## Palliative Care: Research and Treatment



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## Preliminary Report of a Pilot Tele-Health Palliative Care and Bioethics Program for Residents in Skilled Nursing Facilities

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**Abstract:** Currently about 25% of Americans die in nursing homes, many with poorly controlled pain and other symptoms, with minimal provisions for psychosocial support. New models are necessary to lessen structural and process barriers to give effective end-of-life care in nursing homes. **Objectives:** 1) To extend hospital-based Bioethics Consultation Services (BCS) and Palliative Care Services (PCS) at Montefiore Medical Center (MMC) in the Bronx to two local Skilled Nursing Facilities (SNFs), Morningside House Aging in America (MSH) using direct face-to-face consultations and Beth Abraham Health Systems (BAHS) via video consultations (VC); 2) Achieve improvements in quality of life and comfort for elderly residents and their families; 2a) Improve the level of practice and increase staff satisfaction with palliative care content-related knowledge and bioethical analysis. **Methods:** We report preliminary findings of this two group quasi experimental project with results of pre- and post- tests rating content-related knowledge in aspects of end-of-life care for staff. Select pre-test and post-test questions were given to physicians and other staff, but were re-configured for, registered and licensed practice nurses, social workers, and certified nursing assistants from the End-of-Life Physician Education Resource Center (EPERC). Patient, family, and staff ratings of the quality of palliative care were measured with a Palliative Outcomes Scale (POS) one week prior to and post consultation.

**Results:** 72 staff attended in-services; 53 completed pre-tests and 49 post-tests. Overall knowledge scores increased for 9 of the 16 items that were analyzed. There were improvements in knowledge scores in 12 of 16 items tested for staff content related knowledge which were statistically significant in regard to management of cancer pain from 63.8% to 81.5% (p = 0.03) and a trend to significance for assessment and management of delirium from 31.6% to 61.9% (p = 0.073). Seventy five POS surveys were completed from 13 video-conferenced Palliative Care consultations and 14 direct face-to-face consultations from March 2008 to January 2009. There were improvements in ratings for some aspects of quality of care on the POS. Patient and staff aggregate response scores for the POS were significantly improved between baseline and follow-up (Wilcoxon signed-rank test p = 0.0143 and p = 0.005) at the videoconsultation site and for family and staff at the face-to-face consultation site (Wilcoxon signed-rank test p = 0.0016 and p = 0.0012).

**Conclusion:** Preliminary evidence suggests that use of real time videoconferencing to connect hospital-based Bioethics and Palliative Care clinicians with patients, families, and staff in Skilled Nursing Facilities may enhance some aspects of end-of-life care for their residents, as well as content related knowledge in core aspects of end-of-life care for interdisciplinary groups of staff or caregivers.

Keywords: bioethics, palliative care, elderly residents, tele-health

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This is an open access article distributed under the terms of the Creative Commons Attribution License (http://www.creativecommons.org/licenses/by/2.0) which permits unrestricted use, distribution and reproduction provided the original work is properly cited.

This report describes the efforts of a community teaching hospital to extend the reach of hospital-based Palliative Care and Bioethics consultation services to elderly residents of two co-investigative Skilled Nursing Facilities (SNF) through a pilot tele-health initiative. One SNF had Videoconferenced Palliative Care and Bioethics consultations, and the other faceto-face. The projects intent is to evaluate tele-health as a method to lessen structural barriers to effective endof-life care for patients receiving care across multiple institutions in inner city settings and to evaluate if this proves effective for case-based teaching of SNF clinical staff.

The experience of end-of-life care in long-term care facilities: Currently about 25% of Americans die in skilled nursing facilities.<sup>1</sup> There has been significant growth in hospital-based Palliative Care Services in the last 15 years with some impact on acute care health service expenditures and use of non-beneficial life prolonging treatments at the end-of-life.<sup>2,3</sup> While non-beneficial acute health service utilization, such as admissions to the ICU, is lower in hospitals that have Palliative Care consultation services, such as MMC, total end-of-life health care expenditures in the Bronx far exceed state wide averages.<sup>4</sup> Nursing home residents increasingly forgo life-prolonging treatments, but these decisions may not be linked to effective plans for palliation. They often have high rates of untreated pain and other symptoms, and family members receive very little psychosocial and bereavement support. There have been only modest increases in the proportion of nursing home residents who receive hospice care from 1% to 2.5%<sup>5</sup> in the last decade and the vast proportion of potentially eligible nursing home residents do not receive hospice care. For those who do receive some index of end-of-life care the duration of time is only around five months.<sup>5</sup>

The palliative care needs of nursing home patients are therefore often unmet.<sup>6</sup> As many as 30%–80% of them receive inadequate pain management. Minority patients are reported to be less likely to have pain assessed, and their under treatment of pain may relate to both patient and family reluctance to report pain or take analgesics. Furthermore, clinicians experience difficulty assessing pain due to differences in language and culture.<sup>7–12</sup> Family members of persons dying in nursing homes are also reported to have high levels of dissatisfaction with coordination of care,



lack of emotional support, or information about what to expect when the patient is dying.<sup>11,12</sup>

## Barriers to Effective Pain and Symptom Management, Communication of Patient Preferences for End-of-Life Care in Nursing Homes

Barriers to providing high quality end of life care to nursing home residents include misconceptions about palliative care in general, difficulties associated with assessing discomfort in cognitively impaired persons, turnover in leadership staff and other clinical staff, perceived incompatibility between regulatory standards and palliative care, and reimbursement issues.

