A Qualitative Evaluation of Student and Patient Perceptions of a Palliative and End-of-Life Care Curriculum taught in the Nursing Home

"What do college students & nursing home residents take away from a summer immersed in palliative care?"

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Background and Aims

BACKGROUND

Through its ten-week, full-time curriculum, the **Columbia University Center for Science and Society Research Cluster on Science and Subjectivity-ArchCare at Terence Cardinal Cooke (RCSS-TCC) Internship** provides pre-medical college interns with a patient care and accompaniment experience in nursing home palliative care. This experience is designed to provide exposure to these populations and convey foundational pre-clinical skills essential to pre-clinical students preparing for the wards.

SIGNIFICANCE

Medical trainees continue to receive inconsistent formal training in palliative care and end-of-life issues, particularly in the outpatient, hospice, and nursing home settings that many patients utilize at the end of life. As U.S. medical students continue to matriculate with increasing amounts of clinical exposure prior to medical school and preclinical curricula are shortened, earlier exposure to end-of-life issues may better prepare students to assist with the challenges faced by seriously ill or dying patients during their clinical rotations and beyond. **Although research has been performed to identify palliative care competencies for medical students, residents, and fellows, no studies have been performed to evaluate undergraduate college internships with clinical exposure to these populations to identify appropriate competencies.**

AIMS

1. **To evaluate the RCSS-TCC internship curriculum in conveying foundational pre-clinical knowledge and skills necessary to achieve medical student-level competencies in palliative care.**
2. **To assess nursing home residents' perceptions about students' impact on quality of life in the nursing home.**

Who are the Students and Nursing Home Residents?

Nursing Home Residents: FACIT-Pal Survey Results

N = 9 Nursing Home Resident Respondents

Within the past 7 days, have you felt that: (0 - Not at all, 1 - A little bit, 2 - Somewhat, 3 - Quite a bit, 4 - Very Much)	Average Score	# of Residents who answered "Quite a bit" or "Very Much"
I have a lack of energy	1.9	4
I have nausea	0.6	0
I have pain	1.7	4
I worry that my condition will get worse	2.2	5
I am able to enjoy life	2.1	3
I am sleeping well	2.2	4
I am content with the quality of my life right now	1.9	4
I get emotional support from my family	2.7	6
I feel hopeful	1.9	4
I feel sad	2.4	5
I feel like a burden to my family	1.3	3
I am constipated	0.8	2
I am able to openly discuss my concerns with the people closest to me	2.1	3
I have been short of breath	1.3	2

Students: Demographics & Previous Exposure

	Student 1	Student 2	Student 3	Student 4
Undergraduate School (Columbia College, Columbia Engineering, Barnard College, General Studies)	Columbia Engineering	Columbia College	Columbia College	Columbia College
Age	20	20	21	21
Year in Undergraduate Program	3	3	4	4
Gender (M, F)	F	F	F	F
Previous Degree of Exposure to People Age 65+	Low Degree of Exposure	Moderate Degree of Exposure	Moderate Degree of Exposure	Moderate Degree of Exposure
Setting(s) of Past Exposure/Experiences with People Age 65+	Home/Family Life	Home/Family Life, Nursing Home, Community-Based Programs	Home/Family Life, Nursing Home, Community-Based Programs	Home/ Family Life, Nursing Home
Previous Degree of Exposure to People Facing Terminal Illness	High Degree of Exposure	Low Degree of Exposure	No Exposure	Moderate Degree of Exposure

Methods

Study Participants and the Recruitment Process

The study was approved as exempt by the Longwood Medical Area Institutional Review Board and by the Columbia University Institutional Review Board. ArchCare at Terence Cardinal Cooke (TCC) accepted the Institutional Review Boards' determination and gave approval for the study to occur on premises.

All four (4) 2015 RCSS-TCC interns were eligible for the study. They were invited to participate in the study by e-mail. All four (4) 2015 RCSS-TCC interns participated in all aspects of the study.

At the end of internship week 3, each of the 4 interns were asked to identify two to three nursing home residents with whom they had developed a relationship. All nine (9) identified nursing home residents were invited to participate in the study in-person. Nine (9) nursing home residents participated in the study.

Methods

All four 2015 RCSS-TCC Columbia University interns completed **pre- and post- written surveys consisting of 12 items that utilized Likert scales and room for open-ended comments** about their familiarity with palliative care knowledge, skills, and attitudes at the start (June 1st, 2015) and end of their internship (August 7th, 2015), respectively. We conducted a **1 – 1.5 hour semi-structured interview consisting of 38 questions** with each student intern at the end of internship week 2, at the end of internship week 4, at the end of internship week 6, and 7 weeks after the internship had concluded (September 15th, 2015) asking them to reflect on changes in their knowledge, skills, and attitudes surrounding palliative care since the previous interview. In addition, we asked the students to reflect on the impact of internship on quality of life for nursing home resident.

