

# SCIENCE AND SUBJECTIVITY



**RCSS JOURNAL OF UNDERGRADUATE RESEARCH**

VOLUME 3 | FALL 2019 ISSUE



## ABOUT THE RCSS

The Research Cluster for Science and Subjectivity (RCSS) provides undergraduates with the opportunity to take ownership of their own work and strive towards a more complete understanding of their respective fields and communities. We do this by providing stipends for students who propose and carry out their own projects that bridge science, subjectivity, and service.

We envision future generations of scientists, scholars, and professionals building their careers in realization of a more complete human experience.

Projects by the RCSS are made possible by the Center for Science and Society at Columbia and by the late Harvey Krueger (CC '61, Law '64), who provided our endowment when the RCSS was established in 2014.

To learn more, please visit <https://rcss.scienceandsociety.columbia.edu/>

### 2018-19 INTERNS

Abigayle Dolmseth  
Anna Li  
Alex Fu Tang  
Brigid Connelly  
Chantal O'Brien  
Diane Huang  
Eilam Lehrman  
Eva Perez-Greene  
Mariel Sander  
Naazanene Vatan  
Ralitsa Kalfas  
Samia Abedin  
Sandy Zeng  
Sara Castro  
Shalom Omollo  
Sungtae Yoon  
Tony Qian  
Vincent Le

### DIRECTORS

Robert Pollack  
Manoushka Constant

### ADVISORY BOARD

Casey Blake  
Craig Blinderman  
Charles Borrok  
Rachel Chung  
Lisa Dolling  
Rachel Adams  
Rishi Goyal  
Robert Hanning  
Anthony Lechich  
Melinda Miller  
Amy Pollack  
Marya Pollack  
Sonia Reese  
Robert Remez  
Joshua Sakolsky  
Christina Staudt  
Nicole Wallack

*The RCSS Journal of Undergraduate Research was produced and designed by Diane Huang, Mariel Sander, and Chantal O'Brien.*

## TABLE OF CONTENTS

<b>HEALING THROUGH ART</b> <i>A PROFILE OF START@TCC</i> by Chantal O'Brien and Alex Tang	<b>1</b>
<b>THE STARS ARE THE EYES OF HEAVEN</b> <i>PACIFIC STARGAZING IN HAWAII</i> by Tony Qian	<b>4</b>
<b>LIFE AT THE END OF LIFE</b> <i>TEACHING PALLIATIVE CARE THROUGH SERVICE</i> by Brigid Connelly	<b>6</b>
<b>INTERGENERATIONAL SUPPORT NETWORKS IN MUMBAI'S URBAN CONTEXTS</b> by Naazanene Vatan	<b>8</b>
<b>RESEARCHING PERCEIVED HEALTH OUTCOMES OF RECREATIONAL THERAPY</b> by Ralitsa Kalfas and Sungtae Yoon	<b>11</b>
<b>ADVANCING ADVANCE DIRECTIVE DISCUSSIONS LESSONS FROM THE NURSING HOME</b> by Abigayle Dolmseth	<b>13</b>
<b>MEASURING THE HEALING POWER OF MUSIC INVESTIGATING THE MUSIC THERAPY PROGRAM</b> by Vincent Le	<b>15</b>
<b>THE BIOGRAPHY PROJECT</b> <i>EXPANDING OUR UNDERSTANDING OF END OF LIFE CARE</i> by Sara Castro, Sungtae Yoon, and Sandy Zeng	<b>17</b>
<b>ASSISTING THE LATINO COMMISSION ON AIDS</b> by Sara Castro	<b>19</b>
<b>TERENCE CARDINAL COOKE: THE AT YOUR SERVICE VOLUNTEER PROGRAM</b> by Anna Li and Sungtae Yoon	<b>22</b>

# HEALING THROUGH ART: A PROFILE OF START@TCC

by Chantal O'Brien, GS '22; Alex Tang, CC '20

In this article, we highlight a growing RCSS program, the Student-Run Art Therapy Program at the Terence Cardinal Cooke Health Care Center (START@TCC). Through START@TCC, Columbia student volunteers visit the HIV/AIDS unit within the Terence Cardinal Cooke Health Care Center in East Harlem, where they lead art projects for the residents of the unit. Established in Spring 2019, START@TCC hopes to continue growing in Fall 2019, through the recruitment of additional members, establishment of a more organized logistical infrastructure, and formation of deeper relationships with residents of the center.

## START@TCC Mission Statement

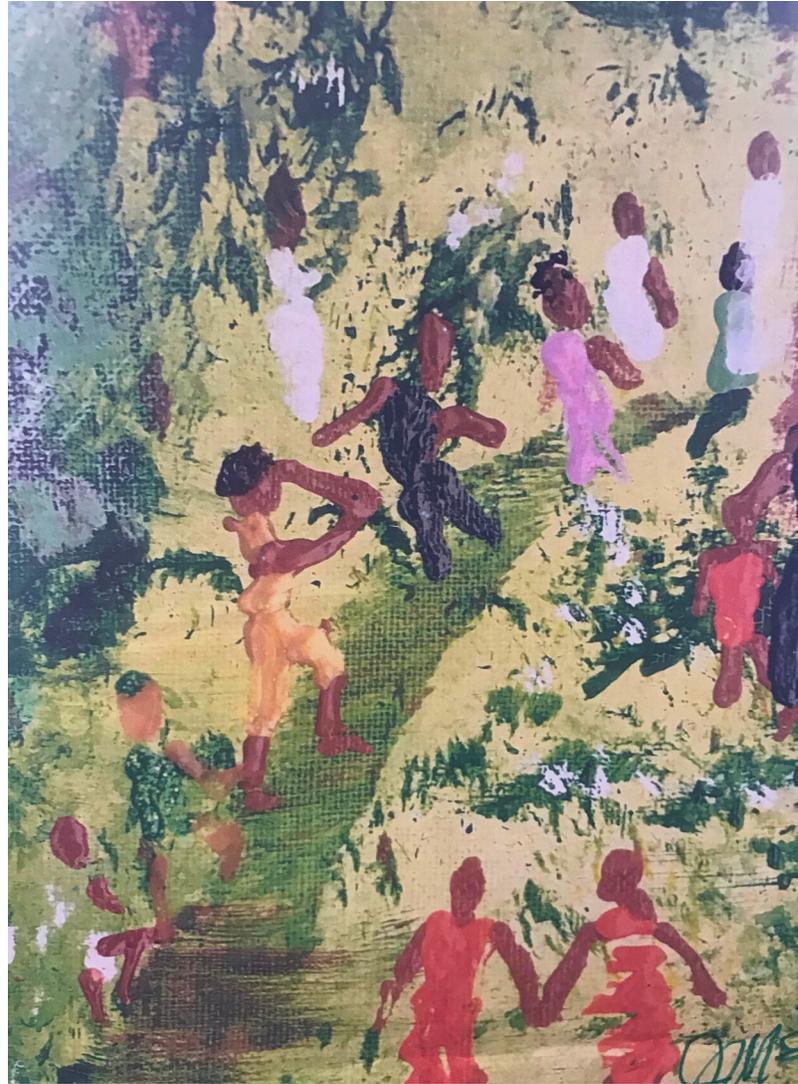
The Student-Run Art Therapy Program at Terence Cardinal Cooke Health Care Center (START@TCC) aims to promote mental and spiritual healing through art. The Program hopes to serve as an outlet in which residents may express themselves and share their stories through art. The Program will foster lasting relationships between Columbia student volunteers and residents of the unit, allowing both parties to learn and grow with each other.

## Beginning the Student-Run Art Therapy Program

The Terence Cardinal Cooke Health Care Center is a medical center in East Harlem, offering care for a variety of health needs, including but not limited to Alzheimer's disease, ALS, and people with developmental disabilities. In particular, the center's 156-bed HIV/AIDS unit provides exceptional palliative care to some of New York's most vulnerable HIV+ patients.

In Spring 2019, Eva Perez-Greene (CC'19) and I, Chantal O'Brien (GS'22), developed an art therapy initiative with the support of RCSS. A seasoned volunteer at TCC's HIV/AIDS unit, Eva saw that residents of the unit were interested in engaging in an activity that could be intellectually stimulating. As a biology and art history double major, Eva was well aware of art's ability to nourish, develop, and challenge the mind, and believed that the residents would enjoy making art. An RCSS intern myself, I immediately felt a connection with the project – HIV/AIDS has always been an important issue to me – I grew up

ALL ARTWORK in this report was created by patients at TCC in the Art Therapy Program.





hearing my mother talk about her advocacy and community work with those living with HIV/AIDS in the late 1980s and 90s, and I felt a sense of responsibility to continue that.

#### Review of Spring 2019

Eva and I held an informational meeting in January 2019 for Columbia students interested in volunteering with our new art therapy project. The informational meeting attracted roughly 25 attendees. At the informational meeting, Eva and I met each of the interested students, explained the ideas behind our initiative, and discussed potential art project ideas.

In Spring 2019, we led two art projects at the TCC HIV/AIDS unit, once in February and once in April. Between 5-10 Columbia student volunteers were present at both events. In February, students led a group of 10 TCC residents in creating Impressionism-inspired watercolor.

The artwork created by the residents varied considerably – some residents depicted floral patterns while others preferred more abstract creations. The residents expressed their interest in creating more art in the future with the volunteers. A major highlight of the event was the interaction between the residents and volunteers – both parties were able to share ideas about art, as well as stories about their own lives.

