondents were white (n = 852, 60%) or black (n = 528, 37%), female (72%), and had a mean age of 65 years. After multivariable adjustment, race/ethnicity was not a significant determinant of receiving rheumatology care or prescription arthritis medicines. However, whites were more likely than blacks to have seen a primary care physician for arthritis care (adjusted odds ratio [OR], 1.49; 95%

confidence interval [CI], 1.12-1.98) or to have used CAM (OR, 1.47; 95% CI, 1.13-1.91) and twice as likely to have used glucosamine and/or chondroitin (OR, 1.99; 95% CI, 1.30-3.05).

Conclusion: In this population of community-dwelling older adults, white race was significantly associated with CAM use and visits to primary care physicians for arthritis care. In contrast, the use of specialists and prescription arthritis medications was better explained by factors other than race/ethnicity, which included female gender, urban residence, higher educational level, and other arthritis-specific variables.

102. Najm, W., Reinsch, S., Hoehler, F., & Tobis, J. (2003). Use of complementary and alternative medicine among the ethnic elderly. *Alternative Therapies in Health and Medicine*, 9(3), 50-57.

Objective: We sought to explore whether the elderly are high users of complementary and alternative medicine (CAM), and to determine which modalities they use. We also sought to describe patterns and positive predictors of CAM use among 3 ethnically diverse groups of community-residing elderly.

Design: A 7-page questionnaire was developed and translated into Spanish and Vietnamese.

Participants: A population of 525 community-residing elderly completed personal interviews.

Results: Two hundred and fifty-one respondents (47.8%) reported using CAM over the past year. Dietary supplements (47.4%), chiropractic (16.3%), home remedies (15.9%), acupuncture (15.1%), and Oriental medicine (12.8%), were the most frequently cited therapies. The majority of CAM users (62.4%) did not inform their physicians that they were using it, but 58% consulted their physician for the same problem for which they used CAM. Family and friends were most relied upon for making the choice of therapy. Among the 3 ethnic groups studied, Asians were higher users of acupuncture (28%) and Oriental medicine (31%), Hispanics were higher users of dietary supplements (56%), home remedies (25%), and curanderos (8%), while white non-Hispanics were higher users of chiropractic (42%), massage (20%), vitamins (20%), diet (17%), and psychospiritual (15%) modalities. Pain was a higher indicator of CAM use among Asians, gastrointestinal problems and diabetes among Hispanics, and stress/fatigue and cardiovascular problems among white non-Hispanics.

Conclusions: Findings indicated a high use of CAM among the elderly and emphasize the likelihood that elderly immigrants use those therapies with which they are familiar.

Modalities and conditions varied with the ethnicity of respondents.

103. Pourat, N., Lubben, J., Wallace, S. P., & Moon, A. (1999). Predictors of use of traditional Korean healers among elderly Koreans in Los Angeles. *The Gerontologist*, 39(6), 711.

Many ethnic groups are known to use traditional healers often in conjunction with Western biomedical medicine, thus combining treatment regimens and medical advice as they see fit. Awareness of the use of traditional healers is an increasingly salient issue due to the growing diversity and aging of the U.S. population. To explore the determinants of use of traditional healers, we studied demographics, health status, and social support networks of a representative sample of elderly Koreans in Los Angeles County,

California. The results revealed that chronic conditions such as arthritis, lung disease, and stomach pain, fewer depressive symptoms, availability of health insurance, and stronger social networks were significant predictors of use of traditional healers. Better understanding reasons for and patterns of health care use may enhance the delivery of care to the heterogeneous elderly population by preventing potential treatment complications and increasing health providers' cultural sensitivity.

104. Schoenberg, N. E., Stoller, E. P., Kart, C. S., Perzynski, A., & Chapleski, E. E. (2004). Complementary and alternative medicine use among a multiethnic sample of older adults with diabetes. *Journal of Alternative & Complementary Medicine, 10*(6), 1061-1066.

Objective: This study describes complementary and alternative medicine (CAM) use for diabetes self-management among a multiethnic sample with an aim of better understanding lay perspectives on CAM's utility and determining whether CAM practices undermine conventional diabetes self-management.

Design: During in-depth interviews with 80 older adults, data were collected on sociodemographics, the full range of self-management practices, and attitudes toward CAM. Analysis included descriptive measures of association and line-by-line coding.