During internship weeks 6 and 7, we conducted **one-time written FACIT-Pal (Functional Assessment of Chronic Illness Therapy – Palliative Care, copyright David Cella PhD) surveys** and **30-minute semi-structured interviews consisting of 8 open-ended questions** with 9 TCC nursing home residents asking about their perceptions of the student interns' impact on their quality of life.

Analysis

We quantitatively analyzed written surveys completed by students and nursing home residents for Likert score results to provide demographic data and to provide context for qualitative analysis. Averages of Likert score survey results were calculated and reported using Excel.

We used qualitative, grounded theory methods to analyze the audio-recorded and transcribed semi-structured interviews. One investigator (A. Shaw) undertook multiple cycles of reading the transcripts to group concepts and themes. These concepts and themes were then discussed with investigator K. Schaefer and each theme was clarified and renamed until the data were fully described and categorized. Themes surrounding the efficacy of certain curricular components in preparing and motivating pre-clinical students to deliver high-quality palliative care and the nursing home residents' perceptions of student involvement were identified to form a coding schema. Transcripts were coded according to the coding schema using the online software Dedoose. Dedoose was also used to generate online reports of coding frequency. Conclusions regarding essential elements of such curricula were then defined.

RCSS-TCC Internship Curriculum

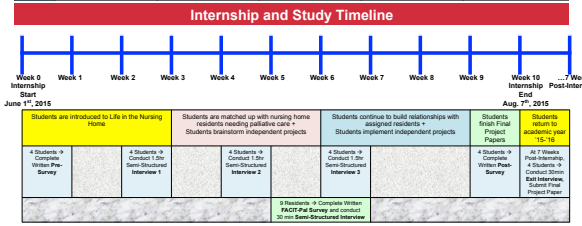
Internship Objectives Adapted from *K. Schaefer, et. al.* **"Raising the bar for the care of seriously ill patients: results of a national survey to define essential palliative care competencies for medical students and residents. Acad Med. 2014 Jul;89(7):1024-31."**

Domain	Learning Objective	Internship Activity
Knowledge	Describes ethical principles that inform decision-making in serious illness, including the right to forgo or withdraw life-sustaining treatment and the rationale for obtaining a surrogate decision maker.	•Conduct relevant literature review •Describe the TCC Palliative Care Protocol workflow •Describe Catholic healthcare principles surrounding end-of-life care •Attend TCC Ethics Council meeting •Interview patients about the factors that affect their decision-making in serious illness
	Describes the roles of members of an interdisciplinary palliative care team	•Participate in daily Morning Report •Observe different roles in TCC's interdisciplinary palliative care team •Attend quarterly and emergent interdisciplinary care planning meetings •Describe each discipline's role in implementing TCC's Palliative Care Protocol
	Defines the philosophy and role of palliative care across the life cycle and differentiates hospice from palliative care.	•Conduct relevant literature review. •Compare and contrast TCC's Palliative Care Protocols and TCC's Hospice Protocols •Interact with Calvary Hospital hospice team •Describe hospice referral process •Spend one day in inpatient hospice setting
Skills	Identifies psycho-social distress in patients and their loved ones.	•Interview residents and loved ones regarding psycho-social distress •Follow and advocate for 4-6 residents throughout dying process
	Explores patient and loved ones' understanding of illness, concerns, goals, and values that inform the plan of care.	•Interview residents and loved ones regarding understanding of illness, concerns, goals, and values •Advocate for residents and loved ones' concerns and goals
	Demonstrates basic approaches to handling emotion in patients and their loved ones facing serious illness.	•Meet one-on-one with the Medical Director to discuss approaches to handling emotion in residents and their loved ones facing serious illness •Implement specific non-pharmacological palliative interventions for assigned residents
	Identifies patients' and their loved ones' cultural values, beliefs, and practices related to serious illness and end-of-life care.	•Interview residents and loved ones regarding cultural values, beliefs, and practices related to serious illness and end-of-life care •Follow and advocate for residents and their loved ones' cultural values to be respected
	Identifies spiritual and existential suffering in patients and families.	•Interview residents and their loved ones regarding spiritual and existential suffering •Follow and advocate for residents and their loved ones' spiritual needs to be met •Shadow TCC chaplains during palliative care and hospice visits.
Attitudes	Reflects on personal emotional reactions to patients' dying and deaths.	•Meet with the Medical Director one-on-one several afternoons a week to reflect on personal emotional reactions to residents' dying and deaths •Journal and blog several times a week
	Agrees that it is possible to tell the truth about a terminal prognosis and still maintain hope.	•Interview and shadow the Medical Director and TCC's attending physicians to understand their role, techniques, and skills in helping residents and their loved ones maintain hope with a terminal prognosis
	Agrees that physicians have a responsibility to help patients at the end of life prepare for death.	•Interview and shadow the Medical Director and TCC's attending physicians to understand their role, techniques, and skills in helping residents and their loved ones at the end of life prepare for death
	Agrees that psychological suffering can be as severe as physical suffering.	•Interview residents and their loved ones regarding psychological suffering •Understand role of interdisciplinary staff members in addressing psychological suffering •Follow and advocate for residents and loved ones' psychological suffering to be adequately addressed