Advance directives are often unavailable or lack sufficient specificity and clarity to impact decisions such as transfers to acute care settings or use of life prolonging treatments in patients with advanced illnesses. Many such patients, particularly in urban settings, are transferred to nursing home staff with little or no information on their wishes for end-of-life care.<sup>11,12</sup>

Many other obstacles to palliative care have been identified, including lack of communication amongst decision makers and structural barriers to communication between acute care and long-term providers. There is often no agreement on a course for end of life care, accompanied by failure to implement a timely end-of-life care plan, and to recognize treatment futility.

## **Tele-Health and Palliative Medicine**

## Video conferencing in urban underserved patients at the end-of-life needing care in SNFs

While hospices in rural areas are increasingly incorporating telemedicine into the delivery of patient care the authors are unaware of reports of its use by programs that serve predominantly urban underserved and minority populations. Most studies assessing potential effectiveness of telemedicine modalities in end-of-life care have been underpowered.<sup>13,14</sup>

## Rationale for this project

For immobile SNF residents the incorporation of video conferencing into the delivery of some core end-oflife services, such as pain management and bioethical



consultation, could avoid potentially several hours of painful and expensive ambulance trips to hospital clinics or emergency rooms. Hospital based specialists are often unable to serve SNF patients because of the time involved in inter-institutional travel. Many nursing homes in urban areas, predominantly lowincome communities, may not be able to sustain such specialty services. Telemedicine could ameliorate some of the challenges facing Palliative Care in underserved settings, such as staff shortages, limitations in funding, and geographic isolation. To Palliative Care clinicians and community care providers of long-term care facilities video-conferencing may facilitate group learning opportunities that otherwise would not be available due to geographical distance.<sup>13–15</sup> This modality has been used and for individual clinical disciplines such as nursing.15-17

Recent technical advances and reduced costs have enhanced the utility of video conferencing in healthcare. There is evidence that interactive educational sessions can change practice and that participants are often more satisfied with this learning method than with other methods,<sup>18</sup> and this widely used in continuing medical education.<sup>8–19</sup> Reports in medical literature suggest between 47% and 91% of physicians who participate in video conferencing report making changes in their practice;<sup>20–24</sup> and reports are increasing of the use of telemedicine in the care of the elderly.<sup>25,26</sup>

Tele-Health presents numerous opportunities for enhancing shared decision-making, empowering and educating staff, and reducing cultural and structural barriers to the provision of effective end-of-life care in urban settings.

## **Bioethics Consultation Services**

Bioethics consultation supports patients and health professionals in making medical decisions that touch upon morally and ethically charged issues, often at the end of life. Bioethics consultants help participants articulate conflicting values and wishes in any given decision, discern which options are medically, legally and ethically viable, and facilitate agreement on which among these options is best in this particular set of circumstances. Often participants must resolve apparent conflicts, such as that between the goals of comfort and cure. With better communication and an opportunity for dialogue, the consultant may help participants find that goals need not always compete and that an acceptable balance may evolve. Bioethics consultation in a nursing home setting offers an opportunity for residents, a vulnerable population, and their family members to articulate values that shape medical choices and goals.

# Rationale for this Project and Project Description

Enhanced inter-institutional information exchange and communication systems need to be implemented and evaluated to improve quality and coordination of care across organizational settings, promote shared decision-making, increase inter-institutional ties, and promote patient safety: while lessening duplicative use of diagnostic tests, other procedures and unnecessary hospitalizations at the end-of-life. This pilot program tests the feasibility of remedying structural and cultural barriers to receipt of care, such as barriers that impede the efficient and timely provision of clinically important information and expertise, within and amongst institutions, insufficient family involvement in goals of care discussions, and inadequate attention to cultural and spiritual factors that relate to the end-of-life. Its goals are three-fold: Primary goals 1) To extend hospital-based Bioethics Consultation Services (BCS) and Palliative Care Services (PCS) to local SNF patients, families, and staff through direct face-to-face consultations and video consultations (VC); 2) Achieve improvements in quality of life and comfort for the elderly residents and families of two SNFs; with secondary goals to improve the level of practice and increase staff satisfaction with Palliative Care content-related knowledge and bioethical analysis.

#### Institutional settings

Montefiore Medical Center (MMC), Beth Abraham Health Systems (BAHS) and Morningside House Aging in America (MSH) highly serves ethnically diversed, culturally diversed, and medically underserved populations in the Bronx. Seventy five percent of BAHS patients are minority as are 79.5% of its staff, and 72% of MSH patients are minority as are 76% of its staff. The Bronx, the poorest New York City borough with many medically underserved is listed by the New York State Department of Health as having 46 nursing homes with total capacity of 12,000 beds. This project is a two-group quasi-experimental intervention with face-to-face consultations conducted at MSH and video-consultations conducted at BAHS.

## Methods

## Recruitment of staff for training

We recruited staff for this project who are directly involved in the routine care of patients participating in this project. Staff includes certified nursing assistants, licensed professional and registered nurses caring for such patients, medical providers, social workers, and "on-site clinical champions"-defined below. A project coordinator met with staff prior to each consultation and discussed their participation in the project. We periodically reviewed logs of attendance of consultations to ensure that participating staff members were exposed to the core elements of the project.