In April, Eva and I organized a more elaborate art project: an Art Soirée. At the Art Soirée, we reserved the TCC auditorium, in which we set up multiple tables dedicated to a certain art project, including Fabergé eggs, origami, and paper lanterns. Around 20 TCC residents attended the Art Soirée. The residents greatly enjoyed making the art, which they were able to take home. In addition, the Columbia volunteers included musicians, led by Vincent Khac Le, who provided ensemble music to accompany the event.

#### Objectives for Fall 2019

This coming semester, we hope to grow the art therapy initiative we started last spring. Over the summer, Alex and I discussed our strategies for growth. We rebranded the initiative as START@TCC, drafted a mission statement, and submitted proposals for RCSS funding. While Alex and I agree that volunteers were able to form budding relationships with the residents at TCC in Spring 2019, we lamented that we had been unable to visit TCC more often, due to lack of volunteer availabilities.

In Fall 2019, we plan to schedule regular visits to TCC, between two to four times per month. To do so, we hope to recruit more volunteers by increasing publicity at the start of school (through Columbia internal listservs and building flyers). We also plan to host an informational meeting at the beginning of the semester, and to send out online applications to gauge volunteer availabilities. Recruited volunteers will be required to visit TCC at least twice monthly. It is our hope that by scheduling regular visits to TCC and by recruiting a dedicated set of volunteers, we will be able to increase the number of art projects we can do with the residents.

Besides visiting TCC at least twice monthly to help run an art project, volunteers will also be required to attend a weekly START@TCC volunteer meeting at Columbia. Such volunteer meetings were not held in Spring 2019, and we hope to begin holding them in Fall 2019. During these

meetings, we will bond together as a group over dinner, plan future art projects, and discuss logistics, questions, and concerns.

#### Reflection: Impact of START@TCC

From the two art projects we've already led at TCC in Spring 2019, we could already see the impact of our initiative on the residents at TCC. The art projects we led (watercolor painting, paper lantern decorating, etc) were designed with safety in mind, and meant to be accessible for any and all residents. Furthermore, we wanted to make our art projects as intellectually stimulating as possible. Our volunteers made sure to explain the art historical significance of each project, to listen to each resident's sense of creativity and style, and to help each resident achieve the end result they had in mind. We hope that in Fall 2019, we will continue to forge stronger relationships between residents and volunteers, and to facilitate creativity and artistic engagement at TCC.

I'd also like to add a few words about the impact of START@TCC on my own interests and educational development. As mentioned earlier, I became involved with the art therapy project in Spring 2018 with Eva. By working alongside Eva, I learned about the logistical effort it takes to run an initiative like this one. I love working with the residents at TCC, many of whom are lifelong New Yorkers like myself – I find the interaction between the residents and myself to be very organic, as we often discuss life as a New Yorker, music, and stories from our own lives.

Alex also finds the project richly fulfilling, as it relates his interests in art history, medicine, and HIV/AIDS advocacy. Through this initiative, he's seen first-hand that allowing residents to express themselves through art noticeably increases residents' sentiments and, over time, quality of life. Furthermore, as an HIV immunology researcher, he feels that the lab often feels far-removed from the population he would like to serve as a clinician. Managing an initiative at an HIV/AIDS unit allows him to bridge the gap between his research and the people he would like to serve. Alex and I feel it to be a great honor to work with the residents, many of whom are long-term survivors of HIV. Despite everything they have been through, they still possess an immediately recognizable zest for life and a desire to meet new people and to try new things. The residents at TCC have provided us with the boundless enthusiasm and optimism for this project's growth in the coming years. •



# THE STARS ARE THE EYES OF HEAVEN

## PACIFIC STARGAZING IN HAWAII

by Tony Qian, CC '17

*O na hoku no na kiu o ka lani*  
«The stars are the eyes of heaven.»  
‘Olelo No‘eau 2513

This summer I volunteered for a USDA forestry project in the tropical rainforest village Hana, on the island of Maui, the second largest island of Hawaii. My daytime work involved planting native trees and shrubs and removing invasive species. But my nighttime work involved studying the stars and reflecting how the celestial skies unite all civilizations across time and space.

One thing different about Hawaii, in comparison to New York, is that the North star hangs very low in the sky. In the West the North star, also called Polaris, can be found just West of the Big Dipper. It gets its name from hanging directly above the North pole. Near the equator however the North star sits almost on the horizon! Our Hana Lani farm was located in the latitude 20.74<sup>1</sup>, and so the North Star was just 20 degrees above the horizon.

All stars travel from East to West, just as the sun and moon travel from East to West. This apparent motion is due to the

rotation of the Earth of course. However the North star appears fixed. That’s why the native Hawaiians call it Hoku Pa’a «the standing star».

Hoku is the Hawaiian word for star. A wise man who studies the stars and tells farmers when to plant or sailors where to head is known as Kilo Hoku or the watcher of stars. On our farm we had the honor to work under the guidance of a such a wise man. His name name is Moke.

### I OVERCAME THIS CHALLENGE BY MOMENTARILY SETTING ASIDE MY ‘PHYSICS HAT’...AND INSTEAD THINKING LIKE AN ANTHROPOLOGIST.

Moke is an experienced carpenter, sailor, and also Kilo Hoku (although he would always refer to himself as a haumana or ‘student’). The art of way-finding is integral to Pacific Islander culture. The ancient sailors navigated the Pacific Ocean with neither compass nor sextant, using instead only their hands and knowledge of the stars. This heritage was nearly extinct. But in 1976, an old master from Micronesia was found and invited to Hawaii. The Polynesian Voyaging Society worked with him to rekindle the art. They named the first boat Hokule’a, and young men travelled aboard the vessel across thousands of miles from Hawaii to Tahiti. The successful voyage sparked a renaissance in this art which had almost been forgotten. Since then there have been several voyages to help modern generations connect with tradition. Moke, our teacher on the farm, was one of these early pioneers at sea.

Hokule’a is Hawaiian for «the Star of Gladness». It is known as Arcturus in the West, or Alpha Bootis in Latin (that means the brightest of the Bootetian, or cowherd, constellation). This star also figures prominently in Chinese mythology, and is called Da Jiao 大角 «Great Horn» as it is the brightest star in the Northern sky and figures prominently in the Chinese constellation of a great dragon.

Our teacher Moke lives in the town of Nahiku. Nahiku is Hawaiian for the number seven, and it is also what Hawaiians call the Big Dipper. If you walk in the direction



ON THE JOB, Tony carefully mulches a Mamaki shrub. This red-veined native plant has medicinal properties; it is known to lower blood pressure and reduce anxiety.

of Nahiku from the Maui's central volcano Haleakala, you will arrive at the town Nahiku. Hale is the name for traditional Hawaiian houses, and La is the name for "sun". Together Haleakala, a dormant volcano standing over 10,000 feet above sea level, means «house of the sun».

Another noteworthy constellation is Ka makau nui a Maui «the great fish hook of Maui». According to legend Maui is a demigod (for whom our island is named) and to whom belonged a magic fish hook. One day Maui sailed out into the oceans with his brothers. The deal was that if the brothers promised to paddle forward as hard as possible without looking back, Maui would show them something special. Soon after the brothers started paddling, they felt something very heavy and momentous catch from behind. Maui was using his magic fish hook in an attempt to uproot the ocean floor! The brothers, not knowing, pushed harder and harder thinking that they had surely hooked a gigantic fish. But finally curiosity got the better of them. They looked back. With this action they broke the magic spell, and Maui's hook went flying into the sky where it became a constellation. What Hawaiians call Maui's magic fishing hook is what the Greeks called Scorpio! While mischievous Maui did not succeed in pulling up the entire ocean floor that day, what he did do is create the islands of Hawaii.

It is interesting that both the Hawaiians and Greeks interpret this set of stars as hooks, one as a fishing implement the other as a poisonous arachnid. Jon Asato, a docent in Honolulu's Bishop Museum, offered me yet a third interpretation. There are Pacific islanders in the Southern hemisphere who see this 'J' shape not as a hook, but as the cradle of a mother carrying a baby on her back!

This project opened several new collaborations. First I worked with Moke Bergau, the overseer on our farm who happened to be an expert sailor. Moke introduced me to Irene Pavao who directs the library in our town, Hana. Irene was very helpful in helping me find printed information about the Hawaiian stars. Later I followed in the footsteps of fellow RCSS intern Joseph Belmont (SEAS '18). Like Joseph, I visited the Bishop Museum in Honolulu and saw the same 32-point star compass which he photographed in Vol. 2 of the RCSS journal! Lastly I found an existing star map online called «Figures in the Sky» which compiles constellations from over 28 civilizations. The constellations come from a free open-source database called Stellarium. I have also contacted the site's creator Nadieh Bremer, an astronomer turned freelance data visualization artist in Amsterdam, for future collaboration.



MOKE TEACHES TONY the safe operation of gas chain saws for the removal of invasive species.