Setting/location: Trained interviewers recruited respondents from four health or social service sites. Sites were selected because they contained a large clientele of the targeted ethnic group and had been involved successfully in previous research studies.

Subjects: Twenty (20) adults age 50 and older from each of the groups most adversely affected by diabetes (African Americans, Hispanics, Native Americans, rural whites) participated in the study.

Outcome measures: Self-management strategies (included CAM) were assessed through a semistructured interview guide. Structured instruments obtained data on sociodemographics and health history. The 15-item Summary of Diabetes Self-Care Activities Questionnaire (SDSCA) assessed the frequency of completing recommended self-management activities.

Results: One in four elders reported using CAM, with respondents' cultural background associated with the CAM modality. We found no relationship between standard biomedical regimens and CAM use, supporting respondents' suggestion that CAM supplements rather than substitutes for biomedical self-management. Respondents suggested that use of CAM was limited by CAM's inaccessibility, and, underlying all, the dominance of conventional biomedical therapies that undermines belief in CAM's effectiveness.

Conclusion: Older adults with diabetes use a flexible configuration of diabetes–self-management techniques, including culturally specific CAM modalities. CAM use, however, occupies a limited role in diabetes self-management, largely because of the predominance of conventional biomedical regimens.

105. Tjam, E. Y., & Hirdes, J. P. (2002). Health, psycho-social and cultural determinants of medication use by Chinese-Canadian older persons. *Canadian Journal on Aging, 21*(1), 63-73.

Explored health, psychosocial, and cultural determinants of the use of traditional Chinese medicines (TCM) and Western medicines among Chinese Canadian older adults. One

hundred six Chinese older adults living in Canada completed face-to-face interviews that included a Chinese version of the Minimum Data Set for Home Care and supplementary questionnaires. All medications including TCM, prescription, and over-the-counter medications were reviewed and recorded. Multivariate regression models found that those experiencing pain symptoms were almost 10 times more likely to use TCM than those without pain. The odds of using TCM for those that were hospitalized were 15 times greater than for those not hospitalized. A curvilinear association between use of TCM and health beliefs was found. Living with a child, physical health problems, and number of diseases were associated with Western medicine use. Both experiencing pain symptoms and previous hospitalization increased the odds of combined use of TCM and Western medicine. Living with a child was significantly associated with a reduced likelihood of combining TCM and Western medicines. Results suggest that targeting pain and social isolation, as well as an education program focusing on the importance of preventive health, will be important in helping Chinese Canadian older adults. (AR) (AgeLine Database, copyright 2002 AARP, all rights reserved)

G. Self-management support and capacity building/community development

While this list by no means professes to be an exhaustive review of the literature available on the topic of SMS and capacity building/community development, we did find that a very limited number of articles dealt simultaneously with the concepts of EMOA, SMS, and capacity building/community development. The one article below that deals with all of these concepts comes from the United States and focuses on a Latin American population in Texas.

a) Self-management support and capacity building/community development among older populations

The following article points the age-specificity of certain medical and functional states and social determinants of health that influence the provision of care to older adults and the multiple community-based strategies needed to address them.

106. Haas, L.B. (2006). [Caring for Community-Dwelling Older Adults with Diabetes: Perspectives from Health Care Providers and Caregivers. *Diabetes Spectrum*, 19\(4\), 240-244.](#)

Most elderly people with diabetes are community dwelling and cared for by local health care providers and frequently by caregivers within the elders' homes. Care for these elders is often suboptimal compared with that of elderly people without diabetes. Issues include polypharmacy, decreased cognition, deficiencies in activities of daily living, functional impairment, decreased health literacy, depression, financial problems, and increased risk of falling. Strategies to address these issues should be part of health care providers' practice. Providers can also assist the caregivers of elderly patients by including them in the medical plan, identifying support systems, providing respite, and acknowledging their value. Many community and governmental resources are available and may be helpful for elderly patients with diabetes.

b) Self-management support and capacity building/community development for ethnocultural minority groups

The following article is of interest because it explores an alternate approach to self-management education for ethnocultural minority populations dealing with diabetes.