The recruitment procedures for patients were the same at both sites. The on-site champions-the medical director at BAHS and the social work leaders at MSH- routinely rounded with staff on nursing units. To determine whether a patient would be eligible for the study, screening questions adapted from those in use in prior studies were employed.27 The screening criteria included an affirmative answer to two or more of the following questions: (1) Would you be unsurprised if this patient were to die in the following year?; (2) Does this patient have one or more of the following diagnoses: Congestive Heart Failure, Dementia, other Neurodegenerative diseases, Cancer, Chronic Obstructive Pulmonary Disease, Chronic Liver Disease, Chronic Renal Failure, HIV/AIDS, or other life threatening conditions?; and (3) Has this patient had one or more hospitalizations in the last year without returning to his (her) prior level of functioning?. Once a potential study patient was identified, the on-site champion sent an encrypted email or called the project coordinator. The project coordinator then created a log of these patients and met with each potential patient after the medical provider determined the patients' ability to provide consent, to assess whether study criteria were met. Once eligibility criteria were determined, the project coordinator explained the purpose of the study and sought informed consent from either the patient or the surrogate if the patient was unable to provide consent. If the patient or surrogate indicates willingness to participate the consenting process was completed by the

research coordinator 24 hours later, thus providing the patient or family with the opportunity to (re)consider participation.

# The inclusion and exclusion criteria are as follows

Inclusion Criteria 1) Meets screening criteria. 2) A score of 25 or greater on the Folstein mini-mental status examination. 3) Ability to read and communicate in either English or Spanish as determined by the medical provider. 4) Documentation on the medical record of one or more advanced medical conditions such as Congestive Heart Failure, Dementia, other Neurodegenerative diseases, Cancer, Chronic Obstructive Pulmonary Disease, Chronic Liver Disease, Chronic Renal Failure, HIV/AIDS, or other life threatening conditions. Exclusion Criteria 1) Clinician report of Karnofsky Performance Status of less than 20. 2) Age less than 21 years. 3) Inability to provide informed consent as evidenced by Folstein mini-mental status examination score of less than 25. 4) Unable to communicate in either English or Spanish as determined by the medical provider. 5) Patients with psychiatric illnesses that interfere with their ability to give informed consent (such as active psychosis, unstable bipolar affective disorder, as evidenced by recommendation of patient's medical provider that the patient not participate in the study). 6) Patients were not recruited if their clinician indicates that they were unable to tolerate the assessment process due to fatigue or other limiting physical symptoms.

Family or other significant designated surrogates for the patient were approached for consideration of participation in this project. If the patient was unable to participate the patient could provide consent and permit family or other surrogates to be approached. Surrogate Inclusion and Exclusion Criteria were as follows: Inclusion Criteria 1) Aged 21 years or older. 2) Identified to the project coordinator by the patient as a person that they wished to participate in consultation. 3) Could communicate in either English or Spanish. 4) Surrogate(s) identified on the patient's medical record as a decision-maker for patients with cognitive impairment. Exclusion Criteria 1) Age less than 21 years. 2) Inability to provide informed consent as evidenced by Folstein mini-mental status examination score of less than 25. 3) Unable to communicate in either English or Spanish. 4) Staff report of physical





frailty or other advanced illnesses, which may interfere in their ability to complete the study questionnaire. 5) Staff reports of lack of contact by the surrogate with the patient during the patient's stay at the SNF or request by the family to not involve the patient. 5) Refusal to provide HIPAA informed consent or to accept consultation assignment.

## **Staff in-Services**

Physicians, nurses, social workers, and certified nursing assistants were all given re-formatted exams and trained in knowledge appropriate groups. Staff at both sites were given an introduction to the project and an overview of palliative care, followed by a pre-test to assess baseline palliative care and bioethics knowledge, followed by a lecture on palliative care and question and answer session led by the Principal Investigator. Finally, to assess knowledge retention and training impact, a post-test was administered. Pre- and posttest questions were selected from the End-of-Life Physician Education Resource Center (EPERC) at the Medical College of Wisconsin. Results of the pre- and post-tests are presented in the evaluation section.

#### The consultation intervention

We conducted 1-2 consultations in both sites each month in the first year of this project.

Both the direct and video-conference consultations included patients, the institutional palliative care champion at each site, a unit social worker, unit nurses and certified nursing assistants (CNA's). Consultations required 60-90 minutes with 15 minutes for case based teaching, discussion and summarization. Within 72 hours of the consultation a summary was prepared by the bioethicist, palliative physician, or geriatrician. Summaries were sent via encrypted emails to the on-site champions. Patients or families were provided with compact discs of the consultations. The consultations involved a direct face-to-face consultation by a palliative care physician at MSH and a videoconsultation at BAHS by a palliative care physician, and a bioethicist. The consultations were scheduled in advance to allow participation by family and staff, and to avoid times that may interfere in patient care. Dates and times of consultations were also planned around times of maximum staffing. We employed convenience sampling techniques for subject recruitment because in the Principal Investigator's

experience, at both sites, use of randomization techniques at two community nursing homes would present an added barrier to subject recruitment and delay the time needed to recruit sufficient subject numbers to be able to demonstrate effect size. We expected this study to provide us with sufficient data on primary outcomes to calculate sample size for a larger multi-site study.

Prior to departing from MMC and upon arrival at the SNF the project coordinator set-up the hardware(s), established internet connection(s), and tested video conferencing software(s), and input and output qualities of video, audio, and microphone were logged. The bioethicist responded to a series of questions by rating and describing video quality (extremely poor, poor, fair, good, excellent); audio quality (clear/echo/ delay [seconds of delay]); and microphone quality (feedback/audible/loudness adequate). Immediately prior to videoconferencing at the SNF the project coordinator adjusted the equipment to suit the patient's, families', and staff's needs. Manipulations were made to the webcam by height, distance, furniture hindrance; microphone by distance and volume depending on the patient's vocal abilities; and speakers by distance, volume, and feedback. The minimum acceptable video quality rating had to be fair or greater to continue. The project coordinator requested video recording from the bioethicist via a click response, and the bioethicist accepted. Once the consult was complete the bioethicist stopped recording and shut down the software. Patients or families were provided with compact discs of the consultations. The video-conferencing Infrastructure included Apple iChat software which allowed for 3-way video conferencing through the internet. An Apple Computer, DSL line, and .Mac account were used to initiate the consultations. In addition, external speakers, external microphones, and an external web camera were useful for enhanced communication. A projector and screen were used to include staff participation in the room