The Center for Science and Society provided me with the opportunity to seek a continuous thread from farm to library to museum. If it were not for Dr. Pollack's continued enthusiasm and encouragement, I may not have persevered through to find these fascinating connections. One challenge I faced was finding a first-hand connection to the stars. It is easy to read from books and look up data charts. But even in Hawaii (where I lived in a cabin without electricity) it was often difficult to see the stars through clouds and jungle canopy. I overcame this challenge by momentarily setting aside my 'physics hat' with its corresponding preference for coordinates and atlases, and thinking instead like an anthropologist, engaging in interviews and outings with sailors, librarians, and astronomers first-hand. •

#### Works Referenced:

1. Stars Over Hawaii, E. H. Bryan Jr. (Book, 2015)
2. The Sky Tonight: Guided Tour of the Stars Over Hawaii, Samuel E. Rhoads (Book, 1996)
3. Stairway to the Stars: Story of the World's Largest Observatory, Barry. R. Parker (Book, 1994)
4. Figures in the Sky (online)  
<<http://www.datasketch.es/may/code/nadieh/>>.

# LIFE AT THE END OF LIFE

## TEACHING PALLIATIVE CARE THROUGH SERVICE

by Brigid Connelly, GS '20

As an intern in the RCSS, I have served as the teaching assistant for the seminar *Life at the End of Life: Palliative Care & Service*, and will do so again for the Fall '19 semester. The course was created in 2016 by RCSS alumna, Tess Cersonsky, to provide opportunities for readings and reflections on the experience of volunteer service work in the *At Your Service* program at Terence Cardinal Cooke Health Care Center in Harlem. The vision was that in providing assistance, support, and companionship to a

resident in the nursing home, undergraduate students would develop a better understanding of, and sensitivity towards, the experience of individuals living with chronic illness and disability or facing the end of their life.

The seminar portion of the course is taught by Dr. Craig Blinderman, Director of the Adult Palliative Medicine Service at Columbia University Irving Medical Center, and is supplemented by a diverse array of guest academics, doctors, and professionals that facilitate discussions on topics that range from medical ethics to the role of relationships, religion, and spirituality at the end of life. This combined seminar and service model offers students who hope to be doctors or other healthcare professionals an opportunity to gain insight into the lived experience of illness and aging, the complex work of caregiving, and the possibilities for deep human connection in these spaces.

# How do we bear witness?

**PUTTING TOGETHER THIS EVENT HAS INSPIRED ME TO MORE ACTIVELY BRING MY INTEREST IN CONTEMPLATIVE CARE TO THE LIFE AT THE END OF LIFE COURSE AND ALSO TO PURSUE ORGANIZING MORE PUBLIC ENGAGEMENT EVENTS ON CAMPUS AS I ENTER MY SENIOR YEAR.**

This fall semester, the seminar will have been offered for the fourth consecutive year by the American Studies department, with over forty undergraduate students having taken it so far and twelve more registered for Fall '19.

Last year, Dr. Blinderman and I reworked the syllabus considerably to diversify the readings and course materials for the Fall '18 semester. We chose to incorporate more fiction, poetry, graphic novels and podcasts; examples of these texts include "Odour of Chrysanthemums" by D. H. Lawrence, *Illness as Metaphor* by Susan Sontag, and "Days" by Philip Larkin, among others. In addition to the doctors and professors who have joined the course over the past

IN COLLABORATION WITH the New York Zen Center for Contemplative Care, Brigid organized an event for the Reimagine End of Life Festival in New York.

**DATE/TIME**  
Thurs. November 1st  
6 - 8 pm

**LOCATION**  
Faculty House,  
Columbia  
University

**INFORMATION**  
Giving and Receiving: A Conversation  
on the Role of Contemplative Practice  
at the End of Life

**ABOUT**  
Reimagine End of Life is a  
citywide event exploring big  
questions about life and death.  
Join all of NYC for a week  
about creativity and  
conversation.

**JOIN US**

**re imagine**  
End of Life

**COLUMBIA UNIVERSITY**  
Center for Science and Society

**RESEARCH CLUSTER ON SCIENCE AND SUBJECTIVITY**

**NEW YORK ZEN CENTER FOR CONTEMPLATIVE CARE**

IN COLLABORATION WITH the New York Zen Center for Contemplative Care, Brigid organized an event for the Reimagine End of Life Festival in New York.

three years, Dr. Blinderman and I brought in new guest lecturers from various disciplines to the class, such as Professor Marcus Folch of Columbia's Department of Classics who discussed the history of institutional confinement, Marie Howe, former Poet Laureate of New York, who led a workshop on listening, observation, and writing, and author Eliza Factor, who shared her own experience raising a multiply-disabled son and reflections on non-verbal communication, family wisdom, and the limits of rational inquiry. This approach introduced students a wide variety of ways to connect their more emotional and personal experiences as companions to a nursing home resident with the theoretical and intellectual concepts explored in the seminar readings.

For the upcoming Fall '19 semester, Dr. Blinderman and I have decided to revisit the syllabus and build on our past revision by inviting new guest lecturers and adding readings such as *Everything in Its Place* by Oliver Sacks, *A Very Easy Death* by Simone de Beauvoir, *Ravelstein* by Saul Bellow, and *Awake at the Bedside: Contemplative Teachings on Palliative and End-of-Life Care* edited by Koshin Paley Ellison.

In addition to the course, last year as an RCSS intern I organized an event for the Reimagine End of Life festival in New York. In collaboration with the New York Zen Center for Contemplative Care, we hosted at Columbia an open conversation with national palliative care leaders, Drs. Ira Byock and Craig Blinderman, and Zen teachers, Senseis Koshin Paley Ellison and Chodo Campbell, to explore the role of contemplative practices in caring for those facing the end of life. The event was a great success, bringing together over a hundred guests from a variety of disciplines, ages, and backgrounds, both within the Columbia community and the general public.

**...WE HOSTED AT COLUMBIA AN OPEN CONVERSATION WITH NATIONAL PALLIATIVE CARE LEADERS...TO EXPLORE THE ROLE OF CONTEMPLATIVE PRACTICES IN CARING FOR THOSE FACING THE END OF LIFE.**

Putting together this event has inspired me to more actively bring my interest in contemplative care to the Life at the End of Life course and also to pursue organizing more

# How do we acknowledge fear?

#### DATE/TIME

Thurs. November 1st  
6 - 8 pm

#### LOCATION

Faculty House,  
Columbia  
University

#### INFORMATION

Giving and Receiving: A Conversation  
on the Role of Contemplative Practice  
at the End of Life



#### ABOUT

Reimagine End of Life is a citywide event exploring big questions about life and death. Join all of NYC for a week about creativity and conversation.

#### JOIN US

COLUMBIA UNIVERSITY  
Center for Science and Society

RESEARCH CLUSTER ON SCIENCE AND SUBJECTIVITY

NEW YORK ZEN CENTER FOR CONTEMPLATIVE CARE

THE REIMAGINE EVENT FLYERS highlighted questions also explored in the course *Life at the End of Life*.

public engagement events on campus as I enter my senior year. One event, in particular, that I am currently developing aims to bring together two acclaimed doctors and thinkers in public conversation--one a neuroscientist-psychiatrist, the other an internist and scholar, and both of whom are over 90 years old age--to reflect on their long careers and share their insights into medicine, service, and living a long and engaged life.

This event is still in the early stages of development, however, I am hopeful that it will be scheduled for sometime during the Spring '20 semester. In addition to these projects, I have also taken on managing the RCSS' finances which has been a tremendous experience to expand my skill set regarding internal operations. •

# UNDERSTANDING INTERGENERATIONAL SUPPORT NETWORKS IN MUMBAI'S URBAN CONTEXTS

by Naazanene Vatan, CC '20

This past summer, I spent five weeks in Mumbai assisting Professor Kavita Sivaramakrishnan with her project exploring intergenerational support networks and aging in Mumbai's deprived urban contexts. Building on a previous workshop held at the Columbia Global Center in Mumbai, I interviewed academics, leaders of local NGOs, physicians, and older residents of Dharavi (Mumbai's biggest informal settlement community) in order to better understand how intergenerational relationships function in this specific setting.



NAAZANENE AT her first day of field work in Mumbai, India.

**THIS STORY PLAYED INTO A LARGER NARRATIVE THAT I READILY ACCEPTED: AMERICAN FAMILIES DIDN'T CARE ABOUT THEIR ELDERS—AND THE FLIP SIDE WAS THAT FAMILIES IN EASTERN CULTURES DID.**

My interest in the themes of this project started long before I had plans to go to Mumbai. For the past two years, I have spent most of my Thursday evenings with Thomas<sup>[1]</sup>, a resident of the Terence Cardinal Cooke Healthcare Center's Huntington Disease unit. During our first couple of meetings, we sat in the HD lounge as Thomas told me about his college basketball days, his fashionable ex-girlfriend and her apartment on the Upper West Side, and his daughter and granddaughter who live in the city but rarely visit.

Thomas never overtly expressed resentment toward his family for not visiting. "They have their own lives," he would tell me. This story played into a larger narrative that I readily accepted: American families didn't care about their elders—and the flip side was that families in Eastern cultures did.

This narrative was shattered during my week at one of the Community Outreach Program's (CORP) community centers in Dharavi. After finding my way through a maze of back alleys, I arrived at the center, a one-room unit with a small kitchen and bathroom. As I opened the door, nearly thirty children dressed in CORP's red and white checkered uniforms circled around to say "Namaste." Ms. Peppy Dias, a social worker who spends each day jumping between the three community centers she helps run, explained that like

**THIS NARRATIVE WAS SHATTERED DURING MY WEEK AT ONE OF THE COMMUNITY OUTREACH PROGRAM'S (CORP) COMMUNITY CENTERS IN DHARAVI.**

[1] Name changed

many of CORP's twenty community centers across Mumbai, the one I visited serves several functions. Every day, 20-30 children ages 0-6 are dropped off by their parents for daycare. In the same one-room facility, up to 25 older women gather every Tuesday and Friday afternoon for tea, snacks, and company. I later learned that most of these women were here because their own children had long abandoned them, and they had no other support network.