107. Greenhalgh, T., Campbell-Richards, D., Vijayaraghavan, S., Collard, A.P., Malik, F., et al (2009). *The Sharing Stories Model of Diabetes Self Management Education for Minority Ethnic Groups: A Pilot Randomised Controlled Trial*. London: Queen's Printer and Controller of HMSO 2007.

Storytelling has attracted interest among diabetes educators as a potentially effective element of culturally tailored education (Greenhalgh, Collard, & Begum 2005b; Utz et al. 2008; Willging, Helitzer, & Thompson 2006). The involvement of the patient in his or her own care is a popular theme in chronic disease management. Lay led 'expert patient' programmes oriented to increasing self-efficacy are widely encouraged (Donaldson 2003). But recruitment to such programmes from lower socio-economic and minority ethnic groups tends to be poor outside the research setting (Greenhalgh 2009), and recent systematic reviews have highlighted the mismatch between policy enthusiasm and the evidence base (Foster et al. 2007; Newbould, Taylor, & Bury 2006; Warsi et al. 2004). Group education in diabetes, when intensively delivered, culturally tailored, and closely linked to clinical care, improves long-term outcomes (Hawthorne et al. 2008; Loveman, Frampton, & Clegg 2008b; Trento et al. 2004). But again, attendance is typically low outside the research setting, especially amongst 'hard to reach' patients such as limited English speakers and those with low health literacy. Lay led, community based peer support sessions for minority ethnic groups are popular and well attended in USA but have not yet been evaluated in adequately powered randomised trials (Feathers et al. 2007; Utz, Williams, Jones, Hinton, Alexander, Yan, Moore, Blankenship, Steeves, & Oliver 2008).

c) Self-management support and capacity building/community development among ethnocultural minority older adults

108. Sotomayor, M., Pawlik, F., Dominguez, A. (2007). *Building Community Capacity for Health Promotion in a Hispanic Community*. *Preventing Chronic Disease*, 4(1), 1-8.

The Latino Education Project (LEP) is conducting a multilevel Racial and Ethnic Approaches to Community Health (REACH) 2010 diabetes prevention project in Nueces County, one of 12 counties located in the Coastal Bend area of south Texas. Nueces County is characterized by high levels of poverty and diabetes-related complications and disability. The LEP chose a community capacity-building approach to diabetes prevention and health promotion to help midlife and elderly *Latinos increase their ability to prevent, control, and manage diabetes and associated disabilities*.

d) Patient empowerment in self-management

The following article outlines models of patient empowerment in chronic disease self-management. This study has been included because of its implications for considering the necessary components of an alternative SMS model suitable for EMOA.

109. Aujoulat, I., Marcolongo, R., Bonadiman, L., & Deccache, A. (2008). Reconsidering patient empowerment in chronic illness: A critique of models of self-efficacy and bodily control. *Social Science & Medicine*, 66(5), 1228-1239.

Studies that focus on patient empowerment tend to address more specifically two issues of patients' experience of illness: managing regimens and relating to health-care providers. Other aspects of illness experience, such as coming to terms with disrupted identities, tend to be overlooked. The outcome of empowerment is therefore usually referred to as achieving self-efficacy, mastery and control. We conducted an inductive exploratory study, based on individual in-depth interviews with 40 chronically ill patients in Belgium and Italy, in order to understand the process of empowerment as it may occur in patients whose experience of illness has at some point induced a feeling of powerlessness, which we conceptualised as a threat to their senses of security and identity. Our findings show that empowerment and control are not one and the same thing. We describe patient empowerment as a process of personal transformation which occurs through a double process of (i) "holding on" to previous self-representations and roles and learning to control the disease and treatment, so as to differentiate one's self from illness on the one hand, and on the other hand (ii) "letting go", by accepting to relinquish control, so as to integrate illness and illness-driven boundaries as being part of a reconciled self. Whereas the process of separating identities ("holding on") was indeed found to be linked to efforts aimed at taking control and maintaining or regaining a sense of mastery, the process of reconciling identities ("letting go") was found to be linked to a need for coherence, which included a search for meaning and the acceptance that not everything is controllable. We argue that the process of relinquishing control is as central to empowerment as is the process of gaining control. As a "successful" process of empowerment occurs when patients come to terms with their threatened security and identity, not only with their treatment, it may be facilitated by health-care providers through the use of narratives.