#### Measurement

Project staff kept routine meeting notes and quarterly logs. These logs recorded information from project planning meetings and consultations, and captured the time and difficulty involved in getting equipment to the consultation venue, issues involved in setting up consultations, estimates of how long the consultations lasted, and indications of the parties involved: staff, patients, families. Indications were made for each consultation as to whether it was face-to-face or video—and whether any issue impeded the completion of the consultation—e.g. fatigue, video breakdown. We also maintain logs of eligible patients, patients who consented, and attendance by patients, staff, and families in the study. These logs are being used to create a series of process measures, and measures of program fidelity.

#### Process measures included

- (1) Obstacles in instituting video-conferencing.
- (2) Number of consultations held and type of consultation.
- (3) Number of participants involved in consultation, and type of participant—e.g. family, bioethicist, clinician, surrogate.
- (4) Barriers to successfully completing the consultation a measure of fidelity of the intervention-such as connectivity problems, patient or family fatigue, meeting interruptions.
- (5) Meetings needed to develop the project.
- (6) Staff participating in meetings.

#### The Palliative Care Outcome Scale

The Palliative Care Outcome Scale (POS) is an outcome measure designed to assess physical, psychological, practical and existential aspects of life in the measurement of quality of care. It can be used to identify problems in individual patients care and for a clinical audit. The measure has been used cross-culturally and translated into many languages including Spanish. It has been used as an outcome measure in palliative care research projects in ethnically and racially diverse populations in the Bronx by the Palliative Care Service at MMC, including the pilot phase of our videoconference SNFs Bioethics Project and for an HIV Palliative Care Program.<sup>29</sup> It includes 10 items addressing pain and other physical symptoms, psychosocial concerns and spiritual domains that are commonly addressed by palliative care clinicians. Participants scored each of the first eight items on a 5-point Likert scale ranging from 0 (no problem) to 4 (bad). POS questions 9 and 10 are scored on a 3-point scale (0-2-4) from 0 (good) to 4 (bad). There is a single open item (POS question 11)

in which respondents can free text their main clinical problems and a subsequent item in which they rate its severity. A mean score of 2.0 or below is considered favorable. Information from individual items can be used to assess improvement or deterioration in individual domains. The total score at the end of the assessment can be used in the measurement of overall well-being and Quality of Care. We present data on the first 10 items in this report. The instrument has a client rated version (POS-C) for patients and a staff rated version (POS-S). As the study outcome measures are not yet validated in tele-educational studies; the investigators have been unable to find sufficient normative data to guide our sample size prediction.<sup>30–32</sup> Also, many family members and staff may not have had face-to-face contact with the patient in the prior 3 days participants were therefore allowed to refer to the proceeding 7 days in order to enhance ascertainment of project outcomes.

#### Staff knowledge and satisfaction

Pre-tests and post-tests included multiple choice type questions that were developed for EPERC. Satisfactions of staff with consultation and educational experience after each session were measured using a 5-point Likert scale within one month of the consultation. These items addressed their satisfaction with the level of interaction and discussion during consultations. Content related knowledge and learners' practice patterns were evaluated one week prior to and one month subsequent to the in-services and consultations. Effect on learners' practice behaviors was assessed via pre and post consultation chart reviews in regards to the quality of end-of-life care, also with intent to change questions. Data has yet to be entered for the chart reviews and therefore will not be presented in this report. Staff willingness to complete some measures such as the City of Hope scale in regards to satisfaction with endof-life care was low due to the time required to complete the measure. We therefore decided to discontinue use of this scale in order to maximize completion of measures specific to its primary goals.

## Chart Review Instrument and Background Socio Demographic Questionnaire

The project coordinator reviewed the medical record with *a standardized chart abstraction tool* and





document ed leading diagnoses, cognitive status, diagnosis of dementia, documentation of advance directives, type of advance directives, assessment and management of pain, psychosocial assessment and support, and inclusion of Goals of Care in the medical and nursing plan of care.

*Data Collection Periods*. The standardized chart abstraction was conducted immediately prior to a consultation and within one-week post consultations by the project coordinator. Patient, staff and family outcome data (POS), were collected within one week of the consultation by the project coordinator.

## **Statistical Analysis**

The statistical analysis presented in this report was conducted for 49 staff completing pre-tests and post tests and for patients, staff, and families who attended 27 consultations (13 face-to-face and 14 video-consultations) that completed the POS. Descriptive statistics includes numbers of patient, family, and staff completing POS measures prior to and one week subsequent to each consultation. Mean, median responses, range of responses, and standard deviations are presented. Numbers of don't knows and not applicable responses are reported in aggregate for all these groups. Wilcoxon Signed-Rank tests were used to test for differences in pairs of responses prior to consultation and one week subsequent to consultation for individual items on the POS for patients, families, and staff. A non-parametric test statistic was chosen because of ordinal distribution of responses. We also used Wilcoxon Signed-Rank tests for median differences in pairs of responses between baseline and one week post consultation for all respondents at each study site. Our null hypothesis was that the median differences among pairs would be equal to 0. Significance level was set at 0.05. The POS was used in a prospective observational study of 471 patients in 16 Dutch nursing homes. Completion rates for individual items varied from 18.3% for an item assessing self-worth to 91.7% for an item rating pain. Completion rates were lower for Dementia patients compared with patients with Cancer. The mean POS item score for non-demented patients was 1.53 (SD 0.57) and 1.48 (SD 0.57) p = 0.575 for patients with dementia.<sup>30</sup> We expected to see a 10% reduction in item severity (i.e. decrease in response of 0.4 points) or approximately 25% effect size in severity of scores for individual items. The significance level for all tests was set at p < 0.05.

