

CITRA Pilot Grant Progress Report

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Investigating Attitudes and Beliefs of Asian-Indian Hindus Towards End-of-Life Care

This pilot grant funded a pilot study using a convenience sample of older Hindu adults attending a community senior center in Queens, New York. The specific aims of this study were:

1. To estimate the prevalence of advance directives and end-of-life care preferences of an Asian-Indian Hindu population at a community center(s) in the borough of Queens in New York City using standardized instruments.
2. To qualitatively assess end-of-life care preferences of the Asian-Indian Hindu population in regard to truth telling, diagnosis/prognosis disclosure, medical decision-making, life-sustaining/prolonging measures, cardiopulmonary resuscitation, and place of death.
3. To characterize the demographic, clinical, and psychosocial attributes of this population using standard and validated geriatrics tools.

To provide this report some structure, I shall begin by discussing the results of the actual study. Subsequently, I will comment on my experiences doing research at a community senior center and briefly mention some of the planned work for the future.

This study was a simple descriptive study of end-of-life care issues in a specific ethnic group. Using validated tools, we have been able to get a glimpse of some of the important issues for this group. In regards to advance care directives (ACDs), this group demonstrated a very low prevalence of having completed ACDs (6-8% of the participants) in addition to a moderately low rate of knowledge of ACDs (14-20% of participants claimed to know something about ACDs). This finding correlates with previous studies of ACDs in different ethnic minority groups. Additionally, participants felt strongly that ACDs are important and have beneficial intentions. However, as with other ethnic groups, the participants felt that they were unnecessary if someone has an involved and supportive family who understands the individual's wishes.

As we had hypothesized, participants in the study were strongly religious and demonstrated an unwavering belief in the fundamental tenets of Hinduism regarding death and dying. Thus, it did not surprise us that the majority of participants were strongly against the use of aggressive medical care in a patient who is terminally ill or dying. Participants were in favor of withdrawing care, withholding care, and allowing a

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person to die if s/he were in a terminal state or actively dying. Many cited a strong faith that death is a natural part of life and “when it’s your time to go, you should go.” There was a strong theme among participants that the use of such life-prolonging or sustaining technologies (including CPR) would only serve to prolong the suffering and pain of a person at this stage of life. Participants also felt strongly about involving the family in all aspects of medical decision-making as well as a tendency to favor truth telling in the context of diagnosis/prognosis disclosures. Finally, participants held doctors and the health care system in high regards.

Most participants were of Guyanese-Indian origin and had been living in the U.S.A. for an average of 15-20 years. Most of the participants lived with spouses or other family members, and were pretty connected in the community. There was an overwhelmingly low rate of educational attainment related to socioeconomic factors in Guyana or their country of origin. The prevailing medical diagnoses correlated with those of the Asian-Indian population in general—diabetes mellitus, hypertension, hyperlipidemia, coronary disease, and arthritis. Many participants reported that their health status was the same/worse this year as compared with 1 year ago—mostly attributing the decline to pain and functional limitations from arthritis. Still, the majority of participants retained independence of their IADLs and were cognitively intact with low rates of depression. One of the problems we encountered during the study was related to the low educational levels of the participants. This often created comprehension barriers to some of the more complicated questions in the Ethnicity and End of Life Attitudes Survey that required some level of abstract reasoning.

One of the most beneficial results of the pilot study was the opportunity to interact with the individuals and the senior center staff. It is an understatement to say that the amount of work and time that Chan Jamoona (the executive director) has put into the creation and development of the center is incredible. She has united a community, provided a very important venue for socialization for a group of older adults who felt “left out” at other senior centers, and enabled health promotion for the participants (visiting lectures, screening days, vaccinations, meditation/yoga/stress reduction). One of the most important things Chan has done is to provide the participants daily with a health vegetarian Indian lunch. She is a remarkable woman and it was a pleasure to be able to work with her and gain some insight into the daily life of a community senior center. However, we also learned that bringing academic research to a community center has its share of problems. The senior center staff is overwhelmed with the amount of day to day work that needs to be done, and quite often did not have enough time to devote to an additional project. More importantly, many community leaders are not well versed with the issues of clinical research and I feel it would be beneficial for CITRA to develop a “training” course for staff at centers participating in research. This training should include some of the basic concepts of research design, methodology, IRB protocols, presenting data, and grant applications (including community grants to fund center projects). If we can find a way to teach this material in a time-efficient and practical

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way, I think we can claim some success in bridging academic research with community centers.

Publications/Presentations since May 2005:

- AGS Annual Conference, May 2005
 - Symposium, “End-of-life Care for Elders from Hindu, Sikh, & Buddhist Backgrounds”
 - Panel member

- AGS 2006 Annual Conference, May 2006
 - Poster, “Attitudes of Asian-Indian Hindu Elders Towards End-of-Life Care: A Pilot Study”

- The data analysis from this study is ongoing and I hope to have a manuscript ready for submission by June or July of 2006.

Finally, I have been discussing ideas for future work with my mentors, and am interested in the area of improving knowledge & access to palliative/end-of-life care among ethnic minorities. I am in the midst of reviewing some literature in the area of barriers to end-of-life care and community-based education efforts in end-of-life care; hopefully, this will lead to some proposals for research in the upcoming year.