As the little kids continued to play with their toys and practice their lessons, the women started to trickle in and form a circle on the floor. One of Ms. Dias' colleagues led the group in some seated arm stretches, accompanied by vocal exercises and prayer songs. Eventually, Ms. Dias introduced me to the group and asked if they would be willing to share their experiences with me.

Although most of the women initially registered with CORP for the monthly food boxes and were heavily dependent on CORP for their daily meals, it was clear that the organization meant more to them than that. The afternoon sessions were the highlight of their weeks; one woman said that she "didn't have happiness in her home" and that the community center is a place where she can restore her "balance of mind" through song, company and prayer. Some of the women did say they bring what they learn at the center to their homes; a couple of women said they do the exercises on their own, and one woman said that she has become closer with others her age through the program.

**THE WOMEN IN THE COMMUNITY CENTER SHARED COMMON CHALLENGES. BECAUSE THEIR HUSBANDS HAD DIED OR WEREN'T AROUND, THEY HAD TROUBLE COLLECTING THEIR STATE-SPONSORED PENSIONS. THEY COULDN'T SEE THEIR GRANDCHILDREN...FOR MANY OF THE WOMEN, THEIR GENERATIONAL COHORT WAS THE ONLY COHORT THEY HAD.**

Understanding the scope of generational community was a central aim of my research this summer. In a society where family ties are often paramount, how much do people



NAAZAENE ASSISTED Kavita Sivaramakrishnan, an Associate Professor of Sociomedical Sciences at Columbia, at the Tata Institute of Social Sciences in Mumbai (pictured above).

identify with those outside their families but in their generational cohort? One of the women told me that her husband had left her because of an argument she had had with her mother-in-law. To her husband, she said, his parents were more his family than she was. His duty to his family had left her without one. Another woman told me that her son and his wife had simply started a new life without her. In cases where a man chooses either his wife or his parents over the other, there is always a woman left behind. Living on her own, without a support network or a way to make a living, it becomes difficult to maintain a healthy "balance of mind."

CORP's physical gathering space outside the home allowed for generational solidarity to bloom. The women in the community center shared common challenges. Because their husbands had died or weren't around, they had trouble collecting their state-sponsored pensions. They couldn't see their grandchildren. In the Tuesday and Friday afternoon gatherings, they vented and found support in one another's company. They played with the daycare children, found peace in group prayer, and most importantly had an excuse to get out of the house and maintain a healthy social life. For many of the women, their generational cohort was the only cohort they had.

In 1982, world leaders came together at the first World Assembly on Aging to tackle the "global aging problem." At



FOR A WEEK, Naazanene walked through Dharavi to one of the twenty CORP community centers.

the meeting, Indian Prime Minister Indira Gandhi insisted that older persons in developing countries are venerated and supported by their families. At the October workshop, however, one participant strongly opposed the notion of the “glorious Indian family where the old are taken care of.” Of course, it is counterproductive to assume that family dynamics are the same globally. However, it is just as harmful to engage in the generalizations surrounding ‘Eastern’ versus ‘Western’ family values. One of the biggest challenges I faced during this project was approaching our research questions without imposing my own perceptions of intergenerational dynamics. During interviews, I quickly realized how easy it was to only hear echoes of the “glorious Indian family” narrative instead of focusing on the important details that pushed back against this idea. The interdisciplinary nature of this project mitigated this challenge to some extent; because I was working with physicians, academics, and social workers, I was able to form my understanding after hearing perspectives from every angle.

**DURING INTERVIEWS, I QUICKLY REALIZED HOW EASY IT WAS TO ONLY HEAR ECHOES OF THE “GLORIOUS INDIAN FAMILY” NARRATIVE INSTEAD OF FOCUSING ON THE IMPORTANT DETAILS THAT PUSHED BACK AGAINST THIS IDEA.**

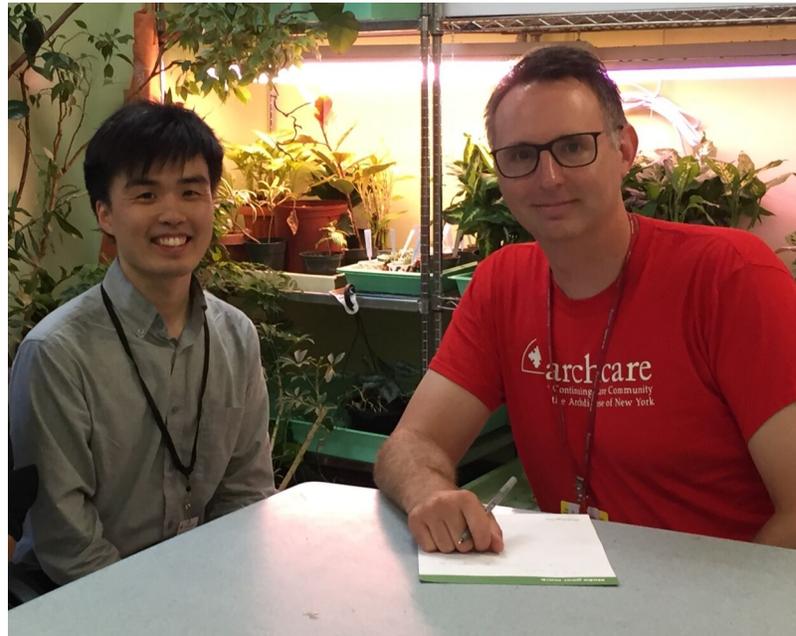
As I bring what I have learned this summer back to my work at TCC, I look forward to understanding how our residents engage not only with their families but also with one another. As they enter a new stage of life, residents can perhaps find new purpose in the relationships they build with their cohort at TCC. •

# RESEARCHING PERCEIVED HEALTH OUTCOMES OF RECREATIONAL THERAPY AT TCC

by Ralitsa Kalfas, CC '19 and Sungtae Yoon, GS '20

Sungtae and I [Ralitsa] have been grateful to work on “Perceived Health Outcomes of Therapeutic Recreation for Huntington’s Disease Patients at Terence Cardinal Cooke: Uncovering Practices of Narrative Medicine” for this Summer through RCSS. This collaboration has enabled our team to pursue a study of perceived health outcomes of recreational therapy program at the Terence Cardinal Cooke (TCC) Huntington’s unit. In pursuing this project, I have been confronted with challenges that have altered the predicted trajectory of the work, but that have nevertheless provided opportunities for growth, collaboration and newfound discoveries. The largest difficulties we have faced in this process have been the research approval protocol and administrative specificities from the Internal Review Board as the research has not yet been approved. I have gained further insight into this application process from the perspective of an undergraduate who cannot apply directly herself (but rather, in my case, through my Principal Investigator, Dr. Lori Quinn, who is the head of the Teacher’s College Neurorehabilitation Lab). However, I have learned how to navigate the position and have provided all necessary edits and revisions that they requested after the initial application submission. I now believe that I have profound insight into this process and can be of assistance to undergraduates (especially within the RCSS) who are interested in conducting research in the future.

Another element that has been important within this process has been the communication and relationship with Terence Cardinal Cooke Health Care Center. I have been extremely fortunate to work with Sungtae Yoon, who acts as a liaison between the health care center’s volunteer services department and the Columbia RCSS At Your Service program. It has been rewarding to gain insight from Sungtae’s scope of knowledge as he studies the scientific underpinnings of human illness as a biologist. While my project focuses on interacting with others who approach human illness from a more social and narrative-based perspective, it is extremely usefully to understand the disease through different disciplines. Amidst this process and time spent waiting to receive revisions and notes from



SUNGTAE (LEFT) WORKED closely with Tom McDonalds (right), the Director of the Volunteer Services and Recreational Therapy Department at Terence Cardinal Cooke.

the IRB, it has been vital to stay connected with TCC, and Sungtae has managed communications with the Director of Volunteer Services and Recreational Therapy.