We conducted Chi-square tests and Fisher's Exact tests to evaluate for differences in the proportion of respondents who gave correct responses to pre- and post-test items for all respondents as well as for differences in correct responses by study site. Odds ratios were calculated for likelihood of correct response by professional background. The Breslow-Day test of Homogeneity was conducted to assess if a single summary measure was appropriate for all professional groups. We conducted spearman correlation coefficients to identify if there were significant correlations between responses to baseline and follow-up POS questionnaire items and time since attendance at in-services by staff. We also conducted linear regression models with POS total scores for the first 10 POS items as the dependent variable and dummy predictor variables for patient, staff and family, and facility with and without a predictor variable for time (days) since in-services to identify if there was an interaction between patient, family and staff's POS response and time since staff attended in-services.

#### Results

Two 60 minute in-services were provided for medical providers (physicians and advanced practice nurses) in February and March 2008, and two in-services were provided for social workers, licensed practice nurses and certified nursing assistants in March 2008. A total of 72 staff attended these in-services (see Table 1). Trainings were tailored to the knowledge base and job function of the different staff members. The following measures were completed by staff attending in-services (Table 2).

## Pre- and post- in service content-related knowledge outcomes

Table 3 summarizes the findings of the pre- and posttest. We used items that were developed by David Weissman and colleagues for the EPERC curriculum. The items addressed pain and symptom management, bereavement risk and treatment, hospice eligibility and services, and bioethical principles in relation to end-of-life such as the withdrawal of medical therapies, physician assisted suicide and the principle of double effect. This has primarily been used for

Staff trained	Site A	Site B	Total
Nurses	7	10	17
CNAs	11	15	26
Psychologists	1	0	1
Physicians	11	1	12
Social Workers*	6	10	16
Total staff trained	36	36	72

medical providers: physicians, advance practice nurses, and physician assistants. Sample size limits the ability to demonstrate statistical significance for some of its findings. For example some items were completed by single professional disciplines: i.e. the proportion of physicians and advance practice nurses who answered correctly to an item in regards to the prediction of prognosis at the end-of-life increased from 42.3% to 70% (continuity adjusted Chi-square test, p = 0.35). That said the results of the test have some interesting findings. Overall knowledge scores increased for 9 of the 16 items that were analyzed. There were statistically significant improvements in knowledge in regards to management of cancer pain from 63.8% to 81.5% (p = 0.03) and a trend to significance for assessment and management of delirium from 31.6% to 61.9% (p = 0.073); and a trend to significance in the difference in odds ratios for the correct identification and management of delirium (the odds of physicians correctly identifying and managing delirium being higher than that of nurses: p = 0.104 for the Breslow-Day test of Homogeneity of Odds Ratio).



Areas of concern were the correct identification of persistent vegetative state and correct identification of addiction (12.1% pre-test and 9.3% post test). Within professional categories there were significant differences in knowledge in regards to addiction (p = 0.03); 23% of social workers correctly identified addiction on the post test, 36% of nurses, and 25% of physicians. All responding CNAs answered this answer incorrectly on pre- and post- tests.

The proportion of correct responses to an item in regards to the initiation of artificial nutrition increased from 22.6% to 77.4% (and from 14.3% to 85.7% for CNAs), p = 0.004, and post test scores for an item assessing physician assisted suicide were correctly answered by 68.2%; and there were marked differences in opinion in regards to the withdrawal of life prolonging treatments at the end-of-life. Only 8% of CNAs gave the correct response pre-test and 21% post. Test scores increased for social workers from 61.5% to 86%. Post-test scores were 80% for physicians and 82% for nurses.

The proportion of persons responding to the delirium item was lower at the direct consultation site than at the videoconsultation site for the pre-test, but not on the post-test (Fisher's Exact Test p = 0.005). The proportion of correct responses to an item related to the assessment and management of depression was lower pre- and post in-service at the direct face-to-face consultation site (p = 0.015 and p = 0.0020, respectively). The proportion of correct responses to an item on withdrawal of life prolonging treatments was lower at the direct face-to-face consultation site (p = 0.001), and for an item on the principle of double effect (p = 0.022) on the post test.

Staff	Pre-test Site A	Post-test Site A	Pre-test Site B	Post-test Site B	Total Pre-tests	Total Post-tests
Nurses	6	7	5	4	11	11
CNAs	9	5	12	15	21	20
Psychologists	1	1	0	0	1	1
Physicians	6	9	1	1	7	10
Social Workers	3	4	10	3	13	7
	25	*26	28	*23	53	*49

Table 2. In-service pre- and post-tests completed.

\*Greater numbers completed the post-tests for some professional disciplines due to late arrival to the in-services.

Table 3. In-service pre- and post-test results.