Sample Student Intern Work Week

	Monday	Tuesday	Wednesday	Thursday	Friday
Morning	9AM – 10 AM Morning Report with entire Interdisciplinary Team	9AM – 10 AM Morning Report with entire Interdisciplinary Team	9AM – 10 AM Morning Report with entire Interdisciplinary Team	9AM – 10 AM Morning Report with entire Interdisciplinary Team	9AM – 10 AM Morning Report with entire Interdisciplinary Team
	10 AM – 10:30 AM Bedside Rounds on emergent hospital transfers with Medical Director & attending physicians	10 AM – 12:00 PM Attend HIV/AIDS Program Comprehensive Care Planning (CCP)	10 AM – 10:30 AM Bedside Rounds on emergent hospital transfers with Medical Director & attending physicians	10 AM – 12:00 PM Attend Huntington's disease Program Comprehensive Care Planning (CCP)	10 AM – 10:30 AM Bedside Rounds on emergent hospital transfers with Medical Director & attending physicians
	10:30 AM – 12 PM Escort residents to in-house Alcoholics Anonymous meeting		10:30 AM – 12 PM Shadow Consultant Palliative Care Nurse Practitioner on Patient Visits		10:30 AM – 12 PM Conduct literature review pertinent to independent project
Afternoon	1 PM – 2 PM Meet with Unit Social Worker to advocate for resident's specific needs (trip to bank, eyeglasses, etc.)	1 PM – 2 PM Conduct audit on advanced directives forms on assigned units	1 PM – 2 PM Attend emergency Ethics Council meeting	1 PM – 2 PM Discuss independent project progress with Medical Director	1 PM – 2 PM Shadow Chaplain on Hospice Rounds
	2 PM – 4:30 PM Sit vigil at bedside of dying resident discussed during Morning Report	2 PM – 4:30 PM Meet with loved ones of assigned resident at bedside	2 PM – 4:30 PM Follow resident and loved ones through hospital admission; visit in hospital	2 PM – 4:30 PM Review TCC Palliative Care Procedure; suggest improvements	2 PM – 4:30 PM Meet with resident and loved ones at bedside
	4:30 PM – 5 PM Debrief day's events with Medical Director	4:30 PM – 5 PM Debrief day's events with Medical Director	4:30 PM – 5 PM Debrief day's events with Medical Director	4:30 PM – 5 PM Debrief day's events with Medical Director	4:30 PM – 5 PM Debrief day's events with Medical Director

Internship and Study Timeline



Coding Schema and Survey Results

STUDENT INTERVIEWS: EXAMPLES FROM CODING SCHEMA

Knowledge & Attitudes Surrounding Interdisciplinary Team Function
- Hierarchy within IDT team
- Student's own perceived role on team
- Knowledge of different team member's roles
- When team members did not fulfill their roles
- Comprehensive care planning conferences

Knowledge of the philosophy of palliative care / hospice
- Changes in knowledge of palliative care / hospice services
  - Previous misconceptions & attitudes
- Experiences or people that most contributed to those changes

Learner attitudes surrounding quality of life in nursing home
- Student's own perceived impact on patients' quality of life
- Relationships with patients
  - Companionship and non-abandonment
- Student's own perceived impact on caregiver team
- Examples of student advocacy

Learner self-reflection
- Coping with overwhelming aspects of internship
  - Therapeutic value of debriefing
- Mental health
- Most important experiences
- Most personally meaningful experiences

Impact of experience on future goals
- Change in desire to go into geri. and pall. care
- Change in respect for caregivers in geri. and pall. care
- Change in academic goals
- Change in career goals
- Change in confidence in one's skills