I have also been able to further strengthen my connections at the health care center through meeting with Mary Ann Emerick, the program director at the Jim and Mary White Unit for the Care of People with Huntington’s Disease. Meeting with Ms. Emerick has been extremely helpful in one, garnering support for the project on the unit and two, in gaining more perspective on the impact of this project. We spoke about the import of residents with Huntington’s

**I HAVE BEEN CONFRONTED WITH CHALLENGES...THAT HAVE PROVIDED OPPORTUNITIES FOR GROWTH, COLLABORATION AND NEWFOUND DISCOVERIES.**

<p><b>What does this study involve?</b></p> <p>This study involves an interview in which you will be asked about your opinions on and/or participation in therapeutic recreation activities and events within the unit.</p> <p>You will be also asked about your perceptions of <b>either</b></p> <p>1) your own health and well-being,</p> <p>2) the health and well-being being of a loved one with HD</p> <p>OR</p> <p>3) the health and well-being of residents with whom you interact.</p>	<p><b>How long will this take?</b></p> <p>The interview will take approximately 1 hour to complete. However, it can be broken into smaller increments based on availability.</p> <p><b>You are eligible to participate if:</b></p> <ul style="list-style-type: none"> <li>You have a diagnosis of Huntington's disease and are a resident at Terence Cardinal Cooke</li> <li>OR</li> <li>You are a family member or loved one of a Huntington's resident at Terence Cardinal Cooke</li> <li>OR</li> <li>You are on staff (such as a recreation staff, nurse, social worker, doctor etc.) at Terence Cardinal Cooke and work on the HD unit with Huntington's residents</li> </ul>	<p><b>If you are interested in participating, please contact:</b></p> <p><b>Ralitsa Kalfas:</b> rk2853@columbia.edu or by phone at 919-536-2935</p> <p><b>NRL email:</b> neurorehablab@tc.columbia.edu</p> <p><b>NRL phone:</b> 212-678-3916</p> 
---	---	--

<p><b>What is the purpose of this research?</b></p> <p>The purpose of this study is to determine the perceived effects of therapeutic recreation on mental and physical health for Huntington's Disease patients at Terence Cardinal Cooke Health Care Center.</p>	<p>Recruiting residents, loved ones and staff from the Huntington's Disease Unit</p> <p><b>Perceived Health Outcomes of Therapeutic Recreation for Huntington's Disease Patients</b></p>  <p><b>at Terence Cardinal Cooke: Uncovering Practices of Narrative Medicine</b></p> <p><small>TC98 Protocol Number:</small></p> <p><b>TEACHERS COLLEGE</b> COLUMBIA UNIVERSITY</p>
--	---

RALITSA DESIGNED recruitment flyers in both English (front and back pictures above) and Spanish. The project is currently awaiting IRB approval.

Disease having the agency and platform to narrate their story and to have their voices validated.

We believe our study will help other patients suffering from Huntington's disease, the family and caregivers of those patients, and their healthcare providers to more accurately understand what kind of effect good quality recreational therapy can have by providing a systemic review of Huntington's patient's experiences with analysis in narrative medicine style. I hope this can provide another solid data point that encourages the use of recreational therapy as a tool to help improve patients' perception of health. Ms. Emerick also provided better comprehension about the reality and role of the staff on the unit, which I would never have been able to receive outside of the TCC administrative lens. In this respect, I have been a witness to the necessity of interdependency across different fields (from recreational therapy to narrative medicine) and positions (from the lab to the health care center) to construct a holistic and beneficial experience of care.

I am also very enthusiastic to express the collaborations that I am cultivating within the Columbia community. RCSS provided us both a platform to connect with students and mentors from various disciplines by providing opportunities for students to engage in meaningful learning experiences outside of the classroom. Sungtae connected me with Sandy Zeng, who is developing an International Palliative Care Internship/Service Project that will likely be held this Winter. Sandy has expressed her interest in assisting me with interviews so that she can prepare for her work with documenting oral histories and biographies. Sandy and I have communicated about the potential for her engagement with my project as a way to gain first-hand experience interacting with residents, palliative care and narrative medicine.

**ONE OF MY GOALS FOR THIS PROJECT IS TO UNCOVER HOW TO INVOLVE MORE UNDERGRADUATES...[TO] LEAVE A LARGER LEGACY OF COLLABORATION AND RESPECT BETWEEN TCC AND THE RCSS.**

I am also very interested in deepening my understanding of the field of oral history as it definitely corresponds to my work and can be another opportunity to strengthen the project through varied methods. We are looking for other possible interdisciplinary collaborators who are more familiar with hospital administration and clinical research to optimize the way we carry out our post-IRB study and execute data collection more efficiently. I also see this project as a potential platform for other new students, (including a rising first year who reached out to me wanting to know more about the RCSS and my project) to have hands-on exposure in the fields of research and narrative medicine. One of my goals for this project is to uncover how to involve more undergraduates so that it will continue with other student interns that come after me and leave a larger legacy of collaboration and respect between TCC and the RCSS. •

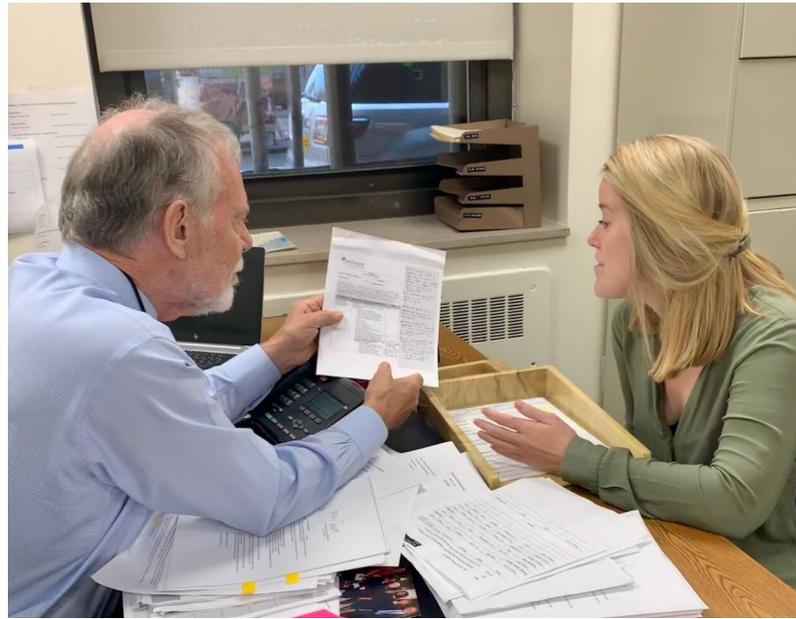
# ADVANCING ADVANCE DIRECTIVES DISCUSSIONS

## LESSONS FROM THE NURSING HOME

by Abigayle Dolmseth, *GS '19*

Over the course of summer 2019, I have continued to work on the project that I initially started planning with the RCSS in summer 2018, and officially began in January of 2019. This project involved two stages, both of which took place at Mary Manning Walsh (MMW) nursing home. The first stage, much of which was completed last semester, included a review of patient records to determine whether and to what extent any advance directive planning had occurred in order to probe whether certain providers have higher or lower rates of full code versus do not resuscitate (DNR) orders. The second stage has been the focal point of this summer, and involved picking a small number of patients to follow more in-depth. This latter part helped me to gain a stronger understanding of the process by which advance directive discussions take place at MMW. Further – and unanticipated in my original project planning – I have helped the medical director at MMW, Dr. Anthony Lechich, in his efforts to develop a more comprehensive and systematic palliative care program at the home.

My efforts to gain a more in-depth understanding of the process by which a few patients' advance directives were put in place were diverse, and ultimately required me to learn more than I anticipated about not just medical but also social, administrative, and regulatory elements of the process. I rounded on new admissions with the medical director, chief of nursing, and head of administration – a daily practice that attempts to ensure that small things, such as the desire for second nightstand or the preferred timing of medication – do not fall through the cracks, as well as make senior staff accessible. I also attended a medical staff meeting, which broached a range of pertinent topics, including issues with the electronic health record software; psychiatry consults not addressing competency issues consistently; difficulty in obtaining labs and tests within an unexpected timeframe; and an unexpected outbreak of a pneumonia on a long-term care floor that had changed the prognosis of certain residents. And I spent time on the floor, simply observing the pace and interactions of the floor. Each of these activities introduced me to key elements that complicate the advance directive discussion process: issues of scheduling, technology, interpersonal dynamics,



ABIGAYLE (RIGHT) DISCUSSES the draft advance directives protocol with Dr. Anthony Lechich (left), the medical director at Mary Manning Walsh nursing home.

staff turnover, and resource allocation. The literature on advance directive discussions, though instructive, failed to provide sufficient preparation for how these elements interplayed in the nursing home setting.

After identifying the patients I was most curious about, I opted to speak to the social work staff about the advance directive process in general, and then about the particular cases in their purview. They explained both the formal and informal role that social work plays in the advance directive discussion, as well as offering their insight into how the process can get tripped up. They identified communication between medical staff, between medical and social staff, and between both medical and social staff and families as key to successful discussion, but as primary points of complication. Often, these communication problems were part and parcel of working in a busy facility – it just is not possible for all schedules to coincide on a timely basis. But they were especially concerned about the occasional failure of the psychiatrists who consult at MMW to adequately assess a patient's competence to make their own medical

decisions – not because the psychiatrists were not technically capable, but because occasionally the reason they were being called to consult was not made clear, or because the social and nursing staff had a different understanding of a patient's day-to-day mental acuity. Also, I learned that even when changes were made to advance directives, it was not necessary that the medical staff that made the changes notify all parties involved in the patient's care. Thus, occasionally there were patients who had serious changes in their advance directive plans – e.g. from full code to a DNR (do not resuscitate) order – that the social work staff learned about only days or weeks after the fact, and without important context for how the decision to change the directives were arrived at.

An interesting and perhaps unique challenge that both the medical and social staff identified as complicating the advance directive discussion was the changing guidelines recently issued by the Archdiocese. Mary Manning Walsh operates under ArchCare, a Catholic institution, and abides by the recommendations of the Catholic Health Association. Currently, advance directives discussions take place on an ongoing basis at MMW, beginning with the completion of the Medical Orders for Life-Sustaining Treatment or MOLST form, which is filled out within 24 hours of admission by a social worker and signed off on by a physician. The MOLST form acts as a jumping-off point, suggesting both to residents and their families or health care proxies that these are decisions they should anticipate having to make. However, there is uncertainty over how these discussions will be initiated given the new Catholic Health Association guidelines. Confusion persists, but the general perception is that advance directive discussions will not be formally initiated by anyone but medical offers at MMW, and will not occur until death is anticipated within six months or less. This limits both who can participate in discussions, and the duration of the conversation – limitations that medical and social staff expressed some concern over.