Question	Profession	Pre	Post	Chi-square/ Fisher's exact test	Mantel-Haenszel test/ Breslow-Day test for homogeneity of the odds ratios
Treatment of Cancer Pain	All	63.8%	81.5%	<i>p</i> = 0.03*	<i>p</i> = 0.11
Identification of Addiction in a patient with pain	MD/NP	12.1%	9.30%	<i>p</i> = 0.60	<i>p</i> = 0.03*
Ethical basis for Withdrawal of life prolonging treatment	All	46.5%	55.6%	<i>p</i> = 0.34	<i>p</i> = 0.31
The principle of Double Effect	MD/NP RN SW	77.4%	89.3%	<i>p</i> = 0.22	p = 0.30
Hospice Eligibility Criteria	SW	60.0%	62.5%	<i>p</i> = 0.65	NA
Services that are covered by Hospice	SW	53.3%	66.7%	<i>p</i> = 0.68	NA
Prognostication in Terminal Illness	MD/NP	42.3%	70.0%	<i>p</i> = 0.35	NA
The identification of Persistent Vegetative State	MD/NP	28.6%	22.2%	NS	NA
Treatment of Delirium	MD/NP RN	31.6%	61.9%	<i>p</i> = 0.073**	<i>p</i> = 0.104
Treatment of Depression	MD/NP	61.1%	71.4%	<i>p</i> = 0.45	<i>p</i> = 0.43
Ethical basis for withholding Artificial Feeding	All	22.6%	77.4%	<i>P</i> = 0.004*	p = 0.69
Confirmation of Patient Capacity	MD/NP	68.7%	82.4%	<i>p</i> = 0.19	NA
Identification of Physician Assisted Suicide	CNA	31.8%	68.2%	<i>p</i> = 0.03*	NA
Psychosocial support for families at the Moment of Death	MD/NP RN	61.3%	60.7%	<i>p</i> = 0.96	<i>p</i> = 0.93
Bereavement Counseling	All	70.7%	81.5%	<i>p</i> = 0.18	<i>p</i> = 0.57
Delivering Bad News	All	48.0%	51.7%	<i>p</i> = 0.70	NS

\*P = < 0.05. \*\*Trend to Significance.

Abbreviations: NA, not applicable; NS, not significant.

## Consultations

Up-to two consultations per month were delivered at each site (March 2008 to January 2009). The patients' clinical issues and description of participants are described in Table 4. A total of 153 staff attended 27 consultations at both sites during this period: 13 video-conferenced Palliative Care consultations conducted at BAHS (72 staff, and 13 family members) and 14 direct face-to-face consultations conducted at MSH (81 staff, and 12 family members).

#### POS survey outcomes

Data entry and analysis was conducted for 75 POS; 23 surveys were completed by family caregivers, 19 patients, and 33 by staff members. Non response (no answer) ranged from 0% for the pain item to 15% for the item rating how well practical concerns were addressed at the first assessment. Don't know responses ranged from 0% for the items related to anxiety, family anxiety, information provision, and sharing patient's emotional reactions, to 20% for an item rating depressed mood. Descriptive statistics on patient, family, and staff responses for the POS are presented in Tables 5, 6, and 7. Median Scores decreased for seven items and increased for one item for POS questionnaires that were completed by families. Median scores decreased for five items rated by patient respondents and increased for four items. Median scores decreased for five items on POS questionnaires rated by staff members and increased for two items.

The Wilcoxon Signed-Rank Test was significant for difference in family respondents ratings for items



**Table 4.** Clinical issues addressed by consultations.

	Video-consultations	Direct consultations
Themes	<ul> <li>Decision making for a resident with Downs Syndrome and CHF</li> </ul>	<ul> <li>Goals of care and advance directives for a man with metastatic lung cancer</li> </ul>
	<ul> <li>Family conflict over non-re-hospitalization of a person with advanced dementia</li> </ul>	<ul> <li>Promotion of dialogue within a family about end-of-life care, advance directives, life legacy in a woman with metastatic endometrial cancer</li> </ul>
	<ul> <li>Clarification of decisional capacity in a person with expressive dysphasia secondary to a CVA</li> </ul>	<ul> <li>Delegated decision making in an elderly man with CHF and dementia</li> </ul>
	<ul> <li>Determination of medical capacity in a resident with schizophrenia</li> </ul>	<ul> <li>Goals of care in a diabetic with CHF who is refusing treatment</li> </ul>
	<ul> <li>Discussion of goals of care and resuscitation status in a patient with advanced dementia and multiple recent hospitalizations</li> </ul>	<ul> <li>Contingency planning for a man with metastatic prostate cancer and advanced dementia</li> </ul>
		<ul> <li>Psychosocial aftermath of an incorrect prognostic estimate for a person living with dementia who survived the holocaust with her daughter</li> </ul>

pertaining to family anxiety (p = 0.005), patients ability to share their feelings (p = 0.028), sense that life was worth living (p = 0.0003), and wasted time (p = 0.0003) between the pre-consultation assessment and the assessment referring to the week after the consultation. The Wilcoxon Signed-Rank Test was significant for differences in patient ratings of pain severity (p = 0.0437) and Sense that life was worth living (p = 0.0158) between baseline and follow-up assessments. Wilcoxon Signed-rank tests showed significant decreases in staff reports of physical symptom severity (p = 0.0291), wasted time (p < 0.0001), and how practical concerns were addressed (p = 0.0162), ability to share and how good the patient felt increased significantly between baseline and follow-up (p = 0.0097) and (p = 0.0062) respectively.

Mann-Whitney tests at baseline did not reveal differences in severity in any of the POS items between either facility. There were significant decreases in median intensity of symptoms, how well practical concerns were addressed, and the amount of time wasted on medical appointments for participants at the face-to-face consultation site. Wilcoxon signed rank tests were significant at (p=0.0032), (p=0.0036), (p<0.001) respectively.