Discussion

State of knowledge on self-management support for ethnocultural minority older adults

Literature on SMS for EMOA is sparse and varied. Two evaluations of the CDSMP for older African-Americans indicate some improvements in health behaviours and health status, slight or no improvement in self-efficacy, and no change in health service utilization.^{8,9}

Unfortunately, viable alternative models of SMS for EMOA do not appear to exist. The chronic disease SMS literature specific to this population primarily examines the more informal self-care practices of these populations. One study on SMS among an older Korean

American group found that in addition to the structured behavioral education component common to traditional self-management programs, home self-management supported by visits and monthly support groups facilitated by a bilingual nurse enhanced self-management.¹⁰

Clearly SMS models for EMOA must consider barriers to health service access faced by these populations. Cultural competency within SMS service delivery therefore must extend beyond translated program materials into an understanding of the cultural context of the chronic disease experience (i.e. how does the concept of self-efficacy – which has poor uptake among EMOA – translate into different cultural scenarios)?

SMS for marginalized populations: What works and what doesn't

A recent evaluation of the UK's Expert Patient Program (EPP) revealed that the program predominately appeals to “white middle-class people with long-term conditions who already viewed themselves as effective self-managers.”¹¹ A further evaluation conducted in Australia found that males, indigenous people, people of non-English speaking background, and those with multiple responsibilities were less likely to participate in chronic disease self-management courses.¹² Echoing these findings, a 2008 report from the European Observatory on Health Systems and Policies notes that: “Reaching diverse and disadvantaged groups has been a challenge for CDSMP courses. Patients tend to be especially disadvantaged if they are older, are less educated, are on low incomes or do not have health insurance, have cognitive or intellectual impairments, or belong to an ethnic minority.”⁵

Not only are marginalized populations not accessing SMS, but as Rogers and colleagues note in a recent paper: “A course [CDSMP], which draws on an essentially middle class population, may have the unintended consequence of lowering expectations and help-seeking activities amongst those who are most in need including those from marginalized groups and lower socio-economic positions.”¹³

There is an evidence gap with regards to the effective use of community resources to support chronic disease management in primary care. This is important because “people with chronic disease manage their condition in the context of their family, workplace and wider community. For example, the most effective self-management programs in disadvantaged communities appear to be those that are developed in partnership with culturally acceptable health workers from within a particular community.”¹⁴ Following from this, appropriate service delivery for specific ethnic groups should incorporate self-management programs run through multicultural community services with primary care practice.¹⁴

McDonald et al ¹⁵ outline the components of successful SMS for marginalized populations: “The importance of organizational aspects of care such as multi-disciplinary teams, provider-client partnerships, culturally appropriate education tools, individualized treatment plans, and greater interaction with the community have been highlighted as aspects which might improve access to care by disadvantaged groups.” In particular, social support through the engagement of local community networks is crucial to successful SMS among these populations.¹⁵

In a review of effective interventions to improve diabetes care in socially disadvantaged populations, Glazier et al¹⁶ state that: “Features that appeared to have the most consistent positive effects included cultural tailoring of the intervention, community educators or lay people leading the intervention, one-on-one interventions with individualized assessment and reassessment, incorporating treatment algorithms, focusing on behavior-related tasks, providing feedback, and high-intensity interventions (>10 contact times) delivered over a long duration.”

From these accounts it appears that a collaborative model of SMS with partnership between local community service networks, primary care, and health authorities is most effective for marginalized groups. Cultural appropriateness in this context means more than merely competency; chronic care services should be embedded within existing community structures to ensure ongoing participation and relevance.

Shifting the paradigm of patient empowerment from the individual to the collective

Based on social cognitive and social learning theory, the CDSMP is intended to mediate positive changes in health outcomes through the enhancement of self-efficacy.¹⁷ Outcome measures of the CDSMP include various indicators of health status, health services utilization, health behaviour and perceived self-efficacy to manage chronic disease. Recent CDSMP evaluations demonstrate improvements in self-efficacy as a key program benefit.¹⁸ As a health outcome measure, however, self-efficacy carries inherent assumptions that have proven problematic in the case of SMS for ethnocultural and other minority groups.