Ultimately, all of the activities I participated in over this summer at MMW underscored a key facet of this project that I had not anticipated when I conceived it: that the

advance care discussion is much different in the long-term care nursing home setting than in a traditional hospital or an outpatient setting. Small changes in a patient's capacity and competency – though perhaps noted by support staff – might not warrant an immediate medical intervention or change, and thus are overlooked until they agglomerate, and are not addressed until triage requires them to be. Family dynamics complicate the large and integral role played by health care proxies and family members in the process. Further, physicians and other health providers may have to juggle providing care to patients with disparate needs – from simple rehabilitation to hospice – which necessitates navigating the gestalt that pervades each of these contexts.

**MY EFFORTS TO GAIN A MORE IN-DEPTH UNDERSTANDING OF THE PROCESS BY WHICH A FEW PATIENTS' ADVANCE DIRECTIVES WERE PUT IN PLACE WERE DIVERSE, AND ULTIMATELY REQUIRED ME TO LEARN MORE THAN I ANTICIPATED ABOUT NOT JUST MEDICAL BUT ALSO SOCIAL, ADMINISTRATIVE, AND REGULATORY ELEMENTS OF THE PROCESS.**

With my interest in advance directives specifically and palliative care more generally, and with the growing knowledge of and comfort with the day-to-day of MMW put me in an excellent position to help Dr. Lechich with his efforts to get a palliative care program off the ground. I began this element of my project as an aside, but it quickly came to play an

important role in how I spent my time on site. First and foremost, I learned about the current palliative care programs at other ArchCare facilities in order to assess their benefits and shortcomings and identify how MMW might build on them. The notes from this review contributed to a palliative care working group, which resulted in a draft protocol for MMW. With this draft protocol in hand, I have been – and will continue to – interview different members of MMW staff to get their input on the protocol, and see if changes to the protocol should be implemented before the pilot program begins. In addition to reading the literature about palliative care programs in the nursing home setting has required speaking with the social work staff, administrator, chief of nursing, and physicians. Recently, I have been tasked with helping the physicians to identify patients within their care that would benefit from a palliative care program immediately, and those who might in the near-to-medium term. In the long-term, I hope to help the palliative care working group develop a volunteering program to help meet the palliative needs of residents. This work has supplanted the provider scorecard effort I initially intended to get involved with. •

# MEASURING THE HEALING POWER OF MUSIC

## EXPANDING THE MUSIC THERAPY PROGRAM

by Vincent Le, CC '21

Music has the power to heal. That is a statement that most musicians can attest to, and that many more will agree with. But what does it really mean? Certainly, music can't cure the flu, or mend broken bones. When I first joined the RCSS program my freshman year, I was introduced to the idea of music therapy: a specific type of musical practice aimed at alleviating the stress and anxiety of patients and residents of hospitals, nursing homes and more. Throughout my time volunteering at the music departments of Mary Manning Walsch and Terrence Cardinal Cooke respectively, I was able to see firsthand how much music meant to these residents. This summer, I wanted to learn more about music therapy: how else did it help people in clinical settings? Can the healing power of music be quantified? Thus, I applied and eventually started interning at the only two clinical research centers in music therapy in New York City: the Nordoff-Robbins Center for Music Therapy at NYU and the Louis Armstrong Department of Music and Medicine at Mount Sinai. By assisting in various studies and volunteering my time as a musician in myriads of hospital units/patient populations, I learned how these studies attempted to quantify the healing power of music. But it was also through these experiences that I was able to see how exactly music changed the experiences of these patients and residents in ways that were truly unquantifiable.

### I WANTED TO LEARN MORE ABOUT MUSIC THERAPY: HOW ELSE DID IT HELP PEOPLE IN CLINICAL SETTINGS? CAN THE HEALING POWER OF MUSIC BE QUANTIFIED?

One study I joined was at Mount Sinai West hospital near Columbus Circle, which focused on the neonatal intensive care unit. Although this happens rarely now because of successful educational efforts on drug use, babies can be born addicted to opioids because of an opioid-addicted mother or sometimes accidental medical opioid ingestion during pregnancy. When this happens, the babies are admitted to the neonatal intensive care unit where they stay to be weaned slowly off the opioids using friendlier opioid



IN ADDITION TO PLAYING HIS KEYBOARD, Vincent also sings and plays the ukelele.

drug mimics, morphine, and other medications. The experience is incredibly stressful on these babies, who are prone to having fits which make it harder for them to wean off the drugs. Over the course of two weeks, music therapists play music for these afflicted babies on alternating days, using singing and other instruments to calm the baby down. Information like heart rate, respiratory rate, and oxygen intake are recorded during these sessions and compared with control days to prove the efficacy of the music on calming the babies down and improving their hospital stay. One baby I watched was undergoing a minor surgery on their right leg and was clearly in a lot of discomfort. The music therapist matched the baby's cries with her own singing/guitar, and then used an ocean drum that mimics the sound of a mother's womb. Amazingly, the baby stopped crying and calmed down, allowing the surgeons to finish their operation quickly. When analyzing

the data, the computer showed me a similar elevated heart and respiratory rate during surgery before and after the music.

**AS MUCH AS MUSIC THERAPISTS HAVE TO TRY TO RECORD THE HELPFULNESS OF THEIR WORK THROUGH A SERIES OF INCONSISTENT VARIABLES LIKE HEART AND RESPIRATORY RATE, THE BENEFITS OF THEIR WORK CAN'T ALWAYS BE QUANTIFIED IN NUMBERS.**

Another study I joined was at the Nordoff-Robbins Center for Music Therapy: where music therapists worked specifically with developmentally disabled children and young adults. Through weekly music therapy sessions, the music therapists played music and encourage the client to sing/play along with the multitude of instruments available in the practice room. All sessions were also recorded with multiple cameras on every angle of the room. The clinical research study I was involved with worked on attempting to quantify the effectiveness of each music therapy session on a scale of 1-6 (1 being no musical engagement and 6 being flexible in initiation/response) to form a music engagement scale. By coding each music therapy session, the goal was to form an effective numerical scale that could show the progress of each client throughout the sessions with the hope that the sessions were coded higher over time. One client whose sessions I coded was very young, and had yet to learn how to speak. After coding 0 for almost a dozen sessions where the client had almost no musical engagement (paying no attention to the music in the room), I finally watched a sessions where the client made sound. The music therapist was singing a simple melody (Twinkle Twinkle Little Stars) and the client responded by singing along to the melody softly on the syllable "ah". There was no more musical engagement after that, but I saw the parents in the corner respond ecstatically to their child's momentary singing. Later I learned that it was the first time the client ever made sound, a beautiful moment happily captured on camera. Many music therapists believe that music is the first universal language, and that it comes before any spoken language. After almost a dozen sessions of a score 0, I finally gave this sessions a score 1 out of 6.

In between studies, I usually volunteer my time as a musician going from room to room of patients and units

with either my ukelele or a portable piano. Many times, the units/patients don't want to hear music. One unit I visited, the nurse manager told me to try asking one difficult patient who kept yelling at the staff and was being generally difficult to work with. I entered the room and encountered a very angry patient who demanded I cleaned up the room, adding a barrage of insults. I introduced myself as a volunteer musician and asked if there was a song I could play, to which I was asked to play Imagine by John Lennon. I sang my rendition as best I could and afterwards, the patient was silent. The patient then told me that I had just made their day and asked me to play more. I stayed there for almost an hour playing and talking with the patient until I had to leave. Afterwards, the nurse manager thanked me for cheering up the patient and spending time with them.

Being in hospitals or nursing homes can oftentimes be a stressful experience. Nurses and doctors are always coming and going, giving medications and performing confusing tasks to the patients. Some patients even struggle to figure out where they are, and the barrage of hospital equipment beeping noises and medical practitioners in scrubs can be incredibly disorienting. Hearing a familiar song or even having a meaningful conversation can alleviate the anxiety and confusion of a hospital stay. As much as music therapists have to try to record the helpfulness of their work through a series of inconsistent variables like heart and respiratory rate, the benefits of their work can't always be quantified in numbers. I've seen music calm down babies, give voice to mute children, cheer up disgruntled patients, make nurses dance and families smile. I may not have real data but after this summer, I can say without a doubt that music really does heal. •

# THE GRIFFITH-COLUMBIA BIOGRAPHY PROJECT

## EXPANDING OUR UNDERSTANDING OF END-OF-LIFE CARE

by Sara Castro, CC '19; Sungtae Yoon, GS '20; Sandy Zeng, CC '21

### Background

Narrative medicine, a relatively new field first developed in Columbia, focuses on the patient's story narratives in clinical practice, research, and education as a way to promote healing. The medical field has traditionally focused on a stoic approach to patients, focusing on the drugs used, treatment plans and objective symptoms. However, as more research is done in the narrative medicine field, it is quickly becoming clear that focusing on empathy, patient's narrative, and listening can create an even more effective and humane approach to healthcare. Catherine Dhavernas is a professor and palliative care scholar at Griffith University in Brisbane, Australia. She teaches a third year undergraduate seminar called The Biography Project in which students explore the challenges of aging and dying. As part of their course work, students are matched with long-term care residents to assist them with the writing of their biography. Her course discusses an often taboo, yet universal topic, creates meaningful friendships with residents, and demonstrates the value of learning from sharing stories and wisdom.