Family anxiety increased significantly (p = 0.0044) and ability to share feelings with family or friends worsened (p = 0.0020). Respondents at the videoconsultation site's rating of time wasted at medical appointments were significantly decreased between baseline and follow-up (p = 0.001). Aggregate scores for the first 10 POS items were significantly improved between baseline and follow-up for patients. Wilcoxon signed rank test (p = 0.0143) and staff (p = 0.0005) but not for families (p = 0.083) at the video-consultation intervention site. Aggregate scores for the first 10 items were significantly improved for family respondents (p = 0.0016) and for staff (p = 0.0012) but not for patients (p = 0.08).

Spearman correlation coefficients were not significant for scores on any of the POS items and time since attendance at in-services (days). The linear regression model for total POS score accounted for only 11.2% of the variance in POS responses. Beta coefficients were not significant for family and patient participants. The beta coefficient for staff responses was significant with and without the inclusion of the time since attendance at staff in-services. ( $\beta = -0.347$ , p = 0.013 and -0.343, p = 0.015) meaning that time since attendance at staff in-services did not appear to influence POS responses.



Variable	Pre-consultation						Post-consultation				
	Ν	Mean	Median	Std. dev.	Range	Ν	Mean	Median	Std. dev.	Range	
Pain	11	1.636	2	1.502	0–4	8	1.125	1	1.246	0–3	
Other Physical Symptoms	11	1.454	1	1.440	0–4	8	0.750	0.5	0.886	0–2	
Anxiety about Illness or Treatment	12	2.167	2.5	1.337	0–4	8	0.375	0	0.744	0–2	
Family/Friends anxiety about Patient	12	2.833	3	1.403	0–4	8	2.375	2.5	1.598	0–4	
Information	11	1.909	2	1.514	0–4	8	0.750	0	1.488	0–4	
Sharing Feelings with Family/Friends	11	2.909	3	1.221	1–4	8	1.750	1.5	1.581	0–4	
Life Worth Living	9	0.889	0	1.364	0–4	8	0.875	0	1.356	0–4	
Felt Good About Themselves	10	1.900	2	1.449	0–4	8	1.75	1	1.488	0–4	
Time Wasted	10	0.200	0	0.632	0–2	8	0	0	0	0	
Practical Concerns addressed	11	1.091	0	1.375	0—4	8	1.25	1	1.488	0—4	

**Table 5.** Descriptive statistics for palliative outcome scale family respondents.

## **Process Outcomes**

Technology Minor technological difficulties have interrupted some of the BAHS' consultations for brief periods of time. Given the potential for audio-quality to interfere in the ability of some of the participants to hear each other the project coordinator has identified that the use of tabletop microphones has been more effective for this purpose. One video-consultation needed to be rescheduled because of connectivity problems. The time taken to transport a patient, and for staff to congregate in an off-unit conference room, and room set-up resulted in the video consultations taking up-to 90 minutes to accomplish. The use of a broadband card is expected to decrease the amount of time that consultations take by allowing consultations to occur in or near to the patients' rooms thereby removing the requirement that patients, family members, and staff congregate off the unit. We also expect that this will make the project more accessible to patients who are very close to the end of life who may not have been able to participate due to immobility. The faceto-face consultations at MSH by contrast often only require 45 minutes with an additional 15 minutes of case discussion, and often took place in the patient's room. The use of broadband internet access will make the video-consultations at BAHS more directly comparable with the experience at MSH where the consultations are unit-based.

## Discussion

To our knowledge this is one of the first projects to target a multi-ethnic, inner-city, population to pilot the delivery of integrated Palliative Care and Bioethics Services to enhance access to end-of-life care, and to provide education to professional caregivers of longterm care residents on culturally competent end-oflife care. Our large inner-city bilingual population provides a unique opportunity to use this project to design, implement and test affordable, replicable and acceptable models appropriate to multi-ethnic communities. The results of this pilot project will provide the necessary elements needed for further refinement of our tele-health and tele-education methods and to launch a full-scale clinical trial of major potential importance, both for health disparities and palliative care.

The improvements in staff knowledge gained through the delivery of a curriculum that was developed primarily for medical providers extended across disciplines. This may help dispel concerns that medical educators may have in regards to exposing 'nonprofessional' caregivers to such material. Given that



 Table 6. Descriptive statistics for palliative outcome scale patient respondents.

one quarter of Americans die in long-term settings and more than 10% of deaths are for residents of longterm care facilities who are hospitalized; it seems short-sighted for educational initiatives in palliative care to continue to be so disproportionately directed toward medical trainees and graduates. We hope to be able to test the impact of focused educational efforts on areas of weakness highlighted in our pre- and posttest on the actual care that patients served by this project receive.

The project faced some unanticipated difficulties. The current economic downturn threatens to impact long-term care institutions disproportionately because of their dependence on state funding. This leaves long-term care institutions struggling to maintain a full complement of services such as social work staff. In order to lessen potential additional perceived burdens on the part of time-stressed nursing home leaders and staff, it becomes important to be open to and act upon their feedback in order to sustain a program such as this. The turn-over in several pivotal staff in this project resulted in inevitable short-term hurdles to its implementation. However the addition of different skill-sets and new insights from incoming staff allowed us to refocus our efforts towards more streamlined engagement of patients, families, and staff. We reduced the amount of time required to

conduct consultations as the project team and nursing home staff built on its comfort level with the project process in response to feedback from the staff at both SNFs.

During the project's second year. We will attempt to lessen perceived time pressures on the achievement of outcomes from a single consultation for individual patients by doing follow-up consultations if the team assesses that this could be of benefit. This will occur when patients and families require time to process information that has been presented during consultations and to allow time to share information among other family members, and to help provide additional support with making decisions about goals of care and additional emotional support. We will also conduct video-consultations for patients of both long-term care facilities when they are hospitalized at MMC when it is possible to coordinate the attendance of key staff at the SNFs. Single patient occupancy rooms have been tested for effectiveness of connectivity with use of a broadband card on several units. Preliminary evidence suggests that this will be feasible.