Self-efficacy is a psychological construct that refers to an individual’s ability to achieve targeted goals.¹⁷ In self-management, self-efficacy describes the capacity for change within an individual who becomes more capable through exposure to the CDSMP.¹⁷ In this construct, the contextual factors mediating an individual’s capacity to self-manage are unaccounted for. Individuals are viewed as failing to have acquired the skills needed to adequately self-manage (or adapting ‘wrong,’ ‘unhelpful,’ or ‘irrelevant’ tactics). The CDSMP thus holds individuals accountable to a normative standard of self-management that neglects to consider diverse experiences of chronic disease that are context-dependant.

Using the social model of disability that relocates the ‘problem’ from the level of the individual to systemic structures of oppression and domination, Kendall and Rogers¹⁷ contend that self-management should focus on personal expressions of illness that are socially-bound: “In contrast to the deficit notion of ‘self’ that is inherent in concepts such as self-efficacy, social perspectives assume that subjective reality takes various forms and consists of multiple dimensions as people traverse their environment.” In this way family and community are integrated into self-management models. For example, among indigenous Australian communities self-management has been redefined as collective self-management.¹⁷

Individual self-management needs to be situated within this collective understanding of empowerment. Conventional SMS models focus primarily on individual autonomy and personal responsibility but neglect to address systemic barriers to access experienced by marginalized communities. Instead of reinforcing the status quo, SMS for ethnocultural

minority older adults should build on community strengths and bolster capacity to meaningfully engage in self-management.

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EVACUATION CLIENT "GO KIT" SUGGESTED CONTENTS

CHECK & INITIAL	SUGGESTED ITEMS
<input type="checkbox"/> BY: _____	FACE SHEET WITH CURRENT EMERGENCY CONTACT INFORMATION
<input type="checkbox"/> BY: _____	HISTORY AND PHYSICAL
<input type="checkbox"/> BY: _____	MEDICATION AND TREATMENT ADMINISTRATION RECORD
<input type="checkbox"/> BY: _____	ADVANCE DIRECTIVE/PREFERRED INTENSITY OF CARE
<input type="checkbox"/> BY: _____	IF POSSIBLE, TRANSFER TRAUMA PLAN AND DISCHARGE NOTE
<input type="checkbox"/> BY: _____	DISASTER ID TAG WITH PICTURE, ID INFO, AND MEDICAL ALERTS
<input type="checkbox"/> BY: _____	MEDICATIONS (72-HOURS)
<input type="checkbox"/> BY: _____	ESSENTIAL MEDICAL SUPPLIES OF SPECIAL DIET REQUIRES (72-HOURS)
<input type="checkbox"/> BY: _____	ESSENTIAL MEDICAL SUPPLIES & EQUIPMENT (E.G. TRACHEOTOMY, COLOSTOMY, O2, GLUCOSE MONITORING)
<input type="checkbox"/> BY: _____	NUTRITIONAL SUPPLIES OF SPECIAL DIET REQUIRES (72-HOURS)
<input type="checkbox"/> BY: _____	WHEELCHAIR/WALKER
<input type="checkbox"/> BY: _____	DENTURES/EYE GLASSES/HEARING AIDS/PROSTHESIS
<input type="checkbox"/> BY: _____	CHANGE(S) OF CLOTHING
<input type="checkbox"/> BY: _____	ACTIVITY SUPPLIES OF CHOICE (RESIDENT'S PREFERENCE)
<input type="checkbox"/> BY: _____	INCONTINENCE SUPPLIES (72-HOURS MINIMUM)
<input type="checkbox"/> BY: _____	LARGE PLASTIC BAG LABELED WITH CLIENT'S NAME FOR ACCUMULATION OF LAUNDRY
<input type="checkbox"/> BY: _____	OTHER (PLEASE SPECIFY): _____



GET READY!

Create A Facility "Action Plan" for Earthquakes

- Conduct a "hazard hunt" to identify not secured objects.
- Don't forget cleaning supplies and chemicals that could spill and mix.
- Identify your facility's "building/structural" weaknesses.
- Develop a checklist for post earthquake hazards, like cracks in walls or broken pipes.

Does your plan address?