### Project Description

We hope to expand the lasting benefit of The Biography Project by creating an international exchange program between Columbia University and Griffith University. Two of our students will travel to Brisbane, Australia and engage in service learning and teaching. These students will be chosen from interested parties who have demonstrated exceptional interest in intergenerational social exchange, exhibited a strong desire to study aged or palliative care, or shown interest in learning to take oral histories in a medical setting. Ideal candidates include students who have taken the Life at the End of Life course (Columbia's palliative care course), participated in the AYS program, are interested in narrative medicine or social justice, or have taken classes in the Department of Oral History at Barnard.

The students selected will work closely with Dhavernas and participate in a condensed, intensive version of The Biography Project seminar in which they will receive training in facilitating a biography and working with

vulnerable persons. Drawing on assigned readings and their experiences, they will explore some of the challenges of aging and end of life issues through classroom and online discussions as well as short written assignments.

They will participate in debrief sessions and lead classroom discussions on their experiences at TCC while simultaneously learning from the experiences of Dhavernas' students. They will facilitate the biography of a long-term care resident, interact with the residents, patients, like-minded student volunteers, and care providers. To aid the Columbia students in their studies and adjustment to life abroad, students from Columbia will be partnered up with Griffith students for support and to partake in social activities outside classes.

**HOWEVER, AS MORE RESEARCH IS DONE IN THE NARRATIVE MEDICINE FIELD, IT IS QUICKLY BECOMING CLEAR THAT FOCUSING ON EMPATHY, PATIENT'S NARRATIVE, AND LISTENING CAN CREATE AN EVEN MORE EFFECTIVE AND HUMANE APPROACH TO HEALTHCARE.**

The first two days of the internship will involve in-class practical training. Following training, Columbia students will begin visits to a St. Vincent's Care facility to meet with their assigned resident. Over the course of the 3 weeks, they will interview the resident, record their story and develop a relationship with them. At the end of the 3 week period, the students will have recorded and compiled the residents' life story, which they will present to the residents in book form as a culmination of their project and a memento of their time together. They will also submit a critical self-reflection on their experience of the biography process.

These interactions offer multiple benefits to our students:

- Witness, firsthand, the conditions of care and treatment provided at end-of-life in long-term care facilities in Australia.

- Develop knowledge on end-of-life issues in Australia and current social-cultural attitudes and approaches toward these issues.
- Develop general knowledge about the Australian public and private health care systems and the population of individuals who have access to each.
- Acquire the skills to record and transcribe oral narratives told by residents.
- Develop meaningful long-term professional partnerships and relationships with students, patients, and scholars from across the globe

**SANDY REALIZED HOW SIGNIFICANT STUDYING THE ETHICS OF AND APPROACHES TO PALLIATIVE CARE WERE TO CREATING BETTER DOCTORS AND BETTER HEALTH SYSTEMS.**

As for the other half of the exchange, Griffith University students will be able to visit NYC in the month of June and partner with Terence Cardinal Cooke Nursing Home (TCC) and Mary Manning Walsh (MMW). We will be collaborating with fellow RCSS intern Sungtae Yoon as the TCC representative and Dr. Lechich, the medical director of MMW.

#### Reflection

Much like most of our peers, we used to think aging and dying were irrelevant topics, something far in the future that we did not need to think about. However, for Sandy Zeng, after her initial passion for narrative medicine was sparked through the University Writing: Medical Humanities class, she realized how significant studying the ethics of and approaches to palliative care were to creating better doctors and better health systems. This project was a perfect way to implement narrative medicine techniques in a hospital while sharing this field with other students. Since Sara and Catherine have brought us on to this project, we have been able to have fascinating discussion with other scholars interested in narrative medicine and palliative care, such as Dr. Lechich. We learned about the stories of life changing friendships and increases in the resident's happiness as students made their weekly visits.

We read about doctors discovering that listening and empathizing with their patients improved the patient's quality of care. Empathy is a difficult quality to develop after years of studying facts and treatment plans, yet no

other quality could be so important. We believe that this program would be a valuable and unique opportunity to educate future doctors, public health researchers, or others about a provocative and compelling topic.

Sungtae was new to the common narrative medicine approach, which borrows its methodology and ideas from the humanities and social science disciplines. Having a natural science background, he was more used to a value system of the natural sciences, where standardized and large data sets are considered more valuable than anecdotal evidence or accounts. Nonetheless, by being part of this project, he was able to not only familiarize himself with the underlying philosophy of narrative approach but also came to see the value of what was expected to come out of collecting and documenting or analyzing individual patients' stories as a means to appreciate and honor the individual experiences of the patients. He believes this experience has taught him that sometimes you have to let go of your preferred way of thinking to fully appreciate new approaches.

**BY BEING PART OF THIS PROJECT, [SUNGTAE] WAS ABLE TO NOT ONLY FAMILIARIZE HIMSELF WITH THE UNDERLYING PHILOSOPHY OF NARRATIVE APPROACH BUT ALSO CAME TO SEE THE VALUE OF WHAT WAS EXPECTED TO COME OUT OF COLLECTING AND DOCUMENTING OR ANALYZING INDIVIDUAL PATIENTS' STORIES...**

#### Current Actions

Currently, the logistics of the inaugural winter program have been set and we are now looking at possible sources of funding. While we have submitted many requests, we have not gotten concrete answers from most. We hope to make this program as accessible as possible, so our goal is to find funding to cover all costs. •

# ASSISTING THE LATINO COMMISSION ON AIDS

by Sara Castro, CC '19

## Background

I met Dr. Susana Morales at the Northeast Region Policy Forum, Crises in our Communities: Opioid Addiction & Immigrant Children Separated From Their Families, organized by the National Hispanic Medical Association. This forum focused on marginalization in medicine and physicians and other health providers discussed ways in which they could support the Latinx community facing deportation and addiction. I told Dr. Morales that RCSS interns Neci and Ewoma had created a course called Marginalization in Medicine, where students learn about the long history of abuse on vulnerable bodies for the benefit of those who hold privilege and power. As part of the course, students were required to participate in an engaged service learning activity. Students would volunteer 4 hours a week for 10 weeks throughout the semester. Dr. Morales suggested we work with the Latino Commission on AIDS to allow our students to engage in an organization that works with vulnerable populations within the Latinx community.

## About the Latino Commission on AIDS

The Latino Commission on AIDS is a non-profit organization founded in 1990. Their mission is in response to the unmet need for HIV/AIDS, viral Hepatitis, STIs prevention and care. The Commission's public health focus is to address the impact of health challenges in the context of addressing health disparities, by spearheading public health mobilization, promoting health education, developing and replicating evidence-based programs and high-risk communities for communicable diseases, and by building capacity across the public health sector including community-based organizations, health departments, healthcare organizations, and key institutions. Please

**THIS PROJECT WILL ENGAGE STUDENTS IN UNDERSTANDING HEALTH LITERACY FOR A POPULATION WITH LIMITED ENGLISH PROFICIENCY (LEP) AND THE LANGUAGE DIVERSITY THAT EXISTS WITHIN THE LATINX COMMUNITY.**

familiarize yourself with the organization by visiting their website (<https://www.latinoaids.org>).

## Purpose of the Project

The Latino Commission on AIDS has PowerPoint presentations in Spanish that need to be translated to English. This project will engage students in understanding health literacy for a population with limited English proficiency (LEP) and the language diversity that exists within the Latinx community. As a team, students assigned to project one are responsible for working together to translate one presentation per month. Throughout the course of the spring semester, Group 1 is responsible for translating a total of 3 presentations.

## THE COMMISSION'S PUBLIC HEALTH FOCUS IS TO ADDRESS THE IMPACT OF HEALTH CHALLENGES

### Project Results

Given unforeseen circumstances, the RCSS team decided to eliminate the engaged service learning component of the course and this project was not completed. I continued to work with the Latino Commission on AIDS by doing a small case study on a pilot 4-day work week at their Oasis Latino LGBTs Wellness Center. I met Leandro Rodriguez, head of the Oasis Latino LGBTs Wellness Center through the Hispanic Healthcare Executives network in New York City. Kimberly Sanchez and Josephine Kabambi, who are not RCSS interns, helped me conduct the study and analyze the data. Oasis was founded in 2015 and it focuses on providing gay, bi, and men who have sex with men with education, counseling, assistance with PrEP and PEP Leadership development. They also host a retreat for Spanish speaking LGBTQ individuals and run other support groups for people living with HIV. Leandro shared that after their first year, the staff at Oasis started to manifest burnout symptoms such as absenteeism and lack of team morale.

As part of a larger project, Leandro wanted to:

- 1) understand how burnout manifests in the millennial workforce (staff is 90% millennial), and
- 2) develop a strategy to reduce staff burnout.

## SURVEY QUESTIONS

1. On a scale from 1-5 (1 being strongly disagree, 2 being disagree, 3 being neutral, 4 being agree and 5 being strongly agree) do you feel the change in schedule was a positive one? Why?
2. Has this change in schedule, forced you to be more assertive with the time at the office? If so, please provide some examples.
3. What are some benefits—if any—that the change in schedule has had on your personal and professional life?
4. If this system were to become permanent, what challenges or barriers might that raise for you?
5. What recommendations do you have to enhance LCOA staff wellness procedures?