Response rates for families and patients to the baseline quality of care measure was less than 50% and for patients completing baseline measures only half completed follow-up measures. This increases



Variable	Pre-consultation						Post-consultation				
	Ν	Mean	Median	Std. dev.	Range	Ν	Mean	Median	Std. dev.	Range	
Pain	16	1.813	2	1.328	0–4	14	0.714	0	0.914	0–2	
Other Physical Symptoms	15	1.2	1	1.265	0–3	15	0.6	0	1.121	0–3	
Anxiety about Illness or Treatment	16	1.5	1	1.366	0–4	13	0.923	0	1.188	0–3	
Family/Friends anxiety about Patient	16	1.438	1	1.504	0–4	12	2.167	3	1.697	0–4	
Information	14	0.857	0	1.292	0–4	14	1.357	0	1.823	0–4	
Sharing Feelings with Family/Friends	15	2.467	3	1.598	0–4	14	2.357	3	1.780	0–4	
Life Worth Living	14	1.929	1.5	1.685	0–4	11	0.818	1	1.401	0–4	
Felt Good About Themselves	13	2.615	3	1.261	0–4	9	2.333	3	1.581	0–4	
Time Wasted	13	0	1	0.451	0–1	16	0	0	0.351	0–1	
Practical Concerns addressed	13	0.769	0	1.013	0–2	12	1	1	1.044	0–2	

 Table 7. Descriptive statistics for palliative outcome scale staff respondents.

the likelihood that real differences between pre- and post-consultation ratings by patients, and families of quality of care were not found to be statistically significant. The attrition rate in this study is in line with the attrition rates in other studies that have been conducted by the investigators and reflective of the difficulties faced in measuring quality of care and quality of life in terminally ill patients.<sup>28,33</sup> This is compounded in long term care settings where high proportions of patients have moderate to severe cognitive impairment. Families and patients may have been reluctant to complete outcome measures as they may have associated the evaluators with the clinical team. Increases in scores for items such as the provision of information to the patient and family suggests that a one-time consultation may be insufficient to impact on quality of care. Practical implications of this would be that incremental services for residents of long-term care facilities who are at the end-of-life should involve options for more frequent contact with end-of-life health care professionals.

The low completion rate by staff may reflect suspicions that participating staff may harbor in regard to research; perceived time burdens associated with completion of the outcome measure and difficulty providing indirect ratings of the impact of care on facets of quality of life as well as lack of direct benefit to the participating patient and family. Staff completion of pre- and post-content related tests was markedly higher (approximately 70%) suggesting that they may be more comfortable with assessing their own content related knowledge. Some of the participants who completed follow-up measures did not complete base-line measures e.g. the pre- and post-measure due to some participants arriving late to in-services.

Some of the project evaluation measures were discontinued because of lack of acceptability to participants as identified by comments by participants to the project coordinator and low completion rates (specifically the Professional Background Questionnaire and the Modified City of Hope Questionnaire). We expect completion rates for patient rated measures to remain low due to cognitive impairment related to dementia and low energy related to advanced physical illnesses. Completion rates of family rated measures such as the POS have also been low. We expect that the initial time frame for response for this questionnaire (the 3 previous days) may also limit the ability of some family members to complete such measures. We have amended this to a one week period pre- and post-consultation.

Further analyses will include a review of chart abstraction data to evaluate the impact of the project

on the care of patients and families served by the project in regards to pain and symptom management, psychosocial support, documentation of advance directives, and the development and communication of contingency plans. We will begin to review administrative datasets such as the Minimum Data Set and data from the office of planning at MMC to evaluate its impact on health service utilization by patients served by this project. Analysis of POS data will be on-going.

#### **Study Limitations**

The quasi research model used in this study makes inference from its results difficult. The selection of the patients involved in this study involved convenience sampling methods and therefore the patients at each study site may not be entirely comparable. Patients at the face-to-face consultation site were disproportionately identified to the research site as being in need of consultation for assistance with pain and symptom management and the absence of participation by a bioethicist in consultations at this site may have skewed the consultations toward a focus on pain and symptom management. This may account for the apparent differences in physical symptom severity pre- and post-consultation at the two sites. The relatively small number of staff attending in-services from individual disciplines makes it difficult to ascertain if the teaching materials and delivery were effective in improving intended outcomes. The choice of the POS as an outcome measure in the SNF setting may limit ability to assess outcomes in relation to pain and symptom management due to confusion on the part of staff and families how to rate the severity of items in non-verbal patients with Dementia. Its short time frame may have limited the ability to ascertain outcomes for family members who can only visit patients weekly at most or for staff members such as social workers who might only round on a patient weekly to bi-weekly. Additionally, as the project coordinator coordinated consultations and recruited patients and other participants as well as distributing project evaluation materials respondents may have felt an onus to give favorable responses to their assessment of the project. The full time medical staffing models in place in both facilities may also limit the ability to generalize from this model to settings where medical staff models are predominantly fee-for service. In such



settings medical buy in may be limited by competing time pressures for medical providers.

#### Conclusion

Preliminary evidence suggests that use of real time videoconferencing to connect hospital-based Bioethics and Palliative Care clinicians with patients, families, and staff in skilled nursing facilities may enhance satisfaction with some aspects of end-oflife care for their residents, as well as content related knowledge in core aspects of end-of-life care for an interdisciplinary group of staff caregivers. Further analyses will include evaluations of the project's impact on health service utilization as well as the quality of end-of-life care through structured medical record reviews and review of minimum data set variables related to the project for participating patients.

## Disclosure

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