Managing Adverse Events & Symptoms with Technology & Realtime Assessment

Project Description
This presentation describes formative, qualitative work conducted to gather key information from the Hispanic cancer survivor community for the purpose of developing a LOW-LITERACY, friendly eHealth application for symptom management support that is CULTURALLY-SENSITIVE and TAILORED based on norms, attitudes, self-efficacy, skills, and environmental constraints.

Using COMMUNITY-ENGAGED RESEARCH approaches, HEALTH COMMUNICATION THEORY, and HEALTH BEHAVIOR THEORY, we have partnered with local Hispanic cancer survivor organizations to conduct focus groups aimed at uncovering:

1) most troublesome and enduring symptoms/side effects post cancer treatment
2) previous strategies and attempts to manage symptoms/side effects
3) previous use, comfort and preferences for symptom support delivered through different eHealth applications
4) ways in which a new eHealth support tool can be culturally tailored, easy to use for low-literacy Spanish speaking cancer survivors, while also paying heed to established health behavior theory.

An Integrative Model of Behavior Prediction

Research Aim
The research aim of MAESTRA is to develop and evaluate a culturally tailored eHealth cancer symptom management support tool for Hispanic/Latino cancer survivors using community engaged research principles.

Educational Aim
The educational aim of MAESTRA is to train, mentor and engage interested college students in cancer health disparities research through formal coursework and programs and hands-on experiential learning.

Research Update
- Literature review on eHealth and Hispanic cancer survivors
- CER Partnership with Alas Wings Cancer Support Organization
- Conduct of focus groups with Hispanic cancer survivors
- Submission of NIH R13 Conference Series Grant to use CBPR to better understand links between chronic stress and obesity in Hispanic community

Educational Update
- Capacity building and career development with NEIU & NU students
- Development & approval of NEIU Course: Health Disparities: Individuals, Communities & Systems
- Initial review and revision of NEIU’s B.A. Community Health track to match accreditation standards for a public health degree

Results Update
- 2 focus groups as of April 30, 2013.
- 17 female; 3 male. 1 female caregiver. 100% Hispanic/Latino.
- Ages ranged 35-78 years old; average = 55 years old

Initial findings indicate that patients did turn to the internet for information on treatment including its side effects. Some felt that their doctors provided little to no information on the effects. Language was perceived to be barrier.

KEY TERMS
Community Engaged Research - A framework or approach for conducting research characterized by the principles that guide the research and the relationships between the communities and academic researchers.
Health Communications – “The study and use of communication strategies to inform/influence individual and community decisions that enhance health”
Health Behavior Theory – “Health behavior theories focus on multiple determinants of behavior at the individual, interpersonal, group, organizational, and/or community levels.”
Low Literacy – Limited ability to use printed-written information to function in society, to achieve goals, and to develop one’s knowledge and potential
Tailored communication – “Messages crafted for and delivered to each individual based on individual needs, interests, and circumstances”

Implications for Delivery & Practice
Cancer is the leading cause of death for Hispanics, which has been challenging to understand given the heterogeneity of sub-groups in terms of education, acculturation, immigration status, risk behaviors, and access to care. Some of this can be attributed to unhealthy health lifestyle practices including increase in smoking, obesity, and alcohol intake, and decreases in dietary quality and physical activity.
Leveraging this population’s increasing use of information and communication technology is one way to reduce health disparities by proving Hispanic cancer survivors with access to important aftercare and support over the long term following their treatment.

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Bibliography

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