For the purpose of this project we define burnout as a state of emotional, mental, and physical exhaustion caused by excessive and prolonged stress. Research shows that burnout manifests itself in the following three dimensions: emotional exhaustion, depersonalization, and reduced personal accomplishment. Emotional exhaustion is the stress dimension of burnout which causes the people to distance themselves from work. Depersonalization is an attempt to put distance between the individual and the recipient. Reduced personal accomplishment appears to be a function of exhaustion, cynicism or a combination of the two. Leandro made this a priority because if Oasis fails to address staff burnout, it will negatively impact the experience of the patients and reduce the efficacy of their programming.

### Project Description

Can Work Schedules Affect Employee Engagement? A Pilot at the Latino Commission on AIDS's OASIS Latino LGBT'S Wellness Center

### Methodology

*Question:* Will shortening the work week from 5 to 4 days improve attendance?

*Null Hypothesis:* Reducing the work week from 5 to 4 days will not decrease absenteeism.

*Test:* Wilcoxon Signed Rank Test

*Critical value:*  $P < 0.05$

*Question:* Will shortening the work week improve self-reported well being?

*Test:* Survey

We did a two-part analysis to determine whether shortening the work week would improve attendance and then whether this change improved staff's self-reported well being. For the quantitative portion, Josephine looked at the attendance before and after the intervention to determine if there was a significant difference. Leandro then administered the survey to determine improvement in self-reported well-being. Kimberly and I performed a qualitative analysis on the data.

### Quantitative Analysis

The 4-day workweek led to a significant decrease in tardiness and decreased variation. Josephine used the Wilcoxon Signed Rank Test because the data was not normally distributed. There was a statistically significant difference between attendance record before and after the intervention.



THE LATINO COMMISSION ON AIDS is a non-profit organization founded in 1990 whose mission is in response to the unmet need for HIV/AIDS, viral Hepatitis, STIs prevention and care. There, Sara investigated burnout among millennials and the staff. (Fair Use: Facebook)

Before: 2-24, After: 2-7n =13, p = .014

88.9% of employees agreed or strongly agreed that the change in schedule had a positive impact on them.

#### Qualitative / Trends & Observations

##### Positive:

- Most employees agreed 4-day work weeks were beneficial
- They felt: *“More assertive” at work; Led to promotions and increased engagement as they felt they had limited time to accomplish team goals; Positively impacted personal life; Improved mental health, More family time*

##### Negative:

- They felt: *Fearred planning around big events; Not having full personnel at hand*

Most employees agreed/strongly agreed that the change in schedule was beneficial and that the extra time allowed them to do more things that benefited them as well as their work with co-workers and with clients. It has also allowed them to be more assertive at work. This is important because this could lead to more promotions and more engagement with work, thus, leading to more satisfaction both to the employer and employee. Most responses stated that they also feel the change in schedule has impacted their personal life. This is important due to the significance of mental health in order to function properly at work and to

succeed professionally. A challenge, however, that the surveyed feared is planning around big events and also perhaps not having full personnel at hand when these large events occur.

#### Reflection

There were a lot of limitations in the survey. Because Leandro conducted it in person, the respondents could have been less truthful in their responses. When we analyzed their responses, we noticed that some participants did not understand the questions given that the quality of the responses suggest that there could potentially be a language barrier preventing them from giving more detailed feedback. In addition, there was a very small sample size and we did not have focus groups. In the future, we can improve the case study by administering the survey via google forms to increase confidentiality and anonymity. We also must provide a bilingual questionnaire to ensure the participants understand the questions. Having focus groups will also enable us to gain a deeper understanding of the challenges and workflows. •

# TERENCE CARDINAL COOKE: THE AT YOUR SERVICE VOLUNTEER PROGRAM

by Anna Li, *BC '19* and Sungtae Yoon, *GS '20*

We have been working together as part of the Executive Board of the Terence Cardinal Cooke (TCC): At Your Service Volunteer Program. Anna served as the Program President and Sungtae served as the Personnel Officer. Together, we have been supporting other RCSS interns and TCC administrators in providing administrative support for student projects running and launching at TCC. Before, At Your Service was independent of RCSS as its own separate club that functioned in conjunction with the RCSS course, "Life at the End of Life," but we decided to integrate starting this semester because we wanted to better support the projects at RCSS, many of which are involved at TCC, and also establish a stronger foundation with RCSS and its resources.

## **AT YOUR SERVICE PROGRAM IS FACILITATE THE TRANSITION OF INTERESTED STUDENTS FROM COLUMBIA'S CAMPUS TO BECOMING VOLUNTEERS AT TCC.**

TCC is a health care center and nursing home that serves many traditionally underserved or marginalized populations, many of which do not have other means of support outside of TCC, which includes not having any accessible contact with family or friends. The variety of special populations at TCC includes HIV/AIDS residents and patients, Huntington's Disease residents, Dementia and Alzheimer's residents, and complex geriatrics and cancer patients. As a result, students come and interact with very diverse palliative care patients in a nursing home and hospital setting.

What we do as the At Your Service program is facilitate the transition of interested students from Columbia's campus to becoming volunteers at TCC. Specifically, there are two components within being a volunteer at TCC: the sub-acute shift, which includes assisting healthcare staff - with the daily needs of patients, checking in on patients and communicating with staff. And, what particularly makes the volunteering experience unique to TCC is the other

component of volunteering, which is that each volunteer is paired with a long-term companion - because many of these residents are at TCC for upwards to many years, and as we have mentioned before, patients may not have access to other means of support from family or friends, volunteers serve as a regular companion to an individual resident and are free to do whatever activities they wish to do together. RCSS interns take advantage of this opportunity to develop their personal projects on top of baseline volunteering services.

Because At Your Service serves a wide variety of special populations, no two volunteers' experiences are alike - through these reflection sessions, volunteers have a wider breadth of understanding the healthcare field, specially with regards to palliative care and nursing homes. Not only do the volunteers share experiences, but we engage in different topics with regards to the healthcare field and share our perspectives on them, especially how our experiences as volunteers have shaped our approaches to these various topics sometimes that also includes inviting guests to share their experiences with the healthcare field.

## **WORKING WITH OTHER [RCSS] INTERNS WITH VARIOUS BACKGROUNDS HAVE ENABLED US TO SEE THE VALUE OF TRUE COLLABORATION.**

These reflection sessions that serve as meetings for our volunteers also highlight a unique aspect of the At Your Service volunteer program, not only are we a part of RCSS, but we are also a student-led club that is within the Columbia University student body. That means that not only do we communicate with TCC and RCSS on volunteering matters, but we also communicate with Columbia administration with regards to holding these reflection sessions and the logistics of our club activities. We are able to reach a wide range of students (from different schools and programs) to help further AYS's mission of serving TCC's residents. Throughout the past

year, we have worked to make the transitioning of board members within AYS more sustainable by standardizing protocols and synchronizing our activities with RCSS.

**WITNESSING HOW ART-THERAPY, MUSIC EVENT, NAIL PAINTING, SPECIAL DISCUSSIONS AND A HOST OF OTHER SERVICES AND EVENTS ORGANIZED BY STUDENT VOLUNTEERS CAN BENEFIT THE PATIENTS AND RESIDENTS IN SMALL AND MEANINGFUL WAYS THAT WE COULD NOT HAVE IMAGINED OURSELVES WAS A TRULY EYE-OPENING AND INSPIRING EXPERIENCE WE WOULD NOT HAVE FOUND ELSEWHERE.**

In terms of facilitating volunteers, we are involved in volunteer recruitment and medical record processing, on-site and off-site student-intern project coordination, and duties as liaisons with ad hoc responsibilities, reporting to both RCSS and the TCC Volunteer Department.

We were involved in providing external support for “Life at the End of Life” class participants, delivering bi-weekly reflection sessions for active student volunteers at TCC, and coordination with Dr. Lechich, ArchCare Sr. VP of Clinical Strategy, to improve volunteering experience and to potentially expand student engagement. We are also assisting individual projects by volunteers to provide more engaging experiences for both the students and the residents at TCC.

AYS also works as a club as a part of Columbia’s campus, so we also work with Columbia University administration to have our programming on campus and more accessible to the student body. This foundation of both Columbia

administrative support and RCSS support provides the resources and support for the At Your Service program to successfully and efficiently connect students to volunteering opportunities at TCC in order to provide students with a more enriched understanding of palliative care within a healthcare facility and nursing home.

Working with other interns with various backgrounds have enabled us to see the value of true collaboration. Witnessing how art-therapy, music event, nail painting, special discussions and a host of other services and events organized by student volunteers can benefit the patients and residents in small and meaningful ways that we could not have imagined ourselves was a truly eye-opening and inspiring experience that we would not have found elsewhere.

**[WHEN] PATIENTS MAY NOT HAVE ACCESS TO OTHER MEANS OF SUPPORT FROM FAMILY OR FRIENDS, VOLUNTEERS SERVE AS A REGULAR COMPANION TO AN INDIVIDUAL RESIDENT AND ARE FREE TO DO WHATEVER ACTIVITIES THEY WISH TO DO TOGETHER.**

Although there would be an occasional disagreement on the best way to pursue a goal, as people from various background proposed different priorities, we learned that with sincere discussion, we can all be firmly rooted in a common mission and pursue the good we seek with greater clarity and efficiency. •