- Downed power and telephone lines;
- Disruption in transportation (closed roads): staff's ability to come to work, ambulance transportation if anyone requires treatment at a hospital;
- Provisions if your facility or county experiences broken pipes (Water & Gas);
- Evacuation to an undamaged part of your facility or relocation site; and
- How to maintain refrigerated food and medications in the event of power loss.

How well does your staff know your disaster plan?

- Does your staff have questions about their responsibilities during an earthquake?

GET SET!

April is "Earthquake Awareness" Month

- Discuss "What to do if an earthquake strikes" (night/day occurrence) with staff & residents. Remember to remind them about after shocks.
- Secure/anchor items that could be displaced or fall during an earthquake.
- Install safety locks on cabinets to keep cabinets closed during a quake.
- Keep flash lights, battery powered radio & extra batteries, and at least one corded phone in an established and easy to find place.
- Conduct regular "Earthquake" drills with staff and residents.

GO!

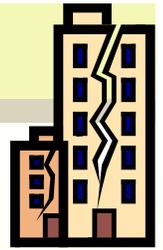
Activate Your Facility's Disaster Plan

- **REMAIN CALM:** Instruct staff & ambulatory residents to "Drop, Cover, and Hold On" Drop to the floor (safely), take cover under a sturdy table, or desk and hold tightly to it until shaking stops. Expect after shocks.
- Instruct residents that if they are in bed when the earthquake occurs to remain where they are and to cover their heads with a pillow.
- Instruct wheelchair patients to stay in their chairs, move away from danger zones (windows, etc.), and lock their wheels and protect their heads with their arms.

After the shaking stops :

- Listen to the portable radio for information and safety advisories.
- With another staff person, survey your facility for damage, injuries to staff/residents that may need immediate attention. Keep written record of everything you find. Whether they require immediate attention or not, this will help identify areas of concern & post event needs.
- Implement evacuation of unsafe/unstable areas of your facility.

Top Ten Additional Suggestions For Earthquake Safety:



- Have earthquake preparedness classes with staff and residents. Include what can be expected. Allow them to ask questions and possibly give suggestions of how to decrease hazards and facility risks. Use “earthquake classes” and drills to reassure residents that your facility is taking the proactive approach to ensure that your facility and staff are prepared for a disaster.
- Keep your “Disaster Plan” in a brightly colored binder for easy visibility.
- Keep a supply of light sticks/glow sticks in case of generator/emergency light failures.
- Have hospital grade surge protectors, to help prevent “arching” in event of flooding (broken pipes/activated sprinkler system), or power surge. Paint the hospital grade surge protectors orange for easier identification.
- Conduct regular facility checks for structural changes and new potential problems before an earthquake.
- Know the “safe spots” in every room. Look for sturdy tables or desks.
- Know the “danger spots” in your facility: windows, mirrors/hanging objects, fireplaces, and tall furniture.
- Have adequate medical and food supplies for residents and staff for a minimum of 3-days. Have a feasible dietary plan for worse case scenarios, including loss of power and road closures due to unsafe conditions.
- Develop a post earthquake inspection checklist to assist staff in identifying hazards (e.g. cracks in walls, pipes and loose cables/wires).
- Have a “post earthquake protocol” for residents. For example, “All residents are to remain where they are until a staff person checks them; UNLESS there is an immediate danger at their location”. This provides your staff better control to account for residents and identify injuries, etc.

FOR ADDITIONAL INFORMATION GO TO:

<http://earthquake.usgs.gov/learning/preparedness.php>
www.shakeout.org/
<http://72hours.org>

We, at CAHF appreciate your thoughts and would like to ask for any disaster related suggestions or “Positive Practices” that you may have. Our goal is to use “Lessons Learned” and “Successful Applications” to help educate other facilities within our Long-Term Care Community.

Let’s work as a T.E.A.M. - Together Everyone Achieves More!

What disaster or event would you like CAHF’s Disaster Preparedness Program to use for a “Ready, Set, Go” Disaster Planning Topic? Contact us at (916) 441-6400.



GET READY!

Create A Facility "Action Plan" for Extreme Heat

Does your plan address?