"Worthy experiences I had... told me I didn't want to do geriatrics, [but] now I have such an appreciation for palliative care, know what it is and how important it is – that was important and meaningful, but really formative for me as a future doctor and as a person." – Student during Exit Interview

RESIDENT INTERVIEWS: EXAMPLES FROM CODING SCHEMA

Role of students in advocacy
- Comments about specific tasks students were able to help with
- Comments about specific tasks students should not be involved with

Individualized relationship
- Comments about sharing interests in activities
- Comments about being treated as an individual
- Comments about being able to leave the unit

Perception of students' time
- Comments about role being "just right"
- Comments about wanting students to play a bigger role
- Comments about wanting more students

STUDENT SURVEY RESULTS	AVG "PRE" SCORE	AVG "POST" SCORE	Δ
Domain: Skills (1: need further basic instruction, 2: able to perform with close supervision, 3: able to perform with minimal supervision, 4: able to perform independently)			
I am able to identify psycho-social distress in patients and their loved ones.	2.3	4.0	+1.8
I am able to explore patient and loved ones' understanding of illness, concerns, goals, and values that inform the plan of care.	1.8	3.8	+2.0
I am able to handle emotion in patients and their loved ones facing serious illness.	2.0	4.0	+2.0
I am able to identify patients' and their loved ones' cultural values, beliefs, and practices related to serious illness and end-of-life care.	1.8	3.8	+2.0
I am able to identify spiritual and existential suffering in patients and families.	1.8	3.5	+1.8
I am able to reflect on my own emotional reactions to patients' dying and deaths.	3.0	3.8	+0.8
Domain: Attitudes (1: strongly disagree, 2: somewhat disagree, 3: somewhat agree, 4: strongly agree)			
It is possible for physicians to tell the truth about a terminal prognosis and for the patient to still maintain hope.	3.3	3.8	+0.5
Physicians have a responsibility to help patients at the end of life prepare for death.	4.0	4.0	0.0
Psychological suffering can be as severe as physical suffering.	4.0	4.0	0.0
Domain: Knowledge (1: not knowledgeable, 2: somewhat knowledgeable, 3: somewhat knowledgeable, 4: very knowledgeable)			
I can describe ethical principles that inform decision-making in serious illness, including the right to forgo or withdraw life-sustaining treatment and the rationale for obtaining a surrogate decision maker	2.0	3.5	+1.5
I can describe the roles of members of an interdisciplinary palliative care team, including nurses, nursing assistants, social workers, case managers, chaplains, dieticians, recreational and occupational therapists, psychologists, administrators, and pharmacists.	2.3	4.0	+1.8
I can define the philosophy and role of palliative care across the life cycle and differentiates hospice from palliative care	1.8	4.0	+2.3

Conclusions

1. Students' increased confidence in possessing the knowledge and skills to respond to patients and family members dealing with serious illness positively impacts their future healthcare career goals
2. Protected time for topic-specific training to respond to challenging scenarios and self-reflection / debriefing are essential elements of such an immersive clinical experience
3. Students identified the growth of personal relationships with patients and examples of successful student advocacy on behalf of patients as the most meaningful outcomes of this immersive clinical experience
1. Nursing home residents reported that student involvement improved their quality of life during the length of the internship
2. Nursing home residents desired more time with students but felt their role was "just right"
3. Students' actions towards nursing home residents were most meaningful to residents when they served to "individualize" the patients in the NH

"I sure would [recommend that other residents have students involved in their care]. You learn something from the students. You learn a whole lot from them. Because [Student]'s a listener." –Nursing Home Resident

Validity and References

Confirmability: **The use of a single individual coder (A. Shaw) who had previously been involved as a participant and administrator of the RCSS-TCC internship presents the possibility of investigator bias which could in the future be minimized by utilizing several independent coders to further confirm and refine the coding schema. However, the presence of unexpected conclusions drawn from grounded theory qualitative analysis may serve as evidence that investigator bias was minimized to the extent possible.**

Credibility: **The interview transcripts were shown to student participants and students reflected on their contents during daily debriefs with the Medical Director, reaching similar conclusions as the investigators.**

Transferability: **This study design could be utilized to study similar pre-clinical educational interventions at nursing homes or healthcare institutions that care for the seriously ill and would likely yield similar results.**

Dependability: **This annual internship utilizes the same learning objectives and curricula each year and the selection process for the student interns and their assigned nursing home residents is consistent. Given the consistency of the characteristics of participants, one could expect replicable results if the study was repeated.**

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