- Chain of command for emergencies.
- Roles of staff in case of extreme heat (or other disaster/emergency event).
- Internal/external communications.
- "Triggers" for the initiation of heat-related emergency measures, such as:
 - ⇒ Disruption of cooling system due to power outage
 - ⇒ Ambient indoor temp rises and remains above 81 degrees for over 2-hours
 - ⇒ Change of condition related to heat is noted in one resident
- Back-up power to preserve medications in case of power outage.
- Meals (Nonperishable foods and/or preparation and serving) for power outage.
- Patient relocation (if need arises).

GET SET!

Are you and your staff really ready?

- Develop an assessment protocol for all residents to be implemented when emergency trigger is reached, such as:
 - ⇒ Vital signs with focus on core temp
 - ⇒ Comfort
 - ⇒ Hydration status
- Discuss signs and symptoms of heat cramp, heat exhaustion and heat stroke with staff (see section on "Additional Tips & Information").
- Discuss what to do during an extreme heat event with residents, such as wearing light clothes.
- Keep your generator and other back-up sources for emergency utilities in operational condition.
- Keep a supply of fans with protective grills.
- Stock-up on fluids (increased frequency and amount to be determined by medical staff) and light snacks, such as popsicles.

GO!

- Activate policies and plans to deal with extreme temperatures.
- Check rooms often to ensure that air-conditioning is in good working order and operating effectively in all rooms.
- Maintain a comfortable indoor environment by keeping drapes and windows closed during the day to keep indoor environment cool.
- Advise patients that electric fans help only if they bring in cooler air from outside.
- Wear light cloths, use misting, and take cool shower or bath.
- Check regularly on patients to be sure they stay cool and well hydrated. Plain water is the liquid of choice, or diluted fruit juice is okay. *NOTE: *Patients who have epilepsy or heart, kidney, or liver disease; are on fluid-restricted diets; or have a problem with fluid retention should consult a doctor before increasing liquid intake.*
- Report change of condition immediately to MD or medical director and plan appropriate treatment of residents who exhibit heat-related symptoms as indicated (see section on "Additional Tips & Information").
- Decrease physical activity for residents.
- Staff should follow first-aid procedures promptly in case of heat stroke, heat exhaustion or heat cramps (see section on "Additional Tips & Information").
- If you have outdoor activities for residents, plan their activities for either before noon or in the evening.
- While outdoors, let residents rest frequently in a shady area to give their body's thermostat a chance to recover.
- For outdoor activities, have residents dressed in loose fitting, light-colored clothes that cover as much skin as possible. Protect face and head by wearing a wide-brimmed hat.



Additional Tips & Information: First Aid for Heat-Induced Illnesses

Sunburn: redness, pain, swelling of skin, blisters, fever and headaches. *Treatment: Leave water blisters intact to speed healing and avoid infection. If breaking of blister occurs, apply dry sterile dressing. Serious cases should be seen by a physician.*

Heat Cramps: heavy sweating can cause painful muscle spasms usually in the legs but possible in the abdomen. *Treatment: Apply firm pressure on cramping muscles or gently massage to relieve spasm; give sips of water, if nausea occurs discontinue sips of water, move person to a cooler place to rest in a comfortable position. Observe the person carefully for changes in condition.*

Heat Exhaustion: heavy sweating, weakness, cold, pale and clammy skin; weak pulse, fainting and vomiting, core temperature usually 38.8 Celsius or higher, but normal temperature is possible. *Treatment: Get patient out of sun, move person to a cooler environment, lay person down and loosen clothing, apply cool wet cloths, give sips of water. If nausea occurs, discontinue sips of water; if vomiting continues, seek immediate medical attention.*

Heatstroke: severe medical emergency, high body temperature, hot, dry skin, rapid and strong pulse, possible unconsciousness. *Treatment - Call 911, if unable to get person to medical help immediately, do the following:*

- *Move person to a cooler environment.*
- *Remove outer clothing.*
- *Reduce body temperature using lukewarm (not cold) water to bath/sponge the person.*
- *Do not give fluids!*

Additional Resources:

Weather Services, Extreme weather service warnings and alerts for California:
www.nws.noaa.gov/alerts/ca.html

Centers for Disease Control and Prevention, Extreme heat prevention guide:
www.bt.cdc.gov/disasters/extremehat/heat_guide.asp

CDPH, Hot Weather Advisory:
www.cahfdownload.com/cahf/dpp/AFL_08-15.pdf

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LET’S WORK AS A T.E.A.M